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## Collaborative partnership between family caregivers and nurses in the care of older hospitalized persons

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# CHAPTER 1

## General introduction

Informal caregiving by family members of older home-dwelling persons is currently intensifying in the context of an aging population and health care reforms. Globally, the number of older people in society is increasing and, correspondingly, the number of people with chronic conditions.<sup>1</sup> In 2016, the global and European Union life expectancy was 72 years<sup>2</sup> and 81 years<sup>3</sup>, respectively, and is expected to increase to 86 years in 2040 in the European Union. In addition, greater numbers of older people will live independently and, more often, will be alone.<sup>4</sup> As long-term care in the Netherlands was reformed in 2015 in order to contain costs but also to deinstitutionalize this care, citizens are now expected to take on more responsibilities and organize their own social safety nets by activating their informal networks.<sup>5</sup> Due to these policy changes, home care support after discharge out of the hospital is not automatically provided, and family caregivers are expected to take over more caring responsibilities. These social developments lead to an increasing emphasis on the self-care of older persons and, consequently, their family caregivers. Support by health professionals such as nurses is almost always temporary and additional in nature. From this viewpoint, patients, families, and nurses should collaborate in order to provide optimal patient care.

### **Role of family caregiver**

When supported by family caregivers at home, older persons are better at managing their chronic conditions and related life style instructions.<sup>6-10</sup> A family caregiver is someone who is important for older persons' informal support at home and identified as such by these persons themselves. They can be a partner, other family members, friends, neighbors, etc. Currently, 18% of the total population in the Netherlands provides some form of informal care.<sup>11</sup> In one of the typical three major roles: providing care to the older person at home, working together with the health care team, and taking care of themselves,<sup>12</sup> family caregivers can be considered an expert of the older person's needs, and they play an active role as an advocate and intermediate between that individual and health care professionals.<sup>13-15</sup> Due to changes in legislation, the role of family caregivers has changed to such an extent that they now form part of the health care system as informal partners in the care of older persons.<sup>16</sup>

### **When an older person is admitted to the hospital**

Older persons are more frequently hospitalized for diagnostics or due to the consequences of their chronic illness.<sup>1</sup> In general, the length of the hospital stay is becoming briefer and, accordingly, these people may not achieve a secure health status before being discharged. Correspondingly, the care and support provided by family caregivers have become more

complex and often result in greater demands when the patient is discharged back to their home.<sup>17</sup> When caregivers are insufficiently acknowledged and involved, discontinuity can arise between the care that was provided prior to a hospital admission and following discharge. This can lead to family caregivers who feel unprepared for caregiving at home and, consequently, have an increased risk of physical and or psychological stress.<sup>18,19</sup> Therefore, the continuity of care of older people before and after hospitalization is at risk when nurses do not sufficiently acknowledge family caregivers as partners in care during the hospital admission.<sup>20</sup>

### **Collaborative partnership**

As shown in Figure 1, it can be expected that, when nurses collaborate (III) with family caregivers of older patients as partners in care, it will have a positive effect on family caregivers' preparedness for caregiving (IV) after the individual is discharged from the hospital. Figure 1 also shows that, in order to develop a collaborative partnership with family caregivers, nurses must first view family caregivers as important for the patient's nursing care (I) and, secondly, assess the supporting role (II) of the family caregiver of the older hospitalized person. A collaborative partnership between nurses and family caregivers develop sequentially in three phases: involvement, collaboration, and empowerment (ICE) in which collaboration requires a more active role of nurses and has a more reciprocal character than involvement and empowerment.<sup>21</sup>

### **Nurses' attitudes toward the importance of family caregivers**

A first step towards the involvement of family caregivers are nurses' attitudes regarding the importance of families in nursing care, as shown in Figure 1 (I), because nurses who have a more positive attitude towards involving families as partners in care are more likely to do so.<sup>22,23</sup> To date, nurses' attitudes have not yet been determined in this context in the Netherlands. A widely used instrument to do so is the Families Importance in Nursing Care-Nurses Attitudes (FINC-NA).<sup>24,25</sup> This originally Swedish instrument is not available in Dutch thus, in order to measure nurses' attitudes, the FINC-NA scale will first need to be translated and psychometrically evaluated in Dutch.



## **Collaboration between family caregivers and nurses**

An important step in the process towards an effective partnership between nurses and family caregivers is the perceived collaboration between family caregivers and hospital nurses, as shown in Figure 1 (III). Collaboration between family caregivers and nurses in the hospital becomes more important as family caregivers increasingly take care of older persons with chronic conditions in the home situation. It is considered a professional responsibility for nurses to collaborate with patients and their families to strengthen self-management of older people in their social context when possible.<sup>28,29</sup> Collaboration is defined as nurses who are responsible for the daily nursing care proactively initiate contact with family caregivers of older patients and actively involve them in a process of information exchange and joint decision-making as partners in care. Current research on collaboration between family caregivers and nurses lacks a specific focus on how family caregivers perceive their collaboration with nurses in order to formulate areas of improvement. To describe family caregivers' perceived level of collaboration with nurses, a valid instrument is needed. The Family Collaboration Scale (FCS) measures this, however, the scale has a broad scope.<sup>30</sup> In order to measure collaboration only, a more specific scale needs to be constructed.

## **Family caregivers' preparedness for caregiving**

When nurses collaborate with family caregivers as partners in care, it is expected to have a positive effect on caregivers' preparedness for caregiving, as shown in Figure 1 (IV) and, consequently, the quality and continuity of care that is offered before and after the hospital admission.<sup>31,12</sup> Preparedness for caregiving can be defined as how well prepared the family caregiver believes him or herself to be for the tasks and stress of the caregiving role.<sup>18</sup> Thus far, no studies on the association of collaboration between family caregivers and nurses in the hospital and their preparedness for caregiving at home were found.

It is evident that the role of family caregivers for older home-dwelling persons is becoming increasingly important. However, there is limited knowledge on how nurses work with family caregivers of older hospitalized persons in their daily nursing practice to prepare family caregivers for this role. Therefore, the aim of this thesis is to gain insight into collaborative partnerships between family caregivers and nurses in the care of older home-dwelling persons who are admitted to the hospital in order to formulate areas of improvement.

This thesis contains the following research questions:

1. What are the psychometric properties of the Dutch Families' Importance in Nursing Care: Nurses' Attitudes scale'? (Chapter 2)
2. What are Dutch nurses' attitudes towards the importance of families in nursing care? (Chapter 3)
3. What aspects of family caregiving are addressed during planned discussions between nurses, patients and family caregivers in the hospital? (Chapter 4)
4. To construct and psychometrically evaluate a Family Collaboration Scale that is focused on collaboration only (Chapter 5).
5. To what extent do family caregivers of older hospitalized patients perceive collaboration with hospital nurses? (Chapter 6)
6. What is the unique contribution of collaboration between family caregivers of older patients and hospital nurses as a possible predictor for preparedness of caregiving after hospital discharge? (Chapter 7)

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