The Challenges of Complex care versus Treatment

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- Declaration of interests relating to this presentation
- I have none to declare

Introduction

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- Ultimately as health care professionals, our aim is to promote a healthy lifestyle, to deliver high quality care and to enable people to live long and healthy lives

- So how do we approach and manage those patients who choose to opt out of treatment or struggle with adherence?

Medication Adherence

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- Adherence is the extent to which someone follows an agreed set of actions. It assumes an equal relationship between two people and is a voluntary process

- Non-adherence to medication means either not taking prescribed treatments or taking them incorrectly

Complex care

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- HIV CNS within the community and the acute are increasingly required to find new ways of working to support patients with complex care

- Patients with complex care needs often suffer from combinations of multiple chronic conditions, mental health problems, drug interactions and social vulnerability, which can lead to healthcare services overuse, underuse or misuse [1]

Statistics

- An estimated 4% of 102,000 people diagnosed with HIV in England are not taking ART [2]

- A caseload review identified reasons why patients opt out of ART (intentional non-adherence) or struggle with adherence. Barriers to adherence were identified

Methodology

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- A comprehensive caseload review was undertaken to identify and explore why some patients opt out of ART/struggle with adherence
- Participants reflected on past cases to identify key components of a best practice model
- 14% of caseload had a detectable viral load
- Of those who struggled with adherence, 40% had opted out of treatment

Barriers to adherence

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- Associating tablets with HIV related stigma-daily reminder
- Adoption of personal belief systems such as religion, alternative therapy, traditional medicine, conspiracy theorists
- Slow progressors who feel well
- Lack of trust in health care professionals
- Denial

Barriers to adherence

- Fear of side effects & medication toxicity
- Medication fatigue
- Invincibility/optimistic bias
- Depression/ low self-esteem

- Social isolation with no incentive for good health and well-being

Barriers to adherence

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- Cyclical periods of good/poor health coinciding with starting/stopping ART
- Desire to survive but not with HIV
- The need to exercise control
- Punishment to significant others

Local population

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- Understanding the local population which we serve gives us deeper insight into the patients we are caring for
- Liverpool has five of the most deprived areas in the country
- People living in ‘Deprived Industrial Areas’ in England and Wales are more likely to be treated for depression and psychological issues than those living in any other type of area [3]

Challenges to engagement

- Location
- Opening times
- Lack of choice
- Stigma (experienced/perceived)
- Previous experiences
- Physical disability
- Social isolation
- Incarceration
- Financial constraints/deprivation
- Psychological issues
- Ill health / end of life
- Substance misuse/dependence issues

Disengagement

- Failure to engage with care is associated with poorer health outcomes and a higher risk of onward transmission

- The need for innovative approaches to engage hard to reach populations cannot be overstated. ‘Ultimately, nursing interventions lead to new or improved resources that drive costs down and advance nursing care and optimal patient outcomes’ [4]

Innovative Practice

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- Liverpool Community Clinic (LCC) was developed so that our patients who do not attend hospital based clinics received timely, safe & appropriate care
- The intervention is delivered by community HIV clinical nurse specialists in patient's homes or bases within the community
- Improves health, wellbeing and quality of life for patients who are difficult to reach, non attenders, defaulted from care (aligning with BHIVA care standards 2018)

Our aims

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- Engage complex, underserved and ‘hard to reach’ patients living with HIV
- Inclusion-ensure that no one is left behind
- Prevent deterioration of health
- Optimise adherence to ART and effective monitoring
- Prevent onward transmission of HIV
- Co-ordinate generalist care for physical, psychological and emotional needs [5]

The Language we use

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- Compliance relates to a more paternalistic or even autocratic relationship, in which someone is seen as either following instructions (compliant) or disregarding them (non-compliant)

- Being labelled 'non-compliant' by health professionals becomes a barrier to empathising with a patient's perspective. It prevents understanding of why the patient is unable or unwilling to adhere to lifestyle changes, medication regimens or advice. It places responsibility for a perceived failure to optimise health outcomes on the patient, and assumes that health professionals know best [6]

The language we use

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- Concordance is an indicator of the quality of decision-making in healthcare. It depends on patients being well-informed

- A concordant relationship promotes self-management of health; it is based on trust, enabling patients to discuss with the health professionals providing care how other aspects of their life influence, and are influenced by, health and health interventions. It is a partnership to achieve the best health and wellbeing outcomes [6]

Role of the CNS

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- Help patients to develop strategies to incorporate lifestyle changes or medications into their routines
- Support significant others
- Supporting and managing change of mind
- Shifting emphasis from medication to other pressing issues

Role of the CNS

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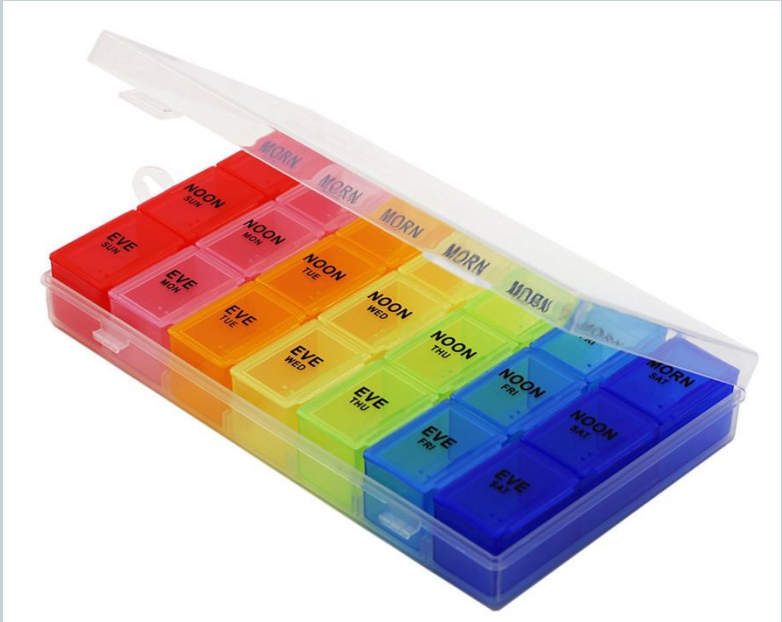
- Robust MDT working & communication
- Advanced communication skills- listening skills
- Secondary dispensing/dosing devices
- Resilience and Patience (don't show frustration)
- Realistic expectations



Role of the CNS

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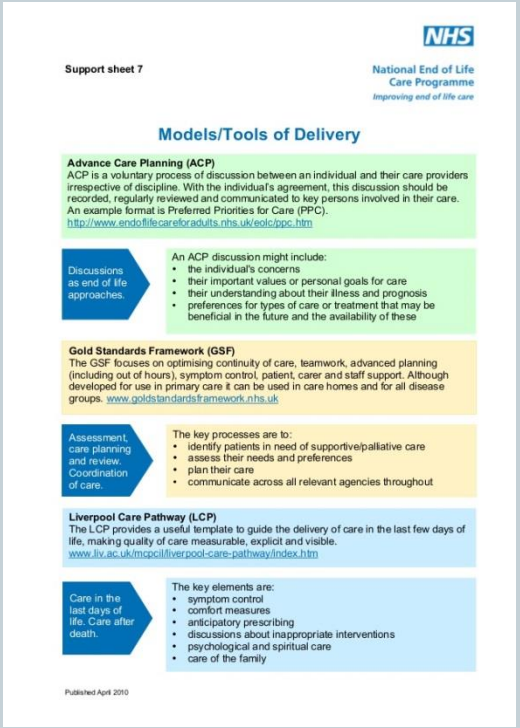
- Maintain engagement (home visits/phone/clinic appointments)
- Flexible approach to tailored care
- Advocacy
- Timely referrals to palliative care (1 year before anticipated death)



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Support sheet 7

National End of Life Care Programme
Improving end of life care

Models/Tools of Delivery

Advance Care Planning (ACP)
ACP is a voluntary process of discussion between an individual and their care providers irrespective of discipline. With the individual's agreement, this discussion should be recorded, regularly reviewed and communicated to key persons involved in their care. An example format is Preferred Priorities for Care (PPC).
http://www.endoflifecareforadults.nhs.uk/eolc/ppc.htm

Discussions as end of life approaches.

An ACP discussion might include:
- the individual's concerns
- their important values or personal goals for care
- their understanding about their illness and prognosis
- preferences for types of care or treatment that may be beneficial in the future and the availability of these

Gold Standards Framework (GSF)
The GSF focuses on optimising continuity of care, teamwork, advanced planning (including out of hours), symptom control, patient, carer and staff support. Although developed for use in primary care it can be used in care homes and for all disease groups. www.goldstandardsframework.nhs.uk

Assessment, care planning and review. Coordination of care.

The key processes are to:
- identify patients in need of supportive/palliative care
- assess their needs and preferences
- plan their care
- communicate across all relevant agencies throughout

Liverpool Care Pathway (LCP)
The LCP provides a useful template to guide the delivery of care in the last few days of life, making quality of care measurable, explicit and visible.
www.liv.ac.uk/mcpcil/liverpool-care-pathway/index.htm

Care in the last days of life. Care after death.

The key elements are:
- symptom control
- comfort measures
- anticipatory prescribing
- discussions about inappropriate interventions
- psychological and spiritual care
- care of the family

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Role of the CNS

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- Prepare to adjust your communication style to meet your patients needs
- Ask about prior experiences of medication to identify any problems
- Respond openly and honestly to questions about medication/side effects
- Provide motivational support but do not be disappointed with non-adherence; try to understand it and respect your patients decision

Example 1

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- Peter 30yrs old
- Decided he would rather die
- Couldn't accept diagnosis
- Stopped taking ART
- DNR in place and Advanced care planning
- Referral to Palliative care team
- Visited for two years often to listen and be there
- In November 2018 decided he didn't want to die and started ART
- Viral load < 30 and CD4 count above 200
- Happy and has come to accept diagnosis

Example 2

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- Paula 38yrs old
- Hoarder
- Intermittent engagement for 5 years
- Religious belief that God had healed her
- Taking ART was showing a lack of faith-stopped ART
- Admitted to hospital with CD4 count of 11
- Discharged 3 days later-clinically dying
- Admitted to Marie Curie Hospice Jan 2018
- Started taking ART whilst in hospice
- Now undetectable with CD4 count over 200

Example 3

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- Sam 22yrs old
- ADHD
- Non adherence
- High risk sexual behaviour
- Injectable options always-STI treatment/contraception
- Application for ART injectables-rejected-appealed
- Successful on compassionate grounds
- Started on Cabotegravir/Rilpivirine monthly injectable February 2019
- Viral Load <30 since March 2019

Conclusion

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- Adherence is an important outcome measure for healthcare because non-adherence increases morbidity and mortality and health service costs, as well as the risk of resistance and onward transmission
- Trust is the most important factor in patient satisfaction and adherence to care; health professionals need to develop a concordant relationship with their patients
- It is vital to understand the psychological reasons and issues which lead to someone struggling with adherence or choosing to opt out of ART so we are better able to help our patients on their journey [7]

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Thank you