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Original Paper

Disclosing the Cancer Diagnosis: the Patients' Experiences

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497 Norwegian cancer patients (346 females, 151 males, mean age = 56 years (S.D. = 12)), admitted to a cancer rehabilitation centre, were surveyed on how they were told their diagnosis. Predictors of general satisfaction with the information were assessed. 43% of the subjects were informed by phone, letter or in the corridor/on the round and estimated that the information was presented in less than 5 minutes. Satisfaction with the information was predicted by perceiving the physicians as personally interested ($B = 0.528$, $P < 0.001$), comprehending the information ($B = 0.245$, $P < 0.001$), being informed in the physicians' offices ($B = 0.338$, $P < 0.001$), being informed by physicians at oncological departments ($B = 0.278$, $P = 0.01$) and increasing time spent on the disclosure ($B = 0.140$, $P = 0.01$). Other aspects of physician–patient communication than the pure presentation of valid information is highly valued by the patients. However, a substantial proportion of physicians present the cancer diagnosis in such a manner that the possibility of engaging in conversation about the diagnosis and the effect upon the patient is very limited. The findings call for remedial attention to the subject and improvement in performance. © 1997 Elsevier Science Ltd.

Key words: truth disclosure, physician–patient relations, neoplasms/px (psychology), patient satisfaction, questionnaires

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INTRODUCTION

REVEALING, AS opposed to concealing, the diagnosis of cancer was established as the preferred policy among American physicians in the 1960s and 1970s [1]. Internationally, and most prominent in Northern and Western Europe, the trend has also been toward more openness in revealing the cancer diagnosis [2, 3].

The great majority (>90%) of cancer patients, according to U.S. studies, prefers full information about their cancer [4, 5]. Information may provide the patients with emotional support [6], positively affect their psychological adaptation [7], reduce psychological morbidity [8], enhance their hopefulness [9] and improve their treatment compliance [10].

In spite of being the preferred practice both by physicians and patients for at least a decade, we know little about the manner in which physicians impart a diagnosis of cancer and how the information is perceived by the patients [11]. In a Swedish study of 231 malignant melanoma patients [12], 35% were informed by telephone and 5% by letter. In an American pilot study of 55 cancer patients [13], 42% had been informed of their diagnosis by telephone or in the recovery room. These patients were more likely to describe the information in negative terms and less likely to describe their doctors as being helpful in understanding their disease. With the lack of literature of other physicians' practices and the patients' preferences, physicians have struggled with these issues independently.

This study was conducted to determine how the cancer diagnosis is initially given, how satisfied the patients are with their physician's disclosure of the diagnosis, and which factors predict their satisfaction with the information.

PATIENTS AND METHODS

A self-report questionnaire, designed specifically for this study, was administrated to patients admitted to a cancer rehabilitation centre ("Montebello-senteret") from April 1993 to October 1994. The questionnaire was distributed and completed at the start of the stay. Nineteen items in the

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questionnaire explored how the cancer diagnosis had been disclosed and the patients' assessments of the disclosure. General satisfaction with the initial disclosure was measured by an interval scale: 1 = very dissatisfied, 2 = dissatisfied, 3 = neither satisfied nor dissatisfied, 4 = satisfied, 5 = very satisfied. The questionnaire also included items on the subjects' sociodemographic status and disease characteristics.

The patients attended one-week courses arranged by diagnosis or diagnostic groups. The courses aimed at improving the patients' ability to cope with their cancer and their quality of life. To achieve this, the patients attended lectures given by oncologists and psychologists/psychiatrists. Information about the cancer and common psychological reactions among cancer patients were presented. Additionally, the patients attended group sessions led by a nurse. In these, the content of the lectures where discussed with reference to the patients' own experiences.

The patients were admitted irrespective of disease dissemination or prognosis. However, they had to be able to care for themselves, and those in need of professional assistance to perform their daily activities or receiving terminal care were excluded. Patients attending 23 different courses during the period of data collection were approached. Out of a total of 540 patients attending these courses, 497 agreed to participate (compliance rate = 92%).

Patient characteristics are given in Table 1. The females (70%) were in excess and significantly younger than the males (mean age 54.8 years versus 57.7 years, $t = 2.46$, $P = 0.014$). When omitting the specific female cancers, the gender ratio was altered to 151/147 with no significant difference in age.

The data were analysed using the SPSS for Windows v6.1 software (SPSS Inc., Illinois, U.S.A.). Percentages are given relative to the total number of actual responses. Statistical procedures included frequency counts, cross-tabulations, chi-square statistics, two-sided *t*-tests (independent samples), one- way ANOVAs, Pearson correlations and stepwise multiple regression. The level of significance was set at $P < 0.05$.

Table 1. Patient characteristics

Parameter	Number of patients (%)
Age (years; *n* = 497)	
Mean (SD)	56 (12%)
Age groups (years; *n* = 497)	
20–44	88 (18%)
45–54	139 (28%)
55–64	138 (28%)
65–83	132 (27%)
Gender (*n* = 497)	
Female	346 (70%)
Male	151 (30%)
Level of education (*n* = 484)*	
9 years or less	186 (38%)
10–12 years	154 (32%)
13 years or more	144 (30%)
Site of cancer (*n* = 497)	
Breast	130 (26%)
Gastrointestinal system	127 (26%)
Female reproductive system	69 (14%)
Haematopoietic system	46 (9%)
Head and neck	46 (9%)
Other†	79 (16%)
Metastasis at time of diagnosis (*n* = 497)	
Yes	161 (32%)
No	324 (65%)
Unknown	12 (2%)
Years since diagnosis (*n* = 493)*	
<1 year	110 (22%)
1 year	212 (43%)
2 years	51 (10%)
3 years or more	120 (24%)
Finished treatment (*n* = 497)	
Yes	299 (60%)
No	171 (34%)
Unknown	27 (5%)
Present health condition‡ (*n* = 490)*	
Very good	52 (11%)
Good	230 (47%)
Not so good	193 (39%)
Bad	15 (3%)

*Some unavailable. †Includes cancers in the urinary tract, skin cancers, lung cancers, brain tumours and those treated with high-dose chemotherapy and bone-marrow transplantation. ‡As evaluated by the respondents.

RESULTS

Who disclosed the diagnosis

Sixty-two per cent of patients were informed by physicians at local general hospitals. Physicians at oncological departments had informed 20% and general practitioners 14%. Five per cent had been informed by others such as nurses or family members.

Site of disclosure (Table 2)

Fifty-two per cent of patients had been told in the physician's office. 19% were told in the corridor/on the round and 19% by telephone. Five per cent had been informed by a letter. No difference between groups with different disease duration were found.

More females than males had been told by telephone or letter (23% versus 10% and 6% versus 1.4%, respectively). Respondents with breast cancer or gynaecological cancers were over-represented among those informed by telephone (49% and 16%, respectively) or letter (41% and 27%, respectively). The differences by gender or cancer types in relation to site of disclosure were not significant when excluding the specific female cancers.

Irrespective of the informing physician's site of work, slightly more than 50% had been told in the physicians' offices. Of those informed by a general practitioner or a physician at a local hospital, 36% and 20%, respectively, had been told by telephone. Thirty-one per cent of the patients informed at an oncological department and 21% of those informed at a local hospital had been told on the round/in the corridor.

Duration of the disclosure (Table 3)

Forty-four per cent of patients stated that the disclosure lasted less than 5 minutes. No significant differences between subjects with different disease durations were found. Among those informed in the physicians' offices, 27% stated that the information was presented in less than 5 minutes compared with 62% and 61% of those informed over the telephone or on the round/in the corridor.

Table 2. Site of disclosure by gender

Site	Males (n = 146)	Females (n = 336)	Total (n = 482)	P-value*
In the physician's office	88 (60%)	161 (48%)	249 (52%)	0.014
On the round/in the corridor	35 (24%)	58 (17%)	93 (19%)	NS
By telephone	14 (10%)	76 (23%)	90 (19%)	<0.001
By letter	2 (1%)	20 (6%)	22 (5%)	0.029
Other place	7 (5%)	21 (6%)	28 (6%)	NS

*Difference in male and female proportions, two-sided P-value.

Other aspects of the disclosure (Table 4)

Forty per cent of the respondents were informed of their prognosis. Being informed of the prognosis was associated with longer duration of the disclosure and not with disease dissemination.

One in five had been offered follow-up consultations after the diagnosis had been revealed, unrelated to the site of disclosure or who had told the patient of the diagnosis. Forty-three per cent had the information of the diagnosis repeated, again unrelated to the site of disclosure or who had told the patient of the diagnosis.

Thirty-eight per cent perceived the informing physician as personally strongly interested. This was positively correlated with increasing duration of the disclosure ($r = 0.33$, $P < 0.001$) and being told the prognosis ($r = 0.26$, $P < 0.001$). No significant differences between the informing physician's site of work in relation to this variable were found. Thirty-three per cent perceived the physician as personally having little interest or not interested.

Seventy-four per cent reported good or very good comprehension of the information. A close statistical significant difference in proportions reporting good/very good comprehension was found in relation to educational level (9 years or less: 67%, 10–12 years: 78%, 13 years or more: 77%, chi-square 5.68, $P = 0.058$). In relation to cancer type, good/very good comprehension was reported most frequently among breast cancer patients (84%) and least frequently among patients with haematopoietic cancer (59%) (chi-square = 13.42, $P = 0.02$). No difference between subjects with different disease duration were found.

General satisfaction with the information of the diagnosis (Table 5)

While 44% were satisfied/very satisfied with the information, 21% were dissatisfied/very dissatisfied and one-third neither satisfied nor dissatisfied. In the bivariate analysis, perceiving the physician as personally interested ($r = 0.56$), comprehending the information ($r = 0.39$), duration of the disclosure (r =0.34) and increasing age of the respondent ($r = 0.17$) all correlated positively with satisfaction ($P < 0.05$). The level of satisfaction was higher among those who were told in their physician's office compared with those who were told in other places (mean = 3.48 versus 3.01, $t = 4.81$, $P < 0.001$). The same was found for those informed of their prognosis compared with those who were not (mean = 3.58 versus 3.01, $t = 5.56$, $P > 0.001$). Neither cancer type, years since diagnosis, disease dissemination, the respondent's gender or level of education nor the informing physician's site of work were associated with significant differences in satisfaction.

In the stepwise multiple regression analysis, 43% of the variance was explained by the selected explanatory variables controlled for the respondents' gender, age, level of education, type of cancer, disease dissemination and actual health. Being informed of the prognosis was not entered into the equation at the selected level of significance.

DISCUSSION

The results of this study indicate great variability in how the initial disclosure of the diagnosis of cancer is conducted. Most patients probably received additional information subsequently. However, the findings indicate serious gaps between the patients' preferences and many physicians' practices.

The findings' relevance is supported by the sample size, the heterogeneous diagnostic groups and the information being presented at different levels of the healthcare system. However, the sample is composed of patients applying for rehabilitation stays. It is over-represented by women and specific female cancer types, and younger as compared to the total sample of Norwegian cancer patients [13]. The sample is, therefore, not fully representative of the total Norwegian cancer population. Further, we do not know if, or in which direction, these factors may have influenced the data on how the doctors presented the diagnosis. Therefore, the generalisability of the findings is somewhat restricted.

The respondents' recollection of the disclosure may be distorted by time since the disclosure. No significant differences in estimation of duration of the disclosure, site of dis-

Table 3. Duration of the disclosure by years since diagnosis

	Years since diagnosis				
	<1 year (n = 101)	1 year (n = 200)	2 years (n = 48)	3 years or more (n = 118)	Total (n = 467)
Duration of disclosure					
<5 min	38 (38%)	88 (44%)	27 (56%)	50 (42%)	203 (43%)
5–14 min	40 (40%)	75 (38%)	14 (29%)	41 (35%)	170 (36%)
15–29	18 (18%)	26 (13%)	3 (6%)	20 (17%)	67 (14%)
>30 min	5 (5%)	11 (6%)	4 (8%)	7 (6%)	27 (6%)

Chi-square = 8.32, df = 9, $P > 0.5$.

Table 4. Aspects of the disclosure

	n	%
Informed of the prognosis	190	(40%)
Received written information	93	(20%)
Had relative present	115	(23%)
Had other health personnel present	66	(13%)
Other patients were present	17	(3%)
Offered follow-up consultation	97	(21%)
Had information repeated	191	(43%)

closure, comprehension of the information or general satisfaction with the information between groups with different disease duration were found. The emotional response to the message of having cancer may have affected the perception during the diagnostic encounter. Such a bias is considered least likely to affect measures of where the diagnosis was disclosed, but may affect measures of the specific content of the disclosure.

Cancer is experienced as a series of expectable psychosocial crises [15]. When revealing a cancer diagnosis, the physician faces a patient probably experiencing the first of these crises.

Women with specific female cancers most frequently had their diagnosis presented by telephone or letter. This may reflect the special diagnostic procedures employed in these cancer types (such as routine smears or routine mammographies). If such tests are accomplished without prior symptoms, these women may have been psychologically poorly prepared for the message.

Physicians have claimed reduction of the patient's psychological distress as the main reason for both revealing and concealing the cancer diagnosis [16]. If disclosure should positively affect the patients' psychological adaption, the communication process (i.e. imparting information, disclosing feelings, giving hope and sharing control) [17] is central. When disclosure so frequently was accomplished outside the physicians' offices and in a short period, it is relevant to hypothesise whether a substantial proportion of the physicians consider imparting the message and not the process of communication as the main point. Further, such a practice provides little opportunity for giving emotional support to patients experiencing a crisis, or responding to the patient's reactions and questions. In addition, those who do not want to know are probably less detected.

Several factors may contribute to the physician's manner of presenting the cancer diagnosis. Firstly, their working conditions including work-load [18] and the structural framework they operate within [19] might be of importance. Secondly, clinical communication skills may be lacking. Contrary to what many physicians believe, clinical communication skills do not reliably improve from more experience. Furthermore, traditional medical education has been characterised as generally ineffective in teaching clinical communication at all levels [20]. Thirdly, the emotional impact of presenting a cancer diagnosis might solely or in interaction with the physicians' psychological characteristics influence their ways of conducting the disclosure [21]. Both the physicians' empathic skills and their handling of their own feelings, such as assuming responsibility for the disease or fear of being blamed for the news [22], might be of importance.

This study's retrospective design restricted collection of data on the communication process. However, 43% of the variance in satisfaction was explained by the selected variables. Because they reflect the patients' subjective impressions, they are clinically highly relevant. One may object that perceiving the physicians as personally interested is inseparable from general satisfaction due to the high intercorrelation. However, the two concepts are substantially different, and previous studies [7, 23] have also found the physicians' interpersonal skills to be of importance.

Our findings emphasise the importance of imparting unpleasant messages in a manner that secures the patient's privacy [24] and communication with the physicians. The physician's competence in information-giving, reflected by the comprehensibility of the message, contributes significantly to increased satisfaction. This is in accordance with the findings in Roter's meta-analysis of physician–patient communication in general [10]. The finding of perceiving the physician as personally interested contributing the most to the patients' satisfaction, is opposed to what has been found in studies of physician–patient communication in general [10]. However, revealing a cancer diagnosis differs from standard physician–patient communication by the accompanying emotional crisis and uncertainty [15, 25]. The focus of the physician on providing valid information may have overshadowed the physician's apprehension of their importance as providers of emotional support by conveying a caring attitude [7].

This study supports empirically what has been advocated as desirable ways of "breaking bad news" [26]. Disclosing a cancer diagnosis quickly in a setting that restricts the possibility of engaging in conversation is not what the patients want. Lacking communication skills on the part of the physician can affect both the patient's comprehension of the message and deprive the patient of emotional support.

Table 5. Predictors of general satisfaction with the initial disclosure of the diagnosis, stepwise multiple regression analysis

Explanatory variable	*B**	*t*-value	*P*-value
Perceiving the physician as personally interested†	0.528	11.54	<0.001
Comprehending the information†	0.245	5.08	<0.001
Informed by doctors at oncological departments‡	0.278	2.60	0.01
Informed in the office§	0.338	3.76	<0.001
Time spent on information†	0.140	2.60	0.01
Age†	0.009	2.60	0.01
Constant	−0.27	−1.03	NS

*The point estimate of the multiple regression coefficient. †Entered as continuous variables. ‡Categorical variable entered as three dummy variables. §Site of disclosure dichotomised into: informed in the physician's office/not informed in the physician's office

Communication skills can be taught [27]. However, neither information-giving techniques nor skills in providing psycho-social support have been important parts of the curriculum in medical schools or during courses in specialisation. Research on the relative importance of these central aspects of physician communication when revealing a cancer diagnosis is indicated. Furthermore, "breaking bad news" as part of medical practice and communication should receive more attention both in the medical curriculum and in the physicians' specialisation.

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