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### Wachten op opname. Hantering van de wachtlijst voor verpleeghuisopname en de gevolgen voor personen met dementie en hun mantelzorgers

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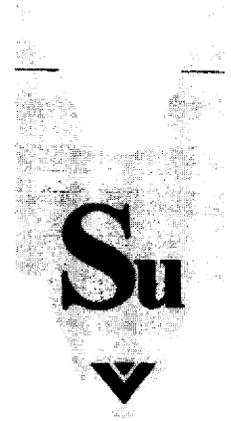
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## Summary

Waiting lists for scarce health care services have been actively discussed in recent years. One of the waiting lists that has been and still is high on the political agenda is the one for psychogeriatric nursing home care. In 1991, at the start of the first study described in this thesis, discussion was focussed on fair patient selection for health care services and whether waiting lists could be used for such selection. Soon after, a debate arose on the problematic features of waiting time. After all, even though waiting lists are necessary as a management tool to plan admissions and for the individuals preparing themselves for admission to a nursing home, waiting time becomes problematic when it lasts longer than is considered acceptable. This is the case when a reasonable time frame has passed or when waiting causes a deterioration in health. Both of these topics, i.e., the procedures and criteria that are used in selecting patients for nursing home admission and whether or not waiting times are problematic, are discussed in this thesis. Three studies were conducted to investigate these topics.

The first study involved a qualitative investigation of the procedures and criteria of managing a waiting list for psychogeriatric nursing home admission. It was part of a larger study on Selection and Waiting Lists in Health Care (1991-1994). The second study was a files study of patients applying for nursing home admission. Data for that study were collected in 1991 and 1992. The third study, "the Waiting List Project", was conducted in two regions of Amsterdam. Starting in March 1997, data were collected from the informal caregivers of patients with dementia. Ninety-three informal caregivers were interviewed when their relatives were added to nursing home waiting lists, at various points during the waiting period (for a maximum of six months), and after their relatives were admitted to a nursing home. Mutations in the waiting lists that occurred during the waiting period were monitored and data on nursing home admission registered. Data collection ended in January 2000.

**Chapter 2** describes the use of a waiting list in selecting patients for psychogeriatric nursing home admission. Qualitative research was conducted in 1991 and 1992 in two large cities: fieldwork comprised attendance at staff meetings and interviews with thirty-nine health care workers. Employees of the Regional Institute for Ambulatory Mental Health Care (RIAGG) in both cities advised on the need for psychogeriatric nursing home admission. A code for the amount of care needed and the urgency with which admission was deemed necessary was assigned to each patient. A patient was selected from the waiting list as soon as a bed became available. In one of the cities, a physician from the municipal health services performed the

selection. In the other, the waiting list was managed by an admissions office that had been set up by the nursing homes. Patient selection in the latter city occurred in one of two ways: 1. an employee of a nursing home chose a patient from the waiting list and presented the choice to the admissions office; or 2. only when admittance of a patient on the list was considered highly urgent, an employee of the admissions office contacted the nursing homes about a bed. In both cities, the selection of patients from the waiting list was based on the following criteria: 1) position on the waiting list (determined by the urgency code, the date of entry on the waiting list, and the place of residence during the waiting period); 2) characteristics of the supply (e.g., the availability of a bed on a specific ward or the amount of care needed by the patients already present); and 3) other (e.g., health care workers had informal ways of "calling attention" to special situations without upgrading the urgency codes). Not only waiting list criteria like urgency and chronology, but also efficiency considerations, characteristics of the supply, and preferences (of patients and their family) for admission to a particular nursing home determined the final selection decision. The application of such criteria, however, in the fair selection of patients has rarely been discussed in the literature.

The use of an urgency coding system in waiting list management is discussed in **chapter 3**. In the "Waiting List Project", ninety-three patients registered on a waiting list and their informal caregivers were followed until the patients' admission to a nursing home. The caregivers were interviewed and the (changes in) urgency codes during the waiting period were monitored. Reasons for high urgency codes, according to the health care professionals, included a decline in the health status of the patient and/or a decline in the capabilities of the informal caregiver. Except for the performance of activities of daily life, the results of the health status measurements did not show a difference between patients with higher and those with "normal" urgency codes. Nor was a difference in the health status and experiences of burden found between the informal caregivers of these patients. High urgency codes were commonly assigned: one third of the patients were given a higher than "normal" urgency code at registration, a percentage that increased to 74% by the time of nursing home admission. The urgency coding system was considered effective in this study, because patients coded with high/highest urgency were indeed admitted sooner to nursing homes. Patients who retained "normal" urgency codes were also admitted to a nursing home, but with long waiting times. It is open to debate whether these long waiting times were problematic since the caregivers' dissatisfaction with the waiting times was not related to actual waiting times.

**Chapter 4** discusses whether waiting times are problematic and whether a files study can be used to assess this. We analysed the files 111 patients registered on the waiting list for psychogeriatric nursing home care in Amsterdam. Eight patients had been assigned a higher than "normal" urgency code, were mildly demented, and had a mean waiting time of nine days. Almost half of the patients with "normal" urgency codes were moderately severely demented. Patients with "normal" urgency codes had a mean waiting time of fourteen weeks. Moreover, their waiting times were longer than those of patients in hospitals and observation clinics awaiting admission to a nursing home. The number of behavioural disturbances did not differ between patients with "normal" and those with higher urgency codes; however, patients with higher urgency codes did present more often with a day-night rhythm disturbance. The National Board of Hospital Services considers a waiting period of eight weeks before admission to a psychogeriatric nursing home acceptable for patients with a "normal" urgency code. When the waiting times of our patients were compared to this norm, they could indeed be considered problematic. However, whether they actually were problematic with regard to negative health consequences in patients or informal caregivers could not be demonstrated since the information needed for such a conclusion was not systematically registered in the files.

The experiences of ninety-three informal caregivers of patients with dementia are examined in **chapter 5**. Informal caregivers were interviewed soon after their relatives were registered on the waiting list. They were questioned about their own situation and experiences with the caregiving situation as well as the situation and health status of their relatives. Half of the respondents were quite heavily to severely burdened at the time their relative was registered on the waiting list. We studied how the characteristics of the patient, the informal caregiver, and the caregiving situation influenced caregiver experiences. These experiences were assessed using three subscales of the Caregiver Reaction Assessment Scale: 1) disrupted schedule; 2) loss of physical strength; and 3) care-derived self-esteem. Characteristics of the patient, the informal caregiver, and the caregiving situation were all related to negative experiences with caregiving. More negative experiences were found when the patients were younger and less severely demented. This was also noted when when more informal care was given, when caregivers co-resided with the patients, and when caregivers received less everyday social support. Positive experiences derived from caregiving were only influenced by the characteristics of the informal caregivers themselves. More positive experiences were found when caregivers were unmarried, when they had a lower income, and when the quality

of their relationship with the patient was good. Since almost half of the informal caregivers were not or just slightly burdened, burden experiences of informal caregivers were not the only reason for the application for nursing home admission. Nevertheless, for those caregivers who were already highly burdened at the moment of registration, the length of the waiting period may put a heavy claim on the amount of energy needed to continue care during that period.

The course of the health status and burden experiences of the informal caregivers and that of the patients' health status are presented in **chapter 6**. Starting in March 1997, ninety-three informal caregivers of patients with dementia were interviewed at the moment of entry on the waiting list. Follow-up interviews took place during the waiting period and after the patient's admission to a nursing home. A comparison was made between health status and burden experiences at the time of entry on the waiting list and six weeks after admission to the nursing home. Fifty-eight caregivers were interviewed on both occasions. Although the burden experiences of the informal caregivers declined after their relatives were admitted to a nursing home, no change was found in general health status or depressive symptoms. Three months later (four and a half months after nursing home admission), the mental health of the informal caregivers had improved. The patients' depressive symptoms and behavioural problems also declined after their admission to a nursing home. This finding may be biased since the informal caregivers, not professionals, supplied the information on the patients' depressive symptoms and behavioural problems. The questionnaires we used, however, did query observable behaviour. A subgroup of nineteen long-waiting (i.e., a waiting period of half a year) patients was also studied. We found that the health status and burden experiences of the informal caregivers and the memory problems, behavioural problems, and depressive symptoms of the patients remained stable during the waiting period. Only the performance of activities of daily living changed: it worsened during the waiting period. Ten of the ninety-three patients registered on the waiting list and one informal caregiver died during the waiting period. Another seventeen patients died during the first four and a half months after nursing home admission. The negative consequences of waiting cannot be described so much in terms of a decline in health status during the waiting period, but more in terms of a delay of the positive consequences of nursing home admission. The positive consequences included fewer behavioural problems and depressive symptoms in the patients and fewer burden experiences of the informal caregivers.

**Chapter 7** reports the main findings of the three studies as well as the methodological limitations and the relevance of the results. A waiting list is considered an important instrument for patient selection, because it ranks the patients with regard to chosen characteristics. The actual selection of patients from a waiting list, however, does not always follow the same order. Not only urgency and waiting time, but also other considerations determine selection for, e.g. nursing home admission. We found that a high urgency code was assigned regularly, at entry on the waiting list or during the waiting period and that those patients with a high urgency code were admitted sooner to a nursing home. Different methods were used to examine whether waiting time could be considered problematic. First, the waiting times of our patients were compared to accepted waiting times. We found that the waiting times of our patients could indeed be considered problematic. Second, the negative health consequences caused by waiting were considered. The waiting period did not cause an increase in the health problems of the patients and informal caregivers or in the burden experiences of the informal caregivers. It must be kept in mind, however, that the level of the depressive symptoms and burden experiences of many of the informal caregivers was already high when the patients were registered on the waiting list. Moreover, a delay in nursing home admission meant that the benefits of admission, e.g., a decline in the caregivers' burden experiences and an improvement in their mental health, were delayed as well. Such a delay would also be seen in the decline in the behavioural problems and depressive symptoms of the patients after nursing home admission. Finally, when the informal caregivers were asked their opinion of the length of the waiting time, twenty-two percent considered it too long. This opinion was not, however, related to the actual waiting times or to the urgency of nursing home admission.

The waiting list for psychogeriatric nursing home admission differs from many other waiting lists. One important difference is the opinion of the waiting patients (or their relatives) with regard to the length of time that is needed until nursing home admission. Some individuals are not ready for admission to a nursing home, while for others admission cannot be realised soon enough. It is important that the first group be given support in the process towards nursing home admission and that there is a possibility to hasten nursing home admission when necessary. With regard to the second group, it is important that nursing home admission occurs post-haste. The urgency coding system is an important instrument for quick admissions. However, while a waiting list is of value to those who work with it (health care professionals, caregivers) and to those who are waiting (patients and their informal

caregivers), its value for policy makers is limited. For example, since waiting times provide no insight into problematic waiting times, it is not possible to assign standard acceptable waiting times. In addition, in order to determine the total amount of psychogeriatric nursing home care needed, more information is required on the attitudes of those waiting with regard to the period in which nursing home admission is considered necessary. The step towards nursing home admission will always be a difficult one and good support during this process is essential. Finally, it is important to invest in a better social climate for the residents of nursing homes and in larger staffs, both of which will contribute to a more positive image of nursing homes.

