



Dignity in the last phase of life.

Patients with a migration background and their relatives in the Netherlands.



Xanthe de Voogd, PhD-Candidate
Dept of Public Health, Location AMC
m: x.devoogd@amsterdamumc.nl
T: +31613634476 / +3120 56664215

Ref: Sociaal Werk Nederland



Meaning of dignity

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Meaning of dignity

- Human dignity

“All humans are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards another in a spirit of brotherhood.”

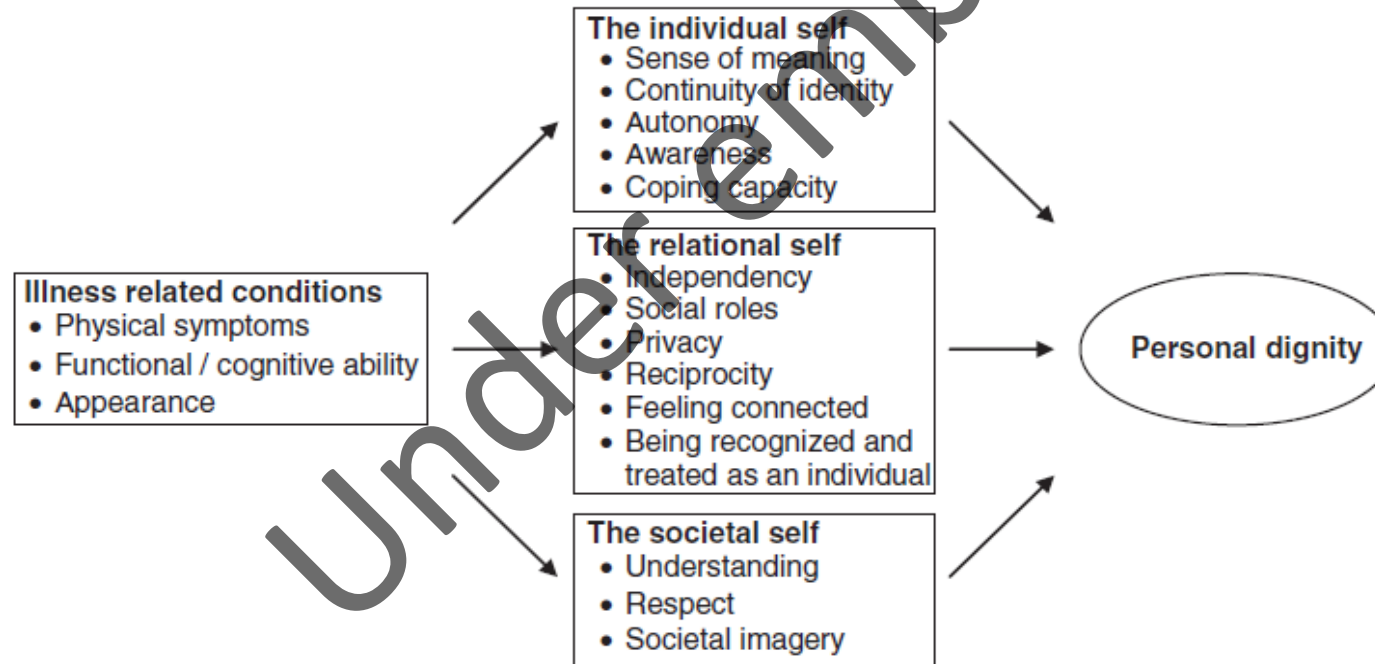
- Personal dignity

Personal sense of worth, associated with personal goals and social circumstances.

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Personal dignity





Migrants in the Netherlands

- 23,6% of people in the Netherlands have a migration background.
- 56,6% of them has a non-western migration background.
- The three largest non-western migrant groups are of Turkish, Moroccan, or Surinamese origin.



Ref: 50 jaar
Marokkaanse
arbeidsmigratie



Ref: Black
achievement
movement



Obtain insight in..

- What migrant patients—and their relatives—in the last phase of life, with a Turkish, Moroccan or Surinamese background find important aspects of personal dignity.
- How relatives of these patients experience their own dignity.
- How care professionals can preserve and strengthen the personal dignity of these patients.



Methods

- Interviews with key informants
- Semistructured interviews with patients and relatives
- Bilingual ethnic-matched interviewers
 - **Dutch: 'waardigheid'**
 - **Turkish: 'haysiyet' and 'değerli(lik)'**
 - **Arabic: 'karama' and 'qima'**
- Data collection between December 2017 and June 2018
- Purposive sampling
- Inductive thematic content analysis
- Definition 'palliative'

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Results

- Interviewed 23 patients and 21 relatives, data from 33 patients.
- Diversity in condition, age, ethnic background, place of living (nursing home or at home)

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Results: Dignity of the patient

Religion

“It is from Him (Allah). You’ll become sick and after that you’ll die, that’s the way it is. We’ve got nothing to say about that, that’s what we believe in. [...] In such situation, I am not focusing on my own feelings. I don’t do that.”

(Turkish patient)

“The neighbors and friends were so used to coming in, that they just wanted to hear a prayer from him and they just came for that. [...] So we always had visitors. He always prayed to God. Everyone said: ‘Ok quiet, we want to hear sir, that he is praying for us. It wasn’t hard at all. He really was a special person.”

(Turkish relative)



Results: Dignity of the patient

Religion

“The spiritual counselor can come and visit me. We can sing together. We can pray together. To give you mental strength.”

“When a human being does not have mental strength, then you are a conformist, then you do not have dignity.”

(Creole-Surinamese patient)



Results: Dignity of the patient

Being meaningful to others

“She really wanted to stay at home. That she found really awful, that her children have put her here (in the nursing home). She found that not nice. Every time we were here she says: ‘I don’t want to stay here.’ She says: ‘You are my children right, you should take care of me.’ That is not nice for her.”

(Turkish relative)

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Results: Dignity of the patient

Autonomy

“Informant: If only I had a wheelchair with a motor. Then I can push a button and I am gone. Because, I had a mobility scooter when I lived at home. [..]”

Interviewer: So you always have to be pushed forward by someone?

Informant: Yes, by someone else. And when that person is not in the mood for it.. I have always found people that gladly pushed me. My children, my son-in-law.”

(Creolo-Surinamese patient, #3)



Results: Dignity of the patient

Dignified care

- Caregiving with love, attention and respect
- Considerate communication
- Physical integrity
- Hygiene
- Privacy

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Results: Dignity of the patient

Dignified care: caregiving with love, attention and respect

“My mother was a dignified woman. A proud woman. Then, you do not, as a stranger to her, talk to her as a child. I have seen this kind of things. These were the things of which I thought ‘Sent them all out. I will do it myself. Yes, ‘Hey missy..’ You know, with a tone of which you think, just shut up. It is a grown-up woman. Treat other people decently. Pay attention to norms and values.”

(Hindustan-Surinamese relative)



Results: Dignity of the patient

Dignified care: considerate communication

“For example, doctor X knows that my mother is dying. She tells it to her (mother) in a beautiful way and says to her ‘Yes miss Y, we did our best.. But, everybody has his dossier, for example the dossier is black, you cannot improve it. You will go, but that does not say anything. There are also people that are healthy and that pass away.’ She tells her ‘I am in the next room and my heart might stop.’ She gives her an example, that says, it is less. So everyone will die. Not ‘Only you will die, I will live long, I am healthy and...’ [...] Yes someone is healthy and could come under [...] a bus, and dies. That is a good way to slap the person that is dying a little less.. the slapping is hard, but less hard.”

(Moroccan relative)



Discussion

- Themes can have concurrent roles in intrinsic and extrinsic dimensions
- Quality and nature of relationships
- **Order of importance or concretization is different : being cared for by family members, surrender to God/Allah.**
- Differences between the groups
 - Surrender as prescription and important in extrinsic dimension
 - Autonomy
- Care professionals

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Dignity of the relative

Care for the carer

“Palliative care is an approach that improves the quality of life of patients **and their families** facing the problem associated with life-threatening illness....”

WHO



Results: Dignity of the relative

- Good care and dignity of the patient
- Generation differences
- Relating to the self and finding balance
- Social interaction
- Care professionals
 - Being taken seriously & warm treatment by care professionals
 - Refraining from judgments regarding dignity of the patient
 - Help with division of care tasks among family members



Results: Dignity of the relative

Good care and dignity of the patient

“In the beginning I’ve been very emotional, because we have put her here (in the nursing home). We have dropped her here. Like, ‘You are a now a burden. You are now a danger. To yourself and to your surroundings.’ What we do, it’s for the best. [...] The responsibility that it would entail, I wouldn’t want it. Because of our history, I wouldn’t want it. But I walk away here. I get in my car and go home. I do leave her behind.”

(daughter of Surinamese patient)



Results: Dignity of the relative

Differences between generations

“When I am not able to take care of myself anymore, then nonetheless she has to stay there (in the nursing home). But, that makes me very sad. I have not confided her to a nursing home for eight years. **And if she then will live her last moments there, that will seriously impair my dignity. Then, my mother’s dignity will also be impaired. [..]** **Actually it is not so terrible. I (myself) would want to go to a nursing home, when I will have a hard time. To not make it to hard for my children. We think about it this way, but the first generation doesn’t think about it like that.”**
(daughter of Turkish patient)



Results: Dignity of the relative

Social interaction

*“And his patience, I said to God, ‘O Lord, also provide me with such patience. [..]’
Sometimes, in the nights, he couldn’t sleep. He just couldn’t sleep and he didn’t even
complain about why he couldn’t sleep. Then he just prayed to Allah. And he also prayed
for me and then for me it was also easy to help him. Therefor I didn’t even became
tired.”*

(Turkish relative of deceased patient)



Results: Dignity of the relative

Relating to the self and finding balance

“When I think about ‘Did I fall short in caregiving?’ No, I don’t think so. I have enough.. We did enough. Have you fallen short in.. I believe that I have given up much of my private life. So, then what is dignity.. You are only caring and caring. You are not thinking about where you are standing, who you.. Yes, you are not consciously thinking about these things.”

(Surinamese relative of deceased patient)



Results: Dignity of the relative

Care professionals

- Being taken seriously & warm treatment by care professionals
- Refraining from judgments regarding dignity of the patient
- Help with division of care tasks among family members

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Discussion

Dignity of relative relates to dignity of patient

Values that are important to the patient

Advocating for good care

The relationship and social interaction

The self and finding balance

Dignity of relative often not studied

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Conclusion

First time that dignity among patients with a migration background is studied.

Order of importance or concretization is different : being cared for by family members, surrender to God/Allah.

Differences between the groups regarding autonomy and religion.

Facilitating relatives in caring for their ill relative.

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Thank you!