

A qualitative exploration of the views of patients and their relatives regarding interventions to minimise the distress related to postoperative delirium.

Meilak C ¹ Biswell E. Willis R ³ Partridge J ^{4,5} Dhesi J ^{4,6}

Corresponding author: Dr Catherine Meilak. Email: catherine.meilak@nhs.net

1. Consultant Geriatrician, Perioperative medicine for Older People undergoing Surgery (POPS), Dartford and Gravesham NHS Trust, Kent, UK
2. Research nurse specialist. Perioperative medicine for Older People undergoing Surgery (POPS), Guy's and St Thomas' NHS Foundation Trust, London, UK
3. Associate Professor of Gerontology. Centre for Research on Ageing, University of Southampton, UK.
4. Consultant Geriatrician, Perioperative medicine for Older People undergoing Surgery (POPS), Guy's and St Thomas' NHS Foundation Trust, London, UK
5. Honorary Senior Lecturer, Division of Primary Care and Public Health Sciences, Faculty of Life Sciences and Medicine, King's College London, London, UK.
6. Honorary Reader, Division of Primary Care and Public Health Sciences, Faculty of Life Sciences and Medicine, King's College London, London, UK.

Keywords: Post operative delirium, distress, qualitative, intervention

Keypoints:

- Postoperative delirium (POD) is distressing
- Patients and relatives want information on POD before, during and after the episode of POD
- Information should be provided by a trained professional, supplemented by written information

Abstract

Background: Postoperative delirium (POD) is common in older people and can be distressing for patients and their relatives. This study aimed to describe the experience of postoperative delirium and explore the views of patients and relatives in order to inform the co-design of an intervention to minimise distress related to postoperative delirium.

Methods: Qualitative study using thematic analysis of semi-structured interviews in patients (n=11) and relatives (n=12) who experienced and witnessed POD respectively.

Results:

Patients and relatives find POD distressing and desire information on the cause and consequences of delirium. This information should be delivered pre-emptively where possible for patients and relatives; during the episode for relatives and in post episode follow up for patients and their families. Information should be provided in person by a health care professional who has experience in managing delirium, supplemented by written

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materials. In addition, participants suggested training to improve staff and public awareness of delirium.

Conclusions:

This qualitative study showed that patients and relatives find delirium distressing, report the need for an intervention to minimise this distress and enabled co-design of a pilot intervention. Refinement and evaluation of this intervention should form the next step in this programme of work.

Background

Delirium is a common syndrome affecting 10-50% of older surgical patients ^(ref 1 NICE). It is thought that between 25 and 75% of patients recall their episode of delirium and that this recollection can be distressing ^(ref 2 PARTRIDGE). Following delirium, patients have reported day-night disorientation, clouding of thought processes or seeing through a fog or mist, strong emotions, lack of control, past and present clouding, misperceptions, hallucinations and delusions ^(ref 2 PARTRIDGE). Negative psychological sequelae have been attributed at least in part to the recollection and experience of delirium. These include symptoms of post-traumatic stress disorder and subsequent anxiety and depression ^(ref 2 PARTRIDGE). The presence of family members during the delirious episode may minimise the unpleasant experiences reported by patients ^(ref 3 GRANBERG, ref 4 STENWALL, ref 5 ROBERTS). However, for family members and caregivers, observing the delirium may impact negatively and contribute towards their own distress, anxiety and symptoms of post-traumatic stress disorder ^(ref 6 NAMBA, ref 7 COHEN, ref 8 JONES). It is difficult to ascertain to what degree distress pertains to the overall experience of illness as opposed to specifically the experience of delirium ^(ref 9 BULL).

Previous studies suggest patients and relatives want information on delirium ^(ref 10 LAITENEN, ref 11 DUPPLIS, ref 12 MCCURRAN, ref 13 DAY). However, despite the likely association of delirium with distress ^(Ref 14 PARTRIDGE) and the requests from patients and family caregivers for information regarding delirium, little is known on how, when and by whom this should be provided. It has been suggested that information given before ^(ref 15 OWENS) and/or after ^(ref 16 JONES, ref 17 CUTHBURTSON) delirious episodes may help to alleviate distress, however, this evidence is limited. The literature does imply that family members may benefit from receiving information from staff on specifically how to communicate with relatives during an episode of delirium ^(ref 13 DAY).

This qualitative study enrolled patients and relatives to address the following aims and objectives:

Aim: To describe the experience of postoperative delirium and explore the views of patients and relatives in order to inform the co-design of an intervention to minimise distress related to postoperative delirium.

Objectives: To understand the views of patients and relatives regarding;

- [1] The content of an intervention to be delivered to patients and their carers
- [2] The timing of an intervention to be delivered to patients and their carers
- [3] Who should deliver an intervention to patients and their carers.

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Methods

A qualitative study was undertaken using semi-structured individual interviews and thematic analysis. The study was approved by NRES committee, London Camberwell; St Giles.

Participants and sampling

Purposive sampling (ref 18 BRYMAN) was used to recruit two sets of participants according to the inclusion and exclusion criteria; first, patients following recovery from postoperative delirium and second, relatives/carers who observed the episode of delirium.

Inclusion criteria

- [1] Patients aged over 18 years discharged from hospital following recovery from postoperative delirium
- [2] Relatives/carers who observed the postoperative delirium

Exclusion criteria

- [1] Functional limitation preventing attendance at outpatient interview
- [2] Cognitive impairment severe enough to prevent consent to the interview and/or lack of capacity to consent
- [3] Terminal prognosis (estimated within three months of death)
- [4] Insufficient spoken English to participate in interview without use of translation services.

The focus of this qualitative work was to develop new knowledge about a topic that would lead to new hypothesis generation.

Setting

The study was conducted in an inner city teaching hospital in London.

Recruitment and consent

Patient and relative participants were identified by the clinical team on the surgical wards, following resolution of the delirious episode. In addition patients and relatives previously recruited into a quantitative study measuring delirium distress (ref 19 PARTRIDGE) who expressed interest in further participation were also approached.

An information sheet was provided and capacity to consent was assessed. When initial verbal consent was given, a time for the interview was arranged and transport offered. At the interview, capacity to consent was reassessed, the participant was offered an opportunity to ask further questions, and written consent was taken.

Interviews

Individual semi-structured interviews were conducted to explore patients and relatives experiences of delirium and their views on interventions to minimise distress (ref 18 BRYMAN). Interviews were audio recorded and transcribed verbatim. The

interviewer adapted the wording and order of the questions based on the responses of each participant, and followed up interesting topics raised unexpectedly by participants. One of two researchers conducted the interviews; a research nurse and a geriatric medicine specialist registrar neither of whom were part of the regular clinical team. The interviews took place in an outpatient clinic and refreshments and travel provision was offered. The interview guides are shown in Appendix 1.

Analysis

Thematic analysis aided by NVivo 10 software was undertaken (ref 20 BRAUN). With no pre-existing coding framework in open coding, this ensures that the descriptive codes and themes are fully supported by the data. The first interviewer read the transcripts repeatedly in order to gain familiarity with the data. The data was separated into meaningful segments and descriptive codes were applied. The content of these codes was reviewed, and codes of related meaning were moved into connected trees. A hierarchy of codes was created and interpretive themes identified. The analysis process continued after the coding process and the practice of constant comparison was used as a way of ensuring validation of the results (ref 21 LEWIS). The second interviewer reviewed the data and codes, and analysis meetings were held to discuss the emerging themes using the One Sheet of Paper method (OSOP) (ref 22 HILTON, ref 23 ZIEBLAND). Where any disagreements occurred, they were resolved by discussion, ensuring all themes were supported by the data.

Results

A total of 11 patients and 12 relatives participated. A further 12 participants initially agreed but subsequently withdrew from the study prior to interview. Although no reason for non-participation was requested, some did offer reasons. Of the patients who declined participation; one was too tearful, one believed that the delirious episode was a past life experience and therefore not delirium, two had poor physical health, one denied having had delirium and one felt that they could not participate as they could not recall the delirium. Of the relatives who declined to participate, one did so due to her husband's poor physical health whilst five did not offer reasons for non-participation.

No patient participants reported underlying cognitive impairment. Of the relative participants, four reported that their family members had pre-delirium cognitive impairment under investigation or a notable cognitive impairment prior to delirium that had not yet been investigated.

Tables 1a and 1b show a summary of the participants and their demographic details. Where participants were related to each other, this is indicated in the table 1a.

A number of themes regarding patient and relative experience of delirium and their views on a potential intervention to reduce POD related distress were identified using thematic analysis. These are presented as overarching and subthemes (see Appendix 2)

Prior knowledge of delirium

Fifteen of the 23 participants had not heard of delirium prior to the episode of POD (eight patients, five relatives). Some participants had some awareness of delirium prior to the experience). Relatives described feelings of frustration, confusion and worry as a result of not knowing about delirium. They felt that a prior knowledge of delirium would have helped minimise these emotions. Those with a prior knowledge of delirium expressed how this equipped them to better understand and manage the situation. One participant felt at an advantage over his relatives as he knew about delirium before it occurred and he felt his family, who did not, were consequently more distressed by the experience. One patient suggested that her knowledge of delirium allowed her to speak freely about it to her attending doctor. No participants expressed negative effects pertaining to a prior knowledge of delirium or positive effects related to a lack of knowledge.

Impact of delirium

Both patients and relatives described in detail the emotional impact of delirium on them personally and the perceived impact on their loved ones. Patients and relatives frequently became tearful during the interviews whilst recounting their experiences. Patients described negative and frightening recollections of delirium. In addition they were worried that their delirious episode had impacted negatively on their family.

Relatives reported distress at witnessing delirium in a family member. This distress related both to delirium and to the observed deterioration in medical condition. Relatives found it particularly distressing when they were not recognised by the patients and when they witnessed angry, irrational and paranoid behaviour. One relative participant reported a fear that the cognitive decline would become permanent, and others had observed permanent cognitive decline following the POD. In contrast, some patients expressed more neutral or positive emotions. For some in the context of life threatening pathology, the delirium was perceived as less important. The need for emotional support or counselling to minimise delirium related distress was suggested. It was acknowledged that a lack of resource may be a barrier to this.

Own attribution to cause of delirium

In the absence of information regarding the cause of delirium, patients and relatives offered their own thoughts on the aetiology. They most commonly attributed delirium to medications. These participants voiced their wish to receive more detailed information on this.

Communication

Both relatives and patients gave examples of how staff cared for and communicated with those with delirium. Some patients recalled positive experiences including provision of explanatory information delivered sensitively. One patient reported mixed experiences of both 'empathy' and 'criticism' and stressed how the former was preferable. Relatives recalled that watching the patients being spoken to in a gentle manner was beneficial. One relative described how observing the nursing staff had demonstrated communication strategies to use with a delirious patient.

Some participants reported that inadequate provision of information increased their distress. Different views were expressed regarding who should be responsible for both initial and on-going communication regarding delirium. Specific recommendations from participants regarding an intervention to minimise delirium related distress included:

- Increased provision of information by staff delivering day-to-day care
- An opportunity to discuss with a staff member who could provide an overview of the patient. This was not necessarily the surgeon but instead someone with experience in managing delirium
- Provision of information and strategies for relatives on how to approach and manage the patient during an episode of delirium.
- Sufficient opportunities to communicate with staff throughout the episode (recognizing that the healthcare team are busy)

Although participants agreed that information on delirium was desirable, there were particular instances where they hypothesised that full and frank discussions with patients may not be appropriate. For example, if delirious patients did not understand the information and if they did not recall the episode, it could be upsetting.

Timing of communication

Before the operation

Some participants felt that knowing about delirium before the operation was important and should be included in the consent process, especially in those at high risk of delirium. Some participants described how understanding the risk of delirium and the possible impact on longer term cognitive deterioration would have been relevant to their decision regarding surgery.

During the delirious episode

Participants felt that communication during an episode of delirium should be directed at the relatives, as patients may be unable to assimilate the information.

Follow-up

The majority of participants volunteered an opinion on follow-up after discharge. Patients and relatives expressed the desire for follow-up to ensure that no new issues had arisen, provide further explanation and discuss any cognitive changes noted. Either telephone or clinic follow-up seemed acceptable. Participants felt that initial telephone contact with the opportunity to attend a follow up clinic would be most appropriate. Two patients felt they did not feel follow-up was necessary, although none expanded on the reason why. One relative, whose mother died, felt that follow-up would not be necessary. Some relatives mentioned that follow-up should only be offered to relatives if they wanted it, because for some patients, recounting the experience again might be too painful.

Delivery of intervention

The most popular mechanism for delivering information was in person. Participants felt that written information would be useful but only as an adjunct to face-to-face discussion with a healthcare professional. They also suggested that reading about other people's experiences may be beneficial.

Environmental considerations

Participants described the impact of the ward environment on the experience of delirium. In particular participants reported finding the colour of the lighting disturbing and were disorientated due to a lack of signs and markers on the ward. The presence of familiar faces was recalled as having a positive effect.

Suggested areas for improvement

As part of the interview participants were asked to reflect on their experience and highlight any areas that could have been improved. These included better staff training regarding delirium and enhanced public awareness of delirium.

Patients and relatives expressed their surprise that delirium was rarely discussed in the public domain and felt that efforts should be made to raise the profile of the condition.

Figure 1 summarises the results from this study and the current literature that require further evidence base and will help to formulate interventions.

Figure 1: Proposed model of intervention for post-operative delirium

Discussion

This is the first study to explore the views of patients and relatives in order to co-design an intervention to reduce distress related to postoperative delirium. Patients and relatives described disturbing and distressing consequences of experiencing POD and had clear views about potential interventions to minimise this distress.

Based on this qualitative exploration the essential components of an intervention to minimise delirium related distress as described by patients and relatives include:

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- A recognition of the need to discuss POD (both on an individual patient basis and as a wider public awareness issue)
- Clarity in the content and format of information provision (to include information on risk and causes of delirium, expected recovery from delirium supported through verbal and written material)
- Appropriate timing of information provision (relative and patient at preoperative stage and follow-up stages of pathway, focus on relative support during episode of delirium)
- Need for trained personnel to deliver the intervention (not necessarily the surgical team, but requiring an individual with an overview of the patient as well as expertise in delirium)
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This potential intervention (figure 1) should be considered in the context of the available literature on delirium distress in other clinical fields. A study in cardiac surgery suggested that a preoperative knowledge of delirium served to make patients feel 'more comfortable' if postoperative delirium occurred (ref 15 OWENS). Post-episode debriefing has also been examined in other populations particularly following intensive care admission (ref 3 GRANBERG, ref 5 ROBERTS). Whilst the effectiveness of post intensive care delirium interventions to minimise distress has not been conclusively shown, this may relate to the difficulty in disentangling the distress related to delirium from the distress related to critical illness as a whole. Similarly, a systematic review concluded that knowledge about delirium in caregivers may reduce their distress (ref 9 BULL). This work acknowledged that carer distress related not only to delirium but also to witnessing a decline in the health of their relative. In palliative care studies, qualitative work has described the need to assist families through providing communication strategies to facilitate their interaction with patients experiencing terminal delirium (ref 6 NAMBA). This approach has benefit in potentially minimising the relatives' distress but may also improve person centred care for the patient experiencing delirium (ref 24 TEODORCZUK, ref 25 OTANI, 26 SOCKALINGHAM, 27 INKLEY, 28 FLAHERTY). This is corroborated by the findings of this present study, which shows the need for pre-emptive information provision, the presence of informed family members during delirium and post episode follow up, was emphasised by participants.

Participants in this study clearly expressed views on who should be delivering an intervention to minimise delirium related distress. The professional background or speciality was less important to participants, who instead focussed on the expertise of the staff. In particular, patients and relatives were keen to receive information from someone with an overview of the patient pathway and experience in managing delirium. This finding is in keeping with previous work that suggests surgical teams may lack knowledge in identifying and managing delirium (ref 29 ROSENBLOOM, ref 30 SHIPWAY) limiting their confidence in communication with patients and relatives.

Finally, participants in this study voiced the need for enhanced education and training in delirium, both for the public and for health care professionals. Previous

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work has described educational programmes to empower multidisciplinary teams in recognition and management of patients with delirium (ref 26 SOCKALINGHAM, ref 27 INKLEY). Such strategies may improve communication with patients and relatives also reducing the stress that staff report when managing patients with delirium (ref 3 GRANBERG). At present there is no cohesive public health strategy to disseminate wider knowledge and understanding about delirium despite the clear need for this as expressed by participants in this study.

Limitations of this study are inherent in all qualitative research. The use of a purposive sampling frame (ref 31 RITCHIE) may have introduced bias through 'outlier opinions' although by virtue of its encompassing nature, this may have deepened our understanding. Recruitment from a single centre limits generalisability but participants in this study were from a variety of geographical areas and spanned the socioeconomic spectrum.

Conclusions

This qualitative study showed that patients and relatives find delirium distressing and report the need for an intervention to minimise this distress. This information enables the design of a pilot intervention. Refinement and evaluation of this intervention should inform the next step in this programme of work.

Conflict of interest

None

Acknowledgements

With thanks to Ramata Carew for transcription of interviews

Funding

Start-up grant from the British Geriatrics Society

Data availability statement: Data is available on request

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Appendix 1

Group 1: Patient Participants. Question guide

- Had you heard about delirium or confusion after surgery before it happened to you?
- If so, what did you know?
- How do you think knowing about it/or not knowing about it affected your experience of it?
- How have things been for you since your delirium/confusion after surgery? Has it affected you in anyway?
- If your friends or family witnessed your delirium or confusion after surgery, how do you think it affected them?
- Do you think you could have been supported in a different way by health care professionals? If so, how?
- If we are trying to make things better for people like you, who have experienced delirium or confusion after surgery, what sort of things do you think may help?
- Did we provide enough information about delirium or confusion after surgery? If not how would you like to receive such information (e.g. written booklet, verbally from nurse/doctor/volunteer, DVD, combination)
- Do you think the staff provided enough support whilst you were confused and as you were recovering from it?
- If yes, what did they do that was helpful and if no how could this be improved and how would you like to receive such support?
- What do you feel about the timing of support to people who develop delirium or confusion after surgery (e.g. should this be given whilst you are confused or just afterwards as you recover)?
- Once you had recovered, did you receive enough information about what had happened and the implications of this?
- Were you offered follow up? Do you think it would have helped to have follow up, by who, when and in what manner e.g. a phone call from a nurse/hospital doctor/GP, or clinic appointment with nurse/doctor/GP?

Group 2: Relative/carer participants. Question guide.

- Had you heard about delirium or confusion after surgery before it happened to your relative or friend?
- If so, what did you know?
- How do you think knowing about it/or not knowing about it affected your experience of seeing it happen to your relative or friend?
- How have things been for you since your relative's delirium or confusion after surgery? Has it affected you in any way?
- How have things been for your relative since they were confused / how has it affected them?
- Do you think your relative could have been supported in a different way by health care professionals? If so, how?
- Do you think you could have been supported in a different way by health care professionals? If so, how?
- If we are trying to make things better for your relative, who experienced delirium or confusion after surgery, what sort of things do you think may help?
- If we are trying to make things better for you witnessing delirium or confusion after surgery and supporting your relative through it, what sort of things do you think may help?
- Did we provide enough information about the delirium or confusion after surgery to you and your relative, if not how would you like to receive such information (e.g. written booklet, verbally from nurse/doctor/volunteer, DVD, combination)?
- Do you think the staff provided enough support to you and your relative whilst they were confused and as they were recovering from it?
- If yes, what did they do that was helpful and if no how could this be improved and how would you like to receive such support?
- What do you feel about the timing of support to people who develop delirium or confusion after surgery and to their relatives and friends who see this (e.g. should this be given whilst you are confused or just afterwards as you recover)?
- Once your relative had recovered, did you and they receive enough information about what had happened and the implications of this?
- Were they offered follow up? Do you think it would have helped either them or you to have follow up, by who, when and in what manner e.g. a phone call from a nurse/hospital doctor/GP, or clinic appointment with nurse/doctor/GP

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Appendix 2: Themes identified in the study with supporting quotes.

Overarching Theme	Sub-theme		Examples of supporting quotes
Prior knowledge of delirium	Negative effect of not knowing about delirium		<i>'We were not told it was delirium until later, so certainly at the time it very frustrating because you know..... I think that delaying not knowing about delirium and realising there is such a thing as delirium, was very worrying and distressing I suppose.'</i> (Stuart, son).
	Positive effect of knowing about delirium		<i>'All I can say with regard to that is that I don't think that I was as disturbed as my relatives were. I felt that this was all part of the process but my partner and my children were very concerned that I was going somewhere other than where I had planned to go, as it were. So, I was more in tune with my delirium than they were.'</i> (Russell, patient). <i>'Er well I guess it did help cos you're kind of expecting it aren't you but, er, so it wasn't a big shock.'</i> (Gareth, son).
Impact of delirium	Negative impact of delirium	Distress of witnessing delirium	<i>'I think she got progressively, she did progressively worse and then dementia definitely fast forwarded over the time and simply accelerated towards the end so she is getting slightly physically but I think worse mentally. She was getting worse, and I knew that she didn't recognise me at all at the end.'</i> (Sally, daughter).
		Negative impact of experiencing delirium	<i>'But I didn't realise that Gavin was sitting next to me, he told me that afterwards, so that wasn't something that I knew about its just I knew I was going to die and that was pretty terrifying.... It was very, very scary, well I had a heart attack whilst this was going on.'</i> (Linda, patient).
		Perception of impact on friends/relatives	<i>'And, the most upsetting bit for me is not particularly what it did to me but what it did to my wife, or to my daughter....Mm, ahem, and the most important thing to me is the people who suffer, who really suffer are the ones on the outside who haven't got the problem because the person i.e. me, the patient I wasn't even aware of what was happening. It was the family and not the family but my wife and my daughter who suffered the most.'</i> (John, patient).
	Neutral/positive impact of delirium		<i>'I didn't know, I just thought they were some quite nice dreams actually.'</i> (Brian, patient). <i>'Yes, because when I was discussed with my daughter, we would say 'well, yes, at least he has got the strength to be being angry. So, in that, no it didn't distress me because it was an improvement on what we had been dealing with, which, we didn't think he was going to make the end of the week, before he came into hospital.'</i> (April, wife)
	Relative noticing cognitive decline since delirium		<i>'Erm, since the operation, he is forgetful. We don't leave him on his own unless it is unavoidable.'</i> (April, wife).

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	View of emotional support		<i>I think treating the patient should be their priority. I mean emotional support is like an endless pocket, you know, and people, some people just abuse it and at the end of the day, you have got to walk out of here and support yourself so, I don't know what emotional support. (Sally, daughter).</i>
Own attribution to cause of delirium			<i>'I realise then that it must have been a drug induced one. And it's gone on from there that I will be very careful what I would take before I go to bed, and just take the normal night cap err night tablets before I go to bed and apart from paracetamol occasionally, that's all, there is no more painkillers.'</i> (Brian, patient).
Communication	Examples of good communication strategies from staff		<i>'For me yes, there was enough support for me, cos I was mirroring what they were saying and they were trying to keep it very light-hearted. (Mary, daughter-in-law).'</i> <i>'Yeah, they were very good at trying to calm her and talk to her I guess and not try to shut up, I don't know, not trying to shut her up, or not ignore her though, but they would acknowledge her and what she was saying and I think just generally talk to her and or were very compassionate and you know.'</i> (Stuart, son).
	Negative effects of lack of communication		<i>'Sometimes they do not know what is going on and sometimes they don't. Sometimes they just come on shift, haven't a clue, you know the communication was extremely poor, frankly.'</i> (Stuart, son).
	Who should be responsible for communication		<i>'It appears to me obviously, that delirium, is can be very, can affect people very badly, I would think. Therefore yes it important to discuss the delirium but not as a separate entity that's why I think that, that training of the staff is very important, junior staff and nursing and so on, and so forth need to be general part of the team or a specialist as long as someone is recognising the problem and addressing it while it occurs.'</i> (Russell, patient).
	Desire for information on how to talk to people with delirium		<i>'Presumably if anything comes out of this study that you know like a guide or a handbook or something like that, but some sort of tips what to expect and advice on how to handle it [delirium]. I still don't know whether I should be pulling him on it, on the fact that he is, or should have, hopefully it's not gonna happen again but whether or not I should have pulled him up on the fact that he is talking to the wrong son or whether I did the right thing in glossed over it and didn't. So he didn't know that he was being delirious. (William, son).</i>
	Formulation of own communication strategies		<i>'Yes. And we just, cos if we tried to sort of say to him 'no, there isn't any artwork' he would get angry, so I kind of take the view that if someone genuinely believes that then it's not gonna actually be any harm to agree with them, you might as well agree with them.'</i> (April, wife).
	Difficulty resulting from open communication		<i>'Well, no I'm, the only thing for me is if it was possible to explain to me what was going on but I fear that the state of my mind at the time,</i>

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			<i>my mind maybe would not have accepted any explanation. It may have dismissed it, you know I, you're trying to tell me stories, you're lying to me – it might have been like that.'</i> (John, patient).
Timing of communication	Before the operation		<i>'And I think the variability, that I think perhaps to say, you know that I, that my foot might fall off or my thingy might fall off is something they did tell me so that doesn't happen to everybody, you know, fingers don't fall off or toes don't fall off, because of emboli or whatever it is. They did discuss that and discuss the fact that they had put monitors on to determine the flow in my arteries and so on and so forth. Maybe they should have said you know that your mind might be disturbed in whatever and made it disturbed I don't know, what makes it disturbed.'</i> (Russell, patient).
	During the delirious episode		<i>'I should...just to be apprehended before you get before you get to the bed. You sort of nip it in the bud before you get there. You know cos you're supposed to say "is it okay to come and visit" and they say "ah, could we have a little chat" and just go in the waiting room and just explain to you what's going on, she is confused and might be saying crazy things and this is what's going on and then I could've gone in there and thought 'oh okay then, we're enjoying the moment cos she's going to get better and she hasn't been brain damaged by lack of oxygen or something'.....Just the, you know visitors, give them a heads up.'</i> (Darwin, partner).
	Follow-up		<i>'It would be nice yeah, just that as you say in a follow up scenario just to make you feel okay cos as I say if I wasn't particularly worried another person might be, so yeah looking from someone else's perspective, I am sure that would be a lovely term of follow up and knowing that things still worry about you and care for you in that respect in the delirium side of things. That would be good.'</i> (Albert, patient).
Format of information	Face to face		<i>'For me personally, I prefer to speak, I prefer to speak to someone. Given me a leaflet or a piece of paper doesn't do it for me.'</i> (Rachel, wife).
	Leaflets/written information		<i>'So if I basically. It would be nice if someone actually come with the information explained it and then left a leaflet.'</i> (Albert, patient).
Environmental considerations			<i>'Only if you can get the patient in a condition where he can orientate himself with regards to his surroundings. And probably see more people but then the nurses can only be in one place at one time.'</i> (Samuel, patient).
Suggested areas for improvement	Improved provision of information		<i>'No, probably just a lot more awareness raising with family members as to what delirium is and what actually happens.'</i> (April, wife).
	Better training of staff members who deal with delirium		<i>'I mean, I suppose if it's an inevitability, which I don't whether it is or not, but if it's an inevitability that it should occur, then I think</i>

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			<i>it's important than awareness is increased, that education is undertaken, that people are taught and trained into how to cope with it.'</i> (Russell, patient).
	Raising public awareness		<i>'Um, and also the general public doesn't know the word. And I have got a prime example this week in that Ellie Goulding has brought out an album called 'Delirious'.....Which obviously, she thinks is quite positive, I mean you wouldn't bring an album out called cancer or Parkinson's or something and that just is an indication of how nobody really knows about it.'</i> (Sally, relative).

Appendix 3: Results section

Prior knowledge of delirium

Fifteen out of the 23 participants had not heard of delirium prior to the post-operative experience in question. Of these 15, 8 were patients and 5 were relatives. Eight participants were somewhat familiar with delirium prior to the experience. Of these 8, 5 were patients and 3 were relatives.

Two themes related to the prior knowledge of delirium and how it impacted on the experience of the episode of POD.

Negative effect of not knowing about delirium

The strongest negative reactions appeared to come from the relatives. Relatives described feelings of frustration, confusion and worry as a result of not knowing what delirium was. This was linked directly to the lack of knowledge to the condition.

'Erm, it was a little bit confusing at first until I realised that Albert was confused.' (April, wife)

'We were not told it was delirium until later, so certainly at the time it very frustrating because you know, when everybody says oh it takes a few days for the anaesthetic, and then it's a week and she is still in a bad state then you kind of, well, something clearly is wrong so um, I think that delaying not knowing about delirium and realising there is such a thing as delirium, was very worrying and distressing I suppose.' (Stuart, son).

Stuart's sister also expressed feelings of frustration and felt that delirium was something she should have heard of before.

'So that made me feel like I wasn't educated or I didn't know what I should have known. If you see what I mean?' (Sally, daughter).

The feeling that knowledge of delirium would have helped to cope better with the situation was also expressed.

'And I didn't know what to do about it. I suppose if I had known, it was something that happened I maybe would have thought of a different strategy or something, but it did catch me unawares.' (Emily, wife).

Patients expressed that they felt the degree to which they 'believed' their delirious experiences might have been affected by their previous lack of knowledge.

'I believed everything that I now know I was imagining but at the time, I believed it 110%.....But up until that moment it was 100% fact and although they told me it wasn't happening I thought they are in with everybody else.' (John, patient).

Positive effect of knowing about delirium

In contrast, those who understood delirium before the event reported that this knowledge benefited them. Those that knew about delirium beforehand expressed how they felt it helped them to cope with the experience and reduced the shock of the experience.

'Erm, I think the whole thing erm was easier to take on board, having worked with as I say in a doctors surgery, having been on erm courses. Erm yes it was quite hard with Ernie but he wasn't actually too, too bad I didn't think.' (Mary, daughter-in-law).

'Er well I guess it did help cos you're kind of expecting it aren't you but, er, so it wasn't a big shock.' (Gareth, son).

One participant felt at an advantage over his relatives, who did not know of its existence and who were far more perturbed than him by the experience.

'All I can say with regard to that is that I don't think that I was as disturbed as my relatives were. I felt that this was all part of the process but my partner and my children were very concerned that I was going somewhere other than where I had planned to go, as it were. So, I was more in tune with my delirium than they were.' (Russell, patient).

One patient inferred that her knowledge of the existence of delirium allowed her to speak freely about it to her attending doctor, which was seen as a positive thing for the patient.

'The only person I mentioned it to was Dr X on the ward but I call him Dr X (do you know him?) and he was on the rounds one morning and he came over to me and I think I must have looked a bit confused, or something, He came over

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and said 'are you alright Barbara?' and then I kind of said to him 'well, I think I am a bit delirious at the minute'. (Barbara, patient).

Some patients hypothesised that if they had had prior knowledge of delirium, this may have helped them to cope with the delirium.

'Mm I think I would rather have known it was possible then I could have rationalised it to myself.' (Samuel, patient).

Impact of delirium

Both relatives and patients spoke freely on the impact of delirium both on their part and commented on the perceived impact on their loved ones. Some relatives became tearful during the interviews whilst recounting their experiences.

Negative impact of delirium

There were three themes that emerged regarding the negative impact of the experience to delirium.

Distress of witnessing delirium

Relatives recounted how disturbed they were watching their relative go through their episode of POD.

'Em, it was, I mean it was incredibly distressing, yes as I say she literally was sitting there at times well difficult to say, I think she was at times in pain but not, it wasn't a major thing she was just very distressed and very confused, you know she was talking about her bridesmaid from 50 years ago or whatever, getting her confused with my sister and things like that. She did occasionally sort of, you know, forget who I was and as I say she had periods when she just wanted to die; which interestingly I think to be fair, was partly the confusion but was partly as her genuine wish, cos she was 88 and so I think she had had enough generally so. But you know that's a difficult when she said, can't the doctor's do something or can't they do something and well, erm, no.' (Stuart, son).

For Stuart and Sally, who were siblings, their distress was clearly not just as a result of the delirium but also their mother's general deterioration and unfortunately their mother passed away during the hospital admission. It is therefore possible that the distress for some, may not be entirely separable from the distress of seeing their loved one's physical health deteriorate.

'I think she got progressively, she did progressively worse and then dementia definitely fast forwarded over the time and simply accelerated towards the end so she is getting slightly physically but I think worse mentally. She was getting worse, and I knew that she didn't recognise me at all at the end.' (Sally, daughter).

Relatives found it very distressing when they were not recognised by the patients.

'I suppose I just learnt with my Dad that it comes in all shapes or forms; it was very, very confused. He did not recognise me which I would say even against the episodes where he was seeing rats and spiders crawling over people and up walls, I think probably the most distressing thing was not being recognised by dad that was a first time I ever experienced anything like that.' (William, son).

Relatives also expressed alarm at angry, irrational and paranoid behaviour patterns in the patients.

'It was quite disturbing, especially because he would get cross and irritated with me because I wasn't giving him the right answers. He was pointing and looking at things and I suppose half of me wanted to laugh because some of it seemed silly but when he was so serious neither could I find a serious answer, so I did find that a bit distressing.' (Emily, wife)

A thought that added to the distress of one relative was the fear that the cognitive decline would represent a permanent change in cognition. Here, a relative recounts his concerns about how this would add to his already large burden of care.

'From her general state, her manner and just really, really going... I thought crikey ...you know, is she going, is she having, has she got some mental health problems you know...and er if this is going to cause her brain damage, I've got quite a lot on my plate cos obviously she's disabled now anyway with her leg missing and she's got, lost her toes but she's still not recovered...and she's got a disabled daughter as well and I've got all this stuff running round in my mind. You know how am I going to manage and cope.' (Darwin, partner).

Negative impact of experiencing delirium

Some patients who experienced delirium expressed their negative recollections of events. For some the experience was recalled as being frightening and as above, some patients became tearful when recounting their recollection of delirium.

'I have had, I have never felt so frightened in my life' (Samuel, patient).

'But I didn't realise that Gavin was sitting next to me, he told me that afterwards, so that wasn't something that I knew about it's just I knew I was going to die and that was pretty terrifying.... It was very, very scary, well I had a heart attack whilst this was going on.' (Linda, patient).

Perception of impact on relatives/friends

Patients who experienced delirium had an additional worry that their delirious episode had impacted negatively on their relatives and friends.

'Well it didn't affect her, the only thing that affected her was when she explained it to you afterwards but she works with the delirium people or dementia people and she was very, very scared that the drugs were affecting me the same way. And or, I had dropped off the edge and gone into a state of dementia. That was really what she was worried about.' (Brian, patient).

'And, the most upsetting bit for me is not particularly what it did to me but what it did to my wife, or to my daughter....Mm, ahem, and the most important thing to me is the people who suffer, who really suffer are the ones on the outside who haven't got the problem because the person i.e. me, the patient, I wasn't even aware of what was happening. It was the familymy wife and my daughter who suffered the most.' (John, patient).

One patient explained that the experience had been so frightening for his close friend, that she stopped visiting for a while.

'My friend came to see me erm in the early stages of the confusion and she was frightened to death when she saw me and met me because of the way I was and the things that I was saying. In fact she was that frightened that she couldn't come to see me for a couple of days... ..she didn't tell me why but I realised afterwards erm that did upset me. So erm I think it's sort of related to the fact that, by that, I am thinking in the terms of am I going insane or you know, is my brain starting to... or is something else [dementia] setting in.' (Jerry, patient).

Neutral/positive impact of delirium

Some patients recounted their delirious episodes in a neutral or positive way in as much as to say that the episode itself did not upset them, or that the recollections were positive.

'I didn't know, I just thought they were some quite nice dreams actually.' (Brian, patient).

'Yeah, but mm, and then it was a couple of other incidents, when my sisters came to me, in the dream like. But like it was a dream, they were holding me, I felt they were healing me for some reason.' (Barbara, patient).

Another interesting point is when patients and relatives describe the delirious episode as an almost neutral event, in view of the fact that compared to the life or death situation they were in prior to surgery, this was not an important feature. In other words relatively speaking, the delirium itself was not as distressing as other health issues they faced during their episode of illness.

'Yes, because when I was discussed with my daughter, we would say 'well, yes, at least he has got the strength to be being angry'. So, in that, no it didn't distress me because it was an improvement on what we had been dealing with, which, we didn't think he was going to make the end of the week, before he came into hospital. So, it

was kind of a little bit a 2 edged sword...Yep, off you go in for a minor operation and you come out with delirium, I think that's another situation and maybe I may have been very distressed by that but he was literally days from death, so to have him actually in position of fighting and arguing was positive.' (April, wife)

Relative noticing cognitive decline since delirious episode

Some relatives had noticed that since the delirious episode there had been a permanent cognitive decline compared to prior to the operation/period of illness and delirium.

'Erm, since the operation, he is forgetful. We don't leave him on his own unless it is unavoidable. We generally make sure somebody is around because I do have concerns about his forgetfulness at times. So, I think a follow-up would possibly have been good to actually see whether his score was the same as it was previously and maybe even sort of three months after to see whether it had now fully recovered or not. Erm, to my knowledge, there wasn't any follow-up.' (April, wife).

'I'd say I've noticed, I'd say 95 per cent there's a few things, she seems a bit forgetful now and err I've told her things and she doesn't remember them and I'm wondering if that is you know, because there must've been a lot going on in her head, it's caused a problem. But yeah I think she's not 100 per cent what she used to be, you know to be quite honest.' (Darwin, partner).

View of emotional support

Following on from the recounting of the distress caused by delirium, some views were expressed spontaneously regarding in particular emotional support (as opposed to purely factual communication). One participant and 2 relatives could see the role of emotional support or counselling, however, one relative did acknowledge that a barrier to this might be lack of resources.

'I mean I was a bag, of well, you know, trying to find a polite word to put on it. But I was just absolutely distraught, I didn't know what I was doing most of the time, I just used to go home probably not eat, sometimes eat, not, have a few glasses of wine, make loads of phone calls. Go to bed, get up in the morning, get ready, getting to come back and do it all over again and your body is just on autopilot and you are just worried all the time. After the operation the worry ceases slightly because you know that hopefully now that's okay but you know, you are drained, you're so emotionally and physically drained that any sort of support, any emotional support is helpful definitely.' (Barbara, wife)

I think treating the patient should be their priority. I mean emotional support is like an endless pocket, you know, and people, some people just abuse it and at the end of the day, you have got to walk out of here and support yourself so, I don't know what emotional support. (Sally, daughter).

Own attribution of cause of delirium

Sometimes patients and relatives were not told the cause of the delirium by healthcare professionals, and they very often offered their own thoughts on what could have caused the episodes. Five patients and 7 relatives offered their own explanations in the interviews. Medications were the most common thing to be blamed for the delirium. One person acknowledged that older age might be a contributing factor.

'I realise then that it must have been a drug induced one. And it's gone on from there that I will be very careful what I would take before I go to bed, and just take the normal night cap err night tablets before I go to bed and apart from paracetamol occasionally, that's all, there is no more painkillers.' (Brian, patient).

'Whether again, you know looking up the risks of people getting delirium I think it's multiples once you get over 65 and things like that postoperatively.' (Stuart, son).

Communication

Unsurprisingly, issues around communication came out spontaneously very strongly in the interviews.

Examples of good communication strategies from staff

Both relatives and patients gave examples of how staff members dealt with and communicated well with patients that were delirious.

Seven of the patients spoke very highly of the nursing staff looking after them. They recalled that having explanations and being spoken to in a gentle manner were positive experiences. One patient recalls being spoken to in both an 'empathetic' and a 'critical' manner whilst delirious and stressed how only the former had helped.

'Yes, but I would think that empathy with you know rather than being a negative thing, then perhaps working with it and saying 'don't worry' or whatever to be more empathetic with the problem than with the patient rather than, you know, get up and do that as it were, you know a bit more critical which I think it was for once or twice.' (Russell, patient).

Patients expressed that explanations of what had happened left them feeling reassured.

'Yeah, I would have been more frightened I think, yeah I would have been a little bit scared but knowing because he explained to me, he[staff] said some people have had this experience.' (Barbara, patient).

Relatives also recalled that watching their relatives been spoken to in a gentle manner was beneficial.

“Yeah, they were very good at trying to calm her and talk to her I guess and not try to shut up, I don’t know, not trying to shut her up, or not ignore her though, but they would acknowledge her and what she was saying and I think just generally talk to her and or were very compassionate and you know.” (Stuart, son).

One relative mentioned how watching the nursing staff and how they dealt well with the patient, taught them how to deal with their relative whilst they were delirious.

‘For me yes, there was enough support for me, cos I was mirroring what they were saying and they were trying to keep it very light-hearted.’ (Mary, daughter-in-law).

Explanation into why the delirium had happened and provision of information was also important to the relatives.

‘Erm I think they said her oxygen was very low and potassium was very low and that that can lead to it as well. I think knowing the reasons for it, helped us understand and we was able to you know reassure her that you know what she was thinking was not real you know.’ (Gareth, son).

Negative effects of lack of communication

Some participants reported that they did not receive enough information from healthcare staff and this impacted negatively on them. One relative expressed that until a specialist team was involved, things had been very frustrating from the point of view of finding out what was happening to their relative.

‘Sometimes they do not know what is going on and sometimes they don’t. Sometimes they just come on shift, haven’t a clue, you know the communication was extremely poor, frankly, initially and to the extent, I think it got, to, where we said we need a meeting with a consultant and that actually coincided with the POPS [specialist team for older people undergoing surgery]. Team getting involved. And communication then, and knowledge went much better for us coming from that point onwards which was probably early January. Except then it was, you know I think communication was very difficult.’ (Stuart, son).

Another relative expressed how they felt they should have been warned before speaking to their relative that they had become confused, as he describes the shock of having the phone passed over to speak to his dad and his surprise at how distressed he sounded.

‘There was no warning she said “Oh your dad just wants to speak to you, is that okay?” “yes” I was put on or he was put on and he just rambled erm so yeah that’s part of the reason I was interested in doing this study because I had no warning. Had I been given a warning that there’s a problem, I wouldn’t have been so surprised. Knowing that it does happen I would’ve...I don’t want to say played along with it but I

would have been more prepared, and would have been able to help him a little bit more than perhaps I did.’ (Peter, son).

Who should be responsible for communication?

Participants offered various views on who from the healthcare team should be responsible for communicating and principally informing patients and families about what was going on regarding the delirium.

The idea of both increased awareness and information giving by the staff members dealing with the patients on a daily basis came up. It seemed important that somebody had an overview of the patient and that this at times was felt to be lacking. However, it seemed that ultimately as long as recognition and communication were taking place the specifics of who delivered this seemed less important.

‘It appears to me obviously, that delirium, is can be very, can affect people very badly, I would think. Therefore yes it important to discuss the delirium but not as a separate entity that’s why I think that, that training of the staff is very important, junior staff and nursing and so on, and so forth need to be general part of the team or a specialist as long as someone is recognising the problem and addressing it while it occurs.’ (Russell, patient).

‘I think probably consistency, erm of starting which is always the challenge erm where you sort of become connected to another person, without adding a constant change which again is always difficult.’ (Clara, wife).

However, there were comments that stated that the surgeons did not seem knowledgeable or even possibly interested in the delirium.

‘Yes, and it seemed to me that the ward doctor doesn’t really know the patient, so it just can get very confused cos I say, a consultant is down as a vascular surgeon, which in this case is irrelevant and not very helpful, so and as I say, the POPS Team definitely helped because they were mostly more knowledgeable about delirium and things like that.’ (Stuart, son).

‘I get the feeling the surgeons do their surgeon bit on whatever’s easiest physically, and whatever, they don’t take the whole picture of the person. I know when we got the POPS Team involved it was a lot better but at that stage by the time that when I had that conversation, I didn’t know about the POPS Team and I did not know about anything, I felt I was kind of fighting a battle myself.’ (Sally, daughter)

There was recognition from participants that limited time was a barrier to someone communicating effectively to patients and relatives. However, recognising and understanding that time was a limitation, did not make the experience any less frustrating.

'What you know, the progress and er ...it was frustrating sometimes that we had to wait so long to see the doctors because obviously the nurses only knew so much and perhaps they couldn't tell you the whole story. So there was a lot of waiting around to see a doctor or a surgeon, surgical team. But you know they're busy people aren't they so...' (Gareth, son).

Desire for information on how to talk to people with delirium

As well as the desire for information or pure knowledge on the topic of delirium, participants often expressed that information given should include how to talk to and deal with people whilst they were delirious, not least because of the display of challenging behaviour.

In response to a questions about how else staff could support the relative through the episode of POD, this was one response.

'So if talking about understanding, how to talk to someone who is actively delirious both from the staff point of view and maybe even from your relative's point of view, trying to help them to understand how to communicate with you whilst you are in that situation?' (Russell, patient).

'Presumably if anything comes out of this study that you know like a guide or a handbook or something like that, but some sort of tips what to expect and advice on (how) to handle it. I still don't know whether I should be pulling him on it, on the fact that he is, or should have, hopefully it's not gonna happen again but whether or not I should have pulled him up on the fact that he is talking to the wrong son or whether I did the right thing in glossed over it and didn't. So he didn't know that he was being delirious.' (William, son).

Formulation of own communication strategies

Where relatives did not receive any guidance on how best to communicate and cope with their delirious relatives, they mentioned some tactics they came up with themselves to deal with the situations they faced. Generally speaking, in the experiences discussed, the most successful tactics were not to contradict the delirious person and to remain calm.

'Yes. And we just, cos if we tried to sort of say to him 'no, there isn't any artwork' he would get angry, so I kind of take the view that if someone genuinely believes that then it's not gonna actually be any harm to agree with them, you might as well agree with them.' (April, wife).

'Yes, it, it was just to reassure him, just to reassure him that...because there was no point in saying that it's you know all in your mind because he wouldn't have believed it, so I wanted to go along which is why I say, had I been prepared I might have been able to do the playing along a bit a little bit better which would have reassured him.' (Peter, son).

One relative had kept a diary of the events whilst the patient was in ICU but found that the patient had not wished to read through it, possibly as they found the prospect too distressing.

'There is a lot of information there... so as I said he has a diary, ahem, mm and he has you know what was going on in the outside world from postcards that we had written but he is not wanting to access that.' (Mary, daughter-in-law).

Difficulty resulting from open communication

Although participants did agree that information on delirium was desirable, there were particular instances where participants hypothesised spontaneously that there could be issues around full and frank discussions for patients.

Firstly there was a concern that informing patients of the potential of delirium before an operation might cause distress and theoretically in itself, increase the risk of delirium.

'I don't, well, will it put this in your mind do you know what I mean. Would you expect delirium, if you spoke to before, I don't know.' (Barbara, patient).

The second issue was that it was felt that there was no point discussing delirium itself to the person who was experiencing it during the actual delirious episode, as they would not be able to process the information.

'Well, no I'm, the only thing for me is if it was possible to explain to me what was going on but I fear that the state of my mind at the time, my mind maybe would not have accepted any explanation. It may have dismissed it, you know I, you're trying to tell me stories, you're lying to me – it might have been like that.' (John, patient).

The third potential issue with openness was that of trying to follow people up and that for some, who may have wanted to forget the experience, trying to talk it through with them could be distressing. In the discussion regarding whether follow-up post the episode of POD, Mabel brought up this discussion:

'Mabel: Well apparently, you know a lot of people don't even remember it so I wouldn't unless they can remember it I wouldn't in case it brings things to the foreground.'

Interviewer: So patients who remember it and have had experiences like you've had?

Mabel: Yes, then I would say it helps but I wouldn't drag it up again if they don't remember.' (Mabel, patient).

Timing of communication

Participants were asked to consider at what point receiving information about delirium would have been most helpful.

Before the operation

Some participants felt very strongly that knowing about delirium before the operation was very important and it was suggested that the risk of delirium should be highlighted during the operative consenting process. This warning appeared to be especially important if the patient was thought to be particularly at risk of delirium.

'And I think the variability, that I think perhaps to say, you know that I, that my foot might fall off or my thingy might fall off is something they did tell me so that doesn't happen to everybody, you know, fingers don't fall off or toes don't fall off, because of emboli or whatever it is. They did discuss that and discuss the fact that they had put monitors on to determine the flow in my arteries and so on and so forth. Maybe they should have said you know that your mind might be disturbed in whatever and made it disturbed I don't know, what makes it disturbed.' (Russell, patient).

One relative mentioned that the potential for mentioning the risk of delirium was especially important if a patient was having less urgent or life-saving surgery as the risk/benefit of having the surgery should be considered carefully, especially if there was a risk of dementia following the episode (the participant understood that delirium can act as a catalyst to accelerate the process of dementia)

'If you then think well if I had this operation, if they had the operation and they have got a bit of dementia it could make it worse and they're quite elderly, is it worth putting them through it running that risk rather than letting them live with whatever they've got for another 6 months or a year and when probably the inevitable it's gonna happen anyway.' (Sally, daughter).

Some hypothesised that prior knowledge would have helped the person experiencing the delirium as well as the relatives.

'Maybe if mentioned before an operation. Maybe that would help, so that if you have strange dreams or you see, you see some of the things you think, it's a dream and actually what's going on is something else. I think that probably would explain you know for people who will eventually go through these things then, ...would you be able to rationalise.' (Linda, patient).

'I personally feel very strongly that because this obviously happens and has been happening for many years, mm I think that when patients of his sort of age group that as you say probably affects more so than younger people, I think that it would be very, very useful if somebody could warn you of this, that is the most important thing I feel because it would have saved so much less heartache.' (Rachel, wife).

Less commonly, as mentioned above, with thoughts on honesty, another feeling was that being too honest might make people worry disproportionately about the risk of delirium occurring.

'No, I don't think relatives' minds are in the right place to be saying then, you're just focussing, on are they going to live, that's what we were focusing on...I don't think so no...'. (Mary, daughter-in-law).

During the delirious episode

Participants felt that the efforts of communication in the form of information giving during the delirious episodes should be focused on the relatives, as patients themselves were unable to take information in. Relatives clearly stated that healthcare staff should inform them about the delirium before the relatives saw the patient.

'I should...just to be apprehended before you get before you get to the bed. You sort of nip it in the bud before you get there. You know cos you're supposed to say "is it okay to come and visit" and they say "ah, could we have a little chat" and just go in the waiting room and just explain to you what's going on, she is confused and might be saying crazy things and this is what's going on and then I could've gone in there and thought "oh okay then, we're enjoying the moment cos she's going to get better and she hasn't been brain damaged by lack of oxygen or something". Cos you don't know what's been going on during an operation. So. So if somebody had just told you when you first got there...Yeah.....rather than you going to the bedside and seeing her...Yeah...mmm cos I, I'm not sure if that was the time she had a heart attack or mild heart attack and er you know I didn't know anything about anything, so. Just the, you know visitors, give them a heads up.' (Darwin, partner).

Follow-up

One patient mentioned that they would have liked a bit more information given to them whilst they were still on the ward, after the resolution of the delirium but before discharge. However, most conversations on this topic revolved around follow-up after discharge.

21 out of the 23 participants expressed an opinion on follow-up post discharge. Six patients and eight relatives expressed the desire for some sort of post-discharge follow-up. The role of this was to check that there were no new issues, further explanation, and for the relatives it was seen as an opportunity to flag up cognitive impairment that they, rather than the relatives had noticed. Either telephone or clinic follow-up seemed acceptable. Phone calls appeared to be the most practical solution initially for participants, which could then be supplemented with clinic follow-up where necessary.

'It would be nice yeah, just that as you say in a follow up scenario just to make you feel okay cos as I say if I wasn't particularly worried another person might be, so yeah looking from someone else's perspective, I am sure that would be a lovely term of follow up and knowing that things still worry about you and care for you in that respect in the delirium side of things. That would be good.' (Albert, patient).

'Yeah have a, have a...when the patients discharged obviously while you're in the hospital you're being monitored, just when you get home have just a phone call if necessary or if you've got concerns come in and see someone, we'll arrange an appointment. That would be quite a good option. Mmm, so somebody that you could actually approach and say to us... Yeah I've got concerns and...I've seen a slight change you know of behaviour.' (Darwin, partner).

Two patients felt they did not feel follow-up was necessary, although none expanded on the reason why. One could hypothesise that they felt they had no further issues regarding the delirium.

'Well everybody was looking after me, I mean I was in here for 4 weeks wasn't I or over 4 weeks.' (Linda, patient).

One relative, whose mother died, felt that follow-up would not be necessary. Three relatives mentioned that follow-up should only be offered to relatives if they wanted it, because for some patients, recounting the experience again might be too painful.

'If he has remembered and he is disturbed, then YES. But if he hasn't then maybe it's just better left.' (Emily, wife).

Environmental considerations

There were comments in the interviews regarding the impact of the ward environment on delirium.

A couple of patients explained that they found certain aspects of their environment disturbing, such as lighting colour, and there was a lack of markers to help orientate them.

'Mm, lights have a lot to do with this, I don't know if it makes any sense to you but night, the television sets, but they are turned to the wall and there was a green glow over the ward and that was most disturbing. I could see the Nurses' office, there was a green light in there, and unless there was someone in there all I could hear were these footsteps and that was the Korean guards [recollection of delirium]..... Only if you can get the patient in a condition where he can orientate himself with regards to his surroundings. And probably see more people but then the nurses can only be in one place at one time.' (Samuel, patient).

The presence of familiar faces was recalled as having a positive effect.

'I think for someone coming out surgery it must be great to have someone with them, family member because even if you are in delirium, I think you have more of rapport because you recognise the voices, and I mean, well I recognise my wife and daughter, but it was just their voices I think as much as anything. Cos I was dropping off a lot of times and that really calmed me knowing that they were there. So I think

for future if someone has got a family member who can be there, when they have come out of surgery and they wake up is fantastic, yeah. To me it was anyway.' (Albert, patient).

There was some discussion about where patients with delirium would be best cared for. The idea of a ward that specialised in dealing with delirium was brought up by one relative, as was the need to minimise ward movements by another relative.

'So I think in terms of the general care that might be a better model [delirium ward] certainly in some cases. And certainly having a patient in hospital for, sorry in a vascular ward for a month after surgery is not, does not seem to me a very good use of a vascular bed shall we say, because the vascular problems weren't the problem anymore and her leg, so yeah.' (Stuart, son).

'I don't know, I mean I know there was some talk at some point of moving her to a geriatric ward or an old people's ward. Um, but they were kind of almost too scared to move her I think because she kind of got established there and they were worried that the change would affect her and by that point by the time we were talking about that she was getting kind of upset when other people in the ward changed, so she was quite mentally ill by that point so any sort of change was disruptive, um and as because she didn't have the third operation until Christmas Eve by the time she got over that we were into January, and then she had kind of had deteriorated quite a lot so there was no, you couldn't really have moved her then so I don't know. But then she was for the last few weeks, for the last few weeks she was yeah, in the wrong place really she should have been in an old people's ward or geriatric ward or, erhm, but to move her would have been too much.' (Sally, daughter).

Format of information

Face to face

Participants were asked how they would like information about delirium to be delivered, and the most common response was a face-to-face discussion with a healthcare professional. Participants wanted to receive tailored advice specific to their case.

'Ok and again as I say my personal opinion is actually leaflets and other sort of things, will never substitute a person talking to you. Yep, mm, saying the old antidote [adage], or whatever you want to call it, is you know knowledge is a good thing, you can never have too much. I mean, all right everybody says too much information. There is no such bloody thing. Excuse me.' (John, patient).

'It was the person being there who would say I am not going to let you die stop being silly. That mattered much more because when you are in this condition, you're not going to be able to pick up the leaflet and read it.' (Samuel, patient).

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For me personally, I prefer to speak, I prefer to speak to someone. Giving me a leaflet or a piece of paper doesn't do it for me. (Rachel, wife).

'Yes yeah you know, you have got somebody to talk to, how can I put it?... You have got somebody alive to talk to. Not just imaginary you have actually got someone there, you are not imaging that they are there. Like the rest of it.' (Miriam, patient)

Leaflet/written information

People did like the idea on leaflets and written information but only really as an adjunct to contact with a healthcare professional. There was also the suggestion that reading about other people's experiences may have been helpful.

'Yeah, might have helped yeah. Yeah, yeah, yeah just that in You know reading about something, or somebody's experience of it.' (Barbara, patient).

'So if I basically. If would be nice if someone actually come with the information explained it and then left a leaflet.' (Albert, patient).

However, leaflets are not appropriate for everyone. There were quite a few suggestions (as above also) that written material is not always read.

'Because sometimes you just look at leaflets and think..... (dismissive tone).' (Barbara, patient)

DVD

Only one person felt a DVD would be helpful but seemed to suggest it should be watched with healthcare professionals nearby. Three other people felt that DVD as a mode of information giving would not be for them

'It could yeah...my first thoughts are as have you got a DVD player, bring it alongside then show it to them. Maybe they want to watch and maybe they don't, that's that but I would mainly concentrate on the larger operations and length of time.' (Brian, patient).

Suggested areas for improvement

As part of the interview participants were asked to reflect on their experience and mention any areas in particular that could have been improved. Three themes came from this.

More provision of information

Some participants felt that not they did not receive enough information on POD and that they should have had more.

'No, probably just a lot more awareness raising with family members as to what delirium is and what actually happens.' (April, wife).

More training for staff members who deal with delirium

One patient felt very strongly that all those that deal with delirium should be able to recognise and handle it proficiently.

'I mean, I suppose if it's an inevitability, which I don't whether it is or not, but if it's an inevitability that it should occur, then I think it's important that awareness is increased, that education is undertaken, that people are taught and trained into how to cope with it. I am not sure you can do anything else really. Because if it's going to happen you have got to deal with it haven't you.' (Russell, patient).

Raising public awareness

One patient and three relatives expressed their surprise that delirium was so unheard of in the public domain and efforts should be made to make it more known about on a public scale.

'Um, and also the general public doesn't know the word. And I have got a prime example this week in that Ellie Goulding has brought out an album called 'Delirious'.....Which obviously, she thinks is quite positive, I mean you wouldn't bring an album out called cancer or Parkinson's or something and that just is an indication of how nobody really knows about it.' (Sally, relative).

'But the other thing which is not quite as important as that but I think very important is to nationally make sure the public are aware of it. They don't have to be a patient to be aware. I mean we all know [now] about HIV [but] when it kicked off did we know about it?'(John, patient).

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Table 1a – Patient participant demographics

Pseudonym	Sex	Age	Time since delirious episode	Current or Previous occupation	Relative also participated in study?	Reports a history of cognitive problems in patient participant
PATIENTS						
Brian	M	73	27 months	Tech Consultant	No	No
Russell	M	76	25 months	Doctor	No	No
John	M	72	23 months	Industry	Rachel	No
Ernie	M	76	4 weeks	BT engineer	Mary, Dennis	No
Barbara	F	67	2 months	Care worker	No	No
Samuel	M	79	28 months	Journalist	Peter	No
Albert	M	68	10 months	Bank employee/handyman	April	No
Linda	F	73	4 months	Data manager	Darwin	No
Mabel	F	76	1 month	Store manager	Gareth	No
Miriam	F	81	3 weeks	Child minder	No	No
Jerry	M	66	8 weeks	Publican	No	No

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Table 1b – Relative participant demographics

Pseudonym	Sex	Age	Time since delirious episode	Relationship to patient participant	Relative also participated in study?	Reports a history of cognitive problems in patient participant
RELATIVES						
Stuart	M	53	8 months	Son	Sally	Being investigated at the time (possibly)
Sally	F	55	8 months	Daughter	Stuart	Being investigated
William	M	49	Present	Son	No	No
Emily	F	74	Present	Wife	No	Yes – noticed sometimes
Rachel	F	69	23 months	Wife	John	No
Mary	F	47	4 weeks	Daughter in law	Ernie	Yes – slight memory loss
Dennis	M	48	4 weeks	Son	Ernie	No
Clara	F	72	4 weeks	Wife	Ernie	No
April	F	55	10 months	Wife	Albert	No
Peter	M	51	28 months	Son	Barbara	No
Darwin	M	57	4 months	Partner	Linda	No
Gareth	M	49	1 month	Son	Mabel	No

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Figure 1: Proposed model of intervention for post-operative delirium

