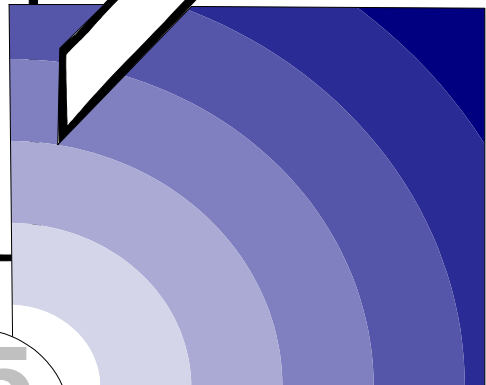
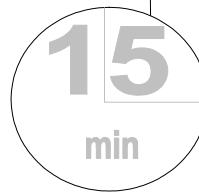


CLIP

15 minute Worksheet



Helping the person with communication difficulties

2: Identifying distress

Introductory level

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Aim of this workshop

To consider ways and means of identifying distress in a person using alternative methods of communication.

How to use this workshop

- You can work through this workshop by yourself, or with a tutor.
- Read the case study below, then work on the questions overleaf.
- The work page is on the right side, the information page is on the left.
- Work any way you want: you can try answering from your own knowledge (in which case fold over the information page), you can use the information page (this is not cheating- you learn as you find the information), or you can use other sources of information
- It should take you about 15 minutes. If anything is unclear, discuss it with a colleague.
- If you think any information is wrong or out of date let us know
- Use the activity on the back page and take this learning into your workplace.

Case study

Margaret is a 50 year old lady with Down Syndrome. She attended a 'special school' when she was young. She was always friendly and happy except for a short time when she was with foster parents. After that she moved in with her sister and manages to look after herself at home while her sister works.

Margaret is usually responsive to others, but over the past few days she has been reluctant to communicate, ignores carers and grimaces during interventions.

Behaviours and signs of distress (the 'language' of distress)

There are many ways that Margaret could express her distress:

- **Expressive:** these may be of 2 types:
 - verbal:* these may be using language (simple descriptions eg 'I'm not right', associated words eg always using the words 'My knee hurts' for any distress), or using sounds (crying, screaming, sighing, moaning, grunting).
 - facial:* these may be simple expressions (grimacing, clenched teeth, shut eyes, wide open eyes, frowning, biting lower lip) or more complex (where patients look sad or angry).
- **Adaptive:** rubbing or holding a painful area, keeping an area still, approaching staff, avoiding stimulation. reduced or absent function (reduced movement, lying or sitting).
- **Distractive:** rocking (or other rhythmic movements), pacing, biting hand or lip, gesturing, clenched fists.
- **Postural:** increased muscle tension (extension or flexion), altered posture, flinching, head in hands, limping, pulling cover or clothes over head, knees drawn up
- **Autonomic:** this may be either sympathetic (the flight or fright response with ↑pulse rate, ↑BP, wide pupils, pallor, and sweating) or parasympathetic (in response to nausea or visceral pain with ↓BP and ↓pulse rate)

The language of observable communication (LOC) *

Like any language, you have to:

- 1) know what the words mean,
- 2) learn a basic vocabulary,
- 3) know how the words are put together and
- 4) make sense of what the person is saying.

In people using alternative communication, the language is made up mainly of behaviours, signs, and verbal expressions (which may be sounds only, or words that indicate distress but do not describe it). Compared to spoken language, the vocabulary in LOC is small, the grammar is basic and the pattern of expressions is unique to each individual. The difficulty is knowing what these behaviours, signs and expressions mean (ie. it's us who have difficulty understanding the person expressing LOC). They can only be understood with close observation.

Some of the LOC 'words' can suggest a meaning when taken together or when seen in their context:

Nausea: this tends to cause an autonomic response with pallor, cold sweating, a slow pulse and vomiting.

Fear: increased pulse, dilated pupils, tremor, and increased respirations, perhaps associated with a particular situation..

Frustration: crying or screaming, rapid and purposeless movements, looking angry, perhaps associated with a particular situation.

Leg pain: holding leg still, rubbing leg, limping, refusing to move.

Margaret's grimacing and ignoring of carers: this tells us very little- we need more information.

* **LOC:** The abbreviation 'Loq' was formerly used as a stage direction and comes from the Latin, *.loquitur* for 'he, she speaks'.

Understanding LOC

A real difficulty is that any cause of distress can be accompanied by any behaviour, sign or expression. Although some LOC 'words' are the same or similar in most patients (eg. the reactions to fear), each individual uses their own 'dialect' of LOC. Although staff are often skilled in picking up distress they often have little confidence in their observation and perceive their observations intuitively as a 'hunch'. We therefore need more information:

Is this behaviour or sign new? For this we need to know their usual behaviour by recording baseline behaviour and asking the main or previous carers what they know. We know it is new in Margaret.

Is this behaviour or sign associated with known distress? For this we need to identify LOC 'words' with known cause of distress (eg. during an episode of constipation, or in a frightening situation). This can only be done if behaviour, signs and expressions are regularly documented.

Is this individuals' behaviour unique? For this we need to document the behaviours in a large number of individuals, estimate the cause of distress and the response to treatment (in order to confirm the cause). This is best done as a research project.

Principles

- The language of distress consists of behaviours, signs and expressions.
- The language of observable communication (LOC) may be unique to each individual
- Documentation of LOC is essential if each individual is to be understood
- The problem is our understanding

Distress may be hidden, but it is never silent.

Write

Write down different ways in which Margaret could respond to distress

Words or sounds

Facial expression

Actions by Margaret that try to ease any pain she has

Actions by Margaret that distract her from distress

Changes in body posture

Reflex nervous system responses

Write

Using your list above (or the one at the top of the page opposite), which behaviours and signs might suggest the following causes of distress

- Nausea:
- Fear:
- Frustration:
- Leg pain:
- Margaret's grimacing and ignoring of carers:

Like us, you may have found this exercise difficult, especially when it came to interpreting Margaret's behaviour.

Write

Write below the extra information you would need to understand Margaret and how you would get that information.

Problem	Information needed	How to obtain information
Is this behaviour or sign new?		
Is this behaviour or sign associated with known distress?		
Is this individuals' behaviour unique?		

FURTHER ACTIVITY: Identifying distress

Think of a typical day in your life:

-write down all the times you use non-verbal language.

FURTHER READING: Identifying distress

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Current Learning In Palliative care An accessible learning programme for health care professionals

Fifty seven 15 minute worksheets are available on:

- An introduction to palliative care (3 worksheets)
- Helping the patient with pain (9 worksheets)
- Helping the patient with symptoms other than pain (11 worksheets)
- Moving the ill patient (2 worksheets)
- Psychological needs (8 worksheets)
- Helping patients with reduced hydration and nutrition (8 worksheets)
- Procedures in palliative care (4 worksheets)
- Understanding and helping the person with alternative communication (learning disabilities) (5 worksheets)
- The last hours and days (4 worksheets)
- Bereavement (3 worksheets)

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