Barriers to the inclusion of underserved groups in research about co-existing dementia and hearing conditions

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Background, Aims and Methods

Introduction:
Dementia and hearing conditions commonly co-occur. It is important that research includes people who experience both dementia and hearing conditions, and people from underserved groups, to address health disparities.

Aims to:
1) Identify who is underserved
2) Identify what barriers they experience in dementia and hearing research

Methods:
• Semi-structured interviews and focus groups with professionals
• Maximal Diversity Sampling: Approached staff from a variety of relevant professions with experience of working with different underserved groups
• This formed the first part of an experience-based co-design method (Fig1)

Results: Barriers related to...

Dementia and hearing conditions
• Stigma associated with dementia and / or hearing conditions
• Misunderstandings and lack of awareness of the conditions
• Difficulties with long-term follow-up (when involving people with dementia)
• Rigid inclusion of research means that having one condition will often exclude participation in research about the other

Organisational priorities and systems
• Mistrust of organisation / health services/ research
• Ineffective information sharing and awareness raising of research and health conditions
• Differing priorities of institutions/ funders from communities
• Poor relationships with ‘gate-keepers’
• Inflexible ethics and system requirements
• Lack of co-ordination between researchers working with underserved groups

Researchers, practices and processes
• Communicating in ways that prioritise researchers’ budgets and time (e.g. communication in English; digitally)
• Not collecting data related to diversity and inclusion
• Reliance on participants being linked into a healthcare system (e.g. for recruitment)
• Lack of funding for more intensive (inclusive) recruitment methods

Conclusions

Barriers are highly context-specific, and intersectionality is important. However, some common barriers were identified, and whilst some reflect societal and structural problems, others could be immediately addressed by organisations and individual researchers to improve the inclusion and participation of underserved groups in dementia and hearing research.

Further work is needed to develop targeted tools, methods and recommendations to address these issues.

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