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How well are the diagnosis and symptoms of dementia recorded in older patients admitted to hospital?

Abstract:

Introduction

In the United Kingdom dementia is generally diagnosed by mental health services. General hospitals are managed by separate healthcare trusts and the handover of clinical information between organisations is potentially unreliable. Around 40% of older people admitted to hospital have dementia. This group have a high prevalence of psychological symptoms and delirium. If the dementia diagnosis or symptoms are not recognised, patients may suffer unnecessarily with resulting negative outcomes.

Methods

To understand areas of unmet need we have described the prevalence of dementia in over 75 year olds admitted to a general hospital, the accuracy of diagnostic recording, and the prevalence of recorded psychological symptoms and delirium. To achieve this we conducted a retrospective review of 116 patients admitted to hospital with known dementia. Psychiatric and medical notes were reviewed, identifying the accuracy dementia diagnosis recording by the hospital and all episodes of documented psychological symptoms and delirium.

Results

The prevalence of documented dementia in the population was estimated at 15%. 74% of dementia diagnoses were recorded in the medical notes. 10% had documented psychological symptoms (depression 4%, anxiety 3%, hallucinations 3%, delusions 4%), 11% had documented delirium. There were no associations between the specialty providing care and the recognition of dementia or the reporting of symptoms.

Discussion

This work suggests an underreporting of dementia and symptoms associated with it in the general hospital. Improving this this requires closer collaboration between metal health and hospital healthcare services and training for staff on how to access diagnostic information and recognise common psychological symptoms.

Introduction:

In the United Kingdom (UK), it is recommended that dementia is diagnosed by a dedicated memory service [1]. In the mainstay this service is managed by psychiatrists working in community mental health services, however depending on local arrangements some cases maybe diagnosed by neurologists, physicians or general practitioners. The diagnosis and clinical information is stored in the patient's psychiatric notes and their general practitioner (GP) is informed of it. It is estimated that 61% of all patients with dementia in the UK living in the community receive a formal diagnosis, although figures vary between geographical regions [2].

Physical health is generally managed by a separate healthcare provider to mental health services. When a patient with known dementia is admitted to hospital, there is no formal system to communicate this clinical information between healthcare providers. Due to data protection safeguards, the direct sharing of patient records between healthcare services is not routine. Instead, this information is provided informally (and therefore potentially inconsistently) via the patient, carer, or GP.

Dementia is prevalent in 42% of older people admitted to general hospital [3] though published prevalence figures range from 5-45% [3-11]. Patients with dementia often have difficulty communicating their needs, and in a hospital setting have a high prevalence of delirium (66%) [12], and psychological symptoms in the absence of delirium (depression (34%), anxiety (35%), delusions (11%) and hallucinations (15%)) [13]. The presence of psychological symptoms are associated with increased agitation and falls [13]. The presence of delirium is associated with increased morbidity, mortality and length of hospital stay [14]. If the dementia diagnosis or the symptoms commonly associated with dementia are not identified and accounted for, patients are likely to suffer and experience worse outcomes.

Current attempts to identify hospitalised patients with dementia in England include asking all patients over the age of 75 years whether they have a dementia diagnosis, and routine screening for cognitive impairment [15]. UK hospitals are largely compliant [2], however without direct access to the psychiatric or primary care notes, information sources maybe unreliable. In addition, although the presence of cognitive impairment is highly predictive of dementia, it is not diagnostic and may simply reflect delirium as a consequence of reversible aetiology.

Several standardised tools exist in order to assist clinicians identify delirium, and psychological symptoms in patients who cannot communicate, for example the Confusion Assessment Method [17] and the Neuropsychiatric Inventory [18].. These tools are all time consuming and require staff training, if symptoms are identified however, effective treatment is often available.

Previous attempts to describe dementia prevalence, and the symptoms associated with it, in a general hospital setting have involved prospective objective memory screening, and subsequent clinical assessment [3-13, 17]. The rigorous screening methods these studies employ may give an accurate account of the hospital prevalence but they potentially overestimate the actual clinical record, that is, the number of patients with a pre-existing diagnosis of dementia identified as such during their hospital stay and the number of symptoms recorded.

Aims:
To describe the prevalence of formally diagnosed dementia in those over 75 admitted to the general hospitals, how accurately this diagnosis is recorded in physical healthcare notes, and the range of documented psychological symptoms and delirium.

Methods:
This was a dataset linkage study with retrospective case note review carried out between the Leeds and York Partnership NHS Foundation Trust (LYPFT) (the mental health care provider) and Leeds Teaching Hospitals Trust (LTHT) (the general hospital).

We obtained a list of all people over the age of 75 admitted to LTHT during May 2014, they were identified only by their National Health Service (NHS) number. The list was randomly ordered using computerised random number allocation and the NHS numbers were cross-referenced against the LYPFT psychiatric electronic-notes system. This established the number of cases admitted to the general hospital with any recorded mental health diagnosis (e.g. depression, schizophrenia, dementia). The electronic-notes system could not automatically identify those with dementia; the target population. To do this we hand searched the patients' psychiatric notes. We recorded any formal diagnosis of dementia and the dementia subtype as recorded at patient's assessment with the memory service. The severity of dementia was recorded by reviewing the most recently completed standardised objective memory test score. Those without a dementia diagnosis were excluded. Based on the predicted prevalence of dementia in the general hospital [3] we aimed to review 40% of cases known to both trusts, to arrive at a sample size of around 200 dementia cases. It was estimated this number of cases would allow us to calculate the prevalence of formally diagnosed dementia in the general hospital with reasonable confidence. We did this by demonstrating the proportion of dementia cases from the number of mental health notes reviewed and extrapolating up to the total population admitted.

To calculate how accurately the general hospital documented dementia diagnosis, and the prevalence of documented psychological symptoms associated with dementia we scrutinised the general hospital notes of the patients with dementia identified above. We compared the dementia diagnostic information recorded in the medical notes to the psychiatric notes. To do this the general medical notes of the people identified with dementia were obtained from the medical records library. Notes were obtained in batches of 20 to reduce clinical disruption. Each set of paper notes contained medical and nursing documentation relating to the May 2014 admission, which was hand searched. Documented dementia diagnosis, subtype and severity were noted. Any documented depression, anxiety, delusions, hallucinations or a diagnosis of delirium were also recorded. To avoid any ambiguity a diagnosis or symptom was only counted if the treating team had specifically written it. Commonly used euphemisms (for example confusion) did not register. No attempt to make a retrospective delirium diagnosis was made [19]. Demographic information including age, gender, reason for admission, the specialty providing care and length of admission were recorded in order to ensure the sample was representative. Where hospital notes were unavailable, incomplete, or in admissions shorter than 48 hours, the case was excluded.

To calculate diagnostic accuracy, the percentage of dementia diagnoses documented by the general hospital was compared with the psychiatric notes, proportional agreement and kappa coefficients (ƙ) were calculated to demonstrate inter-rater agreement.

Associations between the specialty of the team providing care and dementia severity with the accuracy of dementia diagnosis recording were tested using chi squared test.

Descriptive statistics were used to display the documented symptom frequency, percentage and 95% confidence intervals (CI). Associations between the specialty providing care and the frequency of symptom documentation were tested using chi squared test. Where expected cell counts did not meet approximation for chi squared test, Fisher's exact test was applied.

Prior to data collection it was estimated that 100 sets of medical case notes (following exclusions), would be sufficient to demonstrate the prevalence of documented dementia and symptom frequency (primary outcome) with acceptable 95% confidence intervals. However we contingency planned to review more from the available 200 if greater numbers were necessary. In order to check this, once 100 medical notes had been reviewed the data set was analysed, then re-analysed after each subsequent batch of 20. Once the confidence intervals and statistical inference were consistent, or unlikely to demonstrate significance without an unfeasible increase in numbers, data collection ended.

Ethical approval was granted by the University of Leeds, School of Medicine Research Ethics Committee, reference number: SoMREC/14/039.

Results:

Data Collection

A total of 3326 patients over the age of 75 were admitted electively or as an emergency to the general hospital in May 2014. 706 of them (21% [CI 20-23]) were registered with the mental health trust. From this number we reviewed 275 psychiatric notes (40% of total), of which 196 (71% [CI 66-76]) had a diagnosis of dementia, the remainder had other mental health diagnoses and were excluded. From the sample of 196 patients with dementia admitted to the general hospital the paper medical notes were requested and reviewed. Data collection stopped once 153 notes had been reviewed as it was deemed that (following exclusions) this was an adequate number of cases to produce reliable enough data to achieve the research aims, as set out above. Following exclusions 116 cases were included in the study (Figure 1).

Demographics
The mean age of the sample with dementia was 84.3 years old (SD 5.6). There was a predominance of females (63%) to males (37%). The median length of hospital stay was 5 days (range 2-87) (Table 1). The most commonly documented reasons for admission were falls (28%, (CI: 20 – 36)), confusion (15%, (CI 9-22)) and infection (7%, [CI:4-13)). Neither dementia severity nor subtype were significantly associated with age, sex, length of stay, admission reason or the specialty providing care.

The prevalence of formally diagnosed dementia in the general hospital
Prevalence was calculated by first demonstrating the proportion of dementia cases (n=196) from the number of mental health notes reviewed (n-275), 0.71. This proportion was assumed to be the same in all 706 cases known to LYPFT admitted to LTHT. Therefore when extrapolated up one would estimate 501 admissions with known dementia, this is 15% [CI 14-16] of the total sample (3326).

Of those admitted to the general hospital with dementia, 44% [CI 35-53] were classified as having moderate disease severity in the mental health notes. The distribution of dementia subtypes demonstrated a predominance of Alzheimer's (31% [CI 23-40)), vascular (22% [CI 16-31)) and mixed dementias (15% [CI 14-28)) (Table 1).

Accuracy of dementia diagnosis recording
Twenty six percent [95% CI 19-35] of patients admitted to hospital with an existing dementia diagnosis did not have the diagnosis documented in their medical notes. Dementia sub-type was recorded in 41 cases (35% [CI 27-44], however the subtype recorded only matched the psychiatric notes in 25% of patients (kappa coefficient (κ) = 0.05). Dementia severity was recorded in only 16 patients (14% [95% CI 9-21]) but accuracy of recording was better; 75% agreement (κ = 0.44).

There were no associations between the accuracy of dementia diagnosis recording and the specialty providing care or dementia severity, (Table 2).

Frequency of symptom recording
Psychiatric symptoms were documented once or more in 10% (CI 6-17) of case notes reviewed. Specific symptoms were infrequently documented, depression (4%) and delusions (4%) were the most common. Delirium was documented in 11% (CI 7-18). There was no association between the specialty providing care, dementia severity and the frequency of documentation, (Table 2).

Standardised symptom rating scales were never used.

Discussion:

Principal Findings:

The prevalence of formally diagnosed dementia in patients over 75 admitted to the general hospital was around 15%. The diagnosis was documented in 74% of cases. Dementia subtype and severity were recorded in 35% and 14% of cases respectively, the accuracy of recording was poor.

The prevalence of documented psychiatric symptoms (10%) and delirium (11%) in people with dementia in the general hospital was lower than would be expected [12, 13]. There was no association between the documentation of dementia diagnosis, psychiatric symptoms or delirium and specialty of the team providing care or dementia severity.

Strengths and Weaknesses:

The population characteristics of this sample were similar to other UK hospital samples of elderly people with dementia [10, 20-22] making it largely generalisable to the wider UK. It is of note however that this study is limited to a single hospital trust and mental health provider, and while the systems and procedures are largely typical for the UK, other models of care are available. Repeating this study across other regions with contrasting systems of care may improve the reliability of the data and provide useful evidence for quality improvement.

This was a retrospective study, all included cases had a dementia diagnosis made by an accredited memory service prior to the point of inclusion, locally this is the most accurate source of diagnostic information available. Patients who lacked a formal diagnosis were not included in this analysis. It is likely therefore, that we have under-estimated the true prevalence of dementia in hospitalised inpatients, a phenomenon previously described by Sampson *et al*. [3]. However, this approach is advantageous as it describes the true clinical record and allows the number of inaccurately documented diagnoses to be identified. A retrospective design allowed for a greater sample size than a prospective design.

Dementia severity data were taken from the psychiatric notes. This method may create a skewed distribution, as patients who present at memory clinic often do so once the symptoms are more apparent. In the local system severity is reviewed at least yearly in all cases other than vascular dementia, data were taken from the record made closest to the May 2014 admission date. As dementia is a progressive illness the psychiatric notes may be inaccurate at the point when the patient was admitted to hospital, thus reducing the validity of severity agreement data.

Medical notes are live hand written documents and as a consequence they are not always available for review. Where medical notes were unavailable despite several attempts to obtain them, we excluded them from the study (see figure 1). Each set of notes was carefully scrutinised to reduce the opportunity for missed information. Where illegible information was written it was reviewed in the context of the legible information around it. Despite this, missing or inaccurate data is a potential source of error.

The healthcare professionals documenting in the notes were unaware that their record would later be scrutinised, reducing recording bias. The data collection was carried out

by one individual, which ensured consistency, but meant that it was not possible to test inter-rater reliability of the data collected.

The frequency of documented symptoms was low. Prevalence figures were generated by a count of the symptoms documented in the medical notes. Documentation provides an account of what the author has recognised, remembered and seen as relevant. A lower than expected number of reported symptoms does not reflect low rates of symptom prevalence. It does however reflect the true clinical record.

The frequency of documented delirium was counted only where the word 'delirium' or 'delirious' was written in the medical record. No attempt retrospectively diagnose delirium was made as this would not have reflected the treating teams true diagnostic understanding.

Meaning of the study:
Identifying that a patient has dementia at the point of admission to the general hospital allows for care to be tailored to that individual. This study demonstrates that in this trust, despite a large number of patients with known dementia being admitted to hospital, the diagnosis remains unknown in about a quarter of cases. Some initiatives are already in place to try to improve this, and it is reported that in the majority of cases healthcare professionals ask whether the person they are seeing has a dementia diagnosis [2]. If the hospital does not have access to a reliable information source when asking this question however, (for instance the psychiatric notes) then the process is fallible.

Documenting a person's dementia subtype and severity is not currently a defined standard in hospital admission documentation[15]. It is valuable clinical information however; differing dementia subtypes and severities have differing presentations and care needs. The infrequent and inaccurate documentation of severity and subtype information in the medical record indicates either a lack of awareness of the importance of this information or a training deficiency. Prompting such information within admission documentation may help to improve this.

Psychological symptoms, and delirium are common in this patient group, however this prevalence was not represented in the patient notes of the cohort studied. This is unlikely to reflect a low symptom prevalence, but instead a mismatch between symptom prevalence and symptom recognition and recording. It is good medical practice to document patient symptoms, not least because it informs the rationale for strategies aimed to alleviate the symptoms and the suffering caused by them. If the lack of symptom recording was due to a lack of recognition, then this is a barrier to providing tailored care, a key treatment goal in dementia care [23].

Given that dementia is more prevalent in the elderly [24] healthcare staff working on wards that specialise in caring for older people might be assumed to more adept at documenting dementia and symptoms associated with it than their colleagues on other wards, this was not the case. Standardised tools to help improve the detection of symptoms were never used, indicating a potential target for future interventions to improve symptom recognition.

Clinical implications:
In order to improve the accuracy of identifying people with an existing diagnosis of dementia, healthcare professionals need access to reliable diagnostic information. In the healthcare system described this requires closer collaboration between metal health and hospital healthcare information systems and training for healthcare professionals on how to access the information. Nationally; reliable, integrated electronic healthcare records systems, may reduce the chance of missed information. People with dementia and their carers are also encouraged to play an active role in their care, informing hospital staff of their diagnosis and approaches to care that make them feel most comfortable. Systems are already in place to empower patients to do this, for instance the butterfly scheme and 'This is me' booklet produced by the Alzheimer's society, however they all require opt in by the person with dementia and the capability to bring the information to hospital [25, 26].

Reducing the symptom burden of those with dementia is a primary treatment goal [23], the mismatch between expected and observed psychiatric symptoms in this population [12, 13] suggests that healthcare staff are either under recognising or under reporting them; this has the potential to negatively impact patients. Prompting staff to record symptoms and researching the most effective ways to achieve this are important priorities for improving care for hospitalised patients with dementia.

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