



SCAN ME

## 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**

Participant age band	Hearing aid user	Non hearing aid user
16-29 years (n=6)	4	2
30-49 years (n=13)	10	3
50-79 years (n=18)	14	4
80 years – end of life (n=9)	6	3

## References

- May, C et al. (2014). "Rethinking the patient: using Burden of Treatment Theory to understand the changing dynamics of illness." BMC Health Services Research 14(1): 281.
- Pryce, H., S. K. Smith, G. Burns-O'Connell, R. Shaw, S. Hussain, J. Banks, A. Hall, R. Knibb, R. Greenwood and J. Straus (2023). "Protocol for a qualitative study exploring the lived experience of hearing loss and patient reported experience in the UK: the HeLP study." 13(6): e069363.

## 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)

	BURDENS	RESOURCES
ILLNESS WORK	<ul style="list-style-type: none"> <li>Concentration efforts</li> <li>Fatigue</li> <li>Feeling isolated</li> <li>Lack of control over the environment</li> </ul>	<ul style="list-style-type: none"> <li>Resilience</li> <li>Reflection and personal growth</li> <li>Social support</li> <li>Using different communication strategies</li> </ul>
TREATMENT WORK	<ul style="list-style-type: none"> <li>Health uncertainty</li> <li>Ongoing hearing aid management</li> <li>Clinics – lack of awareness</li> <li>Emotional impact of audiology testing</li> </ul>	<ul style="list-style-type: none"> <li>Gathering reliable information</li> <li>Knowledge of hearing technology</li> <li>Good relationship with audiology team</li> <li>Knowledge of treatment options</li> </ul>

## 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.

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