Staff, patients and families experiences of giving and receiving care during an episode of delirium in an acute hospital care setting

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Background

Healthcare Improvement Scotland has a unique role in NHSScotland in terms of driving improvement through an integrated cycle that blends learning from evidence, improvement and scrutiny. Our Improving Care for Older People in Acute Care workstream is a 2-year programme with an overall objective to improve the care for older people in acute care by March 2014. This work is focused on building and spreading improvement in the two key areas of screening for frailty and the identification and immediate management of delirium. The programme aims to improve the identification and immediate management of delirium for people aged 75 and over, admitted to acute care, by March 2014. The focus of this improvement work was shaped by an extensive consultation process and reflects key issues identified through our programme of inspections for the care of older people in acute hospitals.

Delirium project

This report provides details of a project undertaken to explore staff, patients’ and families’ experience of episodes of delirium in an acute hospital setting. The Improving Care for Older People in Acute Care workstream has been working with colleagues from the Scottish Delirium Association and others to design, develop and test a delirium bundle to support staff with the early identification and management of delirium in caring for older people in the acute care setting. As part of this development, the project team was keen to explore what it felt like to both give and receive care during an episode of delirium to:

- enhance our learning about caring for patients and family during an episode of delirium
- help us to improve communication, and
- contribute to the development of a guidance document for the delirium bundle.

Delirium is an acute medical emergency associated with poor outcomes that commonly affects older people admitted to hospital. Older people and people with dementia, severe illness or a hip fracture are more at risk of delirium. It causes great distress to patients, families and carers and has potentially serious consequences such as increased likelihood of admission to long term care and even increased mortality1.

People who have delirium may need to stay longer in hospital or in critical care, have an increased incidence of dementia and have more hospital-acquired complications such as falls and pressure ulcers. Identifying delirium is an important priority as approximately half of all delirium episodes are potentially reversible2. Delirium is currently not identified or managed appropriately in many cases and is a key area of focus for the Improving Care for Older People in Acute Care workstream1.

A collaborative approach has been adopted to develop a change package to support improvements in the identification and immediate management of delirium and to bring together healthcare teams from across Scotland to test changes, share and spread good practice and provide improvement support. The change package includes a care bundle that offers guidance on critical actions to be taken within the first 2 hours of a delirium being identified and links to the Scottish Delirium
Association’s evidence-based pathway for delirium. The acronym TIME, used in the bundle, emphasises thinking about triggers for delirium, investigating underlying causes, implementing management plan to address underlying causes and, crucially, engaging and involving the patient and family members. Testing and refining the delirium bundle can support consistent and reliable identification and early management of delirium and is key to improving the care and experience of patients with delirium. Ten of the 14 NHS boards across Scotland have identified test sites to test and refine the delirium care bundle in a variety of acute hospital settings including surgical, orthopaedic, medical and care of the elderly.

Person-centred care is at the heart of this work. Technical aspects of care are inextricably linked to how care is delivered, to behaviours and language used and to how individuals and their families and carers are involved in care.

**Learning about experiences of those who give and receive care during a delirium episode**

To learn about the experience of giving and receiving care during an episode of delirium, focus group discussions with staff (n=7) and individual interviews with patients (n=1) and families (n=2) were carried out using the process of emotional touchpoints\(^3\). Emotional touchpoints is a method that helps us to tap into the meaning of an experience in a structured way. It focuses on particular points in the experience journey (touchpoints) and asks people to select from a range of emotional words those that sum up what the experience felt like. The storyteller is then asked to sum up why they felt that way and if appropriate what would help to make the experience better.

Staff who attended the focus group worked in a range of inpatient areas, including orthopaedics and accident and emergency. All were registered nurses with the exception of one member who was a student nurse. The patient and family members had been in hospital several months before the interview. Although the sample size was small and we recognise the potential for further work in this area, we collected valuable data to inform future development of the bundle and guidance notes.

Following consultation with the project team, a selection of touchpoints were identified for each of the groups we were to interview. These touchpoints are shown in Table 1. We also had blank touchpoint cards in case the storyteller had a touchpoint that we had not identified before the interview. For example, the patient who we interviewed wanted a touchpoint card to be ‘dreams’ and this was subsequently added. We also collated a range of emotional words, both positive and negative, to use in the interview process. Words such as numb, powerless, bewildered, happy, curious, hopeful and encouraged are examples of words used.
Table 1: Emotional touchpoints for patients, family member and staff

<table>
<thead>
<tr>
<th>Patient</th>
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<tbody>
<tr>
<td>Coming into hospital</td>
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<tr>
<td>Talking to staff</td>
</tr>
<tr>
<td>Being with other patients</td>
</tr>
<tr>
<td>Going for tests</td>
</tr>
<tr>
<td>Getting information</td>
</tr>
<tr>
<td>Being cared for</td>
</tr>
<tr>
<td>Knowing what is going on</td>
</tr>
<tr>
<td>Being with my family</td>
</tr>
<tr>
<td>Having medications</td>
</tr>
<tr>
<td>Support</td>
</tr>
<tr>
<td>Being involved</td>
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<tr>
<td>The environment</td>
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<table>
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<tr>
<th>Family member</th>
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<tbody>
<tr>
<td>Coming into hospital</td>
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<tr>
<td>Talking to staff</td>
</tr>
<tr>
<td>Getting information</td>
</tr>
<tr>
<td>Being cared for</td>
</tr>
<tr>
<td>Care of your friend/relative</td>
</tr>
<tr>
<td>Knowing what is going on</td>
</tr>
<tr>
<td>Visiting time</td>
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<tr>
<td>Being involved</td>
</tr>
<tr>
<td>Support</td>
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<tr>
<td>The environment</td>
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<table>
<thead>
<tr>
<th>Staff</th>
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<tbody>
<tr>
<td>My knowledge about delirium</td>
</tr>
<tr>
<td>Caring for a patient who has delirium</td>
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<tr>
<td>Caring for the family</td>
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<tr>
<td>Talking to other staff about management of delirium</td>
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<tr>
<td>Being able to use knowledge in practice</td>
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<tr>
<td>Medication</td>
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<tr>
<td>Working as a team to care for the patient with delirium</td>
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<tr>
<td>Safety</td>
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<td>Person-centredness</td>
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</tbody>
</table>

A member of the project team approached the member of staff, patient or family member at least 24 hours before the interview. They were given written and verbal information about what would be involved in taking part in the discussion and invited to take part should they wish. They were asked to sign a consent form. Consent was renegotiated at different points throughout the process to check the currency of consent.

All interviews were carried out in a private room and lasted approximately one hour. The touchpoints were laid out on a table and the storyteller was invited to select, from these touchpoints, those that they would like to talk about. It was important that the storyteller decided what was significant and important to focus on. Taking each touchpoint in turn, the storyteller was then asked to describe what happened and select from the emotional words those that best summed up for them how that experience felt. There were blank cards that could be used if the patient used an emotional word that was not in the prepared collection of emotional words.

Storytellers were then invited to say why they felt this way. If appropriate, they were also asked to discuss how things could have been different, particularly if the emotion identified was a negative one.

After the discussion, the interviewer typed up the story and gave this back to the storyteller within one week. This usually filled 1–3 A4 pages and so was relatively short. The storyteller was invited to make changes, ask for aspects to be deleted, and add any other details. The patient was asked if they would be happy for this to be shared with others for the purposes of learning and development. They were reminded that if the story was to be shared with others it would remain anonymous unless they wished otherwise.
Figure 1 shows a touchpoint that was selected by staff, emotional words chosen to sum up the experience and commentary about why people felt the way they did.

**Figure 1: Touchpoint, emotional words and story**

<table>
<thead>
<tr>
<th>Emotional Word</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Vulnerable</strong></td>
<td>In certain situations I feel vulnerable, depending on how the patient is. You could feel vulnerable if the situation has not been managed well. Things can be out of control and the patient feels pretty bad.</td>
</tr>
<tr>
<td><strong>Frustrated</strong></td>
<td>I feel frustrated that I don’t have flexibility to bring in additional support to an area where there are patients with delirium. There is an imbalance in relation to resource allocation to acutely ill patients.</td>
</tr>
<tr>
<td><strong>Let down</strong></td>
<td>I feel let down when a patient has not been managed well. I feel able to talk to my colleagues about this. We freely discuss how it could be better for the patient. For example, we have been asked to give medication instead of looking at other ways to treat delirium. I feel confident to challenge in this scenario and explain other treatments other than go straight to medication.</td>
</tr>
<tr>
<td><strong>Rewarding</strong></td>
<td>It feels great when you have calmed a patient. It’s rewarding when you provide reassurance to a patient and they settle.</td>
</tr>
</tbody>
</table>
This method was particularly useful in focusing the discussion and making sure that the storyteller had some control over what they wanted to talk about. In summary, emotional touchpoints were valuable in that they:

- helped the project team emotionally engage with staff, patients and families and to understand their experience at a deep level
- provided a realistic way in which staff, patients and families can be involved in practice development and service design, and
- helped to uncover aspects of caring practice that are not easy to define.

**Key themes**

Following a process of thematic analysis, key themes were identified that were relevant to all groups. These themes were:

- feeling safe
- knowing the person
- being calm
- varying for everyone
- being kept in the loop
- helping people make sense of things, and
- raising the profile of delirium.

Each of these themes is considered below.

**Feeling safe**

Feeling safe was an issue identified by all storytellers. People felt that this was challenging and required careful thought about strategies to enhance safety for all those involved.

*I’m worried about the patient: they are confused, at high risk of falls and other patient safety issues. I’m concerned that when the ward is so busy, how am I going to keep this patient safe. It’s down to time. (Staff)*

*Safety is a big issue for delirium. I have had to take a patient around with me on a wheelchair while I’m doing other work as too afraid to leave them on their own. (Staff)*

*They moved him to an area where the nurses could see him. Staff kept popping in to see if my mum was ok. Dad gets anxious if my mum’s not around. Dad kept asking for my mum. The only other person he will settle with is myself. He is calm if me or my mum are with him. After his operation and when the delirium started, he was trying to get out of bed. They put someone in to sit with him, even with the change of shifts there was always someone with him. Staff understood the problem. Staff told us it was okay to buzz if we wanted anything – mum didn’t like to bother people – not sure if she would have buzzed. (Family member)*
Lots of people ‘padding around’ giving a nice wave made me feel that there were people looking after me- made me feel there was someone there if I needed anything. (Patient)

Aspects that were important

- Having a presence in and around the patient and family member even if the patient is calm.
- Thinking out of the box about ways in which you can have a presence with the patient even if you are busy.
- Inviting the family member to sit with the patient but remembering to still pop in and make a connection.
- Encouraging the patient and family member to buzz if they need you.
- Articulating to others the need for safety and feeling confident to put forward case for increased resources during acute episodes.

Knowing the person

All storytellers talked about the importance of knowing something about the person, be it patient or family member.

I would find out how the patient is normally, find out about the person and what would reassure them. When you make a connection with the person. Speaking about hobbies. I had a guy who bred cows and his eyes lit up when he spoke about this. Having this connection with the patient really helped to keep him calm. (Staff)

Finding out quickly something about the person allowed staff to make a connection with the patient who was experiencing an episode of delirium. Family members we spoke to knew the patient very well.

I know what triggers to look out for when Dad’s starting to have delirium – “eyes dart about” and when he starts to talk to us it’s confused, it’s rubbish, it’s mixed up. He starts to watch about the room and look about, he says “there it is”, he sees holes and things in the ceilings – he’s starting to have hallucinations. (Family member)

Valuing the knowledge of the family member and their skills and expertise in detecting early warning signs of an episode of delirium was something that we could more deliberately tap into. It may be that there is scope to consider NHS 24’s role in getting expert knowledge from the carer of the person who is having an episode of delirium.

I felt fortunate that one of the nurses knew of me through a cricket club connection – this was just a bonus – it didn’t mean that nurses who didn’t know me delivered any less care. In my mother’s Glasgow tongue “They could read me like a half penny book. (Patient)
It seemed that knowing something about the person to help staff to connect was also considered to be valuable to the patient. The knowing something about the person may also have helped the patient to feel a greater sense of security in that knowledge of the person would inform any actions taken.

### Aspects that were important

- Asking questions to find out something about the patient as a person and using this in dialogue can help create calmness, enhance feelings of safety and develop relationships.
- Asking family members questions about their expert knowledge in knowing their relative can elicit important knowledge to influence caring and help to involve the family member.

Questions we could ask routinely and record and share with others include:

- What is your relative like normally?
- What interests them (for example occupation, hobbies, grandchildren - helping you to connect with the patient)?
- What normally makes them feel reassured?
- How do you want to be involved/how can you help us to care for your relative?

### Being calm

Being calm was a strategy many staff highlighted as being important in caring for a person during an episode of delirium. They believed that staff's demeanor had an impact on the way that the patient behaved. Staff recognised that family members played a crucial role in maintaining a calm atmosphere.

> Sometimes we have to be brave and lift the phone in the middle of the night and call a family member. I've had to do this and the relatives were really relieved that we had called and they came into hospital and sat with their relative and this calmed him down. It works – most of the time when you call a family member they feel included and involved and can help make the patient comfortable and calm. By you being calm, the patient becomes calm too. (Staff)

Helping relatives to feel calm was enhanced by getting timely and relevant information about what was happening and how things had been.

> Staff saw how calm he became when my mum came in to sit with him. It calms me down being able to speak to staff about Dad getting right medication, and why there's been a change of medication. It's comforting and you feel calmer once you know what they're doing. They've had a lot of work with him. (Family member)

> You can't go away because he wants you to stay and constantly try to keep him calm. I feel anxious as I don't want him to pull out his drip. (Family member)
Relatives acknowledged the challenges that everyone faced in caring for the person during an episode of delirium.

**Aspects that were important**

- A key message for staff in caring for a person during an episode of delirium is to be calm. Staff need to feel comfortable to seek support to help them to achieve a calm manner.
- Family members can provide important input into the creation of a calm atmosphere that could benefit all those involved.
- Family can also feel exhausted with visiting and constantly being at the bedside. Staff need to check how the family member is feeling and offer ‘breaks’.
- Family members also need to feel calm and this is aided by timely and relevant information about what is happening.

**Caring for everyone**

All storytellers identified the acute episode of delirium as a challenging time where people needed support. This included support for staff, family member and patient. Storytellers valued if challenges were recognised by others.

_The hospital at night team are very supportive in providing reassurance. Hospital at night team legitimised the fact that sitting with a patient with delirium is the right thing to do. (Staff)_

_The doctors were there for me to ask any questions and explain to me what was happening. He (the Doctor) did it gently, eased me into the situation. He took the time to explain to me, and asked me how I was feeling, it wasn’t just about xxx, it was also about me. (Family member)_

_My family were able to stay in hospital – one room – 2 or 3 nights. (Patient)_

**Aspects that were important**

- Acknowledgement by others that key strategies such as sitting with the patient are valuable and need to be considered a priority alongside other immediate care needs.
- Staff value being supported by others when caring for a person during an acute episode of delirium.
- Family members value careful explanations and being asked about how they feel.
- Offering for family to stay overnight in hospital during this time may be helpful. The important thing is to offer this but to check out what is comfortable for the family member.
Being kept in the loop
Everyone felt it was important to know as much as they could about what was happening. This helped people to feel calm and in control.

I need to know more about delirium to help me to feel comfortable in caring for the person. (Staff member)

I feel anxious when the delirium is present and there’s nothing you can do. I feel less anxious when staff come into the ward and provide an update and information and expectations. It can be like night and day from one visiting time to another. (Family member)

There were times when I was down and needed explanations and my family are not scared about asking questions and expect the truth and that’s what the staff gave them. (Patient)

It may be that not everyone would feel comfortable or would remember to ask questions. It is important therefore that people are asked. We did discuss with storytellers if it would be helpful to have some written information as well as regular opportunities to talk and ask questions. People felt that this may be valuable. It would be important that any written information was developed with patients, families and staff.

Aspects that were important
- Staff value having knowledge about delirium.
- People can feel a lack of control without information about what is happening.
- People value if staff come and update the patient and family regularly.

Helping people make sense of things
The theme of ‘making sense of things’ was mentioned in relation to dreams that the patient who was interviewed had had repeatedly while in hospital. Due to the timing of the interviews (staff interviewed before patient) it was not possible to follow this theme up with staff. However, in reading the quote below there are some important pointers we can consider in how staff and family can support the patient to ‘make sense of things.’

I never discussed the content of my dreams whilst in hospital. I’m not sure when I was experiencing dreams or when this was delirium. I had over 20 dreams and some are still vivid now. I don’t remember speaking to staff in the ward about these but I occasionally spoke to my family. The vividness of the dreams is beginning to dissipate. My family were writing down what I was saying when I was delirious – I didn’t read this until I was back home. I think my daughter found it amusing. I felt amused reading this when I got home.

I only found out how I had been behaving and what I was saying when I got home and read the journal my daughter kept. It would have been
helpful to have talked about this while in the hospital – would have to have been done with a bit of humour, however, and would need to be done sensitively by nurses as not all people would appreciate this and especially if they had had vivid nightmares. That's the skill of the nurse. I have little doubt that I got my leg pulled on a few occasions! (Patient)

The place of humour seemed important in helping patients to feel more comfortable with their behaviour during episodes of delirium:

I was trying to get out of the place – I had things I wanted to get home for. They said there was no way I was getting home. I recall one nurse – I wanted to go to a party I was hosting after a rugby match – I bet the nurse £500 that I will be at the party – I don’t know if that was a dream or if I had delirium at this time. She said ‘I’ll take you on’. She must have thought I was daft. They (staff) took you on. I respected that. (Patient)

Aspects that were important

- Patients can be curious about their dreams or nightmares and may want the opportunity to talk about these. It is important to check this out.
- Staff could suggest to family that keeping a journal of what has happened and how the person with delirium has behaved and communicated may be a useful account that helps the patient to make sense of what has happened.
- Humour can play an important role in engaging in caring conversations with the person who has had an episode of delirium. This has to be done with skill and sensitivity.

Raising the profile of delirium

There was concern from all groups that delirium was something that did not have a high profile and therefore it was difficult to get support for this aspect of care, for example in training.

I've been trying to deliver training in delirium in hospital and there has been little support to implement this. It’s getting easier but I feel unsupported to carry out training. Delirium was never a priority until now. Now that it is a priority things are changing but I don't have back-up and so feel unsupported at the moment.

I think currently we don’t have delirium on the same pedestal as sepsis. When I look at education around Early Warning Signs (EWS) and how much staff have taken on sepsis 6, we need to get the profile of delirium raised and I think the delirium bundle could help. I feel sad that delirium doesn’t have the profile it should. Staff attitudes to patients with delirium makes me feel sad. Patients can get labelled as a ‘difficult patient’. I also feel sad for the staff as it’s really difficult for them to manage people with delirium. Medication is often seen as the first point of treatment – and we know that this is not the most appropriate intervention. (Staff)
I had never heard of the term ‘delirium’. I think this needs to be defined in the leaflet. (Patient)

**Aspects that were important**

- Early warning signs for delirium need to have equal status to other early warning tools.
- There is scope to conduct more education and raising awareness strategies to raise the profile of delirium among staff, and the public.

**Other things that helped**

Storytellers identified a number of other aspects that helped in giving and receiving care when a person experiences an episode of delirium. These included:

- flexible visiting times
- actively seeking expert knowledge from the family
- offering a break to family members
- time to reflect on care and talk about the challenges as a team
- reassurance that the behaviour was not permanent
- seeking permission from family to share with others, for example other visitors or patients that the way the patient was behaving was not their ‘normal’ behaviour
- valuing the time it takes to support person with delirium
- humour and sensitivity, and
- value of experiential learning rather than online (staff).

**Summary and conclusions**

The accounts from staff, patients and family members were invaluable in shedding light on the experiences of giving and receiving care when a person has an episode of delirium. It highlights the importance of continued engagement with everyone during these episodes in order to use experience to influence care giving.

A number of strategies helped patients, staff and family to feel safe including:

- supporting people to be calm in their approach
- finding out something about the person and using this to influence caring and develop relationships
- keeping people up to date about what is happening, and
- helping people to make sense of things.

It is important that these aspects inform guidance notes so that support staff can use the delirium bundle in practice.
References


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