Participatory Action Research with a Medical Social Work Team: Using an academic- practice collaborative approach to evaluate Family Meeting Decision-Making Processes

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Academic Practice Collaboration

- 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 2003:2005; 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).

- Practitioner research is potentially the most useful and relevant source of new knowledge for social work and for service innovation (Bawden & McDermott, 2012; Epstein, 2010; Shaw, 2003).

Practitioner Research

- Irish social work has been slow to develop a research culture and professional structure to support research capacity(Donnelly and Carter-Anand,2016).

- The rationale for the importance of practitioner research (Orme & Powell, 2007) is compelling.

- The view that practice based on knowledge, generated through research, is necessary to legitimate a claim to professional status (Beddoe, 2011).

- 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).

Family Meetings

- '…*involve a number of family members, the patient and the hospital personnel in discussions concerning the patient's illness, treatment and plans for their discharge or their care outside the hospital'* (Hansen et al, 1998:58).

- Although intended to encourage active participation and empowerment of patients and their families in decision making, doubts exist as to whether they effectively carry out this role (Efraimsson et al. 2004).

- Froenck (2005) in small study in a Spinal Rehabilitation Unit in Australia found that patients were active participants in Family Meetings but that family members were less engaged in the meetings process.

- Professional groups such as social workers are expected to take leads in facilitating these processes yet surprisingly, this is often not a routine part of their formal professional education (Hudson et al.,2009).

Family Meetings

(Donnelly, Cahill and O’Neill,2017)

- Knowing the patient and the quality of the therapeutic relationship
- Knowledge of group decision-making processes
- Pre- Meeting Preparation
- Communication
- Impact of Family Members
- Tokenism of Patient Participation
- Balancing Agendas

Self-Determination

Delegated

Decision Making

Shared

Proxy

Deferred

NRH- Context

- Neurological Rehabilitation - Acquired/degenerative illness or injury
- IDT Approach and CARF accredited
- 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
- Unfunded study

Purpose of Family Meetings in NRH

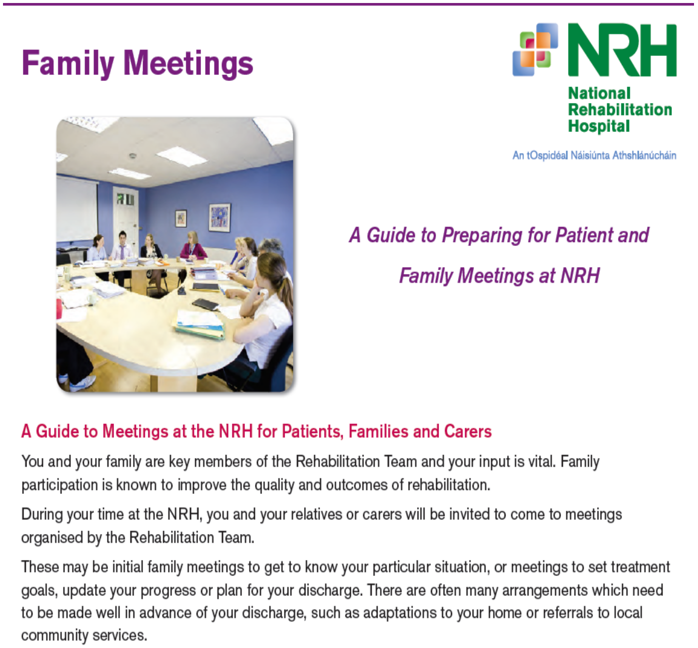
- Information on diagnosis/prognosis/goals and treatment
- What is the patient and family's understanding of the condition?
- Future care options/discharge planning
- Person/family centred care/Patient as part of the rehab team and are active participants in the treatment process
- Family themselves going through a grief/adjustment process as well as the patient. Impacts on information giving.
- There is now very strong evidence that social support reduces morbidity and mortality –NRH tries to up-skill and involve all possible family/ others in the patient's life.
- Understanding can lead to a sense of mastery and renewed hope (Wallengren, 2008) – better rehabilitation outcomes.

Motivations

- There was a concern that we were not doing enough to include patients and families as fully as possible e.g. patients with cognitive communication impairments
- Need to review the timing, format, content and practical arrangements level of preparation and decision making.
- Highlighting the level of skill and training that the Social Work Team can bring to the Family Meetings and how do the other IDT members perceive the social work role.
- How can we improve the meetings.
- The social work team feel that protocols and training should be developed.
- Increased research competency(CPD) and visibility of Social Work research.

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

National Rehabilitation Hospital
An tOspidéal Náisiúnta Athshlánúcháin

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 organised 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.

Healthcare Policy/Legislative Context

- Assisted Decision Making Capacity Act 2015 IE
- HSE Draft Assisted Decision-Making Guide for Health and Social Care Professionals
- HSE Code of Practice for Integrated Discharge Planning(2008) IE
- National Standards for Safer Better Healthcare, HIQA,(2012) IE
- Your Service Your Say HSE Policy 2017
- UN Convention on the Rights of People with Disabilities (CRPD), *'persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life'* (Article 12)
- Quality and Fairness-A Health System for You(2001) IE
- National Consent Policy

Research questions to be addressed include:

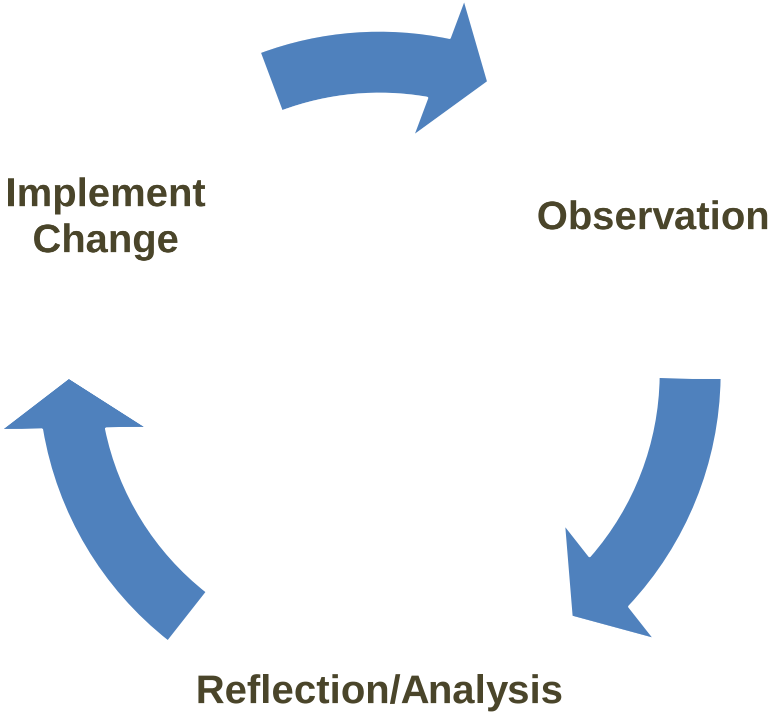
1. What is the purpose and role of Family Meetings for patients and families in a rehabilitative hospital setting?
2. What are patients, family member and IDT member views and attitudes about Family Meetings and their participation within this forum?
3. Are patients and their family members satisfied 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.

Study Design

- A mixed methods study design was adopted, primarily consisting of a survey questionnaire which was administered via 'Surveymonkey' 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.
- SLT Department have tools in the NRH to assist and support communication which we used for data collection with patients who had a cognitive and/or communication impairment.

Participatory Action Research Cycle

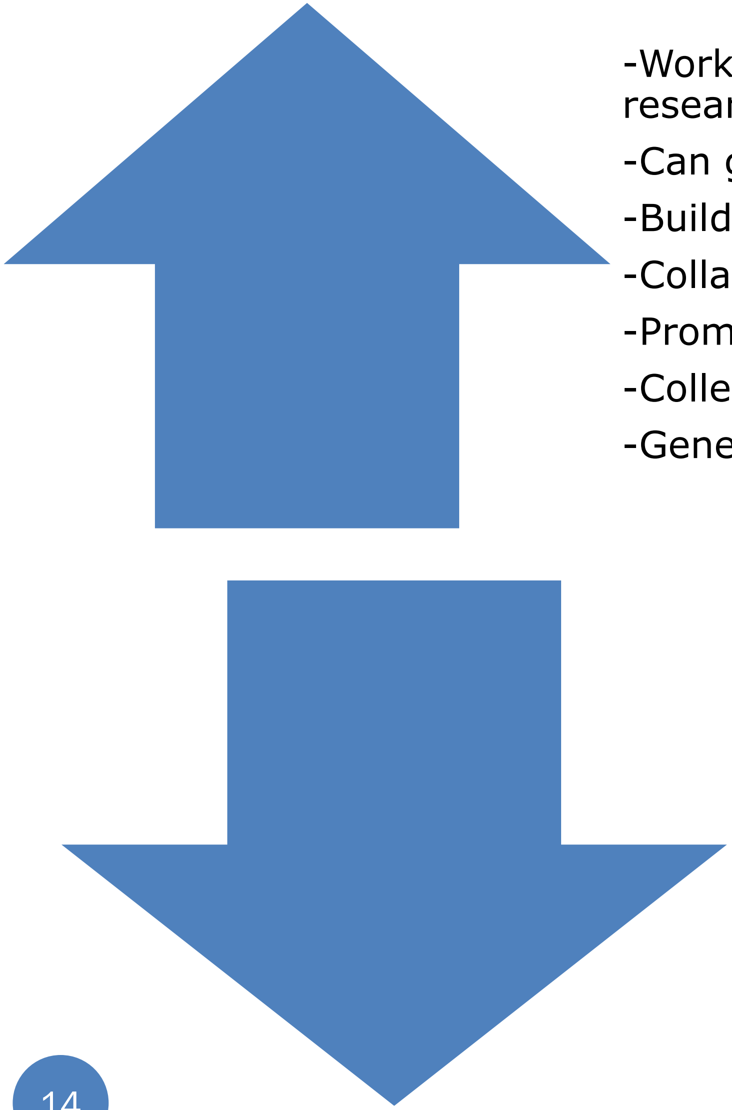


Implement Change

Observation

Reflection/Analysis

Issues for Consideration in PAR



-Works ‘with’ rather than ‘on’ or ‘for’ those being researched

-Can give voice to the marginalised (Friere,1970)

-Building Relationships

-Collaboration through participation and reflexivity

-Promotes empowerment

-Collective Learning and Development

-Generates new knowledge and organisational change

-Conflicting agendas of stakeholders

-Staff resistance to change

-Attention to power dynamics

-Facilitating collaboration difficult

-Time: sustaining commitment

-Who carries overall responsibility for ethical research (long-term leadership support)

-Possible compromise of ownership of project

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.

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.
- The SLT Department within NRH offered invaluable communication assistance and support during interviews.

Social Work Research Team

- All Social Workers involved in study at some level: survey design and gave advice on practicalities

- Principal Social Worker and 2 social workers initially took lead in study, after pilot phase the additional social workers volunteered to be involved in administering patient questionnaires

- Pilot phase

National Rehabilitation Hospital

Consent and Ethical Issues

- Getting through Ethics!
- Informed consent was sought from each individual patient, family member and IDT staff members
- Written and verbal information were provided for all participants. Consent was sought initially and consent was then be revisited prior to the participant completing the questionnaire

Accessing the hard to reach voice

Where there were concerns in relation to capacity to consent to participate in the study the following options were considered:

- Discuss issue of consent with treating Consultant and other members of IDT e.g. OT or Psychology if appropriate/helpful
- Allocated Social Worker could re-visit consent to participate in the study with patient, SLT and/or a Family member present
- Consider/clarify if a second Family Meeting was planned for Patient and if so, decide with Research Team whether to defer patient participation in study until then

Protocol

- It was agreed that if in the process of completion of the survey questionnaire caused either a patient and/or their family member and/or IDT member to become upset or distressed or if any unanticipated serious clinical issues/unmet needs arose which need to be communicated to the IDT, a protocol should be followed.
- A protocol was drawn up on how these issues were to be addressed
- Training for those doing the surveys/boundaries

Data Collection – Aspiration!

- 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-June 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=100).
- Work Package 3(April 2017-June 2017): survey will be given/sent to a minimum of one family member of each patient who has attended a family meeting(N=100).
- All completed patient questionnaires to be entered into Survey Monkey in the SW Department
- Family members could do it on line if they wished

The Reality!

- 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).
- 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).
- All completed patient questionnaires to be entered into Survey Monkey in the SW Department – we will have a lot to input!
- Family members rarely used the online method and they also have to be inputted manually


MARATHON FINISH LINE


80
is THE MAGic
Number
WeLL done

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

Marsh, P and Fisher, M. (2005) Knowledge Report 10. *Developing the Evidence base for social work and social care practice.* London: Social Care Institute for Excellence

Gibbs, A (2000) 'Practitioner evaluation', Social Work Review. 12. 2, 29- 32.

Shaw. I. (2003).Cutting edge issues in social work research', *British Journal of Social Work*, 33, 1, 107-116.

Joint Universities Council of Social Work Education Committee (2006). *A social work research strategy in higher education 2006-2020.* London. Social Care Workforce Research Unit, International Policy Institute, Kings College London.

Epstein, I. (2010). *Clinical data-mining: Integrating practice and research*. New York: Oxford University Press.

Bawden, G., & McDermott, F. (2012). 'Project Discovery': Social work research@Southern Health". *Australian Social Work*, 65, 136144.

References

Donnelly, S and Carter-Anand,J (2016). ''It Took a Leap of Faith.' Care and Connect: A Model for Practitioner Research in Ireland'. *Irish Social Worker*, Winter 2016 (Practice Research):5-9

Orme, J. and Powell. J. (2007). 'Building research capacity in social work: process and Issues', *British Journal of Social Work*, 20, 1-21.

Beddoe, L. (2011). "Investing in the future: Social workers talk about research' *British Journal of Social Work*, 41, 557575.

Joubert. L. (2006). 'Academic-practice partnerships in practice research: A cultural shift for health social workers' *Social Work in Health Care*, 43, 2/3, 151-162.

References

Hansen, P., Cornish, P and Kayser, K. (1998). Family conferences as forums for decision making in hospital settings. *Social Work in Health Care*. 27(3):57-74.

Efraimsson E, Sandman PO, Hydén L-C and Rasmussen, B.H. (2004). Discharge planning: 'fooling ourselves?'– patient participation in conferences. *Journal of Clinical Nursing*. 13(5):562-70.

Froenck, P. (2005). Insights from the family conference: Observations in rehabilitation. *Australian Social Work* 58(4): 395-406.

Hudson, P., Quinn,K., O'Hanlon, B and Aranda ,S. (2009). Family meetings in palliative care: are they effective? *Palliative Medicine.* 23(2): 150-157.

Donnelly,S., Cahill.S and O'Neill,D. (2017) 'Care Planning Meetings:Issues for Policy,Multi-disciplinary Practice and Patient Participation'*. Practice (UK)*

Thank You

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

Any Questions?