Caring for a Brain Injured person; what’s important and how professionals can help during the first year following injury.

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Research study

- The needs of family members of severe traumatic brain injured patients during critical care, acute care and community: A qualitative and quantitative study.
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Why did we do this study?

- Challenges of prognosis and communication for severe TBI
  - Limited radiologic evidence of Diffuse Axonal Injury (DAI)
  - Significant variability in recovery from severe TBI
  - Lack of knowledge of HCP regarding significant progress TBI patients make
• Families
  – vary significantly in response to event
  – need consistent and clear information about the patient’s condition: Duff (02), Kreutzer et al (97)
  – need information about treatment and prognosis that is realistic: Kolakowsky-Hayher et al (01), Bond (03)
  – needs increase over time and families perceive many of their needs are not being met: Stebbins (98)
  – Most needs are related to behavioral problems: Serio et al (95)
Purpose of the study

• To identify the needs of family members of severe TBI patients

• To determine if these needs change over time, during critical care, acute care and community settings
Mixed method design

qualitative - the stories

quantitative – surveys
Study participants

• Level 1 Trauma Center (50 TBI patients with GCS ≤ 8 admitted annually)

• Patient criteria
  – between 16 and 65
  – initial Glasgow Coma Score (GCS) ≤ 8
  – Post Traumatic Amnesia > 1 week

• Family members (up to 2 per patient) as defined by the family

• Bilingual French and English
Data collection: Qualitative

- Demographic questionnaire and semi-structured interviews (individual family members)

- Three open ended questions
  - What has it been like for you since your (....) was injured?
  - What has been most difficult for you?
  - What has been most helpful for you?
Data collection – Quantitative

• **Patient: severity of injury**
  - Glasgow Coma Scale
  - Post Traumatic Amnesia
    - days
  - Functional Independence Measures (FIM)
  - Frontal Systems Behavior Family Rating form (FrSBe)

• **Family members**
  - State Trait Anxiety Inventory
  - Family Needs Questionnaire (FNQ)
Data collection

• Time 1: discharge from ICU
• Time 2: discharge from acute care
• Time 3: 6 months post acute hospital discharge

• Time 1, 2, 3 identify transitions points in time which have been shown to be stressful time for families

• 29 month data collection
Demographic results

- 15 patients
  - 14 male
  - MOI: MVC (12), falls (3)
  - Median age of 30.7 (range 17 – 58 yrs)
  - All admitted to ICU except 1
  - LOS range (17 – 134 days)

- 25 family members (up to 2 per patient) included:
  - Median age: 41.1 (16 – 67 yrs)
  - 40% mothers
  - Fathers, sisters, girlfriends, brother
Presenting to-day

• Needs over the first year:
  • Specific needs
    – Information/communication
    – Professional Support
    – Involvement in care
  • How information and professional support was perceived

• Families’ stories and survey results from the Family Needs Questionnaire
Critical care phase

- Refers to the time from injury and admission to hospital until discharged from the Intensive Care Unit (ICU)
The FNQ was developed to determine the needs of family members of TBI patients. It identifies needs in the following areas:

- Health information
- Emotional support
- Instrumental support
- Community support
- Professional support
- Involvement with care

Needs are rated from “not important” to “very important” on a 4-point scale, and also rated as being met, partially met, or not met.
Family Needs Questionnaire

Time 1

Importance of the needs

Health Information: 3.9
Professional support: 3.7
Involvement in Care: 3.3

Percentage of needs met

Health Information: 100%
Professional Support: 90%
Involvement in Care: 80%
The Needs of the Family

**Involvement in care** Looking for progress  Managing life  Holding on to hope

**Getting the news**  Uncertainty  Making sense of the news  Moving On

**Information**  **Professional support**  Community support

Responding to the Family’s Needs
Informational needs (critical)

• Families consistently identified information as the primary need in this critical time frame

• This need generated the greatest number of descriptors from the family.

• They expressed an intense “need to know” about their relative’s injuries and what the prognosis was.
Information needs and uncertainty

• The “need to know” emanates from the uncertainty regarding the patient’s prognosis

• The initial focus of uncertainty was the patient’s survival, which resulted in the family’s need to be physically close to the patient.
Uncertainty (critical)

• I mean he was so critical, like he was hour by hour you know, he was like that for days and that would be the hardest... the waiting and the unknown
Health care professionals help by:

- Most families wanted information that was consistent, understandable, honest and updated on a frequent basis.

- Important:
  - Communicate often
  - Use understandable language
  - Be hopeful but honest
• How the families lived the experience depended on two overriding influences:

  – the families’ strengths and inter-relationships
  – support they received from professionals, as well as their community
Professional Support (critical)

- Definition:
  - All references to interactions between the family and the professional staff, except those related to information
  - The combination of relevant, understandable information being delivered to the family in a way that was consistent and caring established the development of trust in the family.
• I think everybody has bent over backwards. There have been a few outstanding people. There was one nurse in particular who was just with our son for 2 days, but she realized that we didn’t have the whole story and she’s the one that, although it was hard to deal with, she was the one that forced the issue. She was the one who said you need to have a sit-down with the doctors and find out exactly where you’re going and where your son is going.
Professional support

- Staff members who demonstrated confidence, were upfront and honest, and who responded to family requests, provided reassurance to the family.

- I think just the fact that everybody here realizes here that this is not just one patient, that it’s the whole family and we’ve seen that from the beginning and it’s been very reassuring.
How professionals can help

• Ensure families have a comfortable environment, something to eat, warm blankets

• Check in with the family often and include them in the information that is being discovered

• Be honest but hopeful about the patient’s prognosis
Involvement in care: Need to be Close

- In the initial days and weeks immediately following injury, the family focused almost exclusively on the injured person and maintained a constant presence by the patient’s bedside.

- The need to be close was the primary way families were involved during the initial stages.
• I was not sure she was going to make it and for the first 3 days I felt so often we were losing her but the people here gave me confidence. We stayed here all day and night. I just couldn’t leave - I couldn’t leave. Nothing was - nobody was going to kick me out of there. It was my baby; it was my blood and even though I knew there were nurses – I would have slept in my car if they would have pushed me out. They were very nice to let me stay.
• Bond (2003) identified the family’s need to be involved in physical care and decision-making, which usually began three to six days after admission.

• Duff (2002) reported that seeing the patient’s progress positively affected the family members.

• Family members were vigilant in identifying and trying to provoke improvements in awareness and cognition.

• Positive responses by the injured individual reinforced and intensified family efforts.
• And I remember it took almost two weeks till she started opening her eyes just a little bit. And after that it went fast, within two or three days I think, she had her eyes wide open. She wouldn’t move them too much and had a fixed look but, then again, within a few days she started following us in the room.

• Then it got better, got better because we knew she was saved - she wasn’t dying.
Health care professionals help by:

- Allow the family to have access to the patient, outside of regular visiting hours

- Support the family
  - Providing explanations for what they are witnessing
  - Being available
Acute Care

• Refers to the period of time from transfer out of ICU until transfer from the Ottawa Hospital
Family Needs Questionnaire

Time 2

Importance of the need

- Health Information
- Professional Support
- Involvement in Care

Percentage of needs met

- Health Information
- Professional Support
- Involvement in Care
• Although the need for information remained important, the intense “need to know” diminished.

• The number of exemplars decreased by more than 50% from ICU to acute care.

• Families realized:
  – no definite answers
  – able to judge the patient’s progress similar to professionals.

• Information focus:
  – severity of the injury
  – the steps of the recovery process
  – plans for transfer to a different level of care
• Nobody could tell us the time thing and we understand that... you just always want to know, but there is no real answer. It is sort of unpredictable, so they told us what they could... give us the negatives and the positives - which we always didn’t want to hear the negatives, but they have to and that is the way it is. The positives come along. You just feel you have another accomplishment and they are there to support you.
Professional Support (Acute)

- Professional support elicited the most descriptors during acute care
  - may suggest that emotional support from professionals becomes more important than need for information.
- Nurses identified as providing support most often (~50% referred specifically to nurses).
- Why?
  - Spend so many intimate hours with both the patient and family
  - developed an extremely close link
  - expressions of being treated as family
The nurses make you feel at ease by two ways: you get a good sense of how competent they are... the level of competency, their level of enthusiasm and attentiveness that puts you at ease... that’s support. You know when he is being taken care of by a conscientious dedicated individual, and you know right off the bat who that is, and who it isn’t. That’s... that’s half the stress released. And then the way they communicate with you. Those are all huge (emphasis) things that reduce the stress and involve you in the care of the person.
• Family members:
  – spend extended periods of time with the patient
  – vigilant about noticing and reporting small improvements in patient’s behaviour
  – often the first to notice improvements
• Improvements increased families’ optimism and hope
• Families were able to distinguish the moment where the patient began “connecting” to their environment.
• The first time they opened their eyes, the first time they responded to commands, the first word they spoke—all were intensely positive moments for the family.
Involvement in Care

- Some family members wanted to be more involved physically, but were uncomfortable about caring for a person with such significant injuries, and were concerned that they “do the right thing”.
- Parents of young adults or wives were most involved in giving physical care. For wives, in particular, being involved in this way made them feel that they were helping their husband.
- Nurses played an instrumental role in helping the family become more involved.
Involvement in Care

• Well, I was very nervous at the beginning, but they make it very, very gradual and I remember we started that - with the nurses. One of them asked me if I wanted to help wash her hair, and I was pleased to do it, but I was very, very nervous. But I was offered an opportunity that I could have not taken, but I did and was happy I did. I really felt they let us play the role when it was time for us to. They made us a place and I felt better ‘cause I could feel (my daughter) felt secure even though she was unable to voice it
What can we do as health care professionals (HCP)?

• Recognize the variability of how family members want to be involved
• Assess their readiness to increase their involvement in the patient's physical care
• Guide /reassure them in their attempts to provide care
• Recognize that there may be positive and negative moments and respect their decision to pull back
• Walk them through the steps to becoming autonomous
Community Phase

- Includes the period of time from transfer out of acute care to either another acute care hospital, continuing complex care, rehab or home.
- The needs became somewhat more diverse as patients improved to different degrees.
- All families were very committed to being there for the patient and to understand what their plan of care was.
Family Needs Questionnaire

Time 3

Importance of the needs

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<tr>
<th>Needs</th>
<th>Importance</th>
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<tbody>
<tr>
<td>Health Information</td>
<td>3.8</td>
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<tr>
<td>Professional Support</td>
<td>3.7</td>
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<tr>
<td>Involvement in Care</td>
<td>3.3</td>
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Percentage of needs met

<table>
<thead>
<tr>
<th>Needs</th>
<th>Percentage</th>
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<tr>
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<tr>
<td>Professional Support</td>
<td>90</td>
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<tr>
<td>Involvement in Care</td>
<td>90</td>
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• Even though the patient had been in the health care system for a long period of time, families still required support and to feel they are not alone.

• To make other family members aware there’s help available. You’re not in this alone. That’s the big thing I’ve got because the whole care team at (the hospital) has been great.
With the Rehab they were just really good at ....telling us like “just let him go and let him do and he knows his limitations and let him find himself again”. ....because I find it scary and I had a hard time letting go and letting him do his thing and the Rehab were really good to reassure me
Involvement in care at this stage depended on a variety of factors:

- Current place of living
- Ability of patient to care for themselves
- Family dynamics and abilities to care for the patient
- Tangible and financial support aspects
Involvement in Care: commitment

• But it’s still very hard because she wants so much of me and if anything has to be done in her house, nobody else’s going to do it. It’s gotta be me. But you know she’s trying very hard. She’s made so much progress that I can’t refuse her anything. What makes me really frustrated is when I think of the lady that hit her and why did it happen. She didn’t deserve that. I didn’t deserve that so but it happened. Part of life but it’s bad.

• But still, I don’t know - I don’t see the end of it. It’s been very very hard but I knew that there was no other way. I love her very much and she loves me very much and if I wouldn’t have done it no one would have done it. The other person who’s done it is my ex-wive. One of the specialists told me at the hospital, that the only way my daughter recovered so quickly was because me and her mom were always with her.
Involvement in care: emotional commitment (community)

• And at the same time I’m unable to go to work because my head is full of (my daughter), you know. Full of everything that is surrounding her – the personnel, her wellbeing and her happiness.

• What is it I should be doing with her to make her happier because for her she’s able to live all by herself and she’s really tried to have (some independence). She doesn’t like having strangers living in her house
However, for patients with severe injury who resided at home, the theme of BURDEN was added as families became virtually solely responsible for managing care for the TBI individual and the ongoing strain became more evident.
Involvement in Care: Burden (Community)

- I’ve put my own life on ice for the benefit of my daughter. And I don’t think it’s wrong. I think it’s good. I just hope I’ll continue to have the energy to do that because it is draining.
• Families at this stage continue to require information on the long term aspects of brain injury

• Motor vehicle insurance is a tremendous resource for supporting families in the long term

• Various organizations (Ontario Brain Injury Association) play an important role in assisting families
Information (community)

- I personally don’t have as much need for information … because I kind of know what is out there and what is coming so what I have to deal with.
- At Rehab, it has been very good. I know I can call any time and I have been told that by nursing. So the combination of knowing that I could get the information that I wanted but also that I didn’t feel the same need to have all the information that I needed in the acute phase.
- So what I would say at the beginning reflecting back, the need for information for me was huge (emphatic). In retrospect, oh my God, that was how I coped. I needed to know what the oxygen sats were, how his week was and you know, if his bowels moved. I needed all of that stuff.
- You have let it go maybe? Ya, I think partly because I know that no matter what .. I know it is not going to change much..
• Professional support in the community is required for families caring for individuals at home

• I talked to a lot of different people. I (talked to my) friend …who is a neuropsychologist about it and she advised me that you have to use what is working and if a particular group is not working, …sometimes it’s better to do a fresh start. So it was really hard decision where to go.
How HCP can help?

• Begin planning for transition points early so that families have time to adjust

• Identify resources that are relevant for individual families

• Be realistic with families about the challenges they face without destroying their need for hope
In summary

• Patients recover at vastly different rates and to varying degrees and families react in variable ways to the challenge. Proactive individual planning with family members is crucial.

• Families needs change over the first year following their relative’s injury

• Each family deals with specific challenges and uses individual resources, but all remained committed to caring for their relative and strive to remain hopeful
• The only thing that I can say is if you love your child, if you want to be involved the way I am it’s going to ruin your life for a couple of years and if you’re not retired, if you have other children or a job, you cannot do it. You have to be strong to get through what I’ve been through.

• [What has helped is having] faith that she’ll come back. I accept, I keep hoping that at least she could live on her own in a year or so from now. So for me, the way she’s progressing is good. Enough that maybe she’ll be able to walk and have a good balance in 6 months or a year from here. And she might be able to live by herself.
Selected Bibliography

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Thank – you!