

# **An assessment of the needs of oncology outpatients for the development of Allied Health Services**

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## **Abstract**

*This article presents the findings of a study that arose out of the desire by the Allied Health Professionals (AHP) at the Mater Hospital, Brisbane, to better understand the needs of their clients in order to be able to offer a more effective and appropriate service. A questionnaire designed specifically to explore the needs of patients and their families for AHP services was administered to consecutive patients (n=62) attending the Mater out-patient oncology clinic during one month. The findings provide a wealth of practical information for AHPs to use in planning for the effective utilisation of their services, as well as fresh insights into a number of theoretical issues that need further research.*

## **Background to the study**

The diagnosis and treatment of cancer creates psychosocial needs that patients often find difficult to cope with and resolve (Bunston & Mings, 1995). The present literature suggests that common problems and concerns will include pain, side effects of treatment, psychological needs, problems with activities of daily living, fear of recurrence and death, worries about ability to cope, concerns about social interaction, finances and employment, resuming one's personal life, and sexual functioning (Christ & Siegel, 1990; Friedman *et al.*, 1993; Ganz *et al.*, 1987; Greer, 1994; Guandagnoli & Mor, 1991; Gustafson *et al.*, 1993; Houts *et al.*, 1986; Longman *et al.*, 1992; Pistrang & Baker, 1992; Rapoport *et al.*, 1993; Schag & Heinrich, 1990; Vachon *et al.*, 1990; Waligora-Serafin *et al.*, 1992).

It is important for allied health professionals (AHPs) who work with oncology patients to understand the needs arising from the psychological, physical and social difficulties of patients in order to assist with coping strategies (Ali *et al.*, 1993), improve adherence to treatment (Ali *et al.*, 1993; Dragone, 1990; Mor *et al.*, 1992), seek benefits from the health care system (Mechanic, 1983; Saunders & Baum, 1992; Wiggers *et al.*, 1990) and improve the outcome of medical care (Gustafson *et al.*, 1993; Kiecott-Glaser & Glasser, 1987; Spiegel *et al.*, 1989). To achieve this, it is important not only to identify the psychosocial and functional needs of patients and their families, but also to understand why needs remain unmet, evaluate current care, and determine preferences for future care (Bunston & Mings, 1995).

The work reported here arose from quality assurance activities concerned with documenting the needs of oncology patients for the purpose of development of allied health services. It involved collaboration between the Centre for Public Health Research (CPHR) at the Queensland University of Technology and a team of allied health professionals (AHP) from the Division of Cancer Services of the Mater hospital, Brisbane, Queensland. The impetus for the research came from a keen desire by the AHP team to better understand quality of life issues in relation to their clients in order to be able to provide appropriate and effective services. The initial expectation was that the assessment could be achieved through the use of a standardised QOL research instrument. However, through subsequent discussion and reflection it was decided that a QOL instrument would not address the exact purpose for the research. It was decided to design an instrument specifically for use by AHPs in an out-patient setting. The instrument is now being used in a similar setting in an interstate hospital and so will eventually provide comparative findings.

## Method

The research sought to answer two main questions: what are the specific needs of Mater oncology out-patients and their families from the patient's perspective, and how can the allied health professionals most effectively respond to these needs?

Funding for the project was acquired through the CPHR, ethical clearance obtained from the university ethics committee, a research assistant appointed, and appropriate members of the hospital staff (out-patient clinic) informed of the project and involved in its administration.

Consecutive patients attending the Mater hospital oncology day care ward over a one month period (19th October to 13th November, 1998) were approached at the out-patient clinic with the offer to fill in the questionnaire. Patients were informed of the study by the clinical nurse consultant and then asked if they would like to participate. Following agreement to participate, patients were referred to the research assistant to fill out the questionnaire. Three patients who attended the clinic that month decided not to participate. Sixty-two participants completed the questionnaire. Participants were not screened in any way.

As the details on the demographics and diagnostic categories will later show, this was an adult group with the majority from a wide range of cancer groups and a small minority with related blood disorders and other diseases. As the AHPs at the Mater care for all patients attending the outpatient clinic, not just those with a cancer diagnosis, all who agreed to participate were included in the study.

The content of the questionnaire was developed from the combined insights and professional experience of the AHP team pooled with the consultant researcher's knowledge of the literature available in the area of the needs of oncology patients. This content was developed over several team meetings, organised into questionnaire format by the consultant researcher, and then re-evaluated and refined in further group discussions. The research design incorporated the combined research and professional experience knowledge as baseline material in the form of structured questions. As this was exploratory research with an interest in recording the needs of patients as they perceive them to be, the research instrument built in ample opportunity for open-ended comment (qualitative data). Thus, the questionnaire was designed to produce a mixture of quantitative data (Likert type scales and lists of options to be ticked) and qualitative data (lined space provided for open-ended comment).

The quantitative data were analysed by use of the SPSS package. The responses to the open-ended questions were treated as qualitative data and developed thematically using the actual words of the participants. The number of responses in each category were calculated as a percentage of the total sample to provide some indication of the shared importance of such statements. In the presentation of findings the verbatim text will only be provided where they provide extra material that cannot adequately be expressed through a category title.

## Results

### Demographics

Participants (n=62) in this study recorded a wide number of diagnosis including Hodgkin's disease (n=4), breast cancer (n=11), bowel cancer (n=3), ovarian cancer (n=2), liver cancer (n=3), leukaemia (AML, CLL) (n=5), myeloma (n=6), lung cancer (n=2), lymphoma (n=4), bladder cancer (n=1), bone cancer (n=2), stomach cancer (n=3), cancer (non-descriptive) (n=7), Thalassemia (n=3), anaemia (n=2), and other non-cancer diseases (n=4). Respondents were predominantly female (64.5%). All were adults with only two under the age of twenty. The distribution of ages was fairly evenly spread in the adult years (18–20 years, 3.2%; 21–30 years, 11.3%; 31–40 years, 9.7%; 41–50 years, 17.7%; 51–60 years, 24.2%; 61–70 years, 19.4%; 71+ years 14.5%). Most patients were involved in ongoing treatment (n=38, 61.3%), and the rest were either at the beginning of treatment (n=12; 19.4%) or at the end (n=12; 19.4%).

The majority of respondents (61.7%) recorded incomes of less than \$20,000. A further 26.7% had incomes between \$21,000 to \$40,000. Only seven individuals reported their income to be over \$41,000, four of which estimated their incomes to be more than \$60,000.

### Use of AHP services

The majority of respondents (58.1%) had used the AHP services at the Mater. Of the total group surveyed 19.4% of patients were recorded at the beginning of treatment and hence were unlikely to have been referred to, or approached by the AHPs at the time of this study. As Table 1 demonstrates there was a wide variation in the use of different services with social work most frequently accessed.

**Table 1: Participants use of AHP services grouped according to disciplines.**  
**Note: The percentage exceeds 100% as some clients used more than one service**

Use of Allied Health Services (n=62)		
Type of Service	Frequency	Percent
Social Work	28	45.2%
Physiotherapy	16	25.8%
Dietitian	15	24.2%
Occupational Therapy	5	8.1%
Audiologist	2	3.2%
Speech Therapist	1	1.6%
Other services	Nil	0%
Total (n=62)*		

In response to the question of whether they would use the AHP services if they felt the need, 93.5% reported that they would. Those who did comment (19.4%) on this question just affirmed the result with statements about not having the need but being open to the future possibility (n=7), actual descriptions of present use (n=4) or descriptions of attempts to access service (n=1).

### Current problems – physical

Participants were directly questioned about their experience with physical problems. As Table 2 indicates the responders recorded a wide range of physical problems, the most common of which was fatigue, followed by weakness and sleep problems.

Thirty percent (n=19, 30.6%) of the participants chose to comment on their experience with these physical problems. Four (6.5%) took the opportunity to state very clearly that they were fine and had no problems. Others qualified their answers by comments indicating that it was only early stages of their treatment (n=3, 4.8%) or that although they did not presently have problems they did so in the past (n=6, 9.7%). A further seven patients provided descriptions of their present problems.

**Table 2: Physical problems experienced by participants**

Physical Problems		
Type of Problem	Frequency	Percent
Fatigue	40	64.5%
Weakness	27	43.5%
Sleep Disturbance	26	41.9%
Problems with Mobility	21	33.9%
Problems with Sitting, Standing	20	32.3%
Nausea/vomiting after treatment	19	30.6%
Tension Headaches or Muscle Tension	18	29%
Poor Appetite	18	29%
Other Symptoms	10	16.1%
Problems with Swallowing or Eating	9	14.5%
Nausea/vomiting Before Treatment	7	11.3%
Difficulty Hearing	6	9.7%
Difficulty Communicating	2	3.2%

### Current problems – emotional

Participants were similarly questioned about emotional problems that they might be facing. As Table 3 demonstrates, there was a very poor response to these questions.

**Table 3: Participants' responses to structured questions about emotional problems**

Emotional Problems		
Type of Problem	Frequency	Percent
Depression, Anxiety, Fear or Guilt	11	17.7%
Carer Distress	6	9.7%
Family Difficulties	4	6.5%
Distressed or Upset Children	4	6.5%
Other Problems	3	4.8%
Sexual Problems	1	1.6%
Problems with Domestic Violence	nil	0%
Substance Abuse	nil	0%

In the participants' open-ended comments (n=16, 25.8%) there were indications that a desire to present well may be influencing the data collection. Many of those who commented (n=7, 43.7%) made direct statements to indicate that they could cope well with their own resources without the need for help from others. This 'independence factor' recurs regularly in participants' comments throughout the research. Examples of such statements include the following:

*No, can handle all that myself.*

*No, we know exactly what's happening.*

*No – lots of family support.*

*No, we can handle it.*

*No more than anybody else.*

*Just normal concern due to impact of illness.*

*(I have) a very positive attitude and prayer and good carers!*

Three of the participants made comments that indicated that problems could arise in the future. Another referred to past problems that were now resolved. Others described their problems (n=4) or reiterated that they did not have problems (n=1).

Participants recorded a higher number of responses to questions about problems they experienced with maintaining their sense of self. As Table 4 demonstrates, loss of a sense of independence is documented as the most important problem, followed by problems with motivation and changes in role. Nine patients recorded a sense of loss of control.

**Table 4: Participants responses to questions about maintaining a sense of self**

Sense of Self		
Type of Problem	Frequency	Percent
Loss of Sense of Independence	19	30.6%
Change in Role	15	24.2%
Problems with Motivation	13	21%
Maintaining Self-care (eg. Showering)	10	16.1%
A Sense of Loss of Control	9	14.5%
Self Image Problems	7	11.3%
Other Problems	5	8.1%
Loss of Interest in Life	2	3.24%

Over a third of the participants (n=21, 33.9%) made comments about the difficulty of maintaining a sense of self. Some of the comments just qualified their responses to the structured questions by reaffirming that there were 'no problems whatsoever' (n=2) that it was 'too early to say' (n=3), or that previous problems had now healed (n=2). A couple of participants gave reasons why they were not experiencing problems which included keeping busy and focused and being lucky with their response to treatment. Others went into greater detail about the problems they were experiencing. These responses included problems with frustration (n=2), fear (n=2), change (n=1), 'keeping up with treatment' (n=1), problems managing daily activities (n=3) and 'loss of interest in life' (n=1) as can be seen by the following comments:

*Especially because I was very active. Very hard, makes me feel useless.  
Frustration and feel bad at times when I see things that need to be done but are unable to do them and then my daughter does things although she is studying.  
I feel frightened by this disease, as it now seems to be controlling me. Even the smallest chores are a big deal. I wish I could just do it and not have to depend on anyone else so much.  
I have also gone blind in one eye so I also have to have a night light all night as I have a fear of darkness.  
Not the same, will never be the same.  
Can't do as much as I used to.  
I love cooking, hard to cook, to bend down to get stuff out of the oven. Don't get out much, only occasionally – very occasionally.  
Just feel pretty weak and just don't want to do anything.*

Two participants provided philosophical comments on how they coped with such problems,

*It's a fact of life, it's happening.  
Sometimes you get a little bit down hearted but you think things could be worse.*

### **Current problems – work**

An open-ended question was used to collect data on patients' problems with regards to their work (employment). The majority of the respondents (n=53, 85.5%) took the opportunity to comment. Half of the participants (n=31, 50%) stated that the illness had affected their work. Over a third (n=21, 33.9%) either 'had to give up work' or were 'unable to work'. For some the hope was that this was a 'temporary' state of affairs (n=6, 9.7%). Others (n=6, 9.7%), although not yet forced to give up work, noted that they had to take time off work because of their illness. Participants' comments indicated that this time off work needed to be made up for at a later date (n=1), or used up sick leave (n=1), or was not having much affect at present (n=1). Two participants believed they still had job security in spite of the illness. In another case, the patient's employer took the flexible approach of providing a computer so that the work could be done from home. One participant who owned a business and could not maintain the pace of work, hired extra staff. Four of the participants were retired at the time of the illness. Another three, although still working, anticipated the possibility of having to give up work.

Only two participants commented that there was no problem and one made the very positive statement that work was "what's keeping me going at the moment".

Work roles within the home were also commented on (n=12, 19.4%). This comment centred on the negative changes in terms of what was now more difficult to achieve. The frustration and dependency involved in this state of affairs can be seen by the following comments:

*At the moment my husband does everything.  
Can't look after my kids. Can't clean the house. All of those sort of things.  
No. Some things I can't do at home.  
I don't work. I can't even peel the potatoes.  
Have just continued sharing duties as able.  
Unable to do ordinary chores around the house which were my responsibility.  
I can't vacuum clean or anything heavy. Lost a bit of mobility. Can't do washing.  
No, except can't cook as much but that's coming back.  
I don't do as much around as I used to.  
Well I cannot do what I want.  
Can't do strenuous work. Get tired easily.*

For one participant the problem centred not so much on work but on the fact that he/she “can't play sport the same”.

### **Current problems – isolation**

Seven participants recorded actual problems with isolation and twenty-four (38.7%) made comments about their situation. It is important to note that those who did comment were giving explanations of why they did not experience loneliness.

Many (n=9, 14.4%) of those who commented drew attention to the strong support they received from family and friends. For others (n=3) work was a source of support. It was noted (n=2) that isolation becomes a problem when the patients are “so sick” they are “immobilised”, or “not well enough to get out”. Some patients (n=2) mentioned changes they had to make because of the illness such as having a carer stay even though previously they were a “lone dweller”, or staying with “someone after my operation”.

Geographical isolation is also a problem for some. This is reduced if the patient lives out of town but is close enough to go home at night (n=2). However, some (n=3) had to travel long distances from other centres and experienced the additional problems of relocation. It is of interest that two of the three who commented on this aspect of geographical isolation had haematological malignancies, diseases which require patients to undertake long lengths of stay away for high-tech treatment.

### **Current problems – finances**

Nearly half of the participants (n=25; 40.3%) commented on the financial impact of their illness with thirteen (21%) reporting problems. Again, as noted with other topics (ie. ‘independence factor’), the comments were mainly positive with suggestion about why individuals were able to cope rather than addressing issues they were having problems with.

Two participants directly mentioned that financial problems were not an issue at present and a further three acknowledged that this was possibly a problem for the future. Superannuation was mentioned as a buffer to financial stress (n=2) and so was good job support (n=1). Some (n=5) pointed out that they were coping quite alright (‘independence factor’), as follows:



*No big deal but there is a loss of income.*

*Been coping all right.*

*Not that I need help with. Had insurance that is keeping us going and husband is still working full time.*

*It has created a problem, but not a problem we cannot overcome.*

*Surviving – would always like more.*

Factors that were seen as contributing to financial stress included the pressure of transport costs (n=4), loss of income due to giving up work (n=4), cost of extra specialists because of complications (n=1), bills sent to home address during relocation (n=1), and the need to provide for church commitments and a sick pet (n=1). One participant summed up when he stated,

*I don't particularly like the loss of control over my finances but keep things in perspective.*

*Have to wonder what will happen if I run out of money.*

### Current problems – nutritional

Over half of the participants (n=37; 59.7%) commented on nutritional problems and twenty-four participants (38.7%) indicated that they needed assistance with nutritional problems. The problems mentioned included weight gain or loss (n=8), sore mouth or throat (n=7), and taste changes (n=5). For some (n=2) there were only minor symptoms and for others (n=4) previous problems with symptoms had now passed. Five mentioned actually seeing a dietitian and information was seen as being useful (n=2).

It is important to note that again the 'independence factor' was expressed (n=3) with comments such as these:

*I do but I think I can manage them.*

*But I find it very important and am taking it into my own hands.*

*If I needed help, I would ask. But at this stage no.*

### Information about illness and treatment

Participants were asked directly if they felt they received sufficient information about their illness and the concerns it causes. Although the overwhelming response (n=56, 90.3%) was affirmative, further examination of the comments made (n=32, 51.6%) suggest that this was not as positive as first appeared. Only six (9.7%) were happy with the information provided, praising the openness and honesty of health professionals. Others (n=11, 17.7%) stated that it was up to them to ask questions about what they wanted to know. This is not always a positive experience, as indicated by these comments:

*But you need to ask. But then again, I don't think you want to ask sometimes.*

*I'm a busy body and I like to know what is going on. Well, it's my body.*

Others (n=6, 9.7%) relied on collecting their own information through net searches, reading and support groups. Some (n=5, 8.1%) stated the need for more information because they believe doctors have not provided sufficient information and so consequently the patient "does not know what happens, or what can happen". There were also some patients (n=4, 6.5%) who "did not want to know too much". Their comments included the following:

*Enough that you want to understand. I don't want to know too much.*

*More than enough.*

*More than you want to know. Sometimes the doctors are quite brutal. I have found that I need to bring support because it is quite often not what they say but how they say it and you can feel shattered.*

*Information overload.*

## Knowledge of different AHP services

Participants were asked to rate their understanding of the different AHP services. As Table 5 demonstrates patients do not have an extensive knowledge of the different services.

**Table 5: Ratings by participants of level of knowledge about different AHP roles.**

**Note: Percentages are calculated on one systems missing entry**

Client Knowledge of Different AHP Services				
Type of Service	None	Vague Idea	Some Idea	Familiar
Social Work	4 (6.6%)	12 (19.4%)	31 (50%)	14 (22.6%)
Physiotherapist	12 (19.4%)	9 (14.5%)	22 (35.5%)	18 (29%)
Occupational Therapy	29 (46.8%)	14 (22.6%)	11 (17.7%)	7 (11.3%)
Dietitians	11 (17.7%)	9 (14.5%)	25 (40.3%)	16 (25.8%)
Speech Therapists	27 (43.5%)	11 (17.7%)	14 (22.6%)	9 (14.5%)
Audiologist	34 (54.8%)	7 (11.3%)	13 (21.3%)	7 (11.3%)

## Issues in optimal AHP service provision

A direct structured question was asked about the options that participants would most like in relation to obtaining help from AHPs. The most preferred option was the provision of information booklets (n=29, 46.8%). This was followed by telephone contact (n=19, 30.6%), counselling (n=17, 27.4%), and individual follow-up (n=17, 27.4%). Interestingly, options such as group support (n=9, 14.5%) and educational programs (n=6, 9.7%) were least preferred.

Twenty-nine patients commented on ways they would most like help. Of these, six stated that they did not have suggestions about how best to provide assistance. Others commented on the options they had ticked stating that “all options are important”, “information dispels fears” (booklets), a “love of reading” (booklets), and the importance of telephone contact. On the issue of telephone contact participants stated the following:

*Telephone first, then see from there.*

*More convenient.*

*Instant help if you need it.*

*Telephone contact would be the initial thing to kick things off.*

Interestingly, two patients mention that just “knowing that they (AHPs) are there” helps. Reference (n=3) was made to the support provided by family members that “covers most things”. The ‘independence factor’ also appeared in these comments (n=4) with statements such as these:

*If you need it I suppose any of it. But personally I can handle it.*  
*Have never had any group support, have always had to get on with life and so don't understand why people keep wanting support.*  
*I am at the end of treatment so I don't feel like I need this assistance.*  
*I think that's when you're over the worst of it and then they can come in.*

Other specific suggestions included the following:

*Counselling for my children.*  
*Would like to see them more than I do.*  
*I want to do something, some activity.*  
*Help in the home because I think if I was without the Mrs, I would be handicapped.*  
*Meditation/Relaxation Therapy during treatment because that is when you need it.*  
*Basically updating (doctors) on their patients.*

Participants were asked about the time they would most like involvement from an AHP. As Table 6 indicates, the most preferred time is at the start of treatment.

**Table 6: Times that patients would most preferred to be approached by an AHP**

Staging of Intervention		
Time	Frequency	Number
At the Beginning of Treatment	28	45.2%
Only When a Problem Occurs	21	33.9%
Unsure	13	21%
Now	4	6.5%
Never	nil	0%

The notion of the importance of being introduced to the work of AHP was spelt out by some participants, as follows:

*Being introduced to the Social Worker, then knowing about their role and availability – just to be introduced and know they're there.*  
*Would like to be introduced first to know that they're there and how to contact them.*  
*Being introduced as soon as possible on entry to dispel concerns – its information.*  
*It is good to have knowledge of their role to be able to access when a problem occurs.*  
*I did meet up with some of the others before I needed their help and that was good.*

Social workers were a specific AHP group mentioned in the comments with references to the help they provided especially with accommodation, pre-school arrangements, and reassurance with anxiety producing information. As one participant stated,

There is a lot you can know about what might happen but then it depends on the person as to how that is dealt with – some knowledge can create anxiety for some people. The social worker has been reassuring. Appreciated phone contact and support which made me feel like I wasn't a number.

Although some stated they could not comment because as yet they did not have experience with the AHPs (n=4) others provided very positive feedback (n=5) as follows:

*Definitely, they have been really good to me.*

*Sometimes I look forward to it.*

*Exercises work.*

*Wonderful.*

*It was excellent professional help.*

When asked for suggestions in regard to the improvement of services the majority (n=33, 53.2%) commented. Many just stated that they did not know as there were no deficiencies, while some participants did not have the knowledge to comment (n=11, 17.7%). It should be noted that even in this question the 'independence factor' was evident with one patient stating the following:

*People need to help themselves, not wait for someone to help them.*

The concrete suggestions for improvement included the provision of more literature and information (n=3), assistance with how to handle treatment (n=1), more information about the actual services AHPs provide (n=2), telephone follow-up (n=1), and "shorter chemotherapy!"

Eleven participants who had made contact with these services at the hospital made strong comments expressing their appreciation for the AHPs. These comments stated that these professionals were "very helpful when asked". The contact with the AHPs was described in superlatives such as "excellent", "fantastic", "wonderful", "very helpful", "good", and "great". The AHPs were seen to "always come when asked" and have a very effective appointment system.

## Discussion

This project provided the opportunity to collect data on a population of outpatients in an oncology clinic during one month at a major metropolitan hospital. The expectation is that the findings will not only provide useful information for the development of AHP services at the Mater Hospital, but will also provide important data and insights for the teams of AHPs working in oncology outpatient services elsewhere. Before discussing the implications, however, there are number of issues in relation to the findings that need to be explored.

Firstly, the findings indicated that only a little over half the respondents had used the AHP services at this hospital. Because of the high percent of first admission participants in the study, this percent would be an under-reporting of the number of the total population of outpatients who would eventually see AHPs at this hospital. Those at the beginning of treatment were unlikely to have been referred to, or approached by, the AHPs at the time of this study.

Secondly, the fact that there was a very poor response to questions on emotional distress suggests that the findings may be an artefact of the research instrument or situation rather than an accurate representation of the degree of emotional stress for this group of patients. Research indicates that busy outpatient settings are not conducive to talking about emotional problems (Friedman *et al.*, 1993; Saunders & Baum, 1992). Another factor that may have contributed to the low scores on emotional issues is the number of patients who are only in the early stages of treatment. These participants may have not experienced the emotional consequences of lengthy involvement with treatment. Caution is thus indicated in interpreting these results. Although a number were prepared to acknowledge depression and anxiety, which are known to be problems for oncology patients, this number was still low. It is possible that none of the patients experienced domestic violence or substance abuse, but just as likely that participants would not be prepared to discuss these topics in the outpatient setting.

Thirdly, the patient's desire to present as coping well, an important factor that emerged from this research, can be understood not only by the clear statements made by participants but also by inference. For example, in recording problems with isolation those who did comment were giving explanations of why they did not experience loneliness. This could be an indication that people are less able to record comments about areas in which they feel they are not coping. Only those who were not lonely, in this case, chose to comment. The fact that individuals have a need to be seen as coping (the 'independence factor') has important implications for the way AHP choose to communicate their message of help to clients.

There are a number of findings in this research, which are affirmed by previous studies in psycho-oncology. In the physical domain, it has been well documented for many decades that there are a wide range of symptoms that cause problems for oncology patients (Baider & Cooper, 1995; Barofsky, 1992; Cella *et al.*, 1987; Haskell, 1990). It is now appreciated that the serious problem of physical fatigue, with its debilitating impact on cancer patient's sense of independence, is highly prevalent (Aistars, 1987; Breitbart & Chochinov, 1998; Ferrell *et al.*, 1996; Gallagher & Buchsel, 1998; Groopman, 1998; Vogelzang *et al.*, 1997). Also, in relation to the physical aspect of cancer it is now recognised that nutritional concerns are important (Riboli, 1992; Chiu *et al.*, 1996; Cummings & Bingham, 1998).

Similarly, there is an extensive literature that explores the problems that cancer patients have in maintaining their sense of self when confronted with changes in physical functioning, and altered body image (Bond & Wellisch, 1990; Holland, 1998; Kagawa-Singer, 1993; Lasry *et al.*, 1987; Margolis *et al.*, 1990; Pozo *et al.*, 1992; Schain *et al.*, 1994). Many of the interventions designed for supportive care in oncology are cognisant of the need to assist patients regain a positive sense of self.

Over recent decades there has been an explosion in the literature on informed consent for cancer patients. Within this literature, that acknowledges the individuals' right to be fully informed about their disease and its treatments, there is an increasingly sophisticated understanding of the variety of individual coping strategies that patients bring to the consent process. There is now a body of literature that affirms the findings in this study that some patients find too much information threatening and difficult to process (Holland, 1998; Levy *et al.*, 1992; Manuel *et al.*, 1987; McGrath, 1999; Miller, 1990; Singer, 1984). However, there is still scant empirical research which would affirm the findings on the need to be assertive in asking questions, the difficulty of doing this and the need for the individual to search out their own information.

As well as affirming present research, the research findings also provide fresh, new insights. Some of these insights have quite practical implications that will directly inform AHP service provision at the Mater hospital (Brisbane), as well as elsewhere. The high percentage of patients who shared the perception of the value and usefulness of AHP services and the high percent that already use the services will be affirming to the work of AHPs in hospital settings. This finding, however, needs to be balanced by the evidence that suggests a need for further educational strategies to communicate the different roles of the varied AHP because of the low level of public understanding of the unique contribution of each profession.

The preference by patients for an introduction to AHP services and follow-up from the start of treatment is important information for developing strategies for service provision. The patient's preference for information booklets, telephone contact, counselling, and individual follow-up, provide insights for choices for intervention strategies.

Some of the other insights derived from this research are not only practically useful, but have important implications for significant new directions in AHP research. Although there is a plethora of theoretical literature on the importance of autonomy and the principle of self-determination in health care, there is scant research that explores the idea empirically. The notion titled the 'independence factor', ie. the patient's need to present as coping well through their own resources without the need for help from others, was a recurring and important theme in the research findings. This factor has significant implications for understanding the basis for therapeutic and supportive relationships and should be prioritised in further research.

The high number of low income patients (61.7% under \$20,000) in this target group is worrying and indicates the need for further work on the impact on families of limited incomes when they are coping with cancer. The literature suggests income can influence health indirectly and directly (Gleeson, 1998; Podger, 1998). Low income can lead to reduced social participation, alienation, and poor health outcomes and contributes to health inequalities through the associated inability to purchase goods and services that directly influence health, such as nutritious food and good housing (Podger, 1998). Indeed, recent studies indicate that low socio-economic groups had consistently poorer cancer survival than those who were well off (Kogevinas & Porta, 1997). As yet, however, work on the financial impact on families of cancer is in its infancy (McGrath, 1999).

## Conclusions

This research provides a wealth of practical information for AHPs to use in planning for the effective utilisation of their services. Perhaps the most important and affirming information is that the majority of patients value and use AHP services. The findings, however, do indicate that patients do not have an extensive knowledge of the different services and would need an improved awareness about these services if they were to be used effectively.

In terms of planning for AHP services, it is significant that patients from this target group recorded a high preference for information booklets and telephone contact. This contact, according to this study, is best started at the beginning of treatment and should include the provision of detailed information about the roles of the different AHP services. Educational and support groups have an important role to play but this may be with a smaller sub-set of patients.

There is evidence that progress has been made in terms of information provision about treatment and illness. However, this study indicates that patients are still not satisfied with the material they receive from health professionals and are forced to engage in assertive questioning practices.

Financial distress surfaced as an important issue that needs to be explored with regards to patients in oncology. Indications from this research are that there are a significant group coping on low incomes. Financial difficulties can be exacerbated by loss of income from cessation of work and increasing expenses associated with treatment and transport. This may be a difficult area to study as patients appear to have a need to present as coping well and may be reluctant to reveal the severity of their economic problems.

Lastly, and perhaps most significantly, this study indicates that in planning AHP services, attention must be paid to the 'independence factor'. Some patients will find asking for help difficult, as they perceive this as a sign of their own weakness and a threat to their ability to cope independently. The suggestion of routine telephone contact may be an important way around this impasse as this can be interpreted as a reaching out by AHPs rather than an uncomfortable 'cry for help' by the patient.

It is hoped that the information provided in this study will not only go some way to helping AHPs in other hospital settings in their work with patients, but will provide baseline material from which further research can be developed.

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