

Empowering Patients to make Informed Decisions by Measuring their Needs and Satisfaction

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ABSTRACT

The benefits of good quality patient information are now firmly established. Adequately informed patients, who share decision-making with their medical team, have been shown to have greater autonomy and physical well-being within randomized^{1–5} and prospective^{6–8} observational studies. Patients offered higher levels of information also tend to have improved compliance, and significantly reduced anxiety and depression. In order to empower patients with enough understanding to make truly informed decisions, however, many oncology units have introduced a wide selection of educational tools. In order to identify whether these manoeuvres are satisfying patients' information needs, it is important to determine what these needs are and how to measure them. This article reviews and summarises the literature on the benefits of information provision; describes the development a patient's information satisfaction questionnaire (ISQ) based on their treatment and lifestyle information needs; reports a longitudinal study measuring patient's satisfaction and how this feed back was used to develop information strategies to improve satisfaction and empower decision-making.

KEYWORDS

Cancer, Information Needs, Information Satisfaction, Informed Decision-Making, Lifestyle after cancer.

BACKGROUND

In order for patients to be empowered to share decisions with their medical team they need to truly understand their options. They have to transgress from normal members of society to a cancer expert in a matter of weeks, whilst at the same time coping with the emotional trauma of a cancer diagnosis. The quality and level of information they require after diagnosis and, for that matter at critical stages in the cancer management, is high.^{11,17–20}

What are the consequences of poor information provision?

The unpleasant feeling of being inadequately informed has been linked with more sinister psychological and physical consequences. For example, it can lead to frustration at an inability to make informed decisions, thus preventing patients from fully exercising their autonomy.⁶ Lerman et al.

(1993) demonstrated a link between poor information provision and anger, confusion and poor adjustment to illness. Other observational studies have also demonstrated an inverse relationship between post-treatment anxiety, depression and self-care during radiotherapy and initial satisfaction with information provided pre-treatment.^{1,7–9} Patients with less knowledge before surgery have demonstrated higher anxiety, slower recovery from anaesthetic and were less ambulant post-operatively.^{10,11}

Dissatisfied patients are more likely to turn away from the clinic and look for information from uncontrolled and often inappropriate sources elsewhere.^{12,13} Furthermore, failures in the provision of relevant information are among the most common reasons for official complaints by patients and relatives,¹⁴ which can involve hours of medical, managerial, and legal time and expense.¹⁵

What are the benefits of good information provision?

Providing higher levels of information and involving patients in their own treatment decisions has been shown to have a protective effect on patients' well-being. In both randomized^{1–5} and prospective^{9,16–17} observational studies patients with a variety of cancer types who were offered higher levels of information were significantly more satisfied and had better psychological adjustment to their illness. In another prospective but non-randomised study, patients offered a choice in their management had lower levels of anxiety and depression, better adjustment and more positive attitudes towards the future.⁷ Furthermore, children of parents with cancer coped better when informed of the diagnosis^{18–20} and had lower levels of anxiety when given more complete information.

Ongoing research being carried within our oncology unit, involving 214 patients with breast and prostate cancer, has also demonstrated that information satisfaction is a significant predictor of quality of life ($p < 0.001$, Adjusted R Square = 0.249). To a lesser, but still statistically significant degree, information satisfaction was also found to predict physical, social and family, emotional, and functional well-being in this group of patients.²¹

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What level of information do patients need?

In two separate recent UK studies, an information needs questionnaire was used to estimate the level of information patients wanted after their cancer diagnosis.^{22–23} In 2003, nearly 80% of patients audited over a one month period, indicated that they wanted as much information as possible. By 2007, this has increased to as many as 94%.²¹ Only 6% wished to have only positive information or wanted to let the doctor make decisions for them without informed input.^{22–23} However, for the majority of patients, time pressures and patient numbers mean that consultations are often short. Combined with the tendency of many health professionals to overestimate patients' understanding of their treatment options^{24–25} and underestimate the level of information they require,^{26–27} some patients feel inadequately empowered to take an active role in their own treatment decisions.^{4,6–7}

Measurements of anxiety levels in one of these studies²³ indicated that the group of patients who wanted to let the doctor decide had very low anxiety. The old saying 'ignorance is bliss' therefore stands, and should be respected. For example, Franz Ingelfinger, formerly editor of the new England Journal of Medicine, who himself died of carcinoma of the oesophagus, sensed "*immediate and immense relief*" when he abrogated responsibility to his doctor.²⁸ This tells us it is probably unwise to force information on this small but significant group of patients. Research is, therefore, underway to identify patients' information requirements at the outset.^{29–30}

Most oncology units around the world, including our own, have invested time, money and effort in improving their information strategies and in general patient satisfaction is improving. At the same time, however, patients' expectations for information have also increased in terms of quantity and diversity, making it important to align patient-clinician expectations.³¹ In order not to create a discrepancy with these expectations, regular patient feedback is required to produce even more sophisticated and individualized information strategies.

AIMS

With these diverse information preferences being identified within the literature and through regular audits, a three phase information improvement strategy was carried out. The aim of each phase of this strategy was as follows:

1. Develop a patient's information satisfaction questionnaire
2. Measure patient's satisfaction to information received
3. Develop strategies to improve satisfaction and empower decision-making.

Strategy aims were carried out at The Primrose Oncology Unit, a dedicated outpatient service based in a District General Hospital (Bedford). Patients involved in this initiative are a representative sample of a cross-section of district general hospital patients in terms of socioeconomic status.³² In 2005, 2,400 patients attended

the unit for interventions such as chemotherapy, infusions, and aspirations; 281 were booked in for radiotherapy. Patients vary from breast, prostate, head and neck, and bowel cancer.

DEVELOPING A PATIENT INFORMATION SATISFACTION QUESTIONNAIRE (ISQ)

The first step to enhance an established information strategy was to develop a robust audit tool to unearth the specific issues which concern patients and then measure whether these concerns were being met within routine clinical practice. A number of questionnaires have been developed and have successfully been used to measure global satisfaction, such as that used in the recent UK Department of Health survey.³³ However, such questionnaires fail to distinguish between satisfaction with specific information as opposed to general issues of satisfaction. It is important to evaluate subcategories of information from each other. A questionnaire addressing specific information needs and satisfaction had not previously been available. To address this deficit, we designed a simple study in 2003 which aimed to unearth the specific information issues of most concern to patients with cancer.

Seventy seven consecutive patients with a histological diagnosis of cancer, who had completed active treatment within the last six months, were approached by the clinic nurses whilst waiting for a consultation. This was done over six consecutive outpatient clinics over a 2-week period at the Primrose Oncology Unit. Following a verbal and written explanation of the project, patients were presented with a blank sheet of paper and asked to write five or more of the most important categories of information which either helped them or would have helped them following their diagnosis, during treatment, and on follow-up. The nurses also recorded on the same page the sex, age, diagnosis and treatments the patient received, to allow the questionnaire to be used in audits looking for deficits between patient and treatment types. Four patients declined (2 male, 2 female) and the remaining 73 (95%) patients returned the questionnaire before they left the clinic or returned it later by post. Twenty-four were male and 49 female, aged between 26–78 years (mean 55 yrs); 38% had breast cancer, 28% bowel, and 12% had ovarian or lymphomas. To maintain inter-rater reliability, each of the 303 answers were read by a multidisciplinary panel of nurses, doctors and patients and categorised into 9 main groups of similar themes based in order of frequency (Table 1). Categories were identified as follows:

- "I would have liked more information on transport & parking" ('logistical' category)
- "I wasn't sure if I could exercise" ('lifestyle' category)
- "Information on how I would feel and side-effects during chemotherapy" ('side-effects of treatments' category)
- "Would the treatment work?" ('outcome' category).

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Table 1: Categories of Information which most concerned patients with Cancer (combined and equally weighted into 5 sections),

Combined Categories	No. (% patients)
Side-Effects of Treatment /How will I Feel	65 (87%)
Explanation of Illness / Prognosis / Genetic Risks	64 (83%)
Logistical Issues /Follow-up Arrangements	60 (82%)
Treatment Options /Clinical Trials	58 (75%)
Lifestyle Issues /Support Groups /Complementary Rx	56 (77%)
	303 (100%)

The Primrose Oncology Unit Audit, 2003.

high overall score, the questionnaire was still able to identify limitations in information provision among patients indicating they were from ethnic minorities:

Table 2: Information satisfaction differences between non-ethnic and ethnic patients,

	Satisfied or very satisfied	Difference (Chi ²)
Non-ethnic minorities	93%	24% (p < 0.01)
Ethnic minorities	69%	

The Primrose Oncology Unit Audit, 2003.

The score for each section was then determined by a standard 5-point Likert scale of 'very satisfied' to 'very unsatisfied'.³⁴ An additional question was also included to give patients the opportunity to provide a score for satisfaction with the overall information provided. Finally, three questions asking about patients' desired information levels were added, based on our previous adaptation of an original information needs questionnaire developed for a West of Scotland survey.²²⁻²³ The completed one A4-page Information Satisfaction Questionnaire (ISQ)³⁵ is now freely available on www.cancernet.co.uk in a variety of languages and is used routinely to measure patients' satisfaction to information across a large UK cancer network (West Anglia).

MEASURE PATIENT'S SATISFACTION TO THE INFORMATION RECEIVED

The ISQ has been used in two prospective audits at the Primrose Oncology Unit, the first in 2003 and the next in 2006. On both occasions specific deficits were detected, which helped design new information initiatives.

Audit one

Method – The ISQ was distributed to 220 consecutive patients attending the Primrose Oncology Unit between January–February 2003. It was distributed to patients on arrival in the Unit by a trained member of staff and they were asked to complete the one page form before leaving the Unit that day. One hundred and ninety five forms were returned; 77 were male, 118 female, and the average age was 58 years. Forty-one percent were in ethically approved prospective clinical trials. All patients evaluated during this period had received our standard information package, which included a bespoke information file, free access to the internet, an information video and oral consultation with a specialist nurse.

Findings – The overall score was gratifyingly high (92% satisfied or very satisfied) and an enormous improvement to a similar audit two years earlier using a rudimentary previous satisfaction questionnaire (23% satisfied or very satisfied). Although not directly comparable, it reassured us that the information strategies instigated over this time were having a benefit. Despite these manoeuvres and this

Actions

To address the lower satisfaction among patients from ethnic subgroups, thanks to sponsorship from the UK Department of Health New Opportunities Fund, preparatory information films were made in the 5 most common ethnic UK languages – Urdu, Hindi, Gujarati, Bengali and Italian. In a previous study, ethnic subgroups had demonstrated a particularly strong preference for information in a video format.³⁹ The emphasis is diverted away from the spoken and written word into vision and movement, which may be an attraction to patients whose first language is not English.³⁶ Videos were made with patients from these language groups and were designed to be sensitive to cultural and educational needs. They provided an overview of treatment, risks of side-effects, methods used to alleviate side-effects, as well as showed patients describing their own experiences. Like the previously evaluated English video, it was provided to all patients before chemotherapy or radiotherapy. The video is now available nationally from Cancerbackup.

Audit two

The ISQ was then used in a similar audit in January 2006, this time being distributed to 230 patients to achieve a 200 return. Reassuringly, overall satisfaction remained adequate and patients from ethnic groups were now scoring the same as others (84% v 89% satisfied or very satisfied). However, it did unearth some other issues; advice on logistical issues and follow-up arrangements scored low (73% satisfied) and lifestyle advice appeared to be insufficient (69% satisfied). Of some concern was the finding that 27% of patients not in trials were uncertain whether they were in a clinical trial whereas all those in a trial were aware of this. Table 3 shows that almost twice as many non-clinical trial (NCT) patients indicated they were either very unsatisfied or unsatisfied with information they received as opposed to those who had entered a clinical trial.

Actions

Clinical trial information – The finding that 27% of patients not in trials were not sure whether they were in one or not implies that more trial information is required

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Table 3: Comparison of satisfaction for patients in trials to those not in trials.

<i>Patients Recording Unsatisfied or Very Unsatisfied Scores</i>				
	All (n:200) No. (%)	Trial (n:83) No. (%)	Non-Trial (n:117) No. (%)	Difference (% difference)
Explanation of Illness	19 (9.5%)	5 (6%)	14 (12%)	6% (50%)
Types of Treatments	28 (14%)	9 (11%)	19 (16%)	5% (31%)
Logistics	53 (27%)	20 (24%)	33 (28%)	4% (14%)
Side-Effects	30 (15%)	11 (13%)	19 (16%)	3% (19%)
Lifestyle	61 (31%)	27 (32%)	34 (29%)	3% (10%)
Overall	24 (12%)	6 (7.2%)	18 (15.4%)	8.2% (53%) Chi ² p<0.01

The Primrose Oncology Unit Audit, 2006.

for those not in a trial than those who are. This was addressed with new explanatory posters displayed in patient areas, trial information being included in standard information sheets, and staff now specifically mention to patients that they are not in a clinical study.

Logistical advice – A practical issues and logistics panel was established to gather practical information on transport, travel, clinic times, and parking. Also, money was raised to buy extra cars to bolster the transport services. The audit has also stressed the importance of adequately staffed, good quality clerical staff.

Lifestyle advice – In an attempt to correct the discrepancy between patients' expectations for lifestyle guidance and what they had been receiving, a number of measures have been initiated based on a review of the worlds published literature.³⁷

A series of lifestyle advice sheets have been written and published on the web (cancernet.co.uk/lifestyle) ready to be printed out at appropriate times in patients' management, as well as being included in their hand-held file if required.¹⁷ The most notable examples of these include guidance on:

- Exercise; finding local gyms, dance, yoga, pilates classes, swimming pools, etc.
- Personal fitness instructors
- Diet – including carcinogens in common food and Oxygen Radical Absorbance Capacity (ORAC) ratings of food
- Quitting smoking
- Fertility issues
- Sexual issues
- Complementary therapies
- Psychological counselling
- Alcohol and drug dependence
- Financial advice and Insurance
- Travelling & vaccination advice.

Staff have also been alerted to patient preferences for lifestyle advice. A government grant has been requested to

establish a specific lifestyle clinic within our institution. Finally, a manual entitled 'Lifestyle after Cancer' has been written and is available to patients as well as healthcare professionals that are in contact with patients during their management.

CONCLUSION

In order for patients and their relatives to make informed decisions concerning their own management, they need to be adequately informed. Otherwise, the anger and frustration associated with an inability to understand their treatment options can lead to anxiety, depression, poor compliance and poor co-operation with strategies to reduce treatment related side-effects.

Information is especially important in the area of lifestyle, since more recently published evidence has highlighted that patients who decide to improve their lifestyle will have major benefits in terms of quality of life.^{36–38} Other studies have demonstrated that positive lifestyle change, particularly exercise and diet, can improve physical outcomes.^{37–39} The published evidence for these outcomes can be summarised as follows:

- Slowing the progression of an established cancer
- Reducing the risk of relapse of a treated cancer
- Reducing risks of side-effects **during** cancer therapies, in particular:
 - Reducing fatigue and tiredness
 - Improving mood, thus reducing the risk of anxiety and depression
 - Improving appetite, thus reducing nausea and vomiting
 - Improving digestion, so avoiding diarrhoea, constipation and indigestion
 - Avoiding deep and superficial vein thrombosis
 - Improving skin care.
- Reducing the **long-term** risks and speeding recovery from cancer therapies such as surgery, radiotherapy, hormones and biological therapies. In particular lifestyle helps long-term:
 - Psychological well-being
 - Speeds recovery from post-treatment fatigue

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- Enhances body constitution (more muscle, less fat)
- Can help urinary function and sexual well-being
- Diminishes bowel problems (adhesions, constipation, indigestion)
- Helps skin tone, breast tenderness and joint pains
- Helps hot flushes and bone health
- Reduces the risk of secondary cancers
- Improves intellectual capacity and cognitive skills.

Oncology units around the world have universally accepted data demonstrating the need for quality information provision and have established patient information services with varying degrees of enthusiasm. Providing information, however, is not a solitary procedure and there are still ongoing challenges for medical teams. They have to keep up to pace with the growing expectations from patients and the rapid technological advances in oncology practice. A regular formal patient feedback programme, using questionnaires such as the ISQ, can ensure that unforeseen deficits in information provision are corrected before they impinge on the decision-making process. For example, the ISQ and in-depth interviews with the patients in our network revealed that patients all too often either felt embarrassed to ask their clinicians about everyday nutritional or exercise activities or felt they were taking up too much of their limited clinic time. Of greater concern was that some patients, or their relatives, felt they either did not have the confidence in their clinician's abilities on this subject or were rebuked by a paternalistic retort.⁴⁰ Certainly, patient feedback and the published data on lifestyle after cancer have encouraged our unit to direct more time, expense and effort into lifestyle advice resources such as www.cancernet.co.uk.

It was reassuring that patients within clinical trials are generally very satisfied with the information they have received, with the exception of lifestyle (Table 3). It is likely that patients in trials are fitter and deemed by their clinicians to be easier to communicate with. Nevertheless, trial literature is clearly an example of best practice. Although the paradigm that patients in clinical trials have better clinical outcomes has recently been contested,⁴¹ this audit suggests that patients in clinical trials may be more fortunate in terms of information and satisfaction. This may be a reassuring point to discuss with patients when counselling for trial recruitment.

In summary, the decisions patients make regarding the activities of daily living such as nutrition, exercise, smoking and supplement intake are now as important as those related to conventional areas of oncology management. What's more, these are decisions which allow patients to exert their greatest autonomy. Thus, it is just as important to provide quality information on activities of daily living as it is to provide information on conventional areas of cancer management. Despite the enormous expanse of lifestyle information available on the internet, TV, books and magazines, patients feel more reassurance of their credibility if guidance has the sanction of their medical institution.^{38,42} Thus, information provision is far more than merely supplying information; it constitutes an ongoing communication between patient and clinician in order to assess changes in information needs, monitor information satisfaction, and facilitate a relationship whereby a patient feels able to ask questions to enhance their own understanding of the cancer experience and the options available to them.

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