BARRIERS TO PARTICIPATION IN CANCER TRIALS: A SURVEY ON CLINICAL RESEARCH PERCEPTION

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Patient group importance

• Advocacy groups are considered very important by patients regarding disease-related information, quality of life and unmet needs on patient’s perspective\(^1,2\)

• In oncology, patient’s groups are important to provide emotional support, information and solidarity to patients\(^3\)

Oncoguia Institute

• Created in 2009
• An independent non-profit institution
• Mission: to help cancer patients live better
Channels of Communication

- Oncoguia Web Portal: www.oncoguia.org.br
- Program Of Support And Counseling For Cancer Patients (PAP)
- Advocacy
- Patient Space
- Social Media (Facebook, Instagram, Twitter, YouTube)
- Educational Events
- Public Policy National Forum
- Educational Campaigns
- Strategic meetings
Barriers in Clinical Trials

Recruitment

- Potential Patient Pool
- Study designed & protocol developed
- Patient becomes aware of study
- Contact & pre-screening with call center
- Contact & pre-screening with site
- Screened at site
- Enrolled Patient
- Lost Patients

Public awareness/attitudes about trial
Barriers in Clinical Trials Recruitment

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Patients Awareness on Clinical Research

- Lack of patients’ awareness is one of the major barriers on clinical trials recruitment

- Physician-patient miscommunication and clarifications regarding clinical research impairs clinical trials recruitment

Rationale / Objectives

- Clinical research brings benefits to scientific development and saves money to public system

- In Brazil, lack of information on clinical research may impair patients participation in clinical trials

- For these reasons, the present study aimed to identify level of knowledge on clinical research by the Oncoguia Web Portal users – cancer patients and relatives
Methodology

- Online survey applied to Oncoguia Web Portal users
- Questionnaire applied covered:
  - Clinical research definition
  - Source of information on clinical research
  - Clinical research contribution to cancer treatment development
  - Would you participate on a clinical trial?
  - Do you know anyone who has ever participated on a clinical trial?
Results

- April 2012 to October 2014
- Internet-based survey from Oncoguia Institute to access their knowledge regarding clinical research
  - “What is clinical research?”
- 254 respondents
  - Mainly described as “New Treatment to diseases”
Sources of Information on Clinical Research

- 96% Of Patients Heard of Clinical Research
- 69% Internet
- 18% Hospital Education Material and Healthcare Professionals
- 11% TV, Radio, Magazines and Folders
- 2% Other Patients
Do you believe clinical research can bring advances to cancer treatment?
Improvements brought by clinical research

- Increase scientific knowledge
- Improve treatment
- Seek cure
- Improve quality of life
- New treatment option
Participation in an oncologic clinical trial

Would you participate in a clinical trial in oncology?

Yes: 85.0%
No: 15.0%

Reasons given to participate in a clinical trial
Previous participation in clinical trials

Do you know anyone who has participated of a clinical trial?

Yes: 20.1%
No: 79.9%

Myself (44.2%)
Friends (25.6%)
Relatives (20.9%)
Other (9.3%)
Conclusions

• Survey respondents associate clinical research with an option in cancer treatment

• The main source of information was internet, which can give some misleading information on the topic

• Lack of awareness affect patients’ availability in participating in clinical trials

• Improvement of physician and patients’ awareness are potential solutions to the current scenario

• Improve communication between patient and physician
Obrigada!
Thank you!
Muchas Gracias!

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Você não está sozinho