

Introduction & Background

Living with tinnitus creates work for the person. Not only is there the experience of the tinnitus sound and the distraction it can cause, people also have to cope with the emotional distress associated with hearing the tinnitus sound. In addition to work relating to experiencing tinnitus, patients are also expected to undertake treatment work.

The efforts patients make are referred to as the **'burden of treatment'** theory (May et al., 2014). This theory describes how health services transfer accountability and work to patients to manage long-term conditions. For example, tinnitus patients are expected to undertake help-seeking activities, and to learn about tinnitus and the different management techniques.

As with most chronic health conditions, most of the **workload of tinnitus treatment is assigned to the patient**. Even though patients are doing burdensome work, it is often not acknowledged due to the clinical focus being aimed at the outcome measures, rather than the efforts by patients to achieve those outcomes. This work is important because clinicians negotiate the work that patients are given for tinnitus treatment, but they may be unaware of the burden being experienced by the patient.

Aim: To understand the **cumulative burdens** of tinnitus, including experiencing **the sound** of tinnitus and the **treatments** undertaken by people living with tinnitus.

Methods

Approach:	qualitative
Method:	semi-structured, in-depth interviews
Participants:	38 adults recruited via UK clinical services
Data analysis:	reflexive thematic analysis

- A qualitative approach was used to explore how illness and treatment burden is experienced by tinnitus patients
- Interviews were conducted with 38 participants who had sought help in a variety of UK clinical services. These data were collected with the purpose to understand the experience of help-seeking (see Pryce et al., 2018)
- The procedures described in Braun and Clarke's reflexive thematic analysis (Braun & Clarke, 2006, 2021) were followed to explore the interview data and develop insights into the cumulative burdens relating to the experience of tinnitus.

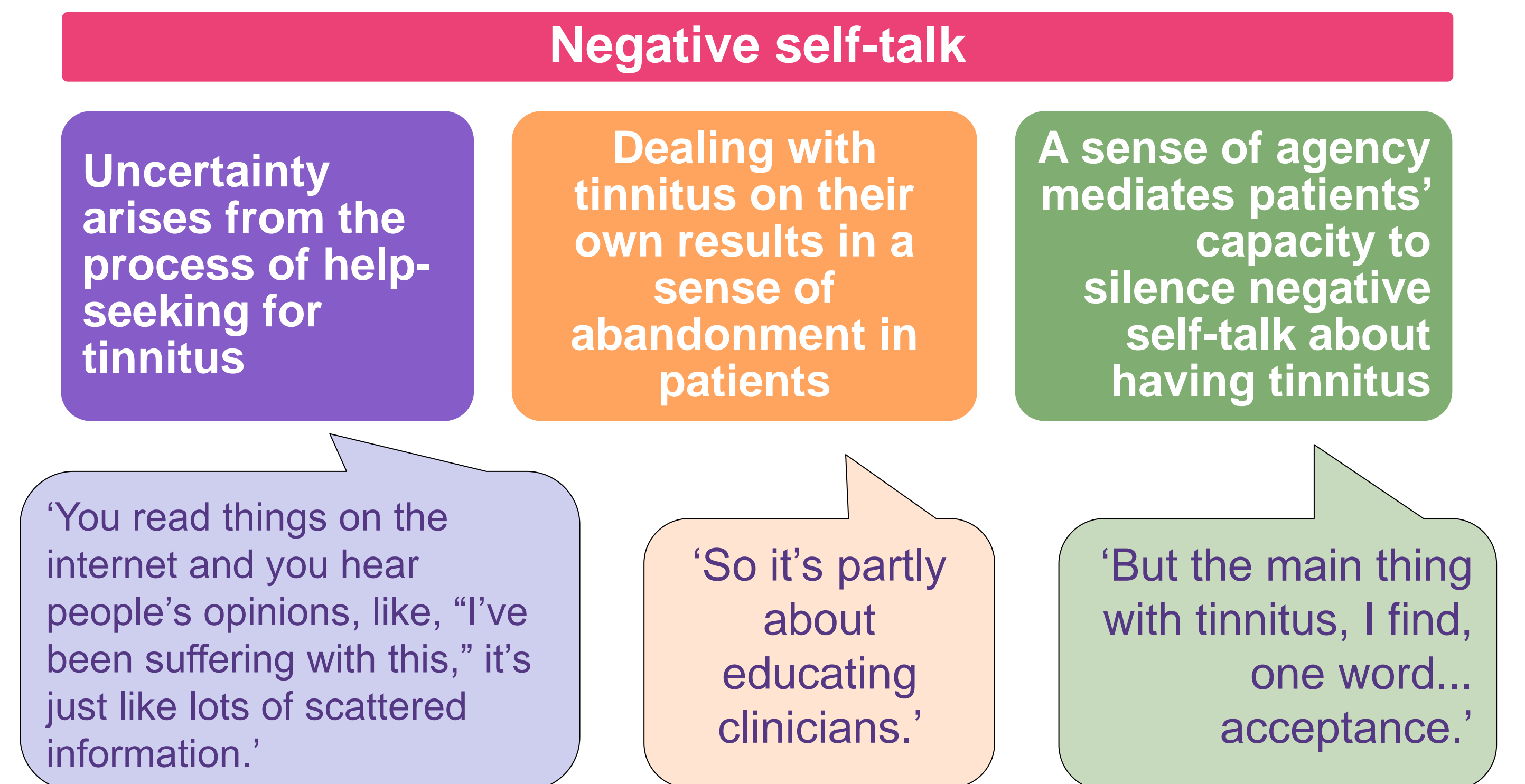
Results

The burden of tinnitus, and the work it requires, is twofold:

1. Coping with the interference of tinnitus in their daily life (illness burden)
2. Seeking help, making sense of tinnitus, and the prescribed interventions (treatment burden).

There was an overarching theme of negative self-talk and 3 main subordinate themes relating to this: uncertainty, abandonment, and sense of agency.

Results (cont'd) & Discussion



Applying the burden of care theory

Key aspects of work incurred by tinnitus and the efforts required to mediate it were identified. Our analysis involved comparing burden of care theory descriptions with the themes and categorizing them as forms of illness or treatment work (see figure 1).

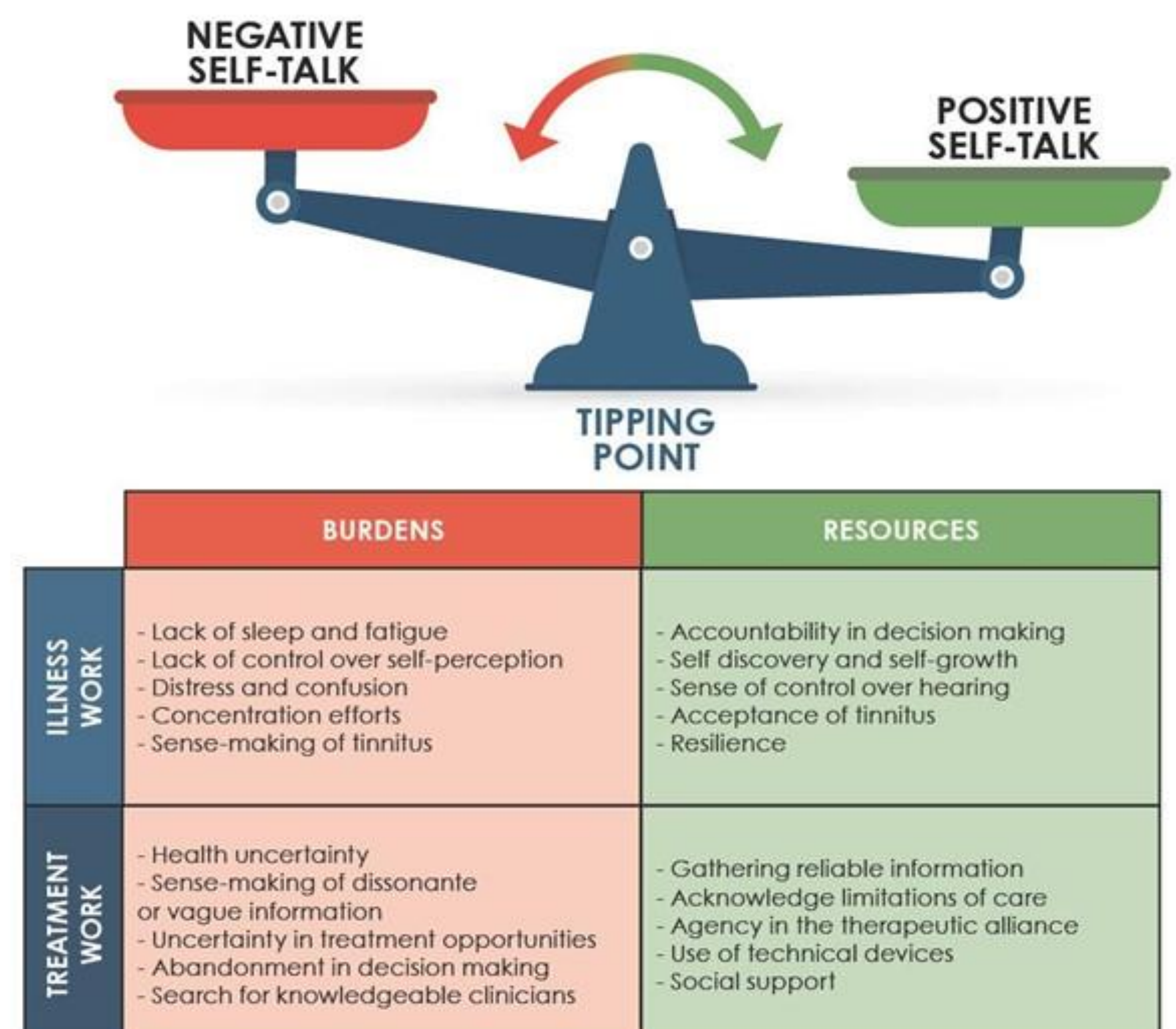


Figure 1. Application of burden of care theory to the thematic analysis

Considerations:

- Agency and capacity to use resources varies and is dependent on factors such as social privilege, having multiple health conditions, and increased treatment demands
- The experience of tinnitus is heterogeneous (Beukes et al., 2021; Cederroth et al., 2019)
- Variation is inevitable given the burden of self-treatment is devolved to the patient.

Conclusion

We hope that this research illustrates the need to broaden models to fully consider contextual burdens of illness and treatment in tinnitus.

References

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