The other information revolution

It is an inevitable experience of participating members of any industrialised society in 1997, to be bombarded on all sides by 'information'. This is received in many forms – the spoken or written word, graphic images, moving pictures and pre-packaged sounds. The growth of consumerism has led us to take it for granted that all these sources need to be consulted almost daily to help us make the simplest to the most complex of choices – from picking a washing powder, to choosing schools for our children, or making decisions between therapies when we are gravely ill. Mostly we take in information about daily life automatically, and we may only notice how much we depend on them if they suddenly stop giving us their regular input. For example, if the daily newspaper fails to arrive in the morning, or the histopathology report has gone missing and the patient who had the lung biopsy last week is walking into the consulting room...

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In domestic and professional life equally, we take the access to all this information as a basic right. Even if we do not choose or need to act on the information, it seems strange when the inputs are missing, and we can get quite disorientated without these anchors, just like we often feel on the first few days on vacation. Of course then it can be quite pleasant to avoid the hassles of our daily life by switching off certain irritating sources of information, such as beepers or mobile phones – until a few days later, when we guiltily switch on the mobile again just to check on a particular patient. Amidst this love-hate relationship that we have with information and its intrusive sources, one thing is clear: everyone is currently just to check on a particular patient. Amidst this love-hate relationship that we have with information and its intrusive sources, one thing is clear: everyone is talking about it, a revolution is going on.

The information revolution is mostly concerned with electronic forms of telecommunication, of which email and the world wide web are prime examples. There is also much talk of the 'information superhighway', although it is not always clear if we are supposed to be Mercedes drivers or bus passengers. However, in healthcare there is another information revolution taking place, which is having a direct effect on how all clinicians work. This arises from the increasingly vocal demand from the public for more, and clearer, information about their condition. This revolution in the clinic and at the bedside is making doctors, nurses and even health managers turn away from their computer screens and telephones, to have face-to-face conversations with patients and their family members. How can we make this new information highway provide the best two-way traffic?

Patients' need for information

In recent years it has appeared that patients want more 'facts' – the raw data about their diseases and treatments, and not paternalistic interpretations issued (often reluctantly) by inarticulate doctors. It is self-evident that the important issues in which patients may seek facts are to do with the diagnosis, the treatments and possible side-effects, their progress and their chances of cure or dying. Is it right always to open the case-book, so to speak, and to make all the documentation available to them at every consultation? Could it be possible, on the other hand, that at different stages of a disease like cancer, patients' information requirements may change? Any practising clinician will know that for different individuals, the answer to either question could be 'Yes'.

But how can we know in advance what the likely information needs are to be? It is surprising that so little evidence exists about these questions.

The risks of not giving enough information, or the wrong information, in terms of dis-satisfying or upsetting patients, are just as bad as giving too much information to someone who is not seeking facts. In this issue of Annals of Oncology, Butow et al. from Sydney, Australia, present a fascinating study of this communication minefield which exists in every cancer clinic. Their paper also covers the extent to which patients express an interest in being involved in decision-making, which is one use of the information they gain, or how much support and reassurance they seek, which is another consequence of receiving the worst kind of information – 'bad news'.

This group already has considerable experience with exploring new methods of improving communication with cancer patients. For example, after tape-recording a series of oncology clinic consultations they randomised patients to receiving a copy of the tape followed by a letter, or receiving a letter followed by a tape [1]. Both were well received and used (patients listened to the tape an average of 2.3 times and read the letter 2.8 times, and 90% shared them with others); overall 46% of patients preferred audiotapes compared with 21% preferring letters. In another randomised study they provided patients with a question prompt sheet which was designed to encourage them to ask relevant questions in the clinic and compared this with a general information sheet about cancer services [2]. The prompt sheet did not
increase the mean number of questions raised in the subsequent consultation, but it was successful in terms of raising the number of times prognosis was specifically discussed, from 16% to 35%.

Study of changing information needs

The present study was an in-depth exploration of which types of information patients would prefer at oncology clinics, and how these preferences changed over time. They defined two time-frames: short-term (before and after a clinic consultation) and long-term (from one consultation and the next visit, which was 3-6 months later). Eighty patients who were attending two male oncologists were studied, and they completed batteries of questionnaires to elicit views about information preferences, desire for involvement in decision-making and need for support and reassurance. This was a heterogeneous group of cancer patients – 75% female, ages ranging from 18–87 and having a variety of solid tumours (43% had breast cancer). Most had a reduced life expectancy at entry (33% weeks or months, 55% years) and 26% were thought to be deteriorating at first consultation. This heterogeneity has mixed blessings – it tends to reflect ‘normal’ oncology clinic practice but it makes it more difficult to extract clear messages about the needs of specific sub-populations.

An important feature of this study is the thorough documentation of patients' preferences using well documented tools. The research team modified published instruments on eliciting preferences on information and involvement, and they used a scale for measuring patient satisfaction with the consultation which they have previously developed. The extent to which patients felt in control of their lives was measured using the Cancer Locus of Control scale. By contrast, the reliance on the oncologists' subjective rating of the patients' overall condition ('improving', 'about the same' or 'deteriorating') seems rather vague and was not substantiated objectively. Furthermore, it could be argued that social desirability – basically, the way in which patients respond to questions about their care in order not to upset their carers – should also have been controlled for. Eighty patients were screened at first clinic visit but only 40 completed the second pre-consultation assessment: males were more likely to drop out.

The results are very revealing and genuinely add to our current insight into cancer patients' needs. At baseline 85% of subjects wanted a large amount of detail about their illness, but whilst 36% wanted collaboration in decision-making, only 22% wanted to take an active role and 41% wanted to leave this to the doctor. Most patients initially wanted information about the progress of the cancer and the likely future changes. Immediately after the first consultation, patients were more likely to be seeking greater reassurance (63%) and 59% expressed a need to talk about their concerns. Just before the follow-up consultation, the picture was mixed: they wanted information on the cancer (92%), feedback (80%) as well as reassurance and hope (72%).

Predictors of change

These findings may seem obvious, but the true value of the study lies in the detailed analysis of how the preferences changed over the short-term and long-term, and in the identification of predictors of these changes. For example, for the majority of patients the type of information being sought remained stable before and after the first visit, but by the second visit the majority wanted less detailed information, and more involvement in decision-making. Specifically, patients wanted significantly less information about illness, less feedback on what was happening to the cancer and less information about the goals of medical care by the second visit. However, those subjects who wanted more detailed information immediately after the first visit were less satisfied with their consultations.

Further interesting analyses explored what features could predict preferences at baseline and which patients were likely to change their preferences over time. Factors which significantly influenced baseline preferences were gender of the patient (females sought more detailed information) and locus of control (patients who believed their lives to be influenced by God preferred less information and fewer details). In addition, patients who had a negative change in their condition at the second visit were more likely to defer decisions to the doctor. On the other hand, patients who started off wanting more involvement at the first consultation tended to increase this desire over time. The doctor himself was a predictor, as patients who saw one of the two study clinicians were more likely to shift towards less information after the first visit.

The primary cancer, age, and the presence of an accompanying person at the clinics did not predict information needs.

The study has flaws which to a minor extent limit its conclusions and generalisability. The predominance of females with breast primary, who are known to be a vocal group of cancer patients, may have biased results towards those seeking more information and involvement, particularly at the second consultation. It is surprising that the researchers did not also control for socio-economic or educational level, which have been shown to influence expressed information needs [3, 4]. The lack of control over social desirability has already been mentioned, and this may cloud the responses regarding satisfaction with the consultations. Although not a design flaw, the tendency for most patients in this study to be deteriorating and the relatively short follow-up time is less helpful for understanding the information and support needs of patients in long-term remission, or of cancer 'survivors'.
Improving clinicians' skills

However, the main lessons from this study are clear: clinicians need to be more sensitive about how much information to offer patients and how much to expect them to get involved in decision-making, and to be more aware of their concerns regarding support and reassurance. There are many specific ways in which further research and training could help to expedite these objectives. For a start, physicians should acknowledge that their own skills in eliciting patients' concerns and needs may be limited. There is good evidence that carefully designed training programs can improve doctors' communication skills [5] and ability to give distressing information [6]. The clinician's own prejudices about psychosocial aspects of care can colour their communication style – in one study physicians with more positive attitudes gave patients more statements of emotion such as empathy, participated more actively in care by expressing opinions and provided more psychosocial and less biomedical information [7]. For those who find structured algorithms helpful, a flow diagram for eliciting current problems in cancer patients may be helpful [8].

It will not be surprising that many cancer patients find it helpful to discuss their worries with nurses, and these have been found to be a preferred source of information over doctors on follow-up after treatment with radiotherapy [9]. However, a recent disturbing study of British hospice nurses showed that even this highly trained and sympathetic group of professionals were unable to identify more than 40% of their patients' major concerns – they were more likely to pick up symptoms and family worries but missed concerns about the cancer, bowel function, treatment and emotional worries [10]. Thus, both oncology doctors and nurses need training in how to identify their patients' concerns and needs.

Cultural variations

Cultural traditions have long been recognised as a source of variation in the amount and type of information that cancer patients seek across the world. In the study described here, we were not informed of the national origins of the patients but it is likely that in an Australian sample there would be considerable heterogeneity. It is time to change our stereotyped views about certain cultures' desire for knowledge. A study of 89 advanced cancer patients in Spain showed that while 46% reported complete or partial awareness of the diagnosis, over 90% of a sample of the general population without cancer would have wanted complete or partial knowledge [11]. However, in another Spanish study whereas 68% of cancer patients had not been informed of their diagnosis, 42% of these did not want to receive more information [12]. Religious and cultural traditions among patients have frequently been cited as reasons why doctors give less information about cancer and prognosis in Spain [12], Hong Kong [13], Japan [14] and Arabian Gulf states [15]. A survey of 250 cancer patients in the West of Scotland showed clearly that increasing socio-economic deprivation predicted a reduced wish for information [3]. In most of these settings, however, there is a movement for the public to demand more information than doctors are willing to impart.

Teaching patients

Perhaps teaching patients to be more assertive and ask appropriate questions could increase their chances of getting the information and involvement they require. Mention has already been made of an earlier study by Butow et al. in which a question prompt sheet increased the number of times patients asked about prognosis [2]. Another randomised study of only 18 patients with lung cancer showed that 'coaching' helped to improve patients' reports of pain, with respect to nurses' assessments [16]. On the other hand, a trial in which 90 cancer patients were assigned to neutrally-, positively- or negatively-framed information about chemotherapy showed that while willingness to participate in treatment was influenced by age, sex and educational level, the framing of information failed to influence patients' choices [4].

The use of audiotapes to improve communication in the cancer clinic has been subject to evaluation in several studies. In one randomised trial of 117 patients attending a medical oncology clinic, patients were assigned to receiving an audiotape or not: on a follow-up clinic there was no difference in the number of questions asked, but more patients from the tape group asked for clarification of information received, and more control patients requested facts that had already been provided in the prior visit [17]. However, the same research group reported that patients who specifically received bad news which was audiotaped may be disadvantaged psychologically by subsequent access to the tape [18]. It has also been shown that doctors of cancer patients are more in favour of individualised letters conveying information to patients rather than audiotapes: hospital specialists were more concerned than general practitioners of the potential risks to patients from tapes [19].

New methods of improving communication

Novel methods of improving communication of medical information need to be assessed. Although not new in other clinical areas such as obstetrics, the use of shared care records which are held by the patient could be useful in oncology. This medium was assessed in a group of 43 advanced cancer patients attending a palliative care unit in England [20]. Fifty percent of the patients, 48% of their relatives and 58% of professionals found them useful. Patients and relatives felt that could write down information that they wanted to transmit to their carers and felt more involved in their care; professionals reported being more aware of patients' feelings.
The shared-care record is a good demonstration of two-way traffic on this information super-highway. Returning to the metaphor of the information revolution, are clinicians making use of current information technologies to inform and involve patients? An interesting study of 100 patients undergoing radiotherapy randomised them to receive information about a hypothetical new trial, either by audiotape or by an interactive computer program [21]. There were no differences in understanding or satisfaction one week later, but subjects who had the computer program tended to be more positive towards trial entry. Women who were better educated tended to refuse the trial more. In another completely different area of healthcare, pregnancy amongst drug-abusers, a study set out to evaluate the role of a voice bulletin board, compared to group meetings, in promoting self-help and utilisation of healthcare services [22]. Four months later, subjects were eight times more likely to use the bulletin board than attend face-to-face meetings. Most of the comments left on the bulletin board were for giving emotional support. The 'electronic' group visited out-patient clinics less frequently, but not at the cost of health status or drug usage.

The future of patient information

The future is exciting with respect to information. Clinicians are being asked increasingly to challenge their old assumptions about who and what to tell, and there is evidence from one systematic review that imprinting more information and allowing greater involvement in healthcare helps patients and their families cope better [23]. At the same time it is possible that more highly informed patients could be more anxious, worried about their health and concerned with physical symptoms [24]. While we professionals reduce forests into rows of learned journals and conference proceedings on our shelves, chatter across the world via email and surf the Internet, we should stop to think about the huge benefits of inviting our patients onto the clinical information super-highway. Re-turning to the metaphor of the information revolution, are clinicians making use of current information technologies to inform and involve patients? An interesting study of 100 patients undergoing radiotherapy randomised them to receive information about a hypothetical new trial, either by audiotape or by an interactive computer program [21]. There were no differences in understanding or satisfaction one week later, but subjects who had the computer program tended to be more positive towards trial entry. Women who were better educated tended to refuse the trial more. In another completely different area of healthcare, pregnancy amongst drug-abusers, a study set out to evaluate the role of a voice bulletin board, compared to group meetings, in promoting self-help and utilisation of healthcare services [22]. Four months later, subjects were eight times more likely to use the bulletin board than attend face-to-face meetings. Most of the comments left on the bulletin board were for giving emotional support. The 'electronic' group visited out-patient clinics less frequently, but not at the cost of health status or drug usage.

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