

'Where do we go from here?': A meta-synthesis of qualitative literature examining the lived experience of Huntington's Disease (HD)

Richie Paul Carreon¹; Julie Ann Hayes¹; Conan Leavey²; Donal Deehan¹

¹ School of Nursing and Allied Health, ² Public Health Institute
Liverpool John Moores University, United Kingdom

Background

A systematic method of identifying available literature in HD lived experience has been carried out as a part of wider PhD study. By synthesising the sampled studies, this offered a better awareness of HD lived experiences and identified literature gaps.

Objectives

To examine the experiences of people with HD in qualitative literature; to identify areas of depth as well as gaps in our extant knowledge base.

Method

A meta-synthesis of qualitative literature was conducted using systematic searches in Scopus, MedLine, Web of Science and CINAHL. The search was limited to studies published in English from 2000- 2020.

Results

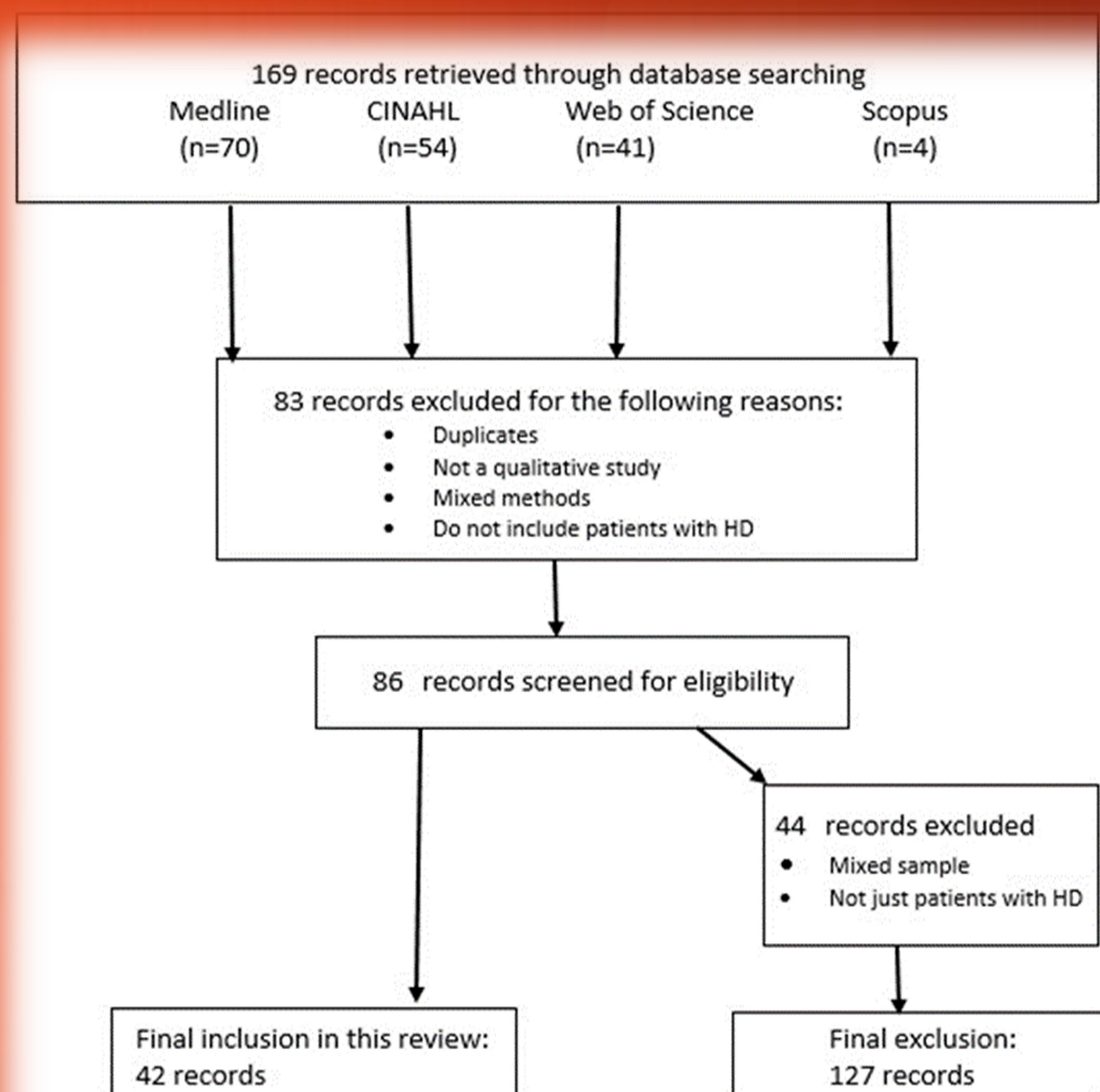
The literature search yielded 169 unique records, 42 met the inclusion criteria. Three overarching broad themes were centred around 'Where do we go from here?:' (a) Route to Diagnosis, (b) Intersections with Health Services (c) Steering through life with HD.

The themes were extracted from empirical findings, scrutiny of abstracts and full text articles which included methodological designs and data collection methods.



Portrait of a person with HD

Source: <https://www.yourgenome.org/facts/what-is-huntingtons-disease>



Flow chart of the process involved in selection and identification of HD qualitative studies.

Conclusion

Our knowledge of the lived experience of HD is mainly informed by clinical observations, genetic risks and experience of genetic testing. There is a lack of qualitative studies that explore HD non- clinical aspects despite the pervasive functional, psychological and social consequences of the disease to individuals, families and communities.

There are methodological limitations in current literature such that the holistic impact of the disease, and experiences of HD late stages were not well described. Qualitative longitudinal research has the potential to help us better understand the experiences of people living with, and affected by HD.