

# **The challenge of chronic illness**

**Living with sickle cell disease**

- Being a person in their own right
- Being ill
- Being unwell but not regarded as legitimately ill

- Being sick = a sick role+relating to others who are healthy
- A world of health tells us:
  - How to be when ill
  - Affects our readiness to
    - acknowledge suffering
    - alter behaviour
    - receive care

An **insider's view** of the world maybe quite different from that of an **outsider**, with contradicting views about what good adjustment or coping well means

The vast majority of admissions occur in:

- Poorly adjusted
- With high levels of distress
- With negative patterns of coping

These variables can:

- Contribute to inadequate pain management
- intensify pain experience

However:

It is a small minority

# Problems in A&E

- Patients unable to understand the wait
- Patients become verbally abusive and refuse to accept explanation
- Fear of dying not unfounded
- Assessment difficult as no clear and consistent physical indications of crisis

# Problems in A&E

- Nurses shoulder the burden of abuse and demands
- This stress = hard to remain non-judgemental and empathic
- This perspective = view SCD patients as difficult



# Problems in A&E

- Patients view nurses as uncaring
- Patients more angry and display more intense emotions
- Patients' reactions appear 'over the top'
- Patients' reactions confirm the staff's preconceived view of 'difficult problematic patients'

# What can help?

- Understanding that abusive behaviour can be a function of lack or loss of control
- With this insight, nurses are less likely to take such behaviour personally

# Stages in adjustment to chronic illness

- Shock
- Denial
- Anger
- Grief/mourning
- Depression
- Acceptance
- Adjustment

# Successful adjustment involves

- Enlarging the scope of one's values
- Containing the effects of illness/disability
- Subordinating physical concerns
- Transforming values based on comparison with others into values placed on one's own assets and strenghts

# Factors associated with adjustment

## Good adjustment:

1. Cognitive restructuring: changing one's beliefs and goals
2. Acceptance of responsibility for illness/symptom management
3. Information seeking
4. Threat minimisation: tending to keep feelings to oneself

# Factors associated with adjustment

## Poor adjustment:

1. Emotional expression: taking it out on other people
2. Wish fulfilment: time consuming fantasies of getting better

# Pain management: patient factors

- Pain coping strategies related to outcomes of painful episodes – hospital admissions, activity reductions, distress:
  - More coping attempts: better outcomes
  - More negative thoughts: worse outcomes

# Hospital staff perceptions of SCD patients

- Staff estimates of drug dependence among SCD patients very high
- Staff estimates twice as high for SCD patients than for other painful conditions
- Analgesic doses (but not pain ratings) higher for occasional rather than frequent hospital attenders



# Important to distinguish

Between:

- Pain-related and
- Non-pain-related

Symptoms of substance dependence

# Pain-related

Associated only with:

- attempts to control pain or
- effects of analgesia when used for pain relief

*I go in late if I have pain; I will phone in and say that I have taken pain killers and am feeling drowsy and will come in later when it wears off (social impairment)*

# Non-pain-related

Associated with:

- Attempts to obtain euphoria
- Alter mood
- in absence of pain
- going beyond attempts to control pain

*I was going through problems – depression. I was staying indoors and not working and being awake all night. It (addiction to Diconal) lasted about two months (social impairment)*

# A study

**Experiences of hospital care and treatment seeking for pain from sickle cell disease: qualitative study (Maxwell, Streetly, & Bevan, 1999):**

Treatment seeking is a social action influenced by social context and individual meanings and experience, and not simply a straightforward individual response to the experience of physiological symptoms

# Experiences of hospital care

- Mistrust
- Stigmatisation
- Control
- Neglect

# **Strategies for management of pain and treatment seeking**

Those who normally managed pain at home showed different strategies from those who were frequently admitted to hospital

# Strategies for management of pain and treatment seeking

At home:

- Assertiveness
- Self-education
- Resistance

So home management not simply a reflection of lesser disease severity

# **Strategies for management of pain and treatment seeking**

Of frequent hospital attenders:

- Developing relationships
- Aggression
- Passivity
- Use of multiple hospitals



# Overtreatment of pain

- Especially in those only rarely admitted to hospital

This suggests:

The approach to treatment not solely due to health professionals' concerns about addiction, but also related to more fundamental issues of trust, control, and patient involvement

# Patients with SCD often

**do not convey their true feelings** about  
their management for fear of not receiving  
adequate treatment of pain

# Patients with SCD may be

Reluctant to discuss:

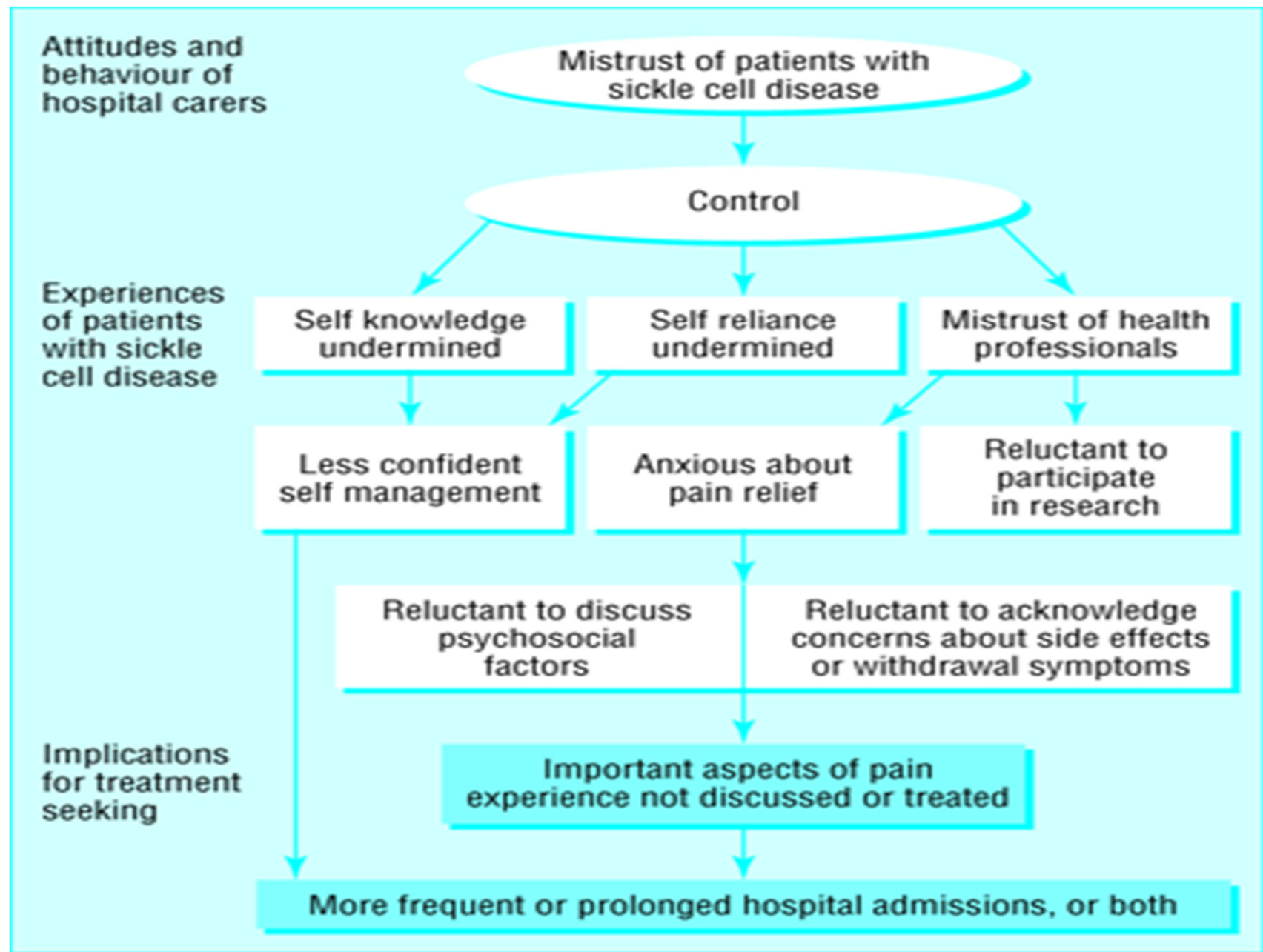
- Withdrawal symptoms
- The influence of psychosocial factors on painful crises and hospital admissions

For fear of:

- Diminishing the validity of their entitlement to treatment in the health professional's eyes

# **This mistrust of health professionals**

- Seemed to have adversely influenced the recruitment to research and clinical trials
- Difficulties experienced in recruiting patients for this study who were frequently admitted to hospital were further evidence of this effect



# Discussion

- **Alienation** – a major theme in studies of London's black population healthcare experiences
- SCD patients: Alienation compounded by the status of a “black disease”

# Discussion

This racialisation contributes to:

- An inadequate policy response
- Underdevelopment of services
- Undercoverage of the condition in medical and nursing curricula

# Discussion

- Finding of the study indicate that management of pain from SCD is still based on the acute care model

Whereas

- Management of chronic disease demands that **health professionals and patients** work **in partnership**



# Enhancing the discussion

Looking at principles of palliative care and models of care for other chronic conditions:

- Communication
- Continuity of care and home care
- Intersectoral collaboration
- A holistic understanding of pain