

Understanding Medical Information: A Challenge for Breast Cancer Patients

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Table of contents

- Introduction
- Real Problem: Understanding of Medical Information
- Objectives
- Methodology
- Analysis and results
- Conclusion
- Bibliography

Introduction (I)

PhD thesis: *Intelligibility of Health Discourse: The Case of a Virtual Community of Breast Cancer Patients*



TOGETHER: overcoming socio-educational barriers and promoting literacy on the interferences and difficulties in understanding information and documentation aimed at families of children affected by rare diseases. RecerCaixa IP: Rosa Estopà (UPF) (70%) and Manuel Armayones (UOC) (30%).

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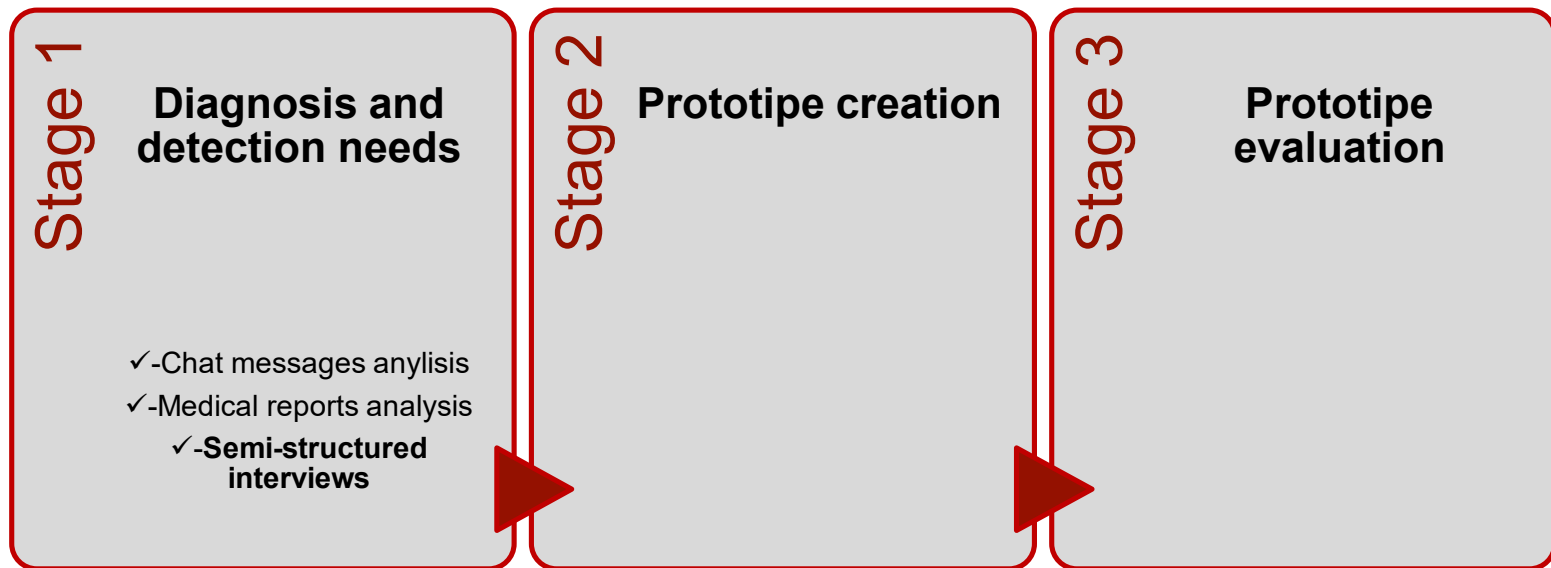


Communities. Psico-oncología online (IP: Dr. Cristian Ochoa) - Unidad de Psico-oncología del Hospital Duran y Reynals, Institut Català d'Oncologia (ICO) / Departament de Salut, Generalitat de Catalunya

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Introduction (II)

PhD thesis: *Intelligibility of Health Discourse: The Case of a Virtual Community of Breast Cancer Patients*



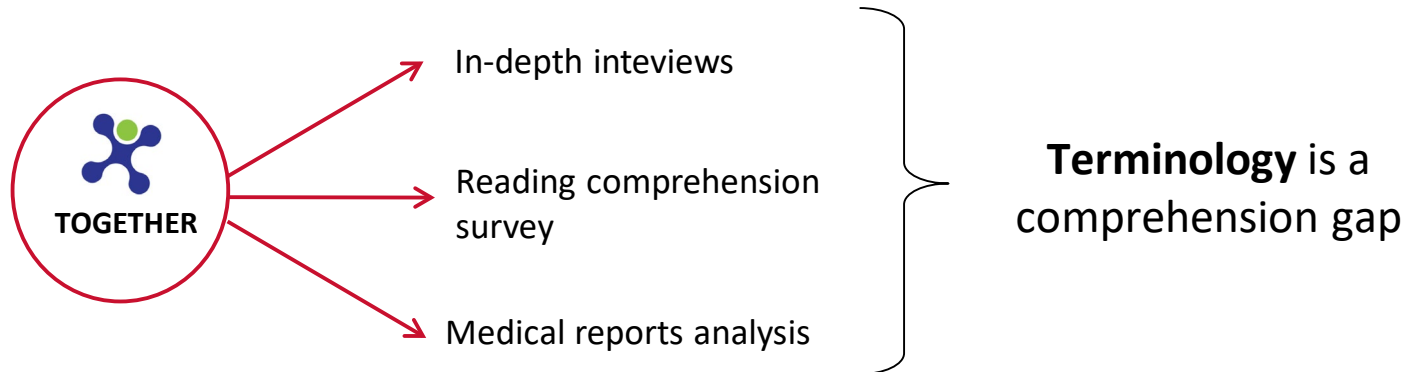
Context: **Virtual community of breast cancer patients**

Real problem

- Medical paternalism
- Empowered patient
- Health literacy
- Health information
- Plain language
- Comprehension of information



TOGETHER Project – IULATERM research group



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Objectives

- 1 Identifying the difficulties or limitations that cancer patients have regarding the available information on diagnosis and treatments.
- 2 Determining the level of knowledge that patients have on diagnosis and treatments through the lexicon and the terminology.

Methodology (I)

1

Interview design

2

Protocol presentation and validation in the participating hospitals

3

Writing the questions guide

4

Selection of participants

5

Interviews

6

Interviews recording

7

Interviews transcription

8

Selection of relevant ideas for the study

9

Ideas classification by thematic categories

10

Interpretation of results



Methodology (II)

Interview: individual, half-structured

Scope: multicentric study



Participants: breast cancer patients

Inclusion criteria

Older than 18 years old
Currently ill
Diagnosed less than one year ago

Exclusion criteria

Patients that abstain to participate
Disease that affects the cognitive state

Sample: convenience sample, 6 interviews (3 per hospital)

Variables: age, time of diagnosis, education level, type of breast cancer, disease stage, treatments

Methodology (III)

Statistical methods: qualitative methods

Questions guide: 5 sections validated by an educational psychologist

1. Personal data
2. Introduction question
3. Diagnosis questions
4. Treatments questions
5. Conclusion

Ethical issues: ethic protocols in each centre, anonymous data, prior oral informed consent

Analysis and results (I)



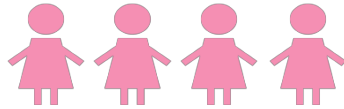
Principal patterns:

- a) Do patients want to receive information about the disease?
- b) Do patients have enough information about the disease?
- c) Which information sources do they use?
- d) Do patients understand the medical information they have?
- e) Which role plays the terminology in the comprehension of information?

Analysis and results (II)

a) Do patients want to receive information about the disease?

Group 1



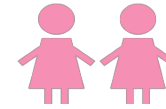
Example 1: "No, no, I always read a lot and in accordance with what they were telling me I started to search on the Internet and I was getting the information."

about the disease

Example 2: "Nobody told me what radiotherapy was or how it worked...No...The truth is that I was curious."

Empowered patients

Group 2



Example 3: "No, because I try not to get a lot of information."

want to receive

Example 4: "No, I looked it up on the Internet ... but I didn't want to ... you know, because I didn't want to know much."

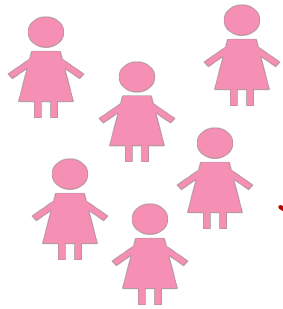
Contradiction

They claim that in any moment of the therapeutic process, they have looked for information about the disease.

Analysis and results (III)

b) Do patients have enough information about the disease?

6 out of 6 patients **lack information** during the therapeutic process.



"But no .., It was missing, right? the information and such, and I know that one day at night I called, I had a doctor's phone number, and I called to tell him, *listen, I need to talk to you because, listen, I do not know if I am dying or not.*"

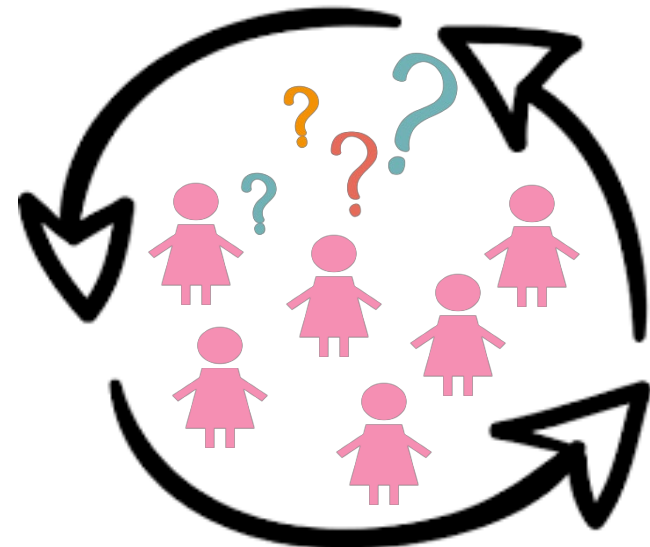
"Of course, I did not know if hormonal ... well, no, I did not know what type of cancer... what treatment you had for hormonal cancer type... But of course, I thought, damn, if they keep finding things in me, more and more, it may involve chemotherapy and then yes, I looked for information, then, *treatments that you have to do if you have...*"

Analysis and results (IV)

c) Which information sources do they use?

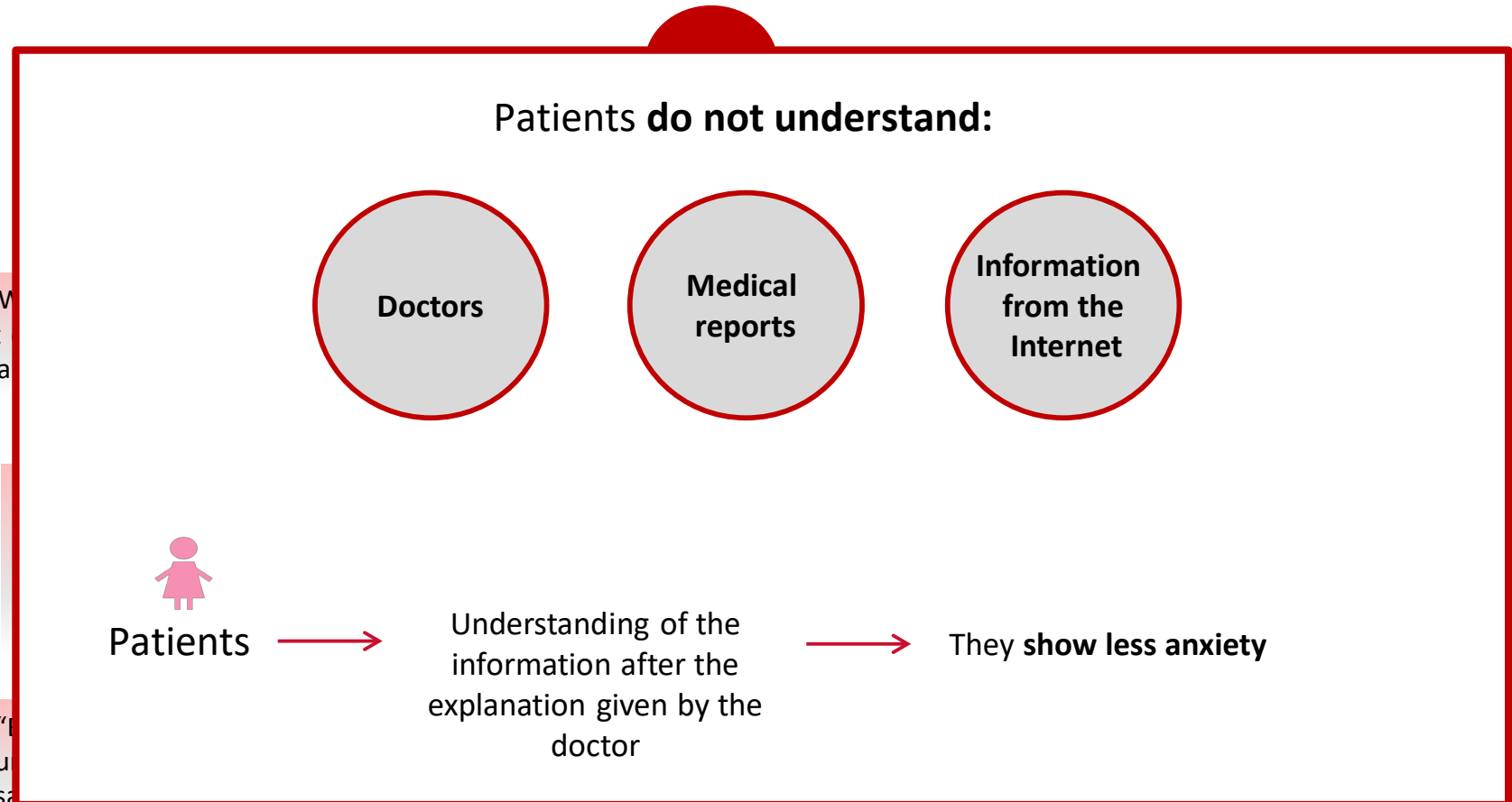
- Internet
- Breast cancer health professionals
- Family or friends who have knowledge of medicine
- Other patients
- Relatives who accompanied them to the visits
- Conferences

Oncologists
Gynaecologists
Nurses



Analysis and results (V)

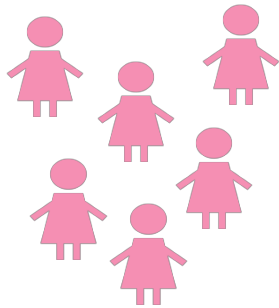
d) Do patients understand the medical information they have?



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Analysis and results (VI)

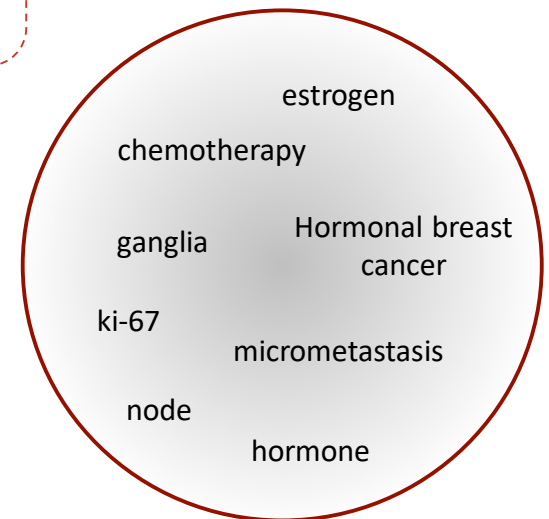
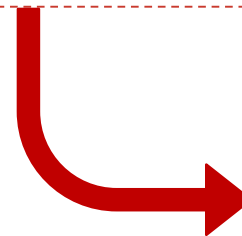
d) Which role plays the terminology in the comprehension of information?



"The words that doctors use...The truth is that they are very difficult for patients to understand because, of course, we have not studied to be doctor. So, it's very distressing about that."

They claim that they do not understand the information because of the terminology.

They can identify some key terms of the disease, but they can not explain them well.



Conclusion

1. Almost 100% of the patients claim to be **users of information**. They also admit having searched for information at some time during the therapeutic process.
2. All patients have felt that **they did not have enough information** about something related to the disease at least one time during the therapeutic process.
3. **Patients are not satisfied with the information sources they have**. All of them use the Internet, although they consider that it is not reliable source of information and having the information to ask health professionals directly is not a fast option. In this sense it would be interesting to prescribe information to patients.
4. All patients claim to have had **problems in understanding** issues related to the disease at least once during the therapeutic process.
5. It is important for patients to understand the information because **it reduces anxiety and favors the active role of the patient** in the disease.
6. Most patients **identify some of the key terms** of the disease, **but they do not know how to explain them** and sometimes they mix up the terms.
7. It is especially important to **explain the disease key terms** when writing a medical text for a non-specialist audience so that the terminology is not a barrier for understanding. * ***Breast Cancer Dictionary for patients*** - Group IULATERM-UPF

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Thank you for your attention

Moltes gràcies

Takk skal du ha

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