

Nurse Led Clinics: Involvement in Patient Management and Follow up: A Patient Centred Approach

Catherine Oakley (RGN, MSc)
NIHR Research Fellow, Nurse Consultant
Guys & St. Thomas' NHS Foundation Trust
London UK

Presentation Overview

- Background – the problem
- Framework for Patient Centred Communication in Cancer Care (Epstein and Street 2007)
- Qualitative Research – Relevance to Patient Centred Communication
- Patient Centred Nurse and Pharmacist Clinic

The image shows a medical chart being held by a person. The left page is titled "Week 2" and has a section for "Date commencing: 20.7.15". Below this, there are four sections for "DRUG 1", "DRUG 2", "DRUG 3", and "DRUG 4". Each section has a line for "Doseage" and a line for "Special instructions". The right page is a large grid for tracking symptoms. The columns are labeled with dates from 10/01 to 10/27. The rows are labeled with times of day: Morning, Evening, Bedtime, Laxation, Bowel, Morning, Evening, Bedtime, Laxation, Bowel. A person's face and glasses are visible on the right side of the frame.



Background: International Concerns About Patient Adherence to Oral Anti-Cancer Drugs

- National Patient Safety (NPSA) (2008; 2010) - Highlight a number of deaths and patient safety incidents in prescribing, dispensing and administration of oral anti-cancer drugs.
- Recent literature coming out of the United States of America and France demonstrates a similar situation to the United Kingdom – high incidence of drug related adverse incidents (Regnier Denois et al (2010), Weingart et al, 2011)
- Reporting of symptoms – Oakley, Johnson and Ream (2010)

What Does the Literature Say?

- Patients cite convenience & autonomy as key preference factors (Bedell, 2003; Liu et al., 1997, Jensen et al, 2008).
- In a study by Twelves et al., (2006), preference rates for oral versus IV chemo fell from 95% pre-treatment to 65% post treatment when patients had experienced both these modalities .
- **Empirical evidence points to lack of service structure:**
 - Few providers have safety precautions in place
 - Reduced monitoring opportunities – poor symptom management
 - Minimal patient preparation and education
 - Lack of control and increased anxiety
 - Poor adherence – e.g. of 4043 patients taking Imatinib only 50% were 100% compliant

(Deery and Faithful 2003, Oakley, Bloomfield and Plant 2006, Tsang et al., 2006, Partridge et al., 2010, Weingart et al., 2007; 2011)

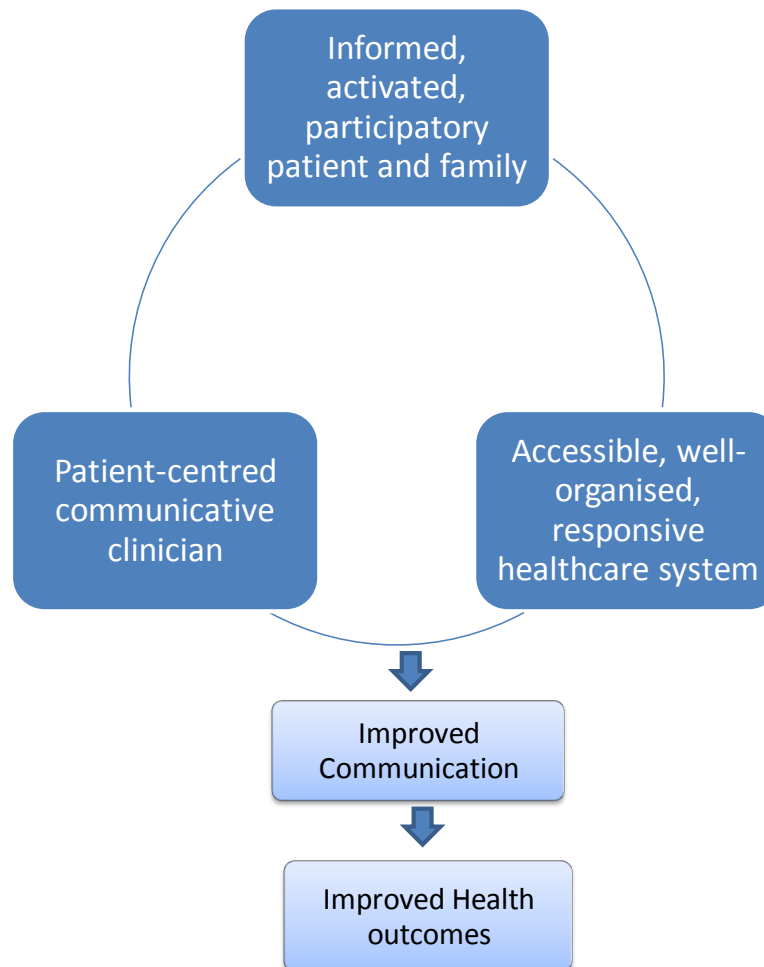
How Might Patient Centred Communication Help with Adherence?

Framework for Patient Centred Communication in Cancer Care (Epstein and Street 2007)

- Conceptualisation of patient-centered communication into six key functions:
 - Fostering healing relationships
 - Exchanging information
 - Responding to emotions
 - Managing uncertainty
 - Making decisions
 - Self management
- Emphasis on research that examines the relationship between patient-centered communication and patient health outcomes including QUALITY OF LIFE

Patient Centred Care

(Epstein and Street 2007)



Fostering Healing Relationships

- Therapeutic relationships can improve medicines adherence (Pringle et al 2011)
- Caring and understanding of concerns, preferences, beliefs and values important aspects of healing relationships (Salender and Henriksson 2005)
- Trust important to adherence

Exchanging Information

- Patients should understand information provided and apply this to their own situation
- HCP tend to over or under estimate understanding (Arora 2003)
- Do not overwhelm, rather:
 - Focus on and repeat most pertinent facts
 - Plain English
 - Assess understanding
 - Provide slowly and avoid technical jargon
 - Supportive information resources
 - Encourage to take notes

Exchanging Information

- Despite knowledge about information exchange patients often do not adhere with treatment Tsang et al 2006, Partridge et al., 2010, Weingart et al., 2010)
- Beliefs may be important and HCP often misjudge patients health beliefs, information needs, feelings and concerns as well as their likelihood to follow treatment plans (Epstein and Street 2007)
- The PCC model supports exploration of illness representations and concerns through employment of PCC skills including open questions to empathy and active listening

Responding to Emotions

- 20-30% of cancer patients experience psychological distress which is a barrier to effective communication (Fallowfield et al., 2006)
- Emotions are likely to be heightened during information sessions and may impact on ability to process information
- Clinicians often miss emotional cues, focusing instead on physical aspects of health
- Can lead to poor adherence (McCormack et al., 2011)

Managing Uncertainty

- Uncertainty in cancer patients can lead to emotional distress and poor sense of control over health and reduced quality of life (Andreassen et al., 2005)
- May be exacerbated through information overload
- PCC should moderate uncertainty and assist patients to manage this
- Provide context e.g. likely side effects pattern and an agreed plan of action should these arise

Making Decisions

- Patients tend to assimilate information from various sources and weigh up the pros and cons of taking particular course of action
- May be positively influenced by understanding of the information provided, including rational for actions

Enabling Self-management

- Self-management differs from information management because it encompasses:

Recommendations (should do communication) instructions (how to communication) and advocacy (can do communication)

(Epstein and Street 2007; page 28)

Enabling Self-management

5A's Assess, Advise, Agree, Assist, Arrange (Glasgow et al., 2006)

e.g. reporting symptoms:

***Assess** beliefs and knowledge, **advise** on the risks of non adherence and benefits of adherence; **agree** on goals for early presentations, **assist** in identification of potential barriers to early reporting, develop strategies to overcome these and **arrange** follow up support*

Qualitative Research: Relevance to Patient Centred Communication

A Systematic Review (Verbrugghe et al., 2013)

- 25 studies
- Predominant factors in non-adherence - Older and younger age and side effects
- **Intentional non adherence** – lack of faith in drugs, think OK to miss a dose, symptom concerns, lower perceived QOL.
- **Higher adherence** - associated with self efficacy and belief in medication
- **Non- persistence** – associated with neutral or negative beliefs about effectiveness

A Systematic Review (Verbrugghe et al., 2013)

Healthcare System Factors – Relationships with HCP

Non-adherence

- Shorter duration of treatment follow up visits
- Conflicting information about consequences of actions

Non-persistence

- Different doctor – follow up
- Not informed about side effects
- Less than preferred involvement in decision making
- Inadequate support

A Systematic Review (Verbrugghe et al., 2013)

Healthcare System Factors - Higher Adherence

- Enhanced knowledge of disease and treatment/higher education
- Longer consultation with specialists
- Expertise in tumour group - e.g. higher number of CML patients seen in last year

Higher Persistence

- Married

Setting up an Oral Chemotherapy Service A Patient Centred Intervention

Setting up the Clinic

- Learning from other Trusts
- Engagement with Consultant Medical Oncologist (Urology)
- Establishment of a steering group
- Agreed TKI pilot - to run alongside existing medical clinic
- Developed Standard Operating Procedure - presented to the Trust Governance Committee

Intervention

- Structured 45 minute pre-treatment consultation and consent in the OPD (in place of doctor). Patient completed CSAS toxicity scale
- Nurse/pharmacist led clinic on alternate visits (in place of doctor)
- Prescribing
- Medicines review- Pharmacist
- Weekly telephone monitoring for six weeks

Standard Operating Procedure

- Pathway
- Referral
- Clinic structure
- Consent
- Training requirements
- Professional, Trust, legal requirements
- Clinical management plan
- Patient information leaflet/Oral chemotherapy diary
- Treatment plan
- C-SAS toxicity tool
- Competency documents
- Consultation check lists
- Medicines review
- Telephone monitoring checklists

Evaluation

Patient population :

15 x patients prescribed a **tyrosine kinase inhibitor (TKI)**

Intervention (n=7)

Control (n=8)

- 25 item patient survey
- Staff reflective accounts
- Medical, nursing and pharmacist records

Pilot Evaluation: Key Findings

Control group

- *Lack of nurse involvement*

Intervention group

- More symptoms identified (self-filled C-SAS scale) - Average - **TKI - 3.1 versus 1.8**
- More confident about how severe side effects should be to call the hospital (patient questionnaire)
- Improved patient confidence in symptom self-management (patient questionnaire)
- Telephone monitoring service most beneficial during cycles one and two
- Potential drug interactions identified by the Pharmacist

Benefits of a Patient Centred Approach

Fostering healing relationships	<ul style="list-style-type: none">• Seeing same nurses/pharmacists – ongoing relationship/telephone contact.• Understanding illness perspective, beliefs, values• Building trust
Exchanging information	<ul style="list-style-type: none">• Tailored to individual• Ongoing, not just at the start of treatment• Facilitate open non, judgemental discussions regarding adherence and consequences of missed doses
Responding to emotions	<ul style="list-style-type: none">• Getting to know patients.• Understanding concerns and worries that might impact on adherence
Managing uncertainty	<ul style="list-style-type: none">• Helping patients to work out which side effects to report• Context regarding likely side effect patterns
Making decisions	<ul style="list-style-type: none">• Understand rationale for actions.• e.g. taking medicines correctly and reporting symptoms so can make informed decisions
Self-management	<ul style="list-style-type: none">• Empower patients to be responsible for own treatment.• Use tools like the oral chemotherapy diary

An Oral Chemotherapy Diary

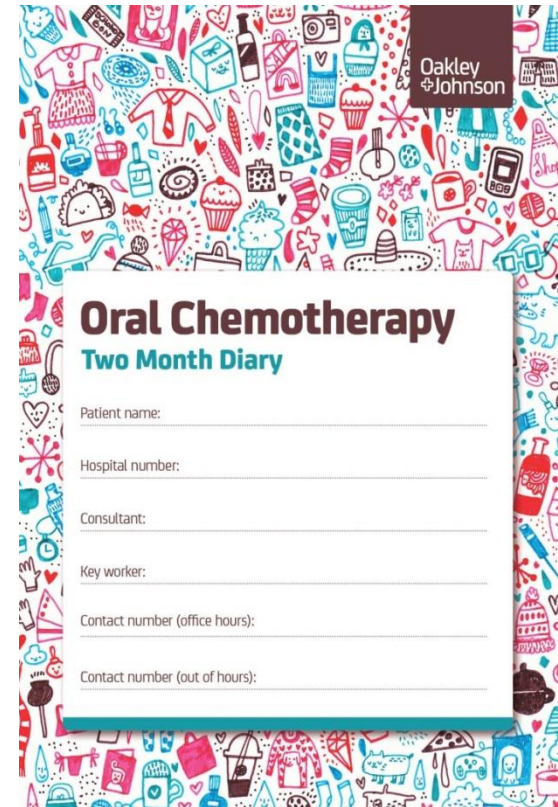
Main Findings of initial study:

- Caregivers & nurses helped patients establish a routine e.g. alarm/meals/tick doses

(also found by Eliasson et al., 2011)

- Patients may not adhere by ringing in if unwell
 - denied side effects would occur
 - didn't know when to call in
 - viewed oral chemotherapy as milder

(also found by Regnier Denois et al., 2010)



Oral Chemotherapy
Two Month Diary

Oakley & Johnson

Patient name: _____

Hospital number: _____

Consultant: _____

Key worker: _____

Contact number (office hours): _____

Contact number (out of hours): _____

Secondary Research




Assessing Integration into Practice

Main findings:

- A simple generic tool
- Used as a prompt and tick off doses taken
- Patients most highly rate the symptom reporting traffic light system
- Works in conjunction with the UKONS telephone triage tool
- Correlation between effective symptom management and increased self-efficacy

Side Effects

Although not experienced by everyone, some medicines can cause unwanted reactions which are commonly called side effects. If you experience side effects then it's very important that you report these to your hospital team as soon as you identify them. Delay in reporting side effects may result in them becoming worse and potential treatment interruptions may occur. Below is a guide to common side effects and recommended actions.

RED	 <p>CALL 999</p> <ul style="list-style-type: none">› Chest pain› Difficulty breathing <p>Call the hospital immediately</p> <ul style="list-style-type: none">› Generally unwell› Shivery episodes or flu like symptoms› Temperature 37.5°C or above or below 36°C› Being sick (vomiting)› Diarrhoea (4+ loose bowel movements in 24hrs)› Bleeding or unusual bruising› Swollen or painful legs› Sore mouth that stops you eating or drinking
AMBER	 <p>Call the hospital within 24 hours</p> <ul style="list-style-type: none">› Sore mouth but can still eat and drink› Itchy or painful skin changes› Sore, watery eyes› Increase in pain› Constipation› Feeling sick (nausea)› Diarrhoea (2-4 loose bowel movements in 24hrs)
GREEN	 <p>Call the hospital within 48 hours</p> <ul style="list-style-type: none">› Tiredness› Skin changes that are not itchy or painful› Mood changes› Difficulty in coping with the treatment› Loss of appetite

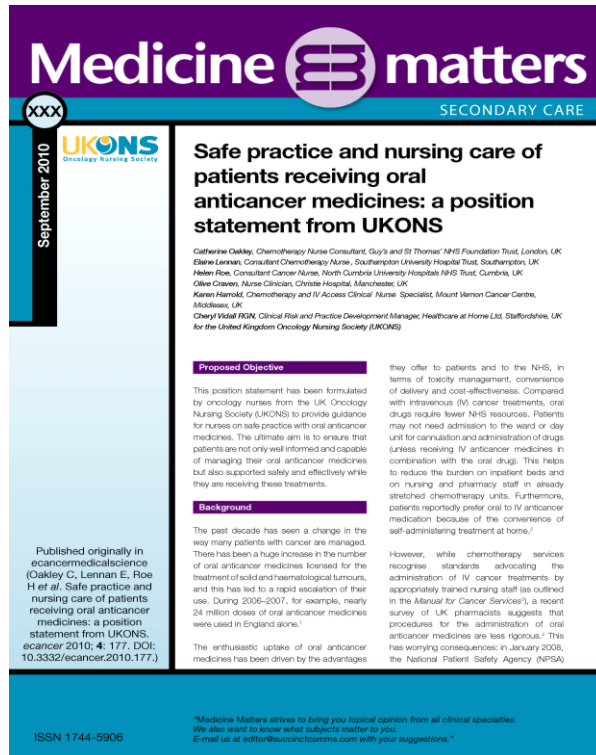
Reflections

- Patient and clinician satisfaction
- Establishing good working relationships are paramount
- Importance of communications between all care partners
- Development of clinical assessment skills and nurse/pharmacist prescribing
- Multiple practitioners
- Practical problems; booking issues, availability for instant advice when required, ordering tests and scans

Further Developments

- Extended colorectal, breast, lung
- Increased pharmacists involvement in clinics and non-medical prescribing
- Increased support telephone and face to face during cycles 1 and 2.

UKONS Oral Chemotherapy Position Statement (2010)



- Principles of safe practice
- Nurse training
- Nurse prescribing & consent
- Pre-treatment consultation
- Proactive monitoring/follow up
- Clinical governance

Full copies may be found at
www.ukons.org/

Membership is now free

Thank you

Any questions?