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\% (\textit{n} = 74) were caregivers for NI and 64.8\% (\textit{n} = 136) for PI. Patients living with their spouse were better informed than patients living with their children (80.0\% vs. 58.7\%; \textit{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, \textit{p} = 0.12) and was due to the psychological frailty of the patient (52.8\% NI vs. 32.8\% PI, \textit{p} = 0.006) and to the fear of severe emotional distress during a fully disclosing patient–physician communication (67.0\%). In PI patients, caregivers considered 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 on 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. 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. Furthermore, cancer has been reported to cause changes in family dynamics due to increased roles and daily functioning patterns.

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. 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. 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. 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 decisions 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. 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.

The psychological status of patients and their caregivers has been investigated and although some studies have shown that caregivers experience depression and anxiety at the time of diagnosis, other studies do not. 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. 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. 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.

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 the 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.
Family caregivers of both PI and NI patients were administered a semi-structured interview by a trained psychologist. This interview was constructed to investigate the motivations and needs of the caregiver's role in not informing the patient. The semi-structured interview was specifically developed for this study and piloted in a single institution before being applied at all study sites. The semi-structured interview is the most adequate tool to capture how a person thinks of a particular domain. The results from the interviews allowed us to obtain specific quantitative and qualitative information and represent an essential requisite for caregivers of elderly people from 47 oncologic centres in Italy.

### 3. Statistical analyses

The associations between grade of information and selected characteristics were assessed by chi-square test (or chi-square test for trend when applicable) considering statistically significant for p<0.05. Moreover, the association was quantified by means of odds ratio (OR) and their 95% confidence intervals (CIs), and the variables considered were: age, gender, Italian zone of reference centre, education level, tumour site, disease stage and performance status (Eastern Cooperative Oncology Group (ECOG)), number of co-habitants and participation by the caregiver to the questionnaire.33,34

### 4. Results

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

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

#### 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.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total n</th>
<th>Partial n (%)</th>
<th>Not Informed n (%)</th>
<th>OR (95% CI)</th>
<th>p*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>210</td>
<td>136</td>
<td>74</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>119</td>
<td>77 (56.6)</td>
<td>42 (56.8)</td>
<td>1.0 (0.6-1.8)</td>
<td>0.985</td>
</tr>
<tr>
<td>Female</td>
<td>91</td>
<td>59 (43.4)</td>
<td>32 (43.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65-69</td>
<td>54</td>
<td>38 (27.9)</td>
<td>16 (21.6)</td>
<td>1.0</td>
<td>0.128</td>
</tr>
<tr>
<td>70-74</td>
<td>72</td>
<td>49 (36.0)</td>
<td>23 (31.1)</td>
<td>0.9 (0.4-1.9)</td>
<td>0.128</td>
</tr>
<tr>
<td>75 +</td>
<td>84</td>
<td>49 (36.0)</td>
<td>35 (47.3)</td>
<td>0.6 (0.3-1.2)</td>
<td>0.128</td>
</tr>
<tr>
<td><strong>Italian Zone of the reference center</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northern</td>
<td>29</td>
<td>25 (18.4)</td>
<td>4 (5.4)</td>
<td>1.0</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Central</td>
<td>65</td>
<td>47 (34.6)</td>
<td>18 (23.4)</td>
<td>2.1 (1.1-4.1)</td>
<td>0.009</td>
</tr>
<tr>
<td>Southern</td>
<td>116</td>
<td>64 (47.1)</td>
<td>52 (70.3)</td>
<td></td>
<td>0.05</td>
</tr>
<tr>
<td>≤5</td>
<td>144</td>
<td>87 (60.0)</td>
<td>57 (77.0)</td>
<td>1.0</td>
<td>0.745</td>
</tr>
<tr>
<td>6-8</td>
<td>36</td>
<td>27 (19.3)</td>
<td>9 (12.2)</td>
<td>2.0 (0.9-4.5)</td>
<td>0.009</td>
</tr>
<tr>
<td>9+</td>
<td>21</td>
<td>18 (9.6)</td>
<td>3 (4.1)</td>
<td>3.9 (1.1-14.0)</td>
<td>0.009</td>
</tr>
<tr>
<td><strong>Oncological site</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colon</td>
<td>59</td>
<td>39 (28.7)</td>
<td>20 (27.0)</td>
<td>1.0</td>
<td>0.745</td>
</tr>
<tr>
<td>Breast</td>
<td>28</td>
<td>19 (14.0)</td>
<td>9 (12.2)</td>
<td>1.1 (0.4-2.8)</td>
<td>0.009</td>
</tr>
<tr>
<td>Lung</td>
<td>45</td>
<td>31 (22.8)</td>
<td>14 (18.9)</td>
<td>1.1 (0.5-2.6)</td>
<td>0.009</td>
</tr>
<tr>
<td>Other</td>
<td>78</td>
<td>47 (34.6)</td>
<td>31 (41.9)</td>
<td>0.8 (0.4-1.6)</td>
<td>0.009</td>
</tr>
<tr>
<td><strong>Disease Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial</td>
<td>28</td>
<td>21 (15.4)</td>
<td>7 (9.5)</td>
<td>1.7 (0.7-4.3)</td>
<td>0.224</td>
</tr>
<tr>
<td>Advanced</td>
<td>182</td>
<td>115 (84.6)</td>
<td>67 (90.5)</td>
<td></td>
<td>0.017</td>
</tr>
<tr>
<td><strong>Performance Status (ECOG)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>67</td>
<td>51 (37.8)</td>
<td>16 (21.6)</td>
<td></td>
<td>0.009</td>
</tr>
<tr>
<td>≥1</td>
<td>142</td>
<td>84 (62.2)</td>
<td>58 (78.4)</td>
<td>0.5 (0.2-0.9)</td>
<td>0.009</td>
</tr>
<tr>
<td><strong>Number of co-habitants</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>24</td>
<td>14 (10.4)</td>
<td>10 (13.9)</td>
<td>1.0 (0.4-2.5)</td>
<td>0.485</td>
</tr>
<tr>
<td>2</td>
<td>104</td>
<td>74 (55.2)</td>
<td>30 (41.7)</td>
<td>1.7 (0.9-3.2)</td>
<td>0.049</td>
</tr>
<tr>
<td>3+</td>
<td>78</td>
<td>46 (34.3)</td>
<td>32 (44.4)</td>
<td>1.0</td>
<td>0.009</td>
</tr>
<tr>
<td><strong>Type of relationship to caregiver</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Son/Daughter</td>
<td>126</td>
<td>74 (54.4)</td>
<td>52 (70.3)</td>
<td>1.0</td>
<td>0.284</td>
</tr>
<tr>
<td>Partner</td>
<td>35</td>
<td>28 (20.6)</td>
<td>7 (9.5)</td>
<td>2.8 (1.1-6.9)</td>
<td>0.048</td>
</tr>
<tr>
<td>Other or NS</td>
<td>49</td>
<td>34 (25.0)</td>
<td>15 (20.3)</td>
<td>1.6 (0.8-3.2)</td>
<td>0.049</td>
</tr>
<tr>
<td><strong>Caregiver questionnaire</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>16</td>
<td>14 (10.3)</td>
<td>2 (2.7)</td>
<td>4.1 (1.0-27.4)</td>
<td>0.048</td>
</tr>
<tr>
<td>Yes</td>
<td>194</td>
<td>122 (89.7)</td>
<td>72 (97.3)</td>
<td></td>
<td>0.048</td>
</tr>
</tbody>
</table>

*chi-square test; **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.

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 to 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 was also the case for 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 = 0.06); 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 diagnosis (66.7% vs. 74.8% of PI and NI 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).
246 (Question 5). When asked how communication would be improved, NI patient’s caregivers indicated a preliminary agreement with the physician on the contents and psychological outcomes in older persons with two different levels of information regarding their clinical status (partially or uninform). 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 partinform 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.

256 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.

266 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.

276 Similar results were reported by Giacalone et al. 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.

286 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. Interestingly, older cancer patients have exhibited similar psychosocial responses compared with younger patients.

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

306 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. PI caregivers considered the prognosis to be more stressful. This finding may be explained by the amount of information that has been shared with the patient (i.e., vague information on diagnosis and treatment with no information regarding prognosis).

316 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.

326 We previously reported that older patients wish to rely on their family in the decision-making process. The important role (i.e., emotional support and clinical decision) of family members during medical consultation is an established observation in medical literature. Different studies have found that an older person’s decision-making abilities decline with age and vary in communication style and beliefs on participation. 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. Our study suggests the need to better support the presence of family caregivers and their role in the communication process.

336 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. Strong evidence of the interpersonal association between the quality of relationships between patient and caregivers on improving anxiety has also been reported.

346 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.

356 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

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