Exploring Patient, Family Member and Professional Perspectives of Rehabilitation Hospital Family Meetings using a Participatory Research Approach

**Principal Investigator:** Dr Paul Carroll, Consultant in Rehabilitation Medicine

**Co-Investigators:**
Anne O’Loughlin, Ellie Russell, Phil Butler, NRH SW Team
Dr Sarah Donnelly, Assistant Professor of Social Work, School of Social Policy, Social Work and Social Justice, UCD.

Sarah.Donnelly@ucd.ie  Anne.O’Loughlin@nrh.ie
National Rehabilitation Hospital - Context

- Neurological Rehabilitation - Acquired/degenerative illness or injury
- 110 beds – 4 Programmes including Paediatrics but 3 involved in research project:
  - **Brain Injury Programme** 56 beds, 260 in-pt programmes in 2015
  - **Spinal Cord System of Care** 36, 157 in-pt programmes in 2015
  - **POLAR Programme** – 10 in pt beds + 7 day beds – 64/39 programmes, 2015
- National Service
- Lengthy waiting list for entry to the service and major issues securing services for discharge
- Changing demographics and social environment – poor community support structures
Practicalities

- All patients are offered at least 1 family meeting with the IDT.
- Social workers are involved in preparation/planning.
- An Information leaflet is available for patients and families.
- Variation between programmes as to who is in attendance.
- Approx 150 staff potentially involved in family meetings which last approx 1-1.5 hours.
- Variety of meeting rooms/styles/times.
- Increasing difficulties in arranging for relatives/friends to be present due to work, child care commitments, finances and length of time since initial injury.

Family Meetings

A Guide to Preparing for Patient and Family Meetings at NRH

A Guide to Meetings at the NRH for Patients, Families and Carers

You and your family are key members of the Rehabilitation Team and your input is vital. Family participation is known to improve the quality and outcomes of rehabilitation.

During your time at the NRH, you and your relatives or carers will be invited to come to meetings organized by the Rehabilitation Team.

These may be initial family meetings to get to know your particular situation, or meetings to set treatment goals, update your progress or plan for your discharge. There are often many arrangements which need to be made well in advance of your discharge, such as adaptations to your home or referrals to local community services.
Research questions to be addressed include:

1. What is the purpose and role of Family Meetings for patients and families in a rehabilitative hospital setting?
2. What are patients, family member and IDT member views and attitudes about Family Meetings and their participation within this forum?
3. Are patients and their family members satisfied with the level of participation and control afforded to them at Family Meetings?
4. Do IDT members feel sufficiently trained in the skills required to participate in Family Meetings?

**Key objectives** are service evaluation, quality assurance - changes and improvements to current practices will be made based on the findings of this study.
• International literature suggests that one of the major reasons for the lack of research activity amongst social work practitioners is the absence of collaborative links between university based researchers and social work practitioners in the field (March and Fisher 2005; Shaw 2003; Gibbs 2001).

• The gap between university based research and practitioner research (JUT SWEC 2006) appears to be widening and there is a need for ‘research by practitioners for practitioners’ (Epstein, 2010).

• In an environment of budget constraints and escalating demands in health and social care, Social Workers are under pressure to demonstrate the effectiveness of their practice and its contribution to quality care through research (Joubert, 2006).
Study Design

- A mixed methods study design was adopted, primarily consisting of a survey questionnaire which was administered via ‘Survey monkey’ which was completed either alongside Research Social Worker (Patient questionnaire), distributed either via email or through completion of a hard printed copy of the survey (Family members and Staff Survey).

- The survey includes a mix of closed, open and multiple choice questions in order to gain the maximum amount of information from survey participants.

- Access to other team members in relation to patients with communication/cognitive difficulties

- Unfunded Study- social workers took on research role in addition to their clinical work.
Inclusion Criteria and Recruitment

- Inpatients of the NRH who are under the care of Spinal, ABI or POLAR service and who have been the subject of a Family Meeting.
- Pt’s with DOC, pt’s who are assessed as unable to participate in their Family Meeting in any meaningful way due to a severe cognitive impairment and pt’s who are children aged under 16 were be excluded.
- The social worker who was involved in each Family Meeting acted as a gatekeeper and invited the Pt and at least one or more family members to participate in the survey.
- A member of the social work team who was not clinically involved with the Pt and family administered the questionnaire.
- All Social Workers involved in study at some level: survey design and gave advice on practicalities.
Data Analysis

- SPSS will be used for checking, cleaning and analysis.

- Descriptive and inferential statistics will be used to analyse the data.

- Thematic analysis of qualitative data from open questions is being carried out by research social workers.

- Identified themes fed back and validated by social work team.
Progress to Date

- **Work package 1 (Dec 2016-April 2017):** survey of all IDT teams in the NRH (N=85 Approx 50% response rate).

- **Work package 2 (April 2017-December 2017):** survey administered to patients by personal interview by research social worker. These patients are under the care of Brain Injury, Spinal and POLAR teams who have attended a family meeting N=80). (originally April to June and N =100)

- **Work Package 3 (April 2017-December 2017):** survey will be given/sent to a minimum of one family member of each patient who has attended a family meeting(N=64). (originally April to June and N=100)

- Family members rarely used the online method and they also have to be inputted manually
Staff Survey Respondents

- Dietician
- Doctor
- Health Care Assistant
- Nurse
- Occupational Therapist
- Physiotherapist
- Psychologist
- Speech and Language...
- Social Worker
- Music Therapist
- Other (please specify)

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Pre-meeting Planning

Do you feel that you receive enough information and that sufficient planning occurs in advance of the Family Meeting taking place?

Answered: 69   Skipped: 16

- There is never sufficient time...
- Generally there is some advance...
- The IDT generally try...
- I always feel that adequate...

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Do you feel that patients are included/involved enough in Family Meetings?

Answered: 69  Skipped: 16

- Yes
- No
- Sometimes
- Unsure
Family Understanding

Do you think that patients and family members receive and understand key messages during Family Meetings? (Please feel free to tick more than one option)

Answered: 69   Skipped: 16

- Key messages are understood
- More follow-up after the...
- Any decisions reached and...
- Written information...

Chart showing percentages of responses.
**Blocks**

- Poor pre-meeting preparation
- Staff arriving late/key IDT members not present
- Poor communication and use of technical jargon
- Differences in opinion between IDT members re; discharge plan
- Pt/Family receiving new information which they have not been prepared for.
- Pt/Family feeling their questions haven’t been answered/not listened to

**Enablers**

- Significant pre-meeting preparation
- Expectations(Pt and Family) managed
- Team Consensus and plan agreed
- Skilled Facilitation
- No interruptions
- Comfortable, informal meeting room
- No new significant information being shared and clarity on supports which can be accessed.
Social work play a key role in relation to explaining the purpose of the meeting...setting agenda items, addressing carer support and other issues, advising on matters of finance, respite options, and questions of capacity and vulnerability. Often the social worker is the professional that family members feel closest to... social workers often have the best knowledge of the many other complex issues within the family and may be in the best position to provide advocacy for the patient.
Having developed a relationship with both the patient and family the social worker can do much preparation... Many family members welcome the opportunity of hearing progress reports on their loved one in language which is clear and simple as opposed to being in Medical speak!
In general, I think that family meetings work well when they are facilitated by social workers...When the social worker has done the preparatory work with the patient and family they can be more at ease with the social worker facilitating, which can help them to hear the information provided and to be involved in discussion.
In your opinion, would it be helpful to have further guidelines or skills training for staff on Family Meetings?

Answered: 69   Skipped: 16
Suggested Improvements

- Pre-meeting preparation
- Guidelines/SOP
- Tailoring meetings to individual patient requirements ‘one size does not fit all!’
- Use of Language/communication styles
- Punctuality
- Greater flexibility in scheduling of Family Meetings (accommodate family members availability)
- Training for IDT members
Reflections On Process To Date...

- Participatory Action Research is an effective methodology for academic practice partnership.
- Mutual understanding of roles, flexibility, trust and respect – between the staff and the SW Dept, between the NRH and UCD
- Duty of care to patients vs research priorities
- Easy to underestimate amount of time required to get to data collection stage.
- Some SW’s eager to gain research experience and increase research capacity of social work team
- Others less comfortable with having this “agenda” with patients and families
- Increased confidence and knowledge in research skills
Closing thought

‘...the skill and effort that we put into our clinical communication does make an indelible impression on our patients, their families and their friends. If we do it badly, they may never forgive us; if we do it well they may never forget us.’

(Buckman, BMJ 2002)


References


To all the patients, family members and staff who participated in this research

Any Questions?