Family/carer input into patient histories to help determine presence of dementia

Abstract:

Many older patients are being admitted into acute general hospitals with confusion. It is well recognised that many older people suffer from dementia but have never been investigated or received a formal diagnosis. At times it can be very challenging to determine if they are suffering from delirium, dementia or a delirium superimposed on top of a pre-existing dementia. A careful history from a carer or family member can help to resolve this problem.

Lack of a formal diagnosis of dementia:

On a daily basis we encounter patients being admitted into an acute hospital suffering from confusion with very little background information available as to their normal baseline status. It is well recognised that dementia is being under diagnosed in Ireland. A study was undertaken by Cahill et al (2010) on the under detection of cognitive impairment in four Nursing Homes in the Dublin area. Only one third of residents had a clinical diagnosis of dementia and approximately one third had a prior MMSE done. The study’s findings (using MMSE) showed that 89% of residents surveyed were cognitively impaired of whom 42% were severely impaired and 27% were moderately impaired. They acknowledge that there were limitations to the study (small size and the use of only a MMSE for diagnosis) however
the results are quite revealing. It is also recognised that General Practitioners experience difficulty diagnosing and disclosing a diagnosis of dementia to patients (Cahill et al, 2006). A qualitative study of both Irish and Swedish General Practitioners found that most were reluctant to diagnose dementia and several acknowledged going to considerable lengths to avoiding using the word “dementia” (Moore and Cahill, 2013).

This lack of a formal diagnosis of dementia is not unique to Ireland.

In a Dutch systematic review article (Van den Dungen et al, 2011) the accuracy of a family physician’s dementia diagnosis was analysed. The review found that a dementia diagnosis was documented in less than one-third of mild dementia patients and in less than two-thirds of moderate to severe dementia patients.

Across the European Union fewer than 50% of people with dementia receive a diagnosis (Bamford, 2010). This information is supported by an English study by Connolly et al (2011) which identified that just under half of the expected number of people with dementia were documented in the GP’s dementia registers.

Good quality early diagnosis and intervention for all was one of the objectives set out in the “Living well with dementia: A National Dementia Strategy” (Department of Health, 2009) document. In March 2013, the Department of Health set about increasing the diagnosis rate of dementia in England. They put in place a new Dementia Directed Enhanced Service to reward GP practices for timely diagnosis and support for people with dementia.

**Information should go both ways:** It is not customary for hospitals to inform GP’s when a patient gets a diagnosis of dementia. The Irish National Audit of Dementia Care in Acute Hospitals (2014) noted that only 14% of patients had their level of cognitive impairment
summarised and recorded on discharge. GP’s are therefore not being informed if and when a diagnosis is made or how advanced the disease has become.

**Diagnosing Dementia:**

Old age is often associated with a continuous decline in memory and along with other forms of cognitive decline can impede the self-management abilities necessary for everyday functioning (Ganzer and Zauderer, 2011). The National Institute for Health and Care Excellence (2015) Guideline CG42 describes a “Dementia Pathway” for both diagnosis and assessment. Memory assessment services should be the single point of referral for people with possible dementia. Investigations comprise of routine blood tests which should include haematology, biochemistry, thyroid function tests and serum vitamin B12 and folate levels. Chest X ray and a midstream urine test are carried out if clinically indicated. A careful history is taken and a physical examination performed. Medications should be reviewed and a formal cognitive test carried out. Imaging such as a CT scan or MRI may be required.

An accurate diagnosis of dementia is also important if you are to identify the cause of symptoms and to exclude depression or treatable causes of cognitive or memory problems (Weatherhead and Courtney, 2012). Hypothyroidism, B12 deficiency and Folate deficiency are all reversible causes of cognitive impairment and need to be identified early and treated promptly.

Improving general cognitive function can be enhanced by educating patients about the benefits of eating healthily and engaging in regular mental and physical activity (Ganzer and Zauderer, 2011).
**Barriers to getting a diagnosis of dementia:**

Barriers to a dementia diagnosis by patients and carers include misinterpretation or denial of symptoms, fear of stigmatism, therapeutic nihilism and fear of institutionalisation (Van den Dungen et al, 2011).

A systematic review was carried out by Koch and Iliffe (2010) on the barriers to a diagnosis and management of people with dementia in primary care; this review found that lack of support, time constraints, financial restraints, stigma, diagnostic uncertainty and disclosing the diagnosis were the main reasons identified. Stigma was also identified as a major obstacle in an Irish survey of General Practitioners (Cahill et al, 2008). Bamford (2010) argues that many GP’s do not diagnose due to the link with stigma and discrimination that they associate with dementia.

**Delirium:**

Dementia is also a risk factor for delirium (Flanagan and Flick, 2010). Failure to recognise delirium jeopardises older adults’ health because the underlying problem is not identified and treated in a timely manner (Bull, 2011). Recognising delirium early is critical if the patient is to be successfully treated. People who develop delirium are likely to have longer stays in hospital, have increased incidences of dementia, have more hospital acquired complications (e.g. falls and pressure sores), likely to need more long term care and are more likely to die (NICE, 2010). An Irish study (Ryan et al, 2013) found that delirium occurs in about 1/5 of general hospital inpatients particularly those with prior cognitive impairment. Another study discovered that delirium is associated with high rates of institutionalisation and an increased risk of death up to five years after the initial event (Eeles et al, 2010). In 2012, Davis et al carried out a detailed study which demonstrated that delirium is a strong risk factor for
incident dementia and cogitative decline in the oldest old. With delirium a careful history and examination with appropriate investigations allows underlying causes to be detected and treated (Lorenzi et al, 2012).


**Challenges for hospital staff:**

If a person presents into an acute hospital from either home or a nursing home with confusion, agitation, disorientation, memory loss etc. and there is no formal diagnosis of dementia and/or background information it can become very challenging when trying to diagnose what is the cause of their symptoms. Problems can arise in trying to distinguish if the patient has dementia (diagnosed or undiagnosed), delirium, a delirium superimposed on their dementia or the confusion could have a totally different cause.

A qualitative study carried out by Baillie (2012) with nursing students found that they struggled to provide care for older people with dementia in hospital – this was affected by environment, knowledge, skills and the attitude of staff. The main challenging areas were nutrition, mobility, communication and emotional needs.

People with dementia can present with behaviour that challenge staff during their hospital stay. This behaviour usually signifies that they have unmet needs. Staff need to be trained in how to identify these needs and address them. An audit carried out by Gandesha et al (2012) showed that less than half of the doctors, nurses and Health Care Attendant have reported that the training they received was sufficient in dementia care/awareness.

Clissett et al (2013) found that while there was examples of good practices in the acute care setting, health professionals were not taking all the opportunities available to sustain personhood for the person with dementia. More telling they describe acute hospitals as potentially harmful places for people with dementia.
People with a recorded diagnosis of dementia were found to have a significantly longer length of stay in acute hospitals in Ireland than those with no recorded dementia (Connolly and O’Shea, 2013).

**Why we require input from carers:**

A history from a relative or a carer of the onset and the course of the confusion is essential to help distinguish between delirium and dementia (Potter and George, 2006), (British Geriatric Society, 2006). Family carers who are familiar with the older adult’s usual behaviour might play a role in detecting delirium symptoms (Bull, 2011).

“The Triangle of Care” (Carerstrust and Royal College of Nursing, 2013) documents how the meaningful involvement and inclusion of carers can lead to better care for people with dementia. They can help in a number of ways including providing valuable information and history. Their early involvement helps to provide the most accurate assessment on which to plan treatment and care.

Staff have no way of knowing what the patient’s base line is like if the patient is confused and/or unable to communicate. The nature of dementia means that the patients self-report may be inaccurate, insight is frequently impaired or denial is used as a self-protective mechanism. (Wheatherhead and Courtney, 2012). Information needs to come from another source – family or carers.

There are several areas where choices are difficult to make when a person has multiple co morbidities along with advanced age. Decisions also need to be made with regards to their resuscitation status, do they have the capacity to made decisions etc. One of the biggest issues is what should be done if the patient has severe dysphagia or is refusing to eat or drink:
should they be started on artificial nutrition? Do we put down a nasogastric tube? What do we do if they continue to pull the nasogastric tube up?

Finucane et al (1999) wrote a seminal article on tube feeding patients who have advanced dementia.

He reported that it:

- Is a risk factor for aspiration pneumonia.
- Has not been shown to prolong survival.
- Does not improve pressure sores outcomes.
- Does not reduce infection
- Does not improve functional status.

How do we make decisions if we do not have all the information about the patient condition? Lack of a formal dementia diagnosis can impede decision making and management (Barber and Murphy, 2011). If there is a formal dementia diagnosis decision making can be guided by research and guidance documents (See NICE Guideline CG042 for guidelines).

**Information about the patient’s functional abilities and why we need this information**

Unless we have good quality background information about a patient who has dementia on their arrival into hospital we will be unable to provide the best possible care required and put any necessary safeguards into place. Knowing the history, preferences, needs, interests and particularities of the person receiving care is fundamental in providing person centred care (Edvardsson et al 2010).

**Essential information** on a person’s functional ability that is required when a confused person is admitted into an acute hospital includes:
1) Does the person need assistance to eat or drink? Were they feeding themselves at home before this hospital admission?

2) Are they normally able to wash and dress themselves? Did they require some assistance?

3) Do they have a history of falls at home?

4) What is their mobility like? Do they use a walking frame? Are they bed bound?

5) Are they continent? Do they normally wear an incontinence pad?

6) How do they take their medication?

7) Are they on a modified diet? Do they use a thickener in their fluids?

8) Is there a history of recent weight loss?

9) Are they inclined to cough when eating or drinking?

10) Have they had periods when they were confused before?

11) What are their verbal communications skills like?

12) Do they normally wear glasses and/or use a hearing aid?

How can we try to get the person to return to their baseline if we do not know what their baseline is? There is no way of knowing if the patient was normally fully functional at home unless we communicate with their family/ carer. We do not know if this is the first time that they were ever confused or maybe their confusion is a long standing problem.

Also how are we going to be able to put safeguards in place if we do not know what the patient’s limitations are?

If self-report is not possible then the family/ carer should be approached and the necessary information obtained from them.
In an acute hospital we do not normally ask a family/carer *how long* a particular symptom has been present. Having an idea about a timeline with regards to loss of mobility, loss of appetite or if there is a history of incontinence can be very helpful when making a clinical diagnosis.

**How to bridge the gap in information:**

Collaborative relationships between families of nursing home residents and nursing home staff are essential for achieving the shared goal of ensuring the optimal quality of life for the resident (Robinson et al, 2007). The same principal should be applied when older people are admitted into an acute hospital from their home. Families and all health care professionals should work together to provide person centred care for the person and ensure that their hospital stay is as safe and as free from distress as possible.

Carers often have invaluable insight into the needs of the person with dementia but this information although shared with the healthcare professional is often felt to be ignored (Douglas-Dunbar and Gardiner, 2007). “Family carers are not passive in the face of the disruption of hospitalisation and respond both by trying to involve themselves in the care and support of their relative and by trying to work in partnership with members of staff. Nurses need to foster this relationship conscientiously” (Clissett et al, 2013).

There should be a document that family members could complete when a person is admitted from home and is in a confused state (*especially if a diagnosis of dementia is suspected*) - thus providing information that the patient themselves is unable to impart. This document could aid in giving a background of baseline information on which a comprehensive medical and nursing assessment can be based. The inclusion of the family in determining baseline mental status is crucial in the identification of delirium (Flanagan and Flick, 2010).
This information will also give some background into the time element of how long the symptoms have been present—hopefully highlighting the presence or not of delirium.

Gathering this information is not part of the routine nursing assessment on the admission of a patient into an acute hospital. Asking how long symptoms have been present is not a normal part of the assessment. A change in practice would help to overcome this by ensuring that the relevant questions are asked and a timeline included.

This can be done in either of two ways:

1. Include the extra questions on the “Nursing Assessment” document that is normally completed on all patients who are admitted into hospital.

2. Have a separate document for staff to give to carers/family of confused patients (when a diagnosis of dementia is suspected) to fill in (see below). Ideally this document should be given to the family/carer as soon as the patient is admitted into the hospital. Some family members/carers may require assistance to complete the form.
<table>
<thead>
<tr>
<th>Family/Carer Input:</th>
<th>Addressograph</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mobility</strong> <em>(please circle):</em></td>
<td>Independent</td>
</tr>
<tr>
<td></td>
<td>Wheelchair</td>
</tr>
<tr>
<td><strong>Transfers</strong> <em>(please circle):</em></td>
<td>Independent</td>
</tr>
<tr>
<td><strong>Estimate how long present:</strong></td>
<td>Days:_____</td>
</tr>
<tr>
<td><strong>Ever fallen</strong> <em>(please circle):</em></td>
<td>Yes / No</td>
</tr>
</tbody>
</table>

| **Personal care** *(please circle):* | Dress /wash themselves  | Needs help  | Full assistance  |
| **Estimate how long present:** | Days:_____  | Weeks:_____  | Months:_____  | Years:_____  |
| **Functional ability** *(please circle):* | Drive  | Pay bills  | Does shopping  | Forget appointments  |
| | Forget people’s names  |
| **Estimate how long present:** | Days:_____  | Weeks:_____  | Months:_____  | Years:_____  |
| **Medication** *(please circle):* | Normal  | Liquid version  | Tablets need to be crushed  |
| **Estimate how long present:** | Days:_____  | Weeks:_____  | Months:_____  | Years:_____  |
| **Nutrition** *(please circle):* | Feeds themselves  | Needs assistance  | Must be fed  |
### Food
- Normal
- Soft
- Minced/Moist
- Pureed

### Fluids
- Normal
- Need to put in “thickener”

### Special Diet
- Yes/No
- Describe: ________________________________

### Swallow
- Get episodes of **choking**: Yes / No

### Estimate how long present:
- Days: _____
- Weeks: _____
- Months: _____
- Years: _____

### Recent weight loss:
- Y/N

## Family/Carer Input: Addressograph

### Continence:

**Bladder (please circle):**
- **Dry:** Day Night Day & Night Never

**Bowel (please circle):**
- **Controlled:** Day Night Day & Night Never
- **Wears a pad:** Never Sometimes Always

### Estimate how long present:
- Days: _____
- Weeks: _____
- Months: _____
- Years: _____

## Cognition:

### Understanding (please circle):
- Normal
- Poor concentration
- Forgetful
- Confused

### Estimate how long present:
- Days: _____
- Weeks: _____
- Months: _____
- Years: _____

### Communication (please circle):
- Normal
- Adequate conversation
- Limited conversation
- No conversation

### Estimate how long present:
- Days: _____
- Weeks: _____
- Months: _____
- Years: _____

### Behaviour (please circle):
- Sudden change in normal behaviour: Y/N
- Agitated: Y/N
- Sleeping more: Y/N
- Hallucinations: Y/N
- Likes to walk – may get lost: Y/N

### Estimate how long present:
- Days: _____
- Weeks: _____
- Months: _____
- Years: _____
Conclusion: the benefit of undertaking this assessment:

A careful history from a family/carer is essential if we are to know what the patients baseline function was prior to their admission into hospital.

By providing information on how long the confusion and other symptoms are present a differential diagnosis can be made between dementia, delirium or a delirium superimposed on an existing dementia. Significantly treatment can commence earlier for delirium where it has been noted that the confusion is of recent onset or there has been an increase in confusion from their normal baseline. In the case of suspected dementia investigations can be carried out.

Once the acute phase of their illness is over rehabilitation can start using this information as a benchmark for the patient to achieve.

The following information is essential if a person centred approach to care is to be achieved.

- **Dietary information**: family/carer information can highlight these issues earlier.
  1. The type of diet the patient takes at home (normal/pureed etc.) – The hospital kitchen can then be informed.
2. The risk of aspiration pneumonia is high if a patient is on a modified diet and/or putting “thickener” into their fluids and the staff have not been informed.

3. Do they need assistance to eat or drink? If not informed by the family it may be a day or two before staff notice that the patient is not eating enough.

4. Diet record charts are also kept on patients who have a history of poor nutritional intake. This can begin immediately if the problem has been highlighted.

5. Earlier knowledge about a lack of adequate nutritional intake can instigate an earlier referral to the dietician.

- Recent **weight loss** observed by family/carer can prompt an earlier referral to the Dietician. The MUST (Malnutrition Universal Screening Tool) score requires information on what the patient’s most recent weight was. If this information is not available it is normally a week after admission when the patient is reweighed and a loss of weight is noted.

- How the patient normally take their **medication** is essential to know and can help to ensure that medication is correctly and successfully given.

- History of coughing when swallowing (**dysphagia**) – this information will prompt an early referral to the Speech and Language Therapist.

- A more accurate **Falls Risk** Assessment can be carried out if the family/carer inform staff that there has been a history of falls at home. Safeguards can be implemented earlier. One of the questions on The FallSafe care bundle is to ask about the patients “falls history” (Dean, 2012).

- Incontinence is often seen by healthcare professionals and older people as an inevitable consequence of aging and difficult to treat (Wright et al, 2007). Baseline
information as to whether the patient was continent or incontinent at home is vital.
While in hospital a patient may become incontinent for many reasons e.g. diuretics, urinary tract infection etc. The nursing staff then put an incontinence pad on the patient. This continues even after the acute phase of their illness is over and the patient can end up wearing a pad long term. For a patient who was previously continent this is quite devastating and has long term implications. By knowing that the patient was continent while at home you have a baseline to work towards – prompted toileting, referral to a continence service if one is available etc. can help to achieve this. Alternately if the patient has been incontinent for a prolonged period of time bladder retraining may be impracticable.

- **Mobility** – does the patient walk independently or use a frame etc. If so the family should be encouraged to bring any mobility aids they use into the hospital from home.
- Knowledge about the patient’s requirements when being transferred from bed to chair etc. can highlight the need for hoists and prevent unnecessary inappropriate handling by staff.
- Skills such as washing and dressing need to be recognised and encouraged as people with dementia can lose these skills if they are not repeatedly being used.
- Does the person like to walk a lot /are they at risk of getting lost? This information will highlight the need for extra vigilance by staff. It may be necessary to locate them in a bed closer to the nurse’s station.
- How they managed their activities of daily living prior to admission will give us realistic goals for what to try to achieve once the acute phase of their illness is over.
- **Cognition:** A history of long standing confusion, poor functional ability and/or poor communication skills may highlight an earlier referral to the Occupation Therapist
and/or the hospital psychiatric liaison service-following on from recovery from their acute phase of this specific illness.

Input from family/carers is essential if we are to provide high quality care to any person who is admitted into an acute hospital suffering from confusion (especially if a dementia diagnosis is suspected). Both their nursing and medical assessments are based on this information. Family/carers can also provide information on the patient’s normal baseline functional ability; this information is vital during the rehabilitation phase of their hospital stay.

References:


