

# *An assessment of family members' needs following ABI to a family member: An Irish Perspective.*

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# Background Information

- ▶ Acquired Brain Injury (ABI) refers to brain injury that occurs after birth and is non degenerative. It can include traumatic and non-traumatic causes.
- ▶ Traumatic Brain Injury (TBI) is one of the leading cause of death and disability in children and young adults

## In Ireland:

- ▶ 9,000-11,000 people sustain TBI yearly
- ▶ 8,000 people diagnosed with stroke yearly

## Changes that can occur due to brain injury:

- ▶ Cognitive
- ▶ Physical
- ▶ Emotional
- ▶ Behavioural
- ▶ Psychosocial

# Background Information

- ▶ Family members can assume the role of care-giver
- ▶ Caring for family member with ABI can cause:
  - ▶ Increased emotional distress, depression and anxiety  
(e.g., Knight et al., 1998; Kreutzer, Gervasio & Camplair, 1994)
  - ▶ Decreased independence and quality of life  
(e.g., Norup, Welling, Qvist, Siert & Mortensen, 2012)
- ▶ Important to identify family members' needs



# Previous Research

- ▶ Identified a range of needs:
  - ▶ Information related to health of family member with ABI
  - ▶ Information about service accessibility and availability
  - ▶ Community reintegration following ABI
  - ▶ Advocacy groups for individuals with ABI and family members
  - ▶ Ongoing support for families
    - ▶ (e.g. Kitter & Sharman, 2015; McDermott & McDonnell, 2015; Leith, Phillips & Sample, 2004)
- ▶ Explored the perceived importance of needs and extent to which they were met:
  - ▶ Needs related to health information rated as most important and most likely to be met
  - ▶ Needs related to professional, instrumental (practical), and emotional support less important and less likely to be met
    - ▶ [Arango-Lasprilla et al., 2010; Doser & Norup, 2014; Murray et al., 2006; Norup et al., 2015]

# Aims

1. Describe, using the Family needs Questionnaire (FNQ) the current situation in Ireland
  - ▶ Explore family members' met and unmet needs
  - ▶ Explore perceived importance of needs
  - ▶ Explore the relevance of unmet needs
  - ▶ not typically examined in research studies
2. Compare the results to those found internationally
3. Gain insight into how unmet needs might be met
  - ▶ Through inclusion of an open-ended question



# Method

- ▶ **Participants:** 29 family members recruited from Headway
- ▶ **Method:** Phone or in-person administration
- ▶ **Measure:** Completion of 37-item Family Needs Questionnaire (FNQ)

FNQ Subscale	Sample Item: 'I need...'
Health Information	To have my questions answered honestly.
Instrumental Support	To have help keeping the house (e.g. shopping, cleaning, cooking etc.)
Professional Support	To be shown what to do when the patient is upset or acting strange.
Emotional Support	Help in remaining hopeful about the patient's future.
Community Support Network	To have other family members understand the patient's problems.
Involvement with Care	To be shown that my opinions are used in planning the patient's treatment, rehabilitation or education.

- ▶ Rating extent to which needs were met
- ▶ Rating importance of needs
- ▶ **Open-ended question added**
- ▶ **Data Analysis:** Statistical and thematic analyses

# Results: Met needs

Item No.	Need	FNQ-R Scale	Met
6.	To have explanations from professionals given in terms I can understand.	HI	51.7
7.	To have my questions answered honestly.	HI	48.3
31.	To discuss my feelings about the patient with someone who has gone through the same experience.	ES	48.3
1.	To be shown that medical, educational or rehabilitation staff respect the patient's needs or wishes.	HI	37.9
2.	To be told daily what is being done with or for the patient.	IWC	37.9
4.	To be told about all changes in the patient's medical status.	HI	37.9
10.	To have complete information on the <u>medical care</u> of traumatic injuries (e.g., medications, injections, or surgery).	HI	37.9
22.	To get enough rest or sleep.	IS	37.9
32.	To discuss my feelings about the patient with other friends or family.	CSN	37.9
13.	To have complete information on drug or alcohol problems and treatment.	HI	35.7

# Results: Unmet needs

Item No.	Need	FNQ-R Scale	Not Met (%)	% of sample rating unmet need as important or very important
15.	To be shown what to do when the patient is upset or acting strange.	PS	62.1	100
20.	To have help keeping the house (e.g., shopping, cleaning, cooking etc.).	IS	62.1	55.6
9.	To have a professional to turn to for advice or services when the patient needs help.	CSN	48.3	100
36.	Help preparing for the worst.	ES	44.8	77
19.	To have enough resources <u>for myself or the family</u> (e.g. financial or legal counselling, respite care, counselling, nursing or day care).	PS	42.9	100
30.	To have the patient's employer, co-workers or teachers understand his/her problems.	CSN	42.9	50
12.	To have complete information on the patient's <u>problems in thinking</u> (e.g., confusion, memory, or communication).	HI	41.4	100
34.	Help getting over my doubts and fears about the future.	ES	41.4	91.6
18.	To have enough resources for the patient (e.g., rehabilitation programmes, physical therapy, counselling, job counselling).	PS	41.4	100
14.	To be told how long each of the patient's problems is expected to last.	PS	37.9	100



# Results: Importance ratings

Item No.	Need	FNQ-R Scale	Mean (SD)	% of sample rating need as not met
11.	To have complete information of the patient's <u>physical problems</u> (e.g., weakness, headaches, dizziness, problems with vision or walking).	HI	4.00 (0.00)	31.0
12.	To have complete information on the patient's <u>problems in thinking</u> (e.g., confusion, memory, or communication).	HI	4.00 (0.00)	41.1
7.	To have my questions answered honestly.	HI	3.97 (0.19)	14.3
15.	To be shown what to do when the patient is upset or acting strange.	PS	3.97 (0.19)	60.7
5.	To be assured that the best possible medical care is being given to the patient.	HI	3.93 (0.26)	14.8
4.	To be told about all changes in the patient's medical status.	HI	3.90 (0.31)	30.8
10.	To have complete information on the <u>medical care</u> of traumatic injuries (e.g., medications, injections, or surgery).	HI	3.90 (0.31)	34.6
8.	To be shown that my opinions are used in planning the patient's treatment, rehabilitation or education.	IWC	3.86 (0.36)	37.5
18.	To have enough resources <u>for the patient</u> (e.g. rehabilitation programs, physical therapy, counselling, job counselling).	PS	3.86 (0.44)	46.2
1.	To be shown that medical, educational or rehabilitation staff respect the patient's needs or wishes.	HI	3.83 (0.47)	16.0

# Results: Importance ratings

Item No.	Need	FNQ-R Scale	Mean (SD)
20.	To have help keeping the house (e.g., shopping, cleaning, cooking etc.).	IS	2.62 (1.12)
30.	To have the patient's employer, co-workers or teachers understand his/her problems.	CSN	3.07 (1.07)
3.	To give my opinions daily to others involved in the patient's care, rehabilitation, or education.	IWC	3.10 (0.86)
32.	To discuss my feelings about the patient with other friends or family.	CSN	3.17 (0.93)
2.	To be told daily what is being done with or for the patient.	IWC	3.17 (0.93)
27.	To have my partner or friends understand how difficult it is for me.	<b>ES</b>	3.25 (0.89)
21.	To have help from other members of the family in taking care of the patient.	IS	3.24 (0.83)
37.	To be encouraged to ask others to help out.	<b>ES</b>	3.28 (0.75)
36.	Help preparing for the worst.	<b>ES</b>	3.31 (0.76)
33.	To be reassured that it is usual to have strong negative feelings about the patient.	<b>ES</b>	3.31 (0.85)

# Results: Thematic Analysis – Suggestions of how needs could ideally be met: 5 categories of responses identified.

Categories and themes	Frequency
<b>Category 1: Need for information</b>	
Need for information about the services available and how to access them post-discharge.	4
Need for information about tailored services - suitable for individuals affected in different ways by ABI.	4
Need for information to be given by professionals in a suitable manner to all of those affected.	4
<b>Category 2: Need for continuation of care post-discharge</b>	
Need for a service that carers can assess to help deal with day-to-day issues.	3
Need to ensure a post-discharge plan is put in place.	4
<b>Category 3: Need for more support from Government</b>	
Need for more financial support for carers.	2
Need for easier access to grants.	1
Need for more recognition of disability for individual with ABI.	1
<b>Category 4: Need for involvement with care</b>	
Need to be involved in decisions.	2
Need for reviews and feedback.	1
<b>Category 5: Needs being met by support services</b>	
Services such as Headway meeting some of these family needs.	7

# Conclusion

- ▶ Family members are being provided with medically relevant information
- ▶ Need for further information and support in caring for individual with ABI post-discharge
- ▶ Need for increased practical and emotional support for family members

## Implications for services

- ▶ Provide family with information about services and accessibility in early stages
- ▶ Communicate rehabilitation goals clearly with family members
- ▶ Reiterate the importance of support for family members and provide ongoing support and education

Thank you for  
listening.  
Any questions



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