Difficulties experienced by nurses, doctors and allied healthcare professionals when communicating bad news

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Why we did our study

• We wanted to explore a subject that was important to the work of all AHP’s
• Gaps in the research
  – little research on the process of breaking bad news or
  – the roles that staff play around breaking bad news
Setting and sample

- Study one – nurses on wards
- 59 inpatient areas in STH took part in the study
- 236 questionnaires were returned
  - 132 from medical areas, 60 surgical areas, 44 others
    - e.g. ITU, neonatology, EBC

- Study two – staff attending BBN study day
- 158 staff attended the study days
  - 138 handed in their questionnaires
  - 109 provided descriptions of difficult experiences
How often have you been involved in these activities in the past 3 months?

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BBN activities within the descriptions

• Tests and test results
  – Information, explanation and support around tests and results

• Impact of illness
  – Information and support around impact of illness on functional ability/independence/goals

• Support after bad news has been given
  – Dealing with reactions, picking up the pieces,

• Complexity around end of life issues
  – Introducing discussions, explaining end of life changes and care
Barriers to breaking bad news encountered by the participants

- Not having time to do it properly - 62%
- Not feeling prepared as it was raised unexpectedly – 61%
- Barriers to communication (e.g. language) – 57%
- Lack of privacy – 51%
- Verbal or physical abuse – 30%
- Nurses not encouraged to be involved – 8%
Difficulties encountered

• Situational

• Organisational

• Patients and relatives

• Individual
Situational factors

• Complex ethical or care events
  – Transitions in care
  – Emotive or technical aspects of care

• Unexpected news or events

• How the news was given
  – Physical factors e.g. by phone or post, difficult environment
  – Approach to BBN (skills and techniques)
    • Information giving poorly handled
    • Who is present (or not there)
Complex events

- When a patient was dying the relatives wanted us to give more drugs to expedite the death. The relatives wanted the death to happen quickly because it was too painful for them to watch.

- A patient in a terminally ill condition had two daughters who did not communicate and hated each other caused a terrible atmosphere around the patients bed side.
Unexpected death

• The consequences of unexpected death
  – dying without a relative present
  – encountering practical barriers such as BBN over the phone
  – Relatives unprepared for the news
    • their reactions included shock, hysteria and disbelief

• In three cases the nurses had given positive information about the patient’s condition shortly before an unexpected cardiac arrest
Examples of situational factors

- When the family visited the patient they found she was improving and were reassured...a few hours later she died and they were not there. It was hard to break the news over the phone and they could not believe me.
How bad news was broken

• Who is (not) present
  – Relatives
    • Bad news broken and relatives not present
  – Doctor from patients specialty medical team
    • Patient an outlier, unable to contact own medical team
  – Nurse
    • Not present at the time so doesn’t know what has been said
Examples of “who is present”

- A lady was told she was unable to have a CABG due to poor health. She was advised to have a relative present but insisted to be told before the relatives arrived. The relatives were annoyed and abusive to staff that she was told without their presence.
- A doctor informed the patient that her disease had spread to her brain. The patient was on her own as a result the patient was distraught, she had already been needing a lot of support from her family, palliative care and the nurses.
Organisational

• Time and staffing
  – Not enough time to manage events as the AHP felt was needed e.g. competing work demands, being rushed
  – Inadequate staffing
  – People not available (shift changes, out of hours)

• Working across services
  – Poor information provision between services
  – Services not supporting staff involved in BBN

• Rules and roles
  – Role expectations – working beyond scope or role
  – Rules around information provision within the organisation (by whom, when and where)
Examples of organisational factors

• The consultant told a patient they have to go for surgery. The patient has no family support and the staff have a lack of time to give to the patient.

• The doctor informed the next of kin that a patient was dying. As the doctor finished at 2030 I then had to speak to about 7 family members when they arrived and explain what the doctor had said. They had lots of questions and I felt out of my depth.
Patients and relatives

• Barriers to understanding
  – Communication barriers: language, deafness

• Reactions to bad news
  – Emotionally heightened responses
  – Denial or non-acceptance

• Issues around the care plan
  – Not agreeing with the care plan
  – Family not able to act on patient’s wishes
    • e.g. unable to cope with patient going home

• Family context
  – Issues around disclosure
  – Poor family dynamics
Examples: patients and relatives

• Informed a patient that treatment had not worked. They were shocked, they were shaking and crying. I offered further explanation, time, tea nothing seemed to help. I felt responsible as I may have led them to believe it was going to work. It felt like a disaster

• Having to tell 3 children aged 25-40 that didn't communicate between themselves that their mum was going to be put on the end of life care pathway. Having to make sure all 3 versions were correct and all questions answered e.g. why stopping some medications, what is a syringe driver etc
Information held by relatives and patients

• Issues around disclosure
  – Relatives don’t want patient to be informed
  – Relatives not being honest with the patient
  – Patient doesn’t want to be informed

• Patients relatives not being aware of fundamental information
  – not having been told the information
  – misunderstood or misinterpreted the information they had been given
Examples “disclosure”

• We had a young girl whose treatment had stopped working and she was commenced on a palliative care regime. However, her parents wanted her to continue to think she was going to be cured. It was difficult to explain anything as you always had to watch everything you said to her.

• A female patient was keen to go home she was aware she was dying. Her partner was agreeing with her while in the room but as soon as he was away from her he was expressing concerns that he wouldn’t be able to manage and didn’t want the responsibility of looking after her.
Reactions to bad news

• Negative reactions included
  – verbal abuse
  – anger
  – physical aggression
  – intimidation
  – hysteria
  – complete denial
Personal and individual

• Knowledge, confidence and skills
  – Being out of your comfort zone,
  – Feeling unable to meet the challenge

• Motivation
  – Feeling responsible to make things better

• Reflection
  – Questioning own actions,
    • Did I make it worse?
    • Could I have done things differently?

• Feelings and emotions
  – Events trigger an emotional reaction
  – Identification can mean it has a stronger resonance
Examples: personal and individual

• A patient died without their son present and I had to ring him with the news....I found this very difficult as I was questioning myself about whether I had done enough and felt guilty he was not there at the end.

• when a young woman my age was diagnosed with bone mets. I found it difficult to distance myself as our children were the same age and I could sense the devastation that was unfolding and her acute fear for her family
Consequences for HCP

• Wide ranging, some shared some specific to themes
  – Time and effort to manage events and resolve issues
  – Not being able to give the care you want to
  – Doubts about own practice, feeling guilty
  – Not feeling in control
  – Being placed in difficult or compromised positions
  – Frustration with colleagues
  – Fractured relationships with patients/relatives
The model....

**Situational**
- Complex care events
- Unexpected and unplanned
- Method e.g. over the phone
- Approach and attitude

**Organisational**
- Time and staffing
- Support across services
- Rules and roles

**Patients and relatives**
- Barriers to understanding
- Reactions to news
- Disagree with care plan
- Family dynamics

**Individual and personal**
- Knowledge, confidence, skill
- Motivation
- Feelings and emotions
- Reflection

**Difficult experiences of breaking bad news**
Conclusion

• Our work identified that BBN was a complex activity often carried out in difficult circumstances
• Being involved in the process of breaking bad news had positive consequences
  – It was also associated with difficulties and challenges
• The majority of the nurses had no formal education in BBN
• We need to
  – Acknowledge the role of all staff in the process of BBN
  – Provide opportunities for them to reflect on their role and their experience
  – Introduce ways in which they can look after themselves when involved in BBN
• Today’s programme is shaped around these themes
Discussion

• Add to the increasing body of evidence about BBN
  – it is a process
  – contribution from HCPs
  – across professions, specialities and settings

• New insights
  – challenges facing staff
  – difficulties faced by patients and relatives
The future for BBN

- Increasing body of evidence on the nurses role in BBN – always more needed!
- Significant implications for practice and practice
- Recognise contribution of nurses/AHPs
- Managers/service leaders aware of the impact on workload and emotional well being
- Evidence based approaches
  - Education and support those involved in breaking bad news in healthcare settings