PATIENTS’ PREFERENCES FOR INFORMATION DURING CHEMOTHERAPY

Carole Farrell and Gary Witham report on survey findings that highlight the emotional effect on patients during treatment and the need to reassess patients’ ongoing need for knowledge from healthcare professionals and their perceived information needs. Lloyd (2001) noted that doctors and patients exhibit a number of biases in risk perception and decision making, notably optimism bias – where a patient perceives a treatment as riskier for other people – and framing bias – 34% of people are alive five years later versus 66% of people are dead five years later. In addition, many patients have poor understanding and recall of risk information (Lloyd 2001), which has implications for healthcare professionals, patients and their families.

Although Cox et al (2006) found most of their respondents had recalled conversations with health professionals about prognosis, there is a lack of evidence related to patient preference of prognostic information before chemotherapy. Chapman et al (2003) further suggested lay understanding of medical terms used in consultations was questionable requiring patient feedback to assess understanding. McPherson et al (2001) suggested that ongoing assessment of patients’ information needs was crucial in order to respond to changes in their information preferences.

There are some variations in information provision, according to different hospital policies. The Christie uses a wide variety of information sources, including Macmillan booklets and leaflets, information from charities such as Breast Cancer Care, information from pharmaceutical companies and hospital-specific leaflets. However, all information is ratified by the patient information committee before use.

THE INFORMATION needs of patients undergoing cancer treatment are integral to their quality of life (Mallinger et al 2005, Davies et al 2008, Vogel et al 2008, Waller et al 2014). Evidence suggests that this information should be targeted and based on individual need and changes at different time points (Luker et al 1996, Rutten et al 2005, Ankem 2006, Vogel et al 2008). However, there are several factors that influence patients’ perceptions of information from healthcare professionals and their perceived information needs.

Abstract

Aim To identify patients’ perceptions of information about prognosis and chemotherapy.

Method A questionnaire survey was undertaken.

Results A heterogeneous sample of 94 patients revealed that 89 (96%) had received written information about their chemotherapy, however, there were differences in their perceptions of its usefulness, sources, recall and understanding.

Conclusion The results highlighted implications for healthcare professionals regarding the emotional effects on patients during information exchange, and the possibility of unmet information needs.

Keywords Chemotherapy, decision making, information needs, outpatient, perception, questionnaires
Aims and objectives
The aims of this study were to identify:
- Patients’ preferences for information (non-specific) and decision making when attending for outpatient chemotherapy.
- Nature and sources of information given.
- Patients’ perceptions of prognostic information.
- The psychological and emotional effect of information about chemotherapy.

Method
A questionnaire was designed to identify patients’ preferences for information and decision making when attending for outpatient chemotherapy. The questionnaire included 36 questions over five pages using a combination of open and closed questions. Questions explored the nature of information given, its usefulness, sources of information, patients’ expectations regarding prognostic information and the psychological effect of information given by healthcare professionals.

A clinical nurse specialist disseminated the questionnaires in the chemotherapy outpatient unit over a two-week period on a consecutive series of patients. The anonymous questionnaires were returned to reception and given to the audit department for analysis. Data were entered onto a database and analysed using descriptive statistics.

Ethical considerations
This questionnaire survey formed part of a larger research project examining the information preferences of vulnerable patients during chemotherapy, for which NHS ethics approval and hospital research and development approval had been granted. This questionnaire survey was conducted in a tertiary referral cancer centre in 2011, and approved by the trust’s audit department.

Results
One hundred and fifty questionnaires were distributed and 94 completed. This was a heterogeneous sample since patients were under the care of 26 consultant oncologists. Patients’ ages ranged from 24–82 years, mean age 60 (SD 11.87). Of the sample, 33 (35%) were male and 60 (64%) female. Information was missing for one patient. Most were white British (n=82/91, 90%), two were Irish, two Caribbean, two Pakistani, two African and one French. Information was missing for three patients. Few patients reported disabilities; ten (11%) reported problems with sight, four (4%) problems with hearing, one reported mental health issues, and three reported other disabilities, although no details were given. No patients reported ‘learning difficulties’, however, no specific criteria for learning difficulties were included on the questionnaire.

The date of diagnosis ranged from 1998 to 2011 with 26 (28%) of patients having previously had a course of chemotherapy and were now receiving palliative chemotherapy. For this current course of chemotherapy, 17/87 (20%) patients were receiving cycle 1, 18 (21%) cycle two, 13 (15%) cycle three, and 39 (45%) cycle four or more. Individual regimens were not recorded.
Nature and sources of information
Of respondents, 89 (95%) reported that they had received written information about their chemotherapy, however three (3%) said this was not before their first cycle of treatment. It was not possible to distinguish between verbal and written information, therefore responses reflect any type of information. One third received information from sources outside the tertiary referral centre (Figure 1), however, they reported that information from a consultant, nurse specialist and cancer information centre was the most useful, although there was no scope in this survey to explore reasons for this. Respondents rated information from media sources – TV or radio, medical books, magazines and newspapers – to be the least useful (Figure 2).

Sixty six respondents (70%) found the information very useful, and 23/90 (26%) quite useful. Of respondents 60/91 (66%) were offered information on a DVD and of these 29/57 (51%) found it useful and 26/57 (46%) quite useful. However, perceptions of the usefulness of information revealed differences with information about emotional issues and trials perceived as the least helpful or not discussed (Figure 3, page 20).

Expectations of information given
There were slight differences in respondents’ expectations of information from doctors and nurses (Figure 4, page 20). The non-numerical data indicated a number of reasons for this including:
- ‘Doctors always too busy and felt they never have enough time to answer all the questions.’
- ‘Didn’t give sufficient detail of side effects.’
- Respondents also expressed anxieties, including:
  - ‘Fear of the unknown.’
  - ‘Not sure what to expect.’
  - ‘The projected life span was shorter than I expected.’

Prognostic information
Sixty two of 91 (68%) respondents were given facts and figures about prognosis. However, 19 (21%) did not receive this information, although did not give reasons for this, and ten (11%) could not remember. Fifteen of 62 (24%) respondents found prognostic information definitely helpful, 13/62 (21%) found it helpful to some extent and one (2%) was not sure. However, some comments highlighted conflicting views about the value of prognostic information, and implications for consultations with patients. For example:
- ‘No genuine figures showing 100% prognosis beforehand.’
- ‘Nothing guaranteed. Each patient is different.’

Some respondents did not expect a precise prognosis, while 8/43 (19%) did not want this information and 17/43 (40%) were not sure. Seventy four of 84 (88%) respondents were able to take in the information given, however, seven of 84 (8%) were not and three of 84 (4%) were not sure.

Some commented:
- ‘Would have been useful if had more information.’
- ‘Feel a little in the dark; more information would have helped especially when other people ask.’
- ‘I want to know what is happening to me and how.’
The following comment highlights how preferences for information change over time:
- ‘Feel ready to discuss this now.’
Respondents also reported that their understanding of information was often facilitated with the help of their families:
- ‘Partner explained procedures after consultation.’
- ‘After heap of information given needed time to assimilate.’
Asking whether respondents understood the information given by healthcare professionals revealed some discrepancies: five of 85 (6%) did not understand the information and a further eight of 85 (9%) were not sure. Specific comments included:
- ‘[didn’t understand] statistics.’
- ‘I didn’t realise the chemo would not get rid of the cancer.’
- ‘Usage of pump details was too much to take in from two minutes of briefing.’

Although 83/89 (93%) respondents felt able to ask questions during the medical consultation, two of 89 (2%) did not and four of 89 (4%) were not sure.

Attendance with a relative or friend
EIGHTY three of 91 (91%) respondents attended their first appointment with a relative or friend, and 82/84 (98%) found that helpful. Typically, respondents thought that with ‘so much information to take in it was... essential to have someone else to remember it all and ask questions.’ This often involved clarification and recalling questions they had forgotten to ask. At times this enabled some to have a written record with friends and/or relatives acting as scribes.

There was also a sense of relatives and/or friends being ‘sounding boards’ to talk issues over with and act as a support if the situation became emotionally difficult. It was ‘reassuring, comforting’ and provided the opportunity for some respondents to have ‘more freedom to speak clearly’. It was also apparent that it kept partners informed with accurate information and led some respondents and their partners to remember different points, thereby getting a more accurate picture of the situation. A relative and/or friend furthermore provided encouragement and company as well as practical support with transport to the treatment centre.

Treatment choices and risks of treatment
All respondents understood why they needed chemotherapy, although nine (10%) only understood ‘to some extent’. Only 14/88 (16%) reported being given a choice about chemotherapy, and eight of 89 (9%) were not sure. Although 73/88 (83%) had enough time to decide about chemotherapy, ten of 88 (11%) did not and five of 88 (6%) were not sure.

Eighty one of 91 (89%) respondents recalled being told about serious problems with chemotherapy, but nine of 91 (10%) said they were not told and one was not sure. In addition, 28/91 (31%) reported not being informed about long-term problems related to chemotherapy, and 14/91 (15%) were not sure.

The effect of information
Twenty seven of 91 (30%) respondents were worried about some of the information given and nine of 91 (10%) were not sure. Typically the fears related to ‘outcome’ and the consequences of treatment failure:
- ‘The information that my chemo was not working and that I needed to change to another one worried me.’
Another important area was related to side effects and, in particular, infections:
- ‘Info on infection told could be fatal’.
- ‘Worried about contracting an infection’.
The list of potential side effects proved daunting with some respondents focusing on specific side effects, for example:
- ‘About pins and needles and being paralysed.’
- ‘Worried about risk of heart attack.’
Others focused on the general number of different potential complications:
- ‘All the side effects that could happen makes you worry at first.’
One respondent was ‘in shock’, while others had ‘enough to deal with/come to terms with, without worrying about complications’.

Emotional issues
Forty of 94 (43%) respondents did not indicate any discussion of the emotional effect of treatment; 23/89 (26%) were upset when discussing some topics, and six of 89 (7%) were not sure. Particular areas of concern involved prognostic information and fears for the future, as one respondent commented:
- ‘The future because I don’t have one.’
Other concerns focused on the spread of cancer and side effects as well as fertility issues.
Respondents were asked to rate their emotions before chemotherapy and during treatment, which showed some interesting differences over time (Figure 5). There was a 30% increase in the number of respondents feeling positive during chemotherapy compared with feelings before the start of chemotherapy. Similarly, the number of respondents feeling anxious fell by 33% and those feeling frightened fell by 6% after respondents started their course of chemotherapy. In contrast there was little change in the number of respondents who felt vulnerable.

Discussion
Some of the results of this survey reflect the literature on information needs and cancer, in particular, the integral part played by specialist health professionals in providing an information resource (Mills and Davidson 2002, Davis et al 2003, James et al 2007). This was also highlighted in the Chemotherapy Patient Experience Survey (Quality Health 2014), where 85% of those surveyed were clearly told about their treatment plan but only 41% were offered written information about their treatment.

In our survey a large proportion of respondents reported that they expected more information about their treatment and prognosis from health professionals than they received. One of the reasons cited for this related to the perceived ‘busyness’ of healthcare professionals, which may reflect general increases in clinical workload. However, addressing patients’ information needs is likely to improve outcomes in terms of better concordance with treatment (Kessels 2003). Information seeking is also associated with improved psychosocial outcomes such as satisfaction with coping, decision making and improved physical function (Fallowfield et al 1994, Fallowfield 2005, Waller et al 2014).

There is also evidence that patients with lower incomes, lower educational attainment and those from minority ethnic groups ask fewer questions and have greater difficulty communicating preferences (Siminoff et al 2006, Eggly et al 2010, 2011). However, this may be influenced more by educational attainment than difficulties with health literacy (Matsuyama et al 2011), while health literacy remains a challenging issue in cancer consultations. For example, if a doctor uses the word ‘seedling’ to describe a spreading cancer, only one third of the lay population would understand (Chapman et al 2003).

The problems associated with information needs are also exacerbated by anxiety and uncertainty, which were experienced by some respondents. The uncertainty associated with a cancer diagnosis is well documented (Wallace 2003). Shaha et al (2008), as is anxiety (Grassi et al 2004, Keller et al 2004, Söllner et al 2004). However, many healthcare professionals have difficulty in conveying meaningful information to patients to improve comprehension. There is some evidence that question prompt sheets (QPS) can be effective if used proactively by health professionals (Brown et al 2001). A QPS is a structured list of questions designed to encourage patients to receive information during medical consultations. There is also evidence that an audiotape of the consultation, complementary to oral information, has value (Hogbin et al 1992, North et al 1992, Ong et al 2000). However, there is no evidence that an audiotape
alone has added value compared with standard consultation and the effectiveness of interventions appears to be based on tailored information related to a specific individual (van der Meulen et al 2008).

The high percentage of internet use by respondents (40%) was interesting, with 90% finding this very/quite useful. This finding reflects recent evidence of the increasing use of the internet by patients with cancer and also health professionals to access chemotherapy information (Davies and Yeoh 2012). However, this contrasts with earlier surveys that indicate much lower internet use by cancer patients (James et al 2007).

Several studies report that 31-60% of cancer patients or caregivers have used the internet for information (Fogel et al 2002, Smith et al 2003, Basch et al 2004). The high rates of satisfaction with the usefulness of internet information may reflect patients’ perceptions of internet sources being more trustworthy than other news media (Newnham et al 2006). However, there is also conflicting evidence suggesting that the accuracy of online resources is questionable leading to further interpretation and advice being sought from healthcare professionals (Eysenbach 2003, Bernstam et al 2008). Furthermore, respondents in this survey considered information from health professionals to be the most useful compared with external information sources.

The high number of respondents reporting that they had no discussion about emotional aspects of treatment (42%) is worrying, yet reflects findings from the Chemotherapy Patient Experience Survey (Quality Health 2014). The lack of information/support in emotionally preparing patients for treatment is an important area in the literature (Waller et al 2014), reflecting the challenging issues related to effective communication in medicine and nursing. Research indicates evidence of blocking behaviours, an over-emphasis on physical rather than psychological issues and poor identification and exploration of patients’ emotional cues (Wittenberg-Lyles et al 2008, Mjaaland et al 2011, Farrell 2014). These difficulties may be rooted in the fear of a patient’s response to bad news (Maguire 1999) and a perceived inability to handle that

References


response appropriately (Maguire 1999, Friedrichsen and Milberg 2006). There are also indications of a discourse of redemption, a ‘restitution’ narrative prevalent in medical/patient discourse in which the basic storyline is ‘yesterday I was healthy, today I’m sick but tomorrow I’ll be healthy again’ (Frank 1995).

Patients whose treatment journey becomes ‘problematic’ through treatment failure or uncertainty can face more clinically challenging situations that demand a response from health professionals. Willig (2011) suggests that there is a ‘cultural imperative to think positively’ and avoid death as a possible outcome in medical consultations with patients. The widespread use of military metaphors provides a context in which ‘positive thinking’, ‘being brave’ and fighting cancer’ are morally required to win the battle (Sontag 1991, Lupton 1994, Seale 2001), however, they can have a negative psychological effect on patients.

It is in these cancer discourses that patients and health professionals navigate their emotional responses. The space required for alternative narratives or consultations can be restricted, which may be one factor associated with limited exploration and discussion of emotional concerns. However, recent research on chemotherapy nurse-led clinics indicates disparities between nurses’ perceptions of their communication skills with patients and observations of their clinical practice (Farrell 2014).

Conclusion
This survey highlighted implications for healthcare professionals regarding the emotional effect on patients during information exchange, and the possibility of unmet information needs. This adds weight to the argument to tailor information for each individual, particularly sensitive prognostic information. Most healthcare professionals address patients’ information needs before chemotherapy. However, they often fail to take into account potential changes over time in information needs and concerns. It is important for health professionals to reassess patients’ ongoing information needs throughout chemotherapy, and to identify and address patients’ concerns alongside this.