Management of Severe Distress in Dementia

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http://www.crugel.3x.ro/index.html

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Summary

- Think of distress
- Severe distress is a far more important concept for the patient than “behaviours that challenge” etc as the latter are not patient centred.
- Pain is both mental and physical
- Do not see it as a single entity
- Look underneath it for the cause
- Treat the underlying cause according to good practice advice

Introduction

- Dementia causes distress.
- Occurring towards the end of life
- In such circumstances the basic precepts of palliative care must be applied;- to affirm life, accept natural death, reduce distress of whatever cause and independence and function wherever possible.
- Dementia, has been studied intensively by subdividing it into "bite size" chunks, allowing a scientific approach with some huge gains in areas such as .
  - Drugs specifically used to treat cognitive impairment in dementia,
  - Drugs for psychosis in dementia and drugs for depression in dementia,
  - Management of behavioural and psychological symptoms in dementia (BPSD).
  - Management of depression
  - Management of physical pain etc.

- **By focussing upon subsets of symptoms the overall balance of managing severe distress may be lost.**
- For example
- Anti-psychotics are either
  - Bad as they cause stroke falls confusion or death
  - Or good as they make people calmer and give the staff an easier time
  - Or good as they actually help to alleviate severe distress
  - Or all of the above! (which is true)

- But antipsychotics are hugely overused and often used as they only treatment for behaviour problems in dementia.
- And yet the causes of behaviour disturbance in dementia are wide and varied.

What is wrong with the concept of behaviour disturbance in Dementia?

- Nothing as it is well researchable and measurable and leads to good quality data
- Except that some behaviour disturbance in dementia is entirely reasonable and may be welcome as an expression of the problems of the illness or the care provided
- Or in other words, we are all entitled to be behaviourally disturbed and so it is not a “pure” problem

Severe distress, a better concept?

- Severe distress in those who cannot understand and cannot choose seems to us to be a stronger concept in terms of palliation than behaviour disturbance
- It is as close as you can get to a “pure” problem
- It enables a philosophical note to be made by those treating and caring for the patient that they must alleviate distress.
- It will still be the case that distress may be allowed as distress some of the time may be well worth it for the better periods of relief.

But generally

- There is a strong requirement to relieve severe distress in those with advanced dementia and the experience of here and now (for them) is arguably far more important than in those who are healthy and able to endure distress (eg of childbirth or saving for that big house) in the hope of a less distressed future.

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Is distress the same as pain?

- We do not think that there is a major philosophical difference between physical or mental pain. Both cause suffering and should be alleviated.
- A number of “pain” scales exist and often think mainly of physical pain. An example is the PAIN AD which does not sem to wrok very well as a screen for distress

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Pain AD

- Pain AD scale:
- Breathing Independent of vocalisation
- Negative vocalisation
- Facial expression
- Body language
- Consolability

- But interestingly, most of the features of physical pain in severe dementia (as above) would be the same features in mental pain. So pain scales are likely to score for mental and physical pain.

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Dis DAT

- A useful scale developed in learning Disability that gives the opportunity for staff to identify key pain issues and monitor them. http://www.disdat.co.uk/
- Lay and professional carers were skilful at identifying distress, but had little confidence in that skill
- This lack of certainty in what carers were observing made it difficult for them to advocate for the person with the communication difficulty when faced with a challenge to their observation.

Our key symptoms of severe distress

- Anger/Frustration
- Aggression/Agitation
- Fear/ Anxiety
- Tearfulness/ misery
- Pain when still
- Discomfort on moving
- Restlessness/Insomnia
- Calling out/ vocalisation
- Wandering
- Autonomic arousal, sweating, tachycardia, hypertension

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Underlying causes of severe distress

- **Depression**
- **Psychosis**
- **Pain**
- **Poor understanding,**
- **Fear and anxiety**
- **Insomnia**
- **Hunger and diet**
- **Boredom, isolation and spiritual care**
- **Poor Environments including poor staff practices etc**

This is the order we put them in, that may be wrong but that is, perhaps how we as a group of mainly doctors think. But we do strongly feel that to leave depression (which affects 30% +) and psychosis (?20 – 50%) which is also very common as the last things to treat after trying all else may be a severe error that leave severe distress untreated.

Specific symptoms of importance

- Continence and elimination
- Wandering
- Sexual disinhibition
- Sundowning
- Scabies

Treatment and management

- Underneath each symptom then there is a recommended set of actions. Some are simple
- eg in Depression;-

- Our group agreed that there should be a low threshold for the use of antidepressants in SDID. 1st line is an SSRI followed in the absence of benefit by, perhaps a more sedative antidepressant (eg Mirtazapine or Trazodone).

- Psychosis
- *Anti-psychotics are useful for psychosis and also where there is behaviour disturbance or inappropriate vocalisation agitation and restlessness. The medications are harmful and it is especially important to understand that the justification for use is distress severe enough to accept risks of Side effects. Where anti-psychotics do not succeed, anticonvulsants and memantine may also be tried.*

- Pain
- *Opiates are effective for pain, but again can be harmful if overused. In apppropriate doses they are safe. Milder pain may be treated with weaker analgesics. Tramodol and fentanyl are useful and can be applied with skin patches. Varying position of those who are very immobile is important. Arthritic pain may respond well to non steroidal analgesics but the risk of gastric bleeding as well as anorexia and soreness needs considering.*
- *It is important not to undertreat pain.*

- Environment
- *Environmental changes, good nursing, careful sensitive approach, spiritual care are important. The correct aids and appliances can be hugely effective in improving the experience of care for people with dementia.*

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- Fear
- *Gentle calm approach, use of sedatives as a last resort. Seek underlying cause of fear, especially including environment, staff approach and psycohisis.*

- **Scabies**
- We mention this just because scabies is a cause of huge suffering and has been seen to be a treatable cause of severe distress. Expertise in identifying and treating is essential. Where advanced dementia causes contractures and makes universal application of lotions impossible, oral Ivermectin should be given.

- And so on with other examples.
- Sadly not yet published, so cannot share full data with you.

So

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