



Self-Care for PLHIV- post Covid 19 Era

Symposium on Neuropsychiatry & HIV

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HIV
neuro
psychiatry



Overview

- ❑ Impact of Covid 19 on PLHIV UK
- ❑ Lessons learned and opportunities for new ways of working together post Covid 19
- ❑ Understanding Self-Care
- ❑ Adopting the 3 approaches to promoting self-care through Compassion, Clarity and Choice
- ❑ Adopting self care approaches



PLHIV – Impact of Covid -19 in UK

- ❑ There are over 100,000 people living with HIV in UK with an estimate 98% of all adults and children living with HIV on Anti retroviral therapy (ART) in 2017
- ❑ Limited data on how Covid-19 is influencing health and wellbeing of adults living with HIV in the UK
- ❑ Online Zoom - COVID-19 Community Involvement: ‘Let’s Talk About... HIV Care’ event in partnership with Imperial College London, PERC (Patient Experience Research Centre) and Positively UK.
- ❑ 25 people living with, affected by, or working in HIV from across the UK participated in this event



PLHIV & Impact of Covid 19 Key Themes

- ❑ Misinformation, conflicting/delayed messaging and shielding advice
- ❑ Avoiding, delaying or being prevented access to healthcare (including GP, hospital appointments, sexual health/HIV services)
- ❑ Maintaining an adequate supply of medication, managing regimens and adhering to therapy were conflicted by in issues around privacy and confidentiality
- ❑ Adapting HIV services to a new model of self-care and digital exclusion



Summary of Key Themes

Impact of Covid-19 for PLHIV in UK

- ❑ Issues of confidentiality and privacy
- ❑ Disruption in services on treatment, access and support
- ❑ Lack of clear messaging and information on service access and shielding
- ❑ Digital exclusion and poverty in marginalised groups (homeless, newly diagnosed, domestic violence, BAME)
- ❑ Social isolation and mental health issues
- ❑ Long term economic sustainability of HIV based NGOs



PLHIV- New Ways of Working

- Developing joint stakeholder recovery plans for PLHIV post COVID-19
- Explore and review across local health and social care pathways the quality and level treatment, access, care and support for PLHIV and services
- What were the barriers and challenges
- What worked well
- What were the lessons learnt
- Innovate and develop new ways of working, integration and partnerships and collaboration

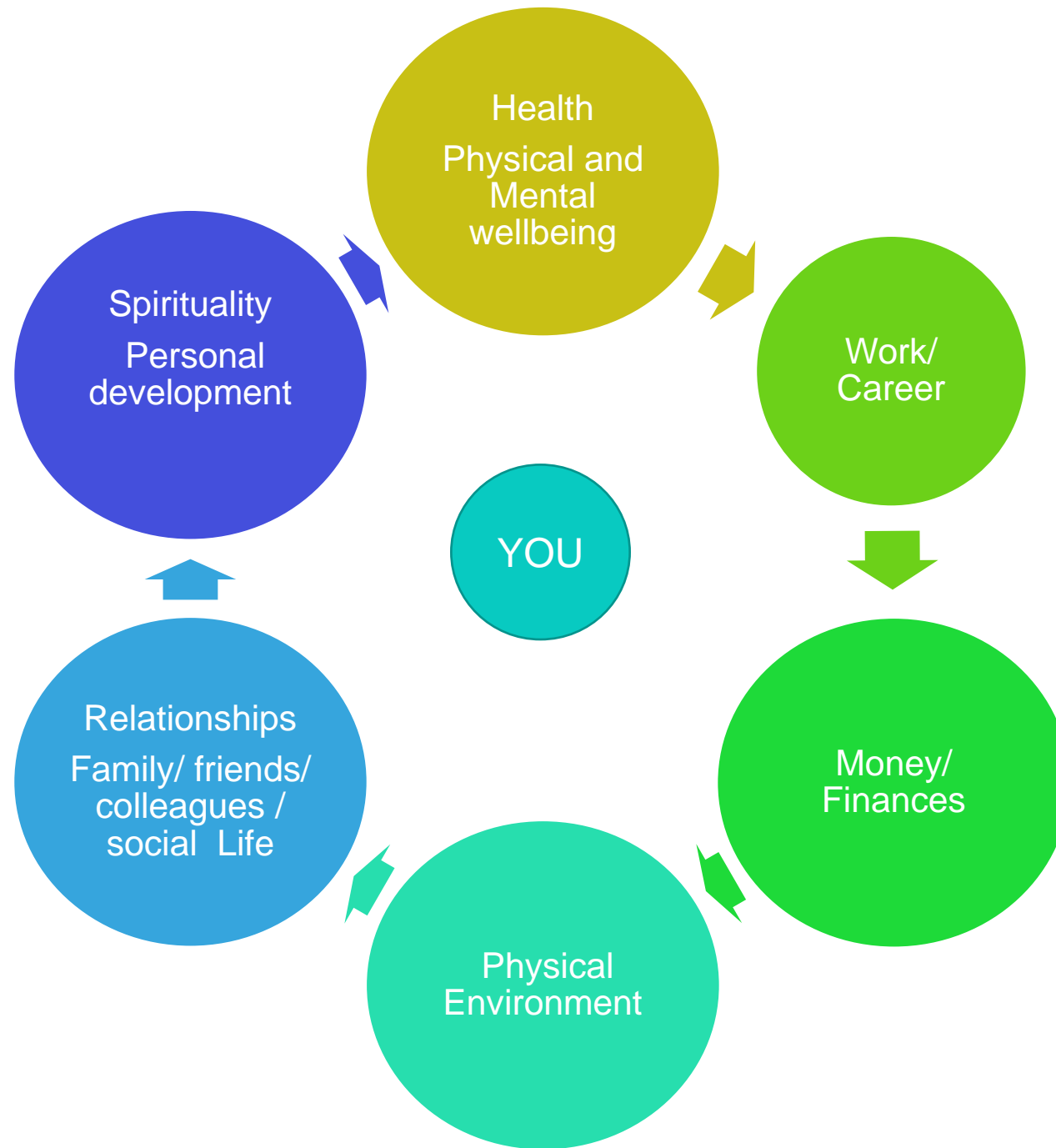


Defining Self-care

- ❑ Self-care is about taking care of oneself and the ability to identify and cultivate the individuals unique own physical and mental lifestyle habits behaviors and believes that promote wellbeing and build emotional resilience.
- ❑ Not all one size fits all- Person centered- identify unique coping strategies for the person
- ❑ Promotion of self empowerment



Disruption in Wheel of Life



7 Core Life Needs toward self-care and wellbeing



Air

Water

Sleep

Food

Shelter

Relationship

Creative Expressions



7 Core Life Needs toward self-care and wellbeing

Air	Without breathe we cannot live, poor quality of air and respiratory conditions can limit QOF and wellbeing
Water	Water-essential to live (1 week)
Sleep	Survive up to 11 days without sleep is essential for the mind and body to rest, regenerate and rejuvenate
Food	Can survive up to 2-3weeks without food



7 Core Life Needs toward self-care and wellbeing

Shelter	Any environment in which you can thrive and positively benefits you
Relationship	a sense of connection with life and purpose- the ability to form and connect with self, nature, pets or others. Some form of connection to be more than who you are and the need to grow
Creative Expressions	Permission towards personal creative expression that allows you to be who you are. To be all seeing, knowing, felt and understood. Engaging and acting at your highest passion and joy E.g. Hobbies, interests



The 3 C's to promoting self-care

3 key approaches to prompting self care & improve Quality of Life for PLHIV

Adopting professional curiosity

Compassion

Clarity

Choice



Compassion and promoting self-care

- ❑ Concern for the wellbeing of others.” (Cosley, McCoy, & Saslow, 2010)
- ❑ It includes kindness, empathy, generosity and acceptance. The strands of courage, tolerance, equanimity are equally woven into the cloth of compassion. (Feldman & Kuyken, 2011)
- ❑ Professional curiosity -Psychological wellbeing impacts patients clinical experiences of service and self care outcomes
- ❑ Cultivating compassionate practice improves patient both physical and psychological wellbeing
- ❑ Allows PLHIV to access support and other services



Compassion and promoting self-care

- ❑ Understanding self care through compassion is the ability to shifting the PLHIV perception and mindset towards a attitude to being kind and caring towards themselves.
- ❑ Seeing PLHIV beyond their diagnosis or label, self stigma. Releasing of emotional barriers that allows openness to SPEAK UP and ask for help, support and guidance around current aspects of their treatment , care to promotion of self care post COVID-19
- ❑ Access to Peer Support services can enable a person to share and explore barriers and strengths within the life wheel and promote self care



Clarity and promoting self-care

Clarity Definition

- ❑ The quality of being clear and easy to understand
- ❑ The quality of being easy to see or hear
- ❑ The ability to think clearly and not be confused

PLHIV can present at states of confusion and fear – guide toward clarity to what they want and prefer in different aspects of their life.

Our and PLHIV needs are changing over time and since Covid-19 around, housing, career, jobs, money, health, relationships with family, friends, partners. Ask what information or support they need. What had helped in the past, identify personal support networks (assets based approach)



PLHIV & Clarity

- Professional curiosity
- Having access to the right information, guidance and at the right time & as when it's needed through their life wheel journey
- To speak up share your concerns and change of circumstances that are impacting patients QOL and improve self care and choice
- Ongoing process



Choice promoting self care

- ❑ Awareness and requesting of other supports and treatments available (patient & clinician)
- ❑ Holistic, Person Centered and Multi agency approach
- ❑ Awareness of patients changing physical, psychological and social needs



Developing self-care support

OPPORTUNITY

Creating a space to:

- Listening non judgmentally
- Build culture of trust and rapport to enable best health and self care outcomes
- Help identify concerns within life wheel
- Reduce isolation

RESOURCES

- Give information and or signpost to other support services and professionals
- Build self help strategies, hobbies and interests
- 5 ways to wellbeing poster
- Mental Health Foundation 'look after yourself' poster



Building self-care and emotional resilience practices



- Notice how you feel
- See Well
- Hear Well
- Eat Well
- Smell Well
- Feel Well
- Rest Well

Deliberately changing your Emotional Set Point

Developing personal emotional resilience practices

- Building self care and emotional Resilience is about moving towards better and or good feeling and states of wellbeing
- See well - movies/ emails, reading
- Hear well - what you are listening to- news music, bird song
- Eat well- notice how the food you eat makes you feel- e.g. Guilt, shame
- Smell well - evoking positive emotion's – bread, perfume
- Feel well - bed sheets
- Rest well - taking time out for self, give your self a break

Developing personal emotional resilience practices

- Do a list of positive aspects- by making a list of things you have now that you appreciate and supports your wellbeing
- Use positive visualisation techniques or affirmations
- Practice quieting the mind/ meditation/ mindfulness
- Pursue or find hobbies and interest that makes you feel good
- Do more of what gives you joy
- Find things easy to love & like (via the 5 senses), people, nature, objects
- Keep a Mood Diary to help you choose and take more control of your emotions and navigate life



5 Ways to Wellbeing



TALK & LISTEN,
BE THERE,
FEEL CONNECTED



DO WHAT YOU CAN,
ENJOY WHAT YOU DO,
MOVE YOUR MOOD



REMEMBER
THE SIMPLE
THINGS THAT
GIVE YOU JOY



EMBRACE NEW
EXPERIENCES,
SEE OPPORTUNITIES,
SURPRISE YOURSELF



Your time,
your words,
your presence



GREAT DREAM

Ten keys to happier living

GIVING



Do things for others

RELATING



Connect with people

EXERCISING



Take care of your body

AWARENESS



Live life mindfully

TRYING OUT



Keep learning new things

DIRECTION



Have goals to look forward to

RESILIENCE



Find ways to bounce back

EMOTIONS



Look for what's good

ACCEPTANCE



Be comfortable with who you are

MEANING



Be part of something bigger

ACTION FOR HAPPINESS

www.actionforhappiness.org

SAHAR- South Asian HIV Advisory Resource



South Asian HIV Advisory Resource

Twitter: SAHAR_HIV

Instagram: SAHAR advisory

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Advisory group of HIV health clinicians, health specialists, activists and/or individuals living with HIV from South Asian backgrounds. The aim of the group is to develop research studies and projects to raise awareness and empower and improve the health and wellbeing outcomes of people from South Asian decent living with HIV and access to HIV support and sexual health services





References

- ❑ Online Zoom- COVID-19 Community Involvement: 'Let's Talk About... HIV Care' event in partnership with from Imperial College London, PERC (Patient Experience Research Centre) and Positively UK. <https://www.imperial.ac.uk/patient-experience-research-centre/covid-19/covid19communityinvolvement/hiv-care/> [accessed 12-8-2020]
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- ❑ The Astonishing Power of Emotions- Esther & Jerry Hicks



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