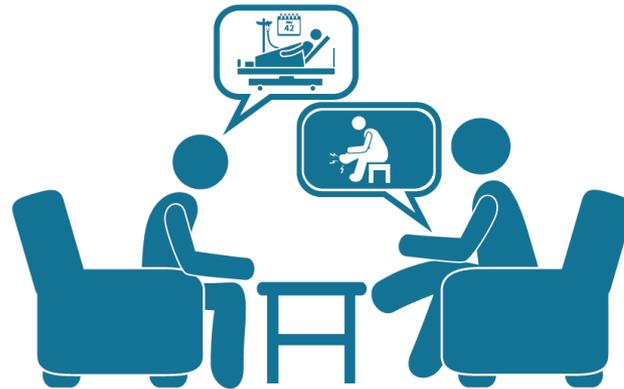


Informing decisions about partial foot amputation using a shared decision-making approach



Michael Dillon, Matthew Quigley, Stefania Fatone

Informed?

People facing prospect of partial foot amputation are often poorly informed



Surgery



Complications



Outcomes

Informed?

People seemed poorly informed about PFA procedure, the expected outcomes and likelihood of complications.

Dillon et al. 2019



“The overriding emotion was like, oh, wow, look how much they took off already... it was horrific, really confronting. I felt violated afterwards.”

“After a week I was told they hadn’t taken enough off and I would need a debridement. I thought it would be like shaving Parmesan cheese off. They should just say, we’re going to chop off another inch or two...”



Surprised?



40%

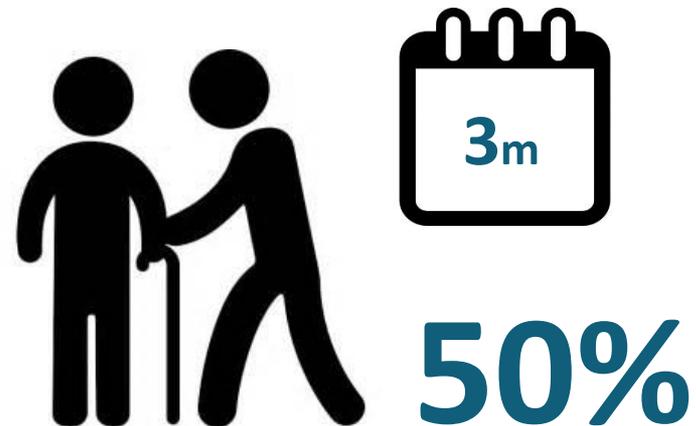
Experience significant complications after PFA; most in the first few weeks or months.

Dillon et al. 2017

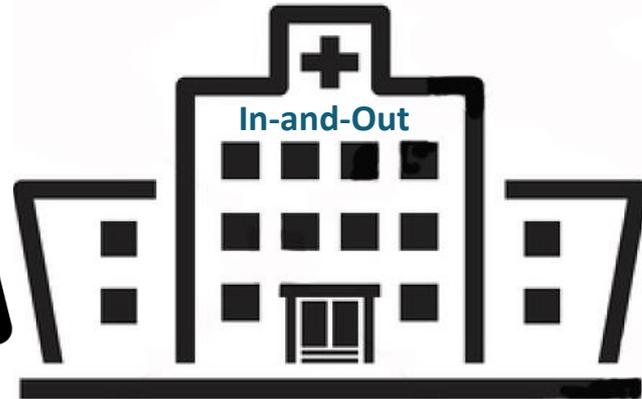
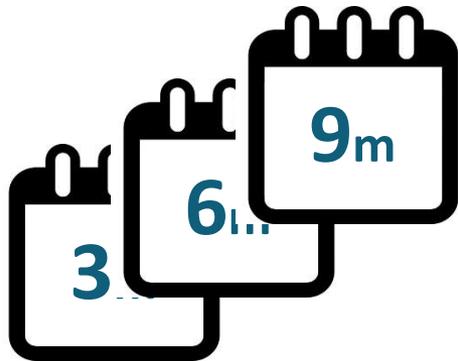
Surprised?

Only half of all PFAs heal by 3 months

Dillon et al. 2017

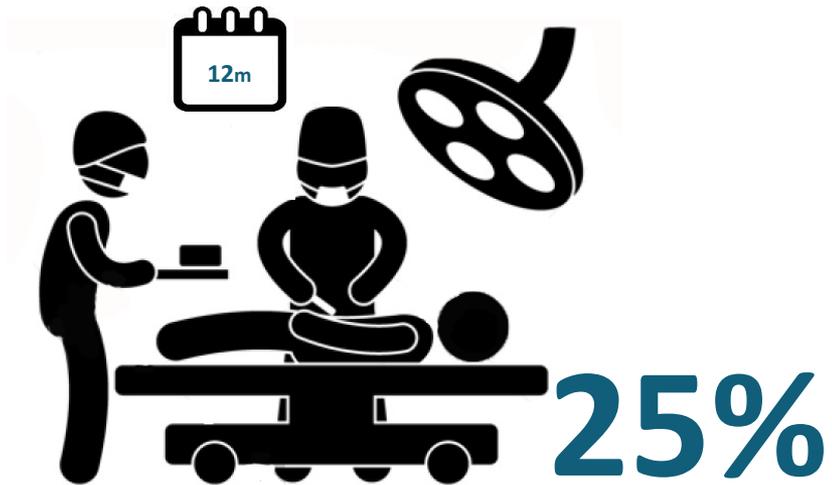


Surprised?



Many people spend months in-and-out of hospital

Surprise?



In 12 months, one quarter
of all PFAs are revised

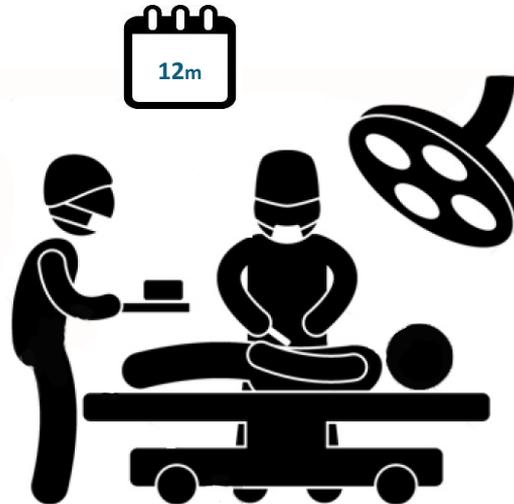
Dillon et al. 2017

Surprised?

In first 12 months, 12% of all PFAs revised 3+ times

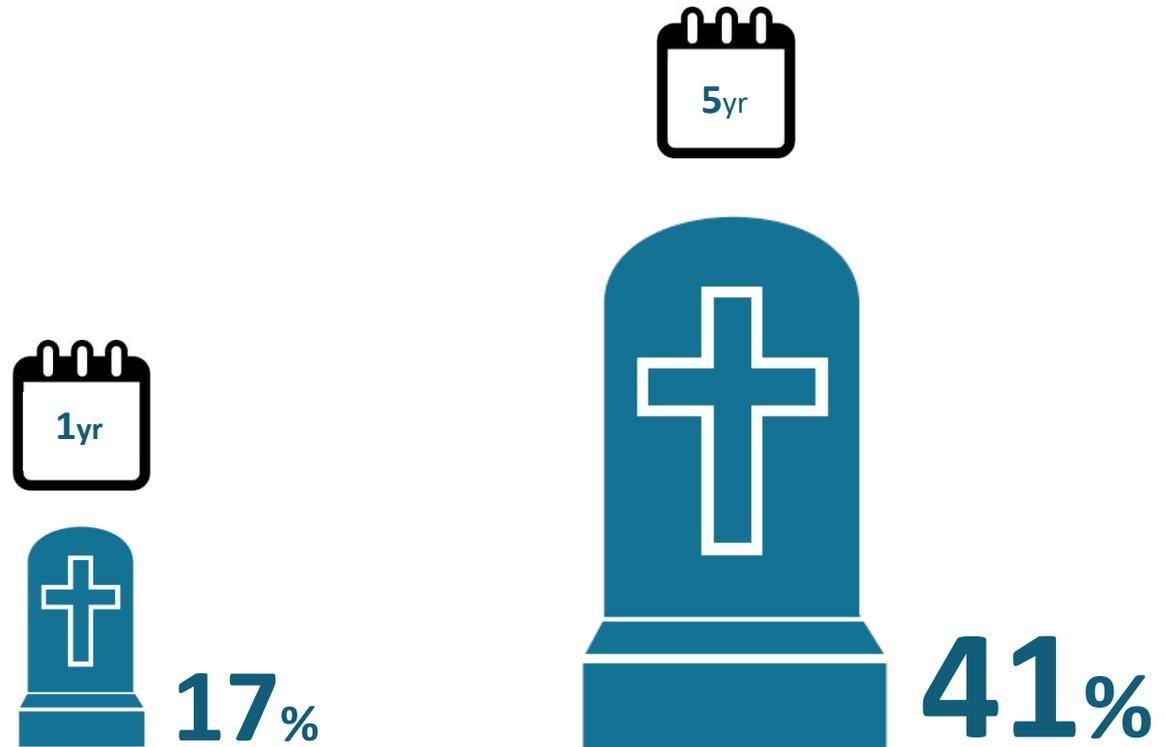
Dillingham et al., 2005

12%



3+
revisions

Surprised?



High mortality in the years following PFA

A truly informed choice.

If people were more knowledgeable about the surgery, the likely outcomes and risks, what sort of decision would they make about their healthcare?



Challenges

Helping older people make informed decisions can be challenging.



Age-related
cognitive
decline



Multiple
medications



Depression



Anxiety



Urinary tract
infection

Voice of experience

Many peoples' description of the experience highlight the challenges to informed decision making.



“ You on massive amounts of pain killers... Your decision making isn't as clear as it would normally be. Your emotions are scattered everywhere...”

“It's very foggy you know. You'd take pain killers and two hours later you realise you're still looking at the fish tank. It made communication so hard.” (Sub 1)

Voice of experience

Upon reflection, it is difficult to know what to ask.



“ Rather than ask how you would cut the toe of leg off, I’d ask how is it going to affect me?” (Sub 3)

“ I would ask what the mobility comparisons would be between the two amputations... I probably should have asked more questions about being confined to the house, everything that was involved around the VAC machine... having to be on pain killers.. The quality of the time. If there were statistics on success rates, I’d point those out too.” (Sub 1)



Voice of experience

Many people suggest ways things can be better.



Sit down, have a cup of tea with them to get to know, get the feeling of them. Just let to conversation flow. (Sub 8)

“ You get information from doctors and nurses, but I find it easier to read something off paper... and let it really sink in [brochures] you can take with you and read them in your room and read them when every you feel like it in your own time.” (Sub 3)



How can we help?

Recognising these challenges, and the advice from the lived experience, we wondered whether a **shared decision making approach** might be helpful.



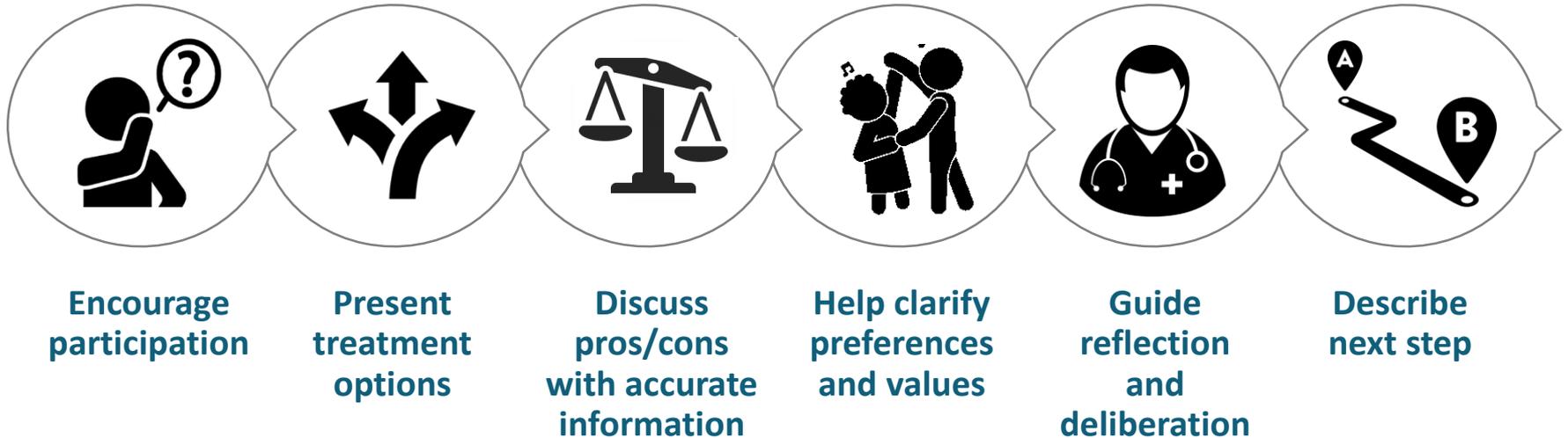
Shared decision making



Consultative process design to help clinicians and patients engage in meaningful conversations focused on informed decision making.

Legare et al. 2006, Hoffman et al. 2014

SDM process





American Orthotic & Prosthetic Association

Resources

A decision aid for people facing partial foot amputation due to peripheral arterial disease

Authors:

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Matthew Quigley, MCPO (Hons)

Graphic design:

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2. Northwestern University Prosthetics-Orthotics Center, Feinberg School of Medicine, 630 N Lake Shore Drive, Suite 1700, Chicago, IL 60611



A discussion guide for healthcare professionals to support decision making about partial foot amputation due to peripheral arterial disease

Authors:

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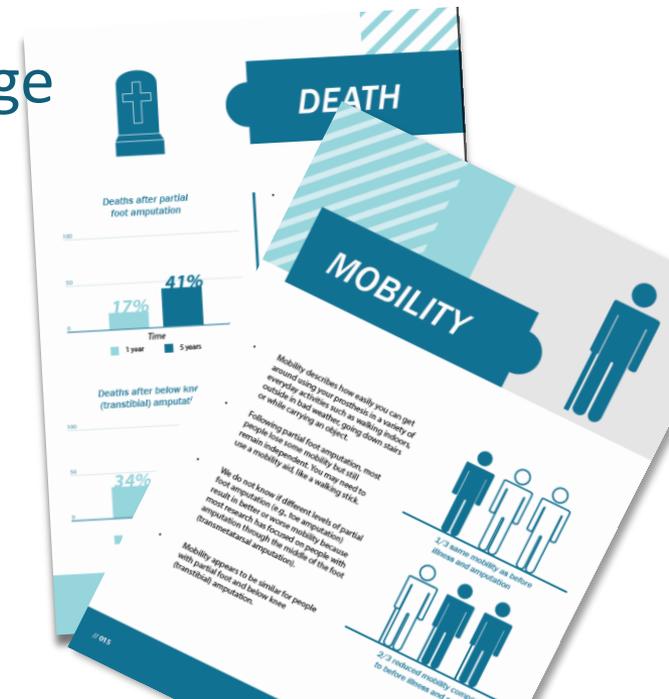
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Decision aid

Resource to support patients to make a decision:

- Focused on a very specific decision
- Clear and easy to understand language
- Explains different options
- Risks and benefits without bias
- Figures/graphics help understanding
- Include prompts to guide reflection



Quality SDM resources

International Patient Decision Aid Standards (IPDAS)

Elwyn et al. 2006; Coulter et al. 2013; Volk et al. 2013



Process



Reading level



Evidenced



Visual appeal



Patient stories



User tested

Develop SDM resources

We developed our SDM resources:

- In keeping with the patient experience
- IPDAS guidelines
- Evidence from systematic review



MOBILITY

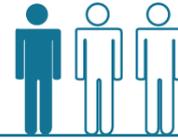


Mobility describes how easily you can get around using your prosthesis in a variety of everyday activities such as walking indoors, outside in bad weather, going down stairs or while carrying an object.

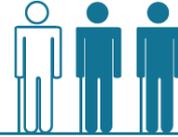
Following partial foot amputation, most people lose some mobility but still remain independent. You may need to use a mobility aid, like a walking stick.

We do not know if different levels of partial foot amputation (e.g., toe amputation) result in better or worse mobility because most research has focused on people with amputation through the middle of the foot (transmetatarsal amputation).

Mobility appears to be similar for people with partial foot and below knee (transtibial) amputation.



1/3 same mobility as before illness and amputation



2/3 reduced mobility compared to before illness and amputation

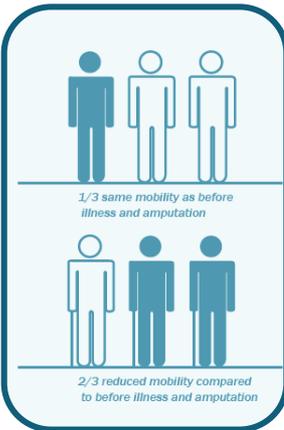
Simple definitions. Lay language.

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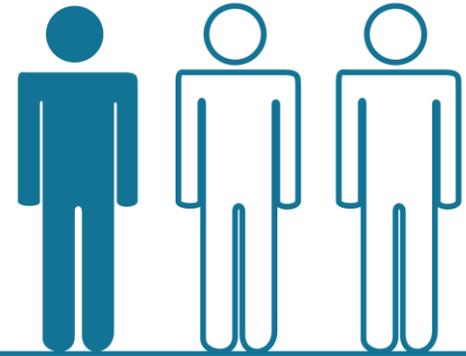
MOBILITY



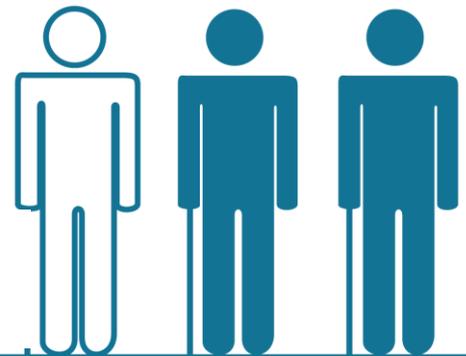
- Mobility describes how easily you can get around using your prosthesis in a variety of everyday activities such as walking indoors, outside in bad weather, going down stairs or while carrying an object.
- Following partial foot amputation, most people lose some mobility but still remain independent. You may need to use a mobility aid, like a walking stick.
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- Mobility appears to be similar for people with partial foot and below knee (transtibial) amputation.



Describe likely outcomes



1/3 same mobility as before illness and amputation



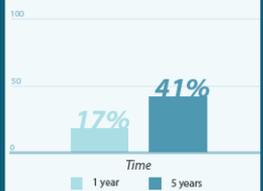
2/3 reduced mobility compared to before illness and amputation

Compare outcomes with simple statistics



DEATH

Deaths after partial foot amputation



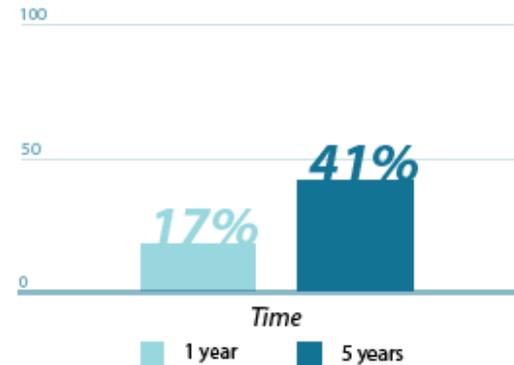
Deaths after below knee (transtibial) amputation



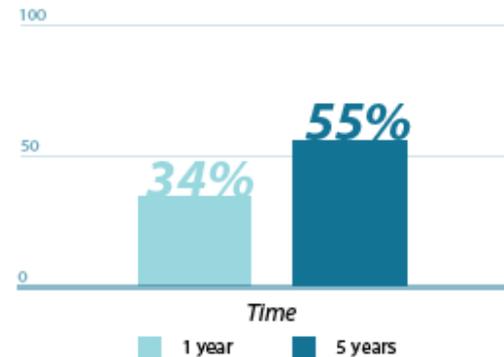
- Many people are not aware of the risk of dying after partial foot amputation.
- We are not sure if there are differences in rates of death for different levels of partial foot amputation because there has not been enough research.
- People who have a below knee (transtibial) amputation may have a greater risk of dying because of worse health at the time of their amputation than people who have partial foot amputation.
- People who die after lower limb amputation often have many other serious health issues such as heart disease, lung disease or kidney disease (renal failure). We think these are the main causes of death, not the choice of amputation level.

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Deaths after partial foot amputation



Deaths after below knee (transtibial) amputation



PSYCHOSOCIAL



- Following amputation, some people experience depression, anxiety and changes in their body image (psychosocial outcomes).
- No studies have investigated psychosocial outcomes in people with partial foot amputation. Because of this, we do not know whether there are differences due to the level of partial foot or below knee amputation.
- A number of studies including people with different types of lower limb amputation describe that experiences such as depression and anxiety are common after amputation. It is reasonable to think that people with partial foot amputation may have these experiences too.
- You may not experience any of these outcomes, but it is a good idea to have a plan in case you do. You may want to talk with your healthcare provider for more information.

Candid about what we don't know.

No studies have investigated psychosocial outcomes in people with partial foot amputation. Because of this, we do not know whether there are differences due to the level of partial foot or below knee amputation.

A number of studies including people with different types of lower limb amputation describe that experiences such as depression and anxiety are common after amputation. It is reasonable to think that people with partial foot amputation may have these experiences too.

Support deliberation

YOUR DECISION

What is important to you?

Q: What are your greatest concerns about surgery?

Q: What are your greatest concerns about life with amputation?

Q: Based on what you have read, do you have a preferred option?



Toes



Transmetatarsal



Below knee

In practice

How are SDM resources incorporated into practice?



Decision aid used in consult & taken home to discuss with family



Decision aid provided as part of referral



Decision aid found online before consult

Will it work?



Effectiveness shown in other areas of healthcare

Prostate screening, breast cancer treatment etc.

Improves

- Knowledge of options
- Accurate perception of risks
- Communication between patients and clinicians
- Participation in decision making
- Clarity about what matters most

Reduces

- Feeling uninformed
- Feeling unsupported
- Uncertainty about decision
- Decision regret
- Uptake of unnecessary or risky treatments

Publications

Systematic Reviews

PROTOCOL

Describing the outcomes of dysvascular partial foot amputation and how these compare to transtibial amputation: a systematic review protocol for the development of shared decision making resources

Open Access

Michael P Dillon¹, Stefania Fatone² and Matthew Quigley³

Development of shared decision-making resources to help inform difficult healthcare decisions: An example focused on dysvascular partial foot and transtibial amputations

Matthew Quigley¹, Michael P Dillon² and Stefania Fatone³

Abstract: Shared decision making is a collaborative process designed to encourage patient participation in decision making by providing accurate information about the treatment options and supporting deliberation with the clinicians about treatment options. The process can be supported by resources such as decision aids and decision guides designed to inform and facilitate shared decision making and the international standards used to guide the development of quality resources for use in areas of prosthetic rehabilitation care.

Clinical relevance: Shared decision making is a process designed to guide conversations that help patients make informed decisions about their healthcare. Having awareness of shared decision making and the international standards for the development of high-quality decision aids and decision guides is important as the approach is introduced in prosthetic rehabilitation care.

Systematic Reviews

RESEARCH

Outcomes of dysvascular partial foot amputation and how these compare to transtibial amputation: a systematic review for the development of shared decision-making resources

Open Access

Michael P Dillon¹, Matthew Quigley² and Stefania Fatone³

Abstract: Background: Dysvascular partial foot amputation (PFA) and transtibial amputation (TTA) are common lower limb amputation procedures. The aim of this study was to compare the outcomes of PFA and TTA in terms of mortality, quality of life, and patient satisfaction.

amplified

edition 1 | 2017



A leg up for the NDIS
How to choose the right prosthesis for you
An insight into shared decision making

ARTICLE IN PRESS

ACRM ARCHIVES OF PHYSICAL MEDICINE AND REHABILITATION

Archives of Physical Medicine and Rehabilitation

FROM THE EDITOR'S DESK

While Mortality Rates Differ After Dysvascular Partial Foot and Transtibial Amputation, Should They Influence the Choice of Amputation Level?

Michael Dillon, PhD,¹ Stefania Fatone, PhD,² Matthew Quigley, MCPO (Hons)³

Abstract: Although there is strong evidence to show that the risk of dying after transtibial amputation is higher than partial foot amputation, we are concerned by the implications that amputation level influences mortality, and that such interpretations of the evidence may be used to influence decisions about the choice of amputation level. We argue that the choice of partial foot or transtibial amputation does not influence the risk of mortality. The higher mortality rates are observed in studies with older people with more advanced systemic disease and multiple comorbidities. Studies that control for the confounding influence of these factors have shown no differences in mortality rates by amputation level. These insights have important implications in terms of how we best inform difficult decisions about amputation at either the partial foot or transtibial level, given a new thoughtful interpretation of the published literature.

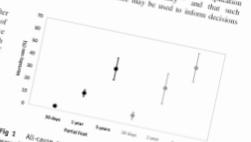


Figure 1: All-cause proportionate mortality at 30 days and 1 and 5 years after PFA and TTA point estimates and 95% confidence intervals are shown. Data were derived from 1000 at 1 year.

A decision aid for people facing partial foot amputation due to peripheral arterial disease

Healthcare professionals to support decision making about partial foot amputation due to peripheral arterial disease

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Final word



For the clinician staff guiding the patient as to what surgical outcomes they can expect: give them the full options. Be prepared to provide a whole host of options and choice. You need to listen. Give the fact base and, um, give them time to contemplate. If that is at all feasible. Do not expect them to choose the one that you would choose as well. Be prepared that whatever that decision is for that person... needs to be made for that - the person needs to make their decision. (Subject 5)