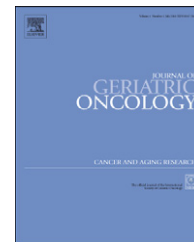


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Telling bad news to the elderly cancer patients: The role of family caregivers in the choice of non-disclosure – The Gruppo Italiano di Oncologia Geriatrica (GIOGer) Study

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ABSTRACT

Purpose: We investigated the caregiver’s role in the choice of non-disclosure in patient–physician communication.

Patients and Methods: A total of 194 family caregivers of partially informed (PI) or not-informed (NI) elderly cancer patients participated in study protocol. PI patients received only approximate information aimed at reassurance; NI patients had no access to any information regarding their health status. The family caregiver, identified by the patient, underwent an interview regarding patient–physician communication.

Results: As many as 35.2% (n=74) were caregivers for NI and 64.8% (n=136) for PI. Patients living with their spouse were better informed than patients living with their children (80.0% vs. 58.7%; p=0.02). The decision to not inform the patients mainly arose in the family (86.1% vs. 77.0% of NI and PI, respectively, p=0.12) and was due to the psychological frailty of the patient (52.8% NI vs. 32.8% PI, p=0.006) and to the fear of a severe emotional distress during a fully disclosing patient–physician communication (67.0%). ~~In PI patients, caregivers offered more destabilising the information on the prognosis (48.4%), while those for NI patients on diagnosis (44.4%).~~

Conclusions: The choice of non-disclosure was independent from an explicit request of the patient and was associated with the caregiver’s fears and needs. Because elderly patients rely on a family caregiver to cope with their disease, early intervention tailored to caregiver’s needs and skills are necessary. Such interventions will avoid the risk of caregiver distress and help medical staff in managing the various aspects of clinical communication with the elderly cancer patients.

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1. Introduction

Geriatric oncology is recognised as a speciality within oncology that focusses on the interplay between cancer and ageing (including the role of co-morbidity, sensory, cognitive and physical deficits and social support) and is constantly rising due to an overall increase in the ageing population with a higher prevalence in the number of cancer patients aged 65 years and over.

Over the past few years, demographic changes and constraints in health-care system costs contribute to the crisis of traditional models of care for elderly patients.¹ Shortened hospital stays have led to an increase in the use of home-care models with an important role of patients' families. Such a family-centred model of care is continuously evolving towards improving the support given to older patients with co-morbidities. A previous study in older persons undergoing palliative treatment for cancer showed a positive correlation between family functioning and the well-being of individual members.² Furthermore, cancer has been reported to cause changes in family dynamics due to increased roles and daily functioning patterns.^{3,4}

Clinical communication seems to play a crucial role in helping both families and patients in coping with quality-of-life changes following diagnosis and during cancer treatment. After a cancer diagnosis, sharing and talking about their disease has been identified as a key tool for successfully coping with it. Studies have shown that, to improve emotional instability, talking about their diagnosis leads to better comprehension.⁵⁻⁸ In the USA and Northern Europe, older cancer patients are generally better informed compared with those from Southern Europe and South America. However, the practice of reducing clinical information to patients with more severe disease is widespread.⁹⁻¹² The ageist non-disclosure views of physicians may be due to their belief that older patients prefer not knowing the truth about their state of health and often fail to recognise the role that their patients would like to assume in the decision-making process.¹³ Furthermore, the reasons why caregivers prefer to not completely disclose information to patients regarding cancer is not completely known. The disclosure of cancer diagnosis and prognosis has been negatively correlated with age and many elderly patients wish to have a limited involvement in medical decisions¹⁴⁻¹⁸ with a greater responsibility for the caregiver. Even though family caregivers of elderly cancer patients assist in activities of daily living and emotional support, they play a crucial role in the patient-physician relationship. The presence of the caregiver is associated with an interactional dynamic on developing a trusting and effective physician-older patient relationship.¹⁹ Although good communication with the family is a core clinical skill, it has often been neglected and the practice of non-disclosure regarding cancer diagnosis and prognosis is still very frequent.^{20,21}

The psychological status of patients and their caregivers has been investigated^{3-18,22-29} and although some studies have shown that caregivers experience depression and anxiety at the time of diagnosis, other studies do not.²⁵ Few studies have focussed on examining the psychological and

clinical differences in providing limited clinical information to elderly cancer patients and their caregivers. Considering that the literature on the impact of limited disclosure on cancer diagnosis and prognosis, including the caregiver's role in medical decisions, is lacking, we investigated the patterns of clinical communication of elderly cancer patients who were partially or not informed of their health status and those of their family caregivers. We report findings from semi-structured interviews administered to 194 caregivers from the Gruppo Italiano di Oncologia Geriatrica (Italian Group for Geriatric Oncology) study, a multicentre observational Italian study of older persons with cancer.³⁰ The purpose was to investigate the role of the caregiver in the choice of partial or non-disclosure in the patient-physician communication.

2. Patients and methods

The GIOGer is a multicentre observational study in which Italian non-academic centres were asked to participate and to recruit at least 10 consecutive eligible older persons (>65 years) living in Italy with a solid tumour, undergoing chemotherapy and a life expectancy ≥ 6 months, in a period of 30 days. Patients with cognitive impairment (Mini-mental state examination (MMSE) <18) were excluded from the study protocol.³¹ At study entry, the following characteristics were collected from each patient: age, years of education, number and degree of kinship of permanent co-habitants, centre in which health care was provided, tumour site, stage and planned treatment. Forty-seven centres from all over Italy voluntarily participated in the study, enrolling a total of 622 eligible patients divided according to the physician-patient disclosure status, into two main categories: a first group of informed and a latter one of partially/not informed patients.³⁰

In this article, we describe the result of an ancillary investigation of the GIOGer study in which the caregivers of the patients composing only the latter group ($n=210$ (33.8%) of the original study group, of which 136 (64.8%) were partially informed) were invited to undergo semi-structured interviews regarding their role in their relative's disease. Of the 210 caregivers, 194 (92.4%) agreed to participate in the study and signed informed consent forms before beginning the study protocol.

Patients who were considered partially informed (PI) received only approximate information regarding their cancer. The contents of the clinical communication were preliminary defined with the caregiver before patient-physician communication. All medical decisions were also previously discussed with the caregiver. Thus, the information on diagnosis and treatment was vague without any information regarding the prognosis. PI patients, therefore, could not manage a personal relationship with the medical team without the presence of their caregiver. Not-informed (NI) patients were considered patients who, by explicit personal request or by the family caregiver's decision, had no access to any information regarding their illness or treatment. The family caregiver was defined as the family member or significant other person identified by the patient, as the primary source of emotional and social support with regard to their health care. This status was confirmed by the designated individual.

164 Family caregivers of both PI and NI patients were admin- 186
 165 istered a semi-structured interview by a trained psychologist. 187
 166 This interview was constructed to investigate the motivations 188
 167 and needs of the caregiver's role in not informing the patient. 189
 168 The semi-structured interview was specifically developed for 190
 169 this study and piloted in a single institution before being 191
 170 applied at all study sites.¹⁸ The semi-structured interview is 192
 171 the most adequate tool to capture how a person thinks of a 193
 172 particular domain. The results from the interviews allowed us 194
 173 to obtain specific quantitative and qualitative information and 195
 174 represent an essential requisite for caregivers of elderly people 196
 175 from 47 oncologic centres in Italy.³² 197

176 3. Statistical analyses

178 The associations between grade of information and selected 200
 179 characteristics were assessed by chi-square test (or chi-square 201
 180 test for trend when applicable) considering statistically 202
 181 significant for $p < 0.05$. Moreover, the association was quanti- 203
 182 fied by means of odds ratio (OR) and their 95% confidence 204
 183 intervals (CIs), and the variables considered were: age, gender, 205
 184 Italian zone of reference centre, education level, tumour site, 206
 185 disease stage and performance status (Eastern Cooperative 207

Oncology Group (ECOG)), number of co-habitants and partic- 186
 ipation by the caregiver to the questionnaire.^{33,34} 187

4. Results

We found that 136 (64.8%) of the study population were 190
 caregivers for PI and 74 (35.2%) for NI. 191

The mean age of the patients was 73.6 (interquartile range 192
 (IQR) 69.6–77.4), 119 (56.7%) were male, 144 (68.6%) had ≤ 5 years 193
 of education, 67 (31.9%) were rated as ECOG Performance Status 194
 (PS) 0 and 182 (86.7%) presented advanced disease. Of the 195
 caregivers, 64.9% ($n=126$) were children, 18% ($n=35$) were spouse 196
 or partners and 12.3% ($n=24$) were other relatives (nephew, 197
 daughter-in-law, brother or sister). Only one caregiver was a 198
 health-care professional (0.5%). Five caregivers (2.6%) did not 199
 provide information about the nature of the family tie with the 200
 patient. The ORs and 95% CIs for the association of the grade of 201
 information and selected patients characteristics are shown in 202
 Table 1. Italian geographical area, years of education, disease 203
 status, ECOG performance status and the nature of the family tie 204
 with the caregiver were associated with the level of information. 205
 Being married or widowed is an important factor influencing the 206
 clinical communication: patients living with their spouse alone 207

Table 1 – Unadjusted and adjusted Odds-ratio (OR) and 95% Confidence Intervals (95% CI) testing the association between the level of information and selected characteristics in 210 oncological patients aged 65 years or more.

		Total n	Grade of Information		OR (95% CI)	p ^a
			Partial n (%)	Not Informed n (%)		
Total		210	136	74		
Gender	Male	119	77 (56.6)	42 (56.8)	1	
	Female	91	59 (43.4)	32 (43.2)	1.0 (0.6-1.8)	0.985
Age (years)	65-69	54	38 (27.9)	16 (21.6)	1	0.128 ^b
	70-74	72	49 (36.0)	23 (31.1)	0.9 (0.4-1.9)	
	75 o +	84	49 (36.0)	35 (47.3)	0.6 (0.3-1.2)	
Italian Zone of the reference center	Northern	29	25 (18.4)	4 (5.4)	5.1 (1.7-15.5)	<0.001 ^b
	Central	65	47 (34.6)	18 (24.3)	2.1 (1.1-4.1)	
	Southern	116	64 (47.1)	52 (70.3)	1	
Years of education	≤ 5	144	87 (64.0)	57 (77.0)	1	0.009 ^b
	6-8	36	27 (19.9)	9 (12.2)	2.0 (0.9-4.5)	
	9+	21	18 (9.6)	3 (4.1)	3.9 (1.1-14.0)	
Oncological site	Colon	59	39 (28.7)	20 (27.0)	1	0.745
	Breast	28	19 (14.0)	9 (12.2)	1.1 (0.4-2.8)	
	Lung	45	31 (22.8)	14 (18.9)	1.1 (0.5-2.6)	
	Other	78	47 (34.6)	31 (41.9)	0.8 (0.4-1.6)	
Disease Status	Initial	28	21 (15.4)	7 (9.5)	1.7 (0.7-4.3)	0.224
	Advanced	182	115 (84.6)	67 (90.5)	1	
Performance Status (ECOG)	0	67	51 (37.8)	16 (21.6)	1	0.017
	≥ 1	142	84 (62.2)	58 (78.4)	0.5 (0.2-0.9)	
Number of co-habitants	1	24	14 (10.4)	10 (13.9)	1.0 (0.4-2.5)	0.485 ^b
	2	104	74 (55.2)	30 (41.7)	1.7 (0.9-3.2)	
	3+	78	46 (34.3)	32 (44.4)	1	
Type of relationship to caregiver	Son/Daughter	126	74 (54.4)	52 (70.3)	1	0.049
	Partner	35	28 (20.6)	7 (9.5)	2.8 (1.1-6.9)	
	Other or NS	49	34 (25.0)	15 (20.3)	1.6 (0.8-3.2)	
Caregiver questionnaire	No	16	14 (10.3)	2 (2.7)	4.1 (1.0-27.4)	0.048
	Yes	194	122 (89.7)	72 (97.3)	1	

^achi-square test; ^b chi-square for trend; OR: Odds-Ratio; 95% CI: 95% Confidence Intervals.

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

Table 2 – Distribution of responses to “Questionnaire For Caregivers of Partially or Not Informed Geriatric Oncological Patients”.

		Partially Informed n (%)	Not Informed n (%)	Total n (%)
t2.4	Total	122	72	194
t2.5	1. The decision not to inform directly the patient has been driven by			
t2.6	A suggestion from the general practitioner	4 (3.3)	2 (2.8)	6 (3.1)
t2.6	A decision shared with other members of the family	94 (77.0)	62 (86.1)	156 (80.4)
t2.7	Explicit request of patient	4 (3.3)	2 (2.8)	6 (3.1)
t2.8	A personal choice	19 (15.6)	5 (6.9)	24 (12.4)
t2.9	2. Which factors have mainly influenced on such a choice?			
t2.9	Previous experiences	6 (4.9)	1 (1.4)	7 (3.6)
t2.10	Don't know personally the oncologist	1 (0.8)	1 (1.4)	2 (1.0)
t2.11	Patient's age	26 (21.3)	14 (19.4)	40 (20.6)
t2.12	Psychological frailty of the elderly	40 (32.8)	38 (52.8)	78 (40.2)
t2.13	Severity of disease	46 (37.7)	17 (23.6)	63 (32.5)
t2.14	3. Which are, according to you, the risks connected to a direct communication patient-physician?			
t2.14	Difficulty of management of information from the relatives	5 (4.1)	7 (9.7)	12 (6.2)
t2.15	Difficulty of patient understanding	35 (28.7)	16 (22.2)	51 (26.3)
t2.16	Destabilizing emotional impact on the patient	82 (67.2)	48 (66.7)	130 (67)
t2.17	4. Which are the information you consider more dangerous for the elderly?			
t2.18	Those inherent treatments and side-effects	8 (6.6)	8 (11.1)	16 (8.2)
t2.18	Those inherent the evolution of the disease (prognosis)	59 (48.4)	31 (43.1)	90 (46.4)
t2.19	Those inherent the diagnosis	55 (45.1)	32 (44.4)	87 (44.8)
t2.20	5. Which could be the reaction of the patient to the communication of diagnosis?			
t2.20	Increased state of anxiety- depression	71 (58.2)	37 (51.4)	108 (55.7)
t2.21	Increased suicide risk	5 (4.1)	2 (2.8)	7 (3.6)
t2.22	Increased refusal of treatments	11 (9.0)	8 (11.1)	19 (9.8)
t2.23	Positive reaction	1 (0.8)	0 (-)	1 (0.5)
t2.24	Other	5 (4.1)	2 (2.8)	7 (3.6)
t2.25	Don't know	29 (23.8)	23 (31.9)	52 (26.8)
t2.26	6. Given the relevance of a corrected communication, which modality could be an optimal way for this communication in the interest of the patient?			
t2.27	Preliminary agreement with the physician on the contents	33 (27.0)	23 (31.9)	56 (28.9)
t2.27	Preliminary meeting with the physician to supply relevant elements about the patient	42 (34.4)	14 (19.4)	56 (28.9)
t2.28	Gradualness of communication	28 (23.0)	22 (30.6)	50 (25.8)
t2.29	To be present to the talk	11 (9.0)	7 (9.7)	18 (9.3)
t2.30	Other	6 (4.9)	4 (5.6)	10 (5.2)
t2.31	7. Does exist, according to you, a relation between an appropriate information and the possibility for the patient to speak about his disease experience?			
t2.32	Yes	45 (36.9)	31 (43.1)	76 (39.2)
t2.33	No	22 (18.0)	16 (22.2)	38 (19.6)
t2.33	Don't know	55 (45.1)	25 (34.7)	80 (41.2)

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

were better informed than patients living with the children (74.8% vs. 54.9, $p=0.01$). Interestingly, the age of the patients was not associated with the degree of information. It was also interesting to note that those living in southern Italy were more likely to decide to not inform patients rather than give partial information compared with those living in the central and northern regions of Italy.

Table 2 reports the responses to the interview given by 194 patient's caregivers (92.4% of the total group of 210 patients). A total of 94 caregivers (77.0%) of PI and 62 caregivers (86.1%) of NI patients indicated their decision to not inform the patient arose in the family and was shared with other family members. As many as 3.3% of PI patient caregivers and 2.8% of NI patient caregivers responded that the decision came from the patient's request (Question 1). The most significant motivations for caregiver's decision regarding the choice of non-disclosure were: (1) psychological frailty of the patient (52.8% vs. 32.8% of the NI and PI caregivers respectively, $p=0.006$); and (2) disease severity (23.6% vs. 37.7% of the NI and PI caregivers respectively,

$p=0.04$) (Question 2). There is a general agreement (66.7% vs. 67.2% of NI and PI patients' caregivers, respectively) that the major risk connected to a fully disclosing physician-patient communication is a destabilising emotional strain on the patient. A presumed difficulty of patient understanding was recorded by 22.2% and 28.7% ($p=ns$) of NI and PI patients' caregivers, respectively (Question 3).

Of PI patient's caregivers, 48.4% consider more destabilising information inherent on prognosis, while 44.4% of NI patient's caregivers consider more destabilising information inherent on diagnosis (Question 4). The family caregivers were concerned about the risk of anxiety and depression (51.4% and 58.2% of NI and PI patient's caregivers, respectively) as well as the refusal of treatments (11.1% and 9.0%) as a consequence of a fully disclosing physician-patient communication. An increased risk of suicide was recorded by 2.0% and 4.1% of the caregivers. Interestingly, a substantial proportion of caregivers of both NI and PI patients answered "I don't know" (32% and 23.8%) regarding the patient's reaction to the clinical information 245

(Question 5). When asked how communication would be improved, NI patient's caregivers indicated a preliminary agreement with the physician on the contents (31.9%) and gradualness of information (30.6%). PI patient's caregivers indicated that the preliminary conversation with the physician about the psychological attitude of the patient and the family context aimed to promote tailored information (34.4%), and a preliminary agreement on the contents of information (27.0%) (Question 6). As much as 40.7% of our sample doesn't know if an informed patient has more opportunities to share disease-related anxieties than an uninformed patient (PI and NI). Surprisingly 39.2% of caregivers, although choosing to not inform the patient, answered positively to the question (i.e., they believe that an informed patient has more opportunities to share anxieties) (Question 7).

5. Discussion

These data highlight the role of family caregivers in several domains of clinical communication including decision making, contents and psychological outcomes in older persons with two different levels of information regarding their clinical status (partially or uninformed). Interestingly, we also found that the geographical area of the caregivers was associated with a different grade of information. A significantly higher percentage of caregivers living in southern Italy preferred to not inform rather than partially inform patients on their health status compared with those living in central or northern Italy. These findings underline the important cultural differences found in a single country.

We found that the family had a significant role regarding the decision to not inform the patients. The decision of non-disclosure was mainly due to the psychological frailty of the patient. We also found that the caregivers of PI patients considered emotional stability a priority on prognosis, while those of the NI patients on diagnosis.

Our data showed that the requests of non-disclosure were independent from the patient's will. Such decisions came from the family caregiver and were explained by the fear of psychological suffering, which would, in turn, increase the risk of treatment refusal.

Similar results were reported by Giacalone et al.³⁵⁻³⁷ that highlight the decision of not informing older patients is generally made by the families, who misunderstand the importance of correct clinical information. These findings provide indirect evidence of the caregivers' uncertainty in their perceived needs and roles. Moreover, family dynamics, such as the caregiver's need to rescue or protect the patient, may arise or interfere with the care management.³⁸⁻⁴¹ However, there is little evidence that communicating a difficult diagnosis is associated with an increased risk for psychiatric disorders or that it may worsen the degree of psychological frailty of the older patient.^{42,43} Interestingly, older cancer patients have exhibited similar psychosocial responses compared with younger patients.^{44,45}

On the other hand, the impact of anxiety and depressive disorders during cancer and treatments has been well documented.⁴⁶⁻⁴⁸ Many studies have found that patients and their caregivers have similar levels of anxiety and depressive

mood.^{26,27} Edwards et al. found that open family functioning (the ability to act openly, express feelings directly and solve problems effectively) was associated with lower levels of depression and anxiety.²⁷

Our study also showed the NI patients' caregivers considered more destabilising information inherent to the diagnosis. This may be due to the phase immediately following diagnosis, which is the most stressful for the caregiver.⁴⁹ PI caregivers considered the prognosis to be more stressful. This finding may be explained by the amount of information that has been chosen to share with the patient (i.e., vague information on diagnosis and treatment with no information regarding prognosis).

There are some limitations in this study. First, because all participants were volunteers, there is a possibility of a potential self-selection bias: subjects might have been more motivated towards clinical communication. However, the goal of this study was to measure several aspects of the complex process of communication with a short semi-structured questionnaire, which is considered an important tool on capturing how a person thinks of a particular domain. Second, the sample was not homogeneous in terms of time since first cancer diagnosis, tumour site, type of therapies and prognosis. However, in our analysis, the final model was constructed adjusting for such confounders.

We previously reported that older patients wish to rely on their family in the decision-making process.³⁰ The important role (i.e., emotional support and clinical decision) of family members during medical consultation is an established observation in medical literature.^{19,50,51} Different studies have found that an older person's decision-making abilities decline with age and vary in communication style and beliefs on participation.^{16,52,53} A cancer diagnosis is a very stressful event for both patient and family. Social support is known to be one of the most important determinants of psychological well-being, overall health and behaviour of patients. The caregivers are an important source of social and emotional support for patients as they provide nursing tasks as well as assist patients in making treatment decisions.^{50,51} Our study suggests the need to better support the presence of family caregivers and their role in the communication process. The patient's perception of being emotionally supported by the family is associated with lower levels of anxiety and depression in addition to a better overall adjustment of their health status.⁵⁴⁻⁵⁶ Strong evidence of the interpersonal association between the quality of relationships between patient and caregivers on improving anxiety has also been reported.^{28,29}

In our experience, elderly patients frequently require the caregiver's presence during the medical consultation, which changes the interactional dynamics. The elderly perception in a trusting physician-patient relationship is assured by the caregiver's presence and may help patients in coping with the vast array of challenges during cancer in old age.^{53,57-59}

Due to demographic changes, there is a growing role in the family's ability to care for elderly family members. Considering the role of the family in providing social protection, a primary emphasis should be placed on strengthening family resources and motivation. Early interventions are necessary to avoid the risk of distress and the burnout syndrome, which are correlated with patient anxiety. Butz et al. found that

364 caregivers, who participated in a psycho-educational support
365 group, reported less mood disturbances and greater confi-
366 dence than caregivers in the control group.⁶⁰ Other authors
367 have reported an improvement in caregiver problem-solving
368 abilities, awareness of community resources and knowledge,
369 following interventions.⁶⁰⁻⁶⁶

370 Indeed, more instructive and personalised information
371 programmes are needed to improve the awareness and adaptive
372 capacities of older patients. To achieve this goal, there is an
373 emphasis on specific training of both the medical staff and
374 family caregivers to manage the various aspects of clinical
375 communication with elderly cancer patients.^{67,68}

376 Conflict of interest statement

378 The authors declare they have no actual or potential conflict of
379 interest that could influence their work.

380 Author contributions

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383 caregiver, discussed the results and wrote the paper.

384 Pierluca Piselli designed the study, analyzed the data,
385 discussed the results and wrote the paper.

386 Marcella Cicerchia interviewed patients performed quality
387 data control.

388 Mimma Raffaele selected patients and performed quality
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390 Angela Marie Abbatecola discussed the results and wrote
391 the paper.

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