

Patient and Caregiver Experiences of Chronic Illness: The Role of Modifiable Factors



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Institute
Assisting Living & Learning

Research focus

Experience of living with chronic illness

Cancer

Type 1
Diabetes

COPD

Multiple
Sclerosis

Fibromy
algia/ME

Patient and caregiver perspectives

Psychosocial impacts

Evaluation of supports

LGBTQ+
health



Rebecca Maguire



NCI Talk 15th June

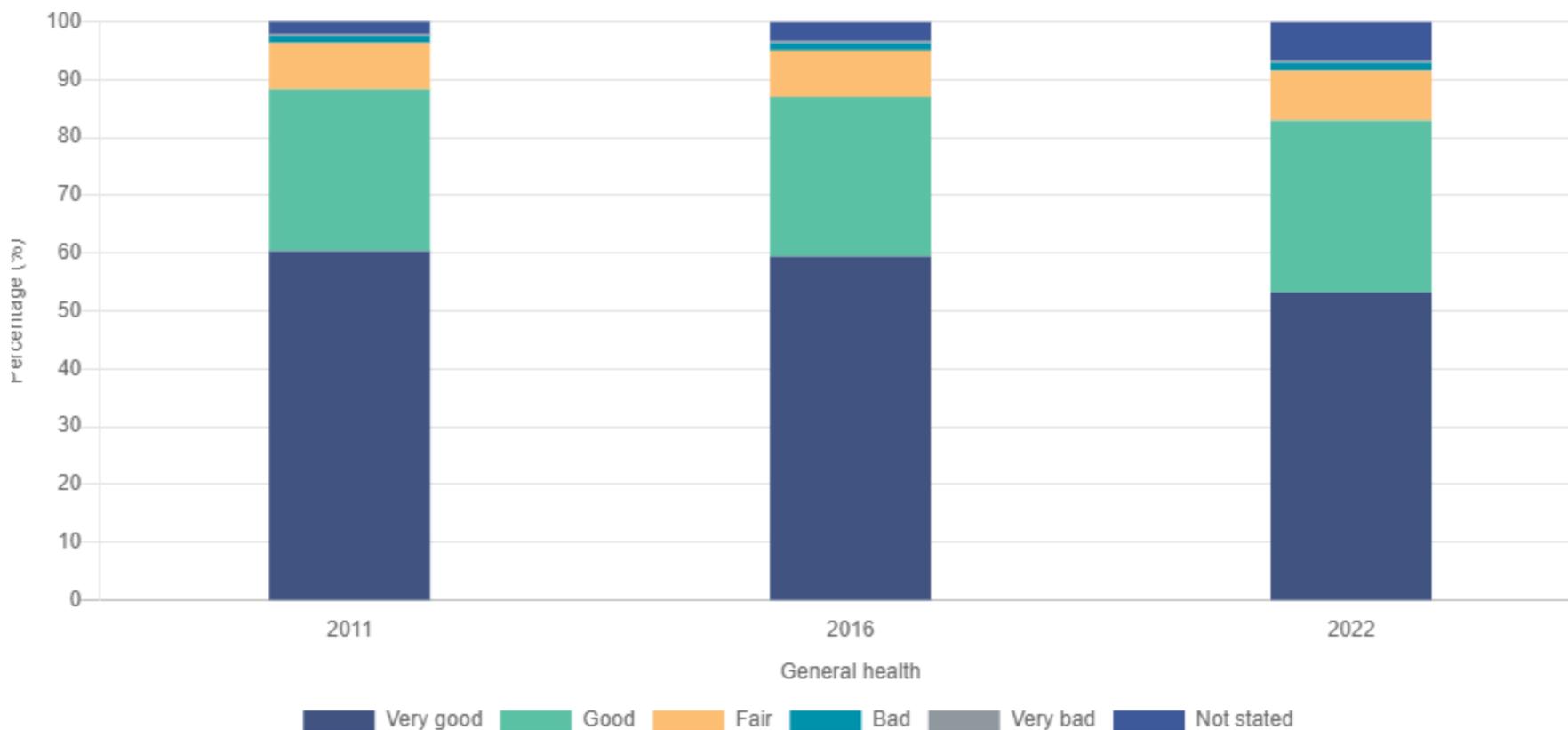
How would you rate your health?



Excellent Very good Good Fair Poor



Figure 3.1 Population by general health, 2011 to 2022



Self-rated health may not always be accurate

971



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promoting excellence in psychology

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Expecting the best or fearing the worst: Discrepancies between self-rated health and frailty in an ageing Irish population

Bill Calvey^{1*} , Joanna McHugh Power²  and Rebecca Maguire² 

¹Hamilton Institute, Maynooth University, Co. Kildare, Ireland

²Department of Psychology, Maynooth University, Co. Kildare, Ireland

Health asymmetry = mismatch between
subjective and **objective** health

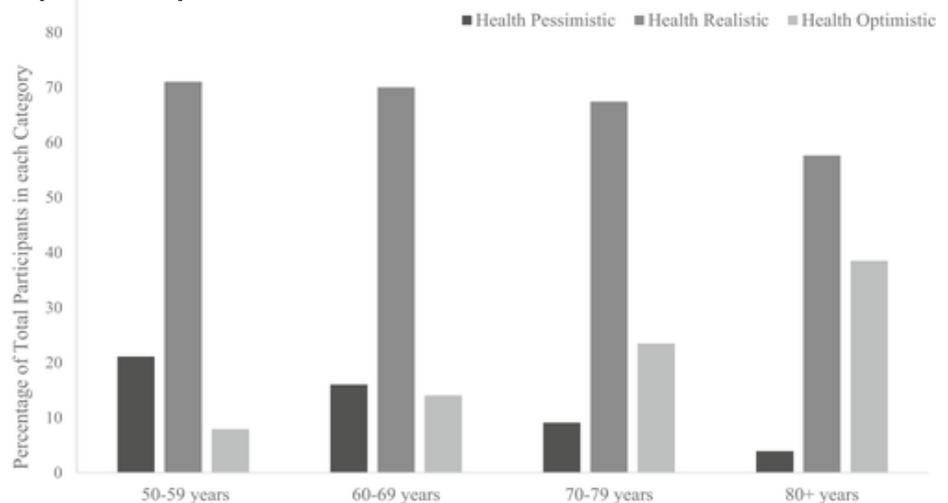
Health asymmetry

Three distinct categories:

1. Health **optimists** (15%)
2. Health **realists** (69%)
3. Health **pessimists** (16%)

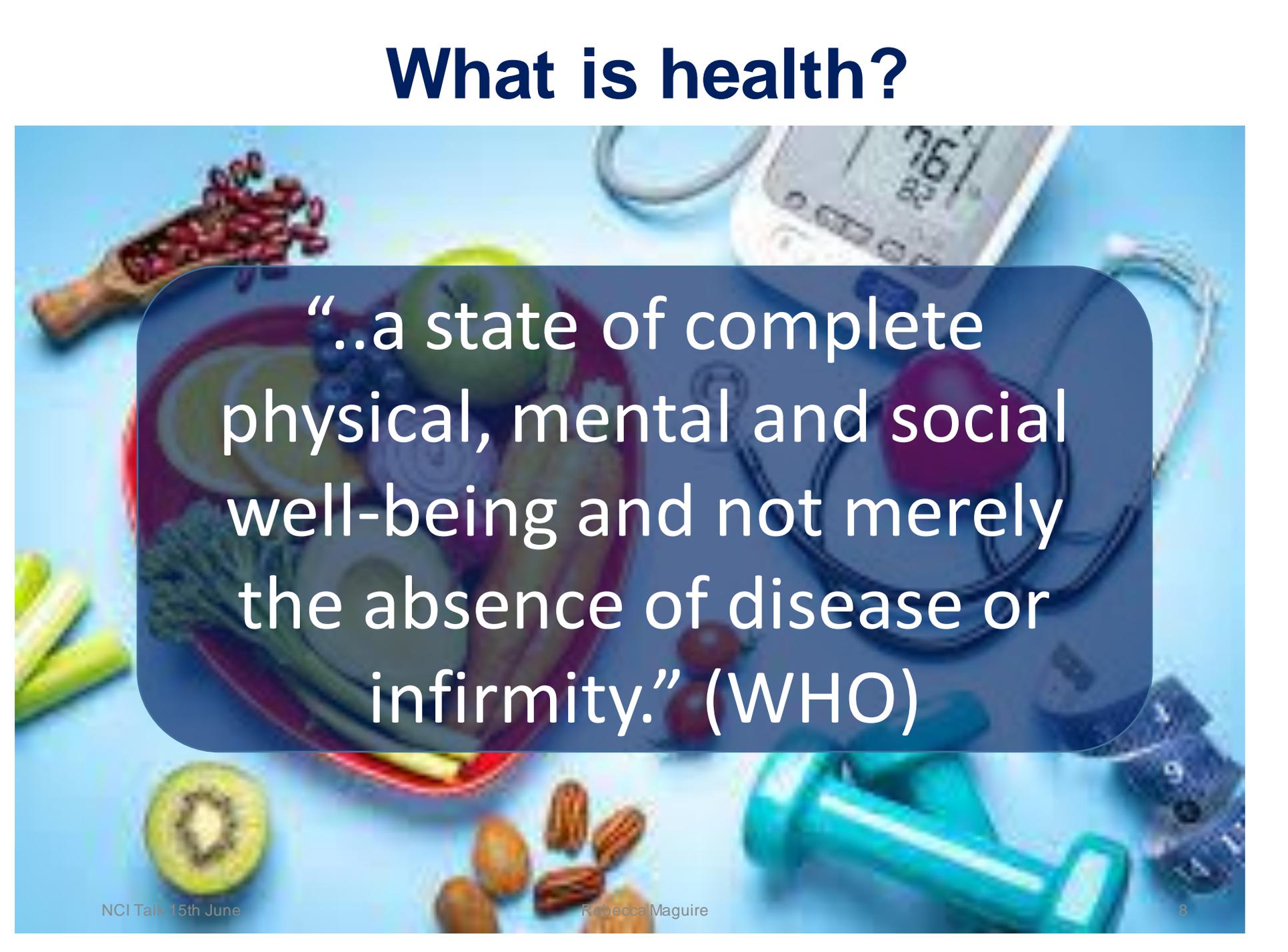


Using TILDA data
(n=6,907)



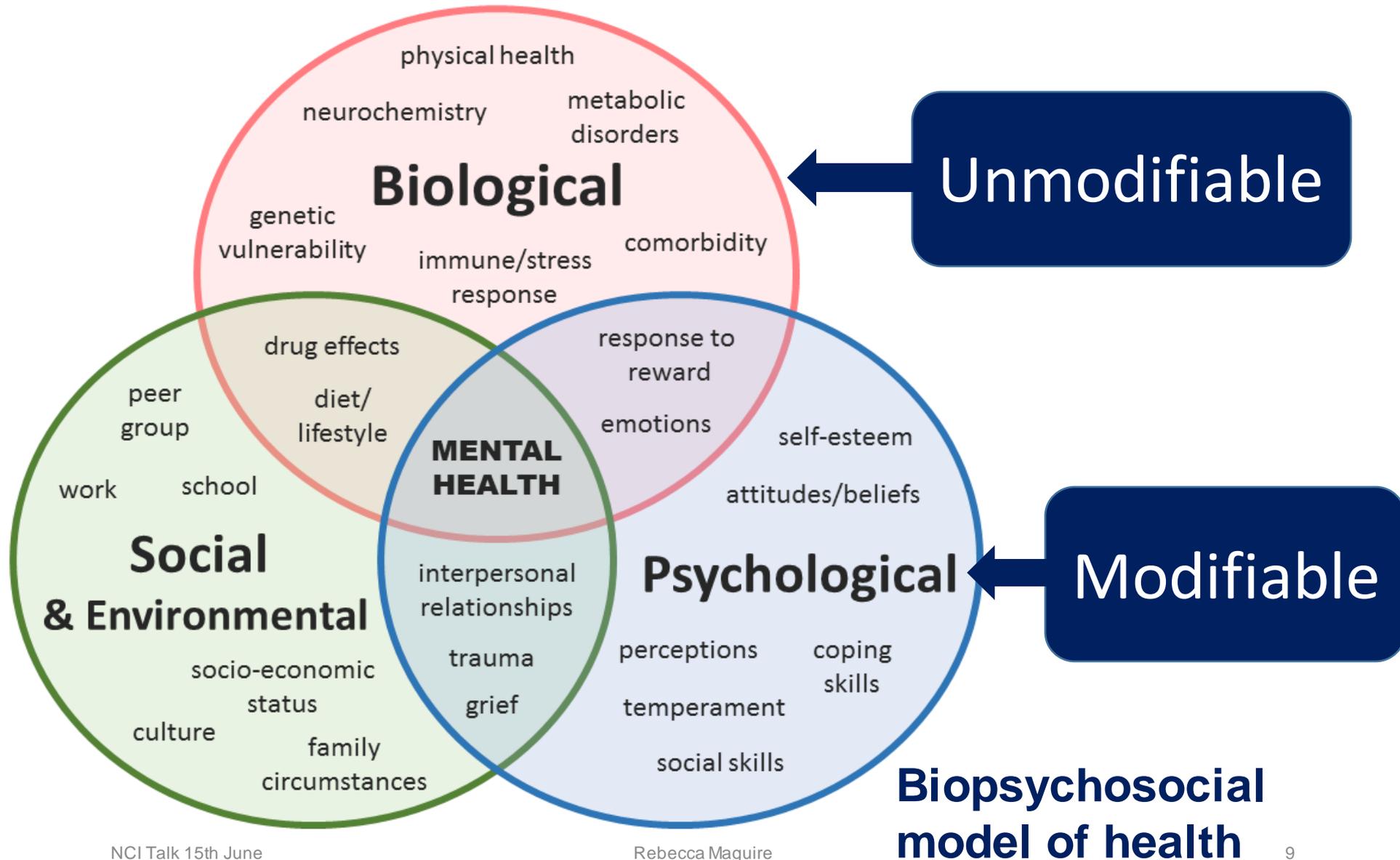
Health optimism increases with age (Calvey et al., 2022)

What is health?



“..a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” (WHO)

Complex interacting systems influence health



Applications for anxiety in MS

DISABILITY AND REHABILITATION
2022, VOL. 44, NO. 26, 8201–8212
<https://doi.org/10.1080/09638288.2021.2022776>



REVIEW

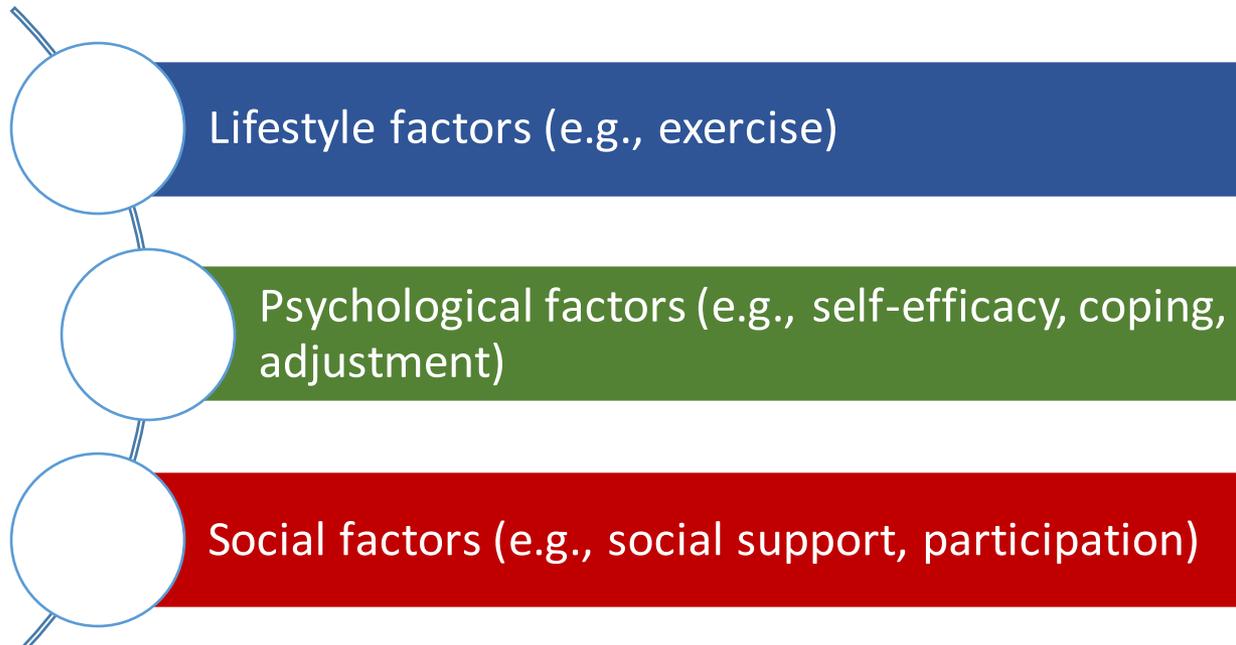


Potentially modifiable associates of anxiety in people with multiple sclerosis: a systematic review

Austin Fahy  and Rebecca Maguire 

Department of Psychology, Maynooth University, Maynooth, Ireland

Three broad categories identified



Ongoing research

(Fahy & Maguire, in prep)



Cross-sectional **Survey** (n=287):



- Anxiety increased for people with MS during pandemic
- Modifiable factors (including **tolerance of uncertainty**) → anxiety



Interview study (n=9)

1. Anxiety as a familiar experience
2. Ongoing impact of Covid-19
3. Anxiety reduced by acceptance, escapism/distraction, positive health behaviours
- 4. Support** highly valued and desired
5. Need for personalised care

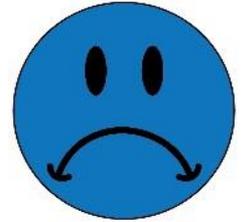
Ways of thinking
about health

Expectations

**Quality
of Life**



Fear of Recurrence impacts QoL in cancer



Received: 7 September 2017 | Revised: 9 January 2018 | Accepted: 23 January 2018
DOI: 10.1002/pon.4660

PAPER

WILEY

Expecting the worst? The relationship between retrospective and prospective appraisals of illness on quality of life in prostate cancer survivors

Received: 7 September 2016 | Revised: 9 December 2016 | Accepted: 23 January 2017
DOI 10.1002/pon.4384

Rebecca Maguire¹  | Paul Hanly¹ 
Linda Sharp⁵ 

PAPER

WILEY

Regret and fear in prostate cancer: The relationship between treatment appraisals and fear of recurrence in prostate cancer survivors

Rebecca Maguire¹  | Paul Hanly¹ | Frances J. Drummond² | Anna Gavin³ | Linda Sharp⁴ 

Worry in Head and Neck Cancer Caregivers *The Role of Survivor Factors, Care-Related Stressors, and Loneliness in Predicting Fear of Recurrence*

Rebecca Maguire ▼ Paul Hanly ▼ Myles Balfe ▼ Aileen Timmons ▼ Philip Hyland ▼ Eleanor O'Sullivan ▼ Phyllis Butow ▼ Linda Sharp

The case of multiple sclerosis



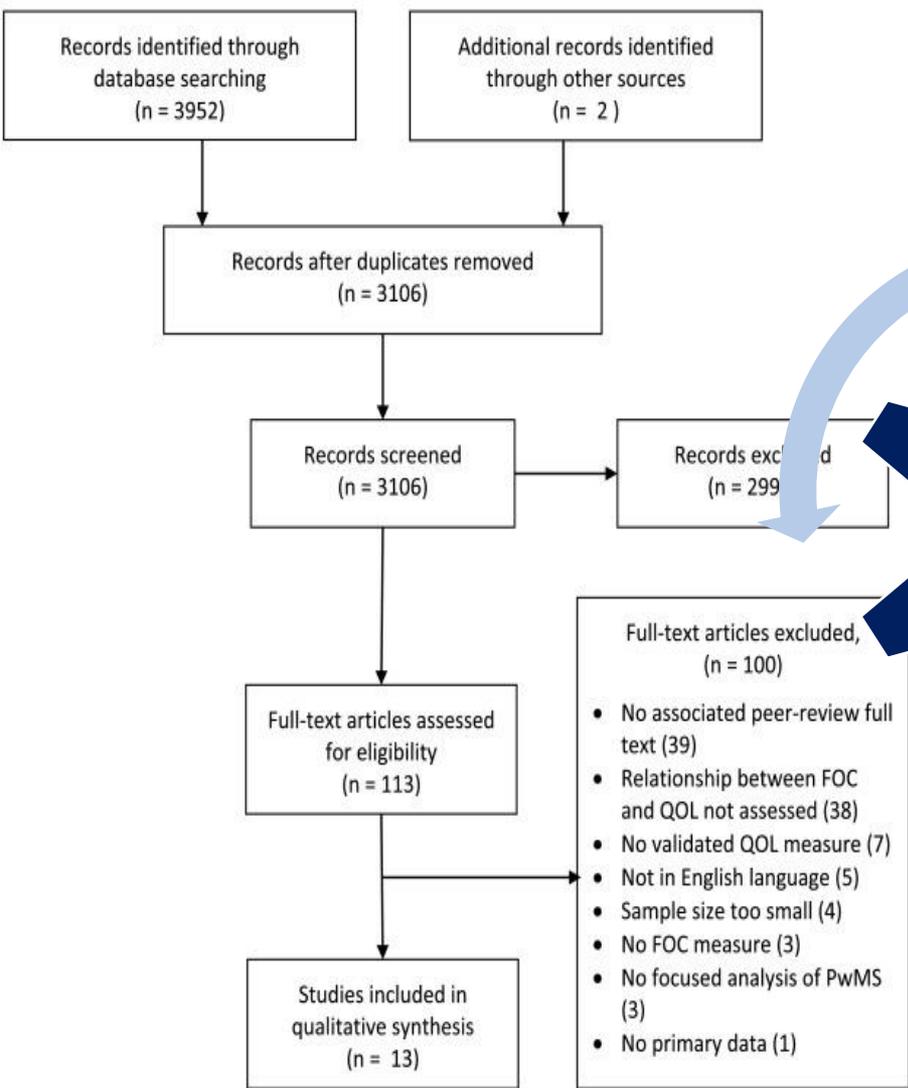
Multiple Sclerosis and Related Disorders

Volume 56, November 2021, 103293



The role of expectations and future-oriented cognitions in quality of life of people with multiple sclerosis: A systematic review

[Rebecca Maguire](#)^{a b}  , [Beth McKeague](#)^a, [Nathalie Kóka](#)^a, [Laura Coffey](#)^{a b}, [Phil Maguire](#)^c,
[Deirdre Desmond](#)^{a b}



Positive Future-Oriented Cognitions → Higher QOL



Positive appraisals important in predicting wellbeing in Europe

Quality of Life Research (2019) 28:2135–2146
<https://doi.org/10.1007/s11136-019-02122-y>



Beyond care burden: associations between positive psychological appraisals and well-being among informal caregivers in Europe

Rebecca Maguire¹ · Paul Hanly² · Phil Maguire³

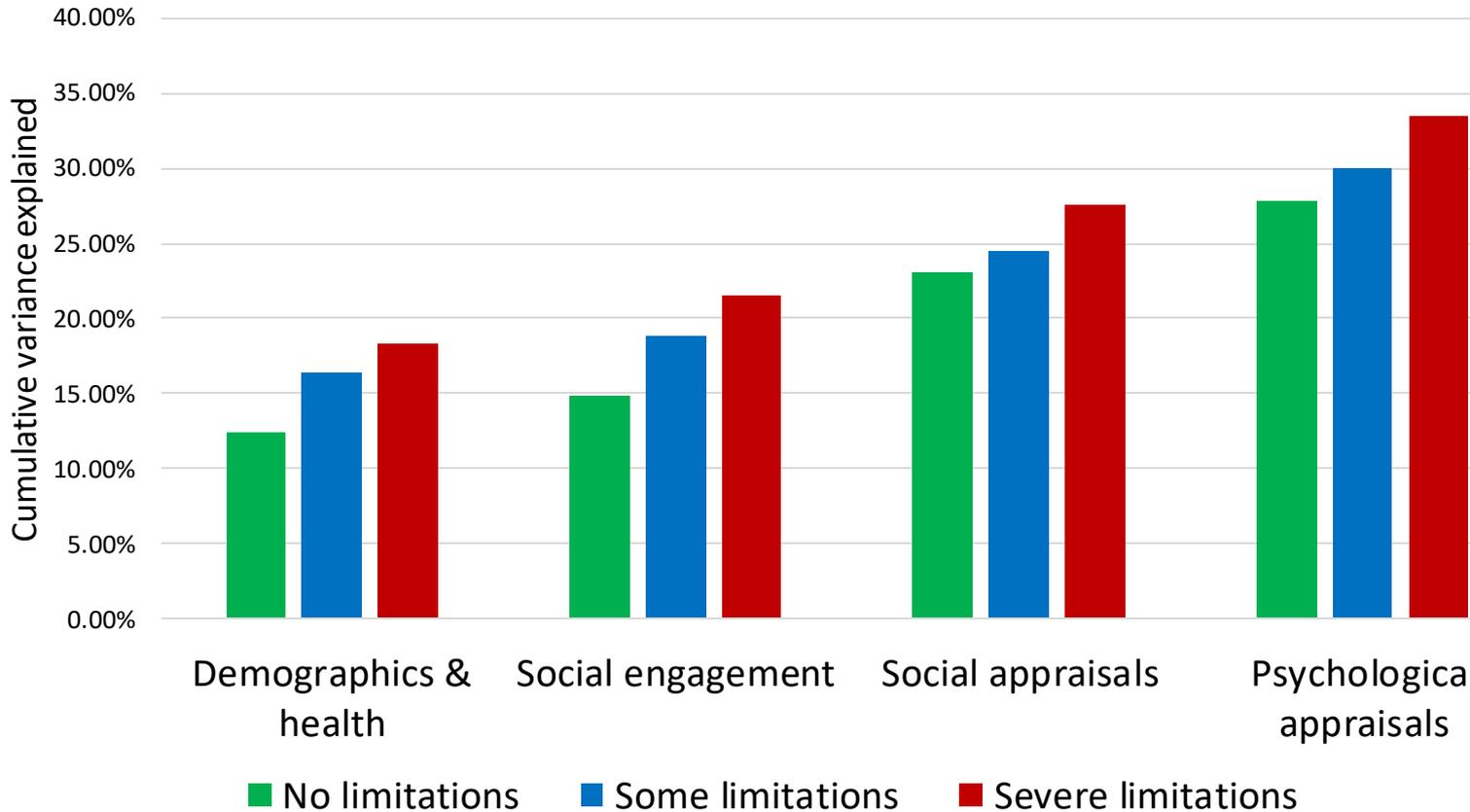
	Significant predictors
Sociodemographic and health factors	Gender Self-rated health
Characteristics of care and burden	Ease of combining care with work Ease of making ends meet Time burden
Psychological and social appraisals	Optimism Purpose Autonomy Resilience Low social exclusion

Living well with chronic illness: How social support, loneliness and psychological appraisals relate to well-being in a population-based European sample

Journal of Health Psychology
1-14
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DOI: 10.1177/1359105319883
journals.sagepub.com/home/hj

Psychological and social appraisals particularly important in those **limited** by illness

Rebecca Maguire¹, Paul Hanly²
and Phil Maguire³



Importance of support

Multiple Sclerosis and Related Disorders 69 (2023) 104419



Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

Multiple Sclerosis and Related Disorders

journal homepage: www.elsevier.com/locate/msard



Original article

An evaluation of the role of community care in meeting the needs of people with multiple sclerosis in Ireland



Rebecca Maguire^{a,b,*}, Jennifer Deane-King^a, Austin Fahy^a, Aidan Larkin^c, Susan Coote^{c,d}

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^b Assisting Living and Learning Institute, Maynooth University, Maynooth, Ireland

^c The Multiple Sclerosis Society of Ireland, Dublin, Ireland

^d School of Allied Health, Physical Activity for Health Research Cluster, University of Limerick, Limerick, Ireland



Emotional or psychological support



Employment accommodations



Information



Financial support



Social support



Coordination of care



Transportation/mobility



Caregiver support



Increasing participation in employment, education and recreation



Accessing equipment



Homecare



Family support

REVIEW

WILEY

The role of Connected Health technologies in supporting families affected by paediatric cancer: A systematic review

Emma Delemere | Rebecca Maguire

Potential of Connected Health Technologies



Home > Supportive Care in Cancer > Article

Original Article | [Open Access](#) | [Published: 06 May 2022](#)

Utility, barriers and facilitators to the use of connected health to support families impacted by paediatric cancer: a qualitative analysis

[Emma Delemere](#) , [Isaiah Gitonga](#) & [Rebecca Maguire](#)

Supportive Care in Cancer **30**, 6755–6766 (2022) | [Cite this article](#)

Technology usage, eHealth literacy and attitude towards connected health in caregivers of paediatric cancer



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REVIEW

WILEY

Impact of connected health interventions on psychological wellbeing and quality of life in patients with cancer: A systematic review and meta-analysis

[Isaiah Gitonga](#)^{1,2} | [Deirdre Desmond](#)^{1,2} | [Natalia Duda](#)³ | [Rebecca Maguire](#)^{1,2}

Conclusions



Living with illness presents **challenges** for all affected



Important to consider **psychological** impact of chronic illness



Interventions should aim to target **modifiable** factors



Clear needs for greater supports

Acknowledgements

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Questions?

