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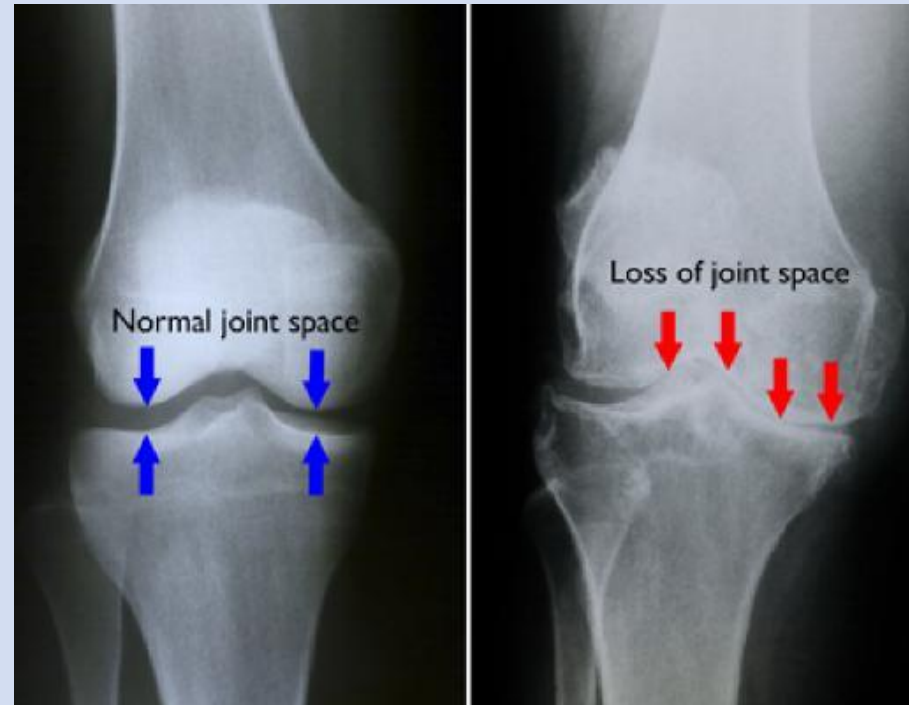
‘Just another knee’: Perceptions of treatment decision making and self-management for working age people with symptomatic knee osteoarthritis



Dr Karen Gillett, Dr Lindsay Bearne, Dr James Galloway, Dr Heidi Lempp

Knee osteoarthritis in working aged people

- Knee osteoarthritis is the most common cause of disability in the UK
- Pain, stiffness, joint deformity and mobility problems have a substantial impact on quality of life (NICE, 2015).
- Tendency to be associated with the elderly but it affects about 25% of people aged 45 years and over (Arthritis UK, 2014).
- More common in women (NICE 2015)



Background to study

The NICE (2014) guidelines for osteoarthritis advocate ‘a therapeutic relationship based on **shared decision-making**’ and suggest that this approach encourages **self-management**, reduces reliance on medication, and **empowers people**.

Self-management can be defined as:

‘A portfolio of techniques and tools to help patients choose healthy behaviours; and as a fundamental transformation of the patient-caregiver relationship into a collaborative partnership’ (de Silva 2011).

Self-management has potential to improve health outcomes in some cases, with patients reporting increases in physical functioning (Challis *et al* 2010).

Self-management can improve patient experience, with patients reporting benefits in terms of greater confidence and reduced anxiety (Challis *et al* 2010)

Aim

To explore the experience and perceptions of working age people with symptomatic knee osteoarthritis in relation to (i) treatment decision making, and (ii) self-management.



Methodology

- Qualitative study using semi-structured telephone/face to face interviews (participant preference)
- Ethical approval King's College London Psychiatry, Nursing and Midwifery Research Ethics Subcommittee (PNM/14/15-45)
- Participants - working aged people with a radiographic diagnosis of systematic knee osteoarthritis living in England (covered by NICE guidelines)
- Aimed to achieve a maximum variation sample to include a mixture of ages, gender, working status, and experience of different health care settings
- Recruitment took place through social media (Facebook and Twitter) and snowball sampling

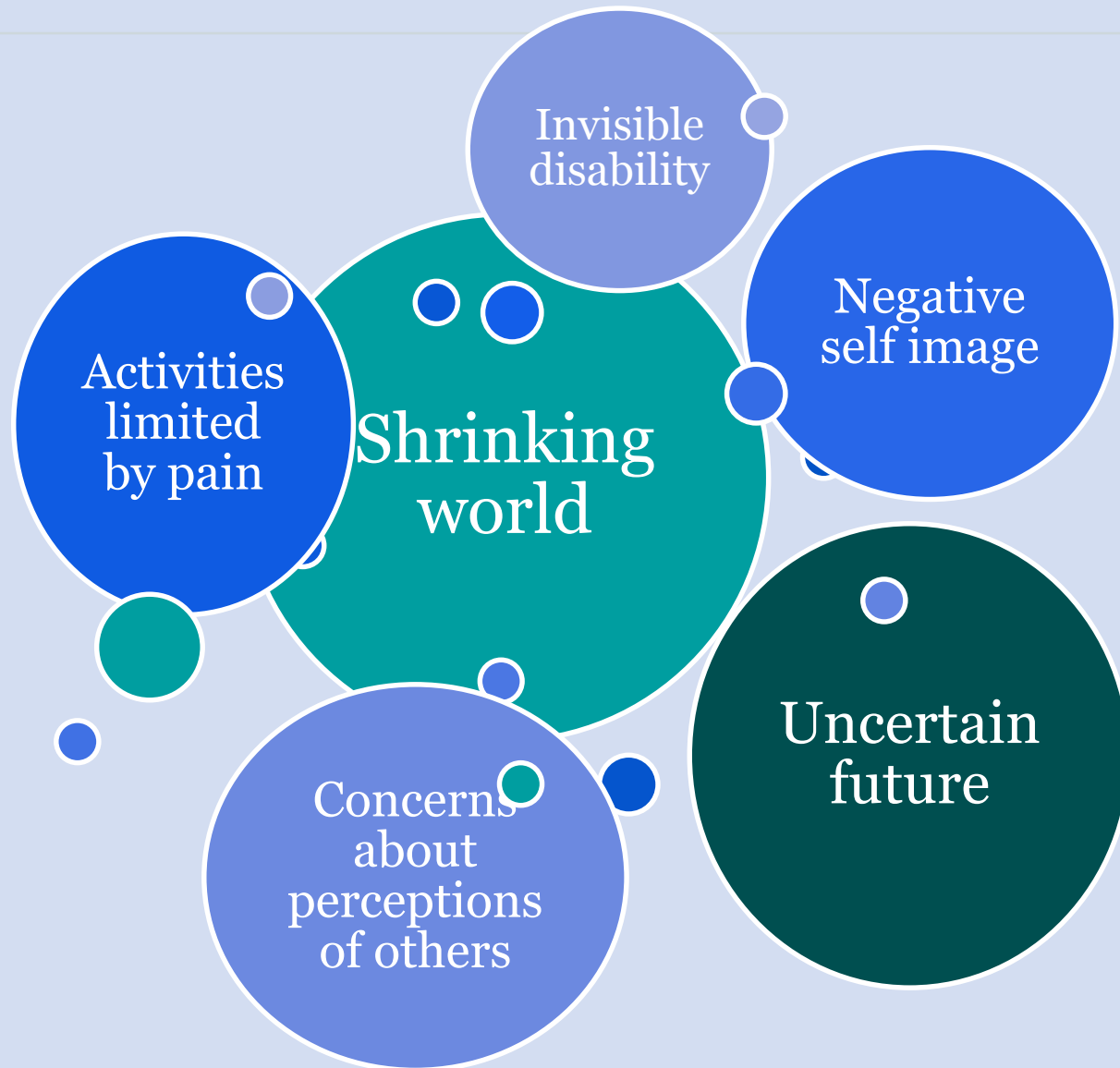
Methods

- Data collection took place between February and July 2015
- Each participant received a £20 voucher in compensation for their time
- Interviews were transcribed verbatim and analysed using the Framework approach (Ritchie and Lewis, 2003)
- Case and theme based approach
- Initial findings were presented to a focus group for member checking and further exploration (n=5)

Participants

Characteristic	n
Gender	
Male	4
Female	11
Age group	
30-39 years	1
40-49 years	5
50-59 years	7
60-65 years	2
Role	
Employee	11
Self employed	2
Home maker	1
Early retirement	1
Knee Replacement Surgery	
Has date	2
Not yet on waiting list	13
Total participants n= 15	

Impact of knee osteoarthritis on the individual



Consequences of knee osteoarthritis

Physical

- Hip problems
- Back problems
- Side effects of medication e.g. NSAIDs
- Weight gain
- Decreased fitness

Emotional

- Anxiety about future
- Low mood (?depression)
- 'Paranoia'
- Irritation
- Fatigue

Social

- Reduced activities
- Isolation
- Stigma

Work

- Early retirement
- Reduced progression
- Not able to do as much
- Having to adjust to manage
- Problems with commute

Management options from health professionals

'Knee exercises' - Physiotherapy

- Often felt not given opportunity to learn
- Many did not practice regularly – some guilt but others had deliberately opted for alternative forms of activity e.g. yoga, walking

Some mentioned arthroscopy

- Various degrees of success
- Generally of short term benefit

Corticosteroid injections

- Short term benefit

Some referral for 'get back to fitness programmes'

- Disappointment if not given the option they wanted e.g. gym instead of hydrotherapy 'the spirit is willing the flesh is weak'

What participants said about pain

- ‘Now it’s even when I am lying in bed at night I can feel them throbbing [...] it’s not just when I am walking or standing up, obviously that is incredibly painful but it’s also when I am resting’ (Maria 44)
- ‘People don’t understand how much pain you’re in – people in the end just think you’re antisocial’ (Cheryl 50)
- ‘Everybody was so lovely and accommodating and everything but it does make me feel older than I should’(Julie 47)

Pain treatment decision making and self management

- Pain biggest problem – not generally well managed
- Pain main reason for limiting activities – work and social
- Reported pain as high ‘9’
- Negativity from health care professionals ‘we don’t encourage people to take analgesia long term’ and one interviewee had been told by occupational health doctor ‘there is a psychological component to pain’
- Commonly prescribed paracetamol but some were taking opioids regularly
- Better results from Non steroidal anti inflammatory drugs (NSAIDs) but gastrointestinal side effects meant many unable to tolerate – some reported trying voltarol gel.
- Invisible nature – hypochondriac, stigma, use of stick
- Alternatives – heat, cold, massage, TENS,

Total knee replacement

- All participants had been told that they needed knee replacement but only 2 were waiting for surgery – found the idea ‘terrifying’, ‘scary,’ ‘shocking’
- Commonly the rest had been told it was 'best to wait as long as possible' , they were 'too young', or to 'come back when it get's too bad to cope with'.
- **NICE (2015) state 'refer if the person has joint symptoms that have a substantial impact on their quality of life – refer before there is prolonged established functional limitation or severe pain'**
- When asked in interviews what would count as 'too bad' several respondents suggested this would be when they could no longer walk, one said 'when I can't stand up to peel the potatoes (Claire, 55).

Discussion

- Noticeable concern about the prospect of knee replacement surgery from the majority of participants
- Participants received minimal support from health care professionals and many reported feeling that little help was available
- They were keen to access information for themselves but a lack of evidence base for many potential self management options left them uncertain about the best approach to take.
- Many participants had tried different approaches including 'anti inflammatory diet, APOS therapy, knee supports, walking with a stick, orthotics, glucosamine, multivitamins, yoga, heat/cold packs,

Empowering?

I don't know somehow it's really hard when you are sat in that room. It's almost like being in front of the headmaster and the easiest thing is to say well not yet I'll come back and see you when it gets worse whereas my concern it's actually knowing when because [...] I think it's quite important that your knees and legs are quite strong and in a good shape before you have the surgery for you to be able to recover from properly because if you wait too long and they are really, really bad then I think, this is me just personally thinking it would be harder to recover from. (Cheryl 50)

Management

NICE (2015) 'Formulate an individualised management plan in partnership with the person with osteoarthritis' talk of 'therapeutic relationships' and shared decision making.

Most of management is done by GPs and participants were aware of the time constraints and often felt that there was little point visiting them because there was 'nothing they can do'

Conclusion

- NICE (2015) talk of holistic assessment and therapeutic relationships which is not realistic for GPs but would benefit the patient
- In many cases access to physiotherapists is limited and they are not able to provide support to patients with longer term needs
- Main constraints to stop guidelines being followed is time
- Patients need access to evidence based information in order to make informed decisions and to self manage effectively
- The current system means they are left with unnecessary anxiety and uncertainty about treatment decisions and management.

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