Ageing with HIV: challenges and potential solutions

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Aging and frailty

• “Normal” ageing comorbidities

• Additional psychological and social burdens
  – Persist alongside ART (Lowther et al Int J Nurs Studies 2014)

• Theories of accelerated ageing due to chronic infection
  – E.g. 70% greater risk of clinically weak grip strength in matched controls
  – greater risk for elevated VL (Schrack et al AIDS 2016)

• HIV independently assoc with prefrailty/frailty in middle-age pts c/f uninfected controls (Kooij et al AIDS 2016)

• Older HIV pts have higher QoL with faster gait/ chair rise/ activity independent of mortality risk (Erlandson et al AIDS)
Function & quality of life

• Design: Cross-sectional self-completion questionnaire (Harding et al AIDS care 2013)
• N=778 participated, 86% response rate
• 3 groups of variables:
  – demographics
  – behavioural/attitudinal measures
  – self-report disease/treatment oriented measures
• Primary outcome tool:
  – EUROQoL-VAS and EUROQol-5D
    (Brooks et al, Health Pol 1996)
# Results 2: Quality of Life EUROQol 5-D

<table>
<thead>
<tr>
<th>Quality of life</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Quality of life A – Mobility</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1: I have no problems walking about</td>
<td>538</td>
<td>71.9</td>
</tr>
<tr>
<td>2: I have some problems walking about</td>
<td>207</td>
<td>27.7</td>
</tr>
<tr>
<td>3: I am confined to bed</td>
<td>3</td>
<td>0.4</td>
</tr>
<tr>
<td><strong>Quality of life B – Self-care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1: I have no problems with self-care</td>
<td>608</td>
<td>81.3</td>
</tr>
<tr>
<td>2: I have some problems with self care</td>
<td>136</td>
<td>18.2</td>
</tr>
<tr>
<td>3: I am unable to wash or dress myself</td>
<td>4</td>
<td>0.5</td>
</tr>
<tr>
<td><strong>Quality of life C – Usual activities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1: I have no problems performing my usual activities</td>
<td>464</td>
<td>62.5</td>
</tr>
<tr>
<td>2: I have some problems with performing usual activities</td>
<td>257</td>
<td>34.6</td>
</tr>
<tr>
<td>3: I am unable to perform my usual activities</td>
<td>21</td>
<td>2.8</td>
</tr>
</tbody>
</table>
## Results 3: Quality of Life EUROQol 5-D

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Quality of Life D- Pain/discomfort</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1: I have no pain or discomfort</td>
<td>413</td>
<td>55.7</td>
</tr>
<tr>
<td>2: I have moderate pain or discomfort</td>
<td>287</td>
<td>38.7</td>
</tr>
<tr>
<td>3: I have extreme pain or discomfort</td>
<td>42</td>
<td>5.7</td>
</tr>
<tr>
<td><strong>Quality of Life E- Anxiety/Depression</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1: I am not anxious or depressed</td>
<td>312</td>
<td>41.9</td>
</tr>
<tr>
<td>2: I am moderately anxious or depressed</td>
<td>355</td>
<td>47.7</td>
</tr>
<tr>
<td>3: I am extremely anxious or depressed</td>
<td>78</td>
<td>10.5</td>
</tr>
</tbody>
</table>
### Results 5: Multiple regression, 5D associations with VAS

<table>
<thead>
<tr>
<th>Variables</th>
<th>Groups</th>
<th>N</th>
<th>B</th>
<th>95% CI for B</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A Mobility</strong></td>
<td>I have no problems walking about [ref]</td>
<td>522</td>
<td>0</td>
<td>0</td>
<td>.004**</td>
</tr>
<tr>
<td></td>
<td>I have some problems walking about/I am confined to bed</td>
<td>200</td>
<td>-5.51</td>
<td>-9.20, -1.81</td>
<td></td>
</tr>
<tr>
<td><strong>B Self-care</strong></td>
<td>I have no problems with self-care [ref]</td>
<td>591</td>
<td>0</td>
<td>0</td>
<td>.166</td>
</tr>
<tr>
<td></td>
<td>I have some problems with performing my usual activities/I am unable to wash or dress myself</td>
<td>133</td>
<td>-2.83</td>
<td>-6.83, 1.17</td>
<td></td>
</tr>
<tr>
<td><strong>C Usual activities</strong></td>
<td>I have no problems performing my usual activities [ref]</td>
<td>454</td>
<td>0</td>
<td>0</td>
<td>&lt;.001***</td>
</tr>
<tr>
<td></td>
<td>I have some problems with performing usual activities</td>
<td>248</td>
<td>-9.48</td>
<td>-12.92, -6.04</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I am unable to perform my usual activities</td>
<td>18</td>
<td>-16.42</td>
<td>-24.99, -7.86</td>
<td></td>
</tr>
<tr>
<td><strong>D Pain/ discomfort</strong></td>
<td>I have no pain or discomfort [ref]</td>
<td>405</td>
<td>0</td>
<td>0</td>
<td>&lt;.001***</td>
</tr>
<tr>
<td></td>
<td>I have moderate pain or discomfort</td>
<td>276</td>
<td>-5.90</td>
<td>-8.90, -2.89</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I have extreme pain or discomfort</td>
<td>40</td>
<td>-13.83</td>
<td>-20.01, -7.65</td>
<td></td>
</tr>
<tr>
<td><strong>E Anxiety/ depression</strong></td>
<td>I am not anxious or depressed [ref]</td>
<td>305</td>
<td>0</td>
<td>0</td>
<td>&lt;.001***</td>
</tr>
<tr>
<td></td>
<td>I am moderately anxious or depressed</td>
<td>344</td>
<td>-9.87</td>
<td>-12.53, -7.22</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I am extremely anxious or depressed</td>
<td>73</td>
<td>-16.05</td>
<td>-20.75, -11.35</td>
<td></td>
</tr>
</tbody>
</table>
Positive futures: social & psychological dimensions

- Survey of UK gay men living with HIV n=347
  - reduced career options (n=204, 57.8%)
  - reduced life expectancy (n=252, 71.8%)
  - “I need to rebuild my confidence and self esteem” (aged 57)
  - “stopped all plans for a future when I didn’t have one other than short-term when diagnosed” (aged 52)

(Harding et al AIDS Care 2006)
Response

• “Evidence-based strategies are needed to address the growing complexity of care of those ageing with HIV so that as life expectancy is extended, quality of life is also enhanced”

  (Current Opinion HIV/AIDS, Althoff et al 2016)
What is Rehabilitation?

Any services or providers with the aim to reduce impairments, activity limitations or social participation restrictions experienced by an individual

(Worthington et al, 2008)

“A dynamic process that enhances body structure and function, activity and social participation to improve the overall health and well-being of individuals.”

Canadian Working Group on HIV and Rehabilitation

www.hivandrehab.ca (CWGHR)
HIV rehabilitation

<table>
<thead>
<tr>
<th>Health Conditions</th>
<th>Health Challenges</th>
<th>Episodic Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Susceptible to conditions arising from HIV, ARVs and Ageing</td>
<td>Physical, cognitive, mental and social health-related challenges</td>
<td>Unique dimensions for people living with HIV</td>
</tr>
</tbody>
</table>

50+

Living Longer
People with HIV living longer

Multi-morbidity
Increasingly common

Disability
Conceptualised as disability; rehab recommended
HIV rehabilitation

- Evidence synthesis
- GRADE quality appraisal
- Consultation with PLWHIV
- 8 over-arching recommendations
Overarching Recommendations on Rehabilitation for Older Adults with HIV (n=8)

1) Rehabilitation Professionals (RPs) should be prepared to provide care to older adults with HIV who present with complex comorbidities...

2) RPs should adopt an individualized approach to practice, sensitive to unique values, preferences and needs of older adults with HIV....

3) Multidisciplinary rehabilitation is strongly recommended across continuum of care...

4) RPs should consider the role of extrinsic contextual factors (stigma, ageism, HIV disclosure, social supports)....

5) RPs should consider the role of intrinsic contextual factors (self-management, spirituality) ....

6) Aerobic and resistive exercise may be recommended for older adults with HIV who are medically stable and living with comorbidities....

7) Cognitive rehabilitation interventions may be recommended for older adults with HIV with mild cognitive impairments and stroke....

8) In absence of high level evidence RPs should refer to high level evidence for recommendations on interventions for a specific comorbidity....
Kobler HIV Rehabilitation class

• Developed & led by Darren Brown at Chelsea & Westminster
• Responds to O’Brien BMJ Open recommendations:
  – 1 Rehab professionals provide care
  – 2 Individualised approach
  – 5 Self management
  – 6 Aerobic exercise and resistance
Kobler HIV Rehabilitation Class
• 10 weeks, 2 meetings per week

The Kobler Rehabilitation Class
  • Twice weekly Supervised Group Exercise
  • The Self-Management Programme
    • Cardiovascular Exercise
    • Progressive Resistance Training
    • Neuromotor Exercise
      • Flexibility Training
      • Guided Relaxation

The Self Management Programme
  • Goal Setting
  • Healthy Diets
  • Fatigue Management
  • Living with HIV – Q&A
  • Sleep Physiologist
  • Sleep
  • Body Image
  • Community Services & Support (Positively UK)
  • Community Organisations
  • Smoking Cessation Nurse
  • Stop Smoking Support
  • Relationships and Sex
  • Confidence & Self-Management
  • Pain Management
  • Stress & Relaxation
  • Psychologist
  • Dietician
  • Occupational Therapist
  • Advanced Nurse Practitioner
  • Community Psychologist
  • Community Health Advisor
  • Community Support Worker
  • Community Support Worker (Local Services)
  • Community Support Worker (YMCA & Local services)
  • Community Support Worker (YMCA & Local services)
Results of cohort evaluation

• Referral patterns
  – 92 referrals
  – musculoskeletal (25.0%), oncological (19.6%), cardio-metabolic (18.5%), mostly male (81.5%), Caucasian (70.7%) older (mean 51.5 years, 32-75)

• Rehabilitation goals
  – improving body image
  – social/group participation
  – mobility, health/fitness, function

(Brown et al AIDS Care 2016)
Evaluation results

- Adherence ≥8/20 sessions (Petroczi et al 2010)
  - Achieved by 42 (46%) patients,
  - Open access utilised by 34 patients, returning (n=19) or restarting (n=15)

- Change in patient outcomes n=37 (40%)
  - 6MWT distance (p<0.001),
  - flexibility (p<0.001),
  - Strength:
    - triceps (p<0.001), biceps (p<0.001),
    - Lattimus Dorsi (p<0.001), shoulder-press (p<0.001),
    - chest-press (p<0.001), leg-press (p<0.001).
Evaluation results

• FAHI HRQOL
  – total score p<0.001*
  – Subscales
    – physical p<0.001*
    – emotional p<0.001*
    – functional p=0.065
    – social p=0.156
    – cognitive p=0.635

• GAS goal attainment scaling
  – 83% of goals “expected” (n=57),
  – 45% “somewhat more” (n=31)
  – 21% “much more” (n=14).
Appropriate settings of care: ACCESScare

• “I really don't want to go into a place where, you know, I'm the only gay guy. Or you know, gay person. Umm, it's just, you know, there's nothing wrong with straight people, but it would be so nice to be in place where you know, I could reminisce about ex-partners, .......... It's very nice, I'm happy for them, but that's not my world.”

67 year old gay man HIV & COPD
• Joe 52, gay man with HIV and COPD
  – “I invariably go into A&E [hospital X], we’re on 1st name terms…they clerk me in easily. I’ve had excellent care. But if I go to [hospital Y]…not a nice place to end up…they don’t have a back story there. It’s hard to go through 20 or 30 years of history when you’re breathless. Before they were happy to drive me to hospital X 45 minutes away, now they don’t think I’ll make it so they take me 15 minutes away to hospital Y.”
  – “The other main symptom I’ve had is falls. I have Cushing syndrome from the steroids and terrible pain and leg weakness. I get stuck in the bath”
  – “I think that's what put me at the suicide risk in the first place. Severe worrying”
PROMs

- Review of HIV-specific PROMs
  - N=117
  - Some QoL measures have functional components
    - E.g. MOS-HIV, EUROQol
  - Specific measure is O’Brien’s *HIV disability questionnaire*  
    (Engler et al 2016 The Patient)

- Assessment is crucial
  - Needs may not be presented or detected
  - PROMs usually used in research not clinical contexts
  - They improve quality and access  
    (Dawson 2012 BMJ)
Overall Aims of UKROC

• To collate in-patient episode data
  – Level 1 and 2 specialist neuro-rehabilitation services in England

• To provide the commissioning dataset
  – Implementation of the multi-level payment model

• To provide national ‘bench-marking’ information on:
  – Case-mix
  – Outcomes
  – Cost-benefits of rehabilitation
    – For patients with different levels of need

• To inform
  – Capacity planning
  – Service development
What can we learn? Recent systematic reviews

• Preventing falls older people in community
  – Cochrane review Gillespie 2012
  – Multicomponent group exercise (inc home exercise) reduce risk and rate of falls
  – Home safety assessment and modification reduces risk of falling
  – 3 trials found cost savings

• Complex community-based interventions
  – Systematic review older people Beswick 2008
  – reduce risk of not living at home, nursing home/ hospital admissions, falls, increase function

• Physical exercise
  – Systematic review frail older people BMC Geriatrics de Labra et al 2015
  – Improve falls, mobility, physical activity, balance, muscle strength, frailty
Future directions

• In UKROC HIV will be reported alongside all other areas of specialist rehab
• POSITIVE outcomes: devpt of PROM face and content validity
• Shift to primary care
• How good are we at managing aging multimorbidity when one of those is HIV?
• Can we ensure existing rehab services are inclusive of people with HIV?
Please come to 13th AIDS Impact conference, submit abstracts online www.aidsimpact.com 13th-15th November 2017