## Please Doc, just cut it off!

# A Qualitative study of patients who have undergone elective amputation

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# **Co-investigators**

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# NBC headline: The run of his life (Feb 8th/09)



- Tom White
- Motorcycle accident 1981
  - → Left ankle injury
- 26 years later requested
   elective amputation



### Two different views

"One of the best decisions I ever made was to have an amputation"

 Other patients with a major limb impairment absolutely refuse an amputation

# Amputation vs. Limb reconstruction after lower leg trauma

- Patients who undergo limb reconstruction generally have MORE
  - Operations
  - Complications
  - Re-hospitalizations
  - Rehabilitation time
- Outcomes are SIMILAR in terms of
  - Pain
  - Quality of life
  - Function

## Background

- The literature does not tell us what factors influence the decision of a patient to have an amputation.
- Why are patients satisfied or unsatisfied with their decision?

## Purpose of study

 To determine the factors that influence one's decision making when choosing to electively amputate a functionally impaired lower limb

### Methods

The protocol was approved by The Ottawa Hospital Rehabilitation Centre Ethics board

 Charts from patients seen in The Rehabilitation Centre's outpatient amputee clinic were reviewed to identify patients that meet the inclusion criteria

## Criteria for study subjects

#### Inclusion criteria:

- Patients who have had an elective amputation for a functionally impaired lower limb.
- Patients whose amputation was more that one year ago.

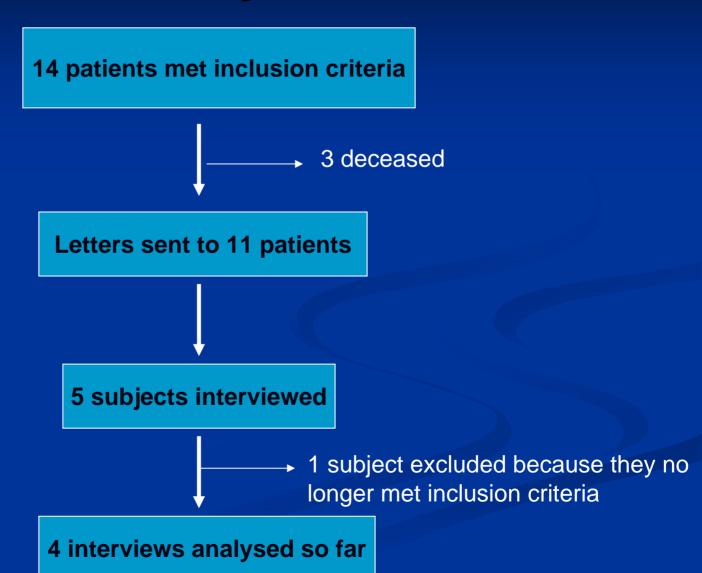
#### Exclusion criteria:

Patients who underwent an amputation because of an acute risk to their health (i.e. cancer or infection).

### Methods

- Semi-structured interviews with each subject (lasting 45 to 90 mins)
- Narrative analysis
  - Analyzed by three independent reviewers ->
    triangulation
  - Identification of key themes
  - Creation of common "story"

# **Preliminary Results**

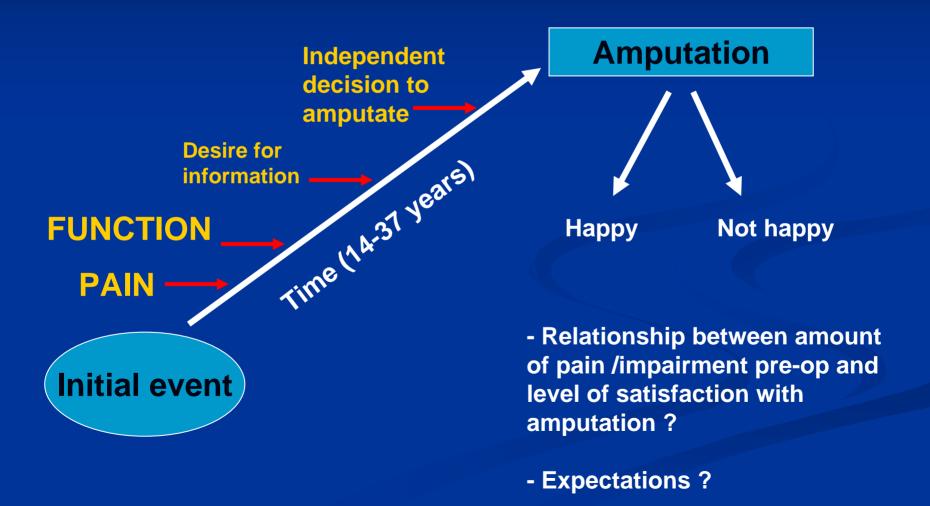


## Results - Demographics

- 4 subjects
- 2 females, 2 males
- Initiating event:
  - 1 polio, 3 trauma
- Age at amputation:
  - Mean = 46 years (min 33, max 58)

- Years between initiating event and amputation:
  - Mean = 24 years (min 14, max 37)
- Years between initial idea of amputation and the surgery:
  - **20**, 5, 2, 1

# Results – Key factor model (preliminary data)



## Pain - preliminary data

"...and it was just like a bad toothache, you know you want to get rid of it..."

"...and I really think if I had chopped it off with a hatchet that wouldn't have hurt as much as what the foot was hurting."



## Function - preliminary data

#### POOR function

"He cut it off and once it was off I asked him to wrap it up in brown paper so I could take it home and feed it to the dog because it would be the first time it was useful in my whole life."

### Hope for IMPROVED function

"I wanted to improve my function. Be able to wear shoes. Walk for extended periods of time, it was a question of trying to improve that limb that wasn't working very, very well."





## Information - preliminary data

### Yes

"I tried to get as much information as possible before I had it done...and maybe I should have looked a little harder"

### No

"Even if I were to have tonnes of information, it doesn't matter, when you want it done, you want it done"

## What does NOT seem to matter?

### Opinion from family and clinicians

- All subjects came to the decision on their own
- Strong sense of self
- Sense of identity independent of body parts

#### Body image

"make it look like a leg, what for? That's only for people to say, "Oh doesn't that look nice?" It doesn't bother me, I couldn't care less; it works! And what I lived with was truly ugly. This even though it's not covered, looks great to me."



## **Preliminary discussion**

- Too soon for conclusions but...
  - PAIN and FUNCTION were prominent factors in the decision making process
  - It's a long process to make the decision
  - Some patients want a lot of information while others do not
  - Minimal role for
    - Opinion from family and clinicians
    - Body image

## Summary

Understanding the VALUES and IDEALS
 patients consider when requesting an elective
 amputation is a necessary step towards
 improving physicians' abilities to assist in the
 decision making process



Questions?