

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



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Research focus

Experience of living with chronic illness

Cancer

Type 1
Diabetes

COPD

Multiple
Sclerosis

Fibromy
algia/ME

Patient and **caregiver** perspectives

Psychosocial impacts

LGBTQ+
health

Evaluation of **supports**



IPPOSI

NCI Talk 15th June



Rebecca Maguire



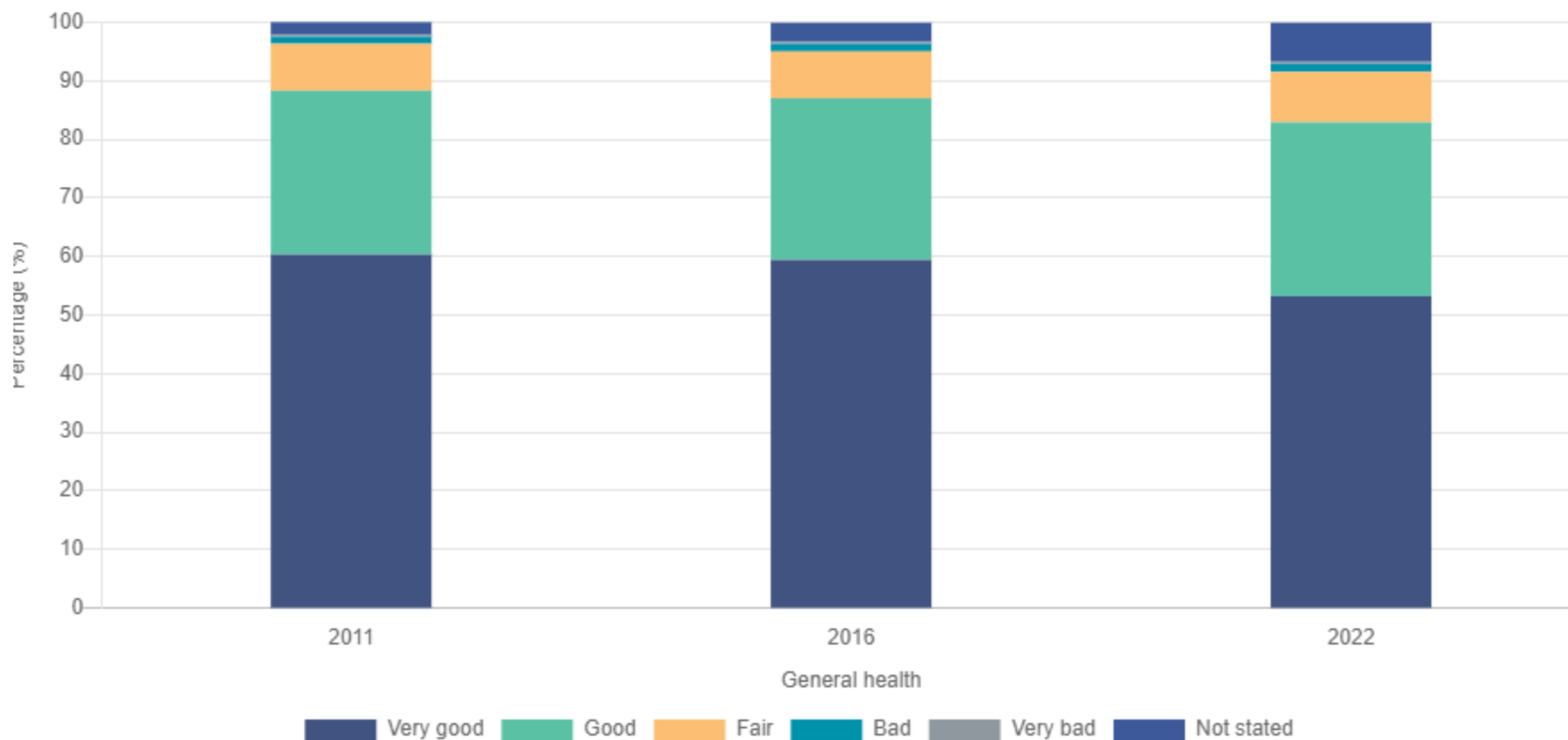
How would you rate your health?



Excellent Very good Good Fair Poor



Figure 3.1 Population by general health, 2011 to 2022



Self-rated health may not always be accurate



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promoting excellence in psychology

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British Journal of Health Psychology (2022), 27, 971–989

www.wileyonlinelibrary.com

971

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

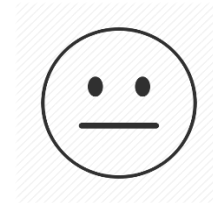
²Department of Psychology, Maynooth University, Co. Kildare, Ireland

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

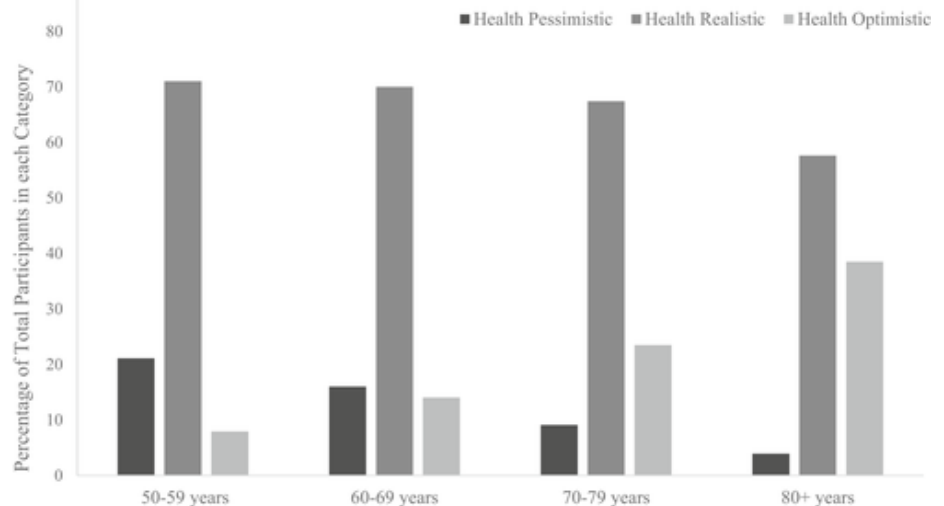
Health asymmetry

Three distinct categories:

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

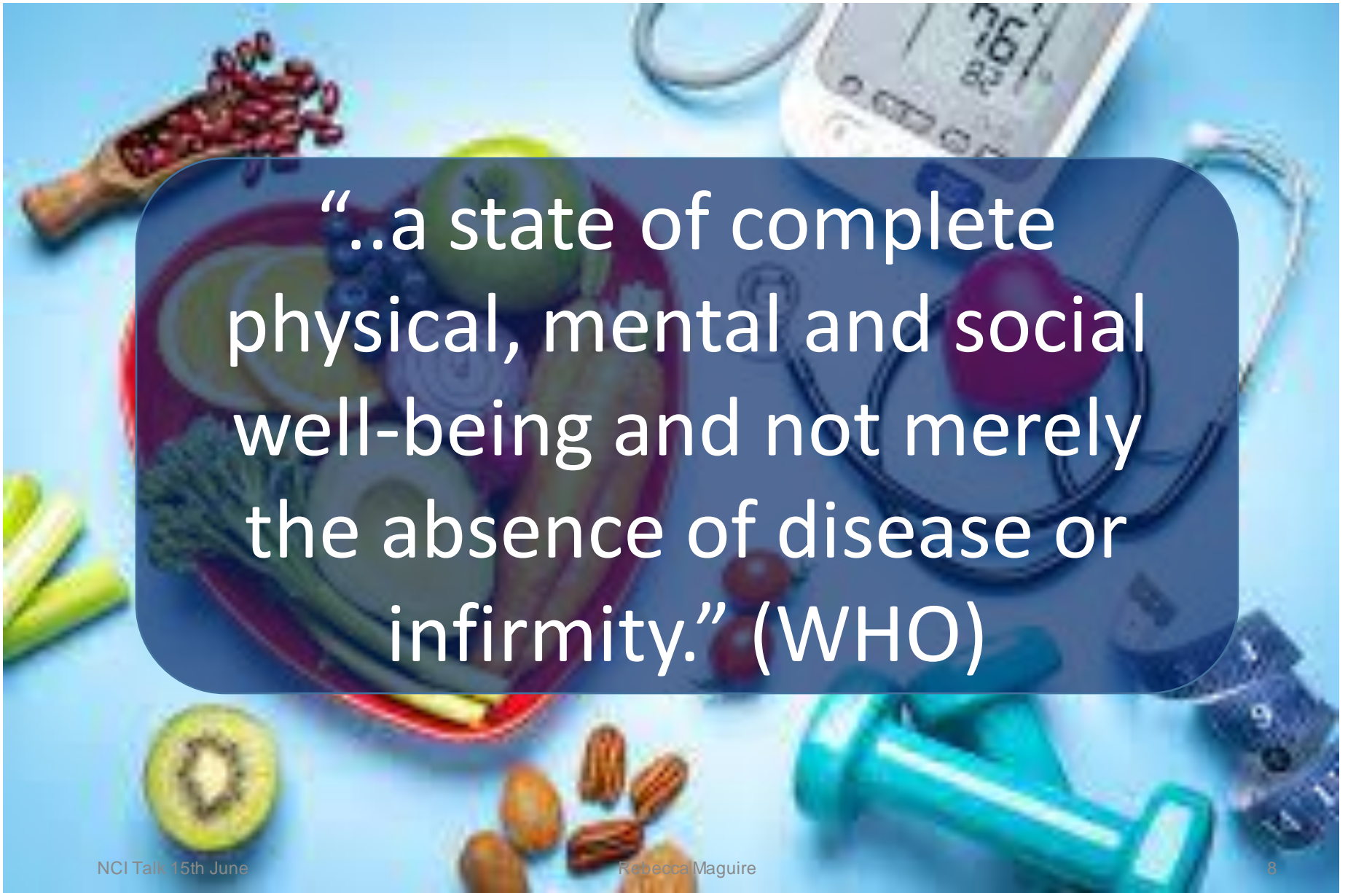


Using TILDA data
(n=6,907)



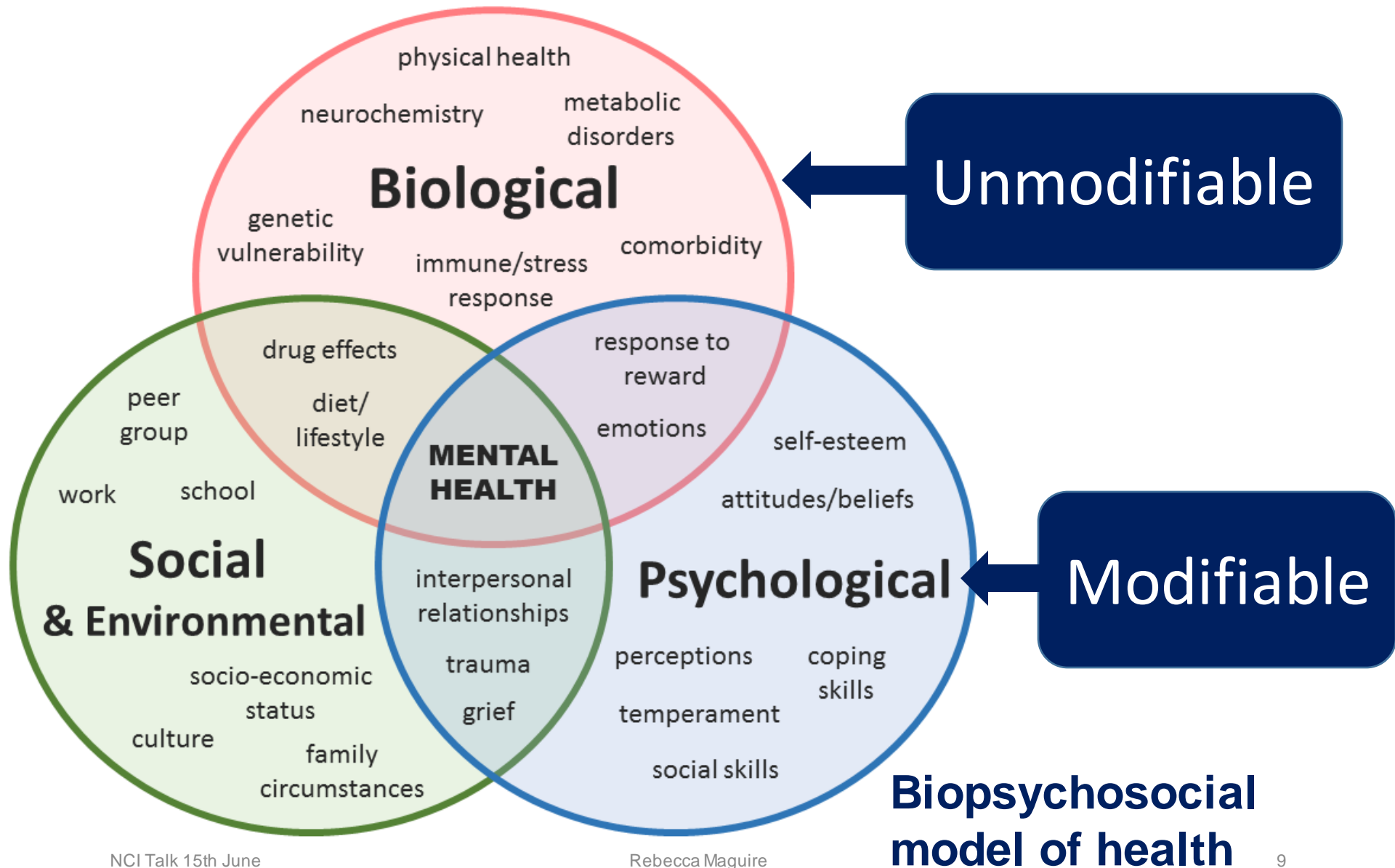
Health optimism increases with age (Calvey et al., 2022)

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>



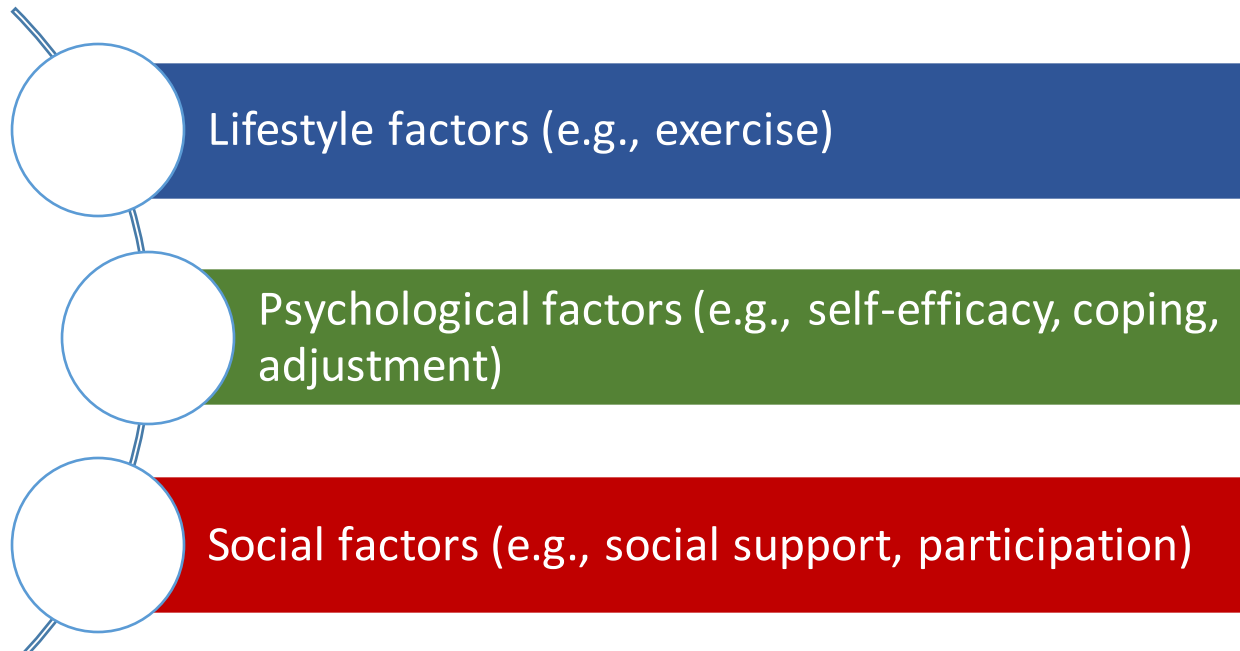
REVIEW

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

Rebecca Maguire¹  | Paul Hanly¹ 
Linda Sharp⁵ 



Received: 7 September 2016 | Revised: 9 December 2016 | Accepted: 23 January 2017

DOI 10.1002/pon.4384

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





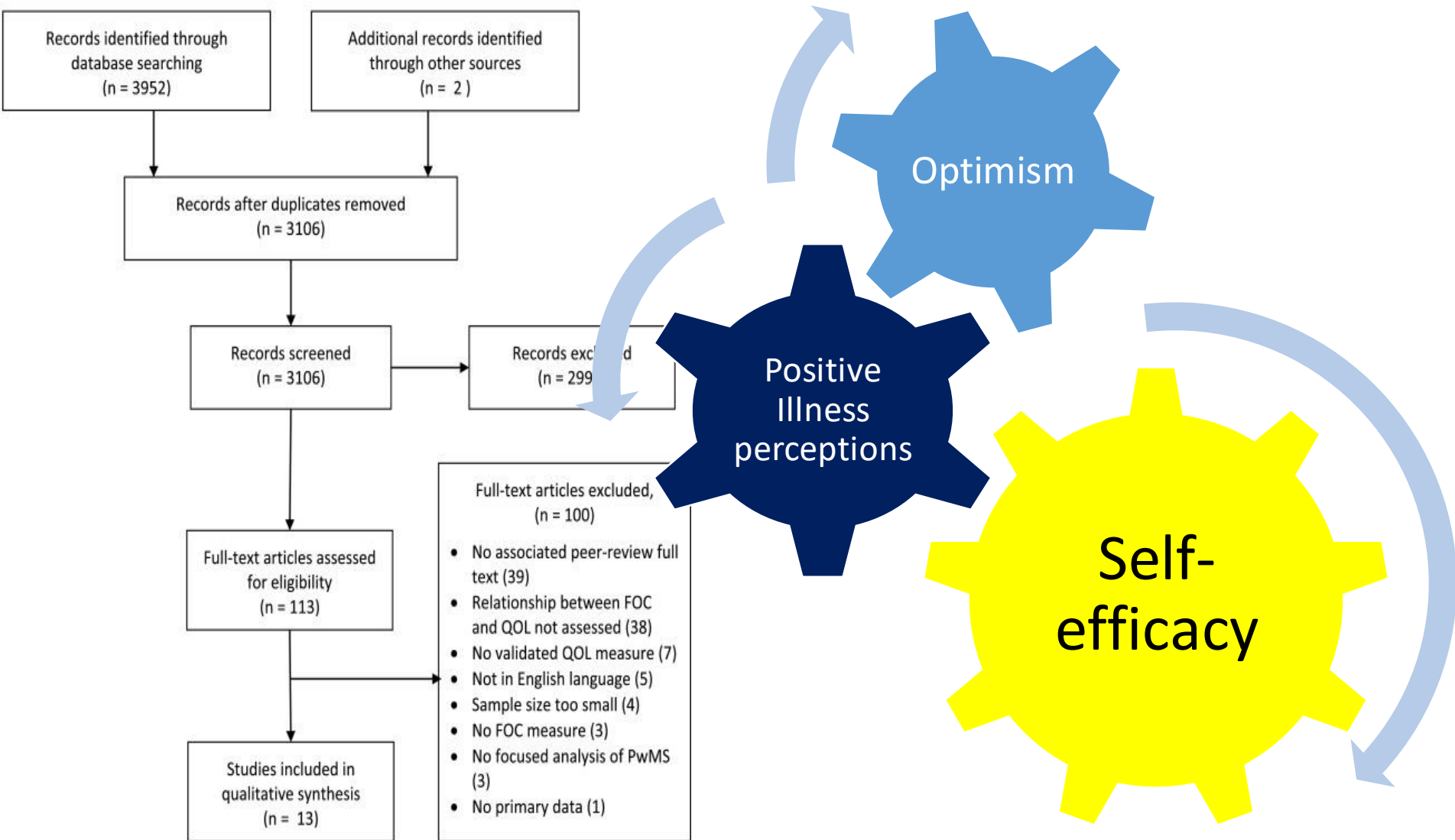
Multiple Sclerosis and Related Disorders

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

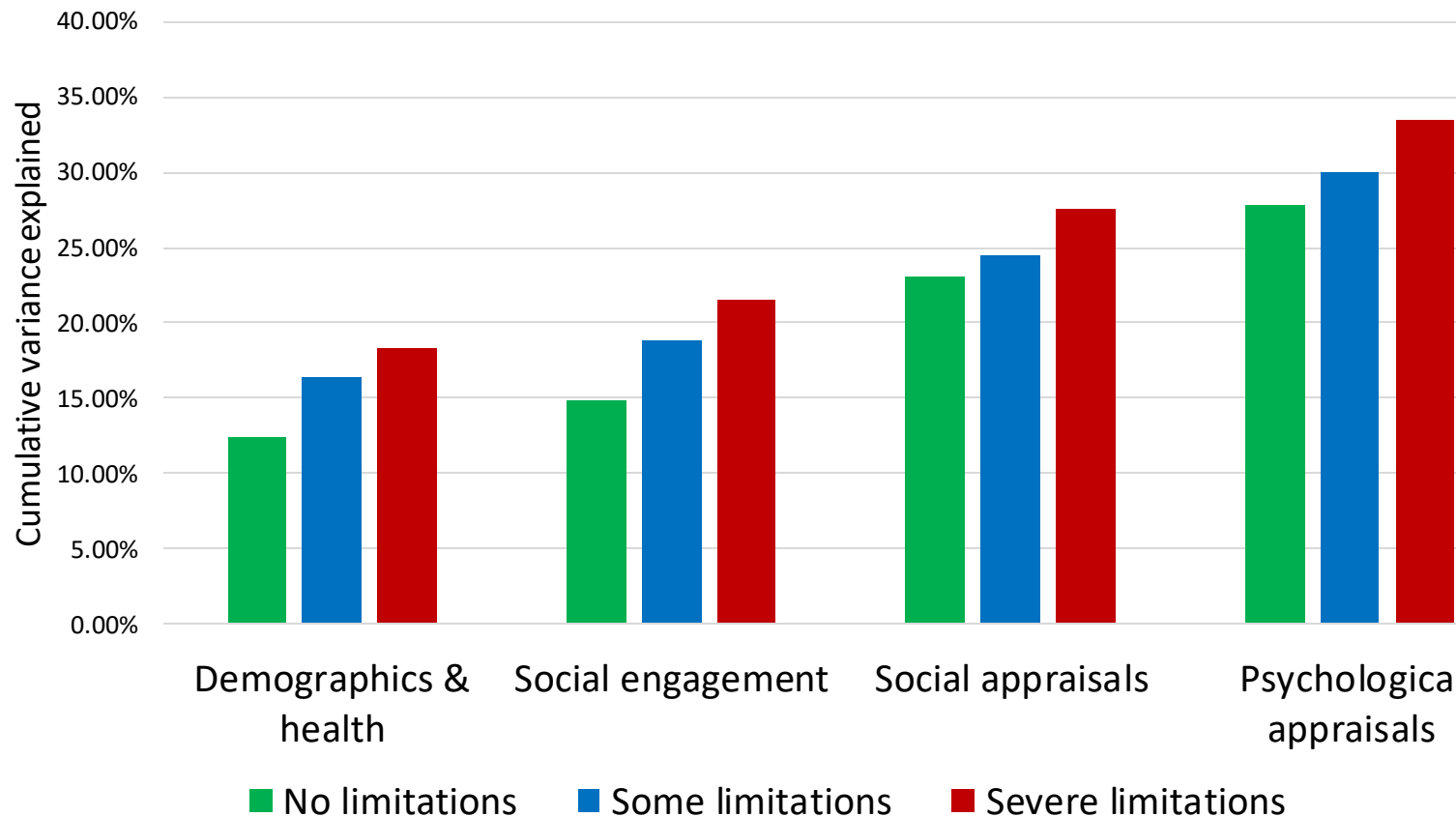
	Significant predictors
Sociodemographic and health factors	Gender Self-rated health
Characteristics of care and burden	Ease of combining care with work Ease of making ends meet Time burden
Psychological and social appraisals	Optimism Purpose Autonomy Resilience Low social exclusion

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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Rebecca Maguire¹ , Paul Hanly²
and Phil Maguire³

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



Importance of support

Multiple Sclerosis and Related Disorders 69 (2023) 104419



Contents lists available at ScienceDirect

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

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Emotional or psychological support



Employment accommodations



Information



Financial support



Social support



Coordination of care



Transportation/mobility



Caregiver support



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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 



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

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Received: 22 April 2022 | Revised: 7 August 2022 | Accepted: 15 August 2022

DOI: 10.1002/pon.6019

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 Duda³ | Rebecca Maguire^{1,2} 

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](#)




ADVANCECRT



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

Thanks to all my postgrads, collaborators, colleagues and PPI contributors for all their insights!



Questions?

