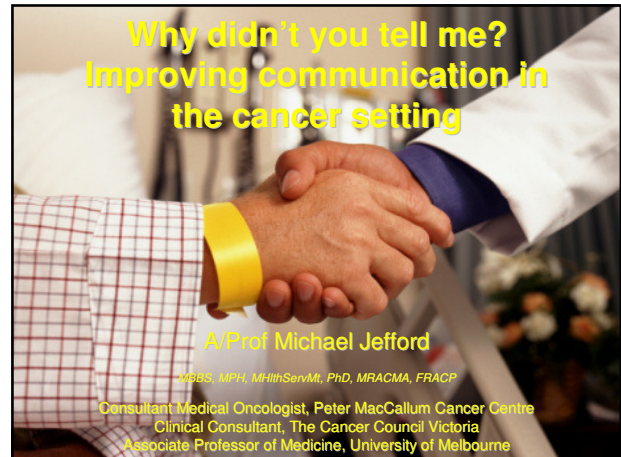




**Cancer Council Update  
2008**

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**Why didn't you tell me?  
Improving communication in  
the cancer setting**

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 Associate Professor of Medicine, University of Melbourne



**Tii Peter Mac**  
EXCELLENCE INNOVATION COMPASSION

The Cancer Council Victoria  
Leading the fight...

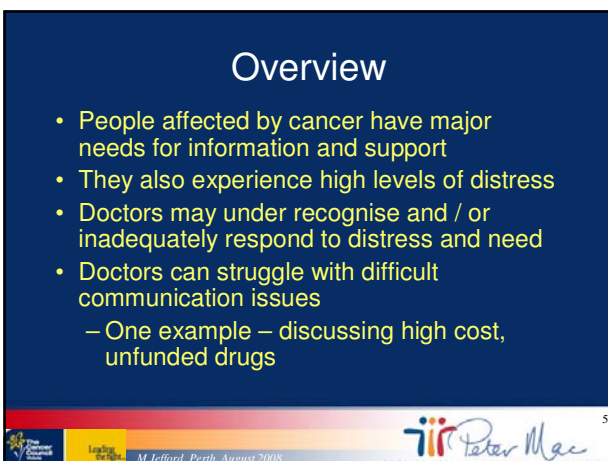
THE UNIVERSITY OF MELBOURNE

M Jefford, Perth, August 2008



**Greetings from Melbourne**

M Jefford, Perth, August 2008



**Overview**

- People affected by cancer have major needs for information and support
- They also experience high levels of distress
- Doctors may under recognise and / or inadequately respond to distress and need
- Doctors can struggle with difficult communication issues
  - One example – discussing high cost, unfunded drugs

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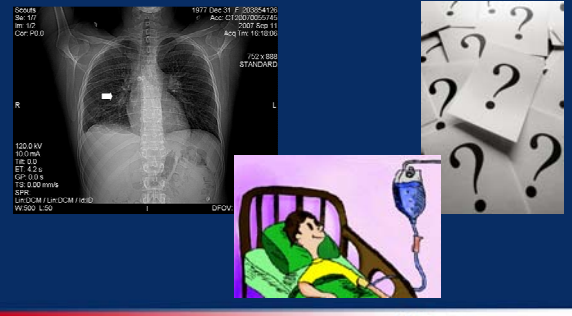


**Overview (continued)**

- Strategies to improve communication
  - Communication skills training for healthcare professionals
  - Strategies for patients
- Sources of information and support

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# Information



# Distress



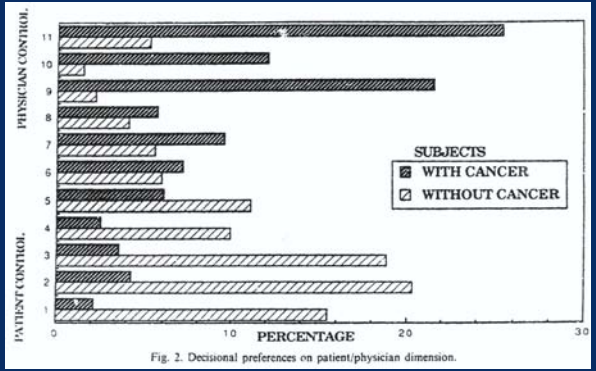
# Unmet needs - psychological



# Unmet needs



# Decision-making



## Significant under recognition of distress



## Discussing complementary and alternative treatments



## Barriers to adequate discussions



## Doctor barriers

- Don't know how to ask
- Afraid they can't 'fix' or 'solve' issues
- Afraid it will 'open Pandora's box'
- Fear of causing distress, harm or worry
- Thinking that the emotional or existential domain is not part of their role / professional role

## Patient barriers

- Feel uncomfortable, embarrassed
- Not knowing how to ask
- Fearing breaking down
- Ashamed to admit problems with coping
- Perceive the doctor to be too busy / disinterested

## Discussing treatment options



# Expensive unfunded drugs



# original article

Annals of Oncology 17: 702-706, 2006  
doi:10.1053/ann.2006.10.136  
Published online 18 January 2006

## Do oncologists discuss expensive anti-cancer drugs with their patients?

J. Thomson<sup>1</sup>, P. Schofield<sup>1</sup>, L. Mileskin<sup>1</sup>, E. Agalinos<sup>1</sup>, J. Savulescu<sup>2</sup>, J. Zalcberg<sup>1</sup> & M. Jefford<sup>1\*</sup>

<sup>1</sup>Division of Haematology and Medical Oncology, Peter MacCallum Cancer Centre, Melbourne, Victoria, Australia; <sup>2</sup>Oxford Centre for Practical Ethics, University of Oxford, Oxford, UK

## Medical paternalism and expensive unsubsidised drugs

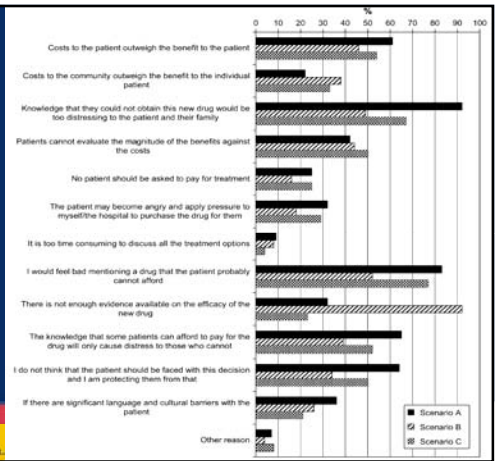
Michael Jefford, Julian Savulescu, Jacqui Thomson, Penelope Schofield, Linda Mileskin, Emilia Agalinos, John Zalcberg

# Do medical oncologists talk about unfunded, expensive drug options?

- Three scenarios described situations where a high cost drug was associated with either
  - A. improved survival
  - B. encouraging anti-cancer activity in a treatment-resistant type of cancer
  - C. better tolerability / improved quality of life

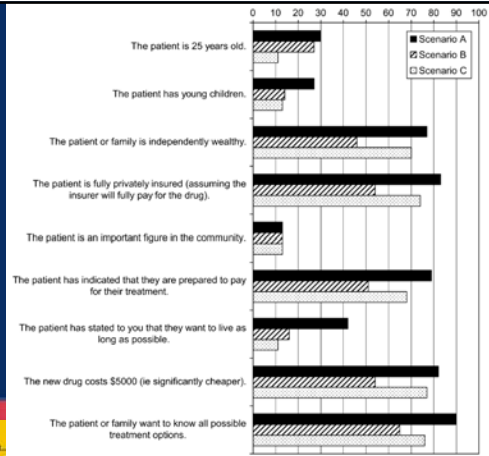
# Reasons for not discussing high cost drugs

Thomson J et al. *Ann Oncol* 2006;17(4):702-8



# Possible reasons to change from a decision not to discuss

Thomson J et al. *Ann Oncol* 2006;17(4):702-8



# British Medical Journal article

## When should options be discussed

- “the evidential test we suggest is: would a reasonable doctor offer or would this patient (given their individual values) reasonably desire this drug or treatment if it were free?”
- “We believe that there are no good reasons for withholding information about new unsubsidised drugs when reasonable evidence is available on safety and efficacy”

## Communication skills training

- Communication skills
  - “a core clinical competency”
- Victorian Cancer Clinicians Communication Program (VCCCP), The Cancer Council Victoria



## Communication skills training modules


- Eliciting and responding to emotional cues
- Breaking bad news (discussing prognosis)
- Discussing the transition to palliative care
- Discussing sexuality
- Discussing complementary and alternative treatments
- *Discussing clinical trials*
- *Discussing end of life issues*



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## Basics

- Listen, wait
- Respond to emotion, empathy
- Check understanding of situation
- Ask
  - patient’s agenda
  - preference for information / decision making
  - prognosis



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## Evaluation of our programs




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## Enhancing patient involvement

- A generational shift
  - People want to be active participants
  - The courts strongly support providing people with information that may be relevant to themselves (supports personal autonomy)
- Improving question asking
  - Question prompt lists
- Improving decision-making
  - Decision aids


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### Asking Questions Can Help

When you see your medical or radiation oncologist today you may have questions and concerns. Often these are forgotten in the heat of the moment, only to be remembered later. We have compiled a list of questions to help you to get the information you want from your oncologist about your illness, and possible treatments. These questions have been developed after discussion with many people. Your oncologist is keen to answer any questions you may have, either now or at future consultations. You and your family may choose to use this list at any time.

We suggest you tick the questions that you want to ask and write down any that you may think of which are not listed. In many cases, your oncologist will have answered the questions without you even asking, and in that instance this pamphlet can serve as a checklist.

[Gardner A et al. Cancer 2008 May 16. \[Epub ahead of print\]](#)



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#### Diagnosis

- \* What kind of cancer do I have?
- \* Where is the cancer at the moment? Has it spread to other parts of my body?
- \* How common is my cancer?

#### Tests

- \* Are there any further tests that I need to have? What will they tell us? Will they confirm my diagnosis?
- \* What will I experience when having the test/s?

#### Prognosis

- \* How bad is this cancer and what is it going to mean for me?
- \* What symptoms will the cancer cause?
- \* What is the aim of the treatment? To cure the cancer or to control it and manage symptoms?
- \* Is the treatment going to improve my chance of survival?

Living A et al. Cancer 2008 May 16. [Epub ahead of print]



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## Notes



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“Oncologists should consider installing audio taping facilities and offer all patients a tape of their consultation”



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## Improving understanding / relieving distress – resources

Cancer Council Helpline 13 11 20

- Support groups
  - Face to face
  - Telephone
  - Internet
- Counselling
- Cancer Connect

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## “7 Minutes” book



Available from  
[www.breastcancer.org](http://www.breastcancer.org),  
[www.amazon.com](http://www.amazon.com), etc



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## Tips

- Be prepared
  - Notes (symptoms, etc)
  - Questions
  - Tape recorder
- Bring someone
  - ? specialized expertise
  - ‘rules for family and friends’

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Rules for Family and Friends




DO

- Follow your job description: drive, handle the tape recorder, carry my stuff, and be responsible for food and drinks.
- Always let me talk first.
- Wait for your cue to ask your assigned question. (Agree on the cue before you go in—like a hand signal or a verbal introduction: "Dad, you were going to ask Dr. Jones more about . . .")
- Ask permission before you jump in if you don't have a specific cue.
- Use my name when you talk about me in front of the doctor.
- Turn off your cell phone. (That goes for BlackBerries, iPods, and any other electronic devices. Just think of my appointment as you would a plane taking off.)
- Bring a notebook and pens—and a tape recorder if we agree upon this up front.
- Watch the doctor's body language.
- Come fed, freshly showered, and properly dressed—nice neat clothes, no stains.
- Be patient with me! I may be feeling more emotional than usual.
- Ask if you can join me during the physical exam.

DON'T

- Talk over me.
- Interrupt me.
- Wear perfume or cologne.
- Mention every doctor you know.
- Eat food, open candy, or slurp down drinks when the doctor is present.
- Come if you have to be somewhere else right afterward—in case my appointment is delayed and that puts you in a bind.
- Assume that you can represent me to my doctor on my behalf or request information about me in the future. Ask for my permission first.
- Demand to know details if they aren't any of your business.
- Be upset with my long list of rules. This is my health and I'm doing my best to protect it.




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## Maybe

- Ask the doctor's experience, particularly with uncommon cancer types or for uncommon cancer procedures (major cancer surgery)

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## Advocacy for patients

- Go along
- Help with the 'to ask' list
- Disclosure
  - Symptoms
  - Adherence to treatment
- Clarify, summarise, next steps

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## Communication

- "Those two simple words – thank you – mean so much to both doctors and their teams"
- "You catch more bees with honey than you do with vinegar"
- Dog / 'Doc' training – getting your Dr to behave in the way that you'd like

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  M Jefford, Perth, August 2008 



## Reasons for Poor Listening at the Doctor's Office

- Being nervous
- Feeling pressured to share questions and concerns quickly, fearing that time will run out
- Not understanding the answer to a question
- Rushing the doctor so you can get a chance to ask the more useful questions
- Asking others' questions, which aren't of great interest to you
- Being afraid of what the doctor might tell you
- Focusing on asking the next question instead of on the answer to the one you just asked
- Losing your place in the conversation—and pretending to be back on top of things. Anxiety builds because you're still lost.
- Modifying additional questions in light of the answers you just received

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## Communication skills

- Dealing with a list of questions
  - "Thank you. This information is really useful for me"
  - "I really appreciate your answer. You're the first to explain it in a way that I can understand"
  - "I know I have a lot of questions today and I can see you're busy. Can you help me make a plan to address the rest of the questions?"

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## Communication skills

- Clarifying things
  - “I’m sorry but I think I missed the last point you made. Do you mind repeating it please?”
- All treatment options considered?
  - “Are there other treatment options? Treatments that might not be available at this hospital? Drugs that might not be covered by the PBS? Or clinical trial options?”

## Other tips

- Get your doctors to communicate with each other
  - Provide a list of contact details
  - Same list at the pathology centre, copy to yourself
  - Calling the doctor’s rooms
    - Find out who the staff are
    - Leave full messages – tests you’re enquiring about / details for prescription repeats



## Another opinion?

- An opportunity to get more information so that you can make the best decisions
  - Confirmation
  - Balanced perspective
  - Review of the whole situation
  - Family concerns
  - Tiebreaker
  - Intermittent consultation



## Changing doctors

- Consider fit – convenience, gender, language, cultural group, etc
- Qualities to look for in a doctor
  - Good training, experience, thoroughness, supportiveness, confidence and decisiveness, good listening skills, openness to input, familiarity, accessibility, compassion, respect for privacy, respect for boundaries, appropriate use of humour, career stage of doctor

## Conclusions

- Good healthcare depends on good communication and good clinician-patient relationships
- Providing information is critical
- We need to (and can) enhance clinicians’ communication skills
- Strategies can enable patients to feel more in control and to gain the information that they need

## Why didn't you tell me? Improving communication in the cancer setting

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**Daffodil Day**  
**Friday 22 August 22**

**Survivor's Walk**  
**Central Park, Perth, 12pm**  
for more information call  
Cancer Council Helpline 13 11 20

