Dementia and Sexuality

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Our journey today

1. Relevant aspects of dementia
2. Changing attention for sexuality in dementia (?)
3. Sex in dementia → ‘negative aspects’
4. Hypersexuality (?)
5. Sex in dementia → ‘positive aspects’
6. Relevant aspects of relationship
7. Challenges for Sexual Medicine

Disclosure:
I have no connection to the pharmaceutical industry
Attention for sexuality & intimacy in dementia?

Sexuality in dementia received very little attention. When addressed, the majority of attention goes to:
♦ are sexual encounters allowed (or not)
♦ sexual abuse by or to demented patients
♦ ‘hypersexuality’

Reasons for the limited attention:
♣ taboo on sexuality in higher age
♣ taboo on sexuality in dementia
♣ etcetera

‘Sex is for the young, the healthy and the beautiful!’
Attention for sexuality & intimacy in dementia?

- Prevalence of dementia is / seems increasing (higher age)
- At higher age, younger cohorts are (and will be) more open to sexuality* (new generations have higher ‘sexual needs’)

* Beckman et al BMJ 2008;337:a279

- Benefits of sexual expression
  There are indications that in some ways sexual behavior in older persons prevents cognitive decline ♥.
  (sexuality preventing dementia ? )

Relevance of paying attention

In case of dementia:
   Aspects of sexual expression can become a very relevant element in the care of the patient.

Especially for institutionalised patients,
   physical contact & sensuality are an important part of the remaining basic needs

When not allowed / provided
   sexuality can become an important part of the unmet needs)

There seem to be great differences (partly cultural diversity) when addressing those elements and dealing with those unmet needs.

For really respecting the sexual rights of the individual patients with dementia and fulfil their sensuous needs, one apparently has to step out of political correctness, religious restrictions, cultural handicaps and institutional routine.
Relevant aspects of dementia

Alzheimer Disease: 62%
Vascular dementia: 17%
Mixed dementia: 10%
Lewy Body dementia: 4%
Fronto temporal Dementia: 2%
Parkinson dementia: 2%
Rarer causes: 3%

UK Alzheimer Society 2012 Report
Prevalence of dementia

<table>
<thead>
<tr>
<th>Age Group</th>
<th>No dementia</th>
<th>Dementia</th>
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<tbody>
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<td>40-64 yrs</td>
<td>1,400</td>
<td></td>
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<tr>
<td>65-69 yrs</td>
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<td>70-79 yrs</td>
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<tr>
<td>80+ yrs</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>90+ yrs</td>
<td>2,5</td>
<td>1</td>
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One in three people over 65 will develop dementia.
Life expectancy at birth

Brazil

USA

Female

Male

6.8 yrs

4.8 yrs
The big female surplus in the higher age cohorts

90+ yrs

No dementia
Dementia

Two thirds of people with dementia are women
Complexities when dealing with this topic

- (The ‘well-group ‘)
- Community dwelling patients
- Institutionalised patients
  - ‘Long-term care’
  - ‘In nursing homes’
  - ‘Residential aged care facilities’ (RACF)
‘Stages’ of dementia

1. Mild stages
   Reducing self-respect and aware of loss.
   Contact with the surrounding is still possible

2. Moderate stage
   Thought processes are gradually lost.
   Disappearing differentiation (past-present; known–unknown people)
   No understanding of own emotions.
   Contact still a bit possible with some reciprocity

3. Severe stage
   Feelings of love and jealousy disappear.
   The only emotions left are lust & displeasure, anger & satisfaction

4. Finally : No more contact with surrounding.
   Emotions and sensations get completely lost
The age of people with dementia in USA

- < 65 yrs: 4%
- 65-74 yrs: 15%
- 75-84 yrs: 44%
- ≥ 85 yrs: 38%

When growing older, sexual behavior tends to change.

- Less performance oriented, more intimacy oriented
- Less penetrative sex, more oral sex
Before the dementia

There is much variety among couples
Some relationships are very close
  with sexuality & intimacy as major contributor to the QoL
Some relationships are rather formal

There is much variety in the moral commitment to promises made
  (‘Till death do us part’)
Some people are (& will stay) intrinsically monogamous
  (even in ‘virtual widowhood’)
Other people need / feel that they deserve a sexual partner
There is much variety in ‘why people and couples have sex?’
(Love; self fulfillment; fun; sharing; physical relief; etcetera)

There can be much difference in the needs of both partners.
(physical needs and / or relationship needs)

One may expect male / female differences

No data were found on separation / divorce and dementia.

• The ‘well-group’
• Community dwelling patients
• Institutionalised patients

Before the dementia
Early-stage dementia

Changes in the relationship
- Problems with changing dependency
- Fights on losing / regaining dependency
These changes can have negative consequences, but also positive consequences in the area of intimacy.

Caring and being cared for can enhance intimacy

Caring and being cared for can destruct intimacy
with frustration, anger and disappointment!

Early-stage dementia

Changes in the relationship
The well partner:
- Complementary roles (included all housekeeping)
- Care for the patient
- Continuously looking after the patient
Causing fatigue → loss of sexual desire


The ‘well-group’
- Community dwelling patients
- Institutionalised patients
Early-stage dementia

Result from focus groups with dementia patients & partners
Dementia caused two distinct different group typologies:

Group 1. Patients / partners were able to develop deeper levels of intimacy (although sexual intimacy diminished). This provided closeness (that many had not had before!)

Early-stage dementia

Group 2. One or both were too devastated by the impact of dementia on their marital relationship. They had not succeeded to develop other means of expressing their love.

NB A good relationship before the start of dementia was not an indicator to arrive in Group 1 or in Group 2!

Early-stage dementia

Regarding sexual behavior (simplified):

**Desire** ? diminished
70% of all patients initiated physical intimate activities!
Satisfaction with intimacy was significantly associated
with fewer stress and depression in female caregivers.

**Orgasm / ejaculation**? : nothing mentioned

**Erection** ? diminished in many men

Both dementia and ED are related to poor-circulation!

- The ‘well-group’
- Community dwelling patients
- Institutionalised patients


I.C.2: Addressing sexuality in the elderly couple

Dementia and Sexuality

16th World Meeting on Sexual Medicine. São Paulo 8-12 October 2014

Woet Gianotten
Later-stage dementia

Gradual changes towards admission in an institution.

Some partners can continue to care at home for a long period without collapsing (too much).

Other partners are less able or have less physical and emotional flexibility and have to accept that the beloved partner is admitted (with additional feelings of guilt → influencing intimacy).

Agitation and aggression were found in 33% in home-dwelling and in 80% in institutionalised patients.

Later-stage dementia

**Partner challenges**

Regarding sexual / intimacy needs
- Does the institution allow physical contact with the patient?

Regarding loneliness (**"Virtual widowhood"**)  
- Regarding sensual / sexual needs (wide variety in needs!)

Developing other relationships?
- (influenced by culture, religion, family and institute)

For some → no option
For others → very relevant to be able to continue visiting the patient
For many → a roller coaster of mixed emotions
Later-stage dementia

**Partner challenges**

Regarding the further deterioration of cognition

- *patient with dementia:* → ‘Who are you?’
- *partner without dementia:* → ‘Is this the one I loved?’

How to deal with ‘inappropriate sexual behavior’ of your partner?

How to deal with his (or her) sexual needs?
(even when realising that it is good for the patient)
Later-stage dementia

Patient problems

Regarding sexual inappropriate behavior?

Much behavior is experienced as sexual, but has nothing to do with sexuality or even sensuality. (forgetting to put on trousers after toilet visit)

Real hypersexuality is rare in demented patients!

Hypersexuality: Inappropriate sexual behavior (ISB).

Observational study in males (60-98 yrs) with dementia

→ 82% never displayed any ISB.

→ When there is ISB, it is mostly brief and minor
Inappropriate sexual behavior

How to deal with behavior when it is disruptive?

Institutions need skills in ‘handling sexuality’
Staff education (both caring and treating staff)
Educating relatives

Part of the behavior is expression of affective needs.
Needs to be touched or held, etc

Very limited information on medicamentous treatment strategies.

- The ‘well-group’
- Community dwelling patients
- Institutionalised patients

Guay DR Am J Geriatr Pharmacother 2008;6:269-88
Appropriate sexual behavior

Sex as a right or sex as a way of care?

Confusing about ‘What is sex?’

Compare little children’s genital play & genital curiosity.

The right to decide? Consent?

Australia, Belgium

The reactions of relatives
‘We need to know what’s going on!’


Bauer M et al. Dementia (London), 2013 March 13
Appropriate sexual behavior

Sex as a way of care?
Limited information on positive effects.
The Eindhoven experience

"an ideological escort agency for psychosocially vulnerable people and psychiatric patients with sexual needs, who have difficulty making contact themselves".

Appropriate sex or abuse?

Most abuse happens by relatives and by staff!

The institute is responsible that there is no abuse.

However, usually more damage is done by preventing physical contact between patients than by preventing abuse!

One cannot eliminate risk, without eliminating the person!
In residential care with dementia patients

"Oh help, I came in the room and two patients were having oral sex! What could I do?"

The young nurse

"Smile, tiptoe away and softly close the door!"

The wise old physician
Challenges for Sexual Medicine?

1. To get geriatry professionals and sexual medicine professionals interested in the later stages of life

2. Do longitudinal research on sexuality / intimacy in patients and partners with dementia (that probably will teach us a lot about the why of sex)

3. Where legally, economically and morally acceptable, investigate the consequences of elements of sexuality / sensuality in the process of care