

Information of Imminent Death or Not: Does It Make a Difference?

Gunilla Lundquist, Birgit H. Rasmussen, and Bertil Axelsson

All authors: Umeå University; Birgit H. Rasmussen, Umeå Hospice, Umeå; Gunilla Lundquist, Center of Clinical Research, County Council of Dalarna, Falun; and Bertil Axelsson, Östersund Hospital, Östersund, Sweden.

Submitted January 4, 2011; accepted July 13, 2011; published online ahead of print at www.jco.org on September 12, 2011.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

Corresponding author: Gunilla Lundquist, MD, Palliativa teamet, Lasarettet, S-771 81 Ludvika, Sweden; e-mail: gunilla.lundquist@tdalarna.se.

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0732-183X/11/2929-3927/\$20.00

DOI: 10.1200/JCO.2011.34.6247

ABSTRACT

Purpose

This study examines whether end-of-life care for patients with cancer who were informed about imminent death differs from care for those patients with cancer who were not informed.

Patients and Methods

This study included all cancer deaths between 2006 and 2008 for which the patient did not lose his or her decision-making capacities until hours or days before death (N = 13,818). These patients were taken from a national quality register for end-of-life care. The majority of the patients—91% (n = 12,609)—had been given information about imminent death; 9% (n = 1,209) had not been informed. Because of the difference in sample size, a matching procedure was performed to minimize bias. This resulted in a comparison of 1,191 informed and 1,191 uninformed patients. Nonparametric methods were used for statistical analyses.

Results

Informed patients significantly more often had parenteral drugs prescribed as needed (ie, PRN), had his or her family informed, died in his or her preferred place, and had family who were offered bereavement support. There was no difference in symptom control (ie, pain, anxiety, confusion, nausea, and respiratory tract secretions) between the groups.

Conclusion

Providing information of imminent death to a patient with cancer at the end of life does not seem to increase pain or anxiety, but it does seem to be associated with improved care and to increase the likelihood of fulfilling the principles of a good death.

J Clin Oncol 29:3927-3931. © 2011 by American Society of Clinical Oncology

INTRODUCTION

Communication about approaching death is considered crucial, because it helps patients participate in decisions about their care, their goals, and their priorities. For example, this information helps patients deal with existential issues, with their preferred place of death, and with personal arrangements after their death.¹⁻⁸ This type of communication helps families and close friends prepare for the loss and may facilitate the bereavement process.⁹⁻¹¹ To ask patients about their need for information and to provide opportunities for discussions as an illness progresses may relieve symptom distress and support a terminally ill patient's sense of dignity.¹²

The awareness and understanding of imminent death and the goal of the care are pivotal issues for the content and quality of end-of-life care.¹³⁻¹⁵ The increasing interest in and use of integrated pathways (eg, the Liverpool Care Pathway, Palliative Care of Advanced Disease, and Pathway for Improving the Care of the Dying)—indicate that more

complete symptom assessment and symptom control¹⁶⁻¹⁸ can improve the care of the dying; however, more research is needed.¹⁹ The majority of studies support the importance of being informed about possible imminent death, but some studies also point out the ambiguity and even conflict patients and families may experience when deciding whether they want or do not want more information about impending death.^{6,7,20-21} According to Kirk et al²² and to Weiner and Roth,²³ information should be given only to those who clearly express a wish to know. This information can either alleviate or increase symptoms and suffering, depending on the clinician's behavior when initiating discussions about end-of-life care. There are individual and cultural differences with respect to informing a patient about his or her imminent death; however, individuals often disagree with the norms of their culture.²⁴⁻²⁶ People vary about the extent they want to know the truth, if they want to know at all, and in their understanding of what constitutes telling the truth.²⁶⁻²⁸

This is applicable to all involved parties: patients, family members, and health care professionals (HCPs).

Irrespective of diagnosis, patients with an incurable illness undergo many transitions during the course of care.²⁹ In some diseases, the trajectory is relatively predictable; in others, it may involve a slower decline with fluctuating symptoms and many hospital admissions before death. Therefore, end-of-life care and palliative care overlap in the management of people with long-term conditions.³⁰ Clearly, diagnosing and communicating the transitions between the different phases of a cancer patient's illness—from curative and life-saving phases to palliative and life-prolonging phases and finally to the dying phase and end-of-life care—are important aspects of health care for the terminally ill.^{2-8,31}

Since the beginning of 2000, there has been an increasing focus on palliative care in Sweden. During this decade, identifying and communicating the transition from the early to late phase of palliative care to optimize and set the right goals for care of the dying have become an important issue. In 2001, the Swedish Government Official Report³² on end-of-life care identified for the first time the phenomena of breakpoint for palliative care at the end-of-life (ie, transition to end-of-life care) and breakpoint communication (ie, communication about transition to end-of-life care).

During the following years, the phenomena of breakpoint for palliative care at the end-of-life (ie, transition to end-of-life care) and breakpoint communication (ie, communication about end-of-life care) became more frequently used and have been adopted in priority discussions in National Guidelines on Cancer Care,³³ in several care programs, and in the Swedish Register for Palliative Care (SRPC),³⁴ a national quality register established in 2005. Although the positive and negative effects of information in this context are still being discussed, data from the SRPC provide a unique opportunity to explore whether and how informing or not informing patients of imminent death influence the content of care and symptom burden during the last week of life. The register enables collection of data from a large number of patients, data that could not be gathered in any other way. Analyses of these data will complement the ongoing discussion about the benefits of informing patients and their families about the transition to end-of-life care.

PATIENTS AND METHODS

Study Population

Data concerning the care delivered during the last week of life were collected from SRPC, a Web-based questionnaire. This online register was completed by the physician and/or nurse responsible for the patient's care during the last week of life, although HCPs were not aware of the research question of this study. The design of the SRPC Web questionnaire does not allow any missing data at submission. The Web questionnaire is based on the 11 principles constituting good death as defined by the British Geriatrics Society¹³ and was designed to be used in any care setting, independent of diagnosis, with the intent to look retrospectively at important aspects of care delivered during the last week of life. The 25 items on the SRPC include 14 questions that cover background data of patient and reporting unit and three questions that cover items not considered relevant to the aim of this study (ie, use of visual analog or numeric rating scales during last week of life, frequency of pressure ulcers, and staff reflection). The remaining eight questions covering, for example, degree of autonomy, information about imminent death, symptom control, parenteral as needed (ie, pro re nata or PRN) prescriptions,

Table 1. Excerpt From the SRPC Questionnaire

No.	Question	Reply Alternatives
13	Has the patient, during the final period in life, received articulated verbal information about the imminent death?	No Yes, by a physician Yes, by a nurse Yes, by a nurse and physician Do not know
14	Has the family received verbal information about the imminent death of the patient?	No Yes, by a physician Yes, by a nurse Yes, by a nurse and physician Do not know
15	How long before death did the patient lose his/her decision-making capacity?	Hours Days Weeks Months Years Do not know
17	Indicate the symptom(s) that was/were not completely relieved during the last week in life.	Shortness of breath Rattles Confusion Pain Nausea Anxiety No troublesome symptoms Other Do not know
20	Did the patient have injectable as-needed (ie, PRN) drugs prescribed during the last 24 hours of life?	Yes or no for each of the following: Pain Rattles Nausea Anxiety
21	Who was present at the time of death?	Staff Family Staff and family No one
22	Did the patient die in his/her preferred place?	Yes No Do not know
24	Has bereavement support been offered to the family?	Yes No Do not know

Abbreviations: PRN, pro re nata; SRPC, Swedish Register for Palliative Care.

and preferred location at time of death, were included in the analysis in this study (Table 1).

During the study period (2006 to 2008), all registered patients who had died as a result of advanced cancer, in which death was expected (according to answers on one register question), were identified. Among these, patients reported as not having lost their decision-making capacities until hours or days before death were initially included (N = 16,042). After initial analyses, patients were excluded if it was unknown whether they had been informed about imminent death; 13,818 registered patients remained. Of these, 12,609 patients (91%) had been informed that they were dying (ie, informed group). The remaining 1,209 (9%) patients (ie, uninformed group) had not been given any information that death was imminent. Figure 1 shows the different care settings and describes whether information about imminent death was given or was not given to the patient and, if so, by whom.

Because of large differences in sample sizes between the informed and uninformed groups and uneven proportions of uninformed and age distribution in different care settings, a one-to-one match was performed to minimize bias. The matching criteria used included age (older than 20 years with a 5-year

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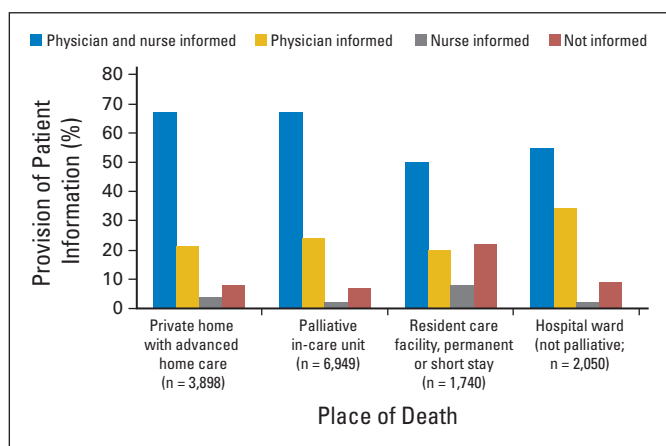


Fig 1. Provision of patient information.

distribution; ie, 20 to 24, 25 to 29, and so on), sex, place of death, and loss of decision-making capacity (hours or days). All patients had a cancer diagnosis, but the register did not provide additional details about type of cancer or any data concerning ethnic, cultural, or socioeconomic backgrounds. This procedure resulted in one group of 1,191 uninformed patients matched with 1,191 informed patients for a total of 2,382 patients.

Study Measures

The matched two groups were compared regarding the content of care during the last week of life, as documented in the SRPC. Several aspects of care were compared: symptom control (including pain, anxiety, confusion, dyspnea, nausea, and respiratory tract secretions); prescribed parenteral as needed medications; if the patient died in his or her preferred place; if the family had been informed about imminent death; people present at the time of death; and if the family had been offered bereavement support. We used the term family to mean all significant others.

Statistical Analysis

Data were analyzed by using Statview software (version 5.0.1.0; SAS Institute, Cary, NC) and were performed with nonparametric methods. Depending on type of variables, the χ^2 , Mann-Whitney *U*, or Kruskal-Wallis test was used. $P \leq .05$ was considered statistically significant. The study was approved by the Regional Ethical Review Board Umeå.

RESULTS

The 13,818 registrations represented 20% of all cancer deaths in Sweden during the study period. In the informed group of 12,609, 21% had been informed by a physician only; 4%, by a nurse only; and the remaining 67%, by both a physician and nurse. In the matched groups, the 2,382 patients were evenly distributed for age, sex, place of death, and loss of decision-making capacity (Table 2).

Symptom Control During Last Week of Life

Registered symptoms (ie, pain, anxiety, confusion, nausea, dyspnea, and respiratory tract secretions) were reported as being relieved in 80% to 96% of the patients during the last week of life. There were no significant differences between the informed and uninformed groups except for the symptom confusion. Confusion was reported as not completely relieved in 60 patients (5%) in the informed group and in 87 patients (7%) in the uninformed group (Table 3).

Table 2. Sociodemographic Data in the Matched Groups

Variable	Informed (n = 1,191)		Uninformed (n = 1,191)	
	No.	%	No.	%
Age, years				
Median	77		78	
Range	25-101		20-104	
Sex				
Male	605	51	605	51
Female	586	49	586	49
Place of death				
Private home with advanced home care	280	24	291	25
Palliative in-care unit	465	39	454	38
Resident care facility, permanent or short stay	299	25	299	25
Hospital ward (not palliative)	147	12	147	12
Loss of decision-making capacity				
Hours	498	42	498	42
Days	693	58	693	58

Prescription of Parenteral As Needed Drugs

The extent of prescribed drugs varied from 97% (for pain in the informed group) to 62% (for nausea in the uninformed). Patients in the informed group had PRN drugs prescribed significantly more frequently than in the uninformed group, regardless of symptom (Table 3).

Table 3. Palliative Care Content in the Studied Groups

Variable	% of Patients per Group		<i>P</i>
	Informed (n = 1,191)	Uninformed (n = 1,191)	
Symptoms not relieved			
Pain	18	20	.08
Anxiety	19	19	.64
Confusion	5	7	.02
Nausea	6	4	.13
Dyspnea	7	9	.11
RTS	15	18	.26
Parenteral PRN prescription			
Pain	97	93	< .001
Anxiety	89	84	< .001
Nausea	71	62	< .001
RTS	88	82	< .001
Family informed about imminent death			< .001
Yes	98	89	
No	1	9	
Do not know	1	2	
Family presence at time of death			.22
Yes	70	67	
No, only staff	19	21	
Died alone	11	12	
Died in his or her preferred location			< .001
Yes	70	39	
No	5	6	
Do not know	25	55	
Bereavement support offered			< .001
Yes	83	78	
No	9	15	
Do not know	8	7	

Abbreviations: RTS, respiratory tract secretions; PRN, pro re nata (ie, as needed).

Information to Family About Imminent Death and Presence of Family at Time of Death

In the informed group, the family had been informed significantly more often (98%) than in the uninformed group (89%). In the informed group, 70% of the patients had the family present at the time of death. In the uninformed group, 67% of the patients had family present at time of death (not significant; Table 3).

Death at the Preferred Location and Bereavement Support

Significantly more patients in the informed group (70%) than in the uninformed group (39%) died at their preferred location. The staff knowledge of the preferred place of death was significantly higher among the informed patients than among the uninformed patients (25% who did not know among informed *v* 55% among uninformed; Table 3). If a patient had been informed of possible imminent death, the family members were significantly more likely to have been offered bereavement support (83% *v* 78%; Table 3).

DISCUSSION

The result of this study shows differences in care between patients who had been informed about imminent death and the patients who had not. The patients in the informed group compared with the patients in the uninformed group were more often registered as dying in his or her preferred place; as having parenteral as needed prescriptions; and as having the HCP aware of his or her preferred place of death, his or her family informed, and his or her family offered bereavement support. However, no difference in symptom prevalence was found, implying that information about imminent death does not increase symptoms, such as pain, anxiety, and confusion, during last days of life.

Several aspects need to be considered when applying the results of this study. First, the SRPC is a new register (started in 2005), and it can be assumed that care units using the register early on were more experienced and knowledgeable in end-of-life care than users in the average health care setting. Supporting this hypothesis is the finding that a vast majority of registrations (78% of the original 13,818 patients) were submitted by units that specialized in palliative care; this may explain why the majority of patients had been given information about imminent death. Second, the register data only stated that there had been information given to the patient, but no details about the actual communication process or content were provided. All data were registered after the patient's death by HCPs. A validity test³⁵ comparing the register data and the medical records has shown deficiencies in the medical documentation of end-of-life decisions and care. The questionnaire is completed shortly after death by the HCP caring for the patient during his or her last days of life. Hence, we propose that this HCP should have knowledge about the actual circumstances during end-of-life care. One should be aware of problems associated with insufficient documentation in the medical records. Third, the collected data do not allow for subanalyses of ethnic and socioeconomic backgrounds. However, the data in our study show that patients in resident care facilities were more often informed by a nurse or were not informed at all (Fig 1), which are conditions that may indicate less availability of physicians in this type of care facility.

The results of this study are consistent with earlier reports that also stress the importance of end-of-life discussions to enable patients and their families to make preparations and arrangements for the last days of life. Steinhäuser et al³ found, when looking at preferences of patients,

families, and HCPs, an overwhelmingly agreement among all groups concerning "the general importance of being prepared for the end-of-life and knowing that one's family is prepared." Much of the patient desire for preparation was "to remove burden from loved ones." Fallowfield et al⁴ concluded that "patients need to plan and make decisions about the place of their death, put their affairs in order, say good-bye." Clayton et al⁵ found that, even though there was a diversity of views among patients, care providers, and health personnel regarding if and when discussions should be initiated, it was better to "err on the side of ensuring that prognosis and EOL (end-of-life) issues are accessible topics for the terminally ill patients and their families." In addition, one study found that physicians who recognize the importance of explicit routines for end-of-life communication with patients and their families reported improved job satisfaction and less risk of burnout.³⁶

To give information about imminent death is a conscious act that involves awareness of the fact that the patient is dying, an awareness that also implies preparedness of the HCP. Such preparedness should increase the probability of a more proactive approach with respect to prescribing palliative drugs and addressing patient and family wishes and needs during the last days of life (ie, a concept of total care). This can be a plausible explanation of the differences shown despite the similarity of symptoms. Our study does not support the view that providing information leads to increased levels of anxiety, pain, or confusion.

Awareness of staff is a prerequisite for the appropriate prescriptions for as needed medications and to enable patients to die at a preferred location. These care activities are two of the main goals in end-of-life care pathways.^{14,18} Another goal in these pathways is offering bereavement support. Even this goal was fulfilled to a greater extent in the informed group. In the informed group, family also had been informed significantly more often. This awareness of imminent death of a family member may facilitate the grief and bereavement process.^{9,11}

The results support the understanding that being informed about imminent death does not lead to more unrelieved pain and anxiety during the last week of life.¹¹ The only significant difference in symptom control between the two groups was a slightly lower confusion rate reported in the informed group (5%) compared with uninformed (7%) patients. Whether this has clinical relevance or not is questionable, but it does point towards a positive effect associated with providing accurate and timely end-of-life information. This study shows an association between information provided to patients about imminence of death and the type of care during the last week of life. This study provides quantitative data that support the importance of end-of-life care discussions to fulfill the principles of a good death.¹³

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

Conception and design: Gunilla A. Lundquist, Bertil Axelsson
Provision of study materials or patients: Bertil Axelsson
Collection and assembly of data: Gunilla A. Lundquist
Data analysis and interpretation: All authors
Manuscript writing: All authors
Final approval of manuscript: All authors

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