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Original Paper

Cancer Information: a Cost-effective Intervention

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There is a considerable knowledge base about the information needs of patients with cancer (and their relatives and friends). Those needs will vary according to the disease, the stage of disease, the patient and his or her age, social class and culture. Lack of information may lead to increased anxiety and distress, may impact negatively on the patient's satisfaction and may influence a patient's treatment choices. Other articless in this special edition deal with psychosocial interventions and complementary therapies for cancer patients and explore their efficacy. The reality is that these are unlikely to be made available to all cancer patients for reasons of cost and practicability. Information, however, is a relatively cheap intervention that could—and should—be part of standard care. This article explores some of the research about the provision of information for cancer patients. © 1999 Elsevier Science Ltd. All rights reserved.

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In a recent (August 1998) letter to the *Lancet* a woman wrote "In April, I was diagnosed with early breast cancer [1]. Since then, my chances of survival have been put at 95% chance of completing my normal lifespan; 90% chance of living for the next 5 years; 80% chance of living for the next 10 years; 90% chance of living for the next 10 years; and 97% chance of living for the next 5 years. I am still deciding which to go with." The author emphasised that the presentation of the benefits associated with different treatments is also confusing. If a treatment is said to add 1–2.5% to the chances of survival, how does the patient relate this to him or her self?

An article by Dodwell some months earlier (to which the letter was a response) noted that 'in the absence of reliable and accurate predictive markers, the benefit for individual breast cancer patients of adjuvant cytotoxic chemotherapy is uncertain' [2]. The benefit can be described as an odds reduction (although the absolute magnitude of the effect depends on the underlying prognosis so may be difficult to predict) or as the percentage improvement in survival probability or the lengthening of the median survival time. The use of adjuvant chemotherapy requires a trade-off between possible future gain and short-term toxic effects and the balance will vary between individuals. The problem facing patients is that at the very time when their lives have been thrown into turmoil they have to get to grips with concepts such as prognosis and treatment efficacy and face a situation where there are many unknowns about the natural history of the disease and the impact of treatment. Their misinterpretation of the likely efficacy of treatment is perhaps understandable. Mackillop reported that almost half of patients on palliative therapy believed they were being given curative therapy [3].

Dodwell adds that "we require a greater understanding of the relation between risk, toxic effects, benefit and their acceptance and comprehension by patients who have different preferences and views depending on their age, social class or culture. Such research is long overdue" [2].

Providing the level of information outlined above to patients is a relatively new phenomenon. Not telling a patient a diagnosis of cancer was advocated by McIntosh in 1976 [4]. As recently as 1993, 60% of European gastroenterologists did not routinely tell their patients a diagnosis of cancer if not asked [5]. Yet, in 1980, when cancer patients were asked what they wanted, only 2% of cancer patients did not want information about their diagnosis, side-effects or treatment [6].

Information—whether good or bad—is wanted by the overwhelming majority of patients [7–9]. Meredith and

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colleagues, in a study of 250 patients, reported that only 4% of patients did not want to know if they had cancer [8]. Harris, in a literature review of the information needs of patients with cancer and their families reports that the National Cancer Institute's Office of Cancer Communications reviewed the literature published from 1979 to 1990 covering information, education and communication [10]. The key findings—which were not published—were first, that patients with cancer wanted information about what would happen to them in the immediate future. Second, that patients wished to be involved in treatment decisions and third, that there is a discrepancy between patients' and health professionals' views of what information patients need.

The provision of information is considered to be an important part of the care of patients with cancer. The blueprint for cancer services in England and Wales, the Calman–Hine Report, recommended that "patients, families and carers should be given clear information and assistance in a form they can understand about treatment options and outcomes available to them at all stages of treatment from diagnosis onwards" [11].

If it is universally agreed that information is an important part of cancer care, the issues that need to be resolved are how much, in what form and when. These will all be affected by an individual patient's approach to seeking information. Factors likely to influence patients' readiness for information include culture, literacy level, psychological adjustment and the behaviour of the health professionals [10].

Prior to a formal diagnosis, putative cancer patients feel the need for information. The time between a GP referring a patient to a specialist and the appointment with that specialist is a particularly anxious time for patients. At that time patients may have two types of informational need [12]: (1), for specific information about the cancer, including prognosis and treatment details. Before a formal diagnosis has been established, uncertainty caused by lack of such information may be difficult to avoid; (2), for procedural and practical information, which it should be possible to provide for all patients. In a study undertaken in Canada, 83% of patients preferred to receive information before the first visit, although no difference in the psychological distress between those who did and those who did not receive the information was found. Interestingly, the authors noted that several patients asked that information be sent confidentially with no indication of sender [12]. It is still the case that some patients see a stigma associated with a diagnosis of cancer.

Increasingly, patients want to be involved in making decisions about their management. The paternalism that used to be the norm in medicine is no longer anticipated or acceptable. Yet patients cannot be expected to participate in the decision-making process unless they have some information to help them. Of 165 adult patients with Hodgkin's disease, 62% reported not receiving written information; of those, 90% would have liked to receive it. Those who felt satisfied with the adequacy of information were more likely to feel happy with their level of participation in the decision making [13]. Those patients who feel they have not been given adequate information about diagnosis and treatment options may exhibit measurable anxiety and depression following treatment [7, 14]. Fallowfield notes that "in their desire to shield patients from reality, clinicians often create more difficulties for their patients". This is borne out by one cancer patient, who reported feeling "humiliated, manipulated and out of control" as a result of being fed "tailored truth and outright lies" [15].

The majority of long-term survivors felt early short-term side-effects were more, or equally, as important as late morbidity with respect to influencing choice of treatment [13]. A qualitative study of head and neck and lung cancer patients draws attention to the need to give accurate information about what to expect in relation to side-effects. Patients who received little or no information about side-effects or who were expecting more minor effects had a greater anxiety, presumably because they were left with the feeling that the treatment had not gone according to plan [16].

Lack of information may lead to increased uncertainty, anxiety, distress and dissatisfaction and may negatively influence patients' treatment decisions [7, 17]. Dissatisfaction with the lack of information about the late effects of treatment, which patients feel deprived them of the opportunity to make an informed treatment decision, has resulted in the formation of pressure groups such as Radiotherapy Action Group Exposure. Patient preferences should be considered in the decision making and there is increasing acceptance that patients should have a role in the design of clinical trials to ensure that they test questions that patients consider relevant. A review of research empirically evaluating the effects of information interventions for cancer patients undergoing chemo- or radiotherapy found that all of the studies reported positive effects [18]. The authors noted that there was a paucity of such empirical studies and suggested that there was a need to evaluate such interventions.

A starting point for such research may be data collected from people seeking information. CancerBACUP is a national cancer information service in the U.K., launched in 1985 [19]. Systematically collected data from first time users of the CancerBACUP information service were compared with cancer incidence data and, for relatives and friends, with population data [20]. There was an excess of female first-time enquirers compared with the population in Great Britain and an excess of calls about women with cancer (60.1%) compared with the incidence of cancer in women (50.9%) ($P<0.001$). The enquiry rate from individuals aged between 30 and 60 years is greater than expected, and the age of patients enquired about is similarly lower than would be expected if calls reflected the cancer patient population. Comparing enquiry rates with incidence rates for specific cancers, there are a number of interesting differences. The enquiry rates for prostate and cervical cancer are close to that expected. For both male and female patients combined, lower than expected enquiry rates are recorded for bladder, stomach and lung cancer, whereas higher than expected rates are noted for brain tumours, leukaemias and non-Hodgkin's lymphoma. For female cancers, there are more enquiries about breast and ovarian than would be expected and for male cancers, the enquiry rate is much higher for testis cancer.

The commonest subjects of enquiry for callers to CancerBACUP are shown in Table 1. Most callers (during April 1997 to March 1998) required information about their specific cancer and about treatment, with enquiries about chemotherapy being slightly more frequent than enquiries about radiotherapy or surgery. 11% of callers explicitly asked for clarification of information they had received and 10% wanted to know more about their prognosis. Because data has been collected since the service began, it is possible to look at trends over time, and it is interesting and encouraging

Table 1. *Commonest subject of enquiry during April* 1997 *to March* 1998

Enquiry	(%)
Emotional support	39
Publications	32
Site-specific information	27
Chemotherapy	19
Radiotherapy	15
Treatment side-effects	14
Surgery	11
Information clarification	11
Prognosis	10
Health professional communication	8
Symptom control	8

Note that the nurses can record more than one subject of enquiry.

to note that the percentage of callers who were given CancerBACUP's contact details by health professionals has risen over the years. Now, almost a quarter of callers cite health professionals as the source, the majority of the health professionals being nurses (74%).

Patients forget between 40 and 50% of the information they have been told [21]. Often, they need to hear the information in different ways and repeatedly. Telephone cancer information services can provide a vital service to patients (and their families) because the person can use the service at a time to suit them and can take as long as they need to obtain the information they require. This does not mean that calls need to be excessively long and the average length of call during April 97 to March 98 was 11 min (Table 2). An evaluation of users of an information service found that there was a more positive effect on mood if the enquirer contacted the service by phone rather than by letter [10].

Younger patients are more likely to want information about all possible treatments (age 15–64 years, 91 versus 79% of age 65–74 years) as are women (95 versus 78%) [8]. Table 3 compares the age range of the patients using CancerBACUP's information service in 1985–1987 with 1997–1998 [19]. A detailed comparison of callers in the higher age groups is impossible because of the way data were previously collected. During the first 2 years, 23% of the patients contacting CancerBACUP were aged 60 years and over, this had increased to 32% in 1997–1998. Enquiries from patients aged 30–39 years had decreased from 23 to 12%. The socio-economic class of CancerBACUP users has changed very little since the early years of the service (Table 4). There has been a very slight increase of users from socio-economic classes III manual, IV and V (13% versus 18%), but not enough to demonstrate any success in reaching this population. Literacy level may impact on the use of cancer information services and low literacy is more prevalent among individuals of low socio-economic status [22, 23]. People of lower socio-economic status also make less effective use of health services generally [24].

Table 2. *Duration of calls to CancerBACUP information service during April* 1997 *to March* 1998

Duration of calls	(%)
≤9 minutes	41
10–19 minutes	46
20–29 minutes	10
≥30 minutes	3

Table 3. *Age group of cancer patients contacting CancerBACUP*

	1985–1987		1997–1998
Age (years)	(%)	Age (years)	(%)
10–19	<1	<19	<1
20–29	8		2
30–39	23		12
40–49	24		24
50–59	23		30
≥60	23	60–69	22
		70–79	9
		≥80	1

There is a concern among some health professionals that independent information services will provide direct clinical advice to their patients that will conflict with their own recommendations. Such a problem is unusual, not least because the advice often given is to consult the patient's own health professional (Table 5).

But what influences patient decisions is not only the information they are given about treatment options, but also their personal experience and the attitudes and beliefs these bring, family, friends, media and other health professionals [25]. The treatment offered depends on factors related to the health state of the individual and on the practitioner consulted and the knowledge base or prejudices of that practitioner. It should also depend on whether the patient's priority is possibility of cure or controlling the disease long enough for death from some other cause to intervene. Mazur and Merz asked patients attending the Veteran Affairs Medical Center in Oregon about their choice of treatment for hypothetical localised prostate cancer [26]. They found that patients who had experienced some symptoms of incontinence were less worried about this as a potential side-effect of treatment. In a separate study, Mazur and Hickham reported that 92% of patients who would choose surgery were influenced by the possibility of complete tumour removal and 80% of those who would choose watchful waiting were influenced by the risk of surgical complications [27]. Choices are also significantly influenced by how the information about life expectancy is presented, including whether the outcome was framed in terms of the probability of living or the probability of dying [25]. Patients report hearing a 70% probability of 5-year survival as a certain death sentence.

Table 4. *Socio-economic class of CancerBACUP information service users*

	April 1985–March 1987	April 1997–March 1998
	(%)	(%)
I	11	8
II	46	45
III non-manual	30	29
III manual	8	9
IV	4	7
V	1	2

Table 5. *Commonest suggestions/referrals given to enquirers during April* 1997 *to March* 1998 *were to contact the groups below*

	(%)
Consultant	15
General practitioner	11
Nurse	8
Local support/self-help group	2
Social services/social worker	1
Other suggestions/referrals	63

How should patient information be presented? Interestingly, the way in which information is presented is often not given enough consideration. Prostate cancer patients were adamant that the term 'side-effects' was completely unacceptable to describe the impotence and incontinence that might result from treatment. Their choice of descriptor was 'unwanted effects of treatment'.

Dalton and Gartenfeld compiled criteria to be applied to patient education materials that related to accuracy, currency, point of view, audience level, scope of coverage, organisation, style and format [28]. Rorden added to this content and objectives and the Society of Teachers of Family Medicine suggested that evaluation (i.e. evidence of effectiveness) and authorship and sponsorship should also be given [29, 30]. They further suggested that cost-effectiveness/practicality would be a useful measure and this is reflected by the work of Mohide who found that a new patient information plan was no more effective than a mini-new patient information plan, but that the cost was significantly lower for the mini version [12]. If cancer information is to be built into the cost of treatment, no doubt in due course there will be calls for cost-effectiveness of cancer information to be demonstrated.

More recently, Coulter and colleagues have looked at the quality of information provided to patients since, if such materials are to be used to support patients' involvement in treatment decisions, they must contain relevant research-based data [31]. They organised reviews of 54 materials by 62 patients with personal experience of the specific health problems and by 28 clinical or academic specialists familiar with the available research evidence. They conclude that groups producing information materials must start with needs defined by patients, give treatment information based on rigorous systematic reviews and involve multidisciplinary teams (including patients) in developing and testing the materials.

Cooley and colleagues compared the reading level of American Cancer Society and National Cancer Institute pamphlets to the reading ability of a sample of patients in three clinics at the Philadelphia Veterans Affairs Medical Centre [32]. Only 27% of their subjects could be expected, based on reading skills, to understand all the material tested. They suggest that materials could be modified to be more helpful to patients and that reading levels should be printed on all materials.

In the U.K., not all treatments are available equitably and the so-called 'postcode prescribing' means that some patients will be deprived treatment based on their Health Authority of residence rather than need. These circumstances present particular problems. Weeks and coworkers "believe that patient preferences should drive choices between alternative therapies, especially when life expectancy varies little and quality of life considerations are prominent" [33]. If the choices are not available, can it be justified to tell patients about treatments they cannot get? Hospitals are producing their own information describing the treatments that will be provided at that centre. National information that sets out all the treatment options—through which patients may learn about treatments they are not offered—may not be acceptable to healthcare professionals in these circumstances.

The need for information is not limited to the immediate period after a diagnosis of cancer. Patients and their carers will often have a continuing need for information, although the type of information is likely to change. As Muzzin comments, a person never really gets over cancer: it is a sword of Damocles that continues to hang over the individual and their family for the rest of the person's life [34]. Health professionals, many of who prefer not to provide patients with information about which of the symptoms that they might develop should be taken seriously, often underestimate this. The underlying concern patients feel is well demonstrated by the impact of Linda McCartney's death on the CancerBACUP information service. In the week immediately after the event, the daily calls about breast cancer increased by 64% and the number of calls logged to the answering machine (when all the lines were in use) doubled [35].

The internet (World Wide Web) is increasingly being used as a source of information for cancer patients, although a survey of callers to CancerBACUP in the summer and autumn of 1998 found that only a small percentage of them had access to, or had used, the web (data not shown). Much has been made of the fact that it is impossible to control the information on the web and that patients can learn about a range of bizarre and possibly dangerous treatments and, worse, buy them.

Impicciatore and colleagues reviewed information available on the web about managing fever in children at home [36]. Using the search engines Yahoo and Excite, they retrieved 41 web pages. Of those, 32 were developed by commercial ventures and the remaining nine produced by individual practitioners, clinics, academic institutions or other organisations with educational purposes. They found that only a few of the web pages gave complete and accurate information for this common condition. Their conclusion was that there is an urgent need to check public-oriented healthcare information on the internet for accuracy, completeness and consistency. Such a proposal is problematic since it is likely to be many years before members of the public apply criteria such as those proposed by McLellan: authorship; attribution; confidentiality; currency; disclosure; legitimacy; purpose [37]. These are similar to those proposed for written information [28–31].

Metcalfe suggests that doctors and their patients travel together on the long road of serious illness and its treatment [38]. Perhaps the way forward for all cancer information—and not just that on the world wide web—is for oncologists to act as information guides rather than information resources [39].

CONCLUSION

With so much published data to demonstrate unequivocally that patients want—and need—information related to a diagnosis of cancer, it is no longer tenable for clinicians to send their patients away without at least some written information. That information should be nationally relevant and produced by an experienced organisation and should have been tested on patients for its appropriateness. It should be funded in the same way that anti-emetics and antibiotics, for example, are—as an adjunct to conventional surgery, radiotherapy and chemotherapy. Providing information in this way will do much to improve the quality of life for cancer patients and their carers and do little to dent the budget of any healthcare system. For those patients who will die from their disease, quality of life must be a priority since survival is unattainable; for those who will recover, it makes sense that they do so without unnecessary psychological sequelae from information deprivation.

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