CHAPTER 2

LITERATURE REVIEW

2.1. Concept of Disease

2.1.1. Understanding Dementia

Dementia is a syndrome characterized by a decline in cognitive functions, including memory, thinking, orientation, comprehension, learning ability, language, and judgment, which interferes with daily life activities. According to the World Health Organization, dementia is a syndrome caused by various diseases that affect the brain and cause cognitive decline beyond the normal aging process (WHO, 2025).

According to the American Psychiatric Association (2022), dementia is included in Major Neurocognitive Disorder which is characterized by a decline in cognitive abilities.gnitive so that it interferes with individual independence in daily activities.

2.1.2. Etiology

Causes of dementia include:

- Alzheimer's disease
- Vascular dementia
- Lewy Body Dementia
- Frontotemporal dementia
- Parkinson's disease

- Head injury
- Central nervous system infection

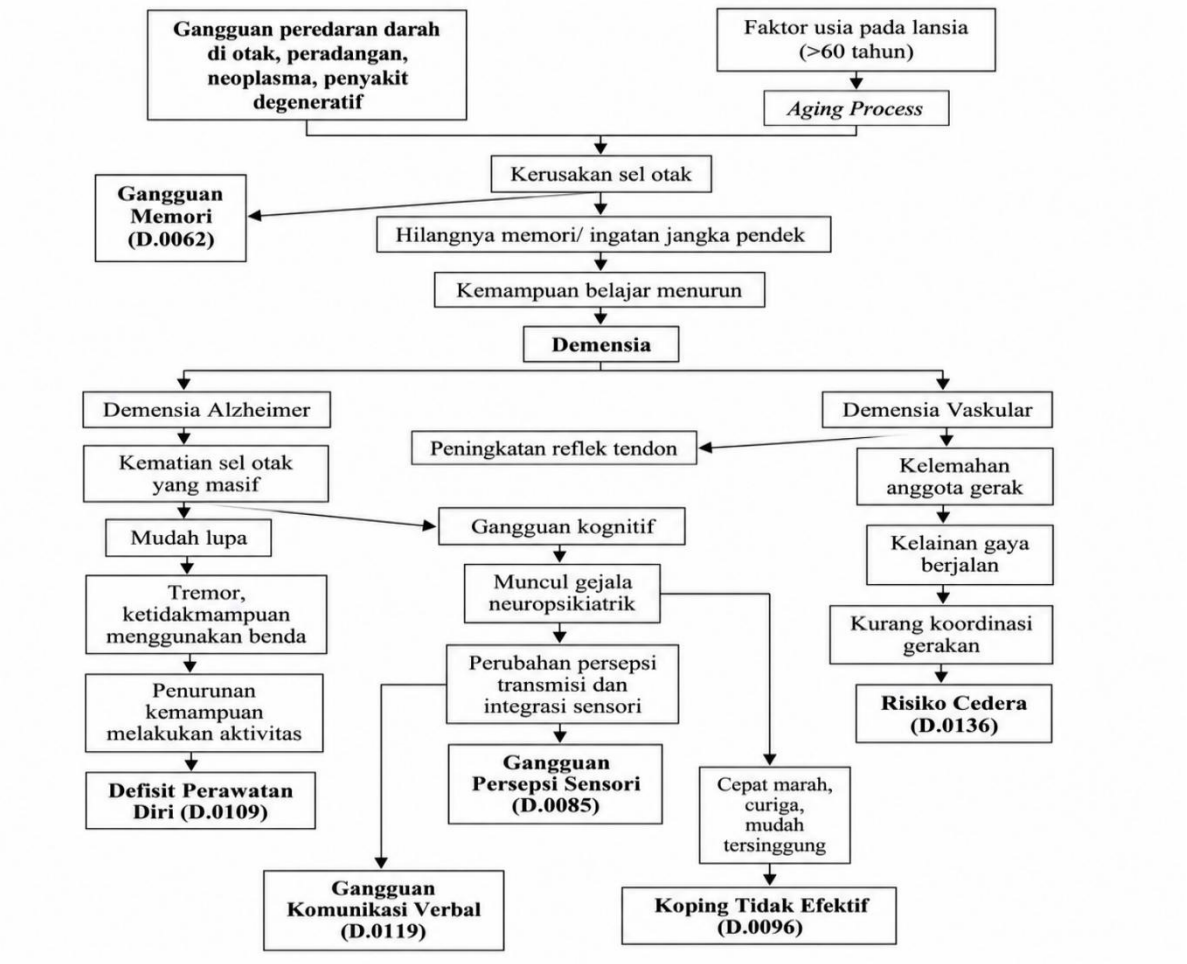
2.1.3. Clinical Manifestations

Dementia affects each person differently, depending on the impact of the disease and the individual's personality when they become ill. Signs and symptoms associated with dementia can be understood in three stages (WHO, 2020):

1. Early Stages: The early stages of dementia are often missed because they are gradual. Common symptoms include:
    - Easily forgetting recent events
    - Forgetting the time
    - Lost in a familiar place
2. Middle stage: As dementia progresses into the middle stage, signs and symptoms become more pronounced and more limiting. These include:
    - Becoming forgetful of recent events and people's names
    - Lost at home
    - Experiencing increasing communication difficulties
    - Need help with personal care
    - Experiencing changes in behavior, including asking repeated questions
3. The Final Stage is one of almost total dependence and inactivity.

- Becoming unaware of time and place
- Having difficulty recognizing relatives and friends
- Have an increased need for assisted self-care
- Having difficulty walking
- Experiencing behavioral changes that may become escalating and aggressive

2.1.4. Pathway



2.1.5. Medical Management

1. Special Therapy

There are several therapies that can be carried out to treat the symptoms and behavior that arise due to dementia, namely:

1) Cognitive Stimulation Therapy aims to stimulate memory, problem-solving skills, and language skills, by carrying out group activities or sports.
2) Occupational therapy aims to teach sufferers how to carry out daily activities safely according to their condition, as well as teaching them how to control their emotions when dealing with developing symptoms.
3) Memory Therapy is useful for helping sufferers remember their life history, such as their hometown, school days, work, and hobbies.
4) Cognitive rehabilitation aims to train the dysfunctional parts of the brain to use the healthy parts. This technique involves working with trained professionals, such as occupational therapists, and family or friends.

2. Family Support

3. Drugs

Several types of drugs that can be used to treat symptoms dementia are acetylcholinesterase inhibitors, memantine, antianxiety,

antipsychotics, and antidepressants.

4. Operation

Dementia can be treated with surgery if it is caused by a brain tumor, brain injury, or hydrocephalus. Surgery canhelps restore symptoms if there is no permanent damage to the brain (Willy, 2019).

2.2. Family Concept

2.2.1. Definition of Family

A family is two or more people who live together because of blood relations, marriage, or adoption who interact with each other and carry out their respective roles.

According to Kaakinen etal. (2022), family is a social system consisting of individuals who are interdependent and work together to fulfill the physical, psychological, social, spiritual, and health needs of family members.

2.2.2. Family Functions

The family is the smallest unit in society and plays a vital role in maintaining, preserving, and improving the health of its members. According to Friedman, Bowden, and Jones (2019), family functions consist of five interrelated primary functions:

1. Affective Function
2. Socialization function
3. Reproductive Function

4. Economic Function
5. Health Care Functions

2.2.3. Family Health Tasks

According to Friedman (2019), families have five family health tasks which are indicators of the family's ability to manage health problems.

1. Understanding Family Health Problems
2. Making Health Action Decisions
3. Caring for a Sick Family Member
4. Creating a safe environment
5. Utilizing Health Service Facilities

2.2.4. The Role of Family Nurses

Family nurses are professionals who provide nursing services to individuals, families, groups and communities with the main focus of improving the family's ability to maintain health and overcome health problems experienced by family members.

According to Kaakinen et al. (2022), family nurses act as facilitators who help families improve their ability to carry out family health functions and tasks so they can achieve optimal health levels.

In the case of families with family members suffering from dementia, the role of family nurses is very important because the family is the primary caregiver responsible for the patient's daily care.

2.3. The Concept of Family Nursing Care for Dementia Patients

2.3.1. Focus of Study

1) General data

a. General family data

Includes family card name, age, gender, education, occupation, address, telephone number, and family composition. Family composition describes the family members identified as part of their family.

b. Genogram

A family genogram is a diagram that depicts a family tree. It contains information about three generations of the family (the nuclear family and the families of each parent).

c. Family Type

Explaining family types and the obstacles regarding these types of families or problems that occur with traditional and non-traditional family types.

d. Tribes

e. Religion

f. Social and economic status

g. Family recreational activities

2) Family History and Stages of Family Development

a. Current stage of family development

   Can be determined by the eldest child of the nuclear family

b. Unfulfilled stages of family development

   Explains the obstacles that prevent family development tasks from being fulfilled and the obstacles to why these development tasks have not been fulfilled.

c. Nuclear family health history

   This includes a history of hereditary diseases, diseases that other family members have suffered from, especially infectious diseases, infections or immune disorders, as well as activities carried out that make the body feel tired and weak.

d. Family health history

   Includes a history of illnesses suffered by the client's family, both related to the illness suffered by the client, as well as other hereditary and infectious diseases.

3) Environmental data

   Which includes the characteristics of the house, the house plan, the characteristics of the environment and community, the geographical mobility of the family, family gatherings and interactions with the community, as well as the family's support system/social network.

4) Family structure

a. Role structure

Explain the role of each family member.

b. Family values or norms

Knowing the values and norms adopted by the family regarding their health.

c. Family communication patterns

Identify ways of communicating between family members.

d. Family power structure

The ability of family members to control and influence others to change behavior.

5) Family functions

a. Affective function

Things that need to be studied are how far the family cares for and supports each other, has good relationships with others, shows empathy, and pays attention to feelings.

b. Socialization function

It examines interactions or relationships within the family, the extent to which family members learn discipline, rewards, punishments as well as giving and receiving love.

c. Nursing function

- Health beliefs, values, and behaviors explain the values held by the family, the prevention and health promotion carried out and the family's health goals.
- Family health status and perceived susceptibility to illness: the family assesses health status, health problems that make the family vulnerable to illness and the number of health checks.
- Family dietary practices involve knowing the sources of food consumed, how to prepare food, the amount of food consumed per day and the habit of consuming snack foods.
- The role of the family in self-care practice is the actions taken to improve health status, disease prevention, family care at home and family beliefs in home care.
- Medical preventive measures include the child's immunization status, dental hygiene after eating, and family patterns of food consumption.

d. Reproductive function

Things that need to be studied regarding the reproductive function of the family are: how many children, what family plans are related to the number of family members, and the methods used by the family in an effort to control the number of family members (Putri, 2021).

e. Economic function

This data explains the family's ability to meet the needs of clothing, food, shelter, savings, and the ability to improve health status.

a. Stress and coping

Review short-term stressors that require less than 6 months to resolve, long-term stressors that require more than 6 months to resolve, the family's ability to respond to stressors, the coping used, and the dysfunctional adaptation strategies used to deal with problems.

b. Physical examination

In addition, a physical examination was performed on all family members. The methods used in the physical examination were similar to those used in a clinic. At the end of the assessment, the family's expectations were assessed by asking about the family's expectations of the healthcare providers.

2.3.2. Nursing Diagnosis

A nursing diagnosis is a clinical assessment of a family's response to a health problem experienced by a family member. In families with dementia, the following diagnoses are often present:

1. Ineffective Family Health Management (SDKI D.0115)

Related to the family's inability to care for a family member with dementia.

1) Major Data

Table 2.1 Major Data

Subjective	Objective
1. The family expressed that they did not understand the health problems experienced by their family members.	1. Symptoms of a family member's illness are getting worse
2. The family expressed difficulty in carrying out the prescribed treatment.	2. Family activities to address health problems are inappropriate
3. Families say they don't know how to care for family members with dementia.	3. The family failed to take action to reduce health risk factors.

2) Minor Data

Table 2.2 Minor Data

Subjective	Objective
1. Families say they have difficulty making decisions regarding their family members' health care.	1. The family is unable to provide care for family members who have health problems.
2. The family said they needed help in managing the health conditions of family members.	2. Family behavior does not comply with the recommended health program.
3. The family said they did not understand the use of health services.	3. The family does not make environmental modifications that support the health of family members.

2.3.3. Nursing Interventions

In the implementation plan, the assessment categorizes subjective and objective data. Then, potential problems and their causes are analyzed.

Table 23Nursing Interventions

Diagnosis (SDKI)	Output (SLKI)	Intervention (SIKI)
D.0115– Ineffective Family Health Management due to the Family's Inability to Care for Family Members with Dementia **DS :** - Families say they don't know how to care for family members with dementia.	Family Health Management (L.12137) After nursing intervention for … x 24 hours, family health management improved, with the following outcome criteria: 1. Ability to explain problems Health experienced improved 2. Family activities to overcome Health problems are on the rise.	**Family support in planning care (1,13477)** **Observation** 1. Identify family needs and expectations regarding health 2. Identify the consequences of not doing it family action 3. Identify the resources available family 4. Identify actions that can be taken Family

- The family said they were confused about the patient's behavioral changes. **DO :** - The family is unable to explain again about dementia disease. - The family seemed confused when asked about patient care. - The patient looks poorly cared for.	3. Verbalization of difficulty performing prescribed care increase. 4. Symptoms of Family Members' Illnesses Decrease.	**Therapeutic** 5. Motivation to develop attitudes and emotions that support health efforts 6. Use the means and facilities available in the family 7. Create optimal changes to the home environment 9. Facilitate families in preparing a Family Self Management Plan (FSMP) **Education** 9. Provide information about health facilities in the family environment. 10. Explain about Family Self Management Plant (FSMP) 10. Recommend using existing health facilities 11. Teach care methods that families can do.

2.3.4. Nursing Implementation

Nursing implementation is the implementation stage of the nursing process carried out by nurses based on an intervention plan that has been prepared to help patients, families, or communities achieve predetermined health goals.

According to Potter & Perry (2021), nursing implementation is the fourth stage in the nursing process which includes carrying out nursing actions according to the plan that has been made based on the needs of the patient and family.

According to PPNI (2022), nursing implementation is a series of activities carried out by nurses to implement nursing interventions based on the Indonesian Nursing Intervention Standards (SIKI) with the aim of achieving the outcomes specified in the Indonesian Nursing Outcome Standards (SLKI). The implementation of the SDKI, SLKI, and SIKI standards is used as a guideline to make the nursing care process more systematic, structured, and measurable.

In family nursing, implementation is not only aimed at patients, but also involves the family as the main support system in health maintenance.

The implementation of nursing care for families with the inability to care for family members with dementia is carried out by implementing nursing interventions based on the Indonesian Nursing Intervention Standards (SIKI), including providing health education about dementia,

increasing the family's ability to recognize health problems, helping families prepare care plans through the Family Self Management Plan (FSMP), providing support in decision-making, increasing the family's ability to care for family members, and providing coping support in dealing with changes in the health conditions of family members.

The intervention is implemented in stages through a Family Empowerment Strategy approach, actively involving the family in the care process. Nurses act as educators, facilitators, and advocates to improve the family's knowledge, skills, and independence in managing the health of family members with dementia. The success of implementation is evaluated based on the achievement of nursing outcomes according to the Indonesian Nursing Outcome Standards (SLKI), namely increasing the family's ability to manage health problems, provide care, and utilize available health care resources.

2.3.5. Nursing Evaluation

Nursing evaluation is the final action in the nursing care process. Evaluation can be in the form of an evaluation of structure, process, and results (Tarwoto, 2015). Nursing care evaluation is documented in the form of SOAP (Sumadi Kaize & Dwi Ningsih, 2022):

1. S (subjective), when the nurse encounters patient complaints that are still felt even though nursing actions have been carried out.
2. O (objective), data obtained from observations based on the results of evaluations of actions that have been carried out, measurements carried

out by nurses are based on direct observation of patients and what patients feel after treatment is carried out.

3. A (assessment), namely subjective and objective data to assess the extent to which goals have been achieved.
4. P (Plan), which is an action plan based on analysis, if the goal is achieved, the nurse stops the plan, if the goal is not achieved, the nurse changes the plan and continues the patient care plan. This evaluation is usually called an evaluation.

Nursing evaluation in families with problems of Ineffective Family Health Management, Knowledge Deficit, and Ineffective Individual Coping is carried out by looking at the achievement of nursing outcomes based on the Indonesian Nursing Outcome Standards (SLKI) after interventions are given according to the Indonesian Nursing Intervention Standards (SIKI).

In the case of Ineffective Family Health Management, evaluation is carried out by assessing the improvement of the family's ability to manage health problems, including the ability to explain the health conditions of family members, determine appropriate treatment measures, carry out independent treatment, modify the environment, and utilize health service facilities.

Furthermore, an evaluation of the implementation of the Family Empowerment Strategy through the Family Self-Management Plan

(FSMP) was conducted by assessing increased family involvement in the care process, increased family self-confidence, and the family's ability to develop and implement care plans independently. The evaluation results were compared with the SLKI outcome indicators to determine whether nursing goals had been achieved, partially achieved, or intervention modifications were needed.

2.4. Family Empowerment Strategy Concept

2.4.1. Definition of Family Empowerment

Family Empowerment is a process aimed at improving the ability, knowledge, skills, self-confidence, and active participation of families in identifying health problems, making decisions, and carrying out independent care to achieve optimal health. Through empowerment, families become not only recipients of information, but also active partners in the care of sick family members. In the context of family nursing, family empowerment is an approach that focuses on strengthening the family's capacity to manage health problems, utilize available resources, and improve the quality of life of family members being cared for.

According to Yoon and Kim (2020), empowerment of family caregivers is the process of increasing the family's ability to understand care situations, develop caregiving skills, increase self-efficacy, and adapt positively to the demands of caring for family members with dementia.

2.4.2. Definition of Family Empowerment Strategy

Family Empowerment Strategy is a strategy or approach to family empowerment designed to improve the family's ability to manage health problems through increasing knowledge, skills, active participation, decision-making, and self-efficacy so that the family is able to carry out care independently and sustainably.

The Family Empowerment Strategy places the family at the center of care (family-centered care) and partners with healthcare professionals in the health care process for family members. This strategy is implemented through education, skills training, mentoring, emotional support, and family involvement in every decision-making process related to the health of a sick family member.

According to the World Health Organization (WHO), family empowerment is a process that allows individuals and families to gain greater control over decisions and actions that affect their health. Through empowerment, families can improve their ability to recognize health problems, determine appropriate actions, and utilize available health resources.

In the context of caring for dementia patients, the Family Empowerment Strategy aims to help families increase their understanding of dementia, develop daily care skills, address patient behavioral issues, reduce the burden on caregivers, and improve the quality of life of patients and their families.

2.4.3. The Purpose of Family Empowerment Strategy

The goal of the Family Empowerment Strategy is to improve the family's ability and independence in carrying out their role in caring for their members through increased knowledge, skills, active participation, and informed decision-making. This strategy helps families become more confident and able to manage health issues independently, thereby improving the quality of life for patients and their families. Specifically, the goals of the Family Empowerment Strategy include:

1. Improving Family Knowledge
2. Improving Family Care Skills
3. Increasing Family Self-Efficacy (Confidence).
4. Increasing Active Family Participation
5. Improving Decision Making Skills
6. Reducing Caregiver Burden
7. Improving the Quality of Life of Patients and Families

2.4.4. Theoretical Basis of Family Empowerment Strategy

a. Empowerment Theory

Empowerment theory explains that individuals and families have the potential to thrive if they receive adequate information, support, opportunities, and skills. Empowerment aims to increase families' ability to identify problems, make decisions, and act independently to maintain their health.

In the Family Empowerment Strategy, the concept of empowerment is realized through the provision of education, skills

training, mentoring, and evaluation so that families become more confident in managing health problems.

b. Friedman's Family Nursing Theory

According to Friedman, the family is a nursing service unit that has a primary function in maintaining the health of its members.

The five tasks of family health according to Friedman include:

1. Get to know health problems.
2. Making decisions about health actions.
3. Taking care of family members.
4. Modifying the environment.
5. Utilizing health service facilities.

The Family Empowerment Strategy is designed to improve the family's ability to carry out these five tasks, making it very suitable for application in the diagnosis of Ineffective Family Health Management.

c. Relationship with SDKI–SLKI–SIKI

The SDKI diagnosis of Ineffective Family Health Management indicates that the family has not been able to manage the health problems of family members optimally.

Through the Family Empowerment Strategy, families gain:

1. increase in knowledge,

2. skill improvement,
3. increased decision-making ability,
4. increased ability to perform maintenance,
5. increasing the ability to utilize health services,

which is then measured using the SLKI Improved Family Health Management indicator and implemented through the SIKI Health Education, Decision Making Support, Family Support, and Coping Promotion interventions.

2.4.5. Family Empowerment Strategy Components

The Family Empowerment Strategy in this study consists of six main components.

1. Family Assessment

The nurse conducts an assessment regarding:

- family capabilities,
- knowledge,
- care experience,
- obstacle,
- family support,
- family needs.

This component aims to identify the initial conditions of the family.

2. Family Education

Nurses provide health education regarding:

- disease,
- reason,
- signs and symptoms,
- complications,
- treatment,
- how to care for it,
- prevention of complications,
- utilization of health services.

This component aims to increase family knowledge.

3. Family Skills Training

Nurses train families about:

- therapeutic communication,
- techniques to help with daily activities,
- injury prevention,
- monitoring patient condition,
- providing psychological support.

This component aims to improve family skills.

4. Family Decision Making

Nurses facilitate families in:

- determine the primary caregiver,
- division of family tasks,
- determine the control schedule,
- determine actions when health problems occur.

This component aims to improve the family's ability to make decisions.

5. Family Self Management Plan (FSMP)

The nurse and family develop a care plan that includes:

- medication schedule,
- control schedule,
- daily activities,
- health targets,
- Division of tasks,
- health monitoring.

This component aims to improve families' ability to manage their health independently.

6. Monitoring and Evaluation

The nurse evaluates:

- increase in knowledge,
- skills,
- compliance,
- implementation of FSMP,
- ability to carry out five family health tasks.

Monitoring is carried out periodically to maintain changes in family behavior.

2.4.6. Evidence Based Family Empowerment Strategy

Various studies have shown that family empowerment-based interventions are effective in improving caregivers' abilities in caring for family members with dementia.

Research by Yoon and Kim (2020) developed an empowerment program for family caregivers of dementia patients, including intensive counseling, health education, mentoring, and telephone follow-up over 12 weeks. The results showed significant improvements in caregiver self-efficacy, caregiving attitude, caregiving appraisal, and well-being compared to the control group.

A meta-analysis by Teahan et al. (2020) concluded that psychosocial interventions including education, skills training, emotional support, and family mentoring effectively enhance caregivers' ability to care for dementia patients and improve various psychosocial outcomes.

Furthermore, a systematic review by Leng et al. (2020) showed that supportive interventions for family caregivers can reduce depression, anxiety, and stress, and increase caregiver self-efficacy, which is a key component of family empowerment.

Based on this evidence, the Family Empowerment Strategy in this study was designed as an intervention package that integrates family assessment, health education, skills training, decision-making assistance, preparation of a Family Self-Management Plan, monitoring, and evaluation to improve the family's ability to manage health problems so that it is suitable for application to families diagnosed with Ineffective Family Health Management.