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BEYOND HEALTHCARE: INFORMATION AND EDUCATION FOR PATIENTS AND CITIZENS

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INTRODUCTION

In recent years, following the development of new technologies, there is greater possibility and easier access to health information but this information is not always correct. So the citizen with a greater amount of information resources available, does not always possess adequate means to distinguish the reliability and accuracy of scientific content, that is sometimes difficult to understand for non-specialist audiences.

"The Patient Library" is a section dedicated to patients and their families, which is part of the Scientific Library of Carlo Besta Neurological Institute (Milan, Italy) and has two souls: one with a narrative purpose provides inpatient readings entertainment for humanizing hospital services; the other one collects information materials on neurological diseases and cancer, through simply correct scientific language. Neuro-Oncology Information Point (PINO) is a welcome and information service that offers free information material and multimedia.

1

AIMS

The main objective is to respond to the information needs; supply personalized information, scientifically correct, current and understandable to improve quality of life as well as physical and mental wellbeing; educate in asking the appropriate questions of health information; provide tools to find quality health information and to evaluate the reliability of resources available on the web.

The Information Point promotes education and patient empowerment, strengthens the ability of individuals to understand the information and to make informed choices; raises the level of health literacy of citizens by improving the state of health or disease management; facilitate communication between the physician and the patient.

2

METHODS

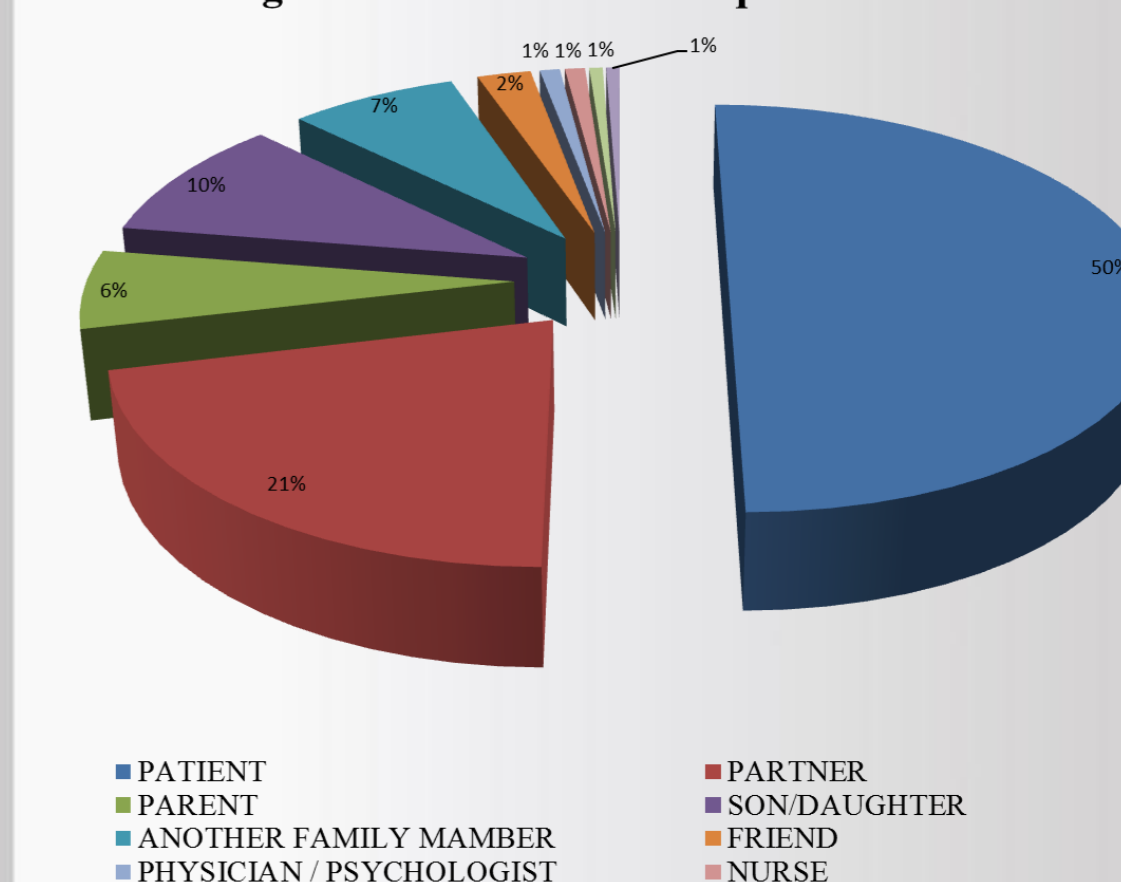
The data was collected at IRCCS Istituto Neurologico C. Besta, Milan, Italy, from March 2014 to March 2016. Data collection with survey form aimed to detect the information's need related to neurological and oncological disease. The users fill out an anamnestic questionnaire and after a satisfaction questionnaire to evaluate the service supplied, the quality of information received, and takeout on how they became aware of the Neuro-Oncology Information Point.

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RESULTS

We approached 338 users and 50% of these patients are. In Figure 1 you can see how the users are distributed.

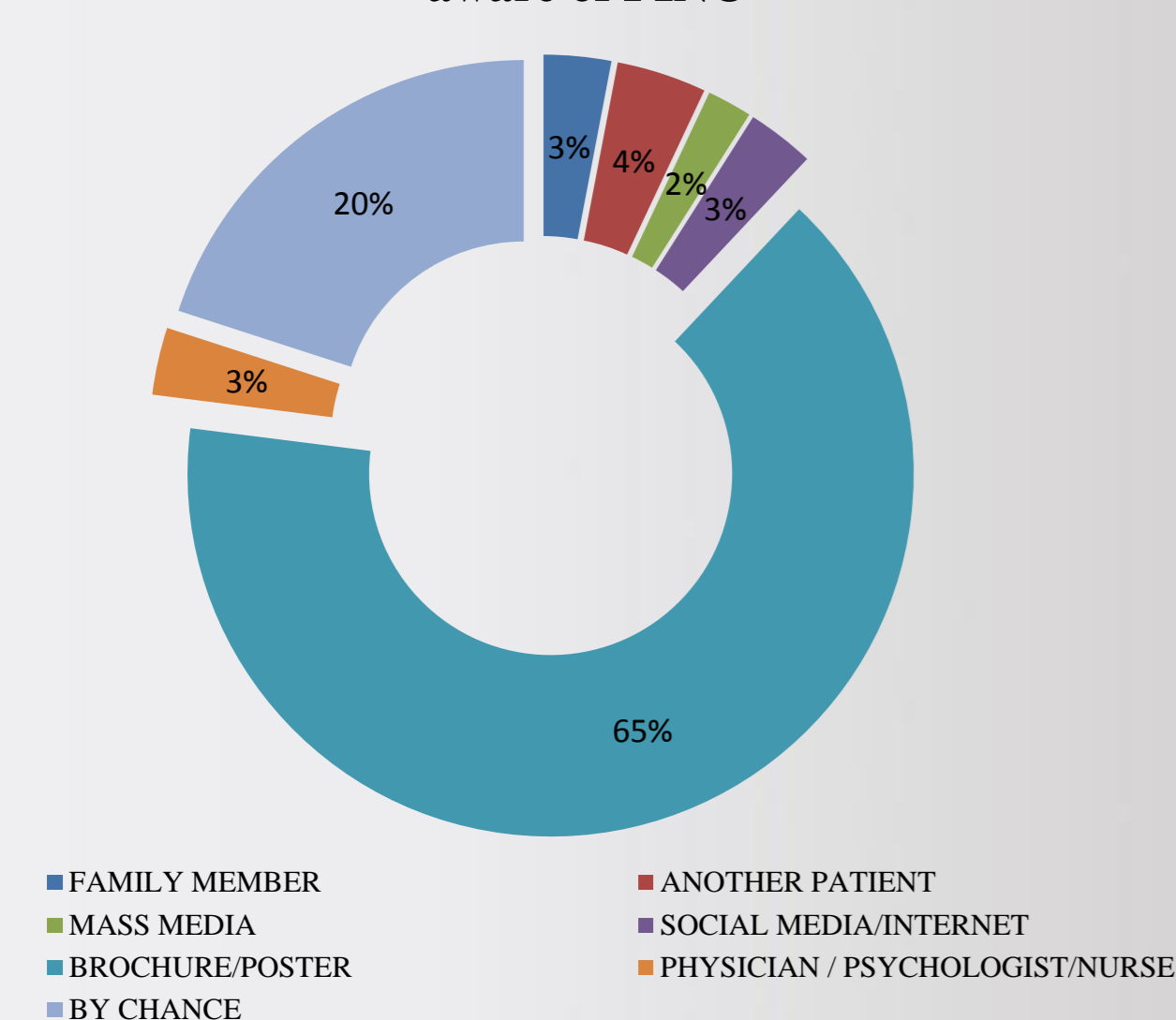
Figure 1: Users who has requested information



4

96% of users have requested information personally while the remaining 4% contacted us by phone or email. Most of those who have requested information (65%) have become aware of the presence of PINO thanks to the brochure distributed by us and posters. The different ways in which users have become aware of the information point are presented in Figure 2.

Figure 2: The different ways to become aware of PINO



5

On average, users were 53 years old. Age ranged from 7 to 86 years old. 53% of users were male whereas 47% were female. 93% of subjects are Italian, 53% were from northern Italy, 37% from the south and from the islands and 10% from central Italy. About half of the users (45%) are high school graduates

The majority of patients (85%) had a brain tumor. 56% of patients had a primary tumor and 16% a tumor recurrence. Table 1 present personal and clinical data.

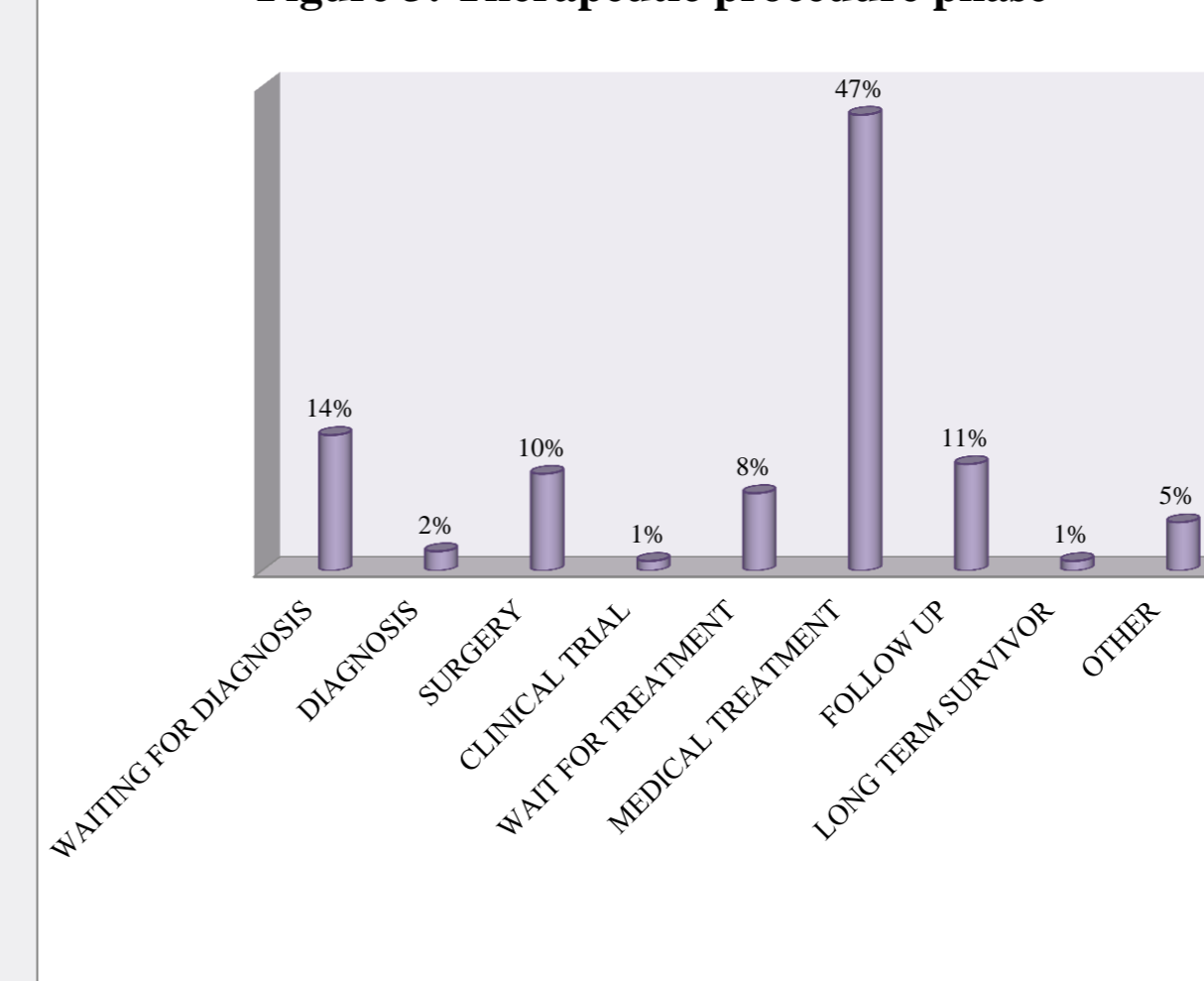
Table 1: Users personal and clinical data

Users age	Mean	Range	Value
Users age	53	7-86	
Users gender	Male	Female	53% 47%
Users Nationality	Italy	North	93% 53%
		Central	10%
		South	37%
		Other	7%
School attendance	Less than compulsory education	Compulsory education	14% 19%
		High School	45%
		Graduate	18%
		Student	4%
Patients tumor type	Brain Tumor	Other	85% 15%
	Primary	Recurrence	56% 16%
		Metastatic	6%
		Remission	4%
		Missing	18%
Place of treatment	At home	Day Hospital	58% 21%
		Hospitalized	20%
		Hospice	1%

6

At the time they contacted us 47% of patients was subjected to medical treatment, 14% had waiting for diagnosis, 11% in phase of follow-up and 8% waiting for medical treatment. Therapeutic procedure phase are described in figure 3.

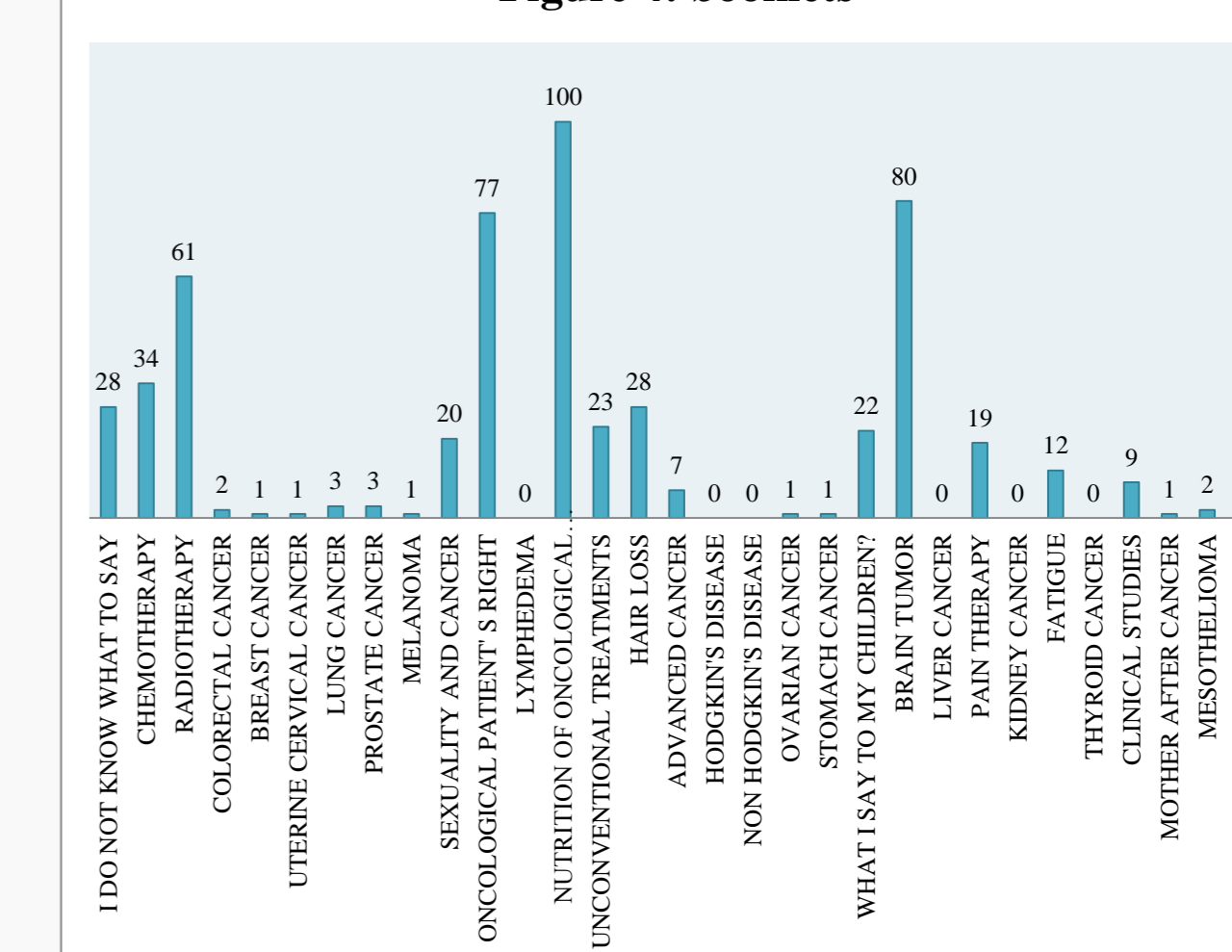
Figure 3: Therapeutic procedure phase



7

We distributed 538 booklets, of these the most requested were "Nutrition in oncological patient" (100), "Brain tumor" (80), "Oncological patient's rights" (77) and "Radiotherapy" (61). In Figure 4 you can see booklets distribution.

Figure 4: booklets



8

Patients report through the satisfaction questionnaire that the information given by the PINO volunteers are helpful and all users would recommend to patients, family members and friends of patients contact the information point.

«Good information is the best medicine»
(D. A.B. Lindberg).

CONCLUSIONS

The data show that among the most distributed booklets were those concerning the brain cancer pathology, this agrees with the hospital setting in which our information point is established. We were in an institution that deals exclusively with neurological disease. The disease phase in which patients or their caregivers contact us asking for information was primary diagnosis. The two phases of the therapeutic process in which patients or their caregivers ask more information were: "Medical Treatment" and "Waiting for diagnosis".

Scientific literature has shown that well-informed patients are better able to follow the doctor's prescriptions, be an active participant during the course of care and make informed decision.

Acknowledgements

We would like to thank AIMaC for helping us to be an active part in patient care through its informative booklets and multimedia tools, with the hope of improving the quality of life of our users.

11

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12

