



Family members' experiences of the healthcare professionals' approach and feeling of alienation in different health care areas: a methodological and empirical study

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#### Content

- The Family Involvement and Alienation
  Questionnaire
- Aim, design and method
- Results interviews





# The Family Involvement and Alienation Questionnaire (FIAQ)

What's that?





Background

Family members' experience of participation in professional care





#### What limits participation in care?

Family members:

- The professionals approach and lack of information
- Feelings of alienation
  - Powerlessness
  - Social isolation





## Developing the concept of family involvement and the alienation questionnaire in the context of psychiatric care

Ewertzon, M., Lützén, K., Svensson, E. & Andershed, B. (2008) International Journal of Mental Health Nursing, 17 (6), pp. 439-449





#### Experience of approach

Respectful approach:

- Openness
- Confirmation
- Cooperation

(Andershed & Ternestedt 2000, 2001)





#### Feeling of alienation

- Powerlessness
- Social isolation

(Seeman 1972, 1976)





#### Research questions:

- Describe family member's experiences of the professionals approach
- Describe what family member's consider as important in the professionals' approach
- *Describe* family member's feeling of alienation from the provision of care
- Describe *association* between their experiences of approach and feeling of alienation
- Describe the level of agreement between their experiences and what they consider as important



#### Further development of the FIAQ

Adapt and develop FIAQ to other care areas: Elderly care, Palliative care and Diabetes care.





#### Aim

- To develop FIAQ to other care contexts than psychiatric:
  elderly, palliative and diabetes care.
- To test validity and reliability of the new FIAQ instrument.





#### Aim cont.

To investigate family members' experiences of the contact with health care professionals in caring of persons with complex needs within psychiatric, elderly, palliative and diabetes care.





#### Method of methodological study

Step 1:

Expert panel discussion  $\implies$  new FIAQ with 33 questions

Added the dimension "continuity"





#### Method cont.

#### Step 2:

## Interviews with family members (13 women and 2 men)







#### Alienation

#### Not relevant in palliative and diabetes care





#### Method Step 3

- Mail/give out of 200 FIAQ(R) / care context
- Test-retest questionnaires

Data collection during 2015.





Conclusion

• The interviews with the family members gave rich information for the development of the FIAQ instrument.





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#### **Experience of Approach**

- Openness is characterised by the family members' experience of sincere information about the patient's state of health. They experience that the psychiatric health-care professionals explain the situation so they could deal with the situation.
- Confirmation is characterised by the family members' experience that the psychiatric health-care professionals see and listen to them as important persons. They experience that the professionals welcome them and care about who they are.
- Co-operation is characterised by the family members' experience that the psychiatric health-care professionals value them and their opinions as important.





## **Feeling of Alienation**

- Powerlessness is characterised by the family member having a sense of low expectancy that his or her own behaviour can control events in the care of the patient; there are others who decide. The family member has a sense that he or she does not have any influence over the care the patient receives.
- Social isolation is characterised by the family member having a sense that he or she is excluded or rejected from the care of the patient.