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Being a relative to patients with chronic kidney disease

Experiences of participation in care and treatment

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Aim
To gain insight into and understanding of the needs of the relatives of patients with chronic kidney disease with regard to their ability to provide support in everyday life, and the expectations of the relatives of participation in care and treatment.

Background
Studies concerning the everyday life of patients with chronic kidney disease, and participation in care and treatment have focused on the patients, and not the relatives.
However, relatives share and are affected by the same consequences as the patient with regard to changes in everyday life, roles in the family and mutual relationship.

Method
A qualitative study based on four focus group interviews with four to eight relatives in each group – in total 27 relatives (Table 1). The groups were formed according to the age and gender of the relatives as well as their relation to the adult patient with chronic kidney disease.

Results
The study demonstrated how relatives provide substantial support to the patient both in everyday life and in care and treatment. In relation to the patient, it was a constant challenge for relatives to find the balance between supporting and taking over. They expressed a need for recognition by both the close relations and the health care professionals as well as a need for sharing their experiences with other relatives in the same situation. The analysis identified six themes (Table 2).

Table 1
Overview of the participants related to age, sex and relation to the patient

<table>
<thead>
<tr>
<th>Group A</th>
<th>Group B</th>
<th>Group C</th>
<th>Group D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 18-35</td>
<td>Age 36-50</td>
<td>Age 51-64</td>
<td>Age 65</td>
</tr>
<tr>
<td>Number of participants in the group</td>
<td>8</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Sex</td>
<td>Female</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Relationship</td>
<td>Spouse/cohabitant</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Mother</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daughter</td>
<td>5</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Son</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Friend</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 2
Themes related to experiences of participation in care and treatment

<table>
<thead>
<tr>
<th>Six themes</th>
<th>Theme 1</th>
<th>Different needs and possibilities for support and participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theme 2</td>
<td>Emotional pressure</td>
<td></td>
</tr>
<tr>
<td>Theme 3</td>
<td>Finding balance between disease and everyday life</td>
<td></td>
</tr>
<tr>
<td>Theme 4</td>
<td>Need for regaining energy</td>
<td></td>
</tr>
<tr>
<td>Theme 5</td>
<td>The importance of recognition</td>
<td></td>
</tr>
<tr>
<td>Theme 6</td>
<td>Collaborating with health care professionals</td>
<td></td>
</tr>
</tbody>
</table>

“‘I’ll be there all the way. This sounds as if I never get tired. Of course I get tired – so tired that I feel like screaming and running away, but that is the one thing I would never do.”

wife 68 years

Conclusion
When collaborating with the relatives with regard to care for patients with chronic kidney disease, the health care professionals should actively recognize the patient support that the relatives already provide in everyday life. Initiatives of participation in care and treatment should be based on collaboration and the needs, expectations and possibilities of both the patient and the relatives.

References

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