Using a Limb Lengthening Informed Consent Module for a Paediatric Population to Assist in Pre-operative Education

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Paediatric Orthopaedics – Why is it so special?

• Not dealing with the patient directly whilst obtaining consent – this task falls to the parent, not the patient
• Must have a full understanding of what consenting to, and implications for everyone, not only self
• Children are not little adults, and respond differently to surgical process
What about Limb Reconstruction? (LR) – Why is this different?

• Difficult concept to grasp
• High engagement and buy in required – compliance issues
• Long treatment times
• Many complications – from the minor to the potentially catastrophic
• Confronting in appearance for parents, siblings and child
• Multi disciplinary approach – so lots of players
• They are children!
• The education process must be thorough, clear and understandable

• And involve all the relevant parties, including the child
However……

- Literature tells us that:
  - 44% of patients are unaware of even the basic nature of the surgery they had recently undergone. Byrne, BMJ, 1988
  - 10 – 29% can’t recall the information given to them 6 months later. Hutson, JBJS 1991
  - Only 40% of patients read the informed consent before signing it. Cassileth NEJM 1980
Learning types

• Visual
• Auditory
• Written
• Kinaesthetic
Ability to learn

- Education
- Culture
- Social
- Literacy
- Trust
- Emotion
Elements of informed consent

- Nature of the problem
- Aim of the operation
- Limitations of the surgery
- Operative details
- Post operative course
- Expected benefits
- Consequences
- Complications
Use of animation

Allows

• The complicated to be made more simple
• Incorporate the various learning styles
• Cope with different learning abilities
Developing the module

- Educational objectives set
- Literature Review
- Script
- Story board
- Animation
- Questionnaire development
Module made use of

- Pictures/Visual

- Words – writing on screen

- Voice / sound – via headphones or speakers
The project – 2007 to 2012

• Commenced recruitment in 2007

• Study: Prospective, randomized, multi-centred, controlled trial

• 68 subjects recruited out of 116 approached
  • Inclusion criteria
    • Significant interest in LR
    • Ability to consent
    • English speaking
    • Over 14 years of age

• Exclusion criteria
  • Cognitive, visual or hearing impairment
Further randomisation:

• Previous involvement in Limb Reconstruction
• Over or under 18 years of age
Module use

• Included as part of the normal preadmission process
• 1 hour information sharing session
• Multi-disciplinary session
• Involves –
  • Seeing/touching a frame, videos, photos, discussion about practical issues, pain management, expectations of appointments, care of the frame, pin site management, LOS, what to look for, what to do, community support, schooling implications – **using all types of learning styles**
Issues identified

• Eligible for inclusion but
  • Changed mind
  • Could not give the time (young children)
  • Subjective decision on our part not to include
  • Illness

• Made preadmission time very long – staff and family
Feedback - on the spot

• Module too long – 30 minutes
• Too confronting – didn’t want to know
• Wanted to see it again
• Wanted to see at home on internet at leisure
• Would like to show it to others
Found improvements in

- Satisfaction with the information
- Consistency of information given
- Ease of decision making
- Retention of knowledge over time
- Compliance
- Decreased hospital stay – patients doing better
So...where to from here?

- Project completed
- Will use the module for all leg lengthening patients (once payment sorted)
- View in own home with a log on
- Module time has been reduced in length
- Cost per view charged to hospital ($7.00)
- Questionnaires no longer done so decreases time
Summary

• Paediatric limb reconstruction is a complex area so we need to find better ways to communicate & illustrate this to families
• Long journey but worthwhile
• Looking forward to a bright future with more improvements in changing how we obtain an informed consent from parents & offer them high level & consistent information
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