Introduction & Background

- Hearing loss is a chronic health condition that rises sharply with age alongside other health conditions.
- Patients are increasingly expected to manage their chronic conditions alongside demands of everyday life.
- The Burden of Treatment Theory is a useful framework for understanding the interaction between the workload transferred to patients and their capacity to manage it (May, Eton et al. 2014).
- This is part of a larger study – the Hearing Loss and Patient Experience study (HeLP study) – to develop a Patient Reported Experience Measure (PREM) to understand the burdens (illness and treatment work experienced by patients) to help tailor audiology care (Pryce et al. 2023).

Aim: To explore the characteristics of the burden of illness and burden of treatment experienced by people living with hearing loss across the life course.

Methods

- Potential participants (young people and adults aged 16 years and older with hearing loss) were recruited from:
  - Clinical services in South-West England and Scotland.
  - Non-clinical routes (e.g. lip reading classes).
- Semi-structured interviews (online or face-to-face) were conducted between 2022-23.
- A topic guide explored emotions about hearing loss, daily efforts and challenges, decisions around interventions (e.g., hearing aids), and experiences with audiology services.
- Data were analysed thematically and informed by the Burden of Treatment Theory.
- A total of 46 individuals who had experience took part, including 34 hearing wearers and 12 who chose not to wear hearing aids.

Table: Participant breakdown

<table>
<thead>
<tr>
<th>Participant age band</th>
<th>Hearing aid user</th>
<th>Non hearing aid user</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-29 years (n=6)</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>30-49 years (n=13)</td>
<td>10</td>
<td>3</td>
</tr>
<tr>
<td>50-79 years (n=18)</td>
<td>14</td>
<td>4</td>
</tr>
<tr>
<td>80 years – end of life (n=9)</td>
<td>6</td>
<td>3</td>
</tr>
</tbody>
</table>

Results

- A sense of frustration permeated participants’ account as they described the different illness and treatment work.
  - The illness burden (Fig 1) appeared to be fourfold; participants worked to:
    - Make sense of the auditory changes and hearing loss
    - Cope with changes in sense of self (emotional work)
    - Cope with daily challenges of communication
    - Use adaptive and coping strategies and educate others
  - Treatment work was characterised by a sense of abandonment; participants needed to be proactive and cope with the challenges of hearing technology with little support.
  - Burdens were alleviated through a sense of agency, influenced by:
    - Psychological factors (e.g., resilience, personal growth)
    - Psychosocial resources (e.g., social and peer support)
    - Health literacy skills (knowledge, critical appraisal)

Table. Application of Burden of Treatment Theory (Examples of illness & treatment work and resources to manage) burdens

<table>
<thead>
<tr>
<th>ILLNESS WORK</th>
<th>BURDENS</th>
<th>RESOURCES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Concentration efforts</td>
<td>Resilience</td>
</tr>
<tr>
<td></td>
<td>Fatigue</td>
<td>Reflection and personal growth</td>
</tr>
<tr>
<td></td>
<td>Feeling isolated</td>
<td>Social support</td>
</tr>
<tr>
<td></td>
<td>Lack of control over the environment</td>
<td>Using different communication</td>
</tr>
<tr>
<td>TREATMENT WORK</td>
<td>Health uncertainty</td>
<td>Gathering reliable information</td>
</tr>
<tr>
<td></td>
<td>Ongoing hearing aid management</td>
<td>Knowledge of hearing technology</td>
</tr>
<tr>
<td></td>
<td>Clinics – lack of awareness</td>
<td>Good relationship with audiology</td>
</tr>
<tr>
<td></td>
<td>Emotional impact of audiology testing</td>
<td>Knowledge of treatment options</td>
</tr>
</tbody>
</table>

Conclusion

- The workload of hearing loss appears largely placed on the patient and often unseen by healthcare professionals.
- A lifeworld approach, with its emphasis on the subjective experience, offers a useful way of exploring the cumulative burdens of hearing loss.

Acknowledgements

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References
