



**Karolinska  
Institutet**

**Institutionen för neurobiologi, vårdvetenskap och samhälle**

# **Dementia in Iran and Sweden: Experiences of persons with dementia and family members**

**AKADEMISK AVHANDLING**

som för avläggande av medicine doktorsexamen vid Karolinska Institutet offentligen försvaras i Hörsal 2 (Grön), Zanderska huset, Alfred Nobels allé 23, Huddinge

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av

**Monir Mazaheri**

BScN, RN, MScN

*Huvudhandledare:*

Docent Lars E. Eriksson  
Karolinska Institutet  
Institutionen för neurobiologi, vårdvetenskap och samhälle

*Bihandledare:*

Professor Sirkka-Liisa Ekman  
Karolinska Institutet, Institutionen för neurobiologi, vårdvetenskap och samhälle

Dr. Helena Sunvisson  
Örebro university  
Institutionen för hälsovetenskap och medicin

Dr. Kristiina Heikkilä  
Karolinska Institutet, Institutionen för neurobiologi, vårdvetenskap och samhälle

Dr. Sadat S.B. Maddah  
University of Social Welfare and Rehabilitation Sciences, Nursing Department, Tehran

Professor Alireza Nikbakht Nasrabadi  
Tehran University of Medical Sciences, School of Nursing & Midwifery

*Fakultetsopponent:*

Professor Kenneth Asplund  
Mittuniversitetet  
Institutionen för hälsovetenskap

*Betygsnämnd:*

Professor Karin Axelsson  
Luleå tekniska universitet  
Institutionen för hälsovetenskap

Professor Johan Lökk  
Karolinska Institutet  
Institutionen för neurobiologi, vårdvetenskap och samhälle

Docent Barbro Wadensten  
Uppsala Universitet  
Institutionen för folkhälso- och vårdvetenskap

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## **ABSTRACT**

The overall aim of this thesis was to explore the experiences of dementia from the perspective of Iranian people with dementia and their family members in Iran and Sweden. The thesis consists of four exploratory studies with qualitative approaches.

Two qualitative approaches, interpretive phenomenology (studies I and II) and qualitative content analysis (studies III and IV), were employed to conduct the studies in urban areas of Sweden (studies I and III) and Iran (studies I and IV). A total of 50 people participated in the studies, 28 female and 22 male, ranging in age from 26 to 88 years old. Participants were people with dementia (studies III-IV) and family members of people with dementia (studies I and II). All data was collected through semi-structured interviews, transcribed verbatim, and analysed with Benner's interpretative phenomenology (studies I and II) and qualitative content analysis (studies III and IV), respectively.

The results revealed that Iranian immigrant family members of people with dementia in Sweden (study I) experienced caring as one of fulfillment. They had difficulties in accepting the diagnosis of dementia of their family member. The shock of not being recognised by their family members with dementia was the turning point for them to accept the situation. Family members who lived with their next of kin with dementia in Iran (study II) described their concerns of losing a sense of togetherness, a sense of future, and social dignity. They created meanings through submission to fate and striving to look on the bright side, in order to make sense of their changed lives. The subjective experiences of living with dementia for Iranian immigrants in Sweden (study III) meant living with forgetfulness, feeling incompetent but still loved, and feeling confident and secure in society but also isolated. Living with dementia in Iran (study IV) was experienced as struggling with an altered life, which included becoming an altered self in the eyes of others, forgetfulness as an irritating condition, being a burden on others, longing to be a valued person, and finding strategies to deal with dementia.

Difficulties in accepting the diagnosis of dementia was beyond participants' cultural background or poor awareness of dementia but it seemed to be mainly related to their life' histories. People should be approached individually for comprehending their personal reasons and motives for resisting diagnoses or medical care. Family members need to learn how to interact with their relatives with dementia with respect and dignity. Nurses can help reconstruct families' broken life stories and recommence an effective connection between families and people with dementia. By gaining insight into the concerns and experiences of people with dementia and their families, nurses can meet them where they are in their unique contextual situation. Therefore, nurses can help people with dementia and their families obtain a meaningful life.

**Key words:** dementia, experience, immigrant, interpretive phenomenology, Iran, qualitative study, qualitative content analysis, Sweden

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