

Living with arthritis: The Socio-economic consequences for women living in Soweto

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- *“I think a lot in the morning before getting out of bed. I think about life and arthritis. I plan how to get through a day and think about what I could have been doing now at the time I didn’t have arthritis.”*
- *“I do not keep in touch with them [friends]. Since I got sick, I feel unworthy and look down upon myself and feel I do not belong with them.”*
- *“Sometimes I ask myself, what does God want from me. This is too much pain for anyone to handle. Sometimes the pills don’t take effect and I can’t sleep at night.”*
- *“I used to have a very nice life – be very active and energetic. I could do anything I wanted whenever I pleased. But now I feel very restricted and my walking pace has slowed.”*

Methodology

- Qualitative series of case studies – thematic analysis + standard structured questionnaire on functioning
- In depth interviews with 60 women – 18 – 59 years old
- Content of interviews:
 - History of diagnosis, cause and treatment
 - Impact on functioning and distress
 - Changes in self identity, social inclusion, use of time, employment, quality of life, and independence
 - Cost implications of having arthritis
- All attending Arthritis Clinic at Chris Hani Baragwanath Hospital, from lower socio-economic group and live in Soweto. All have lost their jobs many because of RA

Description of experience

- ***The lived experience (disability)*** is the outcome of the interaction of the health condition (RA) and the context the person lives in. Context includes both personal and external factors.
- ***Input factors to the interaction:*** health condition, pain, coping style, physical and attitudinal environment, additional costs, support of others.
- ***Outputs of interaction:*** difficulties in functioning, independence, social exclusion, loss of income, quality of life, self identity as disabled or not, satisfaction.

Management of RA and Pain

- Most women reported significant improvement since diagnosis and onset of treatment.
- They are positive about the effects of medication and have used information provided at the clinic.
- They generally understand what RA is and the prognosis.
- Most have significant levels of pain which is invisible and hard to measure and easily seen as being faked by others.
- Severe and extreme ratings of pain were correlated with ratings of 'poor health' and low future expectations.

Physical and attitudinal environment

- Access to hot water is important but often difficult if one has no geyser.
- Bumpy and inclined paths are hard to walk on; distance to the shops are too far to walk with pain. Standing in queues is also difficult.
- There are additional costs such as paying someone to assist with washing; taking taxis more often; buying additional food to ensure they can eat before taking medication.
- Families are understanding generally, outsiders not as much:
 - *“When my hands are painful, my family understands that I can’t do things and they help me.”*
 - *“When I got this arthritis I lost weight. People started saying I have AIDS.”*

Functioning and use of time

- The women had difficulty with:
 - Walking, kneeling, standing, washing clothes, carrying things, washing themselves (especially their back), putting on shoes and clothes with small buttons or fasteners.
 - *“My hands get stiff, they can’t function. And, as you know, we do everything with our hands.”*
 - *“To move around and visit people at places where I used to walk, now I have to take a taxi.”*
 - Moodiness and being short tempered because of the pain
- The intermittent nature of the symptoms is difficult to manage because
 - they cannot plan ahead and
 - people don’t believe that they are sick if one day they can do something and the next day they cannot do it.
- Everything takes longer to do and regular breaks are needed to rest.

Independence, sense of self and social exclusion

- The women expressed sorrow and distress at losing their independence and expressed a feeling of loss of control
 - *“[The arthritis] changed my life. I saw myself not being able to do anything for myself.”*
- They reported a loss of self confidence and changed sense of self:
 - *“I see myself as a useless person, since I can’t be without other people around me and their assistance.”*
 - *“What kind of mother doesn’t help her children? But I can’t.”*
- A common theme was that of limited social interactions and an inability and lack of desire to go out and be with others or ‘expose’ themselves in public.
 - *“I avoid walking on the streets. I rather stay indoors or stay with my family.”*
 - *“Relatives are avoiding me – they pretend as if they don’t know me. When there are some family events they don’t call you, you are useless to them.”*

Conclusions

- RA has a significant impact on a person's life in the domains of mobility, self care and domestic work as well as causing social exclusion and loss of independence, including economic independence.
- RA requires holistic management to ensure:
 - Presence and support of the family and other social networks
 - Access to decent housing, electricity and hot water
 - Adequate social welfare support and social security services when required
- Holistic management requires a multisectoral approach.

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