Does the use of the Wellness Thermometer improve consultations for people living with HIV?

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Quality of life issues

Psychological, interpersonal, spiritual, environmental concerns

- Care paradigm has changed
- Challenges patients face living with a chronic condition
- Challenges to mental well being
- Adhering to treatment
- Impact on sexual relationships
- Housing concerns
- Benefits
- Side effects to treatment
Barriers to communication are many...

Patient

• “Doctor knows best”
• Fear and anxiety (e.g. side effects)
• Embarrassment
• Hopelessness; depression?
• Social difficulties
• Disempowerment; inequality
• Lack of trust in medical system
• Perception of feeling judged
• Complex medical information
• Expectations
• Previous experience
• Resistant to change
• Linguistic ability
• Lack of time
• Illness and cognitive difficulties
• Societal norms

HCP

• “Opening the can of worms”
• Fear and anxiety
• Assuming patient will communicate their problems
• Focus on bio-medical concerns only
• Burden of work
• Lack of time
• Lack of support-supervision
• ‘Burn-out’
• Avoidance behaviour
• Lack of confidence in ability to respond
• Fear of undermining hope
• Telling people what to do
• Medical threats
• Judging
• Poor communication skills
• Over-rating own communication skills
Benefits of patient empowerment and good communication are well recognised

“Physician-patient relationships and communication quality are related to outcomes in HIV care” ¹,²

“Recognising symptoms that patients attribute to ART side effects might avoid loss of adherence and deterioration of trust in the patient-provider relationship” ⁴

“Higher quality communication and relationships are associated with improved patient engagement in HIV care” ³

“Supporting patients requires good communication not just between clinician and patient but also between all healthcare staff involved with their care...including their GP” ⁴

Aim of the project

- To establish if the Wellness Thermometer improves conversations between healthcare professionals and patients
- To establish patients experiences of using the Wellness Thermometer
- To explore how the Wellness Thermometer could be used in clinical practice to improve whole person care
Practical issues

• Ethical approval

Full ethical approval was sort but not required. Project was registered with the NMGH R&D department (14RECNA16)

• Methodology

Service evaluation

• Funding

Good will and an unrestricted educational grant from Gilead
What did we want in a tool?

✓ Easy to interpret

✓ Simple to use

✓ Need to take into consideration a variety of different literacy skills

✓ Contain key information to assist communication
What was already out there?

- The distress thermometer has been found to be an economical and useful screening tool in cancer care and facilitates the identification of practical, family, emotional and physical difficulties in patients.

- The distress thermometer was designed for active disease burdens and not a chronic disease area where the burdens can be different.

1. V2.Iskandarsyah et al 2013
2. Loquai et al 2013
3. iteket et al 2007
The Wellness Thermometer

1. Circle the number from 1 to 10 on the thermometer (below) that best describes how well you have felt in the past 2 to 3 weeks.

Think about your feelings, mood, worries, health.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am not feeling well</td>
<td>I am feeling okay</td>
<td>I am feeling well</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

2. Is there anything that affects your wellbeing?

Circle all of the relevant points below:

- Problems with eating
- Feeling stressed
- Feeling sick
- Vomiting
- Changes in appetite
- Skin problems
- Feeling tired
- Weakness
- Feeling depressed
- Feeling out of breath
- Taking medication
- Feeling sad
- Feeling lonely
- Feeling worried
- Feeling anxious
- Personal relationships
- Sexual relations
- Struggling to sleep
- Starting a family
- Feeling used
- Feeling supported
- Feeling tired
- Feeling angry
- Feeling confused
- Feeling overwhelmed
- Feeling scared
- Feeling worried
- Feeling overwhelmed
- Feeling anxious
- Personal relationships
- Smoking
- Drug and alcohol use
- Need someone to speak to
- Starting a family

3. What would you like to discuss during your appointment today?

- 
- 
- 
- 

positive conversations

GILEAD

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Positive conversations is intended to support you during your appointment. It does not replace the tasks that your doctor or nurse performs. You do not need to complete this form or share it with your doctor unless you do not wish to.
Data collection

- North Manchester General Hospital, East Sussex NHS Healthcare Clinics and Milton Keynes were the sites that explored if the WT worked in practice.

- For 1 month all patients attending HIV clinic were given the WT.

- Total number of patients who took part in the project and completed a survey n=231.

- Patients were given the information and tool prior to their consultation and asked to fill in the tool.

- Patients would then hand over the WT to the HCP, this was reviewed and used as a discussion point.

- After the consultation a "survey card" was given to the patient to capture their views on the WT and consultation in real time.
Findings
The Wellness Thermometer helped me identify my concerns.
The Wellness Thermometer improved my conversation with my doctor/nurse.
The Wellness Thermometer helped me bring up my concerns with my doctor/nurse.
The Wellness Thermometer will help me record my concerns between appointments.
I would recommend the Wellness Thermometer to a friend or family member with a health problem.
I would recommend the Wellness Thermometer to other people with my condition.
What did the HCP’s think?
Summary

- Patients well being is related to clinic outcomes
- Patients value being assessed holistically
- Patients must feel empowered to alert their care team about all the concerns they have in relation to living with HIV
- WT acts as a tool to facilitate holistic disclosure of concerns
- WT has demonstrated an improvement in conversations between HCP and patients
“We need to learn to measure what we value, not value what we can easily measure”

Marcus Aurelius, Roman Emperor and Philosopher, AD 120
Thank you

- All the patients that took part
- Dr Andrew Ustianowski, North Manchester
- Dr Jenny Petrak, Homerton Hospital
- Mr. Martin Jones, East Sussex
- Ms. Shan Walker, Milton Keynes hospital
- Ms. Dee Sheedy, Milton Keynes hospital
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- Mr David Lindsay, Gilead Sciences
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- Dr Ian Reeves, Homerton Hospital
- Gilead Sciences Ltd