Mortality of Nursing Home Residents Admitted to Hospital



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Kristian Furuskjeg

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Preface

The topic for this master thesis is based on several discussions with colleagues where substantial concern regarding the transport of severely ill nursing home residents was raised. My colleagues and I had an impression of nursing homes sending their residents to hospital as a result of low staffing or when the resources for care were exhausted. It was however our impression that several other steps should have been taken before admitting the resident to provide care in his/her "home".

There are several persons I would like to offer my gratitude. First, a special thank you to Stine Haldorsen Bakke for being the one who made me decide to engulf in this project. I would like to thank my own organisation for facilitating so that I could gather data for this thesis. Not once has anyone declined a request for access to systems or work space.

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Kristian Furuskjeg

Abstract

Introduction: Nursing home residents have more than twice the risk of hospitalization compared to community dwellers and have a higher risk for iatrogenic events and hospital death. Reports of adverse events from paramedics in our system as well as existing literature, indicates that these transports may not always be in the patients' interest. To the extreme, transport of moribund patients from nursery homes seems unethical.

Aim: The aim of this study is to examine the 7-days mortality of nursing home residents admitted to hospital by ambulance.

Method: This is an observational study based on nursing home residents admitted to hospital by ambulance in the period 1. January-31. December 2016.

Results: 1772 individual residents where admitted to hospital. The 7-days mortality for residents with problems related to internal medicine was significantly higher (13,9%) than for surgical (10,8%) and orthopaedic (7,1%) conditions (p = <0,05). When isolated into subgroups, 16,2% of the residents with infectious disease died within one week and 21,6% of the patients with respiratory conditions. Patients admitted without being assessed by a physician had a significantly higher mortality than those who had been assessed (7,2% vs. 2,8%, p = <0,05). *Conclusion*: There is a high rate of mortality for residents admitted to hospital with infectious diseases and respiratory problems. In addition, the difference in mortality among those assessed by a physician compared to those who were not assessed indicates that the general practitioner on call plays a vital role in providing access to the correct level of care.

Table of contents

Preface

Abstract

1	. Intr	oduction	1
	1.1.	Background	1
	1.2.	Aim	1
	1.3.	Definitions	2
	1.3.	1. Nursing Homes	2
	1.3.	2. Nursing home residents	2
	1.3.	3. Emergency care admission	3
2	. Pre	sentation of a theoretical framework	3
	2.1.	Previous research	3
	2.1.	1. Factors influencing hospital admissions of nursing home residents	3
	2.1.	2. Post-admission outcome for nursing home residents	5
	2.1.	3. Impact on health policy and economics	6
3	. Pre	sentation of method and methodological considerations	7
	3.1.	Study design	7
	3.2.	Data gathering and analyses	8
	3.3.	Literature search	8
	3.4.	Ethical considerations	9
4	. Res	sults	10
	4.1.	General characteristics	10
	4.2.	Mortality after admission to hospital by ambulance	11
5	. Dis	cussion	13
	5 1	Discussion of methodological issues	13

5.1.1. Survival time after admission
5.1.2. Gathering and analysis of quantitative data
5.2. Discussion of results
5.3. The results in context to theoretical framework
5.4. Implications for practice
5.5. Limitations
6. Conclusion1
References
Article2
Appendix 1: Guide to Authors, link to BMJ Quality and Safety
Appendix 2: Copy of email from The Ethical Board of Bergen Health Trust
Appendix 3: Letter of approval from The Privacy Ombudsman of Bergen Health Trust

1. Introduction

1.1. Background

Nursing home residents (NHR) represents a frail population who are subjects to a variety of adverse events and complications as a result of hospital admission(1, 2). The World Health Organization (WHO) has raised the need for health services to adapt and transform in order to provide services to a growing elderly population(3). The World Bank estimates the population > 65 years of age in Norway to grow from 868.270 (2016) to 951.000 in 2020 and 1.181.000 in 2030(4). According to WHO, adaption of health services to an ageing population may help reduce the need for acute care(5). WHO recommends that research into healthy ageing is conducted in a contribution to supply policy makers with evidence-based knowledge. Research will also help by being translated into a strengthening of systems and change of clinical practice(6).

According to Statistics Norway there were 37836 institutionalized users receiving short-term or long-term care in Norway in 2016(7). Most NHR live in nursing homes (NH) until they die and the time of stay varies significantly. A recent Norwegian survey states a variation from few days until 26 years, with a mean 2,02 years (median 1,31 years). In the same survey, in the 11 municipalities with highest death rates in NH, 1/3 of the total number of deaths in the municipalities occurred in NH(8).

After gradually implementing the Coordination Reform since 2012, development of guidelines for hospital admissions has taken place. These guidelines are among others regulated by Health and Care Services Act § 6-2, 3. The main principle of the guidelines is provision of health care at the lowest effective level of care(9). A legislative right to emergency care is regulated by the Healths and Rights Act § 2-1, b and further in §§ 3-1 and 3-2 the rights to involvement and for information are regulated. The services provided should by law be a result of the resident's involvement(10).

1.2. Aim

Several studies have examined the appropriateness of hospital admissions of NHR. However, to our knowledge, only a few of these have been done in a Norwegian or Scandinavian setting. Even within Scandinavia there are differences regarding the procedure of admitting a patient to hospital, so it seemed eligible to perform a study of a Norwegian system. In addition, there was a growing concern from several of members of our staff, claiming that residents of NH in some cases were transferred to hospital "even though they were already dying" or "only to die". The aim of this study was to examine the 7-days mortality of NH admitted to hospital by ambulance.

1.3. Definitions

1.3.1. Nursing Homes

There is no international definition of nursing homes. Several terms are used which can serve as an alternative such as "residential age care facility" (RACF) or "home for the aged". Arendts, Quine & Howard defined RACF as "facilities that coupled permanent accommodation with the provision of facility-specific nursing services in addition to personal care services"(11). As this is a study of a Norwegian system, we will use the definition set by Norwegian regulations where a NH is an institution which delivers care, treatment and residence at a level not needing hospitalization but too complex to be provided in the resident's home. Access to physicians, physiotherapy and nursing resources should be provided. NH can provide one or more of the following services: medical rehabilitation with the aim of return to the home, temporary relief, permanent stay, adjusted services to physically disabled, screened wards for patients suffering from dementia, special living units for children/youth, day-care services, night-care services and care for the terminally ill. Nursing homes are regulated by the Act relating to the municipal health services(12).

1.3.2. Nursing home residents

As seen above, nursing homes residents (NHR) can suffer from a variety of conditions. In this thesis the term NHR refers to individuals receiving care or rehabilitation on a temporary or permanent basis. Day-care services such as community centres for elders are not included.

1.3.3. Emergency care admission

Several Norwegian legislations regulate emergency care; The Specialized Health Services Act §3-1, the Act on Health and Rights §2-1 b) and The Health Personnel Act §7 all contains such regulations. However, none of these regulations defines a time limit of which care is considered to be of an emergency character or more of an elective character(10, 13, 14). We will use the definition used in the Catalogue of definitions in emergency services, where emergency admission is defined as "referral to or admission of a patient in need of immediate or rapid examination, treatment or care. This involves patients with a suspected need of care to be cared for in a health institution within 24 hours of first contact with health services"(15, p.31, my translation). We will also use the terms "emergency care admission", "hospital admission" and "admission".

2. Presentation of a theoretical framework

2.1. Previous research

2.1.1. Factors influencing hospital admissions of nursing home residents

The factors influencing hospital admissions of NHR are well described in previous research. In the following, a resumé of some of this research will be given.

In an Australian qualitative study Arendts et al.'s aim were to explore factors involved when transferring NHR to hospital and to describe how changes in primary care could reduce such transfers. They conducted interviews with focus groups consisting of family, non-health professional caregivers in NH and other stakeholders in the NH. All focus groups agreed that admission to hospital was the end-result when all other options was exhausted. Five themes emerged as key influencers to hospital admission; staffing, treatment options, end-of-life decision making, communication and bureaucratic requirements. The general concern regarding staffing was that it was inadequate, particularly during the night and the composition of the staff was variable resulting in varying levels of delivered care. Arendts et al. discovered a range of options to seek prior to admitting residents to hospital. However, the use of these could be time consuming. In example, the waiting time for telephone support or a general practitioner (GP) could be so extensive that requisition of an ambulance was far more feasible. Regarding end-of-life decisions staff felt pressure from relatives to seek more active forms of treatment for their

family member but there was also concerns regarding the staff's training regarding end-oflife care and decisions adjacent to this(16). In Norway this is regulated by the Health and Rights Act §§ 2-1(b), 3-1, 4-1 and 4-9. § 2-1(b) entitles the patient to health care from the specialist health care services while § 3-1 contains regulations regarding the patient's right to participate in choices of justifiable service-, examination- and treatment choices. Emphasis must be placed on the patient's opinion when forming services. According to § 4-1, health care presuppose consent from the patient. For the consent to be valid, sufficient information surrounding health condition and the content of the health care should be provided. § 4-9 concerns the right to waive health care in the terminal stages of life.(10).

The theme of communication emerged from a concern over troubled communication with both the GP and the emergency department (ED). This mainly concerned the relationship between the NH and the ED, bringing up issues both prior to admission such as advance warning and documentation and after discharge regarding both documentation and information around initiated treatment. Finally, Arendts et al. described some of the bureaucratic issues influencing hospital admissions. Most important was the lack of GPs providing care in NH. Some of the reasons could be extensive paperwork and little room for flexibility when a resident becomes acutely ill. Arendts et al. concluded that their findings were supported by other studies and that a large number of factors contribute to the decision of admitting residents to hospital in addition to clinical considerations. They suggested policy changes to address these factors such as improved level of staffing in NH, the use of mobile multidisciplinary teams to provide advanced care in the NH and advanced care directives in end-of-life situations(16).

Graverholt et al. conducted a population-based observational study examining acute hospitalisations of nursing home patients in a Norwegian municipality. Their aims were to determine the rate of hospital admissions among NHR compared to community dwellers and to describe the hospital stays of the nursing home population. They used the International Classification of Diseases version 10 (ICD-10) to stratify the different reasons for admission and the hospital patient records to obtain the information. The most common diagnose among the NH population at discharge was diseases of the respiratory system (ICD-10: J00-J99) followed by injuries, poisoning, other consequences of external causes

(ICD-10: S00-T98) and diseases of the circulatory system (ICD-10: I00-I99). During the two-year study period they found 2451 admissions by ambulance of NHR constituting in 1668 individuals. Compared to the population still residing in the community, the NHR had more than twice the risk of being hospitalized. The in-hospital and 30-day mortality was also higher in among NHR than among community dwellers. The authors emphasise the need for improved services for acute and palliative care in NH(2).

Ranhoff & Linnsund raised the question of when it is appropriate to admit NHR to hospital. The authors questioned the usefulness of hospital admissions but found relevant motives such as diagnostics, treatment to improve survival and level of function and palliative care. The authors claimed that patients suffering from acute and threatening conditions may benefit from diagnostics in hospital where more advanced tools are available through laboratory samples, radiology and consult by specialists. Several of these measures could be done rapidly with the residents returning to the NH the same or following day. Hospital admissions with the aim to improve survival or function level could be summarized as hip fractures, pneumonia, other critical infections, heart failure, chest pain with suspicion of myocardial infarction, stroke and severe anaemia. Palliative care should be provided in NH. However, if this is insufficient, hospital admission should be considered as appropriate. As NHR have the same legal rights as other citizens they should receive good quality health care. Although a need to make individual judgements, some patients will benefit with increased survival following hospitalization. Ranhoff & Linnsund called for improved palliative care in NH, continuous service from general practitioners, and sufficient level of competent nursing(17).

2.1.2. Post-admission outcome for nursing home residents

A systematic review of outcomes following emergency transfer of NHR to hospital by Dwyer et al. made a distinction between clinical consequences and consequences for the health system. They found that NHR were subject to a large number of interventions, including invasive procedures such as blood samples, insertion of intravenous canula or urinary catheter. As many as 85% of the residents had radiological examinations and 70% received blood products or medication. A high proportion of NHR developed new pressure

sores during admission and 38% developed delirium. Admission to the ED was also associated with nosocomial infections such as gastrointestinal or respiratory tract infection. A general finding was that acute hospital admission led to functional decline among NRH. Mortality was higher compared to community dwellers and most deaths occurred within one week after admission. Some studies in the review suggested that as many as 52% of the population died within three months of hospitalization(18).

One key hazard mentioned in literature is the information gap occurring during transfer both to and within the hospital. The term information gap could be defined as "previously collected clinical information that is required for patient care but is not available to the treating physician"(19). Morphet et al. showed that information gaps were prevalent. NHR arriving at the ED with insufficient documentation had to undergo far more examinations such as radiology and sample collections compared to residents with sufficient documentation. The length of stay in the ED was also prolonged due to lack of documentation(20). In a study of all transferred patients >60 years of age from NH or senior residence by ambulance Cwinn et al. sought to examine what information NH staff felt was important to the emergency physician in the ED. They collected data of information gaps regarding clinical parameters, descriptive details of the current problem and whether the use of a standardized information form reduced gaps in information. Cwinn et al. identified at least one information gap in 85,6% (n=457) of all the investigated cases. In 79% of the cases the lacking information was considered to be essential to the emergency physician. A standardized transfer form was used in 42,7% of the cases and at least one information gap was present in 74,9% of the cases when the form was used. The rate for information gaps when the form was unused was 93,5%. The authors reported the difference to be statistically significant(19).

2.1.3. Impact on health policy and economics

In a study from Taiwan, a country with one of the most rapid ageing societies, Chou et al. examined the costs associated with ED visits of elderly patients from a veteran care home. The mean cost for an ED visit for a resident was 3,9 times higher than for other ED visits. This may be explained by the complexity of the patient population(21) as they suffer from multiple diagnosis and have complex care needs(22). A cohort study by Gruneir et al. in

Ontario, Canada, examined 21.773 transfers from long-term care homes. 25% of the transfers were rated as potentially preventable. However, 62,4% of the transported residents ended up being hospitalized and 23,6% died within a month(23). The definition of a preventable transfer remains to be settled and is difficult to achieve both from a clinical and medical perspective. An agreement on how to measure appropriateness is therefore also difficult to obtain. From a political view a definition of preventable transfers is urged(24). In another study by Gruneir et al. underlined that preventable transfers should be targeted earlier in the course of illness. They refer to models for pneumonia care as successful for preventing hospitalization. The authors suggest that health politicians implement organizational and policy interventions to improve care for common conditions such as chronic obstructive pulmonary disease (COPD) and chronic heart failure (CHF). They raised the question around "revolving door" patients who frequently visit the ED for the same reason as earlier, suggesting that the problem was not properly solved at first visit. They claimed that information gaps between institutions may be one of the sources of this problem(23), a view supported by Cwinn et al. who recommended to improve transfer documentation by further education, regulatory measures and increased communication between hospitals and NH to improve care for patients(19).

3. Presentation of method and methodological considerations

3.1. Study design

This is a retrospective population-based cohort study examining the population of nursing homes in Hordaland County, Norway, admitted to hospital by ambulance during the period January 1. 2016 – December 31. 2016. Retrospective population-based cohort studies are studies where a population is selected for assessment of exposure-outcome relations over time. To avoid bias such as medical surveillance bias one should perform systematic and periodic data collection which are standardized on all members of the cohort without regards to exposure status. As a rule of thumb, population-based studies relies on databases such as hospital records and death certificates and should also have specially designed procedures for determining study variables(25).

3.2. Data gathering and analyses

All contacts from NH to the Emergency Medical Command Centre (EMCC) are registered into the Acute Medical Information System (AMIS) (CSAM Health AS). All contacts made from January 1. to December 31. 2016 were entered into a spreadsheet (Excel ver. 1804, Microsoft Co.) At the same time patients were included or excluded based on a set of criteria (Table 1). We identified too many sources of error to do an automated extract from AMIS. For example, if staff from a nursing home reported on an incident occurring outside the nursing home (i.e. a car accident), the contact would still be registered as a contact from a nursing home. We therefore found it vital to do this process manually to include the right patients. All included patients in the cohort were examined with emphasis on date of transport, gender, age, reason for transport, origin of transport (all retrieved from AMIS) and date of death (retrieved from The National Population Registry). All data were entered into SPSS ver. 25 (IBM Corp). SPSS was used to perform Kaplan-Meier-analyses with means, medians as well as log-rank test. Kaplan-Meier (KM) analyses are primarily used when investigating the time before an event occurs. Based on a KM table estimation of mean and median time before the event can be done. The log-rank test is used to compare any difference in survival between the compared variables (26).

Based on the information given by the caller to the EMCC, medical conditions were divided into four categories: Illness related to internal medicine, surgical conditions, orthopaedic and others (i.e. gynaecology, ophthalmology and oncology). As we wanted to explore some of the subgroups within the different categories, we isolated hip fractures (from orthopaedic conditions) and respiratory problems and infections (from internal medicine) for this purpose. The primary goal of the study was to examine the 7-days mortality of NH residents admitted to hospital by ambulance.

3.3. Literature search

A search of PubMed was performed March 30. 2017 with the following MeSH terms; 1) ["Emergency Service, Hospital" AND "Nursing Homes" AND (("Patient Transfer" OR "Patient Admission"] and 2) ["Emergency Service, Hospital" AND "Nursing Homes" AND "Hospital Mortality"]. Search strategy 1 yielded 95 articles while strategy 2 yielded 19 articles, in total 114 articles. After examination of title and abstract, 52 articles were read in

full resulting in 46 included articles. All included articles were read and analysed with the use of a structured tool described by Friberg(27) with the results entered into an Excelspreadsheet (Microsoft, ver.1804). Relevant primary sources were included and analysed using the same tool.

Inclusion and exclusion criteria

Inclusion criteria

- Age > 67 years of age
- Resident of a nursing home
- Transport by ambulance from a nursing home to hospital (or via a general physician (GP)
- Admitted to hospital as an in-patient due to a physical condition

Exclusion criteria

- < 67 years of age
- Contact regarding a non-resident of the nursing home
- Non-medical emergency or not a somatic problem
- Out-patient, transport to nursing home after examination of a GP
- Treated by GP/ambulance on scene.

Table 1 Inclusion and exclusion criteria used during manual sieving of contacts to the EMCC from nursing homes

3.4. Ethical considerations

The goal of this study is not to alter the treatment or prioritization of any group of patients. We had noted a rising concern among our staff concerning NHR being admitted to hospital at stages regarded as the end of life. The study was designed as an improvement of carestudy. This view was supported by the Ethical Board of Bergen Health Trust who waived the study. The Privacy Ombudsman of Bergen Health Trust approved the study (2017/2103).

An argument against a study like ours could be the opinion of the emergency services to regard transports of nursing home patients as low-priority and not within the scopes of an emergency service. In our experience, this is not valid as our colleagues mostly express a

genuine empathy and worry for the well-being of this population and several commit great exceptions to deliver high-quality care to their patients. This view is supported by Murphy-Jones & Timmons who reported that paramedics had a desire to act in the patients best interest(28).

4. Results

4.1. General characteristics

We identified 4663 contacts to the Emergency Medical Control Centre (EMCC). 2332 (50%) of these contacts resulted in admission to one of the three hospitals in the catchment area. There were 1722 individuals being admitted. 2 shows the distribution of gender. Median age was 86 years of age (range 67 - 104). The number of transport for each individual ranged from 1 - 9 with a mean of 1,35.

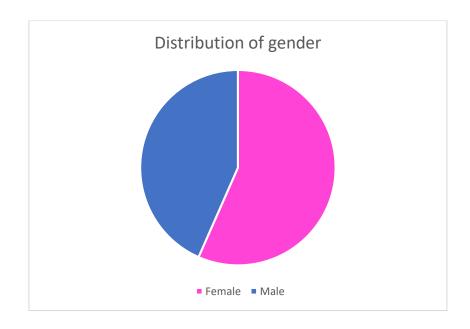


Figure 1 Distribution of gender among nursing home residents admitted to hospital by ambulance

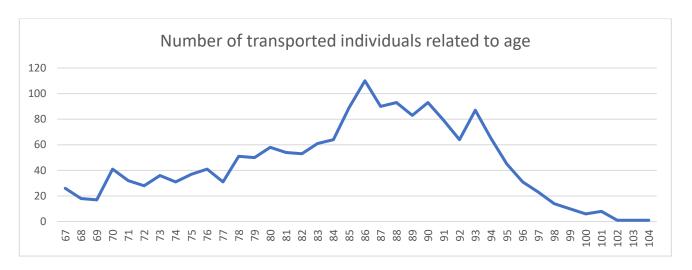


Figure 2 The number of transported individual nursing home residents related to age in 2016

As described in the article, the distribution of categories related to perceived condition was internal medicine 63,8%, orthopaedic 20,2%, surgical 13,5% and other (i.e. oncology, ophthalmology, gynaecological etc.) 2,5% (n=1722). A physician was consulted or assessed the residents prior to admission in 68,2% (n=1722) of the cases.

4.2. Mortality after admission to hospital by ambulance

As described in the article the 7-days mortality for the four main categories was internal medicine 13,9% (n=1098), surgical 10,8% (n=232), orthopaedic 7,1% (n=348) and other conditions (i.e. gynaecology, ophthalmology and oncology) 14% (n=43). A log-rank analysis indicated significantly contrasts between the groups (p<0.01). As we wanted to explore some of the subgroups within the different categories, we isolated hip fractures, respiratory problems and infections for this purpose. The mortality rate for hip fractures (n=159) was 1,3% after 48 hours and 6,9% within 7 days, for infection (n=303) 4,6% the first 48 hours and 16,2% within 7 days. For patients admitted with respiratory problems (n=208), the mortality rate was 7,2% after 48 hours and 21,6% within 7 days.

The mortality for NHR assessed by a physician (n=1174) (either bedside or consulted via telephone) prior to admission was 11,2% within 7 days and 2,8% the first 48 hours. For the residents with no assessment by a physician (n=307) the mortality within 7 days was 16,6% and 7,2% the first 48 hours. Log-rank analysis showed a significant difference between the

groups (p=<0,05). 3 shows the survival among the NHR assessed/not assessed by a

physician prior to admission.

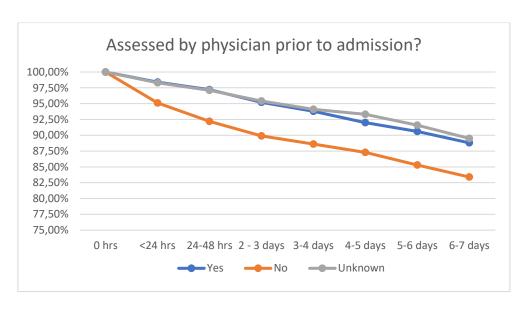


Figure 3 Survival related to assessment of a physician prior to admission to hospital by ambulance.

The Y-axis shows the percentage of survivors and the X-axis shows the progression in time



Figure 4 The survival of women vs. men. Within one week 10,3% of the women had died vs. 14,5% of the men. This is a significant difference as log-rank analysis was p=<0,05.

5. Discussion

5.1. Discussion of methodological issues

5.1.1. Survival time after admission

The aim of this study was to examine the 7-days-survival of nursing home residents admitted to hospital. A key-question is whether a 7-days limit is sufficient to serve as a marker for the appropriateness of admissions. According to a recently published report by the Norwegian Directorate of Health, 28% of deaths in Norwegian NH occurs within six months of admission to the NH. Although beyond the aim of this study, we observed a relatively large proportion of the study population perishing within the first six months after hospital admission. This observation is supported by the study by Dwyer et al. where >50% of the patients died within 6 months(18) and underlines the frailty of the population. The reason to this may be explained by a high co-morbidity as well as a suboptimal function of the organs. Seeing that many NHR are so frail that even a hospital admission for a minor event can cause death within months, we think that a 7-days limit for this study, of which the goal is to examine the appropriateness of hospital admissions, is suitable. A Norwegian study by von Hofacker et al. examined the cases of patients who died within 48 hrs from admission. The aim of this study was somewhat different from ours as the authors set out to describe the features of these patients as well as the services provided to them prior to admission (29). It is however debateable to what extent death may serve as an indicator for this stress as death itself may be caused by a variety of conditions and events. Still, it is one of the few values who is quantitative in this setting.

5.1.2. Gathering and analysis of quantitative data

In this study, the key information system for gathering patient information was AMIS. The use of AMIS is to some degree favourable as it is based on quantitative information such as dates, time stamps and personal identification numbers. Unfortunately, there are some pitfalls. One of these is the categorization of the scene of incident. By manually sieving all contacts from nursing homes, we found several non-related incidents, categorized as occurring in a NH but taking place some other place. The reasons for this could be a caller from a nursing home alerting of incidents taking place outside of the NH, incidents at addresses common to a nursing home or other not explainable reasons. This manual sieving

makes the gathering of data time-consuming when dealing with a large proportion of data and the benefits from the process must be carefully weighed against the impact of the bias made by some irrelevant single entries. However, since we did this manual sieving, all entries should be considered relevant for the study. As EMCC call takers describe the problem of the patient in free text it was to some extent necessary to interpret the condition of the resident. However, the documented problem could usually by entered as "Known COPD, having trouble breathing, Sa02 of 88%" or "Had a fall, left leg is shortened and rotated outwards" leaving little doubt of the actual condition. When there was any doubt we used the oral report from ambulances documented by the EMCC to clarify.

There were some considerations around whether every transport each individual resident made should be included or if we should only use the last transport for each individual in 2016 as a measure point. To keep the workload within the scope of a master thesis we decided to use the last transport for each individual. This may of course alter the results to some degree, but in our view, the challenges and problems related to transfer of NHR to hospital remains well addressed.

5.2. Discussion of results

There are three main results in this study. First, there is a significant difference in mortality between the four main categories. NHR suffering from conditions related to internal medicine had almost twice the risk of dying within the first week of hospitalisation compared to patients with orthopaedic conditions. Residents suffering from diseases related to the respiratory system or infections had up to three times higher risk of dying within one week compared to orthopaedic patients and two times higher than general surgical patients. However, the risk was low for patients with hip fractures, indicating that these patients benefits from the treatment provided in hospital. This is supported by Gjertsen et al.(30) who reported decreased mortality with a risk ratio (RR) of 0,87 (0,83-0,91) compared to earlier data. RR < 1 indicates that the patient benefits from treatment. In Ranhoff & Linnsunds paper there are several conditions listed where hospital admission can be beneficial for NHR, among others hip fractures and infections(17). In our study we find a significant difference in mortality between these two groups. One reason may be that injuries such as fractures are acute and if care is provided within reasonable time there are

few serious consequences. Patients with infections or respiratory problems may have slow onset and can be difficult to detect early in the illness trajectory. To improve survival in these groups there is a need for earlier detection of illness. To achieve this there seems to be a need for improved level of competence in nursing staff, the ability to provide advanced care in NH and continuous services by general practitioners as proposed by both Ranhoff & Linnsund(17), Arendts et al.(16). and Graverholdt et al.(2). This is also supported by the second main finding in our study of which there is a significant lower morality rate among residents who were assessed by a physician prior to admission. This indicates that assessment of a physician function as a filter and that the patients with the best opportunity for survival or improved function level are admitted. However, as addressed by Tingström et al.(31), development of the Early Detection of Infection Scale acts as support for nurses in their decision-making, evaluating and treatment of these patients. On the other hand, our result with higher survival rate among patients assessed by a physician, may reflect the nature of acute illness, which calls for immediate admission to hospital, without time for the physician to respond to the NH. As discussed in the article, the ACADEMIA-study(32) confirmed the presence of antecedents to cardiac arrest, death and admission to intensive care units. Kawaguchi et al., Konrad et al., Herod et al. and Chen et al. all reported improved outcome, reduced mortality and decrease in adverse events after implementation of a Rapid Response System (RSS)(33-36). Implementation of a similar system in NH can lead to similar outcomes provided that the necessary resources, such as easy access to physicians, are available.

The third main result was a significant higher mortality among men compared to women (14,5% vs. 10,3% within 7 days). This is to our knowledge undescribed in similar studies. However, this result can be related to the general lower life expectancy for men compared to women. The national survey of time of stay in NH describes that women lives longer in NH than men with a mean time of stay before death of 3 years vs. 1,68 years for men(8). Although this may be an expression of men being admitted to NH in a later stage of illness than women, it can also be an expression of our findings.

5.3. The results in context to theoretical framework

There is a general impression, as described by Arendts et al.(16), of health care providers in NH with a genuine wish to deliver high quality care to their residents. At the same time, they describe a reality with inadequate staffing, lack of resources for advanced care and sometimes troubled communication with the general practitioner (GP).

Norwegian legislation(10) requires health care providers to involve the patient when forming services and the need for a valid consent when initiating examinations or treatment. Based on Arendts et al. findings and our results with a large proportion of NHR perishing within 7 days after admission it is a reasonable question if legislative requirements are always met.

Early detection of illness, as discussed in chapter 5.2., is important to avoid unwarranted admission of NHR. This is not only important for improved survival, but it is also shown by Dwyer et al.(18) that adverse events are common among hospitalized NHR. Combined with the high frequency of procedures this population are subject to during hospitalization, a reduction in avoidable admissions of NHR could have some impact on health economics. As Chou et al.(21) demonstrated the cost for ED visits by NRH is higher than for other patients and in the context that some of these admissions can be avoidable, either through sufficient resources and treatment options in NH, bridging of the information gap between NHs and hospitals or vice versa or by solving the problem of "revolving door" patients, a better use of available economic resources can be achievable.

5.4. Implications for practice

The findings in our study suggest that there is a need for policy makers to further adapt and transform health services in order to provide good quality health care to a growing elderly population. This includes a rise in nursing staff and increased availability of general practitioners. Both on institutional level and national level there is a need for developing and implementing systems for detecting illness prior to the acute phase to improve survival and functional level of NHR after hospital admissions. An implementation of such systems will at the same time call for improved education for both nurses and physicians in advanced care and decisions adjacent to this. Pathways for common conditions can help

reduce the economic costs involved and at the same time reduce time-of-stay in the ED/hospital and therefore minimize the risk of adverse events.

5.5. Limitations

There are several limitations to this study which should be addressed. First, it was not possible to differentiate between NHR in short term beds and long-term beds. As short-term beds are used for both elderly people needing a temporary stay in a NH and patients discharged from hospital waiting for a long-term bed, our results may be slightly skewed as this is a group of residents who can be slightly more unstable than the remaining population.

It is uncertain whether the patients were considered as dying by the NH staff at the time of admission. A 7-days-life span may be inadequate as an indicator of the appropriateness of transport/admission, as the population of the study is frail and prone to develop other life-threatening conditions, even within a week. In our opinion it may however serve as an indicator and considered the number of subjects in our study still should be considered adequate. In difference to other studies we did not review hospital charts to categorize the patient's problem. We wanted to use the perceived problem of NH staff and we are aware that the training and education of this group may vary. However, it is based on the precepted problem that the decision to request ambulance transport is made. We therefore find it feasible as method.

The residents in the group with "other" conditions had a high 7-days mortality. This is probably a result of a fairly large proportion of patients with cancer where the goal for the admission is palliative care. Based on this, the high mortality in this group seems reasonable and therefore we did not perform any further analysis. Future research should investigate the rationale behind admitting NHR to hospital for palliative care.

6. Conclusion

In this study we have demonstrated a higher mortality of nursing home residents admitted to hospital with an internal medical condition compared to surgical and orthopaedic conditions. Respiratory problems and infectious disease are predictors of high mortality. Residents assessed by a physician prior to admission have a higher likelihood to survive

which may indicate that involving a physician releases other treatment options at the nursing home. However, little is known of the factors leading to hospital admissions of NHR in Norway and further research is needed to gain understanding of the measures needed to provide safe and good quality health care to an already frail population.

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Article

Title

Mortality of Nursing Home Residents Admitted to Hospital

Authors

Kristian Furuskjeg, Akuttmedisinsk Avdeling, Haukeland Universitetssykehus, 5021 BERGEN, furk@helse-bergen.no
Bård Heradstveit, Akuttmedisinsk Avdeling, Haukeland Universitetssykehus, 5021

BERGEN, baeh@helse-bergen.no

Conflict of interest

None

Contribution

In accordance to the ICMJE Recommendations we declare that both Kristian Furuskjeg (KF) and Bård Heradstveit (BH) has contributed to this article. KF has been responsible for data gathering and writing of the article. BH has contributed with statistical analysis and revision of the article. Both authors have read the final result and have given approval of its contents.

Abstract

Introduction: Reports of adverse events related to admission of nursing home residents indicates that hospital admission is not always in the patients' best interest. Few terminally ill patients survive the acute phase and the survivors are prone to introgenic events and a decline in functional level.

Aim: The aim of this study was to explore the 7-days survival of nursing home residents admitted to hospital by ambulance and to explore if there were any groups more prone to deaths within one week of admission.

Method: This is a retrospective, observational population-based cohort study. All contacts

from nursing homes to the Emergency Medical Control Centre resulting in a hospital admission was analysed and survival was estimated using Kaplan-Meier and log-rank test was performed.

Results: 1772 individual residents where admitted. The mortality for residents with problems related to internal medicine was significantly higher than for surgical and orthopaedic conditions (p=<0,05). When isolated into subgroups, 16,2% of the residents with infectious disease died within one week and 21,6% of the patients with respiratory conditions. Patients admitted without being assessed by a physician had a significantly higher mortality than those who had been assessed (7,2% vs. 2,8%, p=<0,05) Conclusion: In this study we discovered a significantly higher risk of dying in the subgroups we identified as infectious disease and respiratory problems. In addition, the difference in mortality among those assessed by a physician compared to those who were not assessed indicates that the general practitioner on call plays a vital role in providing access to the correct level of care.

Key words

Long-term care, nursing home, emergency, transitional care, emergency services, mortality

INTRODUCTION

Nursing home residents transported by ambulance accounts for about 10% of all transports in our system. There are reports of adverse events from both paramedics in our system and in existing literature, indicating that these transports may not always in the patients' best interest[1]. However, calls involving end-of-life conditions are not easy and often transport to the emergency department is viewed as the best option[2]. The majority of hospitalised patients are older adults, a population with complex problems, medications and are susceptible to iatrogenic events and hospital death. As vulnerable patients, they have a need for protection from potential harmful interventions[3]. Nursing home residents (NHR) have more than twice a risk of hospitalisation compared to an equal population in the community[4]. In the preface of the Norwegian Coordination Reform, elderly ill patients and patients with chronic conditions are considered as one group of patients loosing due to insufficient coordination of the Norwegian health system[5]. Palliative care in the nursing home (NH) may seem to be the most appropriate option in some cases[6] and there are few terminally ill patients who survive the acute phase of a hospital admission. The survivors are prone to complications such as decubitus, nosocomial infections and agitation with subsequent falls[7]. According to a report by the Norwegian Directorate of Health, 28% of deaths in nursing homes occurred within 6 months of admission to the NH, probably reflecting their physical condition. The average time from admission to death was two years[8]. Hospital admission can be suitable when the resident's wishes for treatment changes or a reversible reason for contact is identified[2].

The aim of this study was to explore the one-week survival of NH residents admitted to hospital by ambulance and to explore if there were any groups more prone to deaths within one week of admission.

METHODS

Setting

We examined hospital admissions of NHRs in Hordaland County, Norway. This area mainly refers to the dispatch centre located at Haukeland University Hospital, Bergen (HUS) There are three hospitals in this area, the regional hospital for western Norway, Haukeland University Hospital (HUS), and two local hospitals, Voss Hospital (VH) and Haraldsplass Diaconal Hospital (HDS). All three hospitals offer acute care with both medical and surgical capacity. The dispatch centre at HUS is responsible for ambulance services with 30 ambulances located in 24 municipalities. It is staffed by EMTs trained in vocational school, paramedics and/or registered nurses. The hospital trust is responsible for ambulance services in their area while the municipalities are responsible for health care provided to the residents in the municipality. The ambulance service cooperates with local acute care clinics staffed by physicians and nurses. The physician on call provides acute

health care where the patient is located and serves as a gatekeeper between the community and the hospital.

Study population

Hordaland county has 72328 inhabitants over the age of 67 (16,8% of the total population) of which 3190 (4,4%) are residents receiving long-term care in NHs in 2016[9]. The level of care in Norwegian NHs are at the level of skilled nursing homes in other studies[4]. Norwegian regulations define them as facilities providing 24-hour care with relevant nursing, medical and rehabilitation capabilities. Most NHs offer care on both a short- and long-term basis. Short-term beds are used for persons requiring rehabilitation before returning to their home or whenever temporary assistance is needed[10].

Reason for transport and hospitalisation

The reason for transport and hospitalisation was obtained from the records at the dispatch centre (Acute Medical Information System (AMIS), CSAM Health AS) based on the NH staff's perception of the patient's condition. We categorized the patients in four categories; orthopaedic, surgical, internal medicine and other (i.e. gynaecology, ophthalmology and oncology).

Data collection and analysis

We conducted a retrospective search of all contacts from NHs in Hordaland County to the EMCC in our health trust. The included period was January 1. 2016 – December 31. 2016 and all information was gathered from AMIS and the National Population Registry (NPR) accessed through the hospital's electronic records. Patients were included if they met the following criteria: Age > 67 years, resident of a NH, ambulance transport from NH to hospital (direct admission or via physician on call) and admission to hospital as an inpatient due to a physical condition. In Norway, transport to the ED equals hospital admission. Table 2 describes the flow of data collection. Data were entered in and analysed using SPSS® (IBM® version 25). To estimate survival, Kaplan-Meier plots and log-rank analyses were used for determining statistical contrasts between groups. Results were considered significant with a p-value < 0,05.

Ethical considerations

The Regional Committee for Medical and Health Research Ethics considered the study to be a quality insurance study. The Privacy Ombudsman of Bergen Hospital Trust approved the study (2016/1643). All information has been treated confidentially and no persons can be identified.

RESULTS

We identified 4663 contacts to the EMCC resulting in 2332 (50%) hospital admissions by ambulance. This constituted 1722 individual patients.

General characteristics

56,6% (n=1722) of the patients were female. Median age at the time of transport was 86 years of age (range 67 – 104). We identified a total of 88 nursing homes (NH) admitting patients to the hospitals in the region. Haukeland University Hospital (HUS) received most of the patients, 1185 (68.8%), while Haraldsplass Diaconal Hospital (HDS) and Voss Hospital (VH) received respectively 375 (21,8%) and 162 (9,4%) patients. In 49,5% of the cases, ambulance was dispatched at code yellow, followed by code red (31%), and code green (19,6%). The frequency of reasons for admission are listed in figure 1. 68,2% (n=1722) of the patients were assessed by a physician (either bedside or consulted via telephone) prior to admission.

Survival after transport

The one-week mortality for the four main categories was internal medicine 13,9% (n=1098), surgical 10,8% (n=232), orthopaedic 7,1% (n=348) and other (i.e. gynaecology, ophthalmology and oncology) 14% (n=43), (p<0.01). The mortality rates the first 48 hours following admission were respectively for the internal medicine 5%, surgical patients 1,7% and orthopaedic patients 1,4%. None of the patients in the group other died within 48 hours.

As we wanted to explore some of the subgroups within the different categories, we isolated hip fractures, respiratory problems and infections. The mortality rate for hip fractures was 1,3% (n=159) after 48 hours and 6,9% after one week, for respiratory problems 7,2% (n=208) after 48 hours and 21,6% after one week. For patients admitted with infection, the mortality was 4,6% (n=303) the first 48 hours and 16,2% the first week. (Figure 6).

DISCUSSION

Our results show a significant higher rate of mortality for residents admitted with internal medicine conditions compared to those with orthopaedic conditions. When comparing residents with hip fractures to those with respiratory problems, the mortality of the latter was three times higher. This study was performed to identify the mortality among NHR admitted to hospital, as high mortality could indicate a need for better care in NH. The age of 67 years was chosen as this is the age where you obtain general pension benefits in Norway and it also corresponds to the age used in Graverholdt et al.'s study of nursing home patients in Bergen, Norway[4]. The municipality of Bergen is part of Hordaland County, the catchment area of the Emergency Medical Control Centre in our system.

Graverholdt et al. found that in-hospital mortality rate was 16% (n=404) when assessing NH residents transferred to hospital. The mortality was highest for respiratory diseases followed by infectious diseases. The overall mortality rate of the NH population 30 days after discharge was 29% [4]. In this study Graverholdt et al examined both hospitals serving the municipality of Bergen (HDS and HUS) and the results in their correlates to some extent with ours. The in-hospital mortality rate for respiratory disease and infectious disease showed by Graverholdt et al. was respectively 30% and 24% while we found 21% and 16%, respectively. These differences can be explained by the differences in time of measurement as Graverholdt et al. used in-hospital death as variable while we on the other hand set a limit of 7 days. It is not unlikely that some of the deaths in Graverholdt et al. study occurred later than 7 days. The method for dividing residents into groups differs as well, Graverholdt et al. used ICD-10 to categorise while we have used the perceived problem by NH staff.

Partridge points out in an editorial, the need for understanding how to deliver care in an end-of-life setting in NHs and states that there is a need for more training and better interdisciplinary teamwork[11]. As hospitalization may not be in the best interest of the patient, is supported by other S[1 7 12 13]. A guide published by the Norwegian Directorate of Health outlines what may be considered as life prolonging treatment: cardio-pulmonary resuscitation (CPR), respiratory- or cardiovascular stimulating treatment, delivery of nutrition or fluids either intravenously or through tubes, dialysis, antibiotic- or chemotherapy. Futile treatment is defined as treatment with no effect, low probability of effect, low benefit from treatment compared to side effects and low cost-benefit effect of the treatment [14]. However, as described by Gruneir et al., there is a lack of definition of what a preventable acute care use is and there is no clear definition of what is considered preventable admissions[15]. In our study we discovered that the mortality rate within one week for NHR with femoral neck fractures was low (6,9%). Treatment of conditions such as femoral neck fracture should not be considered futile as the patients gain high benefit from treatment compared to a relative low risk or side effects. Conservative treatment of these patients is associated with poorer prognosis compared to surgical intervention. The only exception is patients at the final stages of life[6].

There are three topics emerging from several studies regarding prevention of hospital admissions of NHR; education, staffing and the use of advanced care plans. The nurses interviewed by Stokoe et al. regarded continuity of staff as important to treat residents in the NH, as well as trust to staff. Although, the same respondents pointed to low nursing staff as an obstacle to treat the NHR as desired in the NH with the result that admission to hospital[16]. This is supported by von Hofacker et al. who discovered 4 of 26 admissions where lacking competence in the NH was stated as reason for admission. Also, the availability of a GP on call is problematic as there was not any pre-admission contact with a physician in 8 of 26 admissions in von Hofacker et al.'s study. In addition, 8 patients

arrived at hospital without any medical reason given in the admission letter and 17 of 26 patients were considered to be eligible to palliative treatment in the NH[17].

Stokoe et al. reports of NH staff being confident in their role when residents with chronic conditions deteriorates. Such guidelines can be developed by a general physician or palliative care clinicians and can be developed for several common emergencies among this population. When such guidelines are not in place the staff can have a sensation of not being able to care for them properly, a feeling that is more prominent when a GP is not available. The staff express that they use the support of ambulance services when the situation demands for it[16], but the level of care the paramedics in Stokoe et al.'s study can deliver goes beyond the level of care provided by Norwegian ambulances. Based on the findings in von Hofacker et al.'s study of admissions to a Norwegian hospital[17] it seems possible that nursing staff contacts the emergency medical control centre (EMCC).

The ACADEMIA-study, an international multi-centre study, confirmed previously findings of certain antecedents to events such as cardiac arrest (CA), deaths and intensive care unit (ICU) admissions. In all, Kause et al. were able to identify eight specific antecedents[18] and the question was raised whether some of these adverse events were avoidable [19]. Although the MERIT-trial could not confirm that the introduction of a Medical Emergency Team (MET) as a Rapid Response System (RRS) improved the outcome for patients with clinical signs suggesting a deterioration, there are several studies reporting of an improved outcome either in form of reduced hospital mortality or a decrease in adverse events[20-23]. Although these studies investigated an in-hospital population there can be lessons learnt when caring for nursing home residents as the reported mean age in Konrad et al.'s study was 66[21] and in Herod et al.'s study 70[22]. The rationale behind implementing the RRS is that early intervention can under certain conditions prevent more serious events and the reported age-distribution in the mentioned studies seems to suggest that the method is feasible for older adults. A lack of skilled nursing resources is however reported with an extended use of nurse assistants. This can result in one nurse being responsible for as many as 40 patients at weekends and the nurses describe a situation where several administrative tasks brings the focus away from patient-centred care [24]. Tingström et al. addressed by developing Early Detection of Infection Scale (EDIS) to be used by nursing assistants, and they conclude that reported changes in EDIS by nurses assistants should be taken seriously and statements like "he's/she's ill/not as usual" should lead to further action by the nurse[25].

Another way of addressing the deteriorating NHR could be by implementing the use of wearable or non-wearable technologies. This could be done by measuring respiration, pulse, restlessness, gait speed, stride length and stride time where any abnormalities are reported to staff in computer-based interfaces[26]. There are several issues with this way of detecting changes in the resident's health, first and most important is the personal integrity. The participants in a project examining non-wearable technologies were willing to live with

technology when it is unobtrusive, the data collected is controlled and there is a perceived need for it by the user[26].

A rule of thumb in Norwegian health legislations is the rule of patient consent. The Act on health and rights regulates both the patients right to information and the demand for consent. It also specifically states that a patients has the right to oppose life prolonging treatment[27]. This is in sharp contrast to the findings by Arendts et al. where residents did not feel informed about reason for transfer to hospital or their medical treatment[28]. However, as this is not a Norwegian study it is uncertain to which degree the results will be transferable to a Norwegian setting, and to our knowledge there is no Norwegian studies examining the NHR experiences surrounding hospital admissions.

LIMITATIONS

There are several limitations to this study. First, it was not possible to differentiate between NH residents in short term beds and long-term beds. As short-term beds are used for both elderly people needing a temporary stay in a NH and patients discharged from hospital waiting for a long-term bed, our results may be slightly skewed as this is a group of residents who can be slightly more unstable than the remaining population.

It is uncertain whether the patients were considered as dying at the time of admission. A one-week-life span may be inadequate as an indicator of the appropriateness of transport/admission as the population of the study is frail and prone to develop other life-threatening conditions, even within a week. In our opinion it may however serve as an indicator and considered the number of subjects in our study still should be considered adequate. In contrast to other studies we did not review hospital charts to categorize the patient's problem. We used the perceived problem of NH staff and we are aware that the training and education of this group may vary. However, it is based on the precepted problem that the decision to request ambulance transport is made. We therefore find it feasible as method.

CONCLUSION

In our study we discovered a significant higher mortality rate among some subgroups of nursing home residents being admitted to hospital in ambulance. Care plans have previously been shown to help nursing home staff to manage the situation when residents with chronic illness deteriorates. In addition, there are methods that can be used to standardise observation of the resident to discover those who are deteriorating. Such methods can be based on both clinical impressions and technological data. Both standardised methods and care plans should be used to discover residents at risk and to prevent hospital admissions of already frail patients. However, there is a need for sufficient resources, such as staff and availability of a general practitioner to gather clinical and technological information and to act on in when necessary. Future research should be done to explore both the rationale behind emergency admissions of nursing home residents and

to develop and validate the use of standardised approaches in the effort to discover the deteriorating residents early in the illness trajectory.

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TABLES

Search in Acute Medical Information System (AMIS) for all contacts from nursing homes to the Emergency Medical Control Center (EMCC)

- AMIS-search for all contacts from nursing homes to EMCC
- All contacts entered in spreadsheet and included or excluded based on sort of contact.

Manuel sieving of all related contacts

• This is vital as there are a number of non-urgent contacts from nursing homes regarding both residents with social related problems, non-medical situations (i.e. a fire alarm going off) or employees with sudden illness.

Exclusion of remaining patients not meeting the inclusion criteria

- Included if meeting the criteria:
 - Residents of a nursing home
 - > 67 years of age
 - Admitted to hospital by ambulance either by EMTs/paramedics or general practitioner on call

Search in hospital electronic records (DIPS) for information from the National Population Registry (NPR)

• Based on 11 digit personal identity number obtained from event in AMIS, the NPR was searched for date of death.

Crossmatching of information from AMIS and NPR

Information from AMIS:

- Date of transport
- Gender
- Age at the time of transport
- Number of transports in 2016
- Reason for transport
- Reffering facility
- Proffession of admitting personell
- From NPR
 - Date of death

Table 2 Flow chart for data collection

Reason for exclusion	Explanation
Out-patient, transport to nursing home after	Transported to an out-patient clinic
examination by general practitioner (GP)	Admitted to ED to resolve problems with
on call	suprapubic catheter or urethral catheter
	Other admissions to ED and treated as out-
	patient
	Patients treated at office by GP on call
Non-medical emergency or not a somatic	Contact from nursing home regarding a
problem	non-medical emergency i.e. fire, the need
	for help carrying immobile patients down
	stairs
	Mental diseases
Contact regarding a non-resident of the	Sudden illness among staff, relatives or
nursing home	someone outside the nursing home
Patient treated on-scene	The patient received treatment on-scene by
	ambulance staff and GP on call or by
	ambulance staff only (requires contact by
	phone with the GP on call in the
	municipality)
Age < 67 years of age	

Table 3 Reasons for exclusion during manual sieving of contacts to the EMCC

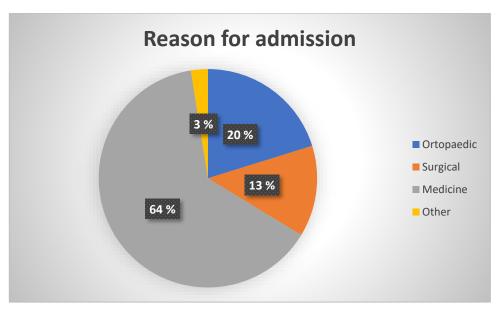
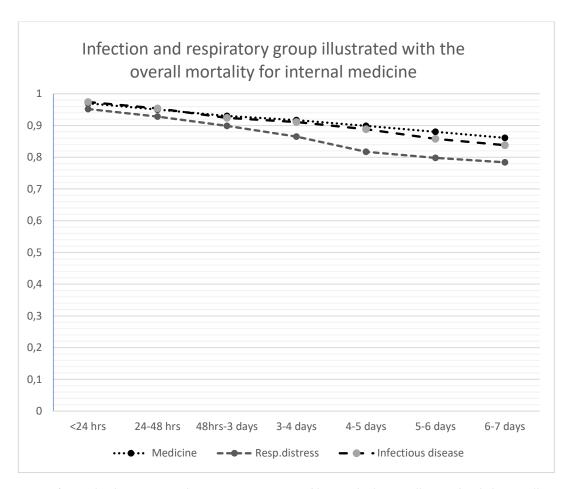


Figure 5 Reason for admission to hospital from nursing homes to hospital



 $Figure\ 6\ Mortality\ for\ patients\ in\ the\ groups\ respiratory\ problems\ and\ infections\ illustrated\ with\ the\ overall\ mortality\ for\ internal\ medicine$

Appendix 1 Guide to Authors, link to BMJ Quality and Safety

The British Medical Journal's "Guide to Authors" is available at: http://qualitysafety.bmj.com/pages/authors/

Appendix 2 Copy of email from The Ethical Board of Bergen Health Trust

Vår ref. nr.: 2016/1643

Prosjekttittel: "Ambulansetransport til/fra sykehjem"

Prosjektleder: Bård E Heradstveit

Til Bård E Heradstveit.

Vi viser til framleggingsvurdering innsendt 20.09.2016.

Min forståelse av prosjektet

Ambulansepersonell opplever ofte at pasienter i livets sluttfase fraktes fra sykehjem og innlegges i sykehus. Studien vil se på transporter fra sykehjem til LV/sykehus, sammenholdes med diagnose og evt tidspunkt for død. Formålet med studien er å vurdere hvorvidt transportene er unødvendige/skadelige.

Vurdering

Helseforskningsloven gjelder for medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale eller helseopplysninger, jf. hfl § 2. Medisinsk og helsefaglig forskning defineres som virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom, jf. hfl § 4. Helse- og omsorgsdepartementet sin veileder til helseforskningsloven definerer kvalitetssikring som prosjekter, undersøkelser og evalueringer som har som formål å kontrollere at diagnostikk og behandling faktisk gir de intenderte resultater. Slike prosjekter regnes som en del av helsetjenesten og trenger ikke søke REK. Etter min vurdering er dette en evaluering av om den helsetjenesten man gir (sykehustransport) gir ønsket resultat. Dette er dermed å anse som et prosjekt som kan gjennomføres som en del av helsetjenesten, og det kreves ikke søknad til REK.

Jeg gjør oppmerksom på at konklusjonen er å anse som veiledende jfr. forvaltningsloven § 11.

Dersom du likevel ønsker å søke REK vil søknaden bli behandlet i komitémøte, og det vil

bli fattet et enkeltvedtak etter forvaltningsloven.

Vær også oppmerksom på at siden du skal samle inn personopplysninger, så må prosjektet klareres med Personvernombudet for forskning ved Helse Bergen HF.

Med vennlig hilsen

Øyvind Straume

seniorkonsulent

post@helseforskning.etikkom.no

Regional komité for medisinsk og helsefaglig forskningsetikk REK vest-Norge (REK vest)

http://helseforskning.etikkom.no

Appendix 3, Letter of approval from The Privacy Ombudsman of Helse Bergen, 3 pages.





Bård Einar Heradstveit, Haukeland universitetssykehus, Kirurgisk Serviceklinikk bard einar heradstveit@helse-bergen.no

 Deres ref:
 Vår ref:
 Saksbehandler
 Bergen,

 2017/2103
 Christer Kleppe, 55975558
 15.02.2017

Uttalelse fra personvernombudet

Viser til innsendt melding om behandling av personopplysninger / helseopplysninger. Meldingen gjelder prosjektet:

2017/2103 Overlevelse etter ambulansetransport fra sykehjem til sykehus

Det følgende er en formell tilråding fra personvernombudet. Forutsetningene nedenfor må være oppfylt før innsamlingen av opplysningene / databehandlingen kan begynne.

Formål:

Prosjektets formål er å undersøke hvor mange oppdrag ambulansetjenesten i Helse Bergen utfører med transport av syke/skadete eldre, hvordan oppdragsmengden fordeler seg i forhold til en grovinndeling av tilstand og hvor lenge pasientene lever etter transport. Prosjektet vil avklare om pasienter kunne vært bedre ivaretatt på sykehjemmene og om svært syke/døende pasienter utsettes for en ekstra belastning.

Vurdering:

Prosjektet har blitt fremlagt for REK som har kommet til at prosjektet faller utenfor helseforskningsloven. I meldeskjemaet fremgår det at formålet med prosjektet er intern kvalitetssikring i Helse Bergen HF.

På bakgrunn av opplysninger i meldeskjema legger Personvernombudet til grunn for tilrådningen at (1) prosjektet har til formål å forbedre kvaliteten på behandlingen internt i Helse Bergen HF, (2) prosjektet vil evaluere praksis mot etablerte standarder, og (3) det skal ikke gjøres noe med pasienter som ikke ellers ville blitt gjort som ledd i vanlig klinisk praksis og kvalitetssikring.

Videre forutsettes det at kvalitetssikringsprosjektet gjennomføres etter oppdrag fra ledelsen, og at person-/helseopplysninger ikke behandles i større grad (tid/varighet/omfang/grad av identifisering) enn hva som er absolutt nødvendig for formålet.

Personvernombudet har vurdert det til at den planlagte databehandlingen faller inn under helsepersonelloven § 26: Den som yter helsehjelp, kan gi opplysninger til virksomhetens ledelse når dette er nødvendig for å kunne gi helsehjelp, eller for internkontroll og kvalitetssikring av tjenesten. Opplysningene skal så langt det er mulig, gis uten individualiserende kjennetegn.

Krav til databehandlingen:

Dersom prosjektet skal kunne gjennomføres som et internt kvalitetssikringsprosjekt, forutsetter det at Helse Bergen er databehandlingsansvarlig for de systemene som opplysningene skal hentes fra.

Videre forutsettes det at person-/helseopplysninger ikke skal behandles i større grad (art, omfang, tid mv.) enn hva som er absolutt nødvendig for formålet.

Det fremgår av meldeskjemaet at det skal behandles informasjon om et stort antall pasienter (5 500). Personvernombudet har ikke innvendinger til dette, under forutsetning av at ansvarlig avdeling på forhånd har vurdert om det er nødvendig med et så omfattende datasett for å oppfylle formålet med prosjektet.

Videre fremgår det at data skal lagres til 31.12.2028 til tross for at prosjektets sluttdato er 31.12.2018. Det fremstår da som om person-/helseopplysninger lagres i lengre tid enn hva som er nødvendig for gjennomføringen av prosjektet. Undertegnede kan ikke tilråde at person-/helseopplysninger lagres etter at prosjektet er avsluttet. Anonymiserte data kan imidlertid lagres etter prosjektslutt. Personvernombudet minner om at dataene ikke kan anses som anonyme dersom det er mulig å knytte opplysningene til enkeltpersoner. Så lenge data lagres på individnivå.

Fra prosjektbeskrivelsen fremstår det som om AMIS-løpenummer skal registreres i prosjektet med sikte på mulige oppfølgingsstudier. Det understrekes at person-/helseopplysninger (herunder også unik ID fra fagsystemer) bare kan registreres i den grad det er nødvendige for gjennomføringen av *dette prosjektet*. Det forutsettes at prosjektleder og ansvarlig avdeling har vurdert og tatt stilling til om opplysningene som skal registreres er nødvendige for gjennomføringen av prosjektet, og begrenset datasettet til det som er absolutt nødvendig. Det kan ikke registreres ekstra data med sikte på fremtidige prosjekter som ikke har et behandlingsgrunnlag enda.

Det bemerkes at data skal lagres identifiserbart på kvalitetsserveren. HBE-rutiner forutsetter at data skal lagres avidentifisert, med koblingsnøkkelen på et eget nøkkelområde. Unntak fra rutinene må særskilt risikovurderes. Dersom det er behov for å lagre data identifiserbart under datainnsamlingen må prosjektleder først bestille en risikovurdering fra IKT-sikkerhetsleder.

Tilrådning:

Personvernombudet tilrår at kvalitetsprosjektet gjennomføres under forutsetning av følgende:

- 1. Avdelings-/klinikkdirektør som har besluttet at dette prosjektet skal gjennomføres for å sikre kvaliteten på tjenestetilbudet internt.
- 2. Opplysninger skal bare samles inn og behandles i den grad det er nødvendig for å ivareta formålet med prosjektet. Dersom prosjektet kan gjennomføres ved at anonyme data lagres, eller ved et mindre datasett mv. skal dette mindre inngripende alternativet velges.
- 3. Bare data som Helse Bergen HF er databehandlingsansvarlig for inngår i prosjektet.
- 4. Behandling av helse- og personopplysningene skjer i samsvar med og innenfor det formål som er oppgitt i meldingen.
- 5. Tilgangen til registeret skjer i overensstemmelse med taushetspliktbestemmelsene.
- 6. Data lagres avidentifisert på helseforetakets Kvalitetsserver. For å få tildelt plass på Kvalitetsserveren må saksnummer på denne godkjenningen (under Vår ref) fylles ut i søknadsskjemaet og selve tilrådingsbrevet må også legges ved. Søknadsskjema finnes på: Helse Bergen Innsiden Personvernombudet for Helse Bergen Annen elektronisk lagringsform forutsetter gjennomføring av en risikovurdering som må godkjennes av foretakets IKT-sikkerhetsleder/personvernombud. Prosjektleder må evt. bestille risikovurdering fra IKT-sikkerhetsleder.
- 7. Kryssliste som kobler avidentifiserte data med personopplysninger lagres enten elektronisk på tildelt område på Kvalitetsserveren eller nedlåst på prosjektleders kontor.
- 8. Data slettes eller anonymiseres (ved at krysslisten slettes) innen prosjektslutt 31.12.2018. Når formålet med registeret er oppfylt sendes melding om bekreftet sletting til personvernombudet.
- 9. Prosjektet kvalifiserer ikke som medisinsk- og helsefaglig forskning slik det er definert i helseforskningsloven, men kan bli publisert som "sykehusets erfaring" eller i "quality improvement reports", som for eksempel i British Medical Journal. Du kan bruke bekreftelsen

fra Regional komité for medisinsk og helsefaglig forskningsetikk (REK) om at prosjektet ikke er fremleggingspliktig som dokumentasjon dersom dette kreves av tidsskriftet.

- 10. Dersom det senere blir aktuelt å forske på det innsamlede materialet, må det søkes om godkjenning fra REK før forskningen starter, se http://forskning.ihelse.net.
- 11. Dersom formålet eller databehandlingen endres må personvernombudet informeres om dette.

Vennlig hilsen

Christer Kleppe

Personvernombud

Haukeland Universitetssykehus, Helse Bergen HF

Kopi til:

Hanne Klausen