Ana Rosa Galvão de Castro

Head and Neck cancer: Rasch analysis in Quality of Life Assessment

UNIVERSIDADE FERNANDO PESSOA
FACULDADE DE CIÊNCIAS DA SAÚDE

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Trabalho apresentado
À Universidade Fernando Pessoa
Como parte dos requisitos para obtenção
Do grau de Mestrado Integrado em Medicina Dentária

RESUMO

A patologia oncológica de cabeça e pescoço (POCP) representa 3% de todos os tumores malignos diagnosticados mundialmente. A POCP inclui várias localizações como: cavidade oral, faringe, laringe e glândulas salivares. A POCP causa impacto negativo no doente oncológico e afecta várias funções. A avaliação da Qualidade de Vida Relacionada com a Saúde (QdVRS) é essencial para melhor compreender e explorar a autopercepção do doente oncológico de cabeça e pescoço.

Contudo, a QdVRS é considerada um *Patient Reported Outcome (PRO)* de carácter subjectivo e multidimensional justificando a necessidade de criar medidas confiáveis, e adequadas.

O nosso objectivo consistiu em optimizar e melhorar a avaliação da QDVRS com recurso a modelos matemáticos. Identificaram-se as questões difíceis do EORTC QLQ C-30 e a habilidade do paciente em responder discutindo o conceito de dificuldade em contextos de saúde.

Foi analisada uma base de dados obtida na Unidade de Cabeça e Pescoço do Instituto Português de Oncologia do Porto. Usou-se o WinRasch software package- versão de demonstração.

Os doentes oncológicos de cabeça e pescoço (n=75) foram selecionados no momento de diagnóstico e agrupados pelo estadiamento da doença. Foi comparado o modelo conceptual com a análise do Modelo de Rasch *(correlação point-measure; dificuldade ou desafio de acordo com os dados; curvas de probabilidade relacionadas com a variável latente; infit e outfit*).

A análise de Rasch suportou na generalidade o modelo conceptual do EORTC QLQ C30 nos doentes oncológicos avaliados. Detetaram-se 3 items problemáticos (Q7, Q20, Q28). Um total de 3 doentes demonstraram resultados fora do esperado baseado na análise.

O Modelo de Rasch aplicado a QdVRS em POCP tem aumentado a precisão e complementado as técnicas estatísticas tradicionais. Esta abordagem optimiza os PRO e facilita a sua incorporação na prática clínica em oncologia.

Palavras Chave: oncologia; cancro cabeça e pescoço; patient reported outcomes; modelo de rasch; teoria de resposta ao item.

ABSTRACT

Head and neck cancer (HNC) represents 3% of all cancer cases worldwide. HNC includes several upper body locations: oral cavity, pharynx, larynx or salivary glands. HNC is the most distressing human cancer disturbing cervicofacial region and affecting several functions. Health Related Quality of Life (HRQoL) assessment in HNC is essential to better understand and explore the HNC patient's perceptions.

Nevertheless, HRQoL is considered a subjective and multidimensional dynamic Patient Reported Outcome justifying the need to build reliable, robust and adequate measures.

Our objective was to optimize and improve HRQoL assessment using mathematical models identifying the EORTC QLQ-C30 questions difficulty and the patients' ability to answer discussing the concept of difficulty in health context.

A database obtained in Oporto Oncology Portuguese Institute, Head and Neck Unit, was explored. It was used the WinRasch software package - demonstration version. HNC patients (n=75) were selected at the time of diagnosis and grouped according to the stage of disease. We compare our construct theory and Rasch Model analysis (*point-measure correlation; difficulty or challenge according to the data; probability curves related to the latent variable; infit and outfit)*.

Rasch analysis supported generally the theoretical constructs of the EORTC QLQ C30 in HNC patients evaluated. RM analyses detected three problematic items (Q7, Q20, Q28). A total of 3 respondents demonstrated misfit pattern at constructs based on Rasch analysis.

Rasch Model applied to HRQoL in HNC as improving precision and complementing traditional statistical techniques. This approach is improving PRO and enabling its incorporation in oncological clinical practice.

Key Words: oncology; head and neck cancer; patient reported outcomes; rasch model; item response theory.

"Segue o teu destino,
Rega as tuas plantas,
Ama as tuas rosas.
O resto é a sombra
De árvores alheias.

A realidade
Sempre é mais ou menos
Do que nós queremos.
Só nós somos sempre
Iguais a nós-próprios."

Fernando Pessoa

DEDICATÓRIA

A todos os docentes que me acompanharam ao longo de todo o percurso académico.

A todos os funcionários da Universidade Fernando Pessoa.

A toda a minha família e amigos, que sempre me encorajaram e protegeram.

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I. Background

1.1 Head and Neck Cancer & Patient Reported Outcomes

Head and neck cancer (HNC) accounts for more than 550,000 cases and 380,000 deaths annually (Global Burden of Disease Cancer Collaboration, 2017). HNC accounts in the United States 63.000 new cases being these numbers higher in Europe - 250.000 new cases. HNC and head and neck squamous cell carcinoma represents 3% and 6% of all cancer cases respectively (Siegel *et al.,* 2017; Gatta *et al.,* 2015).

HNC comprehends several locations: oral cavity, pharynx, larynx, paranasal sinuses, salivary glands and is necessarily related to malnutrition during the disease process and the treatment (Capozzi *et al.,* 2016).

HNC is the most distressing human cancer disturbing cervicofacial region and affecting functions such as: vision, hearing, balance, olfaction, taste, mastication, swallowing, breathing, voice, endocrine and body image. Consequently, when treating HNC, the effects of both disease and treatment are reflected on Patient Reported Outcomes (PRO) that thus need the most serious consideration. Accordingly, Health Related Quality of Life (HRQoL) assessment in HNC is essential to better understand and explore the HNC patient's perceptions (Sequeira *et al.,* 2015; Silveira *et al.,* 2012).

HRQoL outcomes - one of the most studied PRO – have been recognized as very useful in individual and multidisciplinary decisions (Rogers *et al.,* 2016). The benefits of such outcomes have been related to the planning of treatment, follow up and have been successfully included in multidisciplinary protocols (Wotherspoon *et al.,* 2018).

Routine provision of PROs to oncologists positively affects the process of care in aspects such as oncologist–patient communication, awareness of patients' problems and discussion of symptoms during consultations (Detmar *et al.,* 2002; Girgis, Breen & Stacey, 2009; Thewes *et al.,* 2009; Hilarius *et al*., 2008; Nicklasson *et al*., 2013). PRO assessment is

thus crucial to provide effective, evidence-based supportive care, rehabilitation and symptom management (Ringash, 2015; Verdonck-de Leeuw, van Nieuwenhuizen & Leemans, 2012). Symptoms management has been improved by involving patients more actively, and a few reports support that PROs given in a timely manner to oncologists are valuable in clinical care (Basch *et al*., 2016; Chen, Ou & Hollis, 2013).

Nevertheless, HRQoL is considered a subjective and multidimensional dynamic PRO and a gap between clinician and PROs of symptom severity is sometimes described (Mercieca-Bebber *et al*., 2016). This fact justifies the need to build more reliable, robust and adequate measures.

Improvement is needed in the transparent reporting of PRO studies, particularly regarding data collection and analysis for generalization of PRO results (Mercieca-Bebber *et al*., 2016).

1.2 Mathematical models in Health Related Quality of Life (HRQoL): Rasch Model (RM) in focus

RM is a mathematical and a psychometric model. Its denomination is a tribute to Georg William Rasch- a Danish mathematician (Boone, 2016).

RM formulation is founded on a two-dimensional data matrix, denoted U, obtained by administering a test/questionnaire, which consists of n items, to m examinees or persons. It can be used to measure: attitudes, abilities or other variables involving the trade-off between the personality traits and the item difficulty. RM has been used in several areas, including education, marketing, health studies, social sciences and economics (McNeely *et al*., 2018).

The Item Response Theory (IRT) - a mathematical model defined by item parameters for dichotomous items, supports RM. IRT encompasses a group of psychometric models with potential to construct, validate and evaluate health instruments and its results. However, there are some differences: IRT models use three parameters being classified as descriptive and it aims to fit the model to the data and on the other way RM uses one parameter being classified as prescriptive and it aims construct data to fit the measurement model. Rating scale model or partial credit model are commonly used to parameterize data in RM. There are several IRT models, but RM is one of the most used for health research (Yu, 2017; Bond and Fox, 2007).

In health context, RM has presented some advantages:

- RM allows to develop or to improve measures;
- RM optimizes detailed assessment;
- RM can deal with missing data frequently seen in clinical settings;
- RM can be used in studies with several methodological designs;
- RM supports real time analysis for clinical practice utilization proposing RM as an intelligent decision support system;
- Rasch validation, as performed currently, might help qualify a technique or a therapy;
- RM assists in identifying limitations of measures;
- RM enables the exposure of lack of invariance and other measurement problems that may not be easily detected by traditional analyses (Oliveira-Kumakura, *et al.,* 2018; McNeely *et al*., 2018; Amin *et al.,* 2012; Silveira *et al.,* 2011; Hagquist *et al.,* 2009).

RM has been applied to Quality of Life (QoL) assessment and HRQoL evaluation. RM applied to HRQoL has improved precision and the monitoring of quality instruments complementing statistical techniques such as factor analysis, calculation of Cronbach's alpha or point biserial correlations (Boone, 2016). In our work we used the Rating Scale Model (RSM) of Rasch and Andrich, where a set of items share the same rating scale.

Using HRQoL questionnaires and considering the HRQoL score as the latent variable, RM allows difficulty evaluation of each question and explores the capacity of each patient to answer such question. RM has been used for developing PRO instruments and for testing its psychometric properties. Besides HRQoL research, RM has been used in HRQoL assessment for clinical practice use, giving more detailed information in real time – a tool that has been optimizing daily procedures in oncology clinical practice (Silveira *et al*., 2011).

II. Objectives

Our research goal is to optimize and improve HRQoL assessment using mathematical models. In this study we explore RM and IRT for this propose. We aim to identify the questions difficulty and the patients' ability to answer and discuss the concept of difficulty in health context.

RM was used to better understand which HRQoL items assessed with European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30) - Portuguese version, do not fit the model.

III. Methods

A database obtained in Oporto Oncology Portuguese Institute (IPO-Porto), Head and Neck Unit, was explored. HRQoL assessment was carried out in a systematic way as a routine process of the Unit. The team research and clinicians used a Quality of Life informatics platform (OPQoL) developed in Fernando Pessoa University that allows a real time HRQoL analysis (Silveira *et al*., 2011).

The study was carried out in compliance with the Helsinki Declaration. The local research ethical committee previously approved the method and all HNC patients agreed to participate in the research and gave their informed consent. The data were collected for research purposes as part of the routine evaluation. (Attachment I)

HRQoL of HNC patients was assessed using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30) and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Head and Neck Cancer Module (EORTC QLQ-H&N35) - Portuguese version. (Fayers *et al*., 2001) (Attachment II)

HNC patients included in the database were grouped according to the stage of disease and 75 were selected at the time of diagnosis. Considering data protection, all personal identifiers present in the database were eliminated and it was used a substitute artificial identifier.

It was used the WinRasch software package - demonstration version, limited to 25 questions. As EORTC-QLQ C30, 5 questions were removed according to the following criteria:

- QLQ C30: it was excluded the last question in the physical, emotional and fatigue scales (subtotal of 3) and QoL and Health questions (subtotal of 2), resulting in a total of 5 removed questions.

WinRasch software starts displaying the control and data file (Attachment III). The "Category Label File" defines 4 categories of the rating scale: 0="*not at all*"; 1="*a little*"; 2="*quite a bit*"; 3="*very much*". The next step consists of comparison between our construct theory (theoretical original model) and RM analysis (point-measure correlation; difficulty or challenge according to the data; probability curves related to the latent variable; infit and outfit).

IV. Results

4.1 RM analysis: EORTC QLQ C30

i. Point-measure correlation

Point-measure correlations are presented in Table 1. Generally noticeable positive correlations were detected. Negative and close-to-zero correlations sound alarm bells, but were not found. Small positive correlations were found in Q14, and needed further investigation in the following steps. In addition items such as Q7, continue to show unsuitable values, in this case the observed value is higher than expected. Table I presents correlation by item signalizing questions with small positive correlations.

PT MEASUR-AL		EXACT	MATCH	Item
CORR.	EXP.	OBS%	EXP%	
.13	.18	94.7	94.9	Q14
.18	.22	92.0	92.4	Q15
.19	.22	92.0	92.4	Q17
.21	.25	86.7	89.6	Q4
.27	.37	74.7	74.5	Q3
.36	.42	64.0	64.4	Q20
.39	.55	41.3	47.6	Q1
.39	.42	65.3	64.4	Q8
.39	.44	57.3	63.2	Q16
.45	.54	40.5	49.8	Q11
.45	.49	54.7	56.9	Q25
.46	.55	48.0	47.7	Q2
.46	.40	69.3	70.2	Q26
.47	.54	45.3	48.1	Q22
.48	.55	44.0	47.9	Q23
.49	.48	54.7	59.1	Q28
.52	.43	65.3	63.5	Q7
.52	.44	62.7	62.4	Q6
.53	.44	60.0	63.2	Q13
.54	.52	49.3	52.8	Q21
.55	.43	64.0	63.7	Q27
.55	.45	64.0	62.2	Q19
.58	.53	50.7	50.4	Q9
.63	.47	73.0	59.6	Q10
.64	.49	66.7	56.4	Q12

Table 1. Correlations by item

ii. Difficulty or challenge according to the data

In Table 2, questions (Q) are ordered vertically according to their difficulty or challenge, revealing Q14, Q17 e Q15 as the easiest items and Q1, Q2 and Q 23 as the most challenging items.

When analysing the category numbers positions and the empirical average measures order, Q28, Q7 and Q20 were signalized - these items do not agree with the other items and need thus further investigation. When answering those questions patients do not interpret correctly the categories, using them out of order. There is considerable debate whether this disorder shows a flaw in the measurement instrument.

Q28, *"Has your physical condition or medical treatment caused you financial difficulties?"*, is a symptom scale considered as a simple item.

Q7, "*Were you limited in pursuing your hobbies or other leisure time activities?*", when scored together with Q6 constitutes the "Role Functioning", a functional scale.

Q20, "*Have you had difficulty in concentrating on things, like reading a newspaper or watching television*?", when scored together with Q25 constitutes the "Cognitive Functioning", a functional scale (Fayers, 2001) (Attachment IV)

Observed Average Measure for Person (unscored) (by Observed Category)												
0	10	20	30	40	50	60	70	80	90	100	Num	Item
						012	3				1	Q1
						01	2 3				2	Q2
					0	1 2	3				21	Q23
						0 1 2	3				20	Q22
						m012	3				10	Q11
					0	1 2	3				8	Q9
					0	1 2	3				19	Q21
					0 1	2	3				11	Q12
					01	2	3				22	Q25
					1	0 2	3				25	Q28
						1m 2	3				9	Q10
					0	1 2	3				17	Q19
					0 1	2	3				5	Q6
					0	1 2	3				12	Q13
					01	2	3				15	Q16
					33	2	3				6	Q7
				0		1 2	3				24	Q27
						01 2	3				7	Q8
					1	0 2	3				18	Q20
				0		12	3				23	Q26
						12	3				3	Q3
						2	3				4	Q4
						2 3					14	Q15
						2 3					16	Q17
						2 3					13	Q14

Table 2. Difficulty or challenge according to the data

iii. Probability curves related to the latent variable

Figures 1-5: demonstrate the probability curves related to the latent variable for Q1 (the most challenging item), Q14 (the easiest item) and Q28, Q7 and Q20 (the unexpected items).

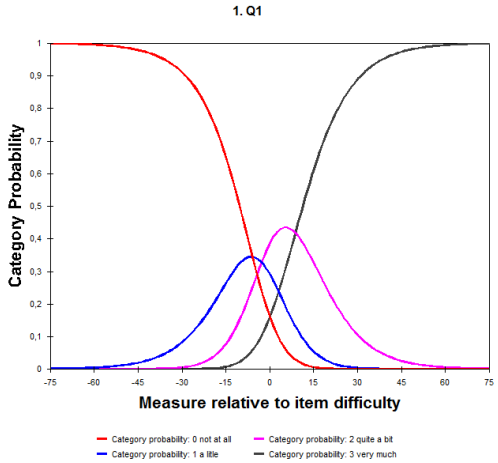

Figure 1. Probability curve for Q1

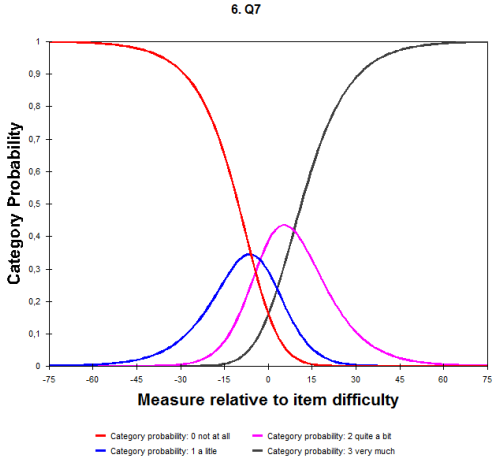

Figure 2. Probability curve for Q7

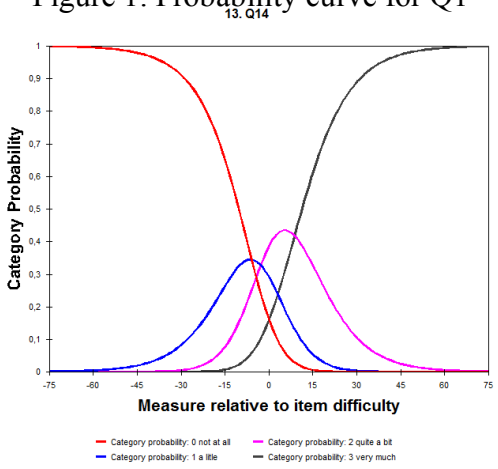

Figure 3. Probability curve for Q14

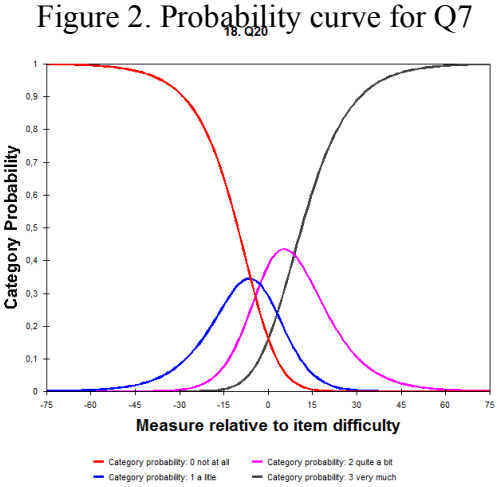

Figure 4. Probability curve for Q20

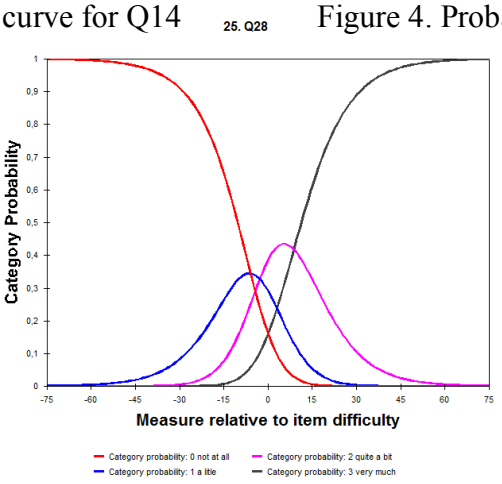

Figure 5. Probability curve for Q28

Figures 6-10: reveals the item characteristic curve as expected by the RM, the HNC patients responses and the confidence interval for Q1 (the most challenging item), Q14 (the easiest item) and Q28, Q7 and Q20 (the unexpected items).

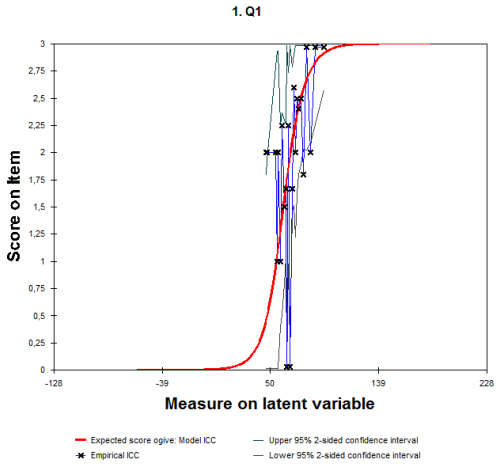

Figure 6. Item characteristic curve for Q1

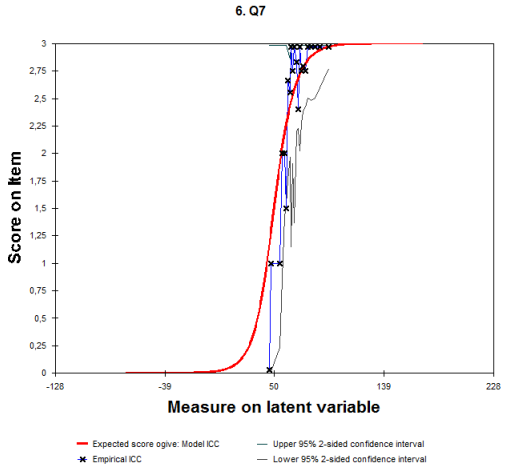

Figure 7. Item characteristic curve for Q7

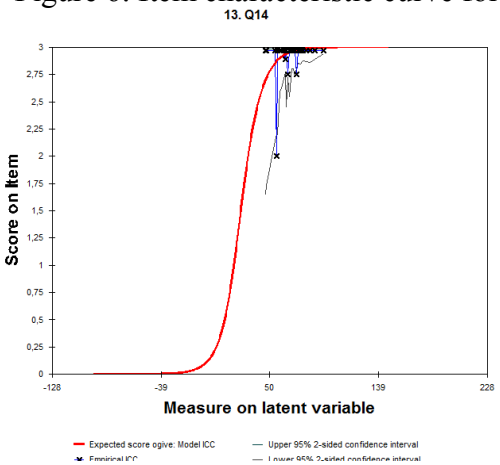

Figure 8. Item characteristic curve for Q14

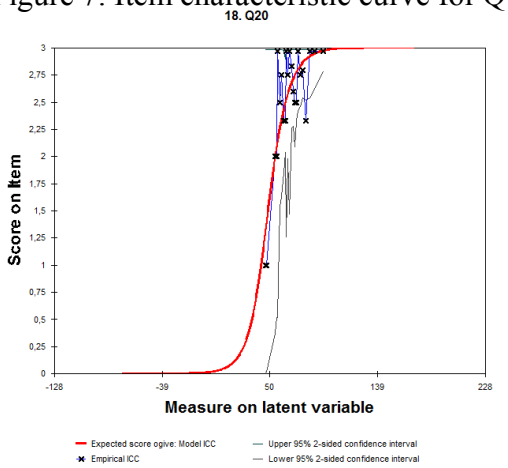

Figure 9. Item characteristic curve for Q20

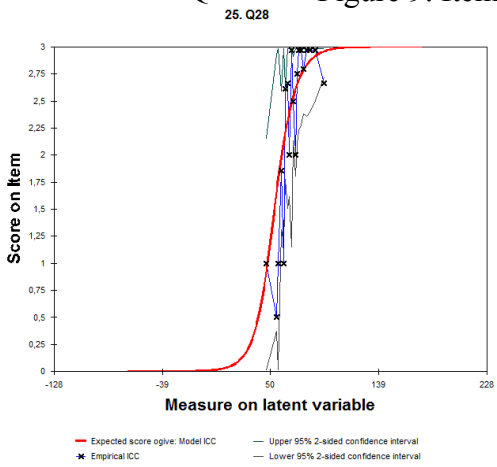

Figure 10. Item characteristic curve for Q28

In Figures 1-5: the Graphics don't show any abnormalities. The intersection of a given curve with the next curve follows the crescent order (0,1,2,3). This means that curve 0, is intersecting curve 1, then curve 1 intersects curve 2, and so on.

There would only be an abnormality if, let's say, curve 0 was intersecting curve 2 before intersecting curve 1.

In Figures 6-10: the Graphics don't show any abnormalities. The answers given follows the curve of the latent variable.

iv. Infit and outfit

Rasch analysis showed that the majority of the items demonstrated good fit demonstrating that in general the responses to the items are sufficiently similar among HNC patients. Table 3 presents "infit", "outfit" and "ability mean". The Q1, Q7, Q20 and Q28, still exhibit unexpected response patterns.

Item	Data Code	Data Count %	Ability		Infit Mnsq	Outfit Mnsq	
			Mean	P.SD			
Q28	0	4 5	60.00	3.83	1.4	1.3	0 not at all
	1	8 11	56.76*	6.80	.6	.5	1 a litle
	2	16 21	67.48	8.69	1.1	2.1	2 quite a bit
	3	47 63	71.83	8.62	.9	1.0	3 very much
Q7	0	2 3	57.79	11.59	1.4	2.0	0 not at all
	1	7 9	57.08*	4.48	.7	.5	1 a litle
	2	13 17	63.85	6.08	.8	.7	2 quite a bit
	3	53 71	71.78	8.87	.8	.9	3 very much
Q14	2	4 5	63.52	5.81	1.5	1.0	2 quite a bit
	3	71 95	68.95	9.79	1.1	1.0	3 very much
Q13	0	3 4	50.76	5.65	.6	.6	0 not at all
	1	4 5	60.45	2.06	1.1	.8	1 a litle
	2	17 23	54.40	4.79	.9	.6	2 quite a bit
	3	51 68	71.78	9.41	1.0	1.0	3 very much
Q21	0	4 5	54.45	7.71	.9	.8	0 not at all
	1	7 9	61.94	6.67	.9	1.1	1 a litle
	2	31 41	66.74	7.41	1.0	1.0	2 quite a bit
	3	33 44	73.62	9.13	.9	.9	3 very much
Q27	0	1 1	46.19	.00	.3	.3	0 not at all
	1	5 7	58.17	1.91	.8	.6	1 a litle
	2	19 25	63.60	6.27	.9	.7	2 quite a bit
	3	50 67	72.08	9.12	.9	.9	3 very much
Q19	0	3 4	51.65	6.91	.7	.7	0 not at all
	1	4 5	60.13	5.46	.9	.9	1 a litle
	2	19 25	64.07	4.90	.8	.5	2 quite a bit
	3	49 65	72.18	9.22	.9	.9	3 very much
Q1	0	8 11	65.11	6.44	1.7	2.2	0 not at all
	1	9 12	66.41	7.27	1.6	2.0	1 a litle
	2	32 43	64.23*	7.68	1.5	1.2	2 quite a bit
	3	26 35	75.99	9.17	.9	.9	3 very much
Q10	1	6 8	57.91	5.74	.7	.5	0 not at all
	2	30 41	63.53	6.44	.7	.6	1 a litle
	3	38 51	76.64	8.43	.7	.7	2 quite a bit
	MISSING*	1 1#	60.08	.00			3 very much
Q20	0	1 1	62.87	.00	2.6	2.0	0 not at all
	1	3 4	51.65*	6.91	.3	.3	1 a litle
	2	21 28	66.40	7.44	1.3	1.3	2 quite a bit
	3	50 67	70.75	9.51	1.0	1.0	3 very much

Table 3. Statistics by item

Table 4 presents the “infit”, “outfit” by entry number. HNC patients 51, 30, 15 e 23 reveal unexpected response patterns. Note that mean squares above 1 indicate presence of noise and thus it can be hard to interpret the responses. Values above 2 denote problematic responses.

ENTRY NUMBER	INFIT MNSQ	ZST	OUTFIT MNSQ	ZSTD	PERSON
51	1.11	.4	3.19	2.7	BW
30	2.25	2.6	2.43	2.2	BD
15	2.36	2.0	1.40	.7	AO
23	1.77	1.6	1.95	1.5	AX

Table 4. Larger infit/outfit by person

V. Discussion

Constructs represented by QLQ-C30 multiple-item subscales were validated when RM was used to improve the questionnaire reliability (Shih *et al.*, 2013). In the present study, Rasch analysis revealed that the HRQoL items contained in EORTC QLQ C30 proved good fit in general, demonstrating that the responses to the items were sufficiently similar among HNC patients.

We intended to estimate the location of an individual with certain ability on the line defined by the difficulty level of the different HRQoL items. According to our results, the items are expected to follow some specific patterns according to the original model defined.

However, EORTC QLQC30 questions (Q7, Q20, Q28) presented unexpected patterns and 4 HNC patients (51, 30, 15 and 23) missfitted the model with responses deviated from the expected. This fact raises some questions:

- Do the items contribute to an adequate assessment in these HNC patients?
- Is there any underlying multi-dimensional structure among individuals?
- Do the HNC patients understand the questions?
- Do the HNC patients really want to be evaluated?

In the present study, *role* and *cognitive* functioning revealed being the most problematic. *Social* dimension, *emotional* and *cognitive* items have already been identified as presenting greater difficulty than the *physical* dimensions (Vélez *et al.,* 2016; Rosnah *et al.,* 2015).

When items are classified by patients as moderately to highly difficult, they tend to get lower scores in these items, indicating better QoL (Shih *et al.,* 2013).

However, items removal from questionnaires is not recommended – missfitting items are worth keeping since they provide valuable information and removing items from a questionnaire could increase the intrinsic variance within the data. Additionally, eliminating

some items could misfit other items, which were not initially misfitted (McNeely *et al.,* 2018).

A total of 3 respondents demonstrated misfit pattern at all constructs based on Rasch analysis – however they were not removed from the analysis. Those misfit respondents were comparable to fit respondents in terms of social-demographic and clinical variables, considering initial HNC patients selection.

HNC patients often present some risk factors related to lifestyle habits: tobacco smoking and alcohol drinking. Studies often disclose a high median age (55-65 years), a low household income and low education (Choi *et al.,* 2016 Silveira *et al*., 2011). This patient profile may difficult questionnaires understanding and compromise questions response. These possibilities emphasizes RM analysis introduction at the measures development to optimizing HRQoL assessment.

VI. Conclusion

The EORTC QLQ-C30 is scored on the basis of classical test theory, which uses the total item score as the scale score. RM allows item-response analysis providing item-level information. This can improve PRO.

Rasch analysis supported generally the theoretical constructs of the EORTC QLQ C30 in HNC patients evaluated.

RM analyses detected three problematic items (Q7, Q20, Q28). A total of 3 respondents demonstrated misfit pattern at constructs based on Rasch analysis. Those misfit respondents were comparable and not significantly different to fit respondents in terms of social-demographic and clinical variables.

RM applied to HRQoL in HNC as improving precision in constructing and validating instruments and monitoring instruments quality complementing traditional statistical techniques. This approach is improving PRO and enabling its incorporation in oncological clinical practice.

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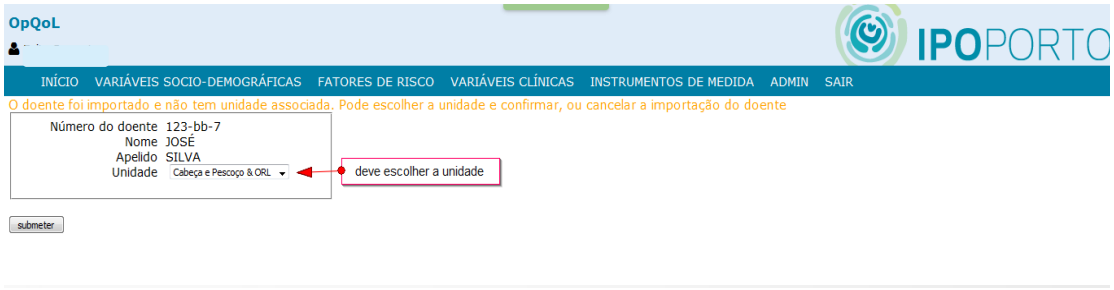
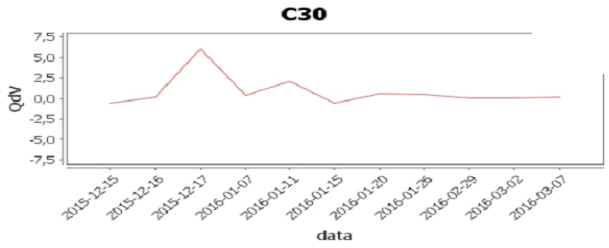
VIII. Attachments

Attachment I. Layout of OPQoL



IPOPORTO

Processo 123-bb-7. Género: masculino, idade: 55. Aplicado em 2016-03-07. QdV: 0,12. Momento: 1ª consulta



O diagnóstico aparece nesta zona do relatório. A localização aparece a seguir.

Neoplasia Maligna do Lábio (N)

1. Custa-lhe fazer esforços mais violentos, por exemplo, carregar um saco de compras pesado ou uma mala?	2
2. Custa-lhe percorrer uma grande distância a pé?	**3**
4. Precisa de ficar na cama ou numa cadeira durante o dia?	2
5. Precisa que o/a ajudem a comer, a vestir-se, a lavar-se ou a ir à casa de banho?	2
6. Sentiu-se limitado/a no seu emprego ou no desempenho das suas actividades diárias?	**3**
8. Teve falta de ar?	2
9. Teve dores?	2
10. Precisou de descansar?	2
15. Vomitou?	3 (1,4)
16. Teve prisão de ventre?	**3**
17. Teve diarreia?	2
18. Sentiu-se cansado/a?	2
19. As dores perturbaram as suas actividades diárias?	2
23. Sentiu-se irritável?	**3**
24. Sentiu-se deprimido/a?	**3**
29. Como classificaria a sua saúde em geral durante a última semana?	**3**

Estado de saúde global/QdV	33
Funcionamento físico	58
Função de desempenho	33
Função emocional	33
Função cognitiva	-
Função social	-
Fadiga	66
Náuseas e vómitos	33
Dor	66
Dispneia	66
Insónia	-
Perda de apetite	-
Obstipação	33
Diarreia	66
Dificuldades financeiras	-

Attachment II. EORTC QLQ- C30 and EORTC QLQ: H&N35 Questionnaires

EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials: ⌊ ⌋⌊ ⌋⌊ ⌋⌊ ⌋

Your birthdate (Day, Month, Year): ⌊ ⌋⌊ ⌋ ⌊ ⌋⌊ ⌋ ⌊ ⌋⌊ ⌋⌊ ⌋⌊ ⌋

Today's date (Day, Month, Year): 31 ⌊ ⌋⌊ ⌋ ⌊ ⌋⌊ ⌋ ⌊ ⌋⌊ ⌋⌊ ⌋⌊ ⌋

		Not at All	A Little	Quite a Bit	Very Much
1.	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2.	Do you have any trouble taking a long walk?	1	2	3	4
3.	Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4.	Do you need to stay in bed or a chair during the day?	1	2	3	4
5.	Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:		Not at All	A Little	Quite a Bit	Very Much
6.	Were you limited in doing either your work or other daily activities?	1	2	3	4
7.	Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8.	Were you short of breath?	1	2	3	4
9.	Have you had pain?	1	2	3	4
10.	Did you need to rest?	1	2	3	4
11.	Have you had trouble sleeping?	1	2	3	4
12.	Have you felt weak?	1	2	3	4
13.	Have you lacked appetite?	1	2	3	4
14.	Have you felt nauseated?	1	2	3	4
15.	Have you vomited?	1	2	3	4
16.	Have you been constipated?	1	2	3	4

During the past week:	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

30. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

EORTC QLQ - H&N35

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week:		**Not at all**	**A little**	**Quite a bit**	**Very much**
31.	Have you had pain in your mouth?	1	2	3	4
32.	Have you had pain in your jaw?	1	2	3	4
33.	Have you had soreness in your mouth?	1	2	3	4
34.	Have you had a painful throat?	1	2	3	4
35.	Have you had problems swallowing liquids?	1	2	3	4
36.	Have you had problems swallowing pureed food?	1	2	3	4
37.	Have you had problems swallowing solid food?	1	2	3	4
38.	Have you choked when swallowing?	1	2	3	4
39.	Have you had problems with your teeth?	1	2	3	4
40.	Have you had problems opening your mouth wide?	1	2	3	4
41.	Have you had a dry mouth?	1	2	3	4
42.	Have you had sticky saliva?	1	2	3	4
43.	Have you had problems with your sense of smell?	1	2	3	4
44.	Have you had problems with your sense of taste?	1	2	3	4
45.	Have you coughed?	1	2	3	4
46.	Have you been hoarse?	1	2	3	4
47.	Have you felt ill?	1	2	3	4
48.	Has your appearance bothered you?	1	2	3	4

During the past week:		Not at all	A little	Quite a bit	Very much
49.	Have you had trouble eating?	1	2	3	4
50.	Have you had trouble eating in front of your family?	1	2	3	4
51.	Have you had trouble eating in front of other people?	1	2	3	4
52.	Have you had trouble enjoying your meals?	1	2	3	4
53.	Have you had trouble talking to other people?	1	2	3	4
54.	Have you had trouble talking on the telephone?	1	2	3	4
55.	Have you had trouble having social contact with your family?	1	2	3	4
56.	Have you had trouble having social contact with friends?	1	2	3	4
57.	Have you had trouble going out in public?	1	2	3	4
58.	Have you had trouble having physical contact with family or friends?	1	2	3	4
59.	Have you felt less interest in sex?	1	2	3	4
60.	Have you felt less sexual enjoyment?	1	2	3	4

During the past week:		No	Yes
61.	Have you used pain-killers?	1	2
62.	Have you taken any nutritional supplements (excluding vitamins)?	1	2
63.	Have you used a feeding tube?	1	2
64.	Have you lost weight?	1	2
65.	Have you gained weight?	1	2

Attachment III. The WinRasch File

TITLE	"QLQ C30 Primeira consulta"
PERSON	Person; persons are...
ITEM	Item; items are....
ITEM1	1; column of response to first item in data record
N1	25; number of items
NAME1	26; column of first character of person identifying label
NAMELEN	5; length of persin label
XWIDE	1; number of columns per item response
CODES	0123; valid codes in data file
CLFILE	*; category label file for category naming
1+0	"not at all"
1+1	"a litle"
1+2	"quite a bite"
1+3	"very much"
; end of CLFILE=*list	
UIMEAN	50; item mean for local origin
USCALE	10; user sclaing or logits
UDECIM	2; reported decimal places for user scaling

Attachment IV. EORTC QLQ C30 Scales and Items

EORTC QLQ-C30	
	Item Numbers
Global health status/QoL	
Global health status/QoL	29, 30
Functional scales	
Physical functioning	1, 2, 3, 4, 5
Role functioning	6, 7
Emocional functioning	21, 22, 23, 24
Cognitive functioning	20, 25
Social functioning	26, 27
Symptoms scales/items	
Fatigue	10, 12 ,18
Nausea and vomiting	14, 15
Pain	9, 19
Dyspnea	8
Insomnia	11
Apetite loss	13
Constipation	16
Diarrhea	17
Financial difficulties	28

Attachment V. Poster Presented in XVII Jornadas de Medicina Dentária da Universidade Fernando Pessoa

Oncologia Oral:

Sistemas de Informação na Recolha dos "*Patient Outcome Results*"

Castro, A.R.[1]; Sequeira, T.[2] ; Gouveia, F.[3]; Silveira, A.[2]

Introdução

Pretende-se analisar a importância dos sistemas de informação na recolha dos *Patient-Reported Outcomes* (PROs) na área da Oncologia Oral, utilizando o modelo matemático de Rasch.

Estudos clínicos e epidemiológicos indicam que os e sistemas de informação contribuem para melhorar a qualidade de vida dos pacientes, bem como optimizar recursos relacionados com a Saúde (fig. 1).

Método

Realizou-se uma revisão narrativa da literatura subordinada às palavras-chave: "*Patient-reported outcomes*", "*PRO*", "*Quality of life*", "*Rasch model*", "*Oral Oncology*", nos motores de busca: *B-on, Pubmed, NCBI.*

Analisou-se a ferramenta Oncology Platform: *Quality of Life* (OpQoL) que regista PROs na Unidade de Cabeça e Pescoço no Instituto Português de Oncologia do Porto.

Fig. 1 – Vantagens dos PROs

Fig. 2 – Aspecto da entrada da plataforma OpQoL

Fig. 3 – Aspecto da apresentação da informação na plataforma OpQoL

Resultados e Discussão

A validação dos PROs reflete a condição de Saúde do paciente, fornecida pelo próprio, configurando um feedback multidimensional que abrange diferentes estados, destacando-se físico, funcional, emocional e cognitivo.

A OpQoL (figs. 2 e 3) é uma plataforma desenvolvida com participação de investigadores clínicos que demonstrou a sua utilidade para a recolha de informação sociodemográfica, clínica e PROs do doente oncológico de Cabeça e Pescoço, mais concretamente dirigidos à avaliação da Qualidade de Vida Relacionada com a Saúde em Oncologia.

A análise Rasch é uma metodologia de modelação matemática que permite medir PROs na mesma escala, possibilitando o enquadramento da perceção individual no grupo de pacientes em questão.

Conclusão

Sendo os PROs dados reportados pelo próprio paciente, admite-se que o seu grau de confiabilidade é elevado. A inclusão dos PROs numa plataforma de recolha sistemática de informação permite não apenas uma rigorosa monitorização da evolução do doente oncológico ao longo do seu percurso na doença bem como a sua contextualização num grupo mais alargado de doentes com a mesma patologia.

A implementação de sistemas de informação que possibilitam a recolha e processamento do PRO que constitui a avaliação da Qualidade de Vida, constitui um importante recurso na prática clínica pois a sua contínua monitorização permite a apreciação da sua evolução, suportando assim a tomada de decisões clínicas em Oncologia Oral.

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Head and Neck cancer: Quality of Life Assessment using Item Response Theory

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Aims:

Explore the role of Item Response Theory (Rash Model) in Head and Neck Cancer (HNC) patients Quality of Life (QoL) assessment comparing person's "ability" and question's "difficulty" by groups.

Methods:

Consecutive outpatients (n=392), with anonymous identifier, admitted to the Otorhinolaringology and Head and Neck Services of Oporto Oncology Portuguese Institute (IPO-Porto) completed EORTC QLQ-C30) and EORTC QLQ-H&N35- Portuguese version immediately before consultation as a part of the routine evaluation. An Informatic Platform for QoL assessment was used. Inclusion criteria were: ability to understand written and spoken Portuguese and provision of written consent. The Item Response Theory (Rasch Model) was implemented by WinRasch Software. IPO-Porto QoL data base was analysed, constructing a line of measurement with the items placed hierarchically providing fit statistics.

Results:

We were able to identify which responses were more unexpected, and what were the question that which patients had greater difficulty in responding. We also organize persons

from high measure to low measure, and the items from low measure (easy) to high measure (hard). The answers can be order by the infit or outfit.

For example the following results shows that the patient A had the outfit higher than infit which means that the answers given do not match the expected ones for this patient.

The question wiht most outfit was Q16: “Have you been constipated?”

The harder question to answer was Q1: “Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?”

ENTRY NUMBER	TOTAL SCORE	TOTAL COUNT	MEASURE	MODEL S.E	INFIT MNSQ ZST	OUTFIT MNSQ ZSTD	PT MEASUR-AL CORR .EXP.	EXACT MATCH OBS% EXP%	PERSON
51	67	25	71.95	3.78	1.11 .4	3.19 2.7	A -28 .31	44.0 69.2	A
30	65	25	69.38	3.42	2.25 2.6	2.43 2.2	B .12 .34	64.0 65.8	B
15	71	25	79.60	5.19	2.36 2.0	1.40 .7	C .23 .22	92.0 85.2	C

Conclusions:

The presente study identified person's "ability" and question's "difficulty" by groups in order to analyze why patients consider some itens labored.

Item Response Theory (Rash Model) identifies unmet problems that can highlight the motives behind discrepancies supporting measurement confidence.

Our research team incorporates QoL assessment in clinical practice and therapeutic decisions. HNC patients are a quite heterogeneus and complex group considering clinical and social-demographic parameters - measurement confidence is thus a crucial goal.