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## Communicating cancer diagnosis and prognosis: When the target is the elderly patient—a GIOGer study

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### ABSTRACT

**Background:** Effective communication to cancer patients allows better emotional response to diagnosis, coping with health professionals and compliance to treatment. We lack specific studies on patterns of clinical communication in elderly patients, their involvement in decision making and the role of their families.

**Patients and methods:** Structured interviews to collect information on diagnosis and prognosis disclosure, satisfaction with information, compliance to disease experience and willingness toward receiving more information and coping, were administered to patients age 65 years and older and receiving chemotherapy.

**Results:** Six hundred and twenty two patients completed the interviews and were evaluated. Four hundred and twelve (66.2%) were informed, 210 (33.8%) were not informed. Information was associated with age, degree of education, geographical area, ECOG-PS, tumour site and family composition and the patient's perception of being supported in the disease experience.

The majority of the patients consider their families as the main source of support in the disease experience (86.5%), wish to have a family member participating in oncology consultation (79.1%) and consider the information received complete and understandable or clear and reassuring (80%). Receiving adequate information facilitates a better patient–health professional relationship for 84.8% of the patients. 63% of the patients dealt positively with cancer and 62.2% showed positive expectations for the future. Informed patients refer better expectation than those not informed.

**Conclusion:** Our study underlines the importance of clinical information for older cancer patients and the need to involve family members in the processes of diagnosis and prognosis disclosure and decision making.

Health professionals must consider specific age-related issues including social, cultural and emotional aspects and understand the role that the family members play in the disease experience of elderly patients. Competent caring for elderly cancer patients must provide adequate information and emotional support not only to the patients but also to their family to assure appropriateness of care.

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## 1. Introduction

Over the past decades, health professionals' attitudes toward clinical communication to cancer patients have changed radically worldwide. However, the gap between legal and theoretical guidelines and current clinical practice remains substantial.<sup>1,2</sup>

Several studies indicated that effective clinical communication to cancer patients allows a better emotional response to cancer diagnosis as indicated by reduced anxiety and depressive symptoms, coping with health professionals and compliance to the treatment plan.<sup>3–5</sup>

Although studies reported that 60% of the patients wish to know their prognosis and a more consistent 72% their diagnosis, currently less than 50% of physicians offer adequate information to their patients.<sup>5</sup>

Clinical communication differs according to cancer site and stage: patients affected by worse prognosis tumours frequently receive only limited information.<sup>1,6,7</sup> Moreover, information varies according to demographic variables, including age, race, education and income, and in different geographical areas and cultures.<sup>8–12</sup>

In the USA and Northern Europe patients are generally better informed in comparison with Southern Europe and South America. However, the practice of reducing clinical information to patients with more severe disease is widespread.<sup>13–15</sup>

Older patients represent an increasingly common aspect of the practice of oncology, accounting for more than 55% of new cancer diagnoses. Due to comorbidity, sensory, cognitive and physical deficits, older patients are heterogeneous and their management requires special attitudes.<sup>16,17</sup>

Clinical communication differs according to the age of the patients.<sup>18</sup> Health professional ageist attitudes, in particular for those patients presenting with poor health status and low socio-economic support, may increase the risk for not receiving adequate care and information and hence exclusion from the decision making.<sup>2,19–21</sup> An accompanying person is frequently present at the medical consultation and many elderly patients may prefer a limited involvement in, and wish to delegate the physician or a family member for, medical decisions driving the choice of non-disclosure.<sup>20–28</sup>

Preferences of older patients for cancer information and involvement in medical decision making have been poorly studied and we lack specific studies addressing the wishes of older patients to know about their disease and the exact role played by the family and health professional in clinical communication.

Thus, we conducted a study in older cancer patients to investigate current patterns of clinical communication in Italy and relevant reasons reported by the patients, the family caregivers and the health professionals who were interviewed. The relationship between diagnosis and prognosis disclosure with patient and tumour characteristics was also evaluated.

This paper reports the results from the interviews administered to 622 cancer patients.

## 2. Patients and methods

This is a multicentric observational study. Italian non-academic centres were asked to participate and to recruit at least 10 consecutive eligible patients.

To be included in the study, patients had to present with a newly diagnosed neoplasm or disease progression, be aged 65 or more, be receiving chemotherapy treatment (at least three courses) at the time of study interview or completed treatment in the previous month, have a life expectancy of at least six months, have a non-professional care-giver who consented to be interviewed, and give consent to participate in the study. Two separate consensuses were asked: one for demographic and tumour characteristic study and one for cancer communication interview. Patients with cognitive impairment (MMSE <18)<sup>29</sup> were excluded. Non professional caregivers were considered the closest and best informed family members assisting and coping with the patient.

At study entry the following demographic and tumour characteristics were collected for each patient: age, years of education, number and degree of kinship of permanent cohabitants, centres in which health care was provided, tumour site, stage and treatment.

Trained health professionals administered a structured interview to the patients to collect information on diagnosis, treatment related side effects and prognosis disclosure. Patients were also interviewed to investigate their degree of satisfaction on information received, their compliance to the disease experience in both clinical and emotional/psychological aspects and their willingness toward receiving more information and coping.

The interview combined a highly structured agenda with flexibility to ask subsequent questions. The interviewer asked the participant their attitude towards the study, how they were feeling, and whether they had any problems. Although this preamble gathered useful information, it was primarily aimed at easing the elderly patients into the interview and making them feel comfortable and relaxed. The interview was very well received by participants. Almost all the questions were found to initiate interesting responses and discussions, particularly those concerning relationships with parents and physicians. For an interview lasting 1 h, around 10–15 questions would typically be asked. Another important aspect of this technique was that the interview was transcribed, providing a protocol for detailed analysis.

Based on information received, patients were categorised into two groups by responsible physicians as follows: informed patients, i.e. patients who received substantial information on cancer diagnosis and prognosis directly from the physician; not informed patients, i.e. patients who received only limited information, aimed mainly at reassurance, the information on diagnosis and treatment was vague and almost non-existent regarding prognosis, or patients were not aware of the severity of their disease.

### 2.1. Statistical analyses

The associations between grade of information and selected characteristics were assessed by means of odds ratios (OR) and their 95% confidence intervals (CI). ORs were adjusted for sex, age, educational level, geographic area, tumour site, disease stage and performance status (ECOG) through multiple logistic regression (MLR) equations.<sup>15</sup> Data management and analysis were performed using SPSS version 15 (SPSS, Chicago, IL). For the purpose of regression analyses we

considered two categories of information: informed and not informed patients.<sup>31</sup>

### 3. Results

Six hundred and twenty two patients were recruited in 47 Italian centres. Characteristics of the patients are shown in Table 1. Mean age of the patients was 72 (interquartile range 68–76), 51.9% were male, 58.8% had <5 years of education, 43.1% were rated as ECOG PS 0 and 81.2% presented advanced disease. Based on received information, we observed 412 (66.2%) informed patients and 210 (33.8%) not informed patients.

Table 2 shows odds ratios and 95% confidence intervals for the association of the grade of information and selected patient characteristics. In the multivariate analysis, the chance to be better informed was significantly associated with age, education level, geographical area, ECOG-PS and the number of family members. Stage of disease was not correlated with the level of information.

Better educated patients have 5.8× more probability and breast cancer patients have 2.5× more probability of being informed in comparison with patients with <5 years of education or those affected by colon cancer respectively. Patients living in Northern Italy were more informed in comparison with patients from Central and Southern areas. Patients living

with two or more persons were less informed in comparison with patients living with just one person, especially if patients were living with their spouse.

Interviews were completed by 598 patients, 24 patients refused the consensus due to concerns by the family caregiver on the possible negative effect of discussing communication issues with the patients.

The distribution of the patients according to levels of information is shown in Appendix B. We observed an association between information and the patient's perception of being supported in the disease experience. 517 patients (86.5%) indicated their family members as the main source of support with only 58 patients (9.7%) indicating health professionals (question 1). For 473 patients (79.1%), having a family member participating in oncology consultation makes the relationship with the physician easier; this observation was not associated with the degree of information (question 3).

Overall, 406 (67.9%) patients were satisfied with the received information. However, satisfaction varied with the level of information with informed patients (*n*.298, 73.0%) being more accomplished with the received information than the not informed patients (*n*.108, 56.8%) (question 4). 49.5% of the patients prefer to be directly informed by the physician with a consistent 45.5% who prefer to be assisted by a family member during oncology consultation (question 5).

Three hundred and fifty three patients (59%) believed their family carer had not received more information than themselves; the large majority of these patients, 286, were informed patients (question 6). When asked if their relatives would have received more information and to explain the reason, 275 patients (46%) were unable to answer. The distribution of the answers was different according to the level of information: 52.6% of the not informed patients indicated that it was a relative's choice, against 21.1% of informed patients (question 7).

Overall, about 80% of the patients considered the information received complete and understandable or clear and reassuring (question 8).

Four hundred and fifty six patients (76.3%) answered that receiving clinical information allows better emotional control of both disease and treatment-related difficulties (question 9).

Regarding the relationship with health professionals, 507 (84.8%) patients claimed that receiving adequate information facilitates a better patient–health professional relationship: among uncertain patients the most represented were not informed patients (*n*. 48, 25.3%) (informed patients *n*. 23, 5.6%) (question 10).

About 84.9% of the patients referred that they had received exhaustive information on potential side effects with no difference according to the level of information (question 11). Providing prior information on possible treatment related side effects is perceived as a source of anxiety by 144 patients (24.1%) and as a tool to better cope with difficulties for 371 patients (62%). Not surprisingly, the proportion of worried patients increased among less informed patients (35.8 versus 25.5%) (question 12).

29.8% of our patients considered being informed in advance on treatment related side effects meaningful in order to decide whether or not to drop out of the treatment (question 14).

**Table 1 – Characteristics of 622 patients aged 65 or more**

	Total	Total n (%)
		622
Sex	Male	323 (51.9)
	Female	299 (48.1)
Age (years)	65–69	231 (37.1)
	70–74	203 (32.6)
	75 o +	188 (30.2)
	Informed	412 (66.2)
Grade of information	Partially informed/ Not informed	210 (33.8)
	Northern	132 (21.2)
Italian zone of the reference centre	Central	233 (37.5)
	Southern	257 (41.3)
	<5	366 (58.8)
Years of education	6–8	112 (18.0)
	9–13	85 (13.7)
	>13	45 (7.2)
	Unknown	14 (2.3)
	Oncological site	Colon–Rectum
Breast		143 (23.0)
Lung		110 (17.7)
Other		209 (33.6)
Disease status	Initial	117 (18.8)
	Advanced	505 (81.2)
Performance status (ECOG)	0	268 (43.1)
	I or II	335 (53.9)
	III or IV	15 (2.4)
	Unknown	4 (0.6)

**Table 2 – Unadjusted and adjusted odds-ratios (OR) and 95% confidence intervals (95% CI) for the association of grade of information and selected characteristics in 622 oncological patients aged 65 years or more<sup>a</sup>**

	Grade of information				Total	Odds-ratio			
	Informed		Not informed			Unadjusted		Adjusted <sup>b</sup>	
	N	%	N	%		OR	95% CI	OR	95% CI
Sex									
Male	204	63.2	119	36.8	323	1		1	
Female	208	69.6	91	30.4	299	1.3	1.0–1.9	1.1	0.7–1.7
Age (years)									
65–69	177	76.6	54	23.4	231	1		1	
70–74	131	64.5	72	35.5	203	0.6	0.4–0.8	0.5	0.3–0.8
75+	104	55.3	84	44.7	188	0.4	0.2–0.6	0.4	0.3–0.6
Years of education									
<5	222	60.7	144	39.3	366	1		1	
6–8	76	67.9	36	32.1	112	1.4	0.9–2.1	1.3	0.8–2.1
9–13	69	81.2	16	18.8	85	2.8	1.6–5.0	2.6	1.4–4.9
>13	40	88.9	5	11.1	45	5.2	2.0–13.5	5.8	2.2–15.7
Italian zone									
Northern	103	78.0	29	22.0	132	1		1	
Central	168	72.1	65	27.9	233	0.7	0.4–1.2	0.6	0.4–1.0
Southern	141	54.9	116	45.1	257	0.3	0.2–0.6	0.3	0.2–0.5
Disease status									
Initial	89	76.1	28	23.9	117	1		1	
Advanced	323	64.0	182	36.0	505	0.6	0.4–0.9	0.7	0.4–1.2
Performance status (ECOG)									
0	201	75.0	67	25.0	268	1		1	
I or II	199	59.4	136	40.6	335	0.5	0.3–0.7	0.6	0.4–0.9
III or IV	9	60.0	6	40.0	15	0.5	0.2–1.5	0.7	0.2–2.1
Oncological site									
Colon–Rectum	101	63.1	59	36.9	160	1		1	
Breast	115	80.4	28	19.6	143	2.4	1.4–4.0	2.4	1.3–4.6
Lung	65	59.1	45	40.9	110	0.8	0.5–1.4	0.8	0.5–1.5
Other	131	62.7	78	37.3	209	1.0	0.6–1.5	0.9	0.6–1.5
Numbers of co-habitants									
1	78	76.5	24	23.5	102	1		1	
2	225	68.4	104	31.6	329	0.7	0.4–1.1	0.7	0.4–1.2
3+	105	57.4	78	42.6	183	0.4	0.2–0.7	0.4	0.2–0.7
Type of co-habitants									
Partner	257	68.4	119	31.6	376	1		1	
Children	63	55.3	51	44.7	114	0.6	0.4–0.9	0.6	0.4–1.1
Other	14	51.9	13	48.1	27	0.5	0.2–1.1	0.7	0.3–1.7

a In some items, the sum does not add up to the actual total because of some missing values.

b Adjusted for sex, age, years of education, zone, oncological site, disease and ECOG status.

Two hundred and seventy six (67.6%) informed patients considered cancer as one of the trials of their life, showing they dealt positively with the disease and 21.1% of not informed patients (versus 15.9% of informed patients) considered the cancer experience an isolated and sore episode in their life, demonstrating poor ability to cope with the disease (question 15). 66.2% of informed patients referred a positive expectation for their future (question 16).

Finally, 270 patients (45.2%) considered cancer treatment fundamental for disease control, 165 (27.6%) useful to improve their health status, and 131 (21.9%) claimed to receive treatment because it was suggested by the physician (question 17).

#### 4. Discussion

Our series of elderly patients, treated with chemotherapy in non academic centres located in all Italian regions, could be

considered as representative of current oncology practice in Italy.

We found that 33.8% of the patients receive only partial or no information on diagnosis and prognosis.

Patients likely to receive more information are younger and better educated, have a good ECOG-PS, live in North Italian regions with only one permanent co-habitant, the spouse preferably, in comparison with the not informed patients. The large majority of our patients consider their families as the main source of support in the disease experience (86.5%), wish to have a family member participating in oncology consultation (79.1%) and consider the information received complete and understandable or clear and reassuring (80%). Satisfaction and emotional control of both disease and treatment-related difficulties varied with the level of information. Receiving adequate information facilitates a better patient–health professional relationship for 84.8% of our patients. 63% of the patients dealt positively with cancer and 62.2%

showed positive expectations for the future. Informed patients refer better expectation than not informed patients.

There are some limitations with our study, thus our conclusions may not be generalised. First, our patients were diagnosed and treated in Italy, a country in which, due to cultural reasons, the practice of non disclosure is still common. Second, our series include patients heterogeneous because of different tumour types, treatments and prognosis. However, our aim was to study the pattern of clinical information to older patients treated with chemotherapy. Third, information was collected by a structured interview that we developed and piloted in a single institution (Oncology Unit INRCA, Rome).<sup>23</sup> Fourth, we collected information from 47 centres. The ability to communicate with and assess patients and relatives emotions and reactions is influenced by many variables even if health professionals have been trained in communication skills.<sup>32</sup>

The physicians' attitude has substantially changed over the past decades in Italy and in Southern Europe as well, moving from a more 'patronising' and protecting attitude sustaining the practice of not telling the truth, toward a more 'democratic' behaviour which recognises an active role for the patients and a 'sharing' of the decision making.<sup>33–36</sup> However, physicians are still reluctant to consider the older patient as an active partner in the process of decision making.

Chouliara et al. recently reported that older patients are generally content with the information received but due to methodological difficulties there are limits in the ability to generalise findings and in doing research in this area.<sup>37</sup> Our study defined relevant characteristics of older cancer patients likely to receive less information and is in agreement with other authors showing that a substantial proportion of elderly cancer patients are not given complete information on their disease status.<sup>1,5,9</sup>

Such practice appears in contrast with theoretical evidence and current recommendations which provide reassurance concerning the possible risks related to fully informing cancer patients.<sup>38,39</sup> Possible reasons for non-disclosure are various, not documented and include the supposed lack of patient's ability to understand information, the family's wish to 'protect' the patient and the fear of discouraging the patient.

Kawakami et al.<sup>21</sup> reported that the decision of not informing older patients is generally made by the family or medical staff.

Previous studies investigated the wish of elderly patients to receive information and showed that older patients want to know about their disease as adult patients. They also showed that perceived satisfaction varied according to the degree of information given, and even if information was clear and exhaustive.<sup>2,40–45</sup>

Little is known about the role of the family in the decision making process.

We documented that the large majority of older patients wish to rely on their family to cope with the disease experience and also in the decision making process, and consider the presence of a family member during medical consultation as beneficial to facilitating a good relationship with health professionals.

Interestingly, in our series, we observed that patients living with their spouses are better informed than patients liv-

ing with another family member (i.e. daughter, son); this observation may be related to the different social role within the family of the patient. Patients living with their spouses are likely to maintain a more active role and autonomy in decision making in comparison with patients living with their child.

The important role of family members during medical consultation is established in medical literature.<sup>46</sup> Other authors reported that older cancer patients received more emotional support from their family than from health professionals and underlined the importance of the family in clinical decision making.<sup>47,48</sup>

Benson and Britten, studying information disclosure, reported that most non elderly cancer patients valued respect for their autonomy when talking with their family.<sup>49</sup>

There is some evidence that elderly patients may prefer a less active involvement in medical decision making in comparison to younger patients.<sup>50–54</sup>

Our findings confirm that older patients are content with information received and confident of not having received less information in comparison with their family member. Older patients appear in agreement in relying on their family for major medical decision making. Different studies have found that patient preferences for involvement in decision making decline with age, and vary with communication style and beliefs about participation. Some older patients could feel more comfortable with a paternalistic style, where they have to exhibit fewer conversational behaviours and when patients and doctors share similar beliefs about patient involvement.<sup>55–57</sup>

Clinical communication to cancer patients plays a crucial role in the care offered, adaptation to the disease and the ability to cope with the disease.<sup>58</sup> Information disclosure is one of the aspects of supportive care, and has been associated with increasing satisfaction with the patient–physician relationship and decreasing levels of anxiety, mood disorders and affective distress.<sup>59,60</sup>

We confirmed that the degree of information received stands for the patient's perception of being involved in a significant support-based relationship.

When a patient is misinformed, fear and isolation can result. Although bad news is difficult to hear, it has been found essential for the patient to have the possibility to broach this communication. Silliman et al. found clinical information provided to breast cancer patients was thought to be helpful by the majority of older women and an opportunity to improve decision making with respect to treatment and emotional health outcomes.<sup>61</sup>

Our data also support that the degree of information is associated with patients' attitudes toward cancer care. Informed patients appeared better aware and more conscious of the meanings of treatment and exhibited a deeper involvement in their cancer care. They show a better ability to cope with psychological and emotional assumptions of their disease and prescribed treatments. Studies examining the adherence of the elderly to treatment regimes have highlighted the importance of patient satisfaction and patient–physician communication: taking time to provide a full explanation of the medications and discussion of the patients' life context is relevant to medication scheduling.<sup>62,63</sup>

Turk–Charles observed that, although the elderly seem to require less information than younger patients, there were no differences when the information seeking was from non-medical sources.<sup>64</sup> An explanation for these findings is that the elderly become more selective in their interactions, preferring people able to elicit a significant emotional relationship.<sup>65</sup> Green et al. found that older patients are less willing to directly ask question and, conversely, are more satisfied and comfortable providing information based on questions from the physician.<sup>66</sup>

We can hypothesise that having someone who understands their condition is extremely important for elderly patients; indeed, in determining satisfaction, the physician's affective style is more important than contents discussed during the visit. Also, the importance attributed to the presence of a family member during medical consultation, observed in our study, may be explained by such a hypothesis.

In conclusion, our study underlines the importance of providing adequate clinical information to older cancer patients and the need to involve family members in the processes of diagnosis and prognosis disclosure and decision making.

Health professionals must consider specific age-related issues including social, cultural and emotional aspects and understand the role that the family members play in the disease experience.

Competent caring for elderly cancer patients must provide adequate information and emotional support, and not only to the patients themselves, but also to their families in order to assure appropriate care.<sup>30</sup>

### Conflict of interest statement

None declared.

## Appendix A

### A.1. Contributors

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## Appendix B. Distribution of the answers to the items included in the questionnaire for the elderly patient

Total		Informed n (%)	Not Informed n (%)	Total n (%)
		408	190	598
1. Who is the person mostly supporting you in this experience?	A family member	344 (84.3)	173 (91.1)	517 (86.5)
	Health care professionals (physician/s or nurse/s)	44 (10.8)	14 (7.4)	58 (9.7)
	Other	16 (3.9)	3 (1.6)	19 (3.2)
	-	4 (1.0)	0 (-)	4 (0.7)
2. For which needs do you think you did not received sufficient help and/or support?	Help in everyday activity	86 (21.1)	50 (26.3)	136 (22.7)
	Company	69 (16.9)	42 (22.1)	111 (18.6)
	Psychological support	104 (25.5)	48 (25.3)	152 (25.4)
	-	149 (36.5)	50 (26.3)	199 (33.3)

(continued on next page)

## Appendix B—continued

Total		Informed n (%) 408	Not Informed n (%) 190	Total n (%) 598
3. Regarding the possibility to establish a good relationship with health care professionals, in your opinion, the presence of the caregiver, has:	Facilitated the relationship with nurse/s	11 (2.7)	9 (4.7)	20 (3.3)
	Facilitated the relationship with doctor/s	321 (78.7)	152 (80.0)	473 (79.1)
	Prevented a direct relationship	18 (4.4)	12 (6.3)	30 (5.0)
	Other	41 (10.0)	15 (7.9)	56 (9.4)
	–	17 (4.2)	2 (1.1)	19 (3.2)
4. Do you feel your request of information is sufficiently accomplished?	No	7 (1.7)	17 (8.9)	24 (4.0)
	Yes	298 (73.0)	108 (56.8)	406 (67.9)
	Somewhat yes	103 (25.2)	64 (33.7)	167 (27.9)
	–	0 (-)	1 (0.5)	1 (0.2)
5. From who do you believe it is better to receive information regarding your health status:	A family member	6 (1.5)	24 (12.6)	30 (5.0)
	The physician but at in the presence of my family member	173 (42.4)	99 (52.1)	272 (45.5)
6. In this circumstances do you believe your relatives have received more information than you?	Directly from the physician	229 (56.1)	67 (35.3)	296 (49.5)
	No	286 (70.1)	67 (35.3)	353 (59.0)
	Yes	49 (12.0)	57 (30.0)	106 (17.7)
7. If your relatives have received more information than you, it happened because of:	Don't know	71 (17.4)	66 (34.7)	137 (22.9)
	–	2 (0.5)	0 (-)	2 (0.3)
	A physician's choice	60 (14.7)	15 (7.9)	75 (12.5)
	My choice	45 (11.0)	17 (8.9)	62 (10.4)
8. How do you consider the information received?	My relative's choice	86 (21.1)	100 (52.6)	186 (31.1)
	–	217 (53.2)	58 (30.5)	275 (46.0)
	Alarmistic	7 (1.7)	3 (1.6)	10 (1.7)
	Clear and reassuring	101 (24.8)	63 (33.2)	164 (27.4)
	Complete e understandable	244 (59.8)	73 (38.4)	317 (53.0)
9. Do you believe that having information regarding your disease could help you in controlling it and its consequences?	Complete but too technical	45 (11.0)	32 (16.8)	77 (12.9)
	Incomplete	9 (2.2)	18 (9.5)	27 (4.5)
	–	2 (0.5)	1 (0.5)	3 (0.5)
	No	16 (3.9)	15 (7.9)	31 (5.2)
	Yes	341 (83.6)	115 (60.5)	456 (76.3)
	Don't know	48 (11.8)	58 (30.5)	106 (17.7)
	–	3 (0.7)	2 (1.1)	5 (0.8)
10. Do you believe that having information regarding your disease could help your relation with health care -professionals?	No	9 (2.2)	11 (5.8)	20 (3.3)
	Yes	376 (92.2)	131 (68.9)	507 (84.8)
11. Have you been informed adequately on potential side-effects of the treatment you have been given?	Don't know	23 (5.6)	48 (25.3)	71 (11.9)
	No	15 (3.7)	12 (6.3)	27 (4.5)
	Yes. Exhaustively	362 (88.7)	146 (76.8)	508 (84.9)
Yes. But superficially.	27 (6.6)	30 (15.8)	57 (9.5)	
–	4 (1.0)	2 (1.1)	6 (1.0)	

## Appendix B—continued

Total		Informed n (%) 408	Not Informed n (%) 190	Total n (%) 598
12. In your opinion, receiving information on potential side-effects (nausea, asthenia, fever, hair loss) of treatment is:	Non influential	48 (11.8)	33 (17.4)	81 (13.5)
	Reason for being worried	77 (18.9)	67 (35.3)	144 (24.1)
	A way to be better prepared to	282 (69.1)	89 (46.8)	371 (62.0)
	–	1 (0.2)	1 (0.5)	2 (0.3)
13. The presence of a treatment side effect (fever, strong asthenia), could lead you to suspend the cure?	No	281 (68.9)	86 (45.3)	367 (61.4)
	Yes	23 (5.6)	35 (18.4)	58 (9.7)
	Don't know	104 (25.5)	68 (35.8)	172 (28.8)
	–	0 (-)	1 (0.5)	1 (0.2)
14. According to you, bein gen informed in advance on potential treatment -side effects could influence your choice to suspend the cure?	No. Even if informed, I will decide to suspend the treatment	40 (9.8)	28 (14.7)	68 (11.4)
	Don't know. Depends on the severity of side-effect	217 (53.2)	111 (58.4)	328 (54.8)
	Yes. If previously informed, I would not suspend the treatment	132 (32.4)	46 (24.2)	178 (29.8)
	–	19 (4.7)	5 (2.6)	24 (4.0)
15. How do you judge this disease experience?	One of several life trials to cope with	276 (67.6)	101 (53.2)	377 (63)
	Un Insurmountable trouble	36 (8.8)	24 (12.6)	60 (10.0)
	An isolated and sore digression	65 (15.9)	40 (21.1)	105 (17.6)
	Other	22 (5.4)	23 (12.1)	45 (7.5)
	–	9 (2.2)	2 (1.1)	11 (1.8)
16. Regarding your future, your expectations are:	Negative	41 (10.0)	36 (18.9)	77 (12.9)
	None	76 (18.6)	48 (25.3)	124 (20.7)
	Positive	270 (66.2)	102 (53.7)	372 (62.2)
	–	21 (5.1)	4 (2.1)	25 (4.2)
17. Do you think that the treatment you are receiving:	Helps me to feel better	98 (24.0)	67 (35.3)	165 (27.6)
	I don't think it is useful	1 (0.2)	3 (1.6)	4 (0.7)
	It's essential to control the disease	209 (51.2)	61 (32.1)	270 (45.2)
	It has to be fulfilled to accomplish my relatives wishes	5 (1.2)	6 (3.2)	11 (1.8)
	It has to be fulfilled as the physician indicated	81 (19.9)	50 (26.3)	131 (21.9)
	–	14 (3.4)	3 (1.6)	17 (2.8)

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