The Family: A Help or Hindrance to the Rehabilitation Process?

Dr Anita Rose
Consultant Neuropsychologist & Director of Clinical Service
Outline

• Family Involvement
  – What is it
  – Need for it

• Empirical evidence
  – Reasons to involve
  – Barriers

• How Titleworth have responded
• Family involvement in Acquired Brain Injury (ABI) rehabilitation is a developing area
• Services more aware of the need to involve family and working towards ways of developing involvement
• Anecdotal reports and opinion papers suggest ways that family involvement might improve the rehabilitation outcomes for patients (Tarvin, 1995)
Recent government policy documents have called for more focus recognising the expertise of the carer and greater involvement of the family in the rehabilitation process after ABI

– Caring about Carers (DOH, 1999) - “helping carers is one of the best ways of helping people they are caring for” (p6)

– National Carers Strategy (DOH, 2008) states that by 2018: “carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role” (p9)
What could family involvement mean in ABI?

• Determine the success of the transition phase from hospital to home
• Facilitate the carryover of rehabilitation strategies to compensate for cognitive difficulties (Fleming, Shum, Strong & Lightbody, 2005; Turner et al., 2007).
• Potentially reduce the length of time required in hospital
• Reduce costs of rehabilitation (Kalra et al., 2004)
• Resolve issues related to family adjustment (for example when a family member may have unrealistic expectations regarding their relatives’ recovery)
What does family involvement mean?

• Very varied when look at empirical literature and service documentation, includes:
  – involvement in goal planning
  – acting as a co-therapist
  – “otherwise involved”
  – Involved in therapeutic activities
  – involvement in discharge planning
• Few guidelines available on how clinicians should involve families in goal planning (Levack et al 2009)
• A recent review of goal planning in the rehabilitation centres in the United Kingdom, found that carers were not always routinely involved despite national recommendations (Monaghan, Channell, McDowall & Sharma 2005)
• Family involvement does not always happen in practice and services may only pay lip service to this despite the recommendations in government policies (Levack et al., 2009; Brereton & Nolan, 2002; Monaghan et al., 2005)
• Important to determine what factors may facilitate or prevent families’ engagement or involvement in order for rehabilitation services to address these and improve the consistency across services.
Inconsistencies between staff and family perceptions

- Shaw et al. (1997) found that the staff and family members differed in their opinions regarding family involvement.
  - Agreement that information should be shared, but differed in opinions
    - family involvement in treatment planning
    - involvement in therapies
    - regarding education – in particular families felt that the education should be more specific to their relative’s condition rather than more general information
Recognition of /lack of recognition of the carers’ expertise and knowledge

- Brereton and Nolan (2002) identified the relationship and communication between staff and families as a potential barrier or facilitator to family involvement
  - Families expressed a wish to be more involved in their relatives’ care
  - reported that they actively made attempts to form partnerships with health professionals in order to gain confidence and acquire skills to be able to carry out care activities with their relatives
  - these attempts were not always acknowledged or were rebuffed some families reported that they felt they were intruding on professional territory when they tried to get involved
  - Families also expressed a need for their knowledge to be recognised and valued
Family involvement in Rehab Therapies

- One study investigated physiotherapists perceptions of family involvement in the rehabilitation process. (Ryan et al. 1996)
- Four main factors that impeded:
  - Family
  - Therapist
  - Healthcare Organisation
  - Patient
Other factors included:
- Families availability/flexibility
- Cognitive skills
- Financial status
- Emotional health
- Relationship with patient
- Unrealistic expectations (particularly of family)
- Experience and confidence of therapist with involving family

Galvin, Cusack and Stokes (2008) found similar results
Family involvement in Goal Planning

• Involving family members in decision-making processes such as goal planning can make the family more willing to engage in the rehabilitation process (Levack, Dean, Siegert & McPherson 2009)

• Family as an integral part of the goal planning process provides an opportunity to families about rehabilitation principles.

• Early discussion of goals could help to prevent conflict from arising at the stage of discharge and to aid the development of realistic expectations of recovery and emotional adjustment
• Has to be acknowledged there are barriers to family involvement:
  – Family members had their own agendas
  – Expectations were unrealistic
  – Clinicians feeling have to limit family involvement, or avoid engaging with the family at all to protect the patient

• Overall research indicates that clinicians are more oriented to addressing the needs of patients rather than the family
Family involvement in discharge planning

• Relatives and health professionals may have different expectations regarding goal setting (Almborg, Ulander, Thulin and Berg 2009)

• Therefore there is a need to develop more effective discharge planning procedures to include provision of information so that they can be more involved in the rehabilitation process

• Services may lack effective practice for involving families