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Pain Assessment in Patients with Communication difficulties

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Session Contents:

1. What is pain?
2. How can assess pain in the cognitively impaired using self-report assessment tools?
3. How can we assess pain in the cognitively impaired using observational method?
4. How can we use pain assessment tools in our practice?

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Definition of Pain

Pain is what the patient says it is and occurs when he or she says it does (McCaffery, 1979)

- Subjective experience
- Cultural variations
- Patient attitudes/beliefs
- Individual differences, e.g coping mechanisms/pain threshold

But, what if the patient cannot say?

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Definition of Pain

International Association for the Study of Pain

International Association for the Study of Pain: An unpleasant sensory or emotional experience, associated with **actual or potential tissue damage** or described in terms of such damage (Merskey & Bogduk, 1994).

- Applies to acute, chronic (>3-6 months), and cancer-related.

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Definition of Pain

International Association for the Study of Pain

But again, what if the patient cannot say?

"The inability to communicate verbally **does not negate** the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment."

But what if tissue damage is not present?

"Many people report pain in the absence of tissue damage or any likely pathophysiological cause; usually this happens for psychological reasons. There is usually no way to distinguish their experience from that due to tissue damage if we take the subjective report. **If they regard their experience as pain**, and if they report it in the same ways as pain caused by tissue damage, **it should be accepted as pain.**"

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The challenges of pain in CI

Is this pain?

- https://www.youtube.com/watch?v=C0QDjXgNyuY
- https://www.youtube.com/watch?v=lMlffJ8MNr4

Seem familiar?

Have you experienced this and if so what did you do?

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How do we access pain in CI?

- We assess pain to determine: pain severity, the impact to the patient, the suitability of a pain medication, the efficacy of a pain medication or alternative therapy……**We assess pain as pre-requisite for effective pain management.**
- **But how? Guidelines and research** indicates we should be using a standardised, formal pain assessment tool (PATs).

Self-report PATs & informal questions → A patient reported measure of **their** pain

Why bother with either?

Observational PATs → A scale consisting on verbal and behavioural indicators that can be used to assess pain and distress

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Self-report PATs & informal questions

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Self-report PAT in CI

Remember: A patient reported measure of **their** pain

Royal College of Nursing

"Children's self-report of their pain, where possible, is the preferred approach"

"Using a self-report pain measurement tool for a patient with known cognitive, sensory, or motor deficits can be useful"

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Self-report PAT in CI

But can CI patients self-report pain? **YES**

Standardised Self-report PATs

"A number of valid and reliable self-report measures are available and can be used even when moderate dementia exists. The Numerical Rating Scale or verbal descriptors can be used with people who have mild to moderate cognitive impairEment." UK Guidelines (2018) (evidence from Kelley, Siegler, & Reid, 2008; Pesonen, Kauppila, Tarkkila, Sutela, Niinisto, & Rosenberg, 2009).

Closs et al. (2014) found a large majority of those with moderate CI were able to use the VRS (97%) and the NRS (87%). There was a notable reduction in the ability to use the scales among those with severe cognitive impairment, but the VRS remained the most successful scale, being completed by more than one-third of this group (Closs et al., 2014). Visual Analogue Scales and the FACES scale can be understood and used by mild CI.

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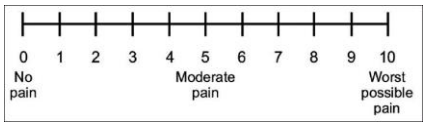
Self-report PAT in CI

Standardised Self-report PATs: Visual Rating Scale (VRS) and Numerical Rating Scale (NRS)



- Validated up to moderate CI (usually dementia), including children of 8-12 years of age
- Easy to use and interpret
- Requires minimal training to apply in practice
- Appropriate for all care settings
- Does not require previous experience of patient or their condition
- Not suitable for patients without numerical understanding

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Self-report PAT in CI

But can patients with learning disabilities self-report pain? **YES**

Standardised Self-report PATs

Zabalia et al. (2005) studied the ability to use self-assessment tools in children aged 8–18 years with mild to moderate intellectual disabilities (IQ from 45 to 70 assessed with the Wechsler Intelligence Scale for Children – WISC-III). Accurately used the VAS and FACES Scale Revised (FPS-R) to rate pain, for both personal pain and using vignettes.

Zabalia & Corfec (2008) explored the ability to recognize emotions and pain assessment in children and adolescents with Down syndrome. Results showed that the children were able to identify emotions and use the FPS-R more appropriately than the VAS.

Does it vary dependent on the learning disability?

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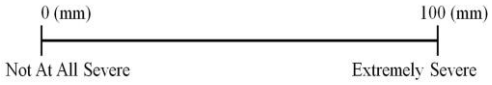
Self-report PAT in CI

Standardised Self-report PATs: Visual Analogue Scale

Note how severe you feel your disease state is with a mark (\) on the line below.



- Validated in mild to moderate learning disabilities
- Not suitable for severe learning disabilities or intellectually impaired
- Easy to administer
- Not setting dependent

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Self-report PAT in CI

Standardised Self-report PATs: The FACES Scale (Wrong & Baker)

- Validated up to moderate learning disability (mental age 5>, and children 4-8 years of age
- More user-friendly for this population than the VAS
- Easy to administer in all settings
- Requires a numerical understanding and emotional
- Measures distress in addition to pain- pain vs. Sad

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Self-report PAT in CI- Pain Experience

But do patients with CI (related to dementia) experience pain? **YES**

The disease process damages the CNS and as a result impairment occurs in memory, language and higher-order cognitive processing.

This DOES impact their ability to communicate pain, however those with dementia CAN still experience pain sensation to the same degree as cognitively intact older adults (e.g. Karp, Shega, Morrone, & Weiner, 2008; Kunz, Mylius, Scharmann, Schepelman, & Lautenbacher, 2009; Scherder, Herr, Pickering, Gibson, Benedetti, & Lautenbacher, 2009).

Pathologic changes CAN affect the interpretation of the pain stimulus and the affective response to the pain experience (e.g. Reynolds, Hanson, DeVellis, Henderson, & Steinhauser, 2008; Scherder et al., 2009).

Differences in pain processing HAVE been observed in varying types of dementia:

- Those with FTD have increased pain threshold and pain tolerance (Carlino, Benedetti, Rainero, Asteggiano, Cappa, Tarenzi, et al., 2010).
- For those with AD they appear to suffer more acute pain (affective pain situations) comparative to chronic pain, suggesting a decline in pain affect (Scherder & Bouma, 2000).

Unclear at current- what about mixed diagnosis?

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Self-report PAT in CI: Summary

Infants/Pre-verbal Toddlers	Critically Ill/unconscious	Dementia	Intellectual disability	End of life
Infants, toddlers, & developmentally preverbal children lack cognitive skills necessary to report & describe pain.	Self-report should be attempted; however, may be hampered by delirium, cognitive & communication limitations, level of consciousness, presence of endotracheal tube, sedatives, & neuromuscular blocking agents.	Self-report of pain often possible in mild to moderate cognitive impairment, but ability to self-report decreases as dementia progresses.	Majority of individuals with ID are verbal & can self-report pain using appropriate self-report pain assessment tool.	Cognitive abilities often fail as disease progresses. Pain assessment must include assuming that pain is present if pain was previously a complaint.
SELF-REPORT ASSESSMENT NOT SUITABLE	SELF-REPORT ASSESSMENT SUITABLE DEPENDENT ON CI	SELF-REPORT ASSESSMENT SUITABLE DEPENDENT ON CI	SELF-REPORT ASSESSMENT SUITABLE DEPENDENT ON CI	SELF-REPORT ASSESSMENT SUITABLE DEPENDENT ON CI

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Self-report PAT in CI- Unstandardised Approach

According to current UK guidelines:

- *Direct enquiry about the presence of pain*

- including the use of **alternative words** to describe pain
- Listen carefully – what words are used?
- May deny pain but admit to discomfort, aching, soreness

Description of pain to include:

- **sensory dimension**
  1. nature of the pain (eg sharp, dull, burning etc)
  2. pain location and radiation (by patients pointing to
  3. pain on themselves or by using a pain map)
  4. intensity, using a standardised pain assessment scale
- **affective dimension** (emotional)
- **Impact** (disabling effects of pain)

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Self-report PAT in CI- Proxy reports

"Credible information can be obtained from a family member or another person who knows the patient well (e.g., spouse, parent, child, caregiver). Parents and consistent caregivers should be encouraged to actively participate in the assessment of pain. Familiarity with the patient and knowledge of usual and past behaviours can assist in identifying subtle less obvious changes..." (Herr et al., 2011)

- Long-term care: HCA/CNA most effective in recognising pain (e.g. Nygaard & Jarland, 2006; Pautex, Herrmann, Michon, Giannakopoulos, & Gold, 2007). BUT Horgas & Dunn (2001) 49% self-reported pain vs. 36% NA/HCA/CNA.
- Acute setting: family members would be most useful as the health care providers do not have a history with the patient (Nygaard & Jarland, 2006).

Do we underdiagnose with proxy pain assessment? Do we need to re-educate?

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Observational PATs

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Observational PAT in CI

- If a patient cannot communicate what non-verbal and behavioural signs can we identify as indicative of pain?

This is the purpose of observational and behavioural PATs.

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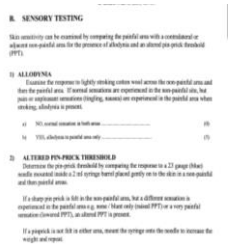
Observational PAT in CI: What one!?

The Leeds Assessment of Neuropathic Symptoms and Signs (LANSS): Self-report and Obs with 7 items to identify severity and cause.

- -Dependent on level of impairment
- -Validated in an array on conditions
- -More appropriate to clinical context
- -Requires training and medical background
- -Cause of pain can be identified



B. SENSORY TESTING

Skin sensitivity can be examined by comparing the painful area with a contralateral or adjacent non-painful area for the presence of allodynia and an altered pin-prick threshold (PPT).

1) ALLODYNIA

Examine the response to lightly stroking cotton wool across the non-painful area and then the painful area. If normal sensations are experienced in the non-painful site, but pain or unpleasant sensations (tingling, nausea) are experienced in the painful area when stroking, allodynia is present.

a) NO, normal sensation at both areas ..... (0)

b) YES, allodynia in painful area only ..... (1)

2) ALTERED PIN-PRICK THRESHOLD

Determine the pin-prick threshold by comparing the response to a 23 gauge (blue) needle mounted inside a 2 ml syringe barrel placed gently on to the skin in a non-painful and then painful areas.

If a sharp pin prick is felt in the non-painful area, but a different sensation is experienced in the painful area e.g. none / blunt only (raised PPT) or a very painful sensation (lowered PPT), an altered PPT is present.

If a pinprick is not felt in either area, mount the syringe onto the needle to increase the weight and repeat.

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Observational PAT in CI: What one!?

The Face, Legs, Activity, Cry, Consolability scale or FLACC scale

- 5 behavioural domains
- (facial expression, leg movement, activity, cry and consolability)
- Scored 0-2 on each domain, highest score 10 (>pain)
- Validated in acute care setting and post-operative pain
- Validated in children aged 4-19 years of age and suitable up to severe CI
- Relevant for learning disabled population

	Scoring		
Categories	0	1	2
Face	No particular expression or smile.	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant frown, quivering chin, clenched jaw
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid, or jerking
Cry	No cry (awake or asleep)	Moans or whimpers; occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging, or being talked to; distractable	Difficult to console or comfort

Note: Each of the five categories Face (F), Legs (L), Activity (A), Cry (C), and Consolability (C) is scored from 0-2, which results in a total score between 0 and 10. From Merkel, Voepel-Lewis, Shayevitz, & Malviya (1997). The FLACC: A behavioral scale for scoring postoperative pain in young children. Pediatric Nursing, 23(3):293-297.

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Observational PAT in CI: What one!?

Disability Distress Assessment Tool (DisDat)

- Ascertains communication ability.
- 4 domains (Facial expression, habits and mannerism, body posture, body observations) comparing 'content' to 'distressed' state.
- Developed for those with disabilities
- Developed for residential/long-term care

But this is a measure of distress not pain!

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Observational PAT in CI: What one!?

- Observational PAT: **The COMFORT scale** (pediatric intensive care)
- 7 domains and HCP VAS (Alertness, calmness/agitation, respiratory response, crying, physical movement, muscle tone, facial tension.
- >score >more pain.

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Observational PAT in CI: What one!?
Pain Assessment in Advanced Dementia Scale (PAINAD)

*Five-item observatal tool (see the description of each item below).
**Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0="no pain" to 10="severe pain").

Items*	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional laboured breathing. Short period of hyperventilation	Noisy laboured breathing. Long periods of hyperventilation. Cheyne- Stokes respirations	
Negative vocalization	None	Occasional moan or groan. Low level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying	
Facial Expression	Smiling or inexpressive	Sad. Frightened. Frown.	Facial grimacing	
Body language	Relaxed	Fidgeting. Tense. Distressed pacing.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	
			Total**	

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Observational PAT in CI: What one!?

PAINAD

- 5 minutes observation before scoring
- End of life
- Validated with older adults with severe CI
- Acute and long-term care validated

-Relevant to chronic pain
-Continues to be validated across care settings and countries (UK recommended)
-High sensitivity but can give false positives
-Easy to use
-More research needed to explore use in black and minority ethic groups

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Observational PAT in CI: What one!? Abbey Pain Scale

Q1. Vocalisation e.g. whimpering, groaning, crying
Absent 0 Mild 1 Moderate 2 Severe 3

Q2 Facial Expression e.g. looking tense, frowning, grimacing, looking frightened
Absent 0 Mild 1 Moderate 2 Severe 3

Q3. Change in body language e.g. fidgeting, rocking, guarding part of the body, withdrawn Absent 0 Mild 1 Moderate 2 Severe 3

Q4 Behavioural change e.g. increased confusion, refusing to eat, alteration in usual patterns Absent 0 Mild 1 Moderate 2 Severe 3

Q5 Physiological change e.g. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor
Absent 0 Mild 1 Moderate 2 Severe 3

Q6 Physical changes e.g. skin tears, pressure areas, arthritis, contractures, previous injury Absent 0 Mild 1 Moderate 2 Severe 3

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Observational PAT in CI: What one!?

- Most user friendly
- No recent studies in the UK
- Popular in different care settings
- Used in palliative settings and ongoing care
- Distress or pain measure?

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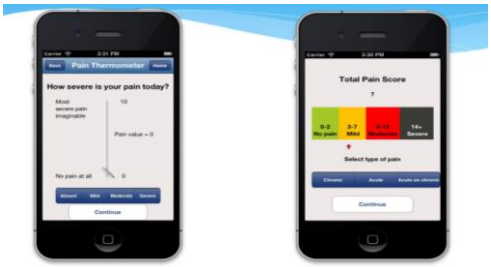
Assessing Pain: Tech Applications



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Assessing Pain: Tech Applications

- PAT do not have to be a pen-and-paper exercise, transition with the times.

Usability Testing of the iPhone App to Improve Pain Assessment for Older Adults with Cognitive Impairment (Prehospital Setting): A Qualitative Study. Docking RE[1], Lane M[2], Schofield PA[1]. Pain Med. 2018 Jun 1;19(6):1121-1131. doi: 10.1093/pm/pnx028

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Observational PAT in CI: Physiological Observations

Physiologic indicators (e.g., changes in heart rate, blood pressure, respiratory rate), though important for assessing for potential side effects and are recommended in some PATs to be observed in addition.

However, these indicators are not sensitive for discriminating pain from other sources of distress.

Although physiologic indicators are often used to document pain presence, the correlation of vital sign changes with behaviors and self-reports of pain has been weak or absent, therefore the absence of a change in vital signs does not indicate absence of pain (Herr et al., 2011).

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What next?

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Determine the cause in CI

According to current UK guidelines:

Find the cause of pain

• examination and investigation to establish the cause of pain

- Resting (we can compare PATs scores during rest and activity)
- Washing and dressing
- Movement and mobility

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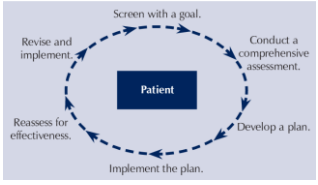
Provide Pain Management

Pain Score from PAT---- Cause of pain------Treatment

PATs should not only be used once, they should be used to re-assess a patient and determine the efficacy of the pain treatment give.



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Is it that easy?

Is it that obvious when someone with cognitive impairment has pain then?

For example:

In dementia, severe pain is less likely to cause wandering, but more likely to display aggressive and agitated behaviours.

How do we distinguish between the impairment and pain? We assess it AND….

Knowledge of the patient
History
Carers or families assistance
Experience with the disease
Facial expression (grimace)
Verbal expression (groaning, moaning)
Protected position – rigid, limited movement
Restlessness, agitation

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Are PATs applied in Practice?

Sadly, not consistently

A survey of care staff across Europe:

- 415 responses (UK 28, Netherlands 139, Germany 147, Denmark 9, Belgium 35, Switzerland 18, Austria 39)
- The majority (48.5%) of the nursing staff currently worked in the hospital.
- Only 25% of sample use guidelines.
- Different scales across countries.
- Dissatisfaction about the current knowledge of pain assessment in cognitively impaired older adults.
- There seems to be an international struggle to interpret findings of the observational pain scales available.

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The Barriers- Myth Busting

Nursing Times

- With my professional knowledge and training I can assess pain

ABSOLUTELY, BUT PATs should be used in conjunction with your clinical knowledge and experience. Consider consistency and experience level.

- I would say just use your intuition

YES, but what if you do not yet have the experience needed with a particularly CI patient group

- It will detract from time with my patients

NO, some PATs tool takes minutes to complete

- CI patients cannot communicate pain or feel it the same

NO, we still need to ask and treat them appropriately

- Its hard to determine what is pain and what it their condition (e.g. aggression in dementia)

YES, PAT can assist in identifying atypical pain behaviours/verbalisations

- When they have an injury, you know they have pain

NO, not all pain will be obvious by tissue damage. PATs help to explore the cause of pain.

FYI- these are real HCP beliefs about PATs

(Chandler & Bruneau, 2014; Chandler et al., 2017; Chandler & Schofield, 2018)

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Summary

- Pain is what the patient tell us it is, but this is complex when CI impairment is present.
- Self-report is the first step in pain assessment, you should use the self-report PAT suitable for your patient group.
- Self-report relies on the patients willingness to communicate and ability, consider how you communicate with these groups.
- If you doubt a self-report or a patient is not able to communicate, you should then refer to observational PATs.
- All PATs have their limitations, however it is recommended they are ALWAYS USED- providing we use them appropriately.
- PATs should be used in conjunction with the patients history, feedback from carers or family members and your clinical knowledge.
- PATs do not appear to be used, or guidelines, so we should educate all healthcare providers in their use.
- There are guidelines for the assessment of pain in cognitively impaired groups, these should be referred to by practioners.

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Take home message:

Pain should be assessed as the firth vital sign using a validated and appropriate PAT. A self-report should always be elicited, followed where needed by use of an observational PAT. PATs are not only for the assessment of pain, but also for the assessment of the efficacy of pain treatment.

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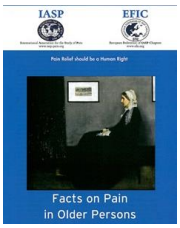
For UK guidelines see:
The **Assessment** of **Pain** in Older People: UK National **Guidelines**
Pat Schofield. *Age and Ageing*, Volume 47, Issue suppl_1, 1 March 2018, Pages i1–i22, https://doi.org/10.1093/ageing/afx192
Published: 19 March 2018

IASP GLOBAL YEAR AGAINST PAIN IN OLDER PERSONS
October 2006 – October 2007
Resources: www.iasp-pain.org



Pain in Residential Aged Care **Facilities**

Management Strategies

August 2005

The Australian Pain Society

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Managing Pain: Populations with Cognitive Impairment (CI)

Guidance on the management of pain in older people (Schofield, Abdulla, Adams, Bone, Elliott, Gaffin, Jones, Knaggs, Martin, Sampson)

Age Ageing (2013) 42 (suppl 1): i1-i57 doi:10.1093/ageing/afs200

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