

Communicating Pain – the expression and identification of pain in people with disabilities and complex communication needs.

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scope
FOR PEOPLE WITH A DISABILITY

Who is Scope?

Scope's mission is to support people with disabilities to achieve their potential in welcoming & inclusive communities.



Why this Research?



2004 Snapshot of the health status of people using Scope residential, respite, day & lifestyle services:

- 27% of people living in Scope supported accommodation
- 60% of people who access Scope respite services
- 59% of people who access Scope day services

are not able to communicate in a way that is easily understood when they are in pain. (Koutoukidis,2004)

Why this Research?

2009 Snapshot of the health status of people using Scope residential, respite, day & lifestyle services:

- 65% of people we support who do not use speech as their primary method of communication

65% - 80% are not able to communicate in a way that is easily understood when they are in pain. (Huska, 2009)



What did the Literature tell us?

- Effective communication essential to assess and manage a person's pain.
(Turk, 2004)
- People with complex communication needs may express pain through a range of behaviours such as screaming, biting, head banging and aggression.
(Tracy and Wallace, 2001)
- These behaviours can be misinterpreted resulting in pain being untreated.
(Stallard, et al., 2001)

What did the Literature tell us?



People with disability and their unpaid carers are ageing along with the rest of the Australian population

(Balandin & Morgan, 2001)

- Failure to address pain is detrimental to health outcomes.
- More presentations within primary & acute health settings.
- Longer periods of hospitalisation.
- Pain management clinics are rarely used (for people with disabilities).

Literature identified Tools for Assessing Pain:

General Tools for:

- Infants – FAC
- Children – behavioural, physiological, psychological (5+ visual analogue scales)
- Adults – self-report scales such as the Brief Pain Inventory
- Older adults – Abbey Pain Scale

Tools for children with disabilities:

- Non-Communicating Children's Pain Checklist (NCCPC)

Tools for adults with Intellectual disabilities:

- Disability Distress Assessment Tool (DisDAT) Regnard et al 2007
- Pain and Discomfort Scales (PADS) Bodfish et al 2001

Selecting a tool for further study:

DisDAT (copyright 2008 Northumberland Tyne & Wear NHS Trust and St Oswald's Hospice)

DisDAT
Disability Distress Assessment Tool

v19

Individual's name:
DoB: Gender:
NHS No:
Your name:
Date completed:
Names of others who helped complete this form:

THE DISTRESS PASSPORT
Summary of signs and behaviours when content and when distressed

Appearance when CONTENT	Appearance when DISTRESSED
Face Eyes Tongue/jaw Skin	Face Eyes Tongue/jaw Skin
Vocal signs when CONTENT	Vocal signs when DISTRESSED
Sounds Speech	Sounds Speech
Habits and mannerisms when CONTENT	Habits and mannerisms when DISTRESSED
Habits Mannerisms Comfortable distance	Habits Mannerisms Comfortable distance
Posture & observations when CONTENT	Posture & observations when DISTRESSED
Posture Observations	Posture Observations

Known triggers of distress (write here any actions or situations that usually cause or worsen distress)

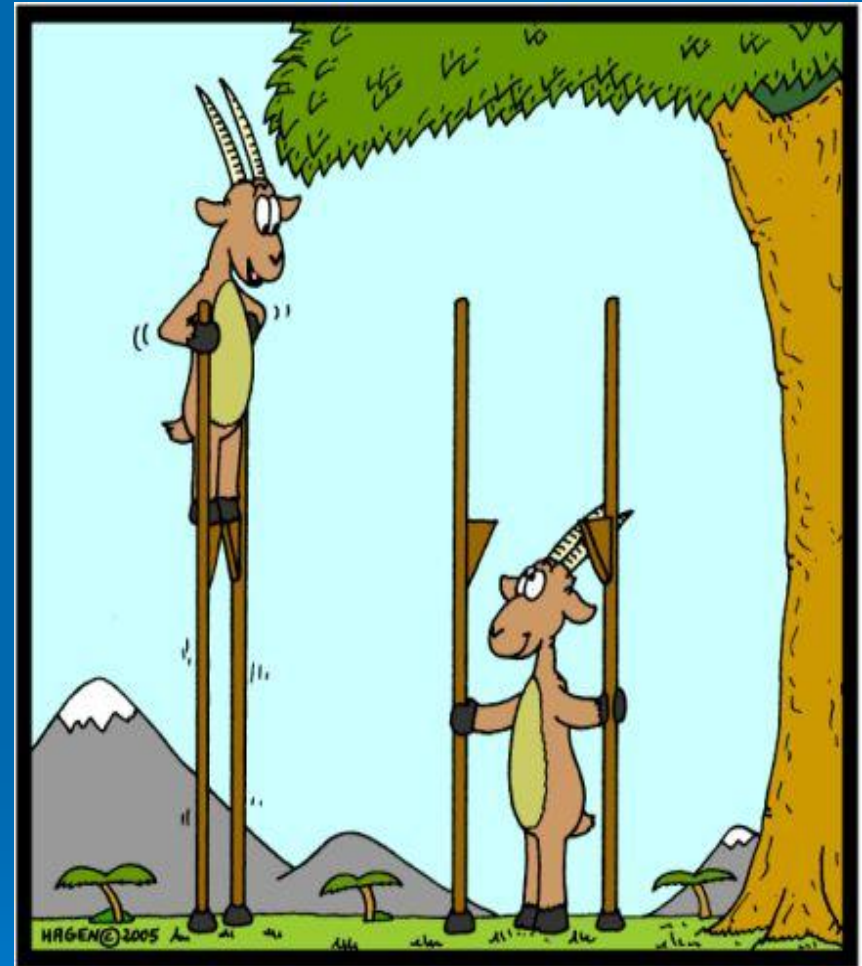
The DisDAT

- only preliminary examination of psychometric properties
(Regnard et al., 2003; Regnard et al., 2007).
- focuses on the identification of distress in people with severe communication difficulties.
- designed to document supporters' intuitive observations
- includes Assessment and Monitoring components.

Research Questions:

1. To what extent does the DisDAT support disability support staff and next-of-kin/carer to identify expressions of pain?
2. To what extent does the DisDAT support disability support staff and next-of-kin/carer to respond to pain?
3. To what extent does the DisDAT support the person with disability &/or their next-of-kin/carer &/or disability support staff to communicate about the person's pain?
4. What modifications to the DisDAT are required to make it more useful to a wider population of people with disabilities and complex communication needs?

Research Aims:



You see it was worthwhile learning to use stilts:
Only giraffes can reach these leaves usually...

Who were our participants?

- 7 people with physical and multiple disabilities with complex communication needs.
 - Scope provides support to the person at one of either residential, respite or day & lifestyle services.
- 7 Disability Support Workers
 - who have regular contact with one of the persons with disability participating.
- 7 Next-of-kin/carer
 - who have regular contact with the person with disability participating.
- All persons with disability were over the age of 18 years.
- All persons with disability were able to give consent or had an identifiable Person Responsible.

What do we mean by “Complex Communication Needs”?



People who don't use speech to communicate

and/or

have speech that is difficult to understand

and/or

who may have difficulty understanding spoken language.

Methodology:

1. Pre – trial interview
2. Training – development of the DisDAT
3. 6 month Trial
4. Post – trial interview

Analysis:

Communication Level

Level 0

This person is unable to show likes or dislikes

Level 1

This person is able to show that they like or don't like something

Level 2

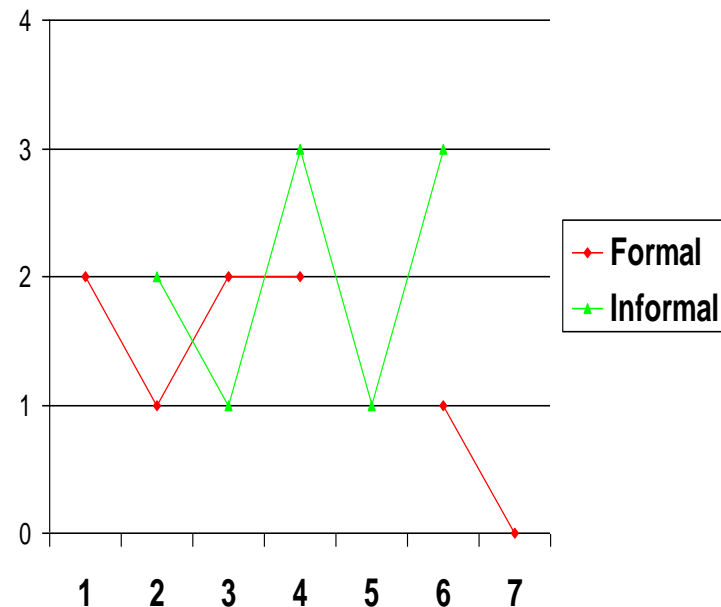
This person is able to show that they want more, or have had enough of something

Level 3

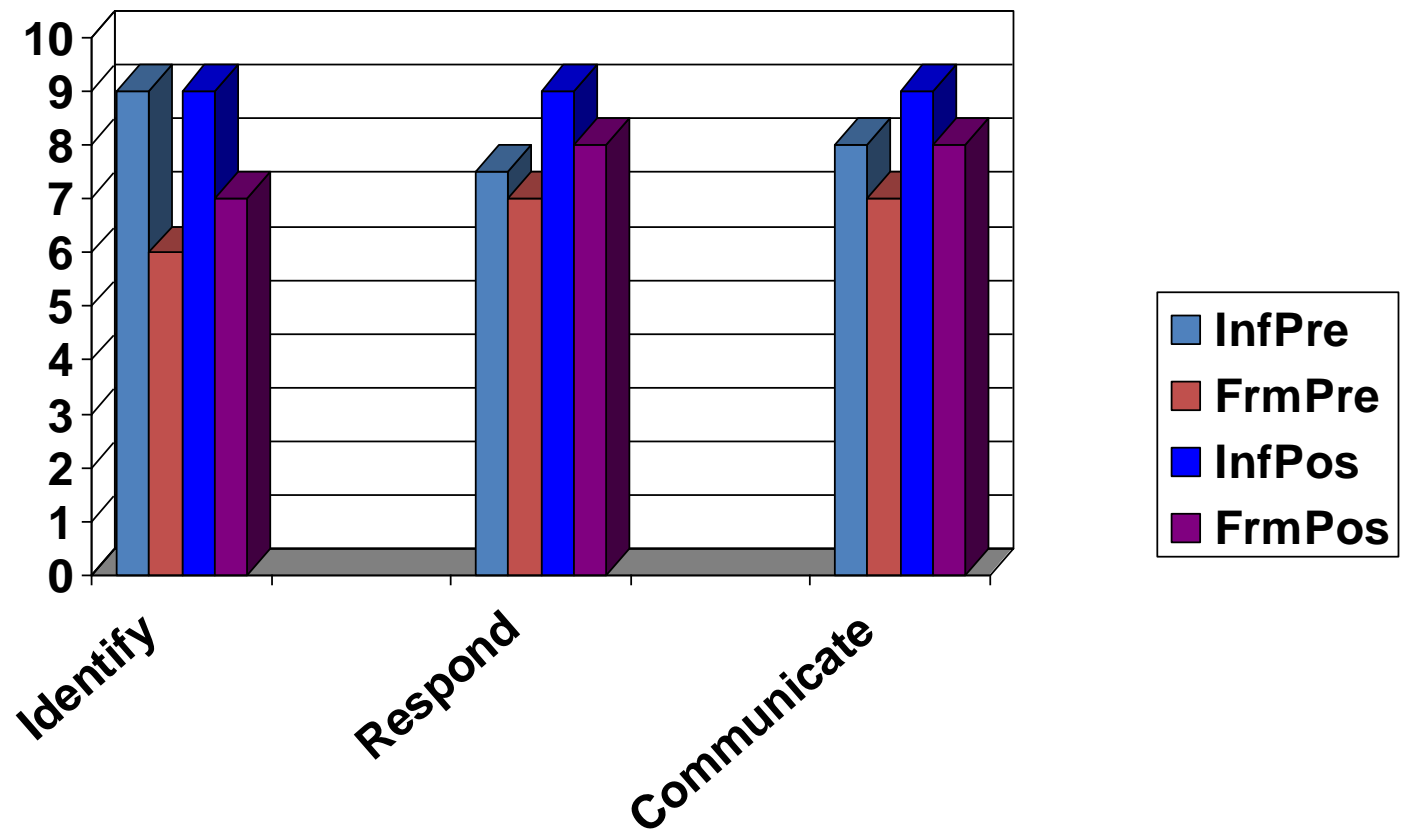
This person is able to show anticipation for their like or dislike of something

Level 4

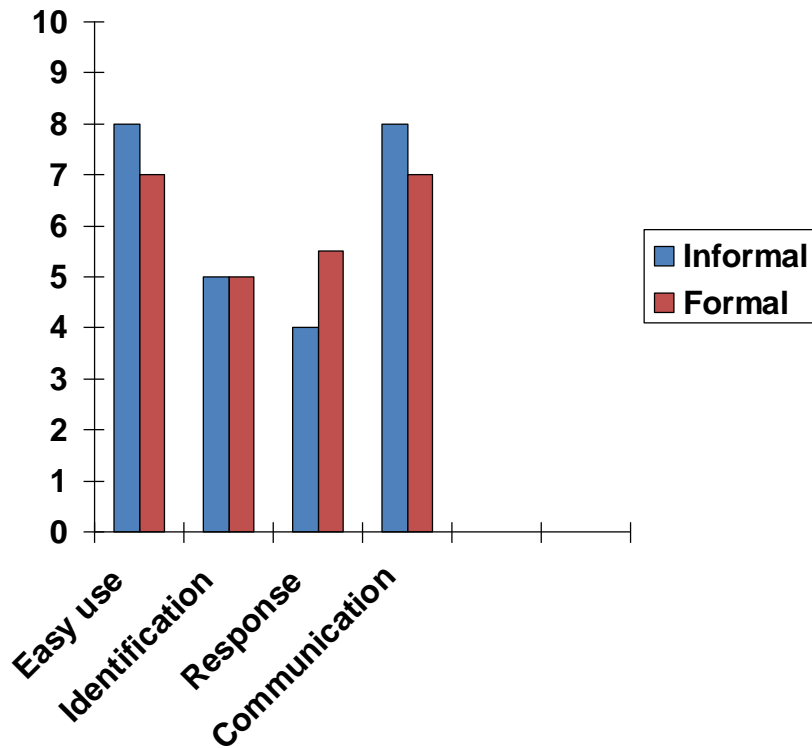
This person is able to communicate detail, qualify, specify and/or indicate opinions.



Analysis: Rater agreement pre & post trial



Analysis: DisDAT - rater agreement Post trial



“If people read the content it would be useful”

“Semi confident. This has made me look at the person deeper”

Conclusions:

- DisDAT is easy to use for non-health professionals.
- Best outcomes are achieved in the development of the summary document when people who know the person well, share their knowledge of how the person communicates distress/pain.
- The DisDAT supports improved communication about distress/pain identification with people (including health professionals) who do not know the person well.
- Health professional clinical assessment enhanced in the presence of a completed DisDAT.

Where to from here?

- **Disseminate**
 - Presentation
 - Publication
- **Develop**
 - Education
 - Resources
 - Modified Tool

➤ Communication
Advocacy

➤ Resourcing

➤ Further Research

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