UNIVERSITY OF AMSTERDAM

UvA-DARE (Digital Academic Repository)

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

Meiland, F.J.M.

Link to publication

Citation for published version (APA):
Meiland, F. J. M. (2002). Wachten op opname. Hantering van de wachtlijst voor verpleeghuisopname en de gevolgen voor personen met dementie en hun mantelzorgers.

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: https://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

UvA-DARE is a service provided by the library of the University of Amsterdam (http://dare.uva.nl)

Download date: 18 Oct 2019

The use of the waiting list in a just selection of patients for nursing home care

Franka J.M. Meiland, Jos A.C. Danse, Aloysia M. Hoos, Johannes F. Wendte, Louise J. Gunning-Schepers. [Health Policy 1996;38:1-11]

Abstract

When health care resources are scarce, waiting lists may be used as a distribution measure in order to enhance the fair allocation of resources through selection of patients. In this study, the structure and use of a waiting list for a fair selection of patients for nursing home admission was studied. Qualitative research took place in two regions in the Netherlands, where scarcity in nursing home care exists. Selection meetings were attended and 39 health care workers were interviewed. Not only did waiting list criteria like urgency and chronology determine the final selection decision, but also efficiency and quality of care considerations (patients' preferences for particular nursing homes and nursing homes' considerations of matching the unit and work load). These considerations, their relative importance, and the resulting need for enforcement of the decision-making procedures, should be part of the discussion of patient selection. This acknowledges the complexity of the selection of patients.

Introduction

In the Netherlands, during the last 15 years, the selection of patients under circumstances of scarcity in health services has been actively discussed. Though money may still be saved by more efficient performance, there is general agreement that in the future demands for care will outweigh the supply of care. In this situation two requirements have to be met: the available care resources should both be used efficiently and distributed fairly. Health care lawyers discuss this fair distribution from the viewpoint of the law (all individuals are equal and as a consequence should have equal chance of receiving treatment), medical ethicists from the viewpoint of morality (norms and values regarding fundamental interests of people).[1-3] Some take the procedural approach. They stress the need for rules in making decisions in patient selection, for this should diminish the chance of arbitrariness.[3 4] Requirements for a fair allocation of health care are formulated as follows: justice in the procedures for selecting patients (equal patients should be treated equally) and acceptability of selection criteria. To achieve these requirements the system of selecting patients should be objective, clear, thorough and open to evaluation.[1,3] The construction of a system of patient selection depends on the type of care being delivered.[2,3] In the area of non-life threatening conditions, waiting lists are being used as selection instruments. This is not to say that waiting lists may not have other functions: institutions may use them to plan an acceptable patient mix and constant workload, while patients are able to prepare for an admission. Also less desirable functions may be noted: the waiting list as a status symbol and/or means of pressure on policy makers.

Various criteria may determine the order of patients on the waiting list, like: first come-first served, urgent cases first, or those with greatest chance of medical success first. These criteria reflect different notions of distributive justice. The first come-first served criterion aims at procedural justice (process), while the other two aim at a fair result of the distribution (outcome). Priority to urgent patients reflects a "need model" of distributing health care. A utilitarian model underlies the criterion of most chance of success, where the main goal is to effectively help as many patients as possible. The importance of the various criteria depends on the type of care asked for, for example in organ transplantation the chance of success is the leading criterion.[5,6] These waiting list criteria are increasingly accepted in patient selection, though not free of debate. Problems arise when waiting time is too long and criteria lose their distinctive properties. Also the determination of urgency or chance of success might not be

unambiguous. Waiting list criteria may contradict each other and should be carefully weighed.[3,5]

An area where the waiting list is being used as a selection instrument is long-stay nursing home care for psychogeriatric patients. This sector is one of several scarce health care services studied in a project called "Selection and Waiting Lists". The main goal was to investigate the different criteria and procedures used by health care workers when selecting a patient for a type of care.[7] Several decisions contribute to the selection of patients for nursing home care. The process starts often with the general practitioner referring the patient for further screening. Thereafter the indication for nursing home care is considered. Patients with a positive recommendation are added to the waiting list, the urgency of the care needed is determined (but may be changed later on). The final decision is the selection of a patient from the waiting list for a vacancy in a nursing home. This last decision is the main focus of this article. Questions are: How is the waiting list organised and used? How and on what grounds are patients selected from the waiting list? Is there a fair selection of patients for nursing home care?

Nursing home care and waiting lists in the Netherlands

The ageing of the population in the Netherlands is modest, compared to other European countries. Yet, the intramural care capacity is one of the highest in Europe.[8] In the Netherlands more than 300 nursing homes accommodate over 50 000 old and frail patients who can no longer be taken care of at home. They make up 2.5% of the population aged 65 years and older and 10.5% of the population over 85 years. About half of the residents are admitted because of a psychogeriatric disorder (in particular, dementia). Admission is open to everybody provided an advisory committee has given a positive recommendation. The costs are covered by the AWBZ (the Exceptional Medical Expenses Act).[9,10]

The number of people admitted to nursing homes has increased in recent years and is expected to increase even further.[11] The number of patients waiting and the mean waiting time increased from 1987 to 1992, but decreased since 1993 after expansion of the number of nursing home beds and of home care projects. In the Netherlands in 1994, 4630 psychogeriatric patients were on a waiting list with a mean waiting time of 15 weeks. There are regional differences in waiting time, with a range from 8 to 23 weeks. In the absence of changes in policy, it is expected that the number of patients waiting for nursing home admission will rise.[12]

Methods

Research method

Because the interest of the study was the complex process of patient selection which was so far unexplored, we adopted a qualitative research method. Two different health care regions, with differences in the procedures of selection of patients, were studied. Fieldwork was done in 1991 (region A) and 1992 (region B). In 1992, region A had a waiting list with an average of 246 patients, while region B had an average number of 309 patients waiting. In both regions the waiting time was somewhat over three months. Starting with participant observations, we selected relevant staff meetings for observation, and selected our subjects for interviews. The interviews encompassed global questions about the procedures and specific questions based on the observations. In region A, the following were interviewed: 10 employees of the Regional Institute for Ambulatory Mental Health Care (RIAGG), two administrators of the waiting list, four admission officials of nursing homes. Ten indication and urgency staff meetings and 37 selections of patients for vacancies in nursing homes were observed. In region B, the following were interviewed: 12 employees of the RIAGG, two employees of the conciliation office, one physician of the indication committee, one medical adviser for sickness funds and seven officials from nursing homes. Seven meetings of the RIAGG were observed, 12 home visits and one admissions meeting with members of the RIAGG, the admissions office, indication committee and officials of nursing homes were attended. In addition, relevant protocols and other written material were collected.

Analyses

All material was transcribed and organised for analysis. A computer program for qualitative research was used.[13] In this program, interviews are divided into smaller segments, which are marked by one or more codes. In order to develop the codes, different researchers independently analysed some data. This resulted in a list of concepts and codes, that were discussed within the research group of the Selection and Waiting List study. Key concepts emerged, which made multi-site comparisons possible. The codes could either be descriptive (acceptance to waiting list, determination of urgency, staff meetings) or interpretative (pressure on decisions, differences between health care workers). The next step was to mark every segment of text by codes. Thereafter, the material was analysed by making matrices in which the columns contained the codes and the rows indicated different types of respondents. In the cells, the relevant information for each respondent was summarised, making further.

comparisons possible.[14] Reliability was enhanced by comparison of different sources (interviews, protocols, observations). Interim reports were discussed within the research group. The final report was send to the regions under study in order to check for false descriptions of the daily routine.

Results

Procedures for admission to a nursing home

In order to be admitted to a nursing home, a positive recommendation is needed. The investigation of the patient's condition and the care-giving potential of family and professional home care is done by a social psychiatric nurse and a geriatrician of the RIAGG, during home visits. Sometimes a patient is referred to an observation clinic for further screening. The employees of the RIAGG give a preliminary recommendation which has to be ratified by an indication committee and a medical adviser of the insurance companies. Thereafter, patients are admitted to the regional waiting list. The social psychiatric nurse and geriatrician also decide upon the urgency of the admission to a nursing home. To see at first glance what kind of a patient is on the waiting list and what type of care is needed, additional codes are given, for instance for the degree of physical impairment and mental impairment.

The allocation from the waiting list is fundamentally differently organised in the two studied regions and will therefore be described separately.

- Allocation in region A. The selection from the waiting list is organised regionally: the admission office is informed by the nursing homes about a vacancy. Simultaneously the requirements for the patient to be selected are reported. Once a day, the responsible physician selects patients from the regional waiting list for the available nursing home beds. Each nursing home receives the name and the indication form of any patient selected for it. The nursing homes have the right to refuse this patient if his profile does not match the requests. The nursing homes have no insight into the composition of the waiting list. In emergency cases, when a patient has to be admitted the same day, the nurse of the admission office actively searches for a bed, by contacting different nursing homes.
- Allocation in region B. In region B, an admissions office, set up by the nursing homes, manages the regional waiting list. Furthermore, each nursing home has a waiting list of patients with a preference for their nursing home. Sometimes home visits are done by an admission official of the nursing home, which makes it possible to create an individual

priority list of urgent patients for different units of the nursing homes. When there is a vacancy the nursing home official selects a patient. It is also possible to contact the admissions office and leave the decision to this office. The admissions office is informed about admissions. In emergency cases, the conciliation office actively searches for a place, just as in region A.

Considerations in patient selection in region A

Waiting list features

The waiting list is always used in patient selection. Several ordering principles determine the position on the waiting list. These are:

1) The urgency code: Three broad urgency categories exist: a low urgency category (C-code) for patients who are on the waiting list as a precaution, a normal urgency category (B-code) for patients who need to be admitted in a short while and a higher urgency category for patients who have to be admitted soon (A2) or immediately (A1). Patients with A1 code must accept any available place, while patients with other codes may wait for their preferred nursing home. The difference between A1 and A2 code is to be determined by the patient and family themselves. The health care worker may advise and explain the expected differences in waiting time.

2) The date of admission to the waiting list: Patients join the waiting list according to the date of indication. The sequence for patients with an A-code is determined by the moment of receiving this code (instead of the date of the indication).

3) The place of residence: Patients who stay inappropriately in hospitals or observation clinics[1] are registered separately on the waiting list. These patients have a B-code and cannot get an A-code.

Supply features

The nursing homes not only report a vacancy, but also request a patient who needs a certain type of care. This is permitted because most nursing homes have divided their departments into care units for mildly, moderately severe, and very severely demented patients (differentiation). Also the average work load in a unit at one point in time is important, as there cannot be too many patients in wheel chairs or too many patients with behavioral disturbances. The

[1] These patients are not being treated anymore, but are merely waiting for admission elsewhere. Care in hospitals is not adequate for patients in need of nursing home care. Also, these inappropriately placed patients are a problem for hospitals when the capacity is limited (otherwise the lower fee -agreed upon for wrong bed patients- is better than no fee at all). [15]

nursing homes may be familiar with a patient on a waiting list, for example because of day care treatment in the nursing home, and may request that this patient should be selected for their vacancy. They state for example: "There is room for a female moderately severe demented patient; we strongly request admission of Mrs X for this vacancy". In order to keep up to the distinctions between units, transfers within the nursing homes are sometimes necessary. Since these transfers contain merely movements from moderately severe to (very) severe units, the vacancies for waiting list patients are mostly open for mildly or moderately severe demented patients.

Other features

Besides the above formal features, other interactions also influence the allocation decision. In an urgent situation not only the formal procedures are followed but informal attention may be asked for a specific situation in order to hasten the admission. This may be done by informal or formal caregivers (family, community nurse), by employees of the RIAGG, or by officials of hospitals or the nursing homes. Reasons not to increase the urgency code officially, even though it should, may be adherence to the nursing home preference of the patients. Employees of the RIAGG may ask for special attention for particular patients during a weekly meeting with the employees of the admission office.

Weighing of different features

The reports of vacancies by nursing homes with the requirements of the patients to be selected, form the starting point of the allocation decision. The manager of the waiting list daily selects patients for the available beds. At first the higher urgency patients (A1 and A2) are considered for a match. Apart from the A1-code, the preference of a patient for a particular nursing home is also part of this match. Next, he considers the longest waiting, 'normal urgent' patients. At the same time the inappropriately placed hospital patients are looked at. Besides this waiting list information, other 'forces' may influence this first search for appropriate patients, for example the health care workers who have given the indication advice may ask special attention for inappropriately placed hospital patients. This information is sometimes marked on the patient's card or written on a piece of paper next to the waiting list. The family of a patient may have phoned constantly or the nursing homes may have requested a particular patient. The manager of the waiting list tries to satisfy most of the involved parties, by selecting a patient from the highly urgent list, a patient who has waited for a very long time and a patient from a hospital, provided that there is more than one bed

available and these patients fit the demands. A decision-maker said: "Look, hospital X has the highest number of psychogeriatric waiting patients, so it is high time that someone gets out of this hospital [..] You can imagine that such a hospital gets upset at having all these psychogeriatric patients waiting for admission [to nursing homes]."
Sometimes none of the highest urgent patients are selected. One day 11 patients had an A2 code and five places were available. The observing researcher asked after the selection had taken place: "So none of the A2 list is being selected? The physician: No, because preferences did not match, except for Mrs. R. Here I considered that the woman I did select had waited extremely long and wanted this nursing home badly, while the preference of Mrs. R was not exclusively for this particular nursing home." In exceptional cases, the manager contacts the nursing home to see if the demands may be interpreted in a flexible way.

Considerations in patient selection in region B

Waiting list features

The regional waiting list as well as the waiting lists of the nursing homes are organised according to urgency and waiting time. The urgency codes resemble the ones in region A, though patients with the A2 code here must also accept any available bed, like patients having code A1. However some patients with a B-code have been given a special code for higher urgency, while keeping their preference, thereby resembling the A2 code in region A.
The home visits by an official of the nursing home enable him to form an opinion about the most appropriate unit for patients, thereby differentiating the patients on the waiting list.

Supply features.

The nursing homes often have different units for different types of care needed. Therefore transfers within the nursing home are needed. Because they manage their own waiting lists, the nursing homes are able to assess the relative urgency of patients on the waiting lists and of internal transfers.

Other features.

Besides the formal procedures, informal ways of asking attention also exist in this region. After having met the admission official during the home visits, family may contact the nursing home, as may employees of the RIAGG and hospitals. There is no special category for hospital patients who are waiting for admission although some hospitals have made agreements with nursing homes for admission of their patients. Just as in region A, these

patients cannot get a high urgency code. In two-monthly meetings with all health care workers involved, special attention may be asked for long-waiting patients and patients in hospitals.

Weighing of different features

The nursing homes have agreed upon criteria and procedures for allocation. For example, those highly urgent and/or waiting longest should be considered first. When they have admitted a patient they are obliged to inform a regional agency. When admissions are not in accordance with the agreements, this regional agency may call the nursing home official to account for his decision. In this way there is some kind of check on decisions. Apart from these procedures, informal pressure on the decision-maker may influence the selection. Family and health care workers may contact the nursing home (several times) to persuade the decision-maker to admit a particular patient. As one social psychiatric nurse said: "Well, of course it is a game, a technique one uses, so to make use of all your contacts [..] Rules are there to be handled with flexibility every now and then." Another nurse: "I have also sometimes worked hand in glove with nursing home X [..] in order to get a highly urgent patient into his nursing home of preference." The nurses admit that this 'lobbying' should be done with discretion, "otherwise everyone's going to scream as loud as possible for his own patient."

Discussion

Considerations in allocating nursing home care.

Even though, for each category of urgency, the waiting list for nursing home care is kept in chronological order, patients are not selected in that order. Pope and Mays[16] state that waiting lists seldom resemble anything like a formal queue, and indeed all sorts of processes are working against the idea of a queue. This could also be said of the use of waiting lists in this study. At first sight, urgency and chronology are the leading principles in selecting patients. In region A the place of residence is also a criterion, which is a kind of efficiency justice: scarce resources -in this case hospital beds- should be used as efficiently as possible, so the number of inappropriately placed patients should be limited.[5] A closer look reveals that those most urgent or waiting longest are seldom uniquely selected, other 'forces' also determine the eventual selection, and the waiting list is merely used as a "pool of work" which one would "dip into".[16] The other 'forces' are the nursing homes, who consider their workload (which becomes heavier as older and more severely handicapped patients are admitted) and the

differentiation of departments according to the care provided. This structuring of care is one of the sources of tension between the nursing homes and the persons involved in the selection of patients for nursing home care.[17] In a study by Haga and Baerts, the nursing homes admitted patients in agreement with the priority setting by the ambulant mental health care advisers in 70% of the cases. The reasons for deviation were circumstances of the nursing homes, such as type of room free and considerations of patient population.[18] This preference for particular patients is also mentioned by Welten and ten Dam-van Lieshout, who identified possible reasons for a preference, including the wish to have a mixed patient population and consideration of the work load (men and less ill patients are preferred).[19]

The patient or his advocates (family, health care workers) also have a personal influence in the final selection, apart from their objectively determined needs and urgency (as assessed by the RIAGG). In part this has to do with the preference of patients for a particular nursing home. Except for the most urgent patients, this preference is an important guide in patient selection. The other part of the patients' influence, which can hardly be spoken of as a guide, is the ability to vocally stand up for one's case and 'cry out' for help.
Many considerations including, patients' needs and preferences, suppliers' requests, utilisation of health care (inappropriately placed patients) and bargaining tactics all contribute to "a melting pot for conflicting demands".[20]

A fair selection?

Efficient use of health care resources, procedural justice and acceptability of criteria are the main requirements for a fair patient selection. In both regions waiting lists are used as distribution instruments, and urgency and chronology are considered amongst other features. The use of the urgency criterion is in accordance with the recommendations of a Dutch committee on choices in health care, established by governmental order, who stated that patients with the highest urgency should be selected first.[6] Also the use of the chronology criterion is accepted. For both criteria however, certain requirements have to be met: consensus on the determination of urgency, which is complex in nursing home care because of the impact of social factors besides the objective health status of the patient, and consensus on the moment of admission to the waiting list.

The discussion on patient selection hardly pays attention to the influence of the other features in the final selection decision. These are an efficient use of healthcare through taking into

consideration the inappropriately placed hospital patients, which aims at and 'quality of care considerations': preferences of patients and matching of the patient's profile with the vacancy in the nursing home. Pressures from family or health care workers are intertwined with urgency notions and with quality of care considerations. These different features may be at odds with each other, leaving us with the need for careful deliberation. In this situation, enforcement of the procedural aspects of decision-making might be even more important.[5] Therefore the decisions should be clear, objective and open to evaluation. In the two studied regions, the procedures were different, with different weaknesses in the decision-making procedures. When the selection is organised centrally, the demand for objectivity is more easily met. All parties involved -RIAGG employees representing the patients, family, hospitals and nursing homes- have to contact or bargain with the same person of an independent institute. This may limit the frequency with which informal pressures are exerted. A disadvantage of the organisation in this region is the nursing homes' lack of knowledge of the sequence of patients on the waiting lists. As a consequence, the nursing homes tend to define the available beds more in terms of their own requirements than in reaction to the patients waiting for admission.

In the decentralised organisation, where nursing homes decide whom to admit, the biggest threat to justice is the lack of objectivity. Nursing homes decide, while having an interest in the decision. The tendency to put pressure on the nursing homes may be stronger, because the family knows the official of the nursing home by means of the home visit or because the employee of the RIAGG deals with different officials of nursing homes. The requirement for the official of the nursing home to account for his decision is a way to enforce the decision-making process and may limit the influence of pressure. The advantage of this organisation is that nursing homes have a feeling for the type and urgency of care asked for, which enables them to adapt the supply.

The focus in the literature on waiting lists as an allocation measure obscures the fact that other influences play a role in the final selection decision. Therefore the demands for acceptability of criteria and for procedural justice should be addressed not only to the waiting list, but also to the consideration of all the features of the selection process.

Acknowledgements

We thank the professionals involved in the selection of patients for nursing home care for their participation in the study. This study was funded by the Dutch Ministry of Public Health, Welfare and Sports.

References

1 Leenen, H.J.J., The Selection of Patients in the Event of a Scarcity of Medical Facilities- An Unavoidable Dilemma, The International Journal of Medicine and Law, 2 (1979) 161-180.

2 Beaufort, I.D. de and Dupuis, H.M., Selection at a microlevel. In I.D. de Beaufort and H.M. Dupuis (Eds.), Handbook of Health Ethics. Van Gorcum, Assen/Maastricht, 1988, pp. 187-195 (in Dutch).

3 Willigenburg, T. van, Waiting for care: who has priority? Ethiek en Recht in de Gezondheidszorg, 16 (1994) VI131-42 (in Dutch).

4 Rigter, H., Who's next? On Selection and Waiting lists in Health Care, Gezondheidsraad, 's-Gravenhage, 1986 (in Dutch).

5 College voor Advies en Bijstand inzake Levensbeschouwelijke Aangelegenheden, Selection of patients, Waiting lists and Models for a fair distribution of Health Care, NZR/NZI, Utrecht, 1989 (in Dutch).

6 The Government Committee on Choices in Health Care, Choices in Health Care, Ministry of Public Health, Welfare and Cultural Affairs, The Netherlands, 1992.

7 Meiland, F.J.M., Varekamp, I., Hoos, A.M., Danse, J.A.C., Krol, L.J., and Wendte, J.F., Selection and Waiting lists in Health Care - In Psychogeriatric Nursing Home Care, Intensive Care for Newborns, and Renal Transplantation, University of Amsterdam, Institute of Social Medicine, Department of Medical Psychology, Amsterdam, 1994 (in Dutch).

8 Huijsman, R., Klerk, M.M.Y. de, Groenenboom, G.K.C., and Rutten, F.F.H., Care for the Elderly from a calculating perspective - Backgroundstudies on behalf of the Committee Modernisation of the Care for the Elderly, BMG/iMTA, Rotterdam, 1994 (in Dutch).

9 Kruit, H.P., and Kruizenga, J.R., Care for the elderly in the Netherlands, Tijdschrift voor Gerontologie en Geriatrie, 18 (1987) 168-170 (in Dutch).

10 Ribbe, M.W., Facts and figures about patients in Dutch nursing homes. In Ribbe, M.W., Verpleeghuisgeneeskunde, Free University Press, Amsterdam, 1989, pp. 33-45.

11 Committee on the defrayal and quality of care for the elderly, Prudent Renewal, Utrecht, 1994.

12 Gerritse, A.J., Nursing Home Care and Waiting Lists in 1994, National Hospital Institute, Utrecht, 1995 (in Dutch).

13 Peters, V., Wester, F., and Richardson, R., Qualitative analysis in practice and manual for Kwalitan version 2, Institute of Applied Social Sciences, Nijmegen, 1989 (in Dutch).

14 Miles, M.B. and Huberman, A.M., Qualitative data analysis, a sourcebook of new methods, Sage Publications, Newbury Park, 1990.

15 Pols, A., Inappropriately placed hospital patients, Epidemiologisch Bulletin, 28 (1994) 3-6 (in Dutch).

16 Pope, C. and Mays, N., Opening the black box: an encounter in the corridors of health services research, British Medical Journal, 306 (1993) 315-318.

17 Robben, P.B.M. and Hinsbergh, W.L.M. van, Admission Policy in Psychogeriatric Nursing Homes. The negative consequences of differentiation, Medisch Contact, 43 (1988) 1563-1564 (in Dutch).

18 Haga, K.H. and Baerts, H. te, Plan Care? Gerontagogisch Centrum Leidse Hogeschool, Den Haag, 1992 (in Dutch).

19 Welten, J.B.V. and ten Dam-van Lieshout, C.A., Problems of Nursing Homes in a big City. A message from Daily Routine, Tijdschrift voor Gerontologie en Geriatrie, 18 (1987) 241-244 (in Dutch).

20 Pope, C., Trouble in store: some thoughts on the management of waiting lists, Sociology of Health and Illness, 13 (1991) 193-212.