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Doctoral Thesis:

**The views of adults with Huntington's disease on assisted dying: a psychological
exploration**

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Table of Word Count

Thesis Section	Text	Abstracts, References, Tables and Appendices	Total
Abstract	N/A	235	235
Literature Review	7988	5859	13,847
Research Paper	7993	4365	12,358
Critical Appraisal	3311	681	3992
Ethics Section	6662	2048	8710
Totals	25,954	13,188	39,142

Thesis Abstract

Neurodegenerative diseases are not typically associated with a palliative care approach, despite poor quality of end-of-life care for people with these conditions. The first aim of this thesis was to understand the views of adults with neurodegenerative diseases on end-of-life care.

Consequently, a metasynthesis was conducted. This review revealed that the care needs of people with neurodegenerative diseases are routinely not being met. It suggests that autonomy and a sense of control are important as well as contextualisation in decision-making. Furthermore, palliative care would be beneficial in meeting the needs of adults with neurodegenerative diseases. Theoretical, clinical and research implications are discussed.

The second aim of this thesis was to explore how people with Huntington's disease (HD, a major neurodegenerative disease) view assisted dying, a frequently debated issue. A thematic analysis was conducted using semi-structured interviews. Participants views were captured in four themes: 1) Autonomy and kindness in assisted dying; 2) HD threatens identity but is part of life; 3) Dilemmas in decision-making on assisted dying: "There are no winners"; and 4) Absence of explicit discussion on dying and HD: "Elephants in the room". The study found that HD influenced views on assisted dying and that participants valued maintaining control of both their life and their death. They faced dilemmas in decision making and limited discussion on EOL issues. The final section of the thesis offers a reflective account of the research process.

Declaration

This thesis records work undertaken in partial completion of the Doctorate in Clinical Psychology at Lancaster University's Division of Health from May 2015 to May 2016.

The work presented here is my original work and has not been submitted for any other academic award.

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Date:

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First and foremost, my thanks to all the people who gave their time to take part in my study. This research would not have been possible without them.

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Contents Page

Section One: Literature Review	1-1
Abstract	1-2
Introduction	1-3
Methods	1-8
Results	1-13
Discussion	1-21
Conclusion	1-30
References	1-31
Tables	1-44
Figures	1-49
Appendix 1-A: Instructions for authors	1-50
Section Two: Empirical Paper	2-1
Abstract	2-2
Introduction	2-3
Methods	2-8
Results	2-12
Discussion	2-23
Conclusion	2-29
References	2-30
Appendix 2-A: Instructions for authors	2-41

Appendix 2-B: Excerpt of an analysed transcript	2-45
Appendix 2-B: Example of the development of an analytical theme	2-46
Section Three: Critical Review	3-1
Introduction	3-2
Conclusion	3-12
References	3-13
Section Four: Ethics	4-1
FHMREC Application	4-2
Research Protocol	4-8
References	4-14
Appendix 4-A: Participant information sheet	4-17
Appendix 4-B: Capacity check form	4-20
Appendix 4-C: Thesis consent form	4-21
Appendix 4-D: Topic guide	4-22
Appendix 4-E: Research poster	4-23
Appendix 4-F: Ethics approval letter	4-24