

# Information needs and information behaviour of patients and family members in a cancer palliative care setting: an exploratory study

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## 1 Introduction

We assume that appropriate and timely information can help in relieving anxiety, taking informed decisions, and coping better. It can however, also increase anxiety, uncertainty and even fear.

Human information behaviour is very complex and can be influenced by a combination of factors. The exploratory study stresses the need to further explore the correlation between factors which might be useful in "predicting" information behaviour and the interventions that may be required, e.g.

- disease related factors (e.g. stage of cancer at the time of diagnosis, expected prognosis, negative changes in prognosis, treatment).
- socio-economic background.
- educational background.
- level of information and IT literacy.
- cultural identity (With 11 official languages South Africa houses a variety of cultural groups including Afrikaners, English, Vendas, Zulus, Xhosas, Indians, Coloureds and immigrants) (<http://www.gov.za>).
- personality and learning style.

## 2 Exploratory Study

The study, using convenience sampling, was conducted at a cancer palliative care setting in Pretoria, the administrative capital of South Africa (<http://www.tshwane.gov.za>). Participants include:

- **Patients** treated in a private medical oncology clinic and family members.
- Treating **oncologists/doctors**.
- **Nursing staff** from the **medical oncology clinic** and **oncology hospital wards**.

### 2.1 Purpose of the exploratory study

We intended to identify

- gaps in our understanding of information behaviour.
- discrepancies in the experiences/perceptions of participants.
- the need for interventions/information.
- directions for expanding the research focus.

### 2.2 Our interpretation of palliative care

We accepted the WHO 2002 definition of palliative care (as cited by Ahmedzai (2004:2193)): "Palliative care can be interpreted as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". **Terminal patients were mostly too ill to participate.**

### 2.3 Methods of data collection

Although very time intensive, the methods provided information rich data.

Participants	Methods
<b>Patients &amp; family members</b>	Semi-structured individual interviews <ul style="list-style-type: none"> <li>• Questionnaire completed by interviewer (social worker)</li> <li>• Tape recorded with consent (transcribed)</li> <li>• Observation of emotional state during interview</li> <li>• Rapport established with participants (not taped)</li> <li>• Post discussion with participants (not taped)</li> <li>• Exploration of opportunities for follow-up sessions</li> </ul>
<b>Oncologists/doctor &amp; nursing staff</b>	Individual interviews <ul style="list-style-type: none"> <li>• Interview guideline; encourage expansion on answers</li> <li>• Both researchers present</li> <li>• Tape recorded with consent (transcribed)</li> </ul>

Anecdotal information is mostly free translations from Afrikaans.



## 2.4 Participating sample group

### (a) Patients

Gender	Type of cancer	Occupation	Language	Age	Qualification	Religion
Female	Breast & bone metastasis	Nurse	Afrikaans	36-45	Post school	Important
Female	Inflammation breast cancer	Was a secretary	Afrikaans	36-45	Post school	Very important
Female	Ovary cancer & liver metastasis	Housewife, was active in local organisations	English	> 65	High school not completed	Very important
Male	Testicle cancer & metastasis to lymph nodes	Electronic engineer	Afrikaans (German background)	26-35	Post school	Important
Male	Differentiated non-hodgkin lymphoma	Pensioner	English (Indian)	55-65	High school completed	Not important
Male <sup>1</sup>	Lung cancer	Administrative	Afrikaans	36-45	High school completed	Very important
Male <sup>2</sup>	Multiple myeloma	Depot manager	Afrikaans	36-45	Post school - technical diploma	Very important

### (b) Family members

Gender	Relationship	Occupation	Language	Age	Qualification	Religion
Female	Wife	Housewife	Afrikaans	46-55	High school completed	Very important
Female	Wife	Administrative position	Afrikaans	36-45	High school completed	Believe in cure
Male	Son	Manager at hamburger enterprise	English (Afrikaans background)	26-35	High school not completed	Yes - but questions

### (c) Nursing staff

Gender	Language	Rank	Professional function
8 female	7 Afrikaans 1 English	1 oncology ward unit manager 1 sister-in-charge 5 sisters 1 staff nurse	3 administrating treatment to inpatients 3 treating patients in hospital 1 sister-in-charge 1 oncology ward unit manager

### (d) Doctors

Gender	Language	Profession
2 male 3 female	3 Afrikaans 2 English	4 oncologists 1 doctor specialising in palliative care

## 3 Selection from Findings

### 3.1 Information needed

Type of cancer, treatment (what to expect, side effects), medication, prognosis, life expectancy ("I need to know when the end will come"), assurance that patient will be cured (Doctor: "My body language when explaining poor prognosis may influence information behaviour"), what will happen next, why things are happening, what to expect before and at the time of death, how to deal with somebody dying, etc.

Information is expected to be tailor-made for individual needs and circumstances (e.g. combination of cancer with HIV).

**Researchers:** Information needs could be plotted against available information sources and information sources that need to be developed. Expressed needs as well as implied information needs (based on the experiences of medical and healthcare professionals must be considered).

### 3.2 Range of factors influencing the information behaviour of patients and their family members

(There is not agreement on the influencing factors.)

<b>Patients</b>	Availability of friends, religion, too much information all at once, lack of time for explanation, profession, forgetfulness due to treatment, etc. "From the first day lots of friends around me." Being a nurse: "You know" ... but you don't know; you are the patient" ... "If I have another chance, I will not mention my profession".
<b>Family</b>	Language and complexity of information given by doctor, lack of time for explanations, uncertainty of whom to ask, contradicting explanations. "You get five nurses and five different explanations". Cannot ask everything from doctor ... "I know others are waiting to have a brief chance of seeing him".
<b>Oncologists/ doctor's perception</b>	Age, severity of prognosis, time from diagnosis before moving to palliative care, educational level, anxiety, etc. "Older patients more understanding ... they understand life comes to an end". "Depend on whether they immediately went into palliative care..."
<b>Nursing staff's perception</b>	Stage of disease (more questions at time of diagnosis), type of treatment (e.g. type of chemotherapy), anxiety (they do not take in the information & require lots of repetition), need to associate with patients with similar cancer & treatment. Patients often do not address questions on sexuality. Needs and information needs are not always verbally expressed. "You can feel the emotional need".

**Researchers:** All influencing factors should be considered in the planning of interventions and information sources. More research is required into dominating influencing factors.

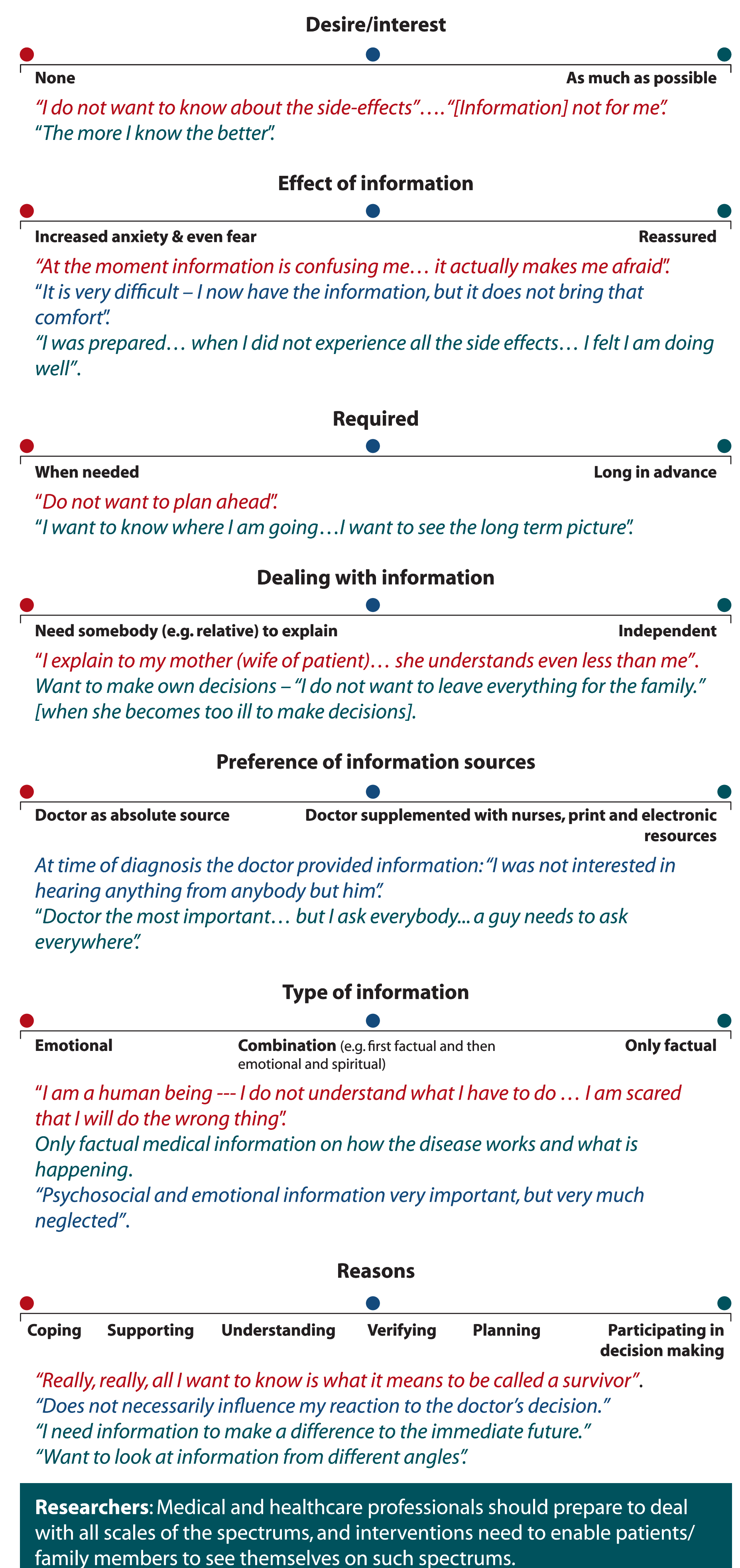
## References

Ahmedzai, S.H. et al. 2004. A new international framework for palliative care: position paper. *European Journal of Cancer*, 40:2192-2200.

(Footnotes)

- 1 Wife sat in on interview and participated
- 2 Patient was too ill to participate; wife and son participated

## 3.3 Information needs can be viewed on spectrums



### 3.4 Patients and family members stress their personality types

"This is unfortunately how I am ... I am too scared to ask ... part of my low self-esteem".  
"I look at the bigger picture" ... "think in boxes and squares".  
"I like to prepare myself for the bigger picture - I am a bigger picture person ... I want to know everything now - prepare, finish".  
"I always was happy-go-lucky".  
"I want to live life fully with quality".

**Researchers:** It seems as if self-awareness, personality types and learning styles may be important since patients/family stressed their personalities without being prompted.

### 3.5 Awareness and acceptance of the prognosis

"Doctor said that I will never go into remission again... before that I really believed that I will be cured".  
"I have received a word from the script that he will be cured".

**Researchers:** Some patients/family accepts their prognosis and require information to prepare, while others are in denial until the end.

## 4 Conclusion and recommendations

The poster can only highlight a few of the findings from the exploratory study. An in-depth analysis will be reported in the subject literature. It is recommended that:

- the project is expanded to include a wider sample population especially with regard to cultural groups, educational and socio-economic backgrounds.
- that the research methods be retained.