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**Keeping hope alive**

or

**the right to know**

**Communication about incurable cancer between  
Turkish patients (in Turkey and the Netherlands)  
and their doctors**

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# Content of presentation

- Background
- Aim of study
- Study design
- Results
- Discussion



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# Background

- 384.000 Turkish immigrants in the Netherlands with a rising incidence of cancer.
- Three models of ‘bad-news’ communication :
  - Full disclosure model – the ‘usual’ Dutch way
  - Individual disclosure model
  - Non-disclosure model – the ‘usual’ way in Turkey (and many other countries!)
- Problems between Turkish families and Dutch doctors due to unwanted full disclosure

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## Aim of this study on communication about incurable cancer : to get insight in

- Wishes and experiences of Turkish individuals
- Differences between respondents in Turkey and in the Netherlands (acculturation?)
- Views and experiences of Dutch and Turkish doctors
  - How do they deal with wishes of their patients or family that are contradictory to their own views?

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# Methods: qualitative design

- **Focus group discussions**
- Turkey 20 Turkish individuals
- Netherlands 14 Turkish individuals
  
- **Semi structured in-depth interviews:**
- Turkey 7 physicians
- Netherlands 8 physicians (GPs)
  
- Inclusion until theoretical saturation was reached
- Variation in gender, age, geographical background, educational level and religion.

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# Results:

## Wishes of Turkish individuals

- **Gentle disclosure of diagnosis cancer**  
*“you need to know because you will go to therapy and wonder why”*
- **Non-disclosure of incurability to the patient**
  - Keeping Hope alive
  - Allah knows what will happen – not the doctor
  - If you know, you lose hope and die faster
  - bad experiences Dutch doctors
    - they easily ‘give up at the patient’
- **Tell a bad prognosis to the family instead**

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## Some quotes

- *If the doctor would tell my mother she will demolish. “Will I die today? Will I die tomorrow?” is what she will think. I think you should keep it secret to the patient, but only inform the family.  
(woman, 25 Years, Turkey)*
- *It is a bad idea to tell the patient he will die. You should motivate him, tell him it’s a serious illness but that there is therapy for that. The physician should tell him he should not be concerned.  
(woman, age 51, the Netherlands, first generation)*

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# Results

## Differences between respondent groups

- No differences between respondents in Turkey and first generation Turkish people in the Netherlands.
- Differences related to educational level:
  - the higher educated, the more respondents want to be informed
- Differences between first and second generation: second generation wants to be informed more (but not when it regards their parents!)

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## Some quotes:

- *I do not want to know, I think I would emotionally deteriorate. The physician should tell me it's something innocent. But he should tell my family, so they can handle with knowledge and help me. (57 Years old Woman, poorly educated, living in Turkey)*
- *I would want to know it myself. But, if it would happen to my father, I would not want him to know. I think that if he knows he will die sooner. (39 year old woman, second generation, living in the Netherlands)*

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# Results Turkish physicians

Acknowledge right of patient to be informed, but

- **Never start the conversation** about bad prognosis unless patient asks
- **First talk to the family**
- **Always honour family 's wishes**  
*“If the family comes in advance and asks us absolutely not to tell, then I absolutely won't tell.”  
(Turkish oncologist)*

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# Results Dutch GPs

**Leading principal:**

**Autonomy of patient and his right to know**

- Start conversation about prognosis
- Problems with families who ask not to inform the patient

*“Don’t tell my mother or father,” is something we hear a lot. But still I will ask the patient himself what he wants to know or not. Because it makes me very unhappy if everybody knows it, but is pretending not to. (Dutch GP)*

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# Example of a cultural clash

*My mother incurable cancer. I spoke to the specialist. I said: "listen, tell everything to me, everything. But NOT to my mother and even not to my father. Because he will also suffer. That's our culture"*

*But he said:" no, I cannot do that, I am not allowed to lie.."  
I said: " that's not lying, that's just our culture, you should have some respect for our culture".*

*He said: " I am.. I have to.. but, I will tell it in a gentle way".  
I said: "Ok."*

*Then he came to my mothers' bed, and he said straight away: " Lady, it's over.. yes.. it's over." My mother started to cry. Because she was still having hope. A few days later she passed away.*

*(man, 40-49 Years, the Netherlands, second generation)*

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## Results: Gps with many immigrants find a way to deal with differing views

*“An old Turkish lady seemed very content in her last weeks. Every time I asked her: “do you have any questions?” And she always answered, with a smiling face: “No, doctor, everything is fine.” And then I thought: “Who am I to interrupt this game?””(Dutch GP)*

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# Discussion

- Some acculturation in second generation?
- Why can Turkish doctors follow the wish of the family and most Dutch doctors not?
- Does the family always know what the patient wants?
- Dutch GPs with many migrant patients had less problems with following the patient and family's wish: what can we learn from them?
- Individual disclosure best model?  
“ask – tell – ask “
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# Questions?

