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 strengths
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
Attitudes and behaviour of hospital carers

Mistrust of patients with sickle cell disease

Control

Experiences of patients with sickle cell disease

Self knowledge undermined

Less confident self management

Reluctant to discuss psychosocial factors

Important aspects of pain experience not discussed or treated

More frequent or prolonged hospital admissions, or both

Self reliance undermined

Anxious about pain relief

Reluctant to acknowledge concerns about side effects or withdrawal symptoms

Mistrust of health professionals

Reluctant to participate in research

Implications for treatment seeking
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