

Relatives experiences of caring for patients at home following a critical illness

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BACCN Belfast 2009





Why is this important to me?

- No –one knows what it is like to take a patient home who has been critically ill
- Apart from the family caring for the patient



What is known?

Patients

- When in critical care
- When discharged

Relatives

- When patients are in critical care
- When patients discharged

What is known? Patients

The physical & psychological effects of critical illness on patients

- Mobility problems
- Neuromuscular problems
- Sexual problems
- A range of psychological issues
- Health state valued to be worse than death



What is known?

Relatives
when patients
in critical care

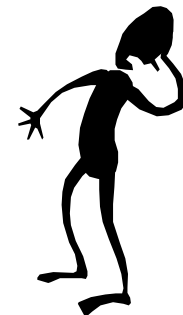
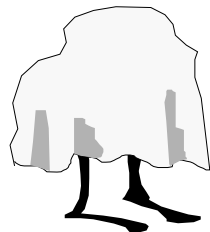
The need

- For relief of anxiety
- For information
- To be with patient
- To be helpful
- To be supported
- To have personal needs met

What is known?


Relatives when
patients are
discharged out of
critical care


- Anxiety & Depression
 - Jones et al 2000 BJA
- ??????????????



Research questions

- To explore and gain an understanding of relatives' experiences of caring for patients at home following a critical illness
- To gain an understanding about aspects of care that are given by relatives to the patients when they are at home
- To explore factors that aid or hinder relatives' ability to provide support to the patients
- To identify practice that may inform the care of these relatives

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- Ethics approval Oct 08
 - Interpretative approach
 - Phenomenology
 - Data collection commenced Dec 08
 - Aim was / is to do 10 interviews
 - 1st at about 2 months
 - 2nd at about 6 months

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- To date seven 1st interviews, four 2nd interviews
 - Semi structured interviews
 - Recorded

 - Participants
 - 5 females and 2 males
 - Age range mid 20's to mid 70's



Data

- Interviews
- Scary for me
- Technology!!
- Balance between researcher and nurse
- Transcribed all myself
- Advantages and disadvantages
- Struggling to get “hold of it” before next interview due



Very initial findings

- Relatives relive the event that took the patient to the ITU
 - Emotional for them
 - Lots of tears
 - Some laughter




- *“...he just started shaking as though he was having a fit and I thought what are you doing and then I thought oh Christ and went up to him oh my God something is happening... (line 36) ” R1*



- *“...I was late coming in. I drove up the drive and his van’s there. That’s unusual for him to be in well before me. I thought lazy bugger, he’s not even brought the dustbin in... I start panicking – got indoor and panicked more. Then I found him still in bed... He didn’t look very well at all, all grey in colour... (line 34) ” R3*



- *“...we went to A&E and he was sent home. By the time we got home his breathing was even worse and I took him straight to the GP, who called 999 and we went back to hospital... (line 28)” R4*

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- *“She had been suffering with a bad flu or ... the day she went in she was really out of it and she was like frothing at the mouth a bit. I rung up the doctor or the on call service and they said you need to get in contact with your GP (line 38) ...in the end me daughter rung the ambulance (line 85) ” R6*

Physical help

- *“...I took first two weeks off (work) and we had a bed in the other room. I slept downstairs on a blow up bed and. So she was near me if she needed me... I helped her go to the toilet, wash...Luckily we have a small toilet downstairs...”* (line 179) R6

Physical help

- “... *helping him when he was going up to have a shower...cause he was finding it very tiring just standing up in the shower* (line 136)... *just helping him get around a bit cause he was a bit unsteady on his feet...*” (line 139) R4

Physical help

- *“He’s a bit more tired (doing things) now (line 312)”*
R3
- *“...for two weeks he sat in a chair and we had to carry him (physically) to the toilet (line 159) R2*

Scared

- *“...the first day actually coming out of the hospital, wonderful absolutely wonderful until we got into the car and was coming home and all of a sudden, I know this sounds really silly but he seemed, I looked at him and he had shrunk...”*


(line 128) R 2


Scared

- *“Scary. I was really frightened to leave him and do anything...”* (line 312) R1
- *“I don’t know, you don’t know if you are doing the right thing (line 195)... that is frightening (line 199)”* R2
- *“He’s still a patient when he comes home (line 204)”* R2

Financial worries

- *“They pay him full money for 6 months. I don’t know what will happen after that”*
(line 432)” R3
- *“He can’t turn over, can’t move (in bed) and they were saying buy a foam mattress and we’re sitting there then and I think we had £10 to our name...”* (line 432) R2

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- Relationship changes
 - “Like bringing a baby home for first time” R6’s daughter – not said at interview but after the interview
 - “I am caring for her and the kids now” R7

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- Role reversals
 - Husbands caring for children
 - Husbands caring for wives
 - Women becoming more dominant???



- Things seem to be improving by 2nd interview
- “Back to normal” e.g. most relatives back at work, most roles back to normal

- Significant work still to be done to analyse data



Conclusion

- Critical care nurses need to consider the experiences of relatives when they are home following a critical illness and assist them to prepare for this
- Any questions?
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