Experiences of and Coping with severe aortic stenosis among patients waiting for aortic valve implantation

International TVT nurse symposium
Copenhagen 2015

Karin Olsson
Umeå, Sweden
HEART CENTRE

Universitets- och regionsjukhus
Länssjukhus

Norra sjukvårdsregionen
0,9 miljoner invånare

Uppsala-Örebroregionen
1,9 miljoner invånare

Stockholms-Gotlandregionen
2 miljoner invånare

Västra sjukvårdsregionen
1,7 miljoner invånare

Sydöstra sjukvårdsregionen
1 miljon invånare

Södra sjukvårdsregionen
1,6 miljoner invånare
The overall study of patients with severe aortic stenosis

Group 1. **TAVI**
- **n = 24**

Group 2. **AVR**
- **n = 24**

Group 3. **Denied**
- **TAVI/AVR, n = 8 - 10**

- **Day before TAVI/AVR**
- **6 Months after**

- **Interview**
- **Cognitive test (MMSE)**
- **HRQoL (Sf 36 and EQ5D)**
- **Functional test (KATZ ADL)**
- **Symptom - questionnaire**
- **Physical test (6 MWT)**
- **Lab-test (proBNP)**

- **Interview**
- **HRQoL**
- After being informed of not accepted for TAVI
<table>
<thead>
<tr>
<th>Socio-demographics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants, n</td>
<td>24</td>
</tr>
<tr>
<td>Women, n (%)</td>
<td>9 (37)</td>
</tr>
<tr>
<td>Age, yrs mean (SD)</td>
<td>80.7 (7.4)</td>
</tr>
<tr>
<td>Living alone, n (%)</td>
<td>15 (63)</td>
</tr>
<tr>
<td>Home care service, n (%)</td>
<td>3 (12)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>NYHA classification*</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>NYHA-class III Moderate symptoms, n (%)</td>
<td>11 (46)</td>
</tr>
<tr>
<td>NYHA-class IV Severe symptoms, n (%)</td>
<td>13 (54)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Co morbidities</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes, n (%)</td>
<td>5 (21)</td>
</tr>
<tr>
<td>Chronic obstructive lung disease, n (%)</td>
<td>7 (29)</td>
</tr>
<tr>
<td>Prior stroke, n (%)</td>
<td>4 (17)</td>
</tr>
<tr>
<td>Peripheral vascular disease, n (%)</td>
<td>7 (29)</td>
</tr>
<tr>
<td>Myocardial infarction &lt; 3 months before TAVI, n (%)</td>
<td>4 (17)</td>
</tr>
<tr>
<td>Prior bypass graft surgery, n (%)</td>
<td>10 (42)</td>
</tr>
</tbody>
</table>
Experiences of and Coping With Severe Aortic Stenosis Among Patients Waiting for Transcatheter Aortic Valve Implantation

Karin Olsson, RN, MSc; Ulf Näslund, MD, PhD; Johan Nilsson, MD, PhD; Åsa Hörnsten, PhD, RN
Living on the edge, but trying to stay in control

• Trying to cope with symptoms and anxiety
• Trying to preserve self and self-esteem despite life-threatening illness
• Trying to process the decision to undergo TAVI
Trying to cope with physical symptoms and anxiety

Managing symptoms and medication

“And you try to do as much as possible in the morning, because in the evening, when you notice that no, I can’t take any more, then you lie down on the sofa and take a rest.”

“And I have been sitting at the kitchen table falling asleep and tumbling onto the floor. I used to have common chairs and I fell from them, but now I sit in an armchair and I put it close to the table. So when I sit there I can fall asleep in front of the table but I don’t fall down on the floor”.

“It’s that damned peeing, not only at night, the whole day. I take Furosemid, and it’s very troublesome. And there’s no routine in the peeing; it was like hell to get this in my life.”
Adapting physical activities and social circumstances

”I can clean my apartment. Of course, I have to take a break and start again, but it works well. You can’t just sit down; you have to go on doing things. But you can’t work the same way as you did before. Now, it takes a little longer, but you allow yourself that it takes more time”.

”So I have found out that it is much better if I can manage by myself. I choose to sleep in my wheelchair and that has been good for me because when I get problems in breathing I tilt myself backwards and I can do it without asking anyone for help, I can tilt myself, so that has been wonderful”.

”My husband and I, we cooperate with the laundry. I sort the laundry and he hangs it up and takes it down, I iron it and, so far, it works fine, but now, lately, I have quickly become weaker....”
Trying to preserve self and self-esteem despite life-threatening illness

*Managing social limitations by shifting focus*

“I contribute with a minimum, it’s my wife that carries the heavy burdens…”

I read a lot of history. In particular biographies, I have a nice collection of biographies. I don’t read as fast as I used to, it takes more time… I read with more reflection. That gives as much contentment or perhaps more”.* (Man 89 years)

“One of my friends used to, she has a car and she can drive, and sometimes she calls and says, “Come on, let’s go here and there.” And it’s funny, because otherwise I would become crazy. Just sit inside, oh God, how awful. I was never that sort of person”. *(Woman 77 years)*
"I did wrong, of course, and it wasn’t good. I went out last summer as I used to, threw my fishing equipment in the boat and pushed it out. Then I got an attack, I fainted and fell in front of the boat. After that I never took out the boat again, I was so scared”.

"Of course, when you lie awake and feel that you can’t breathe, you get a little worried, it is naturel."

"Yes, when I get these kinds of symptoms it brings some anxiety, and I wonder, ‘What the hell is going on?’ But nothing more, it passes quickly.”
Trying to process the decision to undergo TAVI

*Negotiating and deciding whether to have treatment*

"and yes, at the same time I am very thoughtful over this method that they are going to use, is it reliable? It isn’t so well-tried, it’s not so established this technique to go in from the side and operate…"

“You talk to the children and husband, and I said like this, ‘I don’t want to die on the operating table, my heart can beat as long as it can, and I won’t take any operation,’ but the way I feel today, and like my husband also said, ‘You can’t manage anything.’ I can’t do anything, I have no fortitude. So we decided that I should do this”.

"..."
Living with uncertainty about being accepted for TAVI

“And tomorrow it’s time for the operation, maybe, if I am in condition and there are not a lot of problems so that they won’t be able to operate. I don’t know.”

“The doctors have said that I have to have an operation soon but I got a sort of carbuncle. They treated it with Cortisone but it took a long time to heal, they said four to five months but it became more than a year. And the pump is finished; it’s getting worse and worse, so something has to be done”.
"I went to the district Health Care Centre and they ascertained that I suffered from heart failure and I got Furosemide. That was obviously what they thought should help me. But I wasn’t satisfied with that so I asked the doctor straight out, I started to ask a lot of things. [The doctor answered:] “Yes, you ask so many questions, I have to send you to a specialist.”

“Oh, I feel very safe. To come here and be surrounded by competent people, doing everything they can to make me feel better.”

“I hope that it will go fine, that it will go well, and I think it will because the doctors are skilled, a team of doctors.”
Conclusion

Patients with AS planned for TAVI have to cope with increasing symptoms and limitations in social life, but still wish to be and be seen as the people they were before the illness.

They need more support and guidance from healthcare personnel to process their experiences and feelings, to attach personal meaning to clinical information about their condition and it`s treatment and to use all of these in their decision about whether to undergo TAVI.
Patients’ Decision Making About Undergoing Transcatheter Aortic Valve Implantation for Severe Aortic Stenosis

Karin Olsson, RN, MSc; Ulf Näslund, MD, PhD; Johan Nilsson, MD, PhD; Åsa Hörnsten, RN, PhD
<table>
<thead>
<tr>
<th>Decision-making patterns</th>
<th>Number of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambivalent</td>
<td></td>
</tr>
<tr>
<td>Being unsure of diagnosis and benefits of treatment</td>
<td></td>
</tr>
<tr>
<td>Feeling uncertain about the method</td>
<td>8</td>
</tr>
<tr>
<td>Questioning the physicians’ skills</td>
<td></td>
</tr>
<tr>
<td>Being aware of risks</td>
<td></td>
</tr>
<tr>
<td>Obedient</td>
<td></td>
</tr>
<tr>
<td>Being doubtful of the value of one’s own opinion</td>
<td></td>
</tr>
<tr>
<td>Having a fatalistic view</td>
<td></td>
</tr>
<tr>
<td>Relying on experts</td>
<td>12</td>
</tr>
<tr>
<td>Reconciled</td>
<td></td>
</tr>
<tr>
<td>Having no choice</td>
<td></td>
</tr>
<tr>
<td>Being confident of decision</td>
<td></td>
</tr>
<tr>
<td>Regaining hope</td>
<td>4</td>
</tr>
</tbody>
</table>
Ambivalent

“But I am in full swing doing things, so because of that I wonder if it’s worth the risk to take a chance. I don’t know the outcome of the operation, but it is a difficult operation so sometimes you feel that perhaps you should leave off the whole thing and try to go on living, but when it hurts the most you realize that perhaps this isn’t so funny.” (Man 72 years)
Obedient

“I feel fine. So why I'm here is because my doctor has recommended me. Just therefore!” (Man 87 years)

“I don’t feel anxious about the operation. Either it will go well or it won’t. I hope I will survive and that I won’t have more problems than I have today. Of course, I want to survive, but that isn’t my decision.” (Woman 76 years)
Reconciled

“I think that I do not have so many choices; one is surgery [which I have accepted], another is to stay home and die when you are finished. There are only these two alternatives.” (Man 89 years).

“I am so happy to be here [at the hospital]. I thought that it was over, but my doctor lit a flame of hope. I am now afraid of a delay of surgery, since my days are numbered.” (Man 77 years)
Conclusion

Patients offered TAVI need to discuss the risks and benefits in order to participate in treatment decisions. They have different patterns in the way they make decisions and can be helped if doctors and nurses are aware of this in order to be a support to them in the decision process.
Thank you!