Burden of treatment

Viet-Thu Tran, MD, PhD
Une fillette de 9 ans diabétique se suicide près de Lyon

Elle a mis fin à ses jours en se jetant du 5e étage de l'appartement familial à Pierre-Bénite, dans la banlieue lyonnaise. Un acte qualifié d'"exceptionnel" par des experts psychiatres.
Multimorbidity

Barnett K., Lancet, 2012
## Percentage of patients with the row condition who also have the column condition

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage who only have the row condition*</th>
<th>Mean No of conditions in people aged ≥65 years with row condition</th>
<th>Mean No of conditions in people aged ≥65 years with row condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coronary heart disease</td>
<td>8.8</td>
<td>3.4</td>
<td>4.4</td>
</tr>
<tr>
<td>Hypertension</td>
<td>21.9</td>
<td>2.5</td>
<td>3.6</td>
</tr>
<tr>
<td>Heart failure</td>
<td>2.8</td>
<td>3.9</td>
<td>5.6</td>
</tr>
<tr>
<td>Stroke/transient ischaemic attack</td>
<td>6.0</td>
<td>3.6</td>
<td>4.8</td>
</tr>
<tr>
<td>Atrial fibrillation</td>
<td>6.5</td>
<td>3.3</td>
<td>5.0</td>
</tr>
<tr>
<td>Diabetes</td>
<td>17.6</td>
<td>2.9</td>
<td>6.5</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>14.3</td>
<td>2.8</td>
<td>4.5</td>
</tr>
<tr>
<td>Painful condition</td>
<td>12.7</td>
<td>3.1</td>
<td>4.3</td>
</tr>
<tr>
<td>Depression</td>
<td>25.4</td>
<td>2.6</td>
<td>4.9</td>
</tr>
<tr>
<td>Dementia</td>
<td>5.3</td>
<td>4.1</td>
<td>4.6</td>
</tr>
</tbody>
</table>

* Percentage who do not have one of 39 other conditions in the full count

Guthrie, BMJ, 2012
Workload of care

- All demands in patients’ lives for health-related activities (HRAs) (appointments, preventive care, drug management, self-monitoring, visits to the doctor, tests, changes of lifestyle, paperwork, etc.)

- For example, patients with type 2 diabetes managed with oral agents could spend 143 min daily in recommended self-care.

Russel, J Fam Pract, 2005
A hypothetical 79-year-old woman with COPD, type 2 diabetes, osteoporosis, hypertension, and osteoarthritis, would take **12 medications** and a complicated non-pharmacological regimen, if her physician followed strictly clinical practice guidelines.

*Boyd CM, JAMA, 2005*
Time spent in health activities

Buffel du Vaure, BMJ Open, 2016
But the truth is more complex...
Describing the workload of care of HIV patients in Sub-Saharan Africa

• Population:
  – 476 patients living with HIV under ART treatment
  – 33% multimorbid

• Estimation of patients’ workload of care using a method inspired by the Daily Reconstruction Method

Kahneman, Science, 2004
Patient A
- 1 Doctor visit (3h)
- 1 test (2h)
- Home management of medications (10min/day)

Patient B
- Home management of medications (20min/day)
Disentangling the complexity of the Workload of care

- Unsupervised learning methods to identify clusters of patients with similar patterns of workload of care in:
  - **Nature and time** allocated in each HRA
  - **Opportunity cost**
  - **Pill burden**
  - **Temporal dispersion** of HRAs that did not happen at home
  - **Monetary costs**

  - Computing a “global” distance between each patient
    **individual difference scaling methods**

  - **Hierarchical Ascendant Classification** to obtain homogeneous groups of patients
Theoretical avoidable Workload of care

• Some workload of care could be avoided if patients’ visits and tests could be grouped on same days.

• Avoidable workload of care = resources invested by patients in terms of time, money and energy, which could be saved by grouping two doctor visits or tests:
  – occurring on different days
  – spaced by less than 7 days
  – performed in the same geographic location (e.g. same hospital, same clinic, etc)
107 patients (22% of the total population and 35% of the population of patients with ≥2 non routine HRA) had theoretical avoidable workload of care.

For these patients, grouping visits would result in
- A 21% decrease of their time devoted to HRA
- 19% decrease of their reported health expenditures
Paper’s key points

• The workload of care (for HIV patients) is a complex construct involving multiple aspects. It is relatively naïve to summarize the workload of care with estimates such as time spent or pill burden.

• Potential for an important reduction of the workload of care of patients with simple adjustments in visit schedules

• Limits
  – Cross sectional work
  – Monthly workload
  – Spin: Sub-Saharan Africa ≠ Côte d’Ivoire ≠ Abidjan
From the workload of care to the Burden of Treatment
Burden of treatment

- *Impact* of the workload of care on patients’ well being and quality of life

*May, BMJ, 2011*

*Tran VT, BMC Med 2012*
Cumulative Complexity Model

Life demands

Workload

Capacity

Resource scarcity

Burden of treatment

(1) Access care
(2) Use care
(3) Enact self-care

Burden of illness

Outcomes

Shippee N, J Clin Epidemiol, 2012
Measuring the burden of treatment

- Healthcare tasks difficulty scale  
  *Boyd C, Med Care, 2014*

- Patient Experience with Treatment and Self-management scale (PETS)  
  *Eton DT, Qual Life Res, 2017*

- Treatment burden questionnaire  
  *Tran VT, BMC Med, 2012*

- Multimorbidity treatment burden questionnaire  
  *Salisbury, In preparation*
Agreement with physicians

ICC 0.38 [0.29-0.47]
Agreement with informal caregivers

0.60 [0.28-0.79]
Cross country comparison of burden of treatment scores

<table>
<thead>
<tr>
<th>TBQ items</th>
<th>USA (n=351)</th>
<th>United Kingdom (n=53)</th>
<th>Canada (n=51)</th>
<th>Australia/New Zealand (n=21)</th>
<th>Other (n=53)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The taste, shape or size of your tablets and/or the annoyances caused by your injections (e.g., pain, bleeding, bruising or scars)</td>
<td>2.6 ± 3.0</td>
<td>3.5 ± 2.9</td>
<td>1.9 ± 2.7</td>
<td>3 ± 3.1</td>
<td>2.1 ± 2.9</td>
</tr>
<tr>
<td>The number of times you should take your medication daily</td>
<td>2.4 ± 2.5</td>
<td>3.0 ± 2.8</td>
<td>2.7 ± 2.9</td>
<td>1.4 ± 1.7</td>
<td>2.2 ± 2.6</td>
</tr>
<tr>
<td>The efforts you make not to forget to take your medications (e.g., managing your treatment when you are away from home, preparing and using pillboxes)</td>
<td>2.9 ± 2.9</td>
<td>4.0 ± 3.2</td>
<td>2.7 ± 2.6</td>
<td>2.6 ± 2.7</td>
<td>2.4 ± 2.9</td>
</tr>
<tr>
<td>The necessary precautions when taking your medication (e.g., taking them at specific times of the day or meals, not being able to do certain things after taking medications such as driving or lying down)</td>
<td>3.2 ± 3.1</td>
<td>4.2 ± 3.1</td>
<td>3.0 ± 2.9</td>
<td>2.9 ± 3.1</td>
<td>2.7 ± 3.2</td>
</tr>
<tr>
<td>Lab tests and other exams (e.g., blood tests or radiology): frequency, time spent and associated nuisances or inconveniences</td>
<td>3.1 ± 3.0</td>
<td>3.0 ± 2.9</td>
<td>1.9 ± 2.5</td>
<td>3.2 ± 3.3</td>
<td>2.7 ± 2.8</td>
</tr>
<tr>
<td>Self-monitoring (e.g., taking your blood pressure or checking your blood sugar): frequency, time spent and associated nuisances or inconveniences</td>
<td>1.4 ± 2.5</td>
<td>1.0 ± 2.1</td>
<td>0.6 ± 1.1</td>
<td>1.7 ± 2.8</td>
<td>1.6 ± 2.5</td>
</tr>
<tr>
<td>Doctor visits and other appointments: frequency and time spent for these visits and difficulties finding healthcare providers</td>
<td>3.9 ± 3.3</td>
<td>3.8 ± 3.2</td>
<td>2.9 ± 3.1</td>
<td>4.1 ± 3.4</td>
<td>3.3 ± 3.2</td>
</tr>
<tr>
<td>The difficulties you could have in your relationships with healthcare providers (e.g., feeling not listened to enough or not taken seriously)</td>
<td>3.7 ± 3.5</td>
<td>5.4 ± 3.8</td>
<td>3.6 ± 3.5</td>
<td>3.6 ± 3.5</td>
<td>3.5 ± 3.5</td>
</tr>
<tr>
<td>Arranging medical appointments and/or transportation (doctors visits, lab tests and other exams) and reorganizing your schedule around these appointments</td>
<td>3.8 ± 3.4</td>
<td>4.4 ± 3.4</td>
<td>2.6 ± 2.6</td>
<td>4.2 ± 3.5</td>
<td>2.9 ± 3.0</td>
</tr>
<tr>
<td>The administrative burden related to healthcare (e.g., all you have to do for hospitalizations, insurance reimbursements and/or obtaining social services)</td>
<td>3.8 ± 3.4</td>
<td>2.8 ± 3.4</td>
<td>2.1 ± 2.5</td>
<td>3.8 ± 3.4</td>
<td>2.8 ± 3.1</td>
</tr>
<tr>
<td>The financial burden associated with your healthcare (e.g., out-of-pocket expenses or expenses not covered by insurance)</td>
<td>5.6 ± 3.6</td>
<td>4.0 ± 3.9</td>
<td>3.8 ± 3.6</td>
<td>5.1 ± 3.7</td>
<td>4 ± 3.7</td>
</tr>
<tr>
<td>The burden related to dietary changes (e.g., avoiding certain foods or alcohol, having to quit smoking)</td>
<td>3.1 ± 3.3</td>
<td>4.0 ± 3.6</td>
<td>3.3 ± 3.4</td>
<td>3.8 ± 4.0</td>
<td>3.6 ± 3.6</td>
</tr>
<tr>
<td>The burden related to doctors’ recommendations to practice physical activity (e.g., walking, jogging, swimming)</td>
<td>3.7 ± 3.4</td>
<td>4.6 ± 3.8</td>
<td>3.1 ± 3.2</td>
<td>4.3 ± 3.7</td>
<td>3.2 ± 3.6</td>
</tr>
<tr>
<td>How does your healthcare impact your relationships with others (e.g., being dependent on others and feeling like a burden to them, being embarrassed to take your medications in public)</td>
<td>4.9 ± 3.7</td>
<td>5.7 ± 3.7</td>
<td>4 ± 3.5</td>
<td>6.7 ± 3.8</td>
<td>4.1 ± 3.4</td>
</tr>
<tr>
<td>'The need for medical healthcare on a regular basis reminds me of my health problems’</td>
<td>6.1 ± 3.6</td>
<td>5.2 ± 3.8</td>
<td>5.3 ± 3.7</td>
<td>6.4 ± 3.4</td>
<td>5.4 ± 3.5</td>
</tr>
</tbody>
</table>
Causes, aggravating factors and consequences of the burden of treatment

• Survey with open-ended questions to 1,053 participants from 34 (high-income) countries

• Double analysis with
  – « Classic » thematic analysis, in double, with frequent consensus
  – Natural Language Processing methods

*Tran VT, BMC Med, 2015*
How to reduce the burden of treatment?
Patients’ perspectives on how to decrease their burden of treatment

- Adult patients with HIV under ART treatment in Sub-Saharan Africa

- **Qualitative interviews** starting with “What do you believe are the most important things to change in your care to improve your burden of treatment?”

- **Thematic Analysis** by 2 investigators in double and consensus

- Estimation of the point of data saturation using mathematical models
Feasibility assessment

• Assessment of the feasibility of patients’ propositions
  – 6 experts independently evaluated all propositions (+ examples)
    • Director of a large HIV clinic in West Africa
    • a professor in Public Health in Sub-Saharan Africa
    • a decision maker from the Global Fund
    • a physician with experience in clinical research
    • a social worker
    • a patient from the association

  – Classification as
    • “Very difficult and/or costly to implement”,
    • “May be possible to implement but not without costs or effort”
    • “Easy to implement at low cost”.
27 (180 patient quotes), 19 (227 patient quotes) and 13 (341 patient quotes) were easy, moderately and difficult to implement, respectively.

118 (36%) participants elicited at least one easily implementable proposition
Paper’s key points

• To our knowledge, this is the first study to systematically ask PLWH their ideas and propositions to improve their experiences

• Global Minimally Disruptive Medicine

• Our study stands as a proof of concept method to involve patients in improving the quality of care

• Limits:
  – All experts are considered equal
  – No consensus method used
  – Same spin as study 1!
So what now?
What’s next?

• Global Minimally Disruptive Medicine

• Move from propositions to implementable « real interventions » to reduce the burden of treatment (and improve patients’ outcomes)
  – PANAM trial (Virtual Patient Navigator)

• Maybe digital tools can help?