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Enablement of older people with chronic disease attending an Ambulatory Care Centre

Thesis presented by

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Table of Contents

Table of Tables **8**

Table of Figures **10**

Abstract Title: Enablement of older people with chronic disease attending an ambulatory care centre 14

Introduction 16

Chapter 1 Context & Background **19**

1.1 Introduction 19

1.2 Older People, Chronic Disease and Frailty 19

1.3 Enablement & Ambulatory Care 21

1.4 Enablement & Patient Consultation 22

1.5 Rationale for this Study 23

1.6 Summary 25

Chapter 2 Enablement: Origins and Conceptual Relationships **26**

2.1 Introduction 26

2.2 Enablement and Empowerment 26

2.3 Enablement, Collaborative Care & Patient Activation 29

2.4 Enablement and Person Centred Consulting 31

2.5 Summary 32

Chapter 3 Theoretical Perspectives on Enablement. **33**

3.1 Introduction 33

3.2 Theoretical Literature Search Strategy 34

3.3 Enablement Theoretical Underpinnings 36

3.4 Enablement: Concept Analyses 38

3.4.1 Enablement, A Framework for Patient Education 38

3.4.2 Enablement in Health Care Context 40

3.5 Conceptual Models of Enablement 45
3.5.1 Enablement from Patient & Doctors perspective in Consultations.....45
3.5.2 Developing Enabling Health Care Partnership Model 48
3.5.3 The Experience of Enablement within Nurse Practitioner Care.....51
3.5.4 The Consumer Enablement Model 53
3.6 Synthesis of Models 58
Chapter 4 Enablement of People with Chronic Disease consulting with a health professional in an ambulatory care setting: A Scoping Review.....65
4.1 Introduction 65
4.2 Scoping Review Methods.....66
4.2.1 Identifying the Research Question.....66
4.2.2 Identifying relevant literature 66
4.2.3 Selecting the Literature.....67
4.2.4 Charting the Data.....68
4.2.5 Collating, Summarizing and Reporting the Results 70
4.3 Results of Scoping Review.....70
4.4 Definitions of Enablement.....80
4.5 Measurement of Enablement.....82
4.5.1 The Patient Enablement Instrument (PEI).....82
4.5.2 Use of the PEI as a composite of other Research Instruments 84
4.5.3 Other Instruments used to measure enablement 84
4.5.4 Patient Outcome.....86
4.6 Factors Influencing Enablement.....89
4.6.1 Consultation Characteristics 89
4.6.2 Health Professional Skills.....92
4.6.3 Patient Characteristics.....97
4.7 Synthesis of theoretical and empirical literature 103

4.7.1 External Determinants of Enablement 104
4.7.2 Personal Determinants of Enablement 104
4.7.3 Components of enablement 104
4.7.4 The Dynamic Determinants of Enablement 107
4.7.5 Enablement as a Patient Outcome Measure 110
4.8 Research Gap 110
4.9 Summary 112
Chapter 5 Methodology 114
5.1 Introduction 114
5.2 Research Aims and Objectives 114
5.3 Research Hypothesis 115
5.4 Research Design 115
5.4.1 Study Setting 116
5.4.2 Study population 117
5.4.3 Inclusion and Exclusion Criteria 118
5.4.4 Access to the Research Site and Sample 119
5.5 Questionnaire Design 119
5.5.1 Patient Enablement Instrument (PEI) 122
5.5.2 Psychological Morbidity 122
5.5.3 Clinical Frailty Scale 122
5.5.4 Patient Activation 123
5.5.5 Professional Enabling Skills (mPESQ) 124
5.6 Cognitive Interviews 126
5.7 Data collection 128
5.8 Data Analysis 129
5.9 Data storage 130
5.10 Rigour in Quantitative Research 130

5.10.1 Validity 130
5.10.2 Reliability 132
5.11 Ethical Considerations 133
5.11.1 Principle of Autonomy 133
5.11.2 Principle of Beneficence 133
5.11.3 Principle of Justice 135
Chapter 6 Research Findings 136
6.1 Introduction 136
6.2 Population Demographic & Health-related Characteristics. 136
6.2.1 Age, Gender and Living arrangements. 136
6.2.2 Chronic Conditions / Comorbidities 137
6.2.3 Frailty 137
6.2.4 Self-Reported Health 138
6.2.5 Psychological Morbidity 139
6.2.6 Patient Activation 139
6.2.7 Health Service Utilisation 141
6.2.8 Consultation & Ambulatory Care Visit 142
6.3 Enabling Skills of the Health Professional 145
6.4 Patient Enablement (PEI) 147
6.5 Univariate Analysis 148
6.5.1 Patient characteristics & Health Service Engagement 148
6.5.2 Consultation Characteristics 150
6.6 Inferential Statistics: Univariate Analysis 152
6.6.1 Age and Gender 154
6.6.2 Formal and Informal Supports. 155
6.6.3 Patient Health, Fitness and Activity 156
6.6.4 Health Service Engagement 159

6.7 Inferential Statistics: Multivariate Analysis 161
6.8 Final model 163
6.9 Contextual Information (responses to open ended questions) 164
6.9.1 Life Circumstances, Formal & Informal Supports 165
6.9.2 Dynamic Determinants of Enablement 165
6.9.3 Patient Characteristics (Components) 168
6.9.4 Enablement and Improved Patient Outcomes 169
6.10 Hypothesis Testing 170
Chapter 7 Discussion 173
7.1 Introduction 173
7.2 Overview of Results 173
7.3 Predictors of low enablement 174
7.3.1 Gender 174
7.3.2 Frailty 175
7.3.3 Patient Activation 176
7.3.4 Professional Enabling Skills 177
7.4 Other Influencing Factors 178
7.4.1 Unidisciplary versus Multidisciplinary Consultation. 178
7.4.2 Age 179
7.4.3 Formal & Informal Supports 179
7.4.4 Chronic Disease / Multiple Comorbidities 180
7.4.5 Self-reported Health 180
7.4.6 Psychological Morbidity 181
7.5 Measurement of Enablement 181
7.6 Application of the Enablement Model 183
7.6.1 Dynamic Determinants 186
7.6.2 Components of Enablement 188

7.6.3 Enablement as an Outcome.....190
7.7 Implications of Research on Clinical Practice.....191
7.8 Summary 194
7.9 Conclusion.....196
7.9.1 Strengths of the Research 200
7.9.2 Limitations of the Research 201
7.9.3 Recommendations.....202
Reference List.....207
Appendix I Research Setting.....235
Appendix II Communication with Published Experts 240
Appendix III Patient Enablement & Satisfaction Survey.....242
Appendix IV Original Physician Enabling Skills Questionnaire 24240
Appendix V Study Protocol……245
Appendix VI Research Ethical Approval.....266
Appendix VII Review of Research Instrument 246
Appendix VIII Expert Review & Cognitive Interviews.....247
Appendix IX Study Research Questionnaire.....252
Appendix X mPESQ Confirmatory & Exploratory Factor Analysis 261
Appendix XI Participant Information Letter 236

Table of Tables

Table 3.1 Comparative Analysis of Conceptual Frameworks of Enablement ...44
Table 3.2 Characteristics of Enablement at different levels 57
Table 3.3 Synthesis of Enablement Models 62
Table 4.1 PICO.....67
Table 4.2 Scoping Review Results.....72
Table 4.3 Definitions of Enablement 81
Table 4.4 Summary of PEI Scores.....88
Table 4.5 Influencing Factors on Enablement (of varying statistical significance) 105
Table 4.6 (b) Influencing Factors on Enablement (of varying statistical significance) (continued from previous page).....106
Table 5.1 CEM guides selection of questionnaire variables.....121
Table 5.2 modified Professional Enabling Skills Questionnaire (mPESQ) 125
Table 5.3 Scales Reliability.....132
Table 6.1 Psychological Morbidity 139
Table 6.2 PAM 13 Level of Statement Agreement (does not include disagreement calculations) 140
Table 6.3 Population Demographic and Health Profile.....141
Table 6.4 Health Service Utilisation 142
Table 6.5 Characteristics of ambulatory care consultation 143
Table 6.6 Reason for Consultation 144
Table 6.7 mPESQ items Level of Agreement (calculations of disagreement not included).....146
Table 6.8 Percentage Representation of PEI scores.....148
Table 6.9 Association between patient variables and mean PEI 149
Table 6.10 Health Conditions and mean PEI 150
Table 6.11 Consultation Characteristics and Mean PEI Scores.....151
Table 6.12 Non-parametric Spearmas correlation between PEI and quantative variables 151
Table 6.13 Univariate Analysis: Continuous independent Variables associated with Enablement 152

Table 6.14 Univariate Analysis: Categorical independent Variables associated with Enablement 152
Table 6.15 Multivariable logistic regression analyses: factors associated with low patient enablement.....162
Table 6.16 Results of the backward selection multivariable logistic regression analyses investigating factors associated with patient enablement, n=273.....163
Table 7.1 Strategies for enablement for people with different levels of self-management capacity.....193

Table of Figures

Figure 3.1 Literature Search PRISMA Flow Diagram (Moher et al... 2009) 35
Figure 3.2 Framework for Patient Education: an analysis of Enablement 39
Figure 3.3 Conceptual Framework of Enablement in Health Care Context.....41
Figure 3.4 Conceptual Model of Enablement from Patient Perspective 46
Figure 3.5 Conceptual Model of Enablement from Doctor Perspective 47
Figure 3.6 Developing Enabling Health Care Partnership 49
Figure 3.7 Enablement and Satisfaction Model in nurse-led outpatient clinics.50
Figure 3.8 The experience of enablement within Nurse Practitioner Care 52
Figure 3.9 Consumer Enablement Model 55
Figure 4.1 Literature Search PRISMA Flow Diagram ……69
Figure 4.2 A Wordle of Enablement Definitions 82
Figure 4.3 Patient Enablement Instrument (Howie et al. 1998) 83
Figure 4.4 Enablement based on Synthesis of the Theoretical and Empirical Literature 108
Figure 5.1 Population change 2011-2016 by age cohort, Cork & Kerry, Census HSE South, 2016.....117
Figure 6.1 Age Profile 137
Figure 6.2 Frailty Status 138
Figure 6.3 Self-Reported Health 138
Figure 6.4 Patient Activation Category Representation.....139
Figure 6.5 Number of Clinic Visits at Ambulatory Centre 143
Figure 6.6 Professionals seen during Consultation (numbers reported) 143
Figure 6.7 Issues Discussed During Consultation 145
Figure 6.8 Distribution of scores on the PEI scale 147
Figure 6.9 Boxplots of age by patient enablement group 154
Figure 6.10 Gender by patient enablement group 154
Figure 6.11 Bar chart of living alone by patient enablement group.....155
Figure 6.12 Receipt of home help visits by patient enablement group.....155
Figure 6.13 Number of chronic diseases by patient enablement group 156
Figure 6.14 Self-reported health by patient enablement group 157
Figure 6.15 Boxplots of psychological morbidity by patient enablement group 157

Figure 6.16 Boxplots of clinical frailty by patient enablement group 158
Figure 6.17 Boxplots of patient activation by patient enablement group 158
Figure 6.18 Bar chart of admission to hospital in past year by patient enablement group 159
Figure 6.19 Bar chart of First visit by patient enablement group 159
Figure 6.20 Single or multi-disciplinary involvement by patient enablement group. 160
Figure 6.21 Boxplots of professional enabling skills by patient enablement group 161
Figure 6.22 Independent Predictors of low enablement 164
Figure 7.1 Influencing factors on low enablement post Consultation with a health professional 185
Figure 7.2 Consumer Enablement Model for Older People.....187

Declaration

"This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism."

Mary J. Foley, 01:05:2020

Acknowledgements & Dedication

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The older persons with chronic illness who participated in this study shall remain nameless but not forgotten. Their courageous response to life's challenges evokes worthy respect. The diverse needs of this population and the influential role of health care professionals fuelled my interest in the topic of enablement of older people with chronic disease. An enablement approach ensures that services are responsive, user friendly, person centred, and optimum patient outcomes are achieved. As an advanced nurse practitioner in rehabilitation of older people, I appreciate the unique contribution of nursing while also recognising the strengths of co-ordinated interdisciplinary engagement.

This work is dedicated to my family.

Lorraine, you have been a calming influence and a source of inspiration in times of stress. As my daughter and an advanced nurse practitioner yourself, you had an insightful perspective into balancing work, study, and family life. Thank you and Conor for my beautiful grandchildren, Cara & Danny who are source of joy and a welcome distraction.

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Padraig, thank you for your ongoing support and good humour.
Yes…. 'the essay' is finally finished !

Abstract Title: Enablement of older people with chronic disease attending an ambulatory care centre.

Background: Population ageing, and the increasing incidence of chronic disease requires a responsive health service and new enabling models of care (Wren *et al.* 2017, Bridges *et al.* 2019, Kennedy 2019). Within the dynamics of healthcare engagement, there is recognition of the positive influence of the enabling skills of the health professional on patient enablement encompassing knowledge, confidence, coping and management of health and illness (Howie *et al.* 1997, 1998). The clinical consultation is a pivotal exchange between the health professional and patient, so it is vital to optimise its quality (Al Momen *et al.* 2015**,** Pawlikowska & Marinowicz, 2015).

The Consumer Enablement Model (Batterham *et al.* 2017) acknowledges the diverse contexts in which people seek care and identifies dynamic determinants and key components (cognitive, affective/motivational, physical, and relational) that impact enablement. Little is known about the factors influencing enablement in an older adult population living with chronic health conditions attending an ambulatory care service.

Aim: To examine enablement of older people with chronic disease post consultation with a health professional and identify influencing factors for low enablement.

Method: A descriptive quantitative, cross-sectional survey was conducted.

Data Collection: Data were collected using a 72-item questionnaire. In addition to demographic questions, it contained the validated instruments Patient Enablement Instrument (PEI) (Howie *et al.* 1997), Patient Activation Measure (Hibbard *et al.* 2005) and Clinical Frailty Scale (Rockwood *et al.* 2005) and modified Physician Enabling Skills Questionnaire (Hudon *et al.* 2015).

Sample: In total, 300 older people with chronic disease were recruited from an ambulatory care centre (attending nurse, doctor, or therapist). Incomplete questionnaires were omitted, leaving a sample of 273 for analysis.

Data Analysis: Descriptive and inferential statistical analysis was used. Logistic backward stepwise regression examined the association between the independent variables and the dependent variable low enablement (PEI score ≤ 4).

Findings: The study population mean age was 79.7 years (SD 6.8) and 52% were female. Sixty-one per cent of participants had three or more chronic conditions, 35% described their health as fair or poor, and 26% indicated that they were frail (CFS ≥ 5). The population mean PEI score was 4.48 (SD 3.5). In the final multivariate analysis, four variables remained independent predictors of low enablement: female gender (OR 1.96 (CI 1.07- 3.60), clinical frailty (per 1 unit increase) OR 1.26 (95% CI 0.93-1.63), two variables were protective, patient activation OR 0.97 (95% CI 0.95-0.99) and health care professional enabling skills (OR 0.92 (95% CI 0.89-0.94). There were an additional eight variables that were significant in the univariate analysis: older age, living alone, three or more chronic diseases, poor self-reported health, psychological morbidity, receipt of home help, visit from a public health nurse and being seen by a single discipline during the clinic visit.

Conclusion: This research affirms that older people have the capacity to become more enabled and are responsive to the enabling skills of the health professional and proactive coordinated multidisciplinary engagement. Enablement post-consultation is multi-faceted, with risk and protective factors that influence individual health gains. Quality measures & expectations of health gains should be viewed within this wider context.

Implications for practice: Research findings support a person enablement model that provides for a heterogenous population in a state of transition (health, functional, psychological). Modifiable risk factors associated with low enablement, such as frailty and low patient activation require a comprehensive holistic assessment and bespoke interventions beyond a single consultation. The enabling skills of the health professional are important to optimise patient gains and enhance understanding, management and coping with chronic illness. Healthy ageing strategies reinforced by health professionals committed to making every contact count, supports the political and strategic paradigm shift towards sustaining older people in the community.

Introduction

Enablement is a concept that has broad and meaningful application in the context of quality-driven health services and chronic disease management (Siegel *et al.* 2019). Sláintecare aims to sustain older people in the community and recognises the importance of supporting people to look after and protect their health (Department of Health 2018b, 2019). Population ageing and the increasing incidence of chronic disease requires a responsive health service and new enabling models of care (Wren *et al.* 2017, Bridges *et al.* 2019, Kennedy 2019). The Chronic Care Model (Wagner 1998) promotes productive interactions between the proactive health professional and the activated patient; however chronic disease and frailty may present challenges. Enablement is viewed as a multi-dimensional person-centred concept that reinforces capabilities and helps people gain control over their own lives (Barrie 2013). The Consumer Enablement Model acknowledges patient strengths and weaknesses, with enablement viewed as a fluctuating patient state requiring individually targeted interventions (Batterham *et al.* 2017).

As part of this research, a scoping review of the theoretical and empirical evidence on enablement was conducted. Over the last decade, there has been a surge of interest in enablement, providing insight into characteristics of enabling consultations from the perspective of patients and doctors (Pawlikowska 2011) and the enabling skills of the health professional (Hudon *et al.* 2011a, 2015). In the context of management of chronic illness in general practice, the seminal work of Howie *et al.* (1997, 1998) identified characteristics of enabling consultations as health gains concerning patients' understanding of their health condition, coping with life and illness, confidence, and ability help oneself and keep healthy. In more recent years, enablement has been the focus of nursing research in developing enabling healthcare partnerships in general practice and outpatient settings (Desborough *et al.* 2016, 2017, 2018) and experience of enablement within nurse practitioner consultations (Frost *et al.* 2017a,b).

In ambulatory care settings, the consultation is a pivotal exchange between the patient and health care professional (Pawlikowska *et al.* 2010, Frost *et al.* 2015). It is important that the quality and value of this engagement are measured from service users' perspectives and better understood by health care professionals (Entwistle & Cribb 2013). Batterham *et al.* (2017) are critical of the prevailing '*unidimensional*

normative orientation' (p. 14) that presupposes a uniform response to the enabling interventions of the health professional and fails to adequately consider patient variables that influence enablement as an outcome measure (Barrie 2013). Research on enablement to date has primarily focused on people with high enablement who are high functioning with relatively stable health conditions (Entwhistle & Cribb 2013, Batterham et al. 2017). This commonly leads to an overly simplistic interpretation of outcome measures and ill-defined enabling interventions. There is a dearth of evidence that examines the predictors of low enablement in an older adult population. This doctoral thesis focuses on older people living with chronic disease and the factors influencing enablement post consultation with a health care professional.

Outline of Thesis

Chapter 1 provides contextual background in relation to older people with chronic disease and ambulatory care. It provides a rationale for the research topic and justifies the selection of enablement as an appropriate concept to measure gains post consultation.

Chapter 2 examines conceptual boundaries of enablement with other related concepts such as empowerment to provide operational clarity. Enablement is identified as having a narrower operational definition than other concepts with broader application in the context of quality-driven health services.

Chapter 3 provides a more focused examination of the theoretical literature pertaining to enablement. Conceptual frameworks and theoretical models are described, and common constructs are identified. The Consumer Enablement Model (CEM) is identified as the 'best fit' model for this research, and a priori conceptual framework is presented.

Chapter 4 presents the results of a scoping review of the empirical literature on enablement and influencing factors from a patient perspective. Due to the dearth of literature pertaining specifically to an older adult population, the scope of the review is widened to include an adult population attending ambulatory (non-inpatient health care settings). Results of the scoping review identify a significant research gap and inform the research objectives and methodology.

Chapter 5 outlines the aim of the research and rationale for a descriptive quantitative cross-sectional survey design. In addition to demographic and health profile questions, the study instrument contained three validated instruments: The Patient Enablement Instrument (PEI, Howie *et al.* 1997, 1998), the Patient Activation Measure (Hibbard *et al.* 2005) and the Physician Enabling Skills Questionnaire (PESQ, Hudon *et al.* 2015) which was shortened with minor modifications to suit an older population. The study questionnaire was developed based on the evidence, expert opinion, and cognitive interviews with older people with chronic disease.

Chapter 6 presents the research results following descriptive and inferential statistical analysis of data from 273 completed questionnaires. The characteristics of an older adult population with chronic disease are presented. Logistic regression and univariate and multivariate analysis identified influencing factors and independent predictors of low enablement.

Chapter 7 presents a discussion of the findings and compares the research results with current evidence. The identified significant variables are mapped onto the Consumer Enablement Model. Recommendations for practice, education and research are discussed. The strengths and limitations of the research are presented.

Chapter 1 **Context & Background**

1.1 Introduction

This chapter provides a background for this research topic and highlights the relevance of the concept of enablement within the context of an ageing population with an increased prevalence of chronic disease and frailty. Enablement is described as a professional intervention by which the health care provider recognises, promotes, and enhances patients' ability to control their health and life (Hudon *et al.* 2010, 2011a, 2013, Desborough 2016, 2018). This view concurs with chronic disease and healthy ageing strategies where patients are equipped with the knowledge and skills to actively manage their health. It aligns well with Sláintecare health and social care programme for Ireland, which aims to enhance public health and prevention, enable self-care and shift from hospital-centric based services to community integrated services (Burke *et al.* 2018). A key aspect of this is ambulatory care and the quality of healthcare engagement. The author draws on her own clinical experience as an advanced nurse practitioner in the rehabilitation of older people (ambulatory care) to provide a supporting rationale for this research topic.

1.2 Older People, Chronic Disease and Frailty

Nationally and internationally, there is an increasing demand for health services due to an ageing population. In Ireland's last census in 2016 there were 637,567 over 65 years, which increased 19% on the previous census (Central Statistics Office 2017). This is linked with increased incidence of chronic disease, frailty, and disability (van den Bussche et al. 2011, Roe *et al.* 2016, Reyes *et al.* 2017, Sheehan & O'Sullivan 2020). In Ireland, approximately 60% of those aged over 50 years have at least one chronic condition (Department of Health 2017). The Irish longitudinal study on ageing (Roe *et al.* 2016), reported that 65% of older people (> 65 years) live with comorbidity (two or more chronic conditions such as diabetes, asthma, chronic obstructive pulmonary disease, or cardiac failure). Multiple comorbidities in this age group frequently reduce physiological and psychological reserves particularly when social supports are lacking (Kone *et al.* 2015, Petitte *et al.* 2015). Up to 25% of older people in Ireland live with frailty (Roe *et al.* 2016). This is described as an age-related state of increased vulnerability with a decline in reserves and function across multiple physiologic systems where the ability to cope with everyday stressors is compromised

(Wyrko 2015). Frailty is associated with increased incidence of polypharmacy, incontinence, delirium, impaired cognition, falls, and increased risk of adverse outcomes because of illness (Stott and Quinn 2013, Turner & Clegg 2014, Lang *et al.* 2017). Hence the importance of enablement which focuses on increasing patient understanding, confidence and ability to self-care, engage in healthy behaviours, and cope with life and illness (Howie *et al.* 1997, 1998). These elements underpin the approach outlined in Healthy Ireland (Department of Health 2013, 2017), which calls on healthcare professionals to step up to the challenge of informing and enabling service users to become more active participants in their own health.

There is now greater recognition of differences in chronological versus biological age and the importance of healthy ageing (McGarrigle *et al.* 2017). The World Health Organisation (2015) outlines the importance of enabling health promotion strategies that add life to years and reduce functional disability and the negative discourse around ageing. The National Clinical Frailty Education Programme (Lang *et al.* 2017) addresses the enabling skills of the health professional. It is based on the principles of enablement and reablement where the focus is on abilities and optimising function. Enablement of people with chronic illness is central to healthcare quality initiatives that aim to enhance individual coping strategies and self-management (Miller *et al.* 2015).

An extensive survey involving General Practitioners (Darker *et al.* 2011) identified that Ireland compared less favourably with other countries regarding chronic disease management. Darker *et al.* (2014) identified that older people with multiple comorbidities most strongly expressed the need for change in the Irish health system. Internationally, a chronic disease self-care model underpinned by enablement principles is advocated whereby patients (and carers) are encouraged and supported to cope and live well with their condition. The National Self-Management Support Framework for Chronic Conditions (HSE 2017) and Living Well with a Chronic Condition; Framework for Self-Management Support (HSE 2020) target COPD, Asthma, Diabetes and Cardiovascular Disease. These documents promote enabling healthcare interventions and aim to increase patient's knowledge, skills, and confidence in managing their health conditions. Similarly, there are disease-specific programmes such as 'Enhancing and Enabling Wellbeing for the Person with Dementia' (Understand Together, 2019). With an ageing population and paradigm

shift towards community-based models of care delivery in Ireland, it is imperative that health professionals have the skills and confidence to enable older people wherever they access health services.

1.3 Enablement & Ambulatory Care

Nationally and internationally, there is a consensus on building the capacity of primary care and general practice to meet the needs of an ageing population. This involves developing alternatives to acute (secondary/tertiary) care through better integration of expertise between acute and primary care. The scoping review of the literature used a broad definition of ambulatory care to include 'walk-in' health services provided to patients without a hospital admission or overnight stay. The term encompasses preventative and primary care, specialist services and tertiary level care, collectively referred to as non-inpatient care (Ross *et al.* 1998). Ambulatory care services are evolving in Ireland, including central operational hubs, rapid access clinics, specialist expertise, and multidisciplinary outreach teams (HSE 2018). The research setting was an ambulatory assessment & treatment centre for older people with general and specialist clinics and multidisciplinary involvement providing access to diagnostics, treatment, and rehabilitation with close links with hospital and community-based services. The Consumer Enablement Model recognises the significance of wider health and social care engagement and the need for responsive community services (Batterham *et al.* 2017).

The Department of Health (DOH) blueprint for integrated care known as Slaintecare, promotes ambulatory care centres as a responsive solution to the medical and rehabilitation needs of older people, reducing demands on emergency departments and hospital resources (NCPOP 2012, Department of Health 2017, Burke *et al.* 2018, Petrosyan *et al.* 2018, HSE 2018). There is a need for key performance indicators that measure patient experience to scale up ambulatory care centres to meet the growing needs of an older population (HSE 2018). Internationally, the concept of enablement is central to improved patient experience and quality of care (Howie *et al.* 1997, 1998, 1999, Pawlikowska *et al.* 2010, 2011, Frost *et al.* 2015). It goes beyond physiological parameters and satisfaction outcome measures (Barrie 2013) to address health gains (knowledge, coping and self-management skills) because of engagement with a health professional.

1.4 Enablement & Patient Consultation

With approximately 400,000 patients awaiting an outpatient consultation at any given time, there are strategic moves to explore additional alternative options such as telephone, virtual consults and reconfigure outpatient services (HSE 2016b). The focus of this research is on enablement in the context of face-to-face consultations with a health professional. There is increasing emphasis on rapid access ambulatory care clinic slots, health promotion, making every contact count and chronic disease self-management programmes (HSE 2016). In this current climate where demands for services may compromise timely access, continuity of care and quality of engagement, it is important to use patient-reported outcome measures (PROMs) such as enablement to demonstrate health gains and the value of this service. Enablement is considered a more valid outcome measure than patient satisfaction (Howie et al. 1999, Frost *et al.* 2015).

Evidence suggests that differences exist between patient expectations and patient experience of a consultation (Thorsen *et al.* 2001, Redsell *et al.* 2007, Entwistle & Cribb 2013, Darker *et al.* 2014, Barrett & Thomas 2018). This may relate to inadequate consultation skills and failure to address patient's most salient priorities (Pawlikowska 2011). The scoping review of the literature identified: the enabling skills of the health professional as developing an ongoing partnership, providing advocacy for the patient in the healthcare system, starting from the patient's situation, legitimizing the illness experience, acknowledging patient expertise on their own lives, and offering realistic hope (Hudon et al. 2015). This concurs with the aim of rehabilitation to improve function and enable client to live his or her life to his or her fullest potential (Stott & Quinn 2013, p.1). Patients' welcome information regarding their condition and involvement in health-related decisions is not always engaged as active participants in their care and are not given adequate resources to cope with illness (Darker *et al.* 2014).

It is widely acknowledged that patient age-related deficits (physical, cognitive, and sensory) may impact the quality of the consultation (McGilton *et al.* 2018). Multiple comorbidities, complex symptom presentation and polypharmacy, add additional layers of complexity requiring a comprehensive geriatric assessment and specialist input (Gerber *et al.* 2011, Miolina-Garido *et al.* 2013, Frese *et al.* 2016). In addition

to physical complaints, psycho-social determinants of health also need to be addressed in the consultation, with loneliness and social isolation affecting quality of life, management of chronic disease, morbidity, and mortality (Courtin & Knapp 2015, Due *et al.* 2018). As part of the consultation, a comprehensive geriatric assessment includes appropriate onward referral to frailty or specialist care pathways and integrated services responsive to individual patients' needs (O'Reilly & O'Hanlon 2017, HSE 2016a).

The consultation is a pivotal exchange between a patient and health professional when based on enablement principles as it bolsters coping and self-management strategies and promotes healthy behaviours (Al Momen *et al.* 2015, Pawlikowska & Marinowicz 2015). Cognisant of the need for a person-centred outcome measure suitable for use with patients with life-limiting illness, Howie *et al.* (1997, 1998) developed the Patient Enablement Instrument (PEI) designed for use after a single consultation in general practice. The PEI dominates the research literature on enablement and has more recently been used as a quality outcome measure in other ambulatory/primary care settings with both medical and nursing healthcare professionals. The scoping review of the literature presents details of these studies that identify a range of PEI scores and several influencing factors on enablement: patient, health professional, and health service.

1.5 Rationale for this Study

Enablement is gaining recognition as a quality outcome measure with nurses in general practice (Desborough *et al.* 2016), outpatients (Desborough et al. 2018) and nurses in advanced practice roles (Venning *et al.* 2000, Frost *et al.* 2017a, 2017b, Barrett and Thomas 2018). As an advanced nurse practitioner (ANP) in rehabilitation of older people, I am acutely aware of the importance of an enablement approach as a foundation for therapeutic engagement with patients. This involves a reciprocal exchange of information to support optimum chronic disease management and coping with functional limitations associated with life-limiting illness (Foley *et al.* 2014a, b, 2016, O'Caoimh *et al.* 2015, Fox *et al.* 2017a, b). In the author's clinical role, she frequently encounters new clinic attenders with sub-optimum management of chronic illness such as Parkinson's' Disease due to knowledge deficits of their condition and treatment plan. Research evidence confirms that not all interactions are enabling with

missed opportunities for patient education and support strategies (Grover & Joshi 2014).

Chronic disease management requires a proactive response as advocated in the HSE health promotion initiative "making every contact count" (O'Brien & Scott 2016). Traditional approaches may fail to recognise the importance of patients' active participation in their care and therapeutic relationships with health and social care professionals (Bailo *et al.* 2019). More research is needed to identify the characteristics of enabling consultations, particularly with vulnerable groups where age-related changes may hinder active patient participation (Entwistle and Cribb 2013) and impact on enablement as a meaningful outcome measure of service quality. Research to date is poorly representative of older people and predominantly focuses on those with higher levels of enablement (Batterham *et al.* 2017). There is a need to examine factors associated with low enablement.

The enablement process requires health professional enabling skills and interventions focused on recognising, promoting, and enhancing the patients' ability to control their health and life (Hudon *et al.* 2010, 2011a, 2013, Desborough *et al.* 2014, 2016). Research on the enabling skills of the health professional is limited (Hudon et al. 2015) and is predominantly undisciplined. The diverse and complex needs of an older adult population often require the combined efforts of a multidisciplinary team. In the assessment and treatment centre (research setting), patients have access to a range of diagnostic and therapeutic interventions (Appendix I) and a multidisciplinary team which are included in this research study.

The key constructs of enablement, understanding, coping, and self-management underpin older persons, chronic disease, and health promotion strategies (HSE 2015, 2017). Research evidence supports the relevance of enablement in the context of improved patient outcomes and health service quality and efficiencies (Pawlikowska *et al.* 2010, Frost *et al.* 2015). The consequents of enablement include patient satisfaction, a feeling of self-efficacy, skill acquisition, improved health status and quality of life, engagement in health care and trust in health professionals (Hudon *et al.* 2011a). Consultations underpinned by enabling principles are considered more person centred and effective in reducing the dependency of patients on health services.

This aligns well with HSE quality domains person centred care, effective and improved health, and wellbeing (Health Service Executive 2016c).

1.6 Summary

This research focus on the enablement of older people with chronic disease aligns well with policy and strategies to promote active and healthy ageing and chronic disease self-management. It also compliments Slaintecare goals of enhancing community and ambulatory care services, improving the patient experience, optimising functional gains and hospital admission avoidance (Department of Health 2019). The current political climate expects that healthcare performance indicators will be defined and used to monitor quality assurance.

The consultation is an important exchange between the health professional and patient with the potential for gains in relation to understanding, confidence, coping and management (Howie et al. 1997, 1998, Hudon et al. 2011, Pawlikowska 2011, Frost et al. 2015). Enablement is a strengths-based person-centred concept that has broad application, encompassing the process of enablement, enablement as an outcome measure and the patient status of enablement. The constructs of enablement are not well established in the context of an older adult population, justifying the need for further research. The next chapter explores the origins of enablement as a concept associated with but distinct from empowerment. Definitions and overlap with other concepts are also examined to aid conceptual clarity.

Chapter 2 **Enablement: Origins and Conceptual Relationships**

2.1 Introduction

Patient enablement refers to the process or outcome of enabling patients to assess and manage their health conditions more competently, both as individuals and within the practitioner-patient relationship (Frost *et al.* 2015). Enablement is viewed as a core element of patient empowerment (Fumagalli *et al*. 2015), person centred care (Howie *et al.* 1997, 1998, Pawlikowska *et al.* 2012) and collaborative care (Paz Castro *et al.* 2017). It is also linked with patient activation (Siegal *et al.* 2019) and patient engagement (Batterham *et al.* 2017). Blurring of boundaries and interdependency of concepts required an examination of the position of enablement drawing on the work of Fumagali *et al.* (2015) and Valentin-Hjorth *et al.* (2018) who conducted concept mapping exercises.

The origins of enablement are traced back to the concept of empowerment which first appeared in the 1950's to address social inequalities (Hudon *et al.* 2011a). Definitions of empowerment have evolved to include the enabling interventions of health professionals focused on enhancing patient self-management and involvement in care related decisions (Small *et al.* 2013, Cerezo *et al.* 2016, Kayser *et al.* 2019). However, the constructs of power and control inherent in the definition and guiding frameworks of empowerment often negate person centred interventions (Fumagalli et al. 2015). The seminal work of Howie *et al.* (1997, 1998) has established enablement as a person-centred quality outcome measure post consultation. This chapter demonstrates that enablement has a clinically useful narrower definition than empowerment (Siegal *et al.* 2017) and has broad application underpinning person centred (Howie *et al.* 1997, 1998) and collaborative care (Valentin-Hjorth *et al.* 2018) with a close association with other concepts such as patient activation (Hibbard *et al.* 2004, 2005).

2.2 Enablement and Empowerment

A concept analysis on enablement traces its origins to the concept of empowerment and the strong association with the term 'potere' which means to be able (Hudon *et al.* 2011a). The earliest references to empowerment are traced back to oppression and social inequality, later moving into the domain of health focusing on community psychology, critical social theory, gender inequality, rural economy and more recently, health education and empowerment (World Health Organisation 2012). Over the

years, there were several attempts to improve conceptual clarity and operationalisation of empowerment as a clinically relevant and measurable construct with numerous concept maps and reviews on empowerment (Gibson 1991, Hawks 1992, Rodwell 1996, Ellis-Stoll & Popkess-Vawter 1998, Ryles 1999, 2001, Fingeld 2004, Aujolat *et al.* 2007, Virtanen et al. 2007, Rundqvist & Linstrom 2005, Loukanova *et al.* 2008, Holmstrom & Roing 2010, Dowling *et al.* 2011, Fotoukian *et al.* 2014, Castro *et al.* 2016, Cerezo *et al.* 2016, Agner & Braun 2018). Despite its' early origins and extensive literature, the concept of empowerment is deemed relatively immature and challenging to effect person centred outcomes (Dowling *et al.* 2011, Bailo *et al.* 2019). The potential for hidden power influences in favour of the health professional and asymmetric participation disadvantaging patients in consultations permeate the literature on empowerment (Mitcheson & Cowley 2003, Ryles 2004, Powers 2003, Aujolat *et al.* 2007, Tveiten S. & Meyer I. 2009, Dowling *et al.* 2011, Cerezo *et al.* 2016). This limits the application of empowerment in health services that aim to promote person centred care and self-management of chronic conditions.

Dimensions of empowerment are identified as participation in decision making, gaining control, knowledge acquisition, coping skills, a positive attitude, sense of meaning to patients with chronic disease, motivation, trust, self-care, sharing and capacity building (Cerezo *et al.* 2016). Cerezo *et al.* (2016) comment on the wide range of definitions and interpretations associated with this multidimensional concept and concluded that in the context of patients with chronic illness, it is regarded as both a process and outcome. Synthesis of the literature on the concept informed the following definition '*empowerment may be seen as an enabling process whereby health care professionals collaborate with patients to help them acquire knowledge and resources and whose outcome is a patient with greater ability to exercise control, manage his/her condition and to make informed decisions'* (Cerezo *et al.* 2016, p.669). Blurring of boundaries between the concepts of empowerment and enablement are evident in empowerment scales identified as a measurement of enablement (Hudon *et al.* 2010) and enablement scales identified as a measurement of empowerment (Cerezo et al. 2016).

Following an extensive review of the literature and a concept mapping exercise on empowerment and associated concepts (Figure 2.1) , Fumagalli *et al.* (2015) conclude that there are many ambiguities associated with the conceptualisation of empowerment

with lack of clarity regarding its' consequences and connection with neighbouring concepts. Patient empowerment is conceptualised as *'the acquisition of motivation (self-awareness and attitude through engagement) and ability (skills and knowledge through enablement) that patients might use to be involved or participate in decision-making, thus creating an opportunity for higher levels of power in their relationship with professionals'* (Fumagalli *et al.* 2015, p.390). Enablement is viewed as one of the key constructs of empowerment that maybe lost in the broader concept. Umar & Mundy (2015) comment on the multi-faceted collection of elements required to empower individuals regarding their health and the inadequacy of existing models that are inequitably focused on the provider rather than the user. The limitations of empowerment in chronic disease are also exposed by Patterson (2001), who reveal that practitioners frequently disregard the experiential knowledge of patients and do not provide the necessary resources for optimum management and function.

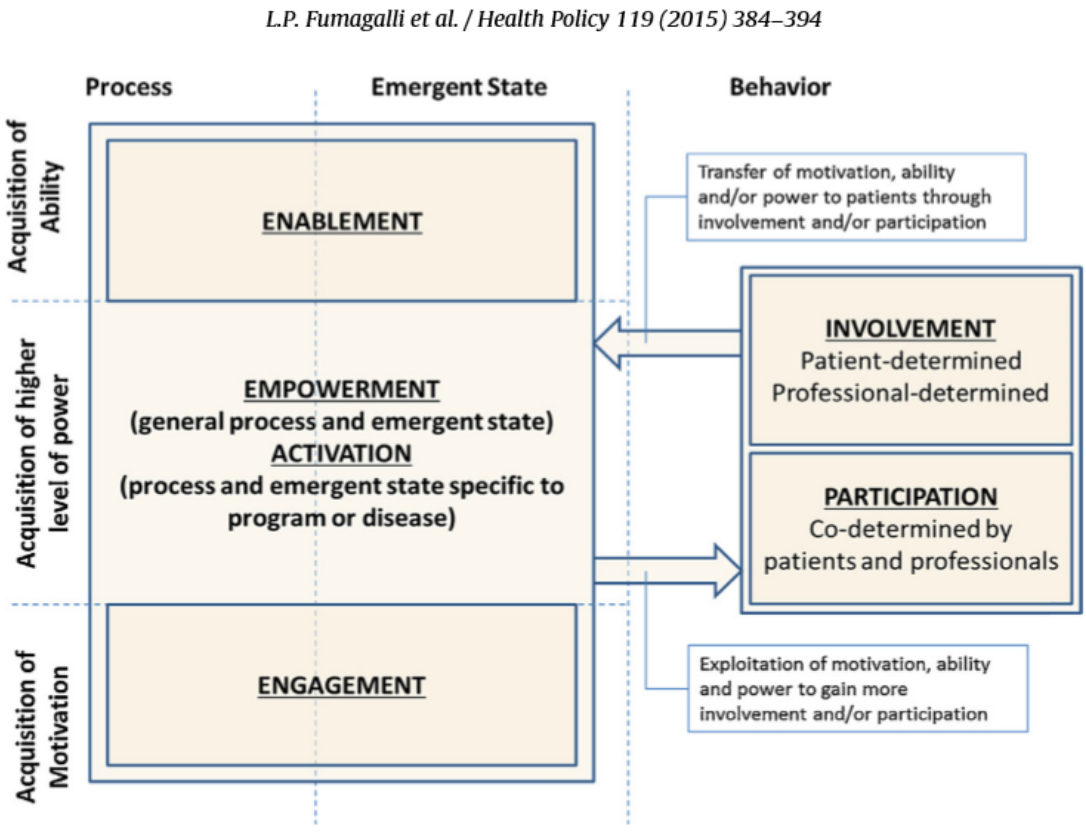


Figure 2.1 Concept Mapping of Empowerment & its neighbours (p. 390)

In more recent definitions of empowerment, there is evidence of concept development with more inclusion of the enabling skills of the health professionals and patients as co-managers active in health-related decisions (Small *et al*. 2013, Kayser *et al*. 2019). Fumagalli *et al.* (2015) concluded that patients are enabled if they have knowledge and skills and can participate in self-care or shared decision making without necessarily the power that is associated with empowerment. This interpretation limits application of enablement to those who have higher functional capacity and is challenged by other researchers (Entwhistle & Cribb 2013, Batterham *et al.* 2017). This is explored further in the theoretical chapter.

2.3 Enablement, Collaborative Care & Patient Activation

It is recognised that the design of healthcare delivery models aimed at reducing the burden of chronic disease requires an understanding of the foundational concepts of patient and healthcare provider collaborative care. Collaborative care is defined as 'patient-provider interactions and exchanges that occur on multiple occasions during (chronic) care management' (Valentin-Hjorth *et al.* 2018, p.2776). An extensive review of the literature identified enablement (in addition to engagement, empowerment, involvement, and participation) as a core concept of a taxonomy towards collaborative care. The definitions below and diagrammatic representation of the taxonomy of collaborative care (Figure 2.2) highlight the complexity and interconnectivity of relationships between concepts.

Enablement: '*the process of acquisition of health-related abilities, whether in the form of skills or knowledge'*

Engagement: *'the degree to which a patient is willing to participate in the care delivery process'.*

Empowerment: '*the process encompassing enablement, as well as that of gaining both control over the patient's own health decision-making and legitimacy'.*

Involvement: '*the degree of participation that providers actively attempt to obtain from patients*.

Participation: '*The tangible actions and behaviours exhibited by patients with the aim of benefiting their own health'.* (Valentin-Hjorth *et al.* 2018 p. 2781)

Patient Activation: Patient knowledge, skills, self-belief, and motivation to actively engage in self-management, health, and well-being (Hibbard *et al.* 2004, 2005).

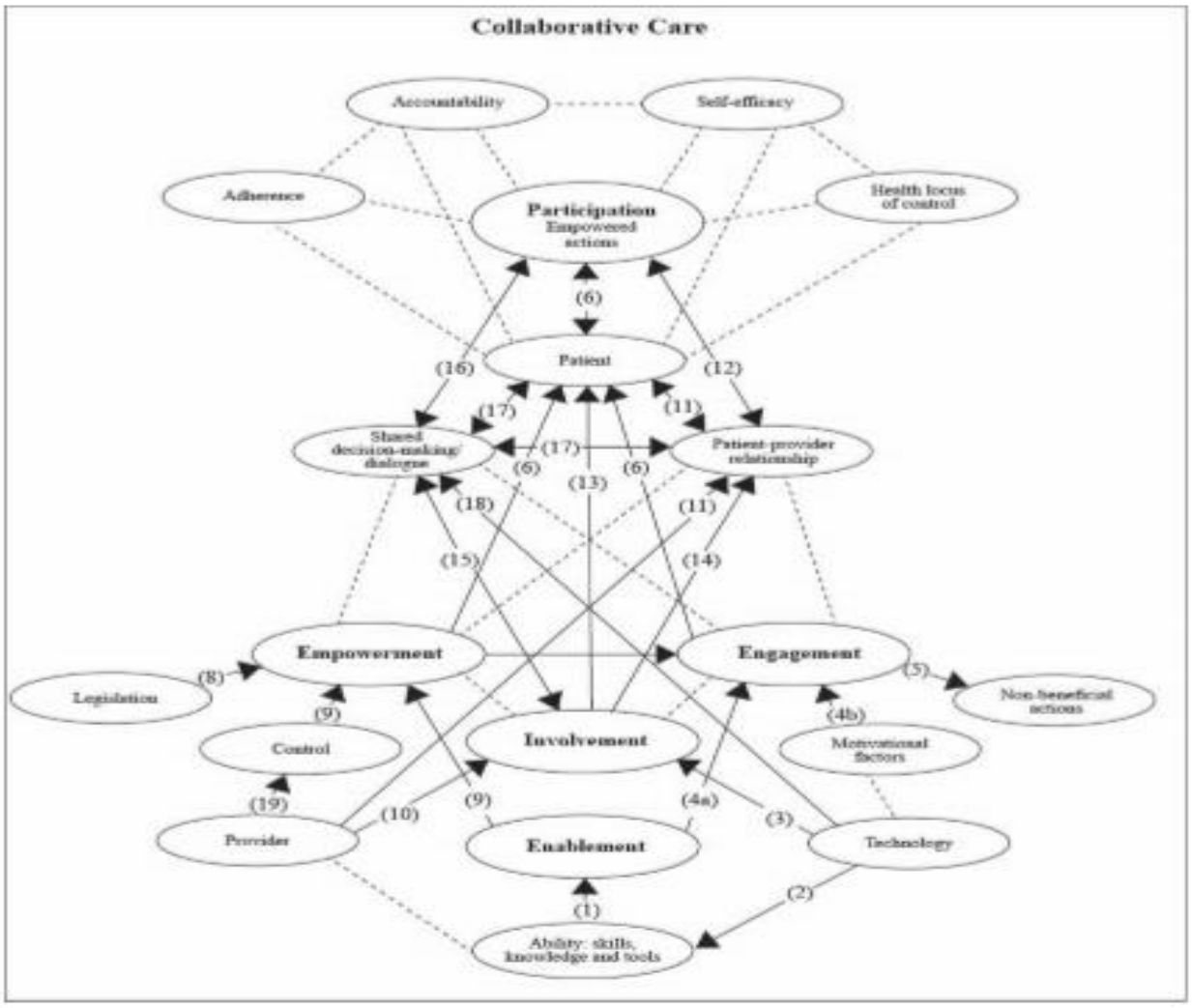


Figure 2.2 Enablement, part of a taxonomy of collaborative care
(Valentin-Hjorth *et al.* 2018, p. 2778)

Valentin-Hjorth *et al.* (2018) defined enablement as '*the process of acquisition of health-related abilities, whether in the form of skills or knowledge'* (p. 2778).

It is suggested that engagement and enablement are tightly connected to patient involvement and participation. Enablement requires patient engagement and is influenced by patients' beliefs and motivation (often termed patient activation), 'health locus of control' relating to empowerment and the degree of influence that individuals believe they have on their own health. This concurs with Siegal *et al.* (2019) who identify enablement as patient knowledge and skills and identify activation as a pre-requisite of enablement. Patient activation is described as patient

knowledge, skills, self-belief, and motivation to actively engage in self-management, health, and well-being (Hibbard *et al.* 2004, 2005). Hibbard and Mahoney (2010) associated low activation with 'negative self-conception' characterised as reduced motivation and a mind-set that the health professional is in control. This has been shown to have a negative impact on enablement (and related concepts) necessitating consideration when conducting research. Of relevance to consultations, Valentin-Hjorth *et al.* (2018) acknowledged that two-way conversations and therapeutic relationships may be limited by patient age, disease severity and cognitive skills and constrained by health professional time constraints and low prioritisation of patient involvement. This highlights the importance of the enabling skills of the health professional and recognition of potential influencing factors on enablement.

Like previous researchers (Bravo *et al.* 2015), Valentin-Hjorth *et al.* (2018) conclude that empowerment is complex and difficult to achieve as it requires a combination of patient enablement, engagement, and professional involvement. Siegal *et al.* (2019) surmise that the term 'enabled patient' has a narrower connotation (intension) but a larger conceptual scope (extension) than the terms 'empowered patient' and 'activated patient' (p. 4866) making it a more useful concept in the context of person-centred quality focused services.

2.4 Enablement and Person-Centred Consulting

Development of the concept of enablement is largely attributed to the seminal work of Howie *et al.* (1991, 1997, 1998) who recognised the inadequacy of existing satisfaction instruments to demonstrate health gains (understanding, management, and coping) post consultation with a general practitioner. Howie *et al.* (2004) identified a proposed theory of 'effective consulting' based on three principles (a) better quality care can be summarised as the achievement of better outcomes for patients with similar needs (b) a positive interaction between the values of patients and doctors and (c) a positive interaction can be helped or hindered by contextual variables. This was based on the premise of the importance of holistic person-centred care as characteristics of a good consultation and an effective practitioner (Howie *et al.* 2004).

Through an extensive literature review and focus group work with patients with chronic disease, Howie *et al.* (1998) identified six items to capture coping with life and illness, knowledge and confidence regarding health, ability to self-manage, and

maintain a healthy lifestyle which informed the development of the patient enablement instrument (PEI). Howie *et al.* (1998) identified that enablement correlates well with satisfaction but is a distinct concept and provides a more meaningful quality outcome measure of patient consultations with a health professional. This work has informed the theoretical development of enablement (Pawlikowska 2011, Desborough *et al.* 2016, 2018, Frost *et al.* 2017) and the PEI dominates empirical investigation of the concept. Developed specifically for primary care, the instrument prioritises enablement as the main aim of consultations whereby the health professional assists the patient to understand and better manage and cope with the health condition, help themselves and live healthier lives (Frost *et al.* 2015).

2.5 Summary

Concept mapping aided identification of the conceptual boundaries of enablement and its overlap with other concepts namely empowerment, engagement, and patient activation (Fumagalli *et al.* 2015). Valentin-Hjorth *et al.* (2018) proposed a taxonomy towards collaborative care which identified the significance of the concepts of enablement, engagement, empowerment, involvement, and participation and their inter-connections. It is acknowledged that empowerment has not provided sufficient operational clarity to effect meaningful change (Chambers & Thompson 2009) and has been limited in its response to an aging population and healthcare demands (Kayser *et al.* 2019). These limitations have led researchers to explore enablement as a competing and more clinically relevant concept (Siegel *et al.* 2019).

Enablement is distinguished from empowerment by the absence of power and self-determination which is replaced by a more facilitative partnership relationship, that involves the acquisition of knowledge and skills and patient involvement in health-related decisions. Enablement is viewed as having broad application which is best suited to chronic disease management. The seminal work of Howie *et al.* (1997, 1998) adds to our understanding of enablement and positions the concept central to person centred consultations. Key constructs are identified as understanding, confidence, coping, self-management, and engagement in healthy behaviours (Howie *et al.* 1997, 1998, Frost *et al.* 2015). To gain further conceptual clarity, the next chapter presents a focused review of the theoretical literature on enablement.

Chapter 3 **Theoretical Perspectives on Enablement.**

3.1 Introduction

Enablement is derived from the verb enable which was first used in the 15th century and defined as '*to make able, to make ready, give power, means, competence or ability to'* (the free dictionary 2017). Enablement is associated with the acquisition of health-related abilities in the form of knowledge, confidence, and ability to self-care, keep healthy, cope with life and illness (Howie *et al.* 1998, 1999). The concept of enablement is commonly used in the context of clinical consultations as an outcome measure that focuses on a patients' emergent state and in particular 'the gained measure in which patients understand their health conditions and feel able to cope with them' (McKinstry *et al.* 2006, p.396). The literature on this topic is complicated by a variety of definitions and different perspectives.

Focusing primarily on the process of enablement and the enabling skills of the health professional, Hudon *et al.* (2010) define enablement as ' *an intervention by which the healthcare professional recognises, promotes and enhances patient's ability to control their health and their life'* (p.1302). Batterham *et al.* (2017) concur with the key constructs of enablement in their definition but focus on 'the extent to which individuals understand their health conditions and have confidence, skills, knowledge & ability to self-manage their health and well-being'. Rather than a process or outcome measure, this definition refers to a 'patient state' and is described more fully as part of the consumer enablement model.

This chapter presents a review of the theoretical literature which includes two concept analyses (Stamler 1996, Hudon *et al.* 2011a) and enablement models informed by research (Pawlikowska *et al.* 2012, Desborough *et al.* 2017, 2016, 2018, Frost *et al.* 2017a, 2017b, Batterham *et al.* 2017). A priori framework was developed based on a synthesis of the theoretical literature which informed model development and research parameters. The chapter begins with an examination of the theoretical underpinning principles of enablement demonstrating the relevance and interpretation of enablement across disciplines.

3.2 Theoretical Literature Search Strategy

The purpose of this theoretical literature review was to establish conceptual definition of enablement and defining constructs. A comprehensive search was performed using the electronic databases Cinahl, Medline, Psych Info and Social Index. Search terms were included Enabl* and (concept * or theory* or model*or framework) and health. Although there is some overlap in the literature, the word empowerment was not used as a search term. This review focused solely on enablement as a distinct concept with unique theoretical frameworks.

The literature search question that guided this review was: what are the theoretical models and conceptual frameworks specific to enablement? The advice of an information specialist was sought to optimise the search strategy. The search included peer reviewed journal articles as well as the grey literature and was limited by language (English) and full text articles. The years of publication were restricted to 1990 to 2020. The timeframe was broad to capture the seminal work of Howie *et al.* (1997, 1998). New publications necessitated ongoing review and synthesis of the literature.

Inclusion Criteria

- relevant to the concept of enablement
- relating to models, theories, or frameworks
- healthcare focused.

Exclusion criteria

- not focused on enablement
- not containing reference to models, theories, or frameworks
- not relevant to healthcare

3.2.1 Results

The search strategy identified 505 articles and an additional 14 articles identified through manual searching. As presented in the prisma flow diagram (Figure 3.1) 22 were selected for detailed analysis which informed an understanding of the theoretical unpinning and constructs of enablement. These articles included two models based on conceptual analysis (Stamler 1996, Hudon *et al.* 2011a) and four models based on

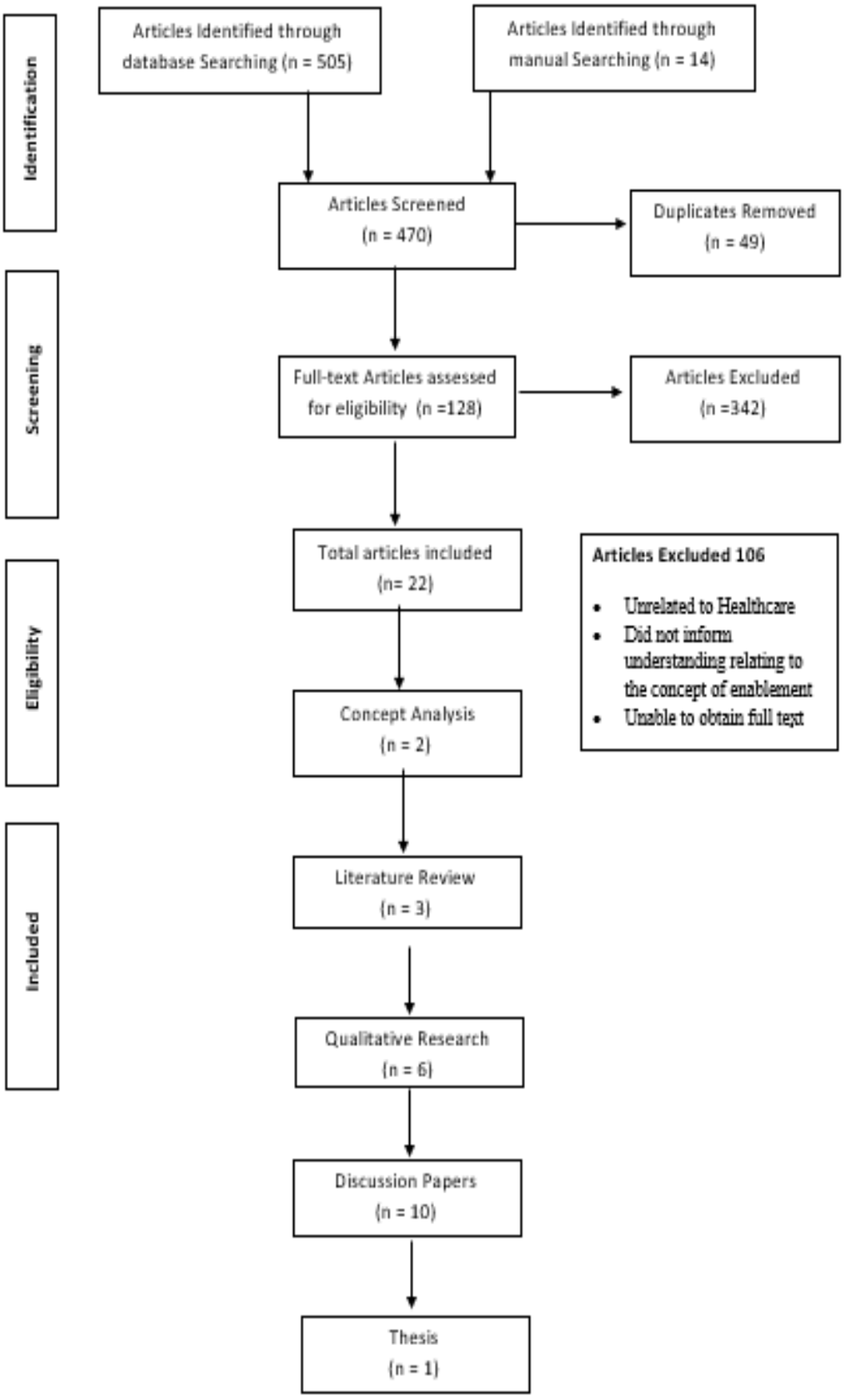


Figure 3.1 Literature Search PRISMA Flow Diagram (Moher *et al.* 2009)

qualitative research (Pawlikowska 2011, Desborough *et al.* 2016, 2017, 2018, Frost *et al.* 2017a. 2017b) and one model based on a rapid review of the literature (Batterham *et al.* 2017). Literature reviews (n = 3) (Hudon *et al.* 2011a, Frost *et al.* 2015, Batterham *et al.* 2017) and a published thesis (Pawlikowska 2011). The remaining articles (n = 10) informed understanding regarding the theoretical underpinnings of enablement (Cox 1981 , Bandura 1989, Lazarus & Folkman 1987, Swanson 1991, Valsiner 2003, Whyte 2014, Townsend *et al.* 2007, Masala & Petretto 2008, Domac & Sobaci 2014, Pawlikowska & Marcinowicz 2015).

The literature on enablement primarily originates from medicine and nursing. Many of the theoretical frameworks relate to enablement in the context of patient consultations with a health care professional and are underpinned by the seminal work by Howie *et al.* (1997, 1998). The most recent consumer enablement model (Batterham *et al.* 2017) provides a comprehensive perspective of enablement and is more patient focused than earlier models. Across models, the dynamic interplay of contextual, patient, and professional factors and outcomes are presented, highlighting the central role of user and provider trusting relationship in achieving enablement. The following section will present the theoretical literature pertaining to enablement drawing on literature from the fields of social psychology, allied health, medicine, and nursing.

3.3 Enablement Theoretical Underpinnings

The underpinnings of enablement are associated with various theoretical influences. In medicine, the concept is linked with the theories of coping (Lazarus & Folkman 1987) and adjustment (Cox 1981) on the basis that enablement significantly influences how individuals feel and perceive life after a medical consultation (Pawlikowska and Marcinowicz 2015).

The social cognitive behavioural theory of Bandura (1989) describes enablement as the enhancement of human agency whereby individuals or groups have the capacity to influence their situation. Outside of the patient and health professional relationship, this theory takes cognisance of the wider influence of families, communities, organizations, and social, local, and statutory agencies on supporting human agency and individual and collective efficacy. This concurs with Domac & Sobaci (2014) who

describe enabling as patterns of interaction which allow individuals to develop and grow. This highlights the significance of formal and informal influences on patient enablement and the enabling role of the health and social care professional.

Nurse theorist, Swanson's (1991) in her middle range theory of caring defined enabling as *'facilitating the other's passage through life transitions and unfamiliar events'* (p.192). The components of the enabling role were identified as coaching, assisting, supporting, guiding, and validating. Kalfoss and Owe (2015) conducted an empirical verification of Swanson's caring processes (knowing, being with, doing for, enabling, and maintaining belief) found in nursing actions. Characteristics of 'enabling' were identified as promoting independence, commitment, complexity of care (i.e., patient monitoring, care planning, onward referral, family dynamics), respectful communication, information, and education, sharing power (collaborative decision making), facilitating individual choice and validation of strengths. This is relevant to enablement of older people in the clinical consultation and broader context of rehabilitation and management of chronic illness.

Townsend *et al.* (2007) proposed the Canadian Model of Client Centred Enablement (CMCCE) and embraced enablement as the core competency of occupational therapy. The CMCCE outlines the key skills for client-centred, occupation-based enablement as adapting, advocacy, coaching, collaboration, consulting, co-ordinating, designing / building, educating, engaging, and specialising (Townsend *et al.* 2007). This model presents a continuum of possibilities including ineffective enablement, missed enablement, minimal enablement and effective enablement and acknowledges that "complex practice conditions as well as therapist choices determine possibilities for enablement" (Townsend *et al.* 2007, p. 130). This was further developed by van Rensberg (2018) who proposed a framework for occupational enablement which identified key enabling strategies as risk management, monitoring and measurement, strategies for sustaining and handover, communication, collaborative planning, interdependence and fostering relationships. In allied health and social care professions, enablement and enabling are synonymous with a holistic person-centred approach (Whyte 2014) and the passing on of techniques and skills (Irish Association of Speech and Language Therapists, 2016, Hutchinson *et al.* 2018).

In 2001, the World Health Organisation introduced a strengths-based enablement model, the 'International Classification of Functioning, Disability and Health' replacing pre-existing disablement models (Masalla & Petretto 2008). The ICF model goes beyond health diagnosis and takes into consideration biological, psychological, and social domains including functional abilities, activities, environment, and community engagement. Although constructs require further development, it is acknowledged that this model has broad application among disciplines and promotes a more holistic person-centred focus (Bruyère *et al.* 2005). Masala & Petretto (2008) identify weaknesses in the ICF model as it fails to recognise enablement as a dynamic fluctuating state.

In the domain of social psychology, the central mechanism of a proposed 'enablement theory' is 'forward-orientating constraining' whereby settings are viewed as dynamic (with enablers and constraints) and the person in the setting as its active re-constructor and co-constructor (Valsiner 2003). This proposed theory illuminates the person-centred principles of enablement and identifies the patient as a central active participant with context specific variables which may positively or negatively influence the enabling process and outcome of this healthcare engagement.

3.4 Enablement: Concept Analyses

Concept analyses provide a solid foundation for research by adding definitional and operational clarity (Walker and Avant 2011). A review of the literature identified two conceptual analysis which outline key constructs of enablement. Stamler (1996) explored enablement within the context of nursing and adult patient education while Hudon *et al.* (2011a) focused on enablement in a care relationship. Both approaches followed the precise and rigorous process of conceptual analysis, identifying the antecedents, attributes, and consequents of enablement.

3.4.1 Enablement, A Framework for Patient Education

In the context of nurse education, a concept analysis of enablement informed the following definition 'to assist the patient to acquire or expand the means, abilities and or opportunities to complete a task, or fulfil a role, to the patient's perceived satisfaction' (Stamler 1996, p.339). The author suggested that enablement may be viewed as two parts, (i) the 'enabler' as the person or object that enables and (ii) the 'enablee' as the person, goal or object that is enabled.

Conceptual Framework of Enablement in Patient Education

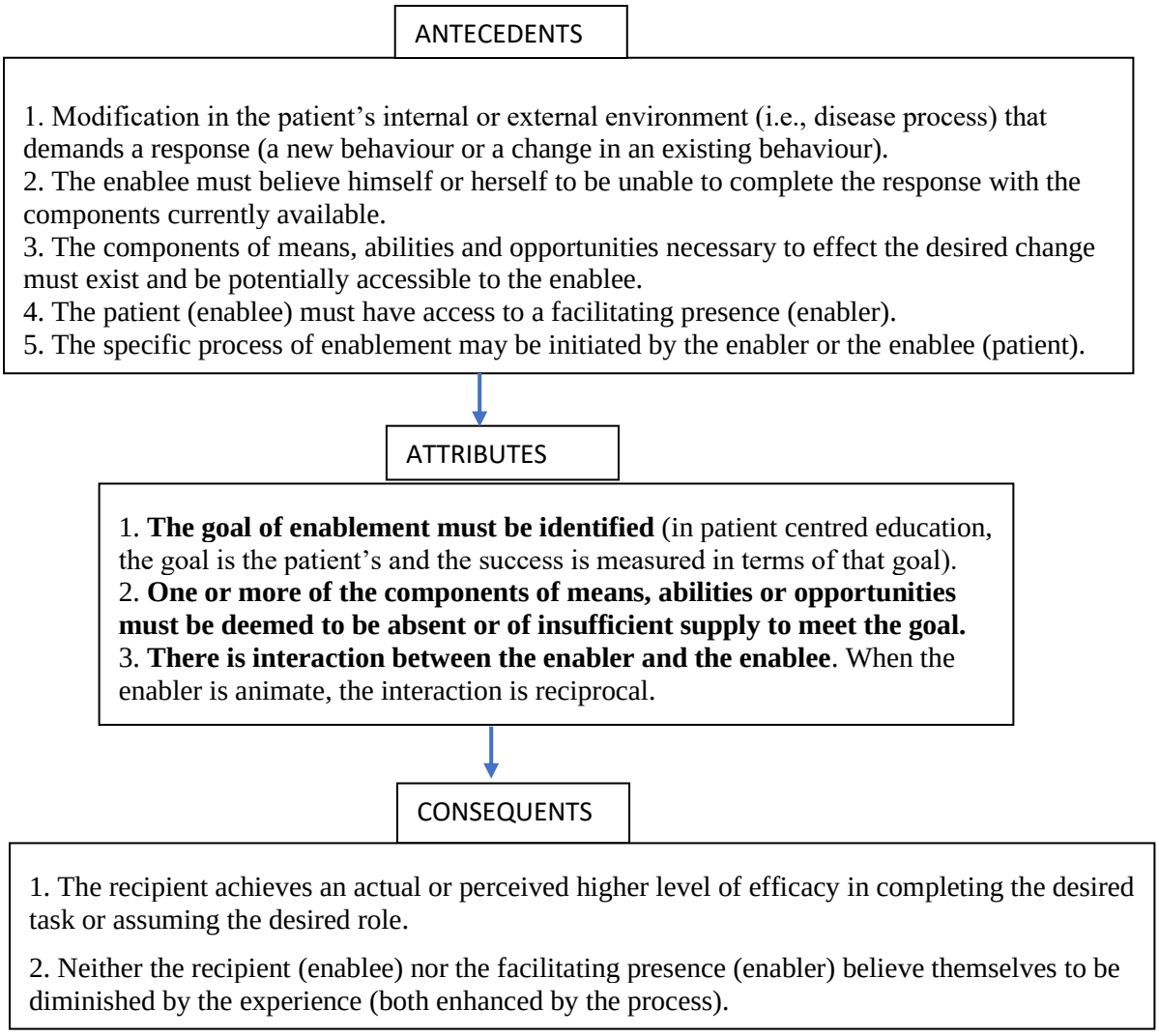


Figure 3.2 Framework for Patient Education: an analysis of Enablement, adapted from Stamler L. (1996) Toward a Framework for Patient Education: an analysis of enablement. *Journal of Holistic Nursing,* 14(4), 332-347

The conceptual analysis on enablement was conducted using Walker and Avant (1995) strategies for theory construction and guidance from Wilson (1969). Although primarily focused on nursing (67% (n=49) of the articles), professional literature from the fields of health, education, psychology, and sociology were included. The resulting framework incorporated three constructs: resources, abilities, and opportunities. Resources included facilitators, time, money, information, cognitive or physical ability and access; abilities were constructed as biological, cognitive, psychological, or psychomotor skills; and opportunities included aspects of permission, power, and practice (Stamler 1996). The antecedents, attributes and consequents of Enablement

in Education are outlined in Figure 3.2. This model identifies 'the enabler (or one who enables) as having the responsibility to help the client become capable of coping with situational or transitional stress. Specific skills used in achieving this included conveying hope; reducing resistance and ambivalence; recognizing and managing feelings; identifying and supporting personal strengths and social assets; breaking down problems into parts that can be solved more readily and maintaining a focus on goals and the means of achieving them. Attributes of enablement relate to education and person-centred goal setting. In addition to the role of the enabler, this model takes cognisance of the important role of the patient (enablee) who must have the means, abilities, and opportunities necessary to effect the desired change. He or she must believe himself or herself to be unable to complete the response with the components currently available requiring the need of a facilitating presence (the enabler).

This model introduces an important consideration that a knowledge deficit or need for modification in the patient's internal or external environment (i.e., behavioural change, skill acquisition, resource requirement) needs to exist for enablement to take place. This suggests that a person who is knowledgeable and optimally managing their health condition within the context of their life may not be further enabled by an interaction with a health care professional (a facilitating presence). As such enablement has a ceiling effect. The consequents of enablement are that the enablee achieves an actual or perceived higher level of efficacy in completing the desired task or assuming the desired role. This enablement framework is supported by research involving patients with diabetes (Stamler *et al.* 2001) and has useful clinical application in the context of older people with chronic disease.

3.4.2 Enablement in Health Care Context

To explain enablement in a healthcare context, Hudon *et al.* (2011a) carried out a concept analysis according to the method of Rodgers (2000) with thematic analysis informed by Miles and Huberman (1994). Both enablement and empowerment (in addition to professional patient relations, nurse patient relations, physician patient relations, human relations) were used as search terms in the synthesis of the theoretical and empirical literature (1980 – 2008). In addition to induced categories, the mixed classification grid also included pre-determined attributes from research (St-Cyr Tribble *et al.* 2008).

Conceptual Framework of Enablement in Health Care Context

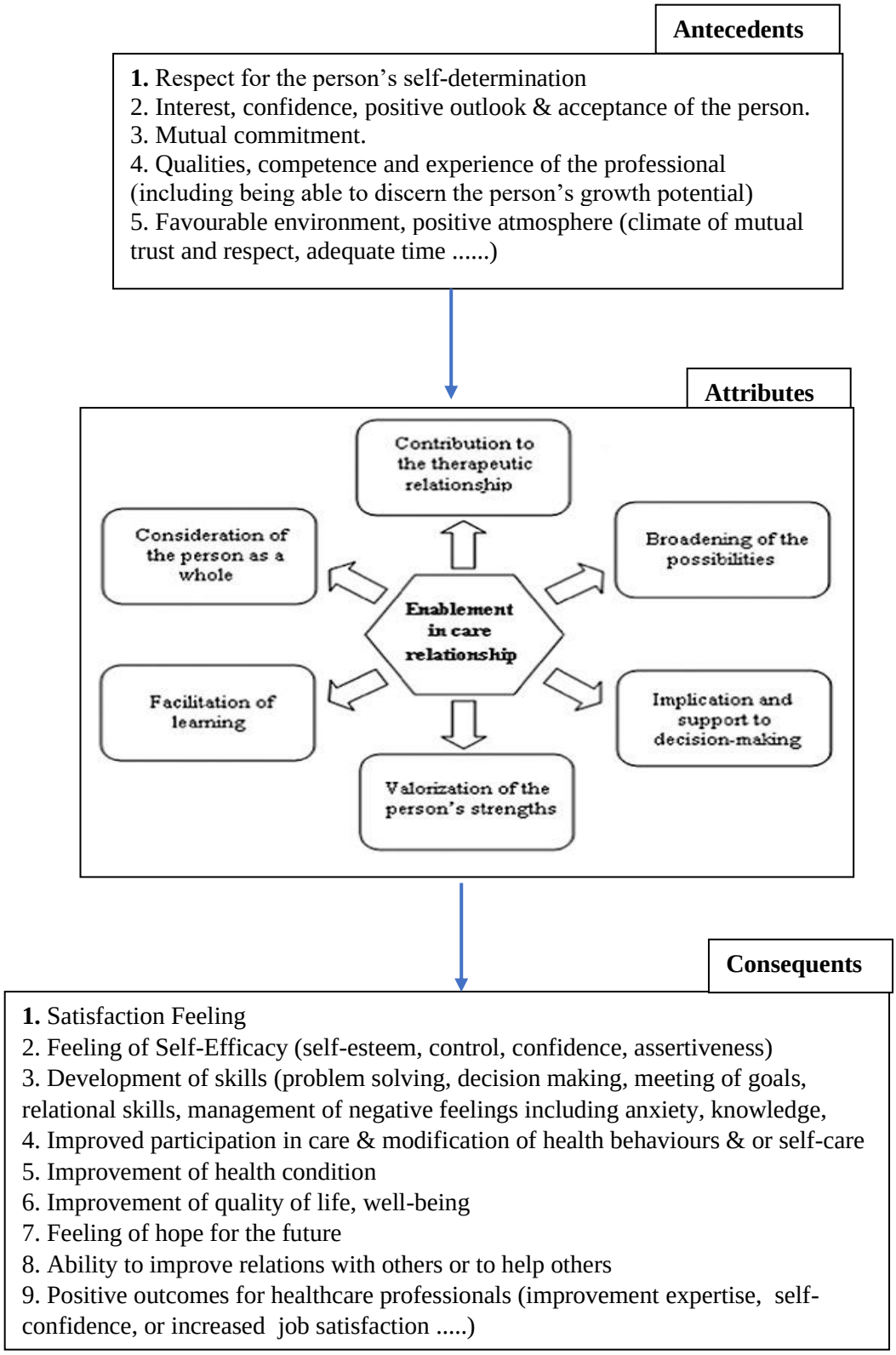


Figure 3.3 Conceptual Framework of Enablement in Health Care Context

Adapted from: Hudon C., St-Cyr Tribble D., Bravo G. & Poitras M.E. (2011a) Enablement in healthcare context: a concept analysis. *Journal of Evaluation in Clinical Practice* 17(1): 143-149

This focused on empowerment interventions, knowledge translation. and exchange from the perspective of health professionals, clients, and caregivers. At the outset, Hudon *et al.* (2011a) identified the focus of their review was on the enablement concept in the context of '*professional intervention aiming to recognize, support and emphasize the patients' capacities to have control over their life'* (p. 144).

The resulting six defining attributes of enablement in a care relationship (see Figure 3.3) were identified as (i) contribution to the therapeutic relationship (active listening, good communication, collaboration, continuity, egalitarian relationship); (ii) consideration of the person as a whole (bio-psycho-social i.e. health, functional independence, psychological well-being, family, work, finances, opinions, feelings and expectations, knowledge and understanding); (iii) facilitation of learning (exchange of information, education, individualized teaching); (iv) implication and support to decision making (advice, patient / family involvement in decisions, choices, advocacy); (v) valorisation of the persons' strengths (acknowledging patient expertise, skills and competence, guidance to the patient in understanding his / her situation); and (vi) broadening of the possibilities (positive future perspective, change in the self-image, process of transformation of thoughts, hope, finding a meaning to events, to life).

The antecedents, attributes, and consequents of enablement in a care relationship are presented in Figure 3.3. Consequents of enablement include patient satisfaction, self-efficacy, skill acquisition, improved participation in self-care, modification of health behaviours, improved health condition and sense of well-being, enhanced quality of life, improved relations with others and ability to support others. A limitation of this framework is the absence of patient characteristics that influence enablement. Also Frost *et al.* (2015) identified the omission of literature relating to enablement and Primary Care settings and addressed this gap with an integrative review of the literature focused on primary care enablement as an outcome rather than an enabling process.

Hudon *et al.* (2011a) acknowledged that their literature search was not exhaustive and included a broad range of literature not specific to ambulatory care settings. They recommended further conceptual and empirical work that would better position the concept of enablement among other concepts such as person-centred care and decision

making. Although conceptual development is limited, application of the six defining attributes (Figure 3.3) of this enablement framework has been used to underpin rehabilitation goal training programmes for healthcare workers in Australia (Agency for Clinical Innovation Rehabilitation Network, 2013). There is no evidence that the programme has been evaluated to date.

Hudon *et al.* (2015) later conducted research which informed development of the physician enabling skills questionnaire (PESQ). While there is some crossover between domains measured in the instrument and attributes of enablement in a health care context, there is a notable omission of facilitation of learning. Development of the PESQ is discussed further in the next chapter.

3.4.3 Conceptual Frameworks: Comparative Analysis

Comparative analysis of the antecedents, attributes, and consequents of enablement as a framework for patient education (Stamler 1996) and the framework for enablement in a care relationship (Hudon *et al.* 2011) is presented in Table 3.1. Both models highlight the importance of the reciprocal relationship between enabler and enablee, but Hudon *et al.* (2011a) more clearly identifies the enabling attributes of the health professional whereas Stamler (1996) refers to it as a facilitating presence. The antecedents of enablement are more patient focused on the latter which is lacking in Hudon *et al.* (2011a) framework as it fails to take cognisance of patient characteristics that influence the outcome of the enablement process. Stamler (1996) provide rationale for the ceiling effects of enablement identifying that it may not be possible to enable someone if no deficit or need exists (i.e., no information or resource requirements).

There are similarities in the consequents of enablement with both authors acknowledging that the enablee (recipient) obtains a higher level of efficacy. In Stamler (1996) this refers to competence in completing a specific task or taking on a new role and in Hudon *et al.* (2011a) this incorporates enhanced self-esteem, confidence, control, and assertiveness. Both models acknowledge the benefits for the enabler (health professional) who is enhanced because of the enablement process with increased expertise, self-confidence, and job satisfaction.

Table 3.1 Comparative Analysis of Conceptual Frameworks of Enablement

Antecedents	**Antecedents**
Modification in the patient's internal or external environment (i.e., disease process) that demands a response (a new behaviour or a change in an existing behaviour). The enablee must believe himself or herself to be unable to complete the response with the components currently available. The components of means, abilities & opportunities necessary to effect the desired change must exist & be potentially accessible to the enablee The patient (enable) must have access to a facilitating presence (enabler) The specific process of enablement may be initiated by the enabler or the enablee	Respect for the Person's self determination Interest, confidence, positive outlook & acceptance of the person Mutual Commitment Qualities, competence & experience of the health professional Favourable environment, positive atmosphere Mutual trust & respect, adequate time
Attributes	**Attributes**
The goal of enablement must be identified One or more of the components of means, abilities or opportunities must be deemed to be absent or of insufficient supply to meet the goal There is interaction between the enabler ad the enable, when the enabler is animate, the interaction is reciprocal	Contribution to a therapeutic relationship Implication & support to decision making Valorisation of the person's strengths Broadening of Possibilities Facilitation of Learning Consideration of the Person as a whole
Consequents	**Consequents**
The recipient receives an actual or perceived higher level of efficacy in completing the desired task or assuming the desired role. Neither the recipient (enablee) nor the facilitating presence (enabler) believe themselves to be diminished by the experience (both enhanced by the process)	Development of skills (problem solving, decision making, meeting of goals, relational skills, management of negative feelings including anxiety, knowledge Improvement of participation in care and modification of health behaviours and or self-care Improvement of health, wellbeing, quality of life Feeling of hope for the future Ability to improve relations with others or to help others Positive outcomes for healthcare professionals (improvement of expertise, of self-confidence, of job satisfaction .....)

3.5 Conceptual Models of Enablement

3.5.1 Enablement from Patient & Doctors perspective in Consultations

Building on the work of Howie *et al.* (1991, 1997, 1998), Pawlikowska (2011) used a multi-method approach to determine the influence of case-mix on enablement scores. Martin Buber's (2004) existentialist philosophical perspective underpinned this research which explored patient-doctor relationships within the context of general practice consultations and the outcome of patient enablement (Pawlikowska 2011).

The PEI was used as an outcome measure post consultation with patients (n = 82) attending one of three family physicians. In this mixed method study, the patient and doctor perspective on enabling (or disabling) aspects of the consultation were explored in semi-structured 1:1 interview (n = 36) which included the two highest and two lowest PEI scoring patients from each clinic session (n = 9). The research findings were related to consultation and enablement data with constant comparative and thematic analysis of participants with high and low enablement scores. This triangulation research method and Bulber's philosophical approach, facilitated construction of two models of enablement one from the patient perspective (figure 3.4) and the other from the doctor perspective (figure 3.5).

According to Pawlikowska *et al.* (2011), the models contain movable components based on individual variation. The left of the model includes elements identified as time (length of consultation), continuity, trust, doctors' communication skills (including listening, explaining, reassurance) and prescribing (mutual weighing up of medication decisions) which contribute to personal tailoring of the consultation. The multiple elements lead to consulting with informed flexibility that contributes to enablement. The significance of these elements and impact on enablement, vary from consultation to consultation, patient to patient (with similar problems), between problems in the same patient, between doctors and with experience over time. It was observed that the milieu (health system and culture) where the model is contextualised (i.e., clinical setting) affects the balance and overlap of these elements.

There were similarities between the patient and physician perspective on the features of an enabling consultation. Enablement was enhanced by continuity of care (joint

history of consultation), trust and recognition and consulting with informed flexibility in accordance with the patients' agenda.

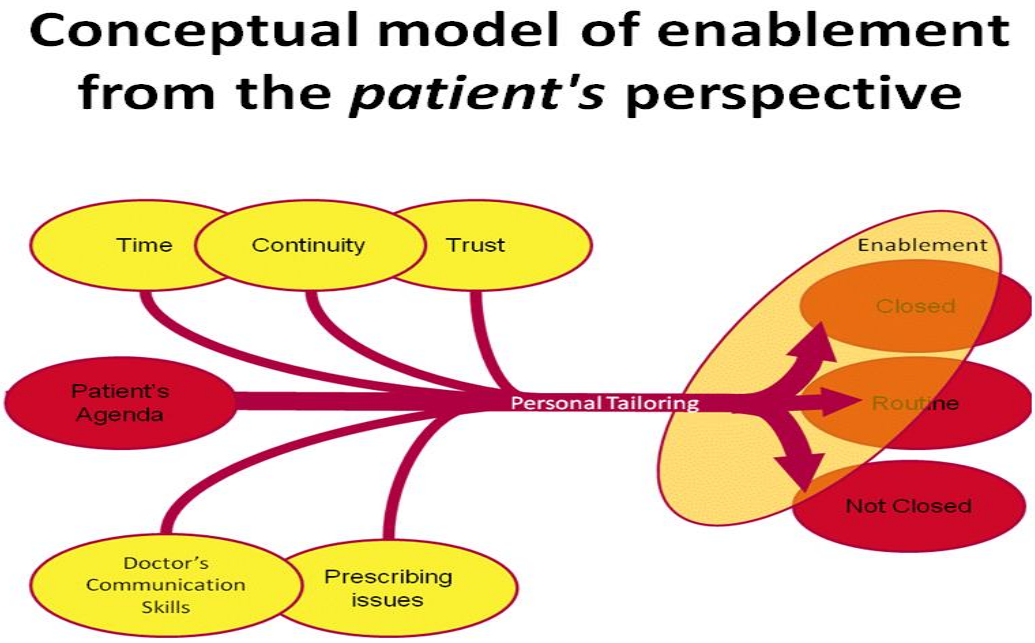


Figure 3.4 Conceptual Model of Enablement from Patient Perspective (Pawlikowska 2011)

The patients' active participation (able to move own agenda forward) positively influenced enablement. Alternatively, patients' non-disclosure of an element hampered the quality of consultations. Doctors identified patients' level of engagement as a significant enabling factor, acknowledging that a patients' cognition or mood may limit involvement in the enablement process. Enablement was likely to be compromised if conversation was dominated by the health professional and the agenda originated with the doctor regardless of bio-medical salience or patients' main presenting concerns.

From the patients' perspective, 'personal tailoring' was the most important aspect of an enabling consultation. This concurred with the doctors' views that flexibility around patient individual needs is central to enabling consultations. Several linked factors influence the personal dimension of consultations and patients' pragmatic taxonomy of their agenda and whether the enablement potential of consultations is achieved.

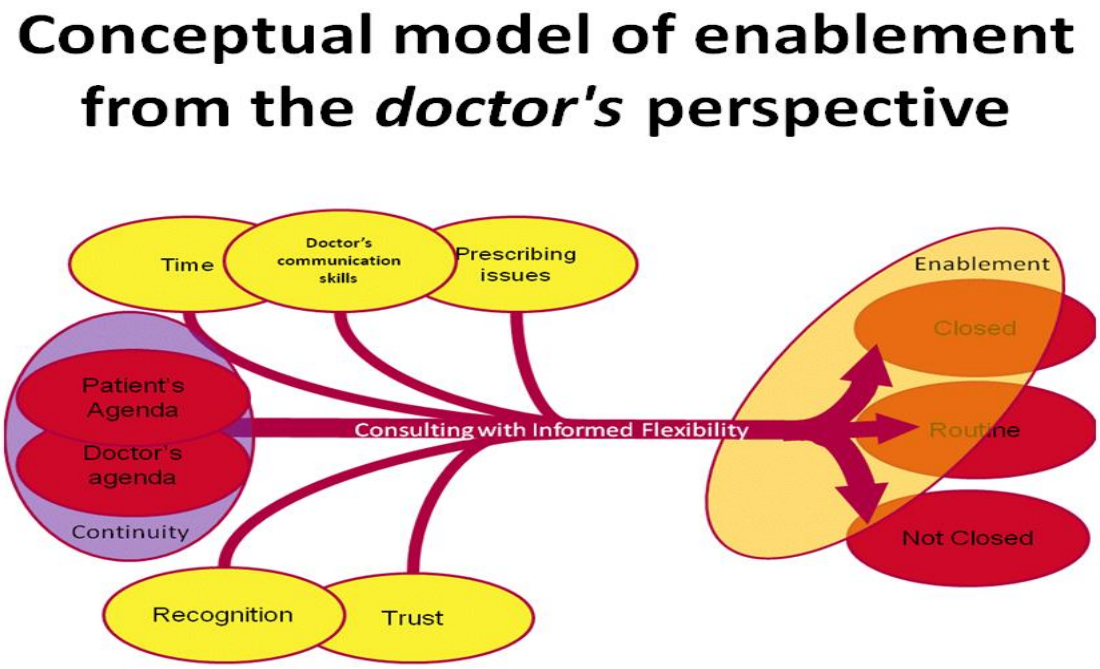


Figure 3.5 Conceptual Model of Enablement from Doctor Perspective (Pawlikowska 2011)

Measuring enablement following the consultation, Pawlikowska (2011) observed that several factors were associated with low PEI scores. Patient enablement was found to be low when closure was not possible due to uncertain diagnosis pending further investigations. Similarly, closure was not achieved when a patient and doctor had differences of opinion on management of a health condition. In general, patients with low PEI scores did not seek new information or present with concerns that could be resolved by the doctor. Like Stamler (1996), Pawlikowska (2011) identified that not all consultations can be enabling, the health professional needs to have an awareness of the patient agenda to identify pragmatic aims and enablement potential.

These models relate to the development of enablement as a concept from the patient and doctor perspective. The importance of informed flexibility and an individualised approach enhanced by the doctor's communication skills, patient ownership of the agenda and the trusting therapeutic relationship between both is highlighted. It illustrates the dynamic interplay of elements which influence enablement. The models also suggest that patient enablement can be characterised as high or low levels of enablement. Pawlikowska (2011) recommended further testing of this model in different settings and with different groups.

3.5.2 Developing Enabling Health Care Partnership Model

Desborough et al. (2017, 2018) used a constructivist grounded theory design to explore the process of patient enablement in general practice nurse consultations. Unlike traditional grounded theory (Clarke 2005), a constructivist grounded theory approach acknowledges the researcher as implicit in the process, working with research participants in the co-construction of meaning and experience (Mills and Berks 2014) informed by existing literature. The process was underpinned by a critical realist perspective (McEvoy & Richards 2006; Maxwell 2012) that acknowledges the existence of reality occurring within the subjective, socially situated perceptions of those who experience this reality.

In-depth interviews were conducted with general practice nurses (n=16) and patients (n=23) from twenty-one general practices over a six-month period. This study was one component of a larger mixed methods investigation examining the relationship between general practice and general practice nurse consultation characteristics and patient satisfaction and enablement. Data generation and analysis were conducted concurrently using constant comparative analysis and theoretical sampling focusing on the process and outcomes of patient enablement.

Developing enabling healthcare partnerships between patients and nurses in general practice was the phenomenon of interest (Desborough *et al.* 2017). It encapsulated a two-stage cyclical process (a) triggering enabling health care partnerships (nurse patient rapport regarding manifestation of a particular disease) and (b) tailoring care in enabling health care partnerships (nurses and patients working collaboratively to contextualise care and promote independence). Inherent to each stage were actions and interactions between nurses and patients, underpinned by activities described as scaffolding (Desborough *et al.* 2017). These scaffolding activities included education using different formats, supporting onward referral to other health care professionals, following up on patients with chronic disease and recalling patients for check-ups. Central to the enablement process was a person centred therapeutic trusting relationship between the nurse and the patient, responsive to changing patient needs and effectively communicating with other health professionals. Figure 3.6 demonstrates the development of enabling healthcare partnerships between nurses and patients in general practice as a process and patient enablement as the outcome of this

process. Based on this work, Desborough *et al.* (2017) proposed the Patient Enablement and Satisfaction Model (PESM).

The enabling process is subject to contextual conditions which influence the degree to which enabling health care partnerships between patients and nurses are developed (Desborough *et al.* 2016). These influencing factors are identified as

- characteristics and behaviours of the general practice nurses, interventions of the 'just right nurse', equipped with knowledge, interpersonal and clinical skills.
- 'very effective patient' who develops desired behaviours and has a particular affinity towards enablement.

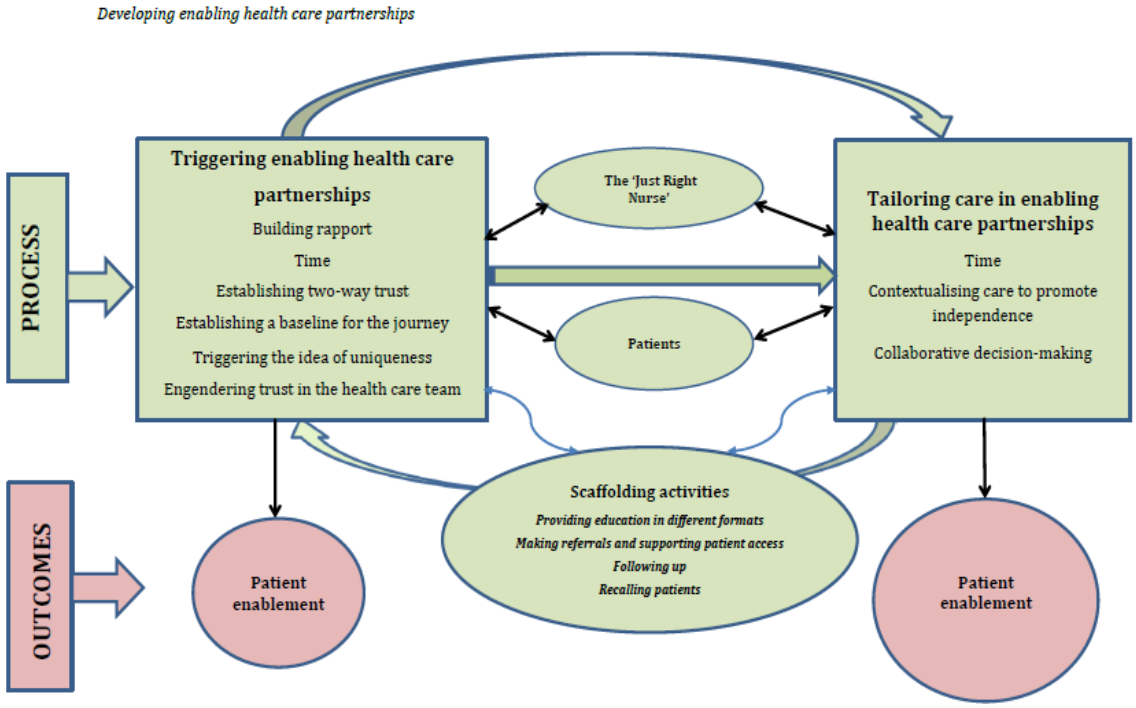


Figure 3.6 Developing Enabling Health Care Partnership

Published in Desborough J., Bagheri N., Banfield M., Mills J. Phillips C. & Korda R. (2016) The impact of general practice nursing care on patient satisfaction and enablement in Australia: A mixed methods study. *International Journal of Nursing Studies,* 64: 108-119

Desborough *et al.* (2017, 2018) states that enablement may manifest at both the triggering and tailoring stages of the process depending on the influence of partnership on patients' ability to manage their health care experience. It highlights the enabling skills of the health professional and aligns with the defining attributes of enablement

identified by Hudon *et al.* (2011) and Pawlikowska (2011) description of the dynamic relationship between patient and healthcare professional. Although not specified in the model, it presents the 'ideal' scenario of the 'very effective patient' and 'just right nurse' and offers little guidance in relation to the diverse, often complex health care needs of patients which are likely to influence enablement.

According to Desborough *et al.* (2017, p.1085), enablement is evidenced by.

(i) Patients' understanding of his or her unique health requirements informing their health seeking behaviours and choices.

(ii) Patients taking an increased lead in their partnership with a nurse and seeking choices in their care.

(iii) Patients getting healthcare that reflects their needs, preferences, and goals.

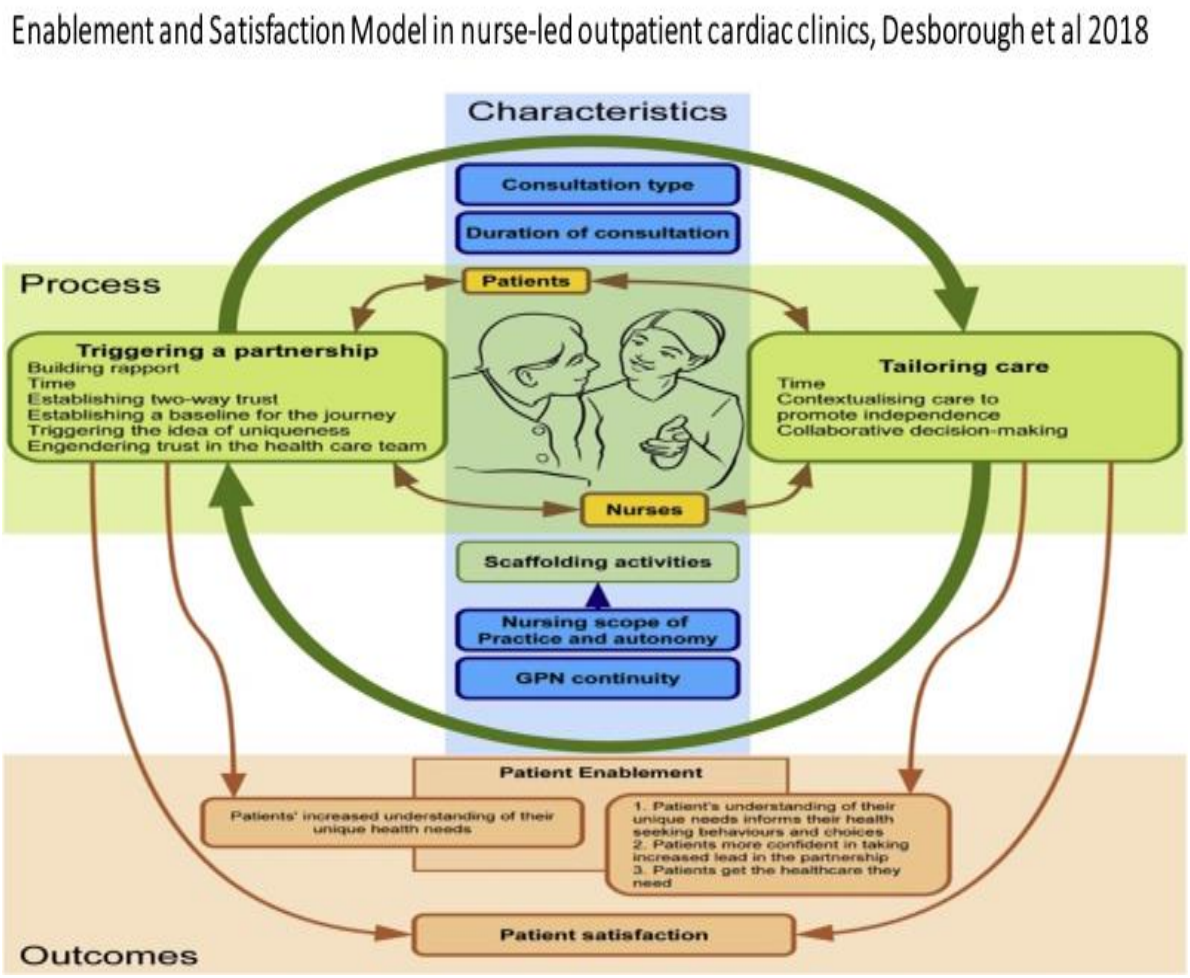


Figure 3.7 Enablement and Satisfaction Model in nurse-led outpatient cardiac clinics

Published in Desborough J., Parkinson A. & Korda R. (2018b) The practical use of the Patient Enablement and Satisfaction Model in nurse-led outpatient cardiac clinics, *Collegian*, 26, 415-421

Desborough *et al.* (2018b) further analysed the applicability of the Patient Enablement and Satisfaction Model (PESM) in four nurse-led outpatient cardiac clinics in Australia where nurses (n = 9) were interviewed before and after implementing the model. It was described as realistic, aligning well to the clinics aims of chronic disease self-management and a person-centred approach with sufficient flexibility to respond to individual patient needs. In the discussion, Desborough *et al.* (2018b) highlighted the significance of nurse's professional scope of practice and the importance of consultation length and clinic type as influencing factors on enablement (as measured by the modified PEI (5 items). Figure 3.7 demonstrates application of the PESM in the context of nurse-led outpatient cardiac clinics. The combination of the concepts of satisfaction and enablement may blur boundaries with overlapping processes. While it clearly identifies patient gains associated with developing enabling partnerships, it neglects to consider patient variables which may influence both process and outcome.

3.5.3 The Experience of Enablement within Nurse Practitioner Care

Frost *et al.* (2017a, 2018b) developed a conceptual framework to demonstrate the experience of enablement within Nurse Practitioner care. This was informed by qualitative interviews underpinned by hermeneutic phenomenology (Van Manen, 1990). The Australian based study used purposeful sampling to recruit seven Nurse Practitioners in primary health care and two patient groups that had attended a Nurse Practitioner as part of a single consultation or multiple consultations. The sample included people aged between 20 to 70 years. A parallel multi-strand approach (Teddlie and Tashackkori, 2009) facilitated thematic analysis with the PEI components used as the lens of enablement to interpret findings.

Frost *et al.* (2017b) conceptual framework (figure 3.8) demonstrates the dynamic interplay between the patient experience which is represented as temporality, relationality, corporality, and care received. Temporality refers to the quality of the consultation regarding patient centred time which is subjective and not rushed. Relationality is conceptualised as trust, acceptance, support, mutual respect, openness, empathy and holistic. Corporality refers to hands on, therapeutic touch, holistic, linked with trust and acceptance, bespoke care. 'Care received' is identified as creating opportunities for education supporting knowledge transference, building on strengths,

and promoting self-efficacy. This dynamic interplay contributes to patient enablement (the outcome) identified as coping, managing, and understanding.

Frost et al. (2017b) acknowledged that the small sample size was not representative of the wider population and recommended further research to explore the fidelity and relevance of this conceptual framework in other primary health care settings and with Nurse Practitioners in other specialities. This framework highlights the importance of the patient experience of the consultation, continuity of care and the enabling skills of the healthcare professional and is similar to Hudon *et al.* (2011a), Pawlikowska (2011) and Desborough *et al.* (2016, 2018). It expands on the antecedents of enablement and introduces elements such as length of consultation, person centred time and therapeutic touch. While Frost et al. (2017b) more clearly identifies enablement as a patient outcome measure (Figure 3.8) it fails to acknowledge patient characteristics and enablement as a dynamic and fluctuating state.

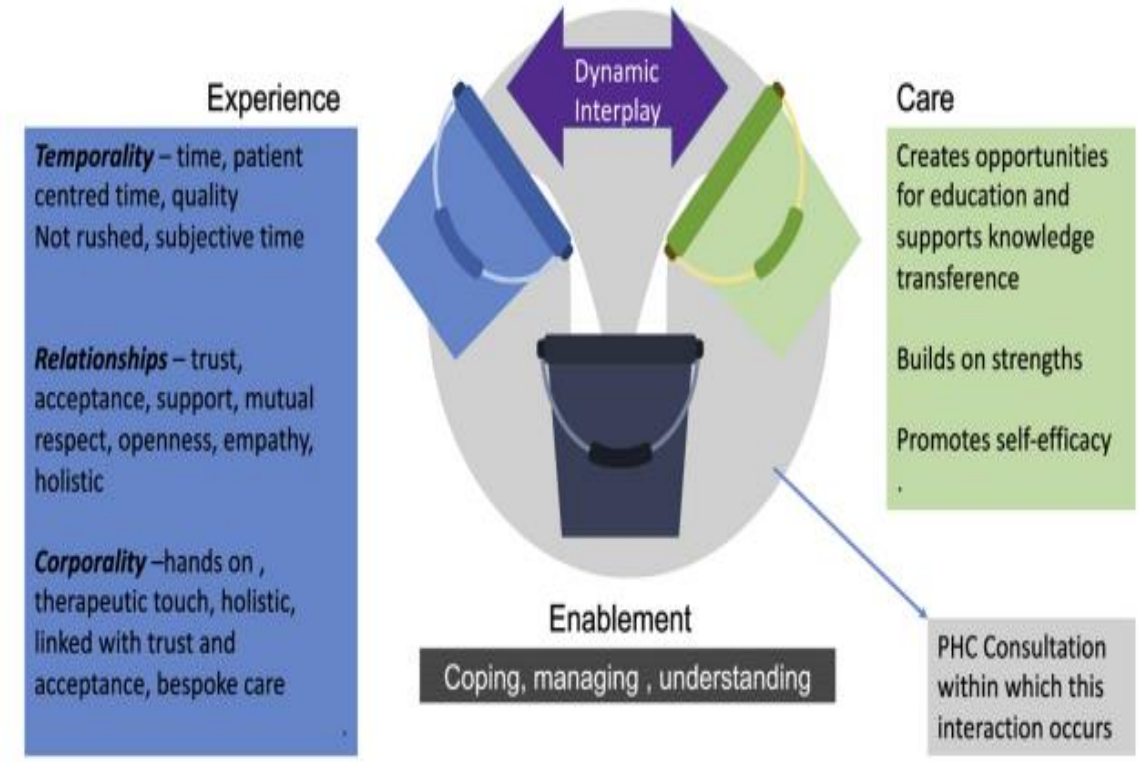


Figure 3.8 The experience of enablement within Nurse Practitioner Care

Published in Frost J.S., Currie M.J., Northam H.L and Cruickshank M. (2017) The experience of enablement within Nurse Practitioner Care : A conceptual framework. *Journal for Nurse Practitioners*, 13(5): 360-367

3.5.4 The Consumer Enablement Model

The final and most recent model reviewed is the Consumer Enablement Model (CEM) which was developed in Deakin University on behalf of the Agency for Clinical Innovation (ACI in New South Wales). The model concentrates on overall patient enablement status rather than gains post consultation. Consumer enablement is described as the extent to which people understand their health conditions and have the confidence, skills, knowledge, and ability to manage their health and wellbeing. Batterham *et al.* (2017) undertook a rapid review of the literature to develop a model that would enhance enablement in people with chronic illness and to engage and support consumers in management of their health thereby avoiding unnecessary hospitalisations. This review identified the dearth of evidence which accommodated differences in enablement needs across the life-course and illness trajectory.

Batterham *et al.* (2017) are critical of a 'prevailing unidimensional normative orientation' that assumes enablement is manifested as more or less the same in everyone and that it is possible to define a list of ideal criteria and enabling strategies. Instead, they recommend a 'multidimensional descriptive or hierarchical orientation'. The multi-dimensional, descriptive orientation recognises that consumer enablement has multiple and distinct components and that people have unique strengths and weaknesses which require different pathways and targeted interventions. A hierarchical orientation hypothesises that consumer enablement is layered and that certain needs must be prioritised before others can be addressed. Individuals will have different components of enablement and will require different interventions to progress up the hierarchy from low to high enablement. Enablement is characterised as a continuum from low to high rather than as dichotomous (enabled not enabled). The CEM acknowledges the significance of illness complexity, health service engagement and life circumstances as factors that influence enablement.

Batterham *et al.* (2017) propose a model of consumer enablement (Figure 3.9) which identifies influences on enablement as determinants (external, personal, and dynamic) and components (cognitive, motivational / affective, physical, and relational). The external and dynamic determinants are considered more modifiable than personal determinants. A person's determinants and components will influence their strengths, weaknesses, needs and preferences at any point in time.

External and Personal Determinants

Determinants are conceptualised as '*attributes of a person and/or their background, as well as external factors that have an impact on the ease and extent to which people develop the capabilities that allow them to look after their health*' (Batterham *et al.* 2017, p21). External determinants include access (i.e., transport or outreach services) and affordability of health services. It may also include bureaucratic services which are difficult to navigate. Personal determinants are usually fixed or are resistant to change and it is recommended that enablement strategies are adapted in accordance with individual culture, language, education, and beliefs.

Dynamic determinants

The dynamic determinants of enablement refer to an individuals' positive or negative experiences when attempting to care for their health which are referred to as positive or negative feedback loops. A positive interaction (positive feedback loop) can build knowledge, confidence, ability to self-manage and cope with illness. Alternatively, a negative interaction (negative feedback loop) can undermine a person's confidence.

Batterham *et al.* (2017) offered examples of health professional enabling interventions which include a person-centred empathic approach, tailoring communication to the individual, shared decision making, motivational interviewing, patient education, sign posting of services and the use of patient reported experience measures. It extends beyond the clinical setting and suggests that health professionals consider family supports, social engagement, peer support networks and a range of other interventions specific to the needs of the individual.

Components

Batterham *et al.* (2017) define components of enablement as '*aspects of a person that have a direct effect on their ability to care for their health and / or to manage the impact of health issues in their lives'* (p. 17).

The four categories of components of enablement are described as
(i) cognitive (including memory function and knowledge regarding illness
(ii) affective / motivational (i.e. motivation, health behaviours, self-efficacy)

(iii) physical components (i.e. health, fitness, functional ability)

(iv) relational components (i.e. relationships with family or health professional)

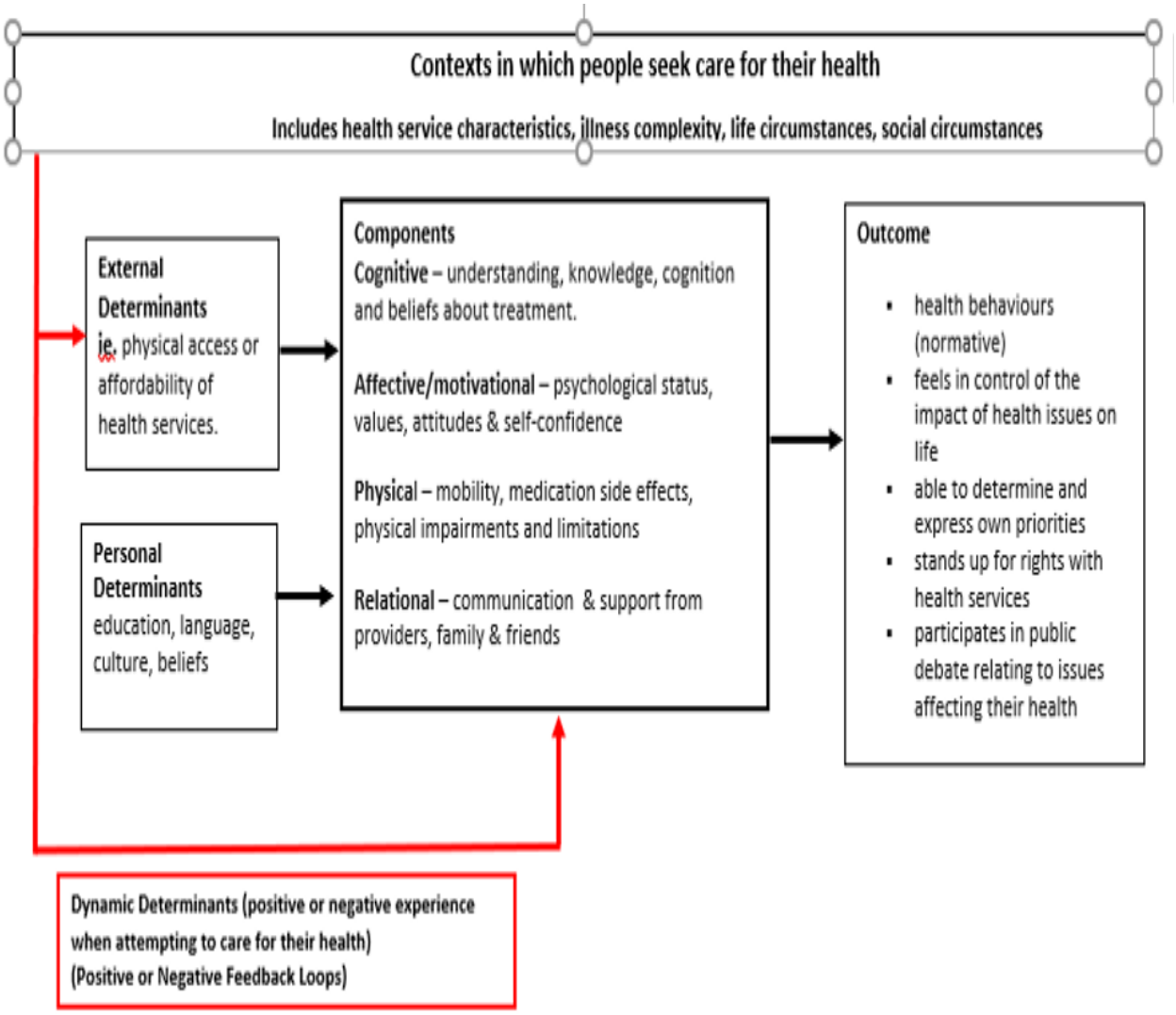


Figure 3.9 Consumer Enablement Model (Batterham et al. 2017) available @

https://www.aci.health.nsw.gov.au/resources/chronic-care/consumer-enablement/guide/about

Levels of Enablement.

A review of an extensive set of client case studies (Batterham 2008), informed descriptors of components as they relate to low, medium, and high levels of enablement (Batterham *et al.* 2017, p19). At a high level of enablement, the patient is independent, proactive in self-management, healthy behaviours, seeking information and at low level an individual may have limited functional capacity due to ill health (Table 3.2). Enablement is viewed as a fluctuating state and strengths in one category may compensate for weaknesses in another. For example, a person who has little knowledge about health issues and few skills in knowledge acquisition may adequately manage their health following the advice of a trusted doctor. Similarly, a person with physical deficits and functional limitations may be enabled by a skilled health professional, instilling confidence, and engaging necessary resources. Batterham *et al.* (2017) emphasise the importance of the trusting relationship between patient and health professional which generally requires longer than one consultation to develop.

Health professionals are encouraged to consider individual contributing factors, including social and environmental barriers that need to be overcome for a person to regain confidence and capability. An example is provided of a patient falls related incident causing a negative (dis-enabling) cycle in an older adult whose confidence and mobility declines due to increased falls risk associated with a fear of falling. A positive (enabling cycle) may be initiated during the consultation by comprehensive assessment and appropriate onward referral leading to a higher level of enablement. This reinforces the importance of the dynamic determinants to positively affect changes on the components of enablement. Batterham *et al.* (2017) enablement model has a broad scope which is applicable to a variety of contexts in which older people engage with health services, the authors recommend that this model is further developed for specific groups based on empirical investigation.

Table 3.2 Characteristics of Enablement at different levels

Batterham R.W., Osborne R., McPhee C., Mech P. & Townsend B. (2017) Consumer enablement: An Evidence Check rapid review brokered by the Sax Institute for the Agency for Clinical Innovation. NSW

	Low	Medium	High (HARP pop)	High (general community)
1. Cognitive components including knowledge	Lacks insight in relation to their current limitations or health risks. Unable to participate in decision making. May lack knowledge of basic concepts related to health or disease and hold several false beliefs.	Limited ability to understand cause and effect relationships between health related behaviours (including compliance with treatment) and health outcomes. Limited ability to formulate action plans related to goals.	Understands the relationship between personal health behaviours, compliance with treatment and expected health and personal benefits. Able to form coherent action plans in relation to goals (with or without assistance)	Has a good understanding of concepts of biology and causes of health and illness. Confident in ability to find and access services as required. High ability to find understand and use information independently
2. Affective/ motivational components	Psychological state makes it difficult to consider medium or long-term issues. May have difficulty dealing with day-to-day motivation. OR Rejects the need to change or has other priorities which consistently over ride health care priorities	Expresses willingness to change and a desire to improve health status. May have difficulty following through on actions but generally cooperates with treatment or actions initiated by others.	Able to follow-through on agreed actions and initiates some actions to better participate in health care or to improve health. May still face difficulties with periods of relapse and/or require assistance to overcome set-backs such as acute health events.	Has established routines for maintaining health and fitness that they can maintain with minimal support from friends and family. Invests time and energy into finding out how to improve health and into planning steps to do so and implementing these steps.
3. Physical components	Severely limited in their ability to undertake self-care and basic health care tasks or participate in any health promoting activities.	Physically capable of doing most self-care and health care tasks independently though may need some assistance with transport. Limited ability to achieve physical activity levels necessary to maintain or improve their health.	Physical limitations not a barrier to participating in self-care and health care tasks and achieving a level of physical activity sufficient to produce improvements in fitness and physical status.	No physical limitations affecting ability to maintain a high level of health and fitness
4. Relational components	Has lost trust in health providers and/or feels they have lost trust in him/her. Has no relationships with a trusted provider. May be either constantly trying to engage different services or ceased engaging. No stable, supportive personal relationships.	Has some relationships with health providers but these may be dysfunctional in some aspects such as: a) ad hoc and disjointed; b) highly dependent; c) fearful and unwilling to ask questions. Personal relationships may be limited, have aspects of dysfunction (as above), or encourage unhealthful behaviours.	Has a trusting long-term relationship with at least one health care provider that they are confident enough to raise concerns and questions with. Some supportive family and friends. Able to negotiate ways to do the tasks and live the lifestyle necessary to maintain their health within their social contexts.	Moves in a social milieu that encourages healthful activities. Very strong trusting relationship with at least one health care provider who knows them well.

3.6 Synthesis of Models

Despite the different contexts, there are synergies and cross-linking constructs between enablement models. A summary of the similarities and differences are presented in Table 3.3 under the heading's definition, contextual variables, patient characteristics, health professional enabling skills, shared dynamic, and improved patient outcome.

3.6.1 Definition

There is overlap between the models constructs but each model has a particular emphasis and strength. This includes patient education (Stamler 1996), enabling skills of the health professional (Hudon *et al.* 2011a), patient and health professional perspective on influencing factors on enablement (Pawlikowska 2011), developing enabling healthcare partnership (Desborough *et al.* 2017, 2018a, 2018b), experience of enablement within nurse practitioner care (Frost *et al.* 2017a, 2018b) and patient focused consumer enablement (Batterham *et al.* 2017).

There was no singular interpretation of enablement although there are commonalities. Definitions predominately relate to the interventions of healthcare professionals which concur in their positive person-centred enabling focus, building on patients' strengths and promoting self-efficacy (Frost et al. 2017), supporting acquisition of skills (means and abilities to complete a task or fulfil a role) (Stamler 1996) and supporting patients to control their health and their life (Hudon *et al.* 2011a, Desborough *et al.* 2017, 2018a, 2018b). Knowledge transference and patient understanding underpins these definitions which is more explicit in Pawlikowska (2011), Frost *et al.* (2017a, 2017b) and Batterham *et al.* (2017). Pawlikowska (2011) is more focused on the information exchange and personal connection between patient and health professional within the consultation. Batterham *et al.* (2017) define enablement as the extent to which individuals understand their health conditions and have confidence, skills, knowledge & ability to self-manage their health and well-being'.

3.6.2 Context Variables

Enablement in the wider context of healthcare engagement with patients with chronic disease is the focus of Stamler (1996), Hudon *et al.* (2011a) and Batterham *et al.* (2017) where a favourable environment and positive atmosphere enhance the enablement experience. Other models focus more specifically on the patient consultation (Pawlikowska 2011, Desborough *et*

al. 2017, 2018, Frost *et al.* 2017a, 2017b). Time is a construct of most models, described as subjective quality time that is unrushed, and person centred (Pawlikowska 2011, Desborough *et al.* 2017, 2018a, 2018b, Frost *et al.* 2017a, 2017b).

3.6.3 Patient Characteristics

The Consumer Enablement Model (CEM) focuses on the interdependent and multicomponent nature of enablement, which is applicable to an older population living with dynamic states of medical, functional, psychological, social, and environmental change that characterise the ageing process. Unlike previous models (see comparative analysis, Table 3.3), the CEM takes cognisance of variables such as complexity of health issues, life circumstances, stability of social networks and supports, environment and cultural diversity which impact on enablement. The model fits well with a comprehensive geriatric assessment and management model which is the gold standard for multidisciplinary care planning in older people living with multimorbidity and frailty (Ellis *et al.* 2017, HSE 2012). CGA takes account of medical, functional, psychological, social, and environmental factors that impact on health and focuses on the older person's priorities and preferences and thus the enablement of the individual. Pawlikowska (2011) also gives credence to patient specific factors which require personal tailoring and consulting with informed flexibility. This model highlights the significance of the patient agenda and enablement potential. This concurs with Stamler (1996) who states the pre-requisites for enablement are a patient deficit or need (i.e., information and the necessary resources (i.e., self-belief, physical capacity) for the desired change.

Other models (Hudon *et al.* 2011, Desborough *et al.* 2016, 2018a, 2018b, Frost *et al.* 2017) are focused on the enabling experience and skills of the health professional and while there is reference to holistic assessment and bespoke care, patient variables are not adequately represented.

3.6.4 Health Professional Enabling Skills

The enabling skills of the health professional is to the fore in all enablement models. While it is less explicit in the CEM, the enabling skills of the health professional are captured under the dynamic determinants of enablement. All the models and concept analyses concur with Swanson's' (1991) mid-range theory describing the dynamic nature of the health care experience and importance of the enabling role of the health professional. Desborough *et al.* (2017, 2018) describes triggering and tailoring enabling healthcare partnerships and

scaffolding activities such as co-ordinated case management, onward referral to allied health professionals, family engagement and securing resources. From a medical perspective, Pawlikowska (2011) identified the importance of communicating with informed flexibility in accordance with the patient agenda and introduced the concept of prescribing issues as significant in a medical consultation.

The defining attributes of enablement in a care relationship (Hudon *et al.* 2011a) provides a comprehensive framework for the enabling skills of the health professional which is reinforced by the theoretical constructs of other models. 'Consideration of the person as a whole' encompasses a bio-psycho-social rather than a disease focused medical model. Holistic care underpins all enablement models but is more clearly evident in the CEM (Batterham *et al.* 2017) with patient components that influence enablement categorised as cognitive, affective / motivational, physical, and relational.

As patient knowledge and understanding is a core construct of enablement, common to all models is the facilitation of learning, education, and the reciprocal exchange of information. This is a key requisite for supported decision making frequently identified as collaborative, with the enabler viewed as a facilitating presence (Stamler 1996). Valorisation of the persons' strengths**,** acknowledgement of patient expertise, skills and competence underpins an enabling approach with the promotion of patient self-efficacy and independence a key outcome measure. 'Broadening of the possibilities' is unique terminology to Hudon *et al.* (2011a) and includes a process of transformation of thoughts whereby the enabling skills of the health professional may facilitate a more positive perspective, provide hope and adaptation to life changes associated with illness related functional decline. As the goal of enablement includes patient coping, it is reasonable to assume that 'broadening of possibilities' is implicit across the other models. Contribution to the therapeutic relationship encompasses active listening, good communication, collaboration, and continuity of care. Frost *et al.* (2017a, 201b) is the only one to identify the significance of hands-on therapeutic touch in creating an enabling experience. The qualities, competence and experience of the health professional are identified as antecedents of enablement (Hudon *et al.* 2011a) and are acknowledged in the wider literature.

3.6.5 Shared Relationship Dynamic

The shared relationship dynamic and reciprocal interaction between the enabler and the enablee is a key influential factor on enablement. There is uniform agreement that the quality of the consultation and engagement with health services is largely based on the interpersonal

connection and trusting relationship between patient and health professional. Establishing a rapport and developing an enabling partnership is enhanced by continuity of care, mutual respect, and commitment (Desborough 2016, 2018). Frost *et al.* (2017a, 2017b) identified the significance of openness, acceptance, empathy, and support which are recurring themes in the literature. This forms the basis of consulting with informed flexibility and personal tailoring of interventions (Pawlikowska 2011).

In an enablement model, decision making is collaborative and supported and requires reciprocal exchange of information (Hudon *et al.* 2011a). Pawlikowska (2011) identify potential differences between the patient and doctor's agenda (priorities) and possible unequal partnership where the patient may be less engaged in the consultation due to lack of confidence in communicating healthcare needs combined with inadequate enabling skills of the health professional. This concurs with Batterham *et al.* (2017) who identified within the dynamic determinants of enablement, the possible occurrence of a positive or negative engagement with health services which can either bolster or undermine a patients' confidence and ability to manage and cope with chronic illness.

3.6.6 Outcome

The proposed outcomes of the enablement process are largely influenced by the seminal work of Howie *et al.* (1997, 1998) who identified enablement as health gains post consultation with a health professional. This relates to improved patient understanding, confidence and ability to care for oneself and engage in healthy behaviours, cope with life and illness (Howie *et al.* 1997, 1998, Pawlikowska 2011). Understanding, coping and management (self-efficacy) is common to all models. Enhanced coping is identified as reduced negative feelings or anxiety (Hudon *et al.* 2011,Desborough *et al.* 2018). Modification of health behaviours was proposed by Hudon *et al.* (2011a), Pawlikowska (2011), Batterham *et al.* (2017) and Frost *et al.* (2017a, 2017b).

Self- efficacy relates to patient proficiency in completing a desired task or taking on a new role (Stamler 1996), self-esteem, control, confidence, and assertiveness (Hudon *et al.* 2011a), development of skills such as problem solving, decision making and goal attainment (Hudon *et al.* 2011, Desborough *et al.* 2018), self-care and functional ability (Batterham *et al.* 2017, Frost *et al.* 2017) and relational skills (Hudon *et al.* 2011, Desborough *et al.* 2018).

Table 3.3 Synthesis of Enablement Models

	Stamler 1996 **Enablement: Framework for Patient Education (concept analysis)**	**Hudon *et al.* 2011** **Enablement in a care relationship (concept analysis)**	**Pawlikowska 2011** **Conceptual models of patient & doctors' perspective of enablement**	**Desborough *et al.* 2016 / 2018** **Developing Enabling Healthcare Partnership Model**	**Frost *et al.* 2017** **The experience of enablement within Nurse Practitioner Care**	**Batterham *et al.* 2017** **Consumer Enablement Model**
Definition of Enablement	*'to assist the patient to acquire or expand the means, abilities and or opportunities to complete a task, or fulfil a role, to the patient's perceived satisfaction'*	*'to recognize, support and emphasize the patients' capacities to have control over his or her life'*	'facilitated by appropriate information exchange (e.g., closing patient agendas), personal connection (embodied in agreements, approvals, laughter & legitimization), an engaged patient & an attentive doctor'.	"a **professional intervention** by which the health care provider **recognise**s, **promotes** and **enhances patients' ability to control** their health and life"	*'Nurse practitioners enable patients by creating opportunities for education & knowledge transference & building on patients' strengths & promoting self-efficacy.*	*'is the **extent** to which individuals **understand** their health conditions and have **confidence, skills, knowledge** & **ability to self-manage** their health and well-being'.*
Context / Consultation	Health Service Engagement Patients with chronic disease	Health Service Engagement Time (adequate), Favourable environment, positive atmosphere	Medical Consultation Time, Prescribing Issues Contextual variance	Consultation with Practice Nurse Time	Consultation with Nurse Practitioner, t**ime** (subjective, patient centred, unrushed)	Health Service Engagement Health Service Characteristics / Access Social & Physical Environment
Patient Characteristics	Modification required in patient's internal or external environment. (health related) Has means, abilities & opportunities necessary to effect desired change. Self-Efficacy, patient must believe in own ability to complete desired response with existing resources	Consideration of the person (bio-psycho-social i.e., health, functional independence, psychological well-being, family, work, finances, opinions, feelings and expectations, knowledge and understanding)	Pre-enablement (health concerns, information requirements) Open or Closed Agenda Psychological Morbidity			**Cognitive** (knowledge, confidence etc) **Affective Motivational** (mood, motivation, self-efficacy, coping with illness, health behaviour **Physical** (function, mobility, self-care ability etc health complexity & fitness etc) **Relational** (trust in health provider, family & social supports, relationships)
Health Professional Enabling Skills	Enabler is a facilitating presence. The goal of enablement must be identified (components of means, abilities or opportunities must be deemed to be absent or of insufficient supply to meet the goal).	Contribution to therapeutic relationship Broadening of the possibilities Implication & support to decision making. Valorisation of the person's strengths Facilitation of Learning, Holistic Care. Pre-requisite: Interest, confidence, positive outlook & acceptance of patient Respect for Person's self determination Qualities, competence & experience of the health professional a pre-requisite	Informed Flexibility Recognition Communication / Consultation Skills	Individual approach (uniqueness) Engendering **trust** in healthcare team **Tailoring care** Contextualising care to promote **independence / Education.** **Referrals / Follow-Up** Supporting **patient access**	Individual Approach Bespoke Holistic Care Education & knowledge Builds on strengths, Supports self-efficacy. Openness, Empathy	Relational Component : Trusted Health Care Professional, Continuity of Care. Capacity to influence positive or negative cycles. Assessment of components & determinants, targeted interventions to maintain and improve enablement.
Shared Dynamic	Reciprocal interaction between enabler & enablee Enabling process	Mutual Commitment Mutual trust & respect	Personal Tailoring Continuity of Care Trusting Relationship Patient vs Doctor Agenda	Enabling Partnership Collaborative decision making Building Rapport, 2-way trust	Mutual trust & respect Acceptance & Support relationality, temporality & corporality.	Dynamic, Positive, or negative experiences with healthcare service / professional
Improved Patient Outcome	Increased self-efficacy in completing desired task or assuming desired role. Patient enhanced by the process	Self-Efficacy (self-esteem, control, confidence, assertiveness) Wellbeing, Self-Care Ability, Skills, (problem solving, decision making, goal attainment, ability to help others), Reduced negative feelings / anxiety, Knowledge, health behaviours, Quality of life, Satisfaction, Hope, Good social relationships	In accordance with PEI Knowledge, Confidence Independence Coping with illness / life Health Behaviours	Development of skills (problem solving, decision making, meeting of goals, relational skills) Coping, management of negative feelings (i.e., anxiety) Knowledge	Participation in care / Self care Modification of health behaviours	Improved health status / behaviours in 1 or more Components: Cognitive, Affective, Physical, Relational (low -high) i.e. .Feeling in control of illness, coping. Improved self-care ability / function, Established provider-patient interaction. Ability to advocate on issues that affect patients and families

The CEM is explicit in identifying outcome indicators suggestive of high enablement status because of limited research evidence on those with lower levels of enablement. Based on an extensive case review, Batterham *et al.* (2017) provided a comprehensive multilevel framework for the measurement of enablement which maps the components of enablement 'cognitive, affective, physical and relational' into low, medium, and high outcome characteristics (Table 3.2).

Constructs of this model more closely reflects the multivariate enablement status of older people with chronic illness acknowledging that strengths in one area may compensate for weaknesses in another. It provides a useful framework for individual assessment and focused interventions and provides a framework for examination of factors which influence enablement.

Batterham *et al.* (2017) acknowledged the challenges of measurement of patient enablement status as an outcome measure and identified the importance clinical judgement and disease specific instruments. The distinction between enablement identified as health gains post consultation (Howie *et al.* 1997, 1998) and enablement status (Batterham *et al.* 2011) is important. It is possible to surmise that there may be an association between (i) patient enablement status (components) and potential for health gains (enablement) post consultation with a health professional and (ii) gains post consultation leading to improvements in enablement status. Batterham *et al.* (2017) suggest the need for further research and development of the CEM.

Summary

Enablement models are based on the premise that people will feel more enabled if services are person centred, user friendly and integrated with health professionals who instil trust and confidence. Enablement strategies have the potential to effect meaningful change if environments are created where self-efficacy, self-management and agency are the norm. In contrast, people can be 'dis- enabled' by fragmented, bureaucratic, technical, and unfriendly services and poor or mediocre consultation experiences. There is uniform acknowledgement of the importance of health professional enabling skills which include communication, knowledge transference, empathy, collaborative decision making and informed flexibility. Enablement is depicted as a dynamic interaction between both process (enabling skills of the health professional) and patient outcome influenced by contextual factors. The inadequate representation of patient related factors is suggestive of a unidimensional approach biased towards those who present with higher levels of enablement. Older people with chronic disease are a heterogeneous population whose life and healthcare experiences shape their response to illness and adaptive strategies. Development of a responsive intervention framework for enablement requires moving beyond traditional 'one size fits all' approaches.

The Consumer Enablement Model (Batterham *et al.* 2017) acknowledges that patients with chronic disease have various strengths and weaknesses and that levels of enablement fluctuate depending on changing circumstances. A downward spiral can be halted and often reversed by the enabling skills of the health professional who proactively addresses individual needs. The CEM provides a good model fit for an older adult population as it captures the complexity of individual, social and environmental factors, enabling characteristics of the healthcare setting, the enabling skills of the health professional and the relationship dynamic. However further development is needed for research application with an older adult population with chronic disease. The next chapter examines the empirical literature on enablement with a specific focus on ambulatory healthcare services and consultations involving older people living with chronic disease.





Foley, M. J. 2020. Enablement of older people with chronic disease attending an ambulatory care centre. PhD Thesis, University College Cork.

Please note that Chapter 4 (pp. 65-113) is unavailable due to a restriction requested by the author.

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Chapter 5 **Methodology**

5.1 Introduction

Research methodology refers to the techniques used to structure a study and consists of orderly disciplined procedures to acquire information (Polit & Hungler, 2013). As outlined in previous chapters, this research has been shaped by a scoping review of the theoretical and empirical literature on enablement. Based on the synthesis of the literature, the following definition is proposed. Enablement is 'an outcome of healthcare engagement which reflects a positive change in a persons' ability to understand, manage or cope with his or her illness and which is influenced by individual needs and resources and the enabling skills of the health professional'. The definition informed the subsequent research design and methods. The gap in the literature on enablement highlighted the need for further research on enablement focused on an older adult population and especially those who report lower levels of enablement. This chapter outlines the design of a quantitative cross-sectional survey which includes questionnaire design, sample population, data collection methods, data analysis plan and ethical considerations.

5.2 Research Aims and Objectives

The overarching aim of this study was to examine enablement of older people with chronic disease post consultation with a health professional and identify influencing factors for low enablement.

The specific objectives of the study were to:

- describe the study population characteristics (demographic, health profile and patient activation) attending ambulatory care.
- describe the health care profession enabling skills using the modified PESQ.
- describe the patient enablement scores using the PEI.
- examine the association between patient characteristics and the PEI.
- examine the association between health care profession enabling skills and the PEI.
- identify factors associated with low enablement (PEI ≤ 4)
- identify univariate and independent predictors of low enablement in the study population.

5.3 Research Hypothesis

A hypothesis is a tentative and formal prediction about the relationship between two or more variables in the population being studied (Simpson 2015). The empirical literature and research design informed the formulation of the following hypotheses:

Hypothesis 1: Higher number of chronic disease and lower levels of self-reported health are associated with lower patient enablement scores.

Hypothesis 2: Higher frailty scores are associated with lower enablement scores (alternate hypothesis).

Hypothesis 3**.** Higher levels of psychological morbidity are associated with lower patient enablement scores.

Hypothesis 4**:** Lower levels of patient activation are associated with lower patient enablement scores. (Converse: higher patient activation is protective).

Hypothesis 5: First time clinic attenders have lower enablement scores compared to patients who have repeat clinic visits.

Hypothesis 6**:** There is a positive correlation between better health professional consultation skills and patient enablement (better skills are protective against lower patient enablement)

5.4 Research Design

A quantitative, descriptive cross-sectional survey design was used to meet the aims and objectives of the study. It is suggested that quantitative research produces more objective and generalisable results than qualitative research and it can be replicated and repeated giving it a high degree of reliability (Hannigan *et al.* 2018). Descriptive studies facilitate estimation of specific parameters in a population and identification of associations (Kelley *et al*. 2003) therefore facilitating the aims of the study.

A few hypotheses can be tested simultaneously making cross sectional surveys time efficient and valuable means of data collection. These were important considerations as there were no financial resources available to support this study. A cross-sectional study was chosen rather

than longitudinal as the aim was to measure enablement (gains) at a single point in time (post consultation with a health professional).

A survey is described as a research method used for collecting data from a pre-defined group of respondents to gain information and insights on a particular topic (Gray *et al.* 2017). This approach was selected because of the need to collect data from a large diverse sample of older people and the nature of the knowledge base on enablement. Although not specifically focused on an older population, the review of the theoretical and empirical evidence had identified a best fit model (CEM) and key variables which informed the instrument selection in a bespoke questionnaire.

A limitation of a cross sectional survey is that it cannot establish cause-and-effect relationships. This method identifies associations between variables, but it may be difficult to determine temporal relationships (Curtis and Drennan 2013). For example, is low enablement the result of low patient activation or the cause. Research aims required descriptive data in relation to an older adult cohort which would facilitate identification of relationships (influencing factors) and independent predictors of enablement. A cross-sectional survey design facilitated identification of relationships between the dependent variable enablement and independent variables such as age, chronic illness or enabling skills of the health professional. The approach is deductive facilitating the collection of data for the purpose of testing ideas and hypotheses (Balnaves and Caputi 2001). Clear research questions were identified, and hypothesis were formulated.

A questionnaire was selected to collect the volume of information required and to facilitate independent non-biased responses (outside perspective). Self-completion questionnaires facilitate more honest responses regarding the quality of services. I was mindful that patients with low enablement status may have difficulty completing the questionnaire alone, thus patients could receive support from a relative or a research assistant to reduce risk of low response rate and incomplete questionnaires. The next section addresses study setting and sample population.

5.4.1 Study Setting

The setting for the present study was a single ambulatory care centre (Assessment and Treatment Centre / Day Hospital) with rapid access, follow-up and specialist clinics for older people including Parkinson's movement disorder, falls & syncope, stroke follow-up continence (appendix I). It is located on the grounds of a hospital with rehabilitation and

continuing care facilities for older people and has strong links with community primary care service. This is the largest such centre in the Community Health Organisation serving Cork City and County with specialist services extending into neighbouring counties. Over the last 10 years, the Centre has seen an increased demand for ambulatory services due to an ageing population in the region as illustrated in the most recent 2016 census survey (Figure 5.1).

Age Cohort	2011	2016	% increase
60-64	33409	36384	8.9
65-69	26909	32719	21.6
70-74	20442	25221	23.4
75-79	16060	17947	11.7
80-84	10994	12766	16.1
85+	8963	10224	14.1

Figure 5.1 Population changes 2011-2016 by age cohort, Cork & Kerry, Census HSE South, 2016

The main source of referral to the Centre are from consultant geriatricians following acute and rehabilitation in-patient hospital stay and from out-patient clinics. There are also direct community referrals from general practitioners for diagnosis, treatment, and therapy interventions (appendix I). Patients usually require the input of two or more disciplines which consist of doctors, nurses with extended scope of practice, an advanced nurse practitioner, an occupational therapist, dietician, and physiotherapists. Approximately 320 patients attend the Assessment & Treatment Centre each month and of these approximately 80 (23%) are new referrals to the service.

5.4.2 Study population

The target population in this study were older people defined as 60 years and above and who were receiving health care through the Assessment & Treatment Centre. Sixty-years and above is the referral criteria to the centre. From a health perspective, biological age rather than chronological age is more important and people who live with chronic long-term conditions exhibited accelerated cellular ageing (Waziry *et al.* 2019). For this reason, the older adult services in the region accept referrals from those aged sixty years and above. While there is no international agreement on exact chronological definition of older age, the United Nations generally use 60+ years to refer to an older population (UN, 2001). In the scoping review of the literature, 60 was used as a marker of an older adult population (Bikker *et al.* 2005, Mead *et al.* 2008, Mercer *et al*. 2002, 2012).

Patients were recruited from across a range of unidisciplinary and multidisciplinary clinics. A sample size calculation, based on annual clinic attendance of 5000 (excluding psychiatry or memory clinic patients), suggested a sample size of 357 patients was required for 95% confidence level and 5% error rate (margin of error). A confidence interval to 90% required sample size to 257 (http://www.raosoft.com/samplesize.html). Over a six-month period, recruited 300 eligible patients were recruited which provided a 5-8% margin of error and >90% confidence interval.

The primary aim of this study was to investigate factors associated with low patient enablement Multiple logistic regression will be used to investigate factors associated with low patient enablement. In accordance with guidance from Peduzzi *et al.* (1996), a minimum sample size of 260 participants would be required for a multiple logistic regression with up to 13 independent variables and assuming a best-case scenario of 50% in each group.

Time and resource constraints and the need for a large sample negated selection of a random sample. A convenience sample was used, which is a specific type of non-probability sampling method that relies on data collection from population members who are conveniently available to participate in the study. Convenience sampling can contribute to sampling and systematic bias (Gray *et al.* 2017). This was minimised by inclusion of all eligible patients during the data collection period and adherence to inclusion and exclusion criteria. Using convenience sampling, new and follow-up patients with a range of chronic diseases were recruited from general and specialist clinics except for the dementia / memory clinics (see exclusion criteria). This included patients who had consultations with a single HCP (doctors, nurses, or therapists) and others who had consultations with the wider MDT (2 or more HCP).

5.4.3 Inclusion and Exclusion Criteria

The researcher with the support of the ATC nurse manager screened the daily patient caseload in advance and identified those who met the inclusion criteria.

Inclusion Criteria:

- Patients attending the Assessment & Treatment Centre
- Older People ≥ than 60 years of age
- Presenting with at least 1 chronic disease.
- Physically and cognitively able to complete questionnaire with or without assistance (no formal test of cognitive function was undertaken)
- Voluntary participation.

Exclusion Criteria:

- Patients < 60 years
- Patients who were acutely unwell
- Patients who were in the terminal phase of their illness & in receipt of palliative care.
- Patients attending memory or psychiatric clinics.
- Patients with a recorded diagnosis of dementia or significant cognitive impairment (MOCA / MMSE < 20 / 30). Formal tests of cognition were not undertaken as part of the survey, however pre-screening of referral or clinical letters identified those with a diagnosis of dementia or significant cognitive impairment who were excluded.
  Understanding enablement in the context of dementia is a separate study and requires a different methodological approach, the questionnaire format used would place too great a burden on the person with dementia.

5.4.4 Access to the Research Site and Sample

The researcher works as an Advanced Nurse Practitioner (ANP) in this setting which facilitated gatekeeper negotiation and access to the patient population. Permission to access the study site was sought from the gatekeepers (i.e., General Manager, Director of Nursing, A&TC Nurse Manager, Medical Consultants and Senior Therapists) who were provided with information and the study protocol (appendix V). Ethical approval was sought and granted (appendix VI) through the Cork Research Ethics Committee (CREC).

Due consideration was given to potential conflicting responsibilities associated with the role of nurses as research assistants and care providers in the ambulatory care setting and their responsibility to the patient (Nursing & Midwifery Board of Ireland, 2015). An information session was provided to all staff in the A&TC on the research protocol and an opportunity for questions was provided. Research assistants were not involved in the patient consultation or care of patients as part of their clinic visit.

5.5 Questionnaire Design

The Consumer Enablement Model (CEM) (Batterham *et al.* 2017), was used to guide the selection of variables that potentially influence enablement in an older population. The CEM is a comprehensive model that includes many influencing factors (determinants and components) that effect patient enablement. It would not be possible to measure all possible variables in a single study, especially in an older adult population. Batterham *et al.* (2017) state

that the dynamic determinants (healthcare experience) and components (patient characteristics) are subject to greater influence and have most clinical relevance. This focused questionnaire design and the inclusion of variables which were prioritised in accordance with the review of the theoretical and empirical evidence. Table 5.1 outlines the relationship between the CEM, and variables included in the final questionnaire, it also identifies previous empirical research studies that measured these variables. For ease of completion the questionnaire was laid out in two parts. Part I was designed to be completed pre-consultation while patients waited for the health professional and contained 38 items. Part II contained 33 items and was designed to be completed post-consultation as it contained the PEI and mPESQ which measured enablement post consultation and the enabling skills of the health professional. It was hoped that this would reduce the burden of completing a lengthy questionnaire. It is important to note, this was not a pre and post study design, both sections of the questionnaire could have been completed post consultation.

In accordance with the CEM (Batterham *et al.* 2017), the research questionnaire sought to collect information regarding the contexts in which people seek care for their health as potential influencing factors on enablement as an outcome measure. The value of including an open-ended question to elaborate responses to closed questions and allow respondents to identify new issues not captured in the closed questions is recognised (O'Cathain & Thomas 2004). In this research study, two open-ended questions were included to provide a narrative contextual backdrop and facilitate more meaningful interpretation of research findings and potentially highlight influencing factors on enablement which may need to be considered in further research.

A review of empirical evidence identified variables associated with low enablement which included enablement personal determinants and enablement components categorised as cognitive, motivational / affective, relational, and physical. This encompassed patient related characteristics (age, gender, social support, self-reported health, chronic disease and presenting complaint, psychological morbidity, functional ability, and expectation regarding receipt of a prescription). Dynamic determinants refer to the healthcare experience which can be positive or negative. Research items included health professional enabling skills and consultation specific factors related to length of consultation, first or follow-up appointment and receipt of a prescription. The questionnaire contained several validated instruments including the PEI (measurement of the dependent variable) and modification of the PESQ which are discussed in the next section.

Table 5.1 CEM guides selection of questionnaire variables

CEM	Item Descriptor / Instrument	item	Empirical Evidence
Contexts in which people seek healthcare	GP / Public Health Nurse Visits	2a, 2d	Howie *et al.* 1997, 1998, Pawlikowska *et al.* 2010, 2012, Batterham *et al.* 2017
	Attending other health professionals	2b	Batterham *et al.* 2017
	Hospital Admissions in last year	2c	Rolfson *et al.* 2006, Batterham *et al.* 2017
	Additional community services needed	2f	Batterham *et al.* 2017
COMPONENTS **Cognitive**	Patient Activation (PAM 13)	3h (1-13)	Hibbard *et al.* 1994, Wensing *et al.* 2007, Chan *et al.* 2019, Hudon *et al.* 2015, Batterham *et al.* 2017
Affective / Motivational	Expectation of Prescription	3d	Howie *et al.* 1998, 1999
	Psychological Morbidity	3e (1-6)	Rolfson *et al.* 2006, Howie *et al.* 1997, Pawlikowska *et al.* 2002, Mercer et al. 2002, 2012, Weenick 2014
	Medication to help mood	3f	Bandeira *et al.* 2018
Relational	Relationship Status Living Arrangements	1c 1d	Howie *et al.* 1999, Mercer *et al.* 2008, Pawlikowska *et al.* 2010
	Informal / Formal Supports	1e, 2e	Rolfson *et al.* 2006, Batterham *et al.* 2017
	Social Outings	1f	Batterham *et al.* 2017
Physical	Age Gender	1a 1b	Howie *et al.* 1999, Mead *et al.* 2008, Kurasawa *et al.* 2012, Pawlikowska *et al.* 2010, Lam *et al.* 2010, Chan *et al.* 2019
	Health Conditions / Multi-morbidity Patient main complaint / symptoms Self-Reported Health Issues discussed with HCP	3a 3b 3g 4c	Haughney *et al.* 2007, Hudon *et al.* 2013, MacPhearson *et al.* 2003, Simmons & Winefield 2002, Rolfson *et al.* 2006, Mead *et al.* 2008. Adzic *et al.* 2008, Mercer *et al.* 2008. Pawlikowska et al. 2010, Yu *et al.* 2015, Al Momen *et al.* 2015, Tolvanen *et al.* 2017
	Fitness / Frailty (Clinical Frailty Scale)	3i CFS	Mercer et al. 2002, Rolfson *et al.* 2006, Wensing *et al.* 2007, Kurasawa *et al.* 2012, Frost *et al.* 2015, BGS / RCGP 2015
	Polypharmacy	3c	Rolfson *et al.* 2006, Clegg *et al.* 2013
Dynamic Determinants	1st or follow-up appointment ATC	4a	Howie *et al.* 1998, 1999, Mead *et al.* 2008, Pawlikowska 2011, Tolvanen *et al.* 2017, Chan *et al.* 2019
	Health Professional Seen Uni-disciplinary / Multidisciplinary	4b	Adzic *et al.* 2008, Kurosawa *et al.* 2012, Desborough *et al.* 2016b, Chan *et al.* 2019
	Length of Consultation	4b	Howie *et al.* 1998, 1999, Denley *et al.* 2003, Bikker *et al.* 2005, Mercer *et al.* 2007, Adzic *et al.* 2008, Frost *et al.* 2017, Pawlikowska *et al.* 2002, 2010, Mercer *et al.* 2002, , Kurosawa *et al.* 2012, Al Momen *et al.* 2015, Yu *et al.* 2015
	Receipt of a prescription	4d	Howie *et al.* 1998, 1999, Pawlikowska *et al.* 2010
	Professional Enabling Skills (mPESQ)	4g (1-21)	Hudon *et al.* 2015, Desborough *et al.* 2016b, 2018 Frost *et al.* 2015
	Comments relating to enabling experience	4h	Desborough et al. 2016, 2018, Batterham *et al.* 2017
	Satisfaction with consultation	4i	Howie *et al.* 1998, Simmons & Winefield 2002, McKinley *et al.* 2004, McKinistry *et al.* 2006, Mead *et al.* 2008, Desborough *et al.* 2016, 2018, Tolvanen *et al.* 2017
Outcome	Patient Enablement (PEI)	4e (1-6)	Howie *et al.* 1997, 1998, 1999

5.5.1 Patient Enablement Instrument (PEI)

As the dependent variable, central to this study was the measurement of enablement which was operationalised by the PEI (Howie *et al.* 1997, 1998). The PEI focuses on the constructs of coping, managing, and understanding and it is widely validated in research (Frost *et al.* 2015, Chan *et al.* 2019). However, as a transitional scale, it measures gains at a single point (post consultation) and does not measure overall enablement status. No modifications were made to the 6-item tool which uses a four-point Likert scale: "not applicable" (score=0); "same or less" (score=0); "better" or "more" (score=1) and "much better" or "much more" (score=2).

Participants were asked to rate improvements in their confidence and ability to cope with life, cope with illness, keep healthy, understand illness, and help oneself following their consultation with a health care professional at the clinic. If patients saw more than one HCP at the clinic, they rated the combined enablement effect and the enablement skills of the health professionals involved. Prior permission was not sought to use the PEI in this study as the instrument is freely available from multiple websites and other published surveys of patient enablement. During questionnaire testing, the PEI was deemed clear and relevant, and no changes were made. The PEI demonstrates good internality reliability with Cronbach Alpha from previous studies ranging from 0.84 (Lam *et al.* 2010, Skarbaleine *et al.* 2019) to 0.93 (Howie *et al.* 1998, Hudon *et al.* 2011b). The internal consistency of the PEI has been shown to be high in previous studies (Howie et al. 1997, 1998, 1999, Kurosawa *et al.* 2012, Roost *et al.* 2015)

5.5.2 Psychological Morbidity

Psychological morbidity was measured using 6 items based on best practice guidelines on screening for depression in older people with chronic physical health problems (National Institute for Health and Care Excellence, 2012). Participants were asked to consider in the previous month, how often they had been bothered by the following symptoms: 1) feeling anxious, nervous or on edge, 2) feeling down, depressed, or hopeless, 3) little interest or pleasure in doing things, 4) feeling worthless, 5) having poor concentration and 6) recurring thoughts of death and dying. This was rated on a 4 item Likert scale which specified 'not at all', occasionally (1 – 2 times in the month), frequently (several days) and nearly every day.

5.5.3 Clinical Frailty Scale

In strategy, research and clinical practice, more credence is now attributed to a persons' physiological rather than chronological age (Rodríguez-Laso *et al.* 2014). Frailty is a concept

widely used in gerontology research and clinical practice and is defined as a multidimensional syndrome of loss of reserves (energy, physical ability, cognition, health) that gives rise to vulnerability (Rockwood *et al.* 2005, Blasimme 2016). Frailty is identified as distinct from but overlapping with both comorbidity and disability which was found to negatively impact on enablement (Chan *et al.* 2019). Frailty presents challenges in the context of medical intervention, rehabilitation, and positive patient outcomes (Fried *et al.* 2004, British Geriatric Society 2015) therefore I hypothesised that a patient's level of frailty would impact on enablement.

The Clinical Frailty Scale (CFS, Rockwood *et al.* 2005) is a validated tool which rates frailty in terms of functional ability on a nine-point scale from fit to terminally frail (bed bound) (Rockwood *et al.* 2005). For this research, the 9th point was not included as terminally frail patients were very unlikely to attend the clinics. In other contexts, the CFS has been shown to yield useful predictive information on patient outcomes (Basic and Shanley 2015, Lewis *et al.* 2020). The CSF is a freely available tool for research and clinical practice. Items relating to perception of health and social support from the Edmonton Frailty Scale (Hilmar *et al*. 2009) were also included in the questionnaire.

5.5.4 Patient Activation

The scoping review highlighted the significant influence on patient enablement of patient confidence (Howie et al. 1997, 1998, Frost *et al.* 2015), knowledge, beliefs, and self-efficacy (Haughney *et al.* 2007, Pawlikowska *et al.* 2012, Batterham *et al.* 2017), personal control and desire for involvement in healthcare decisions (Wensing *et al.* 2007). The Patient Activation Measure (PAM), (Hibbard et al. 2004, 2005) is a validated tool for the measurement of patient knowledge, skills, confidence, and motivation regarding self-management of health. The PAM is reported to be predictive of healthy behaviours, self-management and health information seeking in patients with chronic disease (Mosen *et al.* 2007, Rask *et al.* 2007, Dixon *et al.* 2009, Anderson *et al.* 2010, Begum *et al.* 2011, Skolaskey *et al.* 2011, Aung *et al.* 2015, 2016, Anderson & Wallace 2017, Barker *et al.* 2017). It has demonstrated high internal reliability with Cronbach's alpha ranging from .80 to .88 (Rademakers *et al.* 2016).

The PAM is a 13-item tool and uses a 4-point Likert scale. It generates a total activation score out of a 100 which categorises individuals into one of 4 levels of activation, (1) believing the patient role is important (more passive) (2) having the confidence and knowledge necessary to take action, (3) actually taking action to maintain and improve one's health, and (4) staying

the course even under stress. No changes were made to the PAM-13 which was included in part I of the questionnaire and was completed prior to the consultation. It is suggested that the concept of activation is similar to enablement (Fumagalli *et al.* 2015, Batterham *et al.* 2017, Siegel *et al.* 2019) and it is recognised as central to patient engagement and involvement (Hibbard *et al*. 2005). Like enablement where those less knowledgeable regarding their condition are likely to gain more from the enabling interventions of the health professional (Pawlikowska *et al.* 2012), Hibbard *et al.* (2014) observed that lower activated patients have the potential for greater gains if adequately supported (Hibbard *et al.* 2014). The licence for use of the PAM in this study was purchased from Insignia Health.

5.5.5 Professional Enabling Skills (mPESQ).

The influence of professional enabling skills on patient enablement was a recurring theme in the literature (Frost *et al.* 2015, Pawlikowska *et al*. 2010, 2012, Batterham *et al.* 2017). The Physician Enabling Skills Questionnaire (PESQ, Hudon *et al.* 2015) was developed for use in an ambulatory healthcare setting and was validated with an older adult population with chronic disease. Hudon *et al.* (2015) advised that the 34-item questionnaire could be shortened and adapted for use by other health professionals. The PESQ has only been used in one study (validation) which demonstrated adequate reliability and consistency of its' six dimensions (Cronbach alpha .69 to .92).

In this study, the PESQ was modified from 34 to 21-items (mPESQ) using a three-phase process. The initial process involved a discussion with the researchers' academic supervisors (external experts), medical mentor, a consultant geriatrician and an older adult who had previously attended the ambulatory care centre (internal experts) which resulted in reduction of items from 34 to 24 based on relevancy to the contextual setting. The word physician was replaced with health professional. In phase 2, the mPESQ was included in the questionnaire which was given to an expert group comprised of clinical nurse manager, consultant geriatrician, older adult, physiotherapist, occupational therapist, dietician, psychologist, and external expert (appendix VII). The reviewers commented on the clarity, consistency and relevancy and cumulative feedback (appendix VIII) resulted in further reduction of the mPESQ to 21 items and minor formatting changes. This was prompted by comments regarding unnecessary duplication and length of the questionnaire.

Table 5.2 modified Professional Enabling Skills Questionnaire (mPESQ)

Professional Enabling Skills Questionnaire: (modified PESQ, 21 item version)	**original, 34 item Physician Enabling Skills Questionnaire (Hudon et al. 2015)**	**PESQ DIMENSIONS**
The health professional(s) made me feel at ease.	I feel at ease with my family doctor	**Developing an ongoing partnership**
The health professional(s) discussed my medical history	My family doctor knows my medical history	**Starting from the patient's personal situation**
The health professional(s) asked about my health problems & how it affects my life.	My family doctor asks about the consequences of health problems on my life	**Starting from the patient's personal situation**
The health professional(s) asked about my feelings	My family doctor asks me about what I feel	**Starting from the patient's personal situation**
The health professional(s) gave me useful information and advice	My family doctor gives me tips or useful advice	**Acknowledging the patient's expertise regarding their own lives**
The health professional(s) understood and addressed my symptoms.	I feel that my doctor understands my suffering or my problems	**Legitimizing the illness experience**
I feel that the health professional respects my choices	I feel that my family doctor respects my choices	**Developing an ongoing partnership**
The health professional(s) discussed home help and my care needs.	My family doctor is open to discussing my concerns	**Starting from the patient's personal situation**
The health professional(s) listened to me and appeared interested.	My family doctor listens to me	**Developing an ongoing partnership**
The health professional(s) asked about my home environment & family	My family doctor asks about my life context (family, work etc)	**Starting from the patient's personal situation**
The health professional(s) reassured me & helped me see things more positively.	My family doctor knows what to say to reassure me	**Offering Realistic Hope**
The health professional helped me obtain the care I need	My family doctor helps me obtain the care I need	**Providing advocacy for the patient in health care system**
I trust the health professional(s)	I trust my family doctor	**Developing an ongoing partnership**
The health professional(s) helped me see what I can do to improve my health.	My family doctor helps me see what I am capable of doing to improve my health	**Acknowledging the patient's expertise regarding their own lives**
The health professional(s) looks after my interests in the health system	My family doctor looks after my interests in the health system	**Providing advocacy for the patient in health care system**
The health professional(s) gave me hope and encouragement.	My family doctor knows (or would know) how to provide encouragement if I needed it	**Offering Realistic Hope**
The health professional provided an opportunity to ask questions.	My family doctor encourages me to ask questions	**Developing an ongoing partnership**
The health professional(s) involved me in decisions	I am satisfied with the way my family doctor involves me in decision- making.	**Developing an ongoing partnership**
The health professional helped me become more independent.	I feel that my family doctor and I are a team	**Developing an ongoing partnership**
The health professional(s) links well with other professionals & agencies	My family doctor seems to collaborate well with other health professionals	**Providing advocacy for the patient in health care system**
The health professional(s) asked about my interests & social activities	My family doctor asks about my hobbies and interests	**Starting from the patient's personal situation**

The final 21-items identified in Table 5.2 represent the following 6 domains of PESQ as identified by Hudon *et al.* (2015)

- Developing an ongoing partnership: items 1. 7. 9, 13, 17, 18, 19 (7 items)
- Starting from the Patients Personal Situation: items 2, 3, 4, 8, 10, 21 (6 items)
- Acknowledging the Patients expertise in their own lives: 5, 14 (2 items)
- Legitimizing the illness experience: 6 (1 item)
- Offering Realistic Hope: 11, 16 (2 items)
- Providing advocacy for the patient in the health system: 12, 15, 20 (3 items)

The instrument uses a 5-point Likert scale ranging from 5 (strongly agree), the mid-point option stated as sometimes or unsure to 1 (strongly disagree). As part of the review process, the sometimes option was deemed unnecessary and was replaced by unsure for all items (appendix IX). The range score for the mPESQ was 21 to 105 compared to 34 to 170 for the original PESQ (Hudon *et al.* 2015).

As the mPESQ was significantly modified for the purpose of this study, confirmatory and exploratory factor analysis (appendix X) was conducted to examine the stability of the items and reliability of the overall instrument. The mPESQ represented two domains (from the original six). There was overlap in the items therefore following consultation with a statistician and academic supervisors, it was treated as a single construct measuring overall HCP enabling skills. The Cronbach alpha for the mPESQ was calculated at 0.94 demonstrating good reliability and internal consistency for use in this research. In phase 3, the 21 item mPESQ was included in the research instrument, which was piloted with 10 older people, using a process of cognitive interviewing.

5.6 Cognitive Interviews

The 3rd draft of the questionnaire contained 72 items (39 in part 1 and 33 in part 2). To further test the readability, clarity and ease of completion of the questionnaire, I undertook cognitive interviews with a volunteer group of older people. I was mindful that older people with chronic disease may have difficulty interpreting the questions or may have reduced manual dexterity negating questionnaire completion. The cognitive interview process aims to identify problems with comprehension of questionnaire items or difficulty formulating a response (Chernyak *et al.* 2012). Volunteer pilot participants were recruited from the on-site stroke support group which included their spouses who had other chronic conditions (appendix VIII). Their age range was 66 to 80 years and they had varied functional capacity (clinical frailty scale 3 – 6).

They were interviewed individually except for a man with Parkinson's disease (participant 4) who asked for his wife to be present because he had a tremor in his hand.

In accordance with guidelines for cognitive interviewing (Drennan 2003, Beatty 2004), respondents were encouraged to think out loud while completing the questionnaire. Participants were asked to reflect on the last time that they had attended a health professional and to complete the questionnaire based on this experience. These reflections related mainly to consultations with their general practitioner. Permission was obtained to record notes that captured their verbal feedback on questionnaire items. Problem indicators were classified as non-response, clarification sought, relevance considered or hesitant response.

The process confirmed readability of the questionnaire and relevancy of the content. While there was some hesitancy in responses, particularly in relation to completion of the clinical frailty scale and items in the patient activation scale, participants interpreted the questions correctly and completed the questionnaire appropriately. Participant 1 did not fully complete items on the psychological morbidity scale and asked for more clarification than others. This reinforced the need for support to be available to assist with completion of the questionnaire if required. Participant 4 had reduced manual dexterity and hesitant speech associated with his Parkinson's disease, but his comprehension was excellent. His Wife assisted with completion of the questionnaire but had to be reminded at the outset that it was important that his opinions were captured and not her own. Participant 10 had a visual and hearing impairment which did not impact on her ability to complete the questionnaire, but it raised awareness of the need to ensure that participants had visual and audio aids and were afforded privacy.

Only one item was classified as problematic as it presented difficulty for 20% of participants (n = 2) with (15% or more being the cut off for problematic items Chernyak *et al.* 2012). This item was retained but reworded to improve clarity. All participants agreed that the content was relevant, and their narrative provides an insightful perspective on their enabling experience (appendix VIII). During the testing period, the length of time to complete the questionnaire was noted and it varied from 16 minutes to 38 minutes with one older adult commenting that it was long. This may have been felt more acutely in the pre-test as Part 1 and 2 were completed together without the break of the consultation. The length of the questionnaire and potential burdening of questions in an elderly population was a concern for the researcher. Therefore, it was decided that if required, participants could take the questionnaire home and return it within a week.

Minor amendments were made to the questionnaire (i.e., bold text to highlight that all items were to be completed). Coloured paper was used to distinguish part 1 and 2 of the questionnaire (appendix IX). As the researcher, I found the process of cognitive interviewing useful to pre-test the questionnaire prior to distribution to the sample population. It also informed education of staff who would assist with data collection.

5.7 Data collection

The final 72-item structured questionnaire was designed following a comprehensive review of the existing literature and included the most pertinent items for an older population. The questionnaire was distributed to a convenience sample of older people aged 60 years and older attending general, specialist (medical, nursing and therapy) clinics in an ambulatory assessment & treatment centre (A&TC). In total 324 questionnaires were distributed and 300 were returned, giving a response rate of 93%. The challenges of engaging older people in research are recognised (Quinn 2010, Schilling & Gerhardus 2017) with potential age related sensory (i.e., visual) and functional limitations (i.e., reduced manual dexterity) hampering self-completion of the questionnaire. Therefore, provision was made for assistance by a family member or health professional (not involved in care). A tick box on the questionnaire indicated whether it was completed by the patient alone or with assistance.

Data collection was conducted over a six-month period (August 2018 to Jan 2019). Daily A&TC caseload were discussed, and potential participants identified based on inclusion and exclusion criteria. On arrival to the clinic these patients were given an information leaflet. To preserve anonymity, I did not seek separate written consent, completion of the questionnaire indicated consent to participate. Those willing to participate were given information by a research assistant (lead researcher or staff member trained to support the research) and offered support if required regarding completion. The health professionals directly involved in the patient consultation were not aware of research participants and patients were asked to conceal the partially completed questionnaire during consultation to reduce bias. Post consultation, part II of the questionnaire was completed and placed in sealed box in reception. Most patients completed the questionnaire immediately after the consultation while 2% (n = 6) took it home and returned it within a week.

5.8 Data Analysis

Data obtained from completed questionnaires were entered into SPSS version 18 for windows. The first stage of the analysis plan involved descriptive statistics. Categorical data (e.g., gender, living arrangements) were summarised as frequency distributions with proportion and percentages. Analysis of continuous variables such as age, PEI, mPESQ, PAM involved calculation of the central tendency (mean and median) with measures of variability including the range (the difference between the lowest and highest value or score), variance and standard deviation (measures of the spread of the scores around the mean) and confidence intervals (CI) (provides a given statistical probability). Data were presented in tables and graphical displays (bar chart, histograms, and pie charts) to aid interpretation of the data.

Inferential statistics extends beyond descriptive statistics in determining relationships between variables (Guetterman, 2019). With the support of a statistician, univariate and multivariate analysis was performed using Stata (version 15.0, StataCorp LP, College Station, TX, U.S.A.). The PEI was the primary outcome and the dependent variable. The PEI scores did not have a normal distribution, following initial attempts to use log transformation to improve the distribution, the decision was made to use logistic regression (Pett 2016) and to treat the PEI as a dichotomous outcome. As there is no standardise cut-off for the PEI to indicate low, moderate, or high enablement, in consultation with the statistician, a median cut-off on the observed data was used as this is a standard way of categorising continuous data. A median (4.0) cut-off rather than a mean was used as the data were not normally distributed (with many participants having a score of 0). In the published literature, Mercer et al. (2012) similarly used a measure of central tendency to select the cut-off between low and high enablement. All statistical analysis was performed using a binary grouping low (0-4) compared to high enablement (5-12). As the PEI scores are whole numbers (0,1,2,…12), the data were coded into group 1=0-4 (low enablement) and group 0=5-12 (high enablement).

Logistic regression is used to obtain odds ratio where there is more than one explanatory variable (Sperandel 2014). Univariable and multivariable logistic regression models (Alexopoulus 2010) were used to investigate relationships between the independent variables and PEI (dependent variable). Independent variables with a p-value<0.25 in the univariable analysis were eligible for inclusion in the multivariable analysis. The Hosmer-Lemeshow goodness of fit test (Hosmer and Lemeshow 2000) was used to determine the fit of the model. Prior to performing the multivariable logistic regression analysis, multicollinearity among the

independent variables was tested using the variance inflation factor (VIF). All tests were two-sided and a p-value<0.05 was statistically significant in the final multivariate model.

5.9 Data storage

Best practice guidelines regarding data management were adhered to (Corti *et al.* 2014). Data storage complied with the general Data Protection Regulation (GDPR) (2018). The paper-based questionnaire data was entered into an electronic spreadsheet on a password protected computer. When data cleaning and verification was complete, paper questionnaires were destroyed. Electronic files are stored on UCC One Drive which allows for secure file storage and sharing between the research team. Files are password protected. Participants were made aware that data would be encrypted and stored for a period of 10 years as per university code of research conduct (University College Cork 2018).

5.10 Rigour in Quantitative Research

The researcher sought to promote accuracy, honesty and rigor throughout the steps outlined for this study. The two key concepts when establishing the rigour of quantitative research are testing the reliability and validity (Robson, 2002).

5.10.1 Validity

Validity is understood at two levels. The fist type of validity refers to the extent to which an instrument measures what it is intended to measure (Lehane and Savage 2013). The three types of validity include content validity, face validity and construct validity. On a broader level, study validity assesses the quality, accuracy and utility of a study design and is categorised as internal validity and external validity (Mc Dermot 2011).

Internal Validity

Internal validity concentrates on the rigour of the conduct of the study and assesses the ability of the study instruments to accurately measures the phenomenon of interest. Internal validity is the extent the researcher can be confident in the study results (Mc Dermott *et al.* 2011). In the current study the extensive theoretical and empirical literature review informed the selection of the most pertinent study variables and instruments associated with the outcome of interest. In addition, the involvement of external clinical and academic experts and older people in the design of the questionnaire promotes confidence in the internal validity of the questionnaire.

The main threat to internal validity of a survey is selection of participants, as this was a cross sectional study involving a single group this was not a significant concern. There was a risk that patients with low enablement were less likely to participant in the survey. Patients were offered support to complete the survey, but due to participant anonymity we were not able to compare characteristics of non-responders with responders. Another consideration is history, i.e., was there a particular external programme or intervention that could have influenced enablement in this population (Flick 2009). As a practitioner working in this area, I knew there was no such programme at this time. Other treats to validity were participant self-report e.g., frailty and psychological morbidity, these were not confirmed by clinical practitioners.

External Validity

Refers to the extent the results are generalizable to a similar population. The use of a convenience sample may reduce the generalisability of results, but the sample size was adequate and there was a high response rate. External validity is achieved through replicating the study in similar populations in different care settings. The detailed description of the design decisions and publication of the methodological decisions and results will promote external validity (Mc Dermot 2011).

Content Validity

This type of validity addresses how well the questionnaire items were developed to measure and operationalise a construct (Kimberlin and Winterstein 2008). The PEI has been validated internationally addressing the core constructs coping, managing, and understanding (Frost *et al.* 2015) with good psychometric properties.

Face Validity

Face validity of a questionnaire design examines if the combination of instruments and bespoke questions are reasonable in the context of the issue or phenomenon being studied. Research using new, changed or previously unexamined scale items should be judged for face validity (Hardesty and Bearden 2004). This is the extent to which a measure captures what it is intended to measure and the degree that users (respondents) judged that the items of an assessment instrument are appropriate to the targeted construct and assessment objectives. In this research study, an expert review was conducted by six health professionals who made recommendations regarding section headings and wording of items. This provided face and content validity and ensured that questions were appropriate and measured what they claimed to measure. The process was enhanced by cognitive interviewing which provided valuable insight into an older

person understanding of the questionnaire and identification of problematic questions. It is particularly useful for younger or older age groups who may have some difficulty interpreting questions or completing questionnaires (Drennan 2003).

Batterham *et al.* (2017) suggested that the PEI may be open to 'hypothesis' guessing and may lack face validity for patients with chronic conditions who are frequent attenders at the clinic rating their overall experience rather than a single consultation. Murphy *et al.* (2018) highlight that, transitional scales may be inconsistently completed with some patients forgetting during completion, that they are measuring a change from baseline. In this study, explanation was given to participants prior to completion of the questionnaire to aid clarity. Design of the questionnaire prompted rating of enablement and the enabling skills of the health professional immediately after the consultation.

5.10.2 Reliability

Reliability relates to the consistency and precision of an instrument and its ability to reproduce the same results regardless of the user (Gerrish & Lacey, 2006). The questionnaire contained two previously validated instruments the PEI (6 items) and the PAM (13 items). A third instrument the PESQ was modified for the purpose of this study (the number of items reduced from 34 to 21). The 6-item psychological morbidity scale was informed by evidence-based guidelines for screening for depression in older people with chronic physical health problems (NICE 2012). The Cronbach's alpha was calculated to assess the reliability and internal consistency of the instrument items within the context of this study. See table 5.3 which demonstrates high Cronbach's alpha of 0.82 – 0.94 indicating good reliability of the instruments.

Table 5.3 Scales Reliability

Instrument	**Original Reference Source**	**No of items**	**Cronbach's Alpha**
Patient Enablement Instrument (PEI)*****	Howie *et al.* 1997	6	0.91
Patient Activation Measure (PAM 13) *****	Hibbard *et al.* 2005	13	0.92
Modified Professional Enabling (mPESQ)	Hudon *et al.* 2015	21	0.94
Psychological Morbidity Scale	Based on NICE 2012	6	0.82.

***** indicates that no changes were made to the original instrument.

5.11 Ethical Considerations

Research ethics may be described as ‘a set of practical tools that a researcher draws on to help reflect on and explore the possible implications of the research for participants and for the integrity of the research process’ (Swinton 2009, p26). Throughout the design and conduct of the study, the researchers’ primary aim was to conduct ethically appropriate research. Ethical approval was sought and granted from the Cork Research Ethics Committee (appendix VI).

There are four primary ethical principles outlined in the Belmont report (National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1979), namely autonomy, beneficence, non-maleficence, and justice.

5.11.1 Principle of Autonomy

Autonomy is the right of an individual to make their own decisions (Nursing Midwifery Bord Ireland 2015). The researcher operationalised these principles within the research study as follows:

Consent:

Completion of the questionnaire was considered consent to take part in this study. Participants were advised that participation or non-participation would not impact negatively on their care. An information leaflet (with large readable font size) was provided giving a description of the planned research, invitation to partake in completing the questionnaire and contact details of the researcher (appendix XI). The researcher and informed staff were present to offer support as required.

Voluntary Participation & right to withdraw from research.

Patients were assured that participation was voluntary and that non-participation would not impact (positively or negatively) on the care that they received. Patients were advised of their right to refuse to partake in the study without adverse repercussions. Participants were also made aware that once the questionnaire had been completed and placed in the sealed container, it would not be possible to withdraw due to the absence of an identifier.

5.11.2 Principle of Beneficence

Beneficence relates to improving the situation of others. Participants were made aware that there may be no immediate benefits to them in participating in the study. This research is of social value as it will assist in understanding enablement from the perspective of older people

with chronic disease. Results aim to inform clinical practice, education, and research. To date research on enablement under-represents older people who are the main users of health services. Best practice guidelines (University of Sheffield, 2011) reinforce that, studies of an adult population which exclude older people only for convenience's sake, are unscientific and unethical. There is wide recognition that older people are a diverse group that require special consideration. The researcher was mindful of challenging potentially stereotypical ageist attitudes by capturing the heterogeneity of an older adult population with varying levels of fitness and frailty.

If participants became upset and raised issues of concern such as loneliness or depression, patients were advised to discuss this further with a health professional.

Non-maleficence

In addition to making efforts to secure participants wellbeing (beneficence), this principle also addresses protection of participants from harm (non-maleficence). Older people are a potentially vulnerable research population (Aselage *et al.* 2010), particularly those with advanced chronic illness. In this study, the researcher provided eligible patients with easy-to-read illustrated information to facilitate their participation in the research. Patients with a diagnosis of dementia were excluded from this study as the tools have not been tested in this population. Formal cognitive testing was not carried out therefore some participants may have had mild cognitive impairment. In accordance with the philosophy of the unit, communication was person always centred and respectful.

The research setting is accessible and familiar to patients attending for nursing assessment, medical review, therapy, or multidisciplinary interventions. Research activity was coordinated with scheduled clinic visits and fitted around clinic activity to minimize the impact on participants and clinic staff. It was acknowledged that completing the questionnaire may place a research burden on older adult participants who may also have deficits in relation to health literacy. Provision was made for assistance with completion of the questionnaire and health professionals involved received an information session and a copy of the research protocol (appendix V). There was no participant identifier on the data collected, therefore maintaining confidentiality. In accordance with University research data management policy and the General Data Protection Regulation, research data was kept securely in both paper and electronic form.

5.11.3 Principle of Justice

The principle of Justice is about fairness and treating people equally (Belmont Report, 1979). Bias describes any deviation from the truth (Simundic 2013) was avoided in the data collection, data analysis and interpretation with the oversight of academic supervisors. Participants were informed that anonymity and privacy would be protected. To preserve anonymity, no personal details were included on the questionnaire. A sealed box was provided for completed questionnaires. Participants were informed that participation or non-participation would not impact on their consultation and their relationship with the health professional (appendix XI). Concealment of questionnaire during consultation prevented identification of those who were study participants therefore minimising potential influence on the consultation.

Conclusion

In this chapter, the methodological design and data collection process was outlined. A cross-sectional survey, using a structured questionnaire facilitated data collection from a convenience sample of older people attending an ambulatory Assessment and Treatment Centre. Details in relation to the sample selection were explained. The questionnaire design was based on the Consumer Enablement Model. Individual questions and research instruments were selected in line with external, personal, and dynamic determinants and components of enablement (patient characteristics). The primary outcome was enablement post consultation with a health care professional and was measured with the PEI.

Data analysis was performed using Statistical Package for Social Sciences (SPPS version 18) and Stata with descriptive statistics identifying characteristics of an older adult population. Data analysis used univariate and multivariate analysis to examine the relationships between the dependent variable enablement as measured by the PEI and independent variables identified as significant following a scoping review of the literature. The next chapter presents the research findings identifying independent predictors and influencing factors associated with low enablement.





Foley, M. J. 2020. Enablement of older people with chronic disease attending an ambulatory care centre. PhD Thesis, University College Cork.

Please note that Chapter 6 (pp. 136-172) is unavailable due to a restriction requested by the author.

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Chapter 7 **Discussion**

7.1 Introduction

This chapter presents a discussion of the research findings drawing on the evidence presented earlier in this thesis and the broader literature. In an Irish context, this is the first study to focus on the concept of enablement and internationally, it is one of only a few studies in an older population with chronic disease. It is also unique in its research setting, an ambulatory care centre with a multidisciplinary team. The overarching aim of this study was to examine enablement of older people with chronic disease post consultation with a health professional in an ambulatory care setting and identify influencing factors on low enablement. In this chapter, the independent predictors of enablement and other influencing factors identified following univariate and multivariate analysis are discussed. The alignment between the research findings and the CEM are examined, and a refinement of the model, the Consumer Enablement Model for Older People (CEMOP) is proposed. The CEMOP acknowledges the broader determinants of health and encompasses patient components and dynamic determinants of enablement in this population. Finally, the implications for clinical practice, education and further research are presented.

7.2 Overview of Results

Patient enablement was examined in 273 older people living with chronic disease attending an ambulatory care service. The health and social profile of participants demonstrate the heterogeneity of an older adult population. The mean age of respondents was 80 years making this the oldest population in which enablement has been measured. In comparison with other research (Al Momen *et al.* 2015), there was a higher burden of chronic disease in this study cohort, with 61% living with three or more conditions. It is likely that higher levels of chronic disease and more advanced age in this study population contributed to high levels of frailty, psychological morbidity, and poor self-reported health. Notwithstanding this, 81% of respondents demonstrated a positive change in their enablement (PEI score >0) post consultation with a health care professional, demonstrating the consultation's value in increasing understanding, coping, self-management, and healthy life choices.

The mean PEI score was 4.48 in this study cohort which is in the mid-range of reported mean PEI scores in the literature (Table 4.4). Other studies of an older adult population (> 60 years) reported PEI scores from 3.0 to 6.0 (Howie *et al.* 1999, Chan *et al.* 2019, Adzic *et al.* 2008). Cultural nuances may partly explain variations in scores. This is borne out in a European study

(Wensing *et al.* 2007), secondary analysis of data relating to older people attending general practice (mean age 77), where the lowest mean PEI score was in the United Kingdom (mean PEI 3.9) and the highest in Slovenia (mean PEI 7.2). This is the first Irish study to use the PEI; therefore, comparisons are limited. Future research is required to compare PEI scores of older people in different care contexts, including primary care.

The research was guided by the theoretical literature on enablement, predominantly the CEM, which provides the best model fit to examine the influencing factors on enablement in the context of an older adult population. The questionnaire examined the multifaceted nature of enablement, considering patient components (cognitive, affective/motivational, physical, relational) and dynamic determinants (consultation characteristics, health care professional consultation skills). In the multivariate logistic regression analysis, there were four variables that were independent predictors of low enablement and a further eight variables that were significant in the univariate analysis but were not significant in the multivariate model. There are similarities and important differences in this study's findings compared to the wider literature. These will be discussed in greater detail under predictors of low enablement and other influencing factors.

7.3 Predictors of low enablement

As presented in the scoping review of the literature, there is no standardised cut off for low enablement. Other studies have used PEI cut-offs between 1.0 (Pawlikowska 2011) to 6.0 (Adzic *et al.* 2008, Chan *et al.* 2019). Mercer et al (2012), used the population mean to select the cut-off between low versus high enablement. In this study, in consultation with the statistician, the median value (4) was selected rather than the mean (4.48) as the data were not normally distributed. The binary categories were low enablement (PEI 0-4) and higher enablement (PEI 5-12). In this cohort, 54% (n = 147) of respondents were categorised as low enablement. In the final logistic regression model, four variables remained independent predictors of enablement post-consultation (gender, frailty, patient activation and enabling skills of the health care professional).

7.3.1 Gender

Female gender was identified as an independent predictor of enablement with lower PEI scores in women (3.94 (SD 3.5)) compared to men (5.08(SD 3.5)). This concurs with other research,

which found that females had significantly lower enablement scores than males (Howie *et al.* 1998, 1999, Mead *et al.* 2008, Al Momen *et al.* 2015, Yu *et al.* 2015, Chan *et al.* 2020). Tuohy and Cooney (2019) suggested that gender differences shape older women's experience of ageing, health, illness, and engagement with services. This research lends support to this viewpoint; however, in the scoping review, results on gender differences were mixed. There is a need to better understand gender differences on perceptions of health and well-being.

7.3.2 Frailty

Frailty, as measured by the CFS (Rockwood et al. 2005), was identified as an independent predictor of enablement with a one-unit increase in the CFS associated with a 26% (OR 1.26) increased risk of low enablement. Frailty is viewed as a distinctive health state related to the ageing process in which multiple body systems gradually lose their in-built reserves (Clegg *et al.* 2013). Risk factors for frailty include chronic disease, lifestyle, and bio-psychosocial influences (Clegg *et al.* 2013). Frailty as a distinct concept has not been examined before in relation to enablement, but there is evidence to suggest that people who have functional deficits and complex health problems (biomedical, psychological, and social issues) report lower enablement (Mercer *et al.* 2002, 2012, Adzic *et al.* 2008, Pawlikowska *et al.* 2010, Al Momen *et al.* 2015, Batterham *et al.* 2017, Chan *et al.* 2019*).*

A limitation in this study may be that frailty was self-assessed by respondents rather than diagnosed by an HCP. Results indicated that 55% of respondents were frail, which is in the upper limit of prevalence estimates (4%-59%) of frailty in older people (Collard *et al.* 2012). Higher levels of frailty are expected in an older adult population with chronic disease (i.e., Parkinson's disease) with complex presentations requiring specialist multi-disciplinary services of the ambulatory care centre. In Ireland's Longitudinal Cohort Study on Ageing (Tilda), 24% of community-dwelling older people (>50 years) were categorised as pre-frail or frail (Roe *et al.* 2016, 2017), and frailty was associated with higher use of social and medical care services (Oeseburg *et al*. 2009, Fried *et al.* 2004).

Frailty is regarded as a stronger predictor of disability, hospitalisation, long term care or death than multimorbidity (Gill 2006, Dent *et al.* 2014, Blasimme 2017). It is recognised that an older person can transition in either direction between the different levels of frailty (Kidd *et al.* 2019). Physical exercise, improved nutrition, and better chronic disease management are protective and can reverse frailty (Michel *et al.* 2015, Vetrano *et al.* 2019). Much depends on

the enabling interventions of health professionals and an older person's capacity and motivation to engage with evidence-based interventions.

7.3.3 Patient Activation

Patient activation was significantly associated with enablement, whereby a one-unit increase in PAM-13 was associated with 3% risk reduction of low enablement (protective). The PAM-13 data indicated that 24% of respondents were disengaged and overwhelmed, while another 18% had knowledge deficits and believed health was largely out of their control. These findings concur with Hibbard and Cunningham (2008), who reported that 25 - 40 per cent of populations sampled have low levels of activation. It is acknowledged that enablement may be more difficult to achieve in situations where patients are less engaged in the consultation process and are reluctant participants in their care (Pawlikowska 2011, Wensing *et al.* 2007). These patients require knowledgeable health professionals' facilitation and motivational skills and individually tailored interventions that often extend beyond a single consultation (Hibbard and Gilburt 2014).

The importance of patients understanding their health care needs, which in turn influences health-seeking behaviours and choices, is a recurring theme in the enablement literature (Pawlikowska 2011, Hudon *et al.* 2011a, 2013, Frost *et al.* 2015, Desborough *et al.* 2016, 2017, Chan *et al.* 2019). In this study, 89% of participants indicated they had received useful information and advice from the health professional (mPESQ item), and 65% had an improved understanding of their illness (PEI item) because of their consultation. Patient factors influence patient activation and enablement. Cognitive deficits may hinder knowledge transfer and activation, while patient expertise and an already good level of knowledge reduce the ability of the PEI and PAM-13 to measure gains post healthcare engagement (Pawlikowska 2011, Hibbard and Gilburt 2014, Batterham *et al.* 2017).

The chronic care model promotes productive interactions between proactive professionals and activated patients with the aim of achieving optimum management of long-term illness (Bodenheimer *et al.* 2002). Currently, 80% of GP consultations and 60% of hospital bed days relate to chronic disease management hence the importance of 'making every contact count' (O'Brien and Scott 2016). This research highlights the complexity of factors that impact on enablement of older people, with patient activation an important modifiable factor. It affirms the importance of a person-centred collaborative approach where patients are enabled to be active participants in their health and self-management of chronic illness. Batterham *et al.*

(2017, p.49) acknowledged that '*the operationalisation of enablement is more complex when seeking to sustainably engage hard-to-reach and disadvantaged consumers, living in low resource environments* and suggested that a priority is to '*create environments where self-efficacy, self-management, and agency (defined as the potential for ongoing enablement) become routine parts of the lives of people with low enablement.* There may be an unconscious bias that older people lack the to change ability (Wyman *et al.* 2018). This research challenges this view and emphases that older people should be afforded the same opportunities for patient activation and enablement as younger groups.

7.3.4 Professional Enabling Skills

The enabling skills of health professionals (measured using the mPESQ), was protective against lower enablement scores. Hudon *et al.* (2015) reported the PESQ had good predictive validity with the PEI ($p \leq .001$), but there is no other research on the relationship between patient enablement and professional enabling skills. Outside of the clinical consultation, there is evidence of the benefits of the enabling skills of health professionals (Hudon *et al.* 2013, Frost *et al.* 2015). Examples are provided in relation to asthma and the facilitation of patient dose adjustment (Haughney *et al.* 2007). In this study, the high mPESQ scores suggest that patient enablement as measured by the PEI may be constrained by factors other than the enabling skills of the health professional. In an ambulatory care setting, consultation characteristics such as length of consultation or receipt of a prescription were not important considerations compared to studies in general practice (Howie *et al.* 1999, Biker *et al.* 2005, Al Momen *et al.* 2015).

The dimensions of the mPESQ (starting from the person's situation, legitimizing the illness experience, acknowledging patient expertise, developing an ongoing partnership, offering realistic hope, providing advocacy for the patient in the health system) offer a framework for developing the enabling skills of the health professional. The mPESQ, takes a holistic view of the patient beyond the medical presentation, which aligns well with a comprehensive geriatric assessment model (CGA). For example, in the mPESQ, 76% of participants agreed that health professionals worked well with other agencies, and 73% indicated that the health professional helped them obtain the care they needed. CGA focuses on determining an older person's medical, psychological, and functional capability to develop a coordinated and integrated plan for treatment and long term follow up (British Geriatric Society 2019). Central to patient enablement and CGA is that patients receive the right care by the right person in the right place at the right time (HSE 2018). The dynamic nature of patient enablement and the changing needs

of older people with chronic disease (HSE 2020) require that all MDT members have a core skill set to promote enablement.

7.4 Other Influencing Factors

In addition to the four independent predictors of enablement, there were an additional eight influencing factors on low enablement identified as significant in the univariate analysis. These factors were: age, chronic diseases, self-reported health, psychological morbidity, unidisciplinary consultation, living alone, receipt of home help and public health nurse visits. Although not significant in the final model, they make an important contribution to understanding enablement in this population.

7.4.1 Unidisciplinary versus Multidisciplinary Consultation.

This is the first study to consider enablement in the context of multidisciplinary clinics in an ambulatory community-based setting. Findings indicate there may be a greater improvement in PEI scores following consultation with two or more disciplines compared to a single health care professional. The benefits of an integrated multidisciplinary person-centred approach are well documented (HSE 2018, Clare 2016, HSE 2018, Shrubsole 2019).

Comparing the mean PEI scores of various disciplines suggests some interesting patterns that should be considered in future multi-site research with a larger sample. Patients seen by a therapist (physiotherapist, occupational therapist, or dietician) had a higher PEI score (mean 5.1) than those consulting with a medical consultant (4.2) or less senior doctor (3.5). This may be related to a patient's rehabilitation potential as distinct from patients with more complex medical issues requiring return appointments. The importance of continuity of care, knowledge, expertise and trusting therapeutic relationship between patient and consultant is reflected in the higher PEI scores of medical consultants (4.2) compared with non-consultant doctors (3.5). This concurs with other research findings (Howie *et al.* 1998, Yu *et al.* 2015).

The ANP mean PEI scores (6.4) compared favourably with those of doctors (4.2), which concurs with Barrett & Thomas (2018*)* and Venning *et al.* (2000). It is recognised that an ANP have more opportunity to build therapeutic relations and provide continuity of care compared to junior doctors who transition through the unit (Coyne *et al.* 2016). The significance of continuity of care and the therapeutic nurse-patient relationship was further explored in the context of nurses in general practice (Desborough *et al.* 2016, 2017,2018a), outpatients (Desborough *et al.* 2018b) and advanced nursing practice (Frost *et al.* 2017a, 2017b).

Pawlikowska *et al.* (2015) highlighted the significant contribution of nurses with prescriptive autonomy, specialist skills in chronic disease management who consult with a hybrid person-centred style combining the nursing ideology of holism and their knowledge of biomedicine.

The pivotal role of all nurses in ambulatory care settings is recognised by Esposito *et al.* (2018) in relation to educating, encouraging, motivating, and supporting patients to engage in achieving healthcare goals and the mean PEI scores of nurses (4.3) in this study affirm their significant contribution within the multidisciplinary team. Within an ambulatory care setting, this study confirms the value of developing the enabling consultation skills of all HCPs and working collaboratively with the patient using an integrated interdisciplinary approach responsive to the individual needs of the older adult with chronic disease.

7.4.2 Age

In the univariate analysis, increasing age was associated with lower enablement. Mean enablement scores were significantly higher in respondents aged 60 to 79 years (PEI 5.28, SD 3.6) compared to those aged 80 years and older (PEI 3.85, SD 3.4). This concurs with other research (Howie *et al.* 1999, Yu *et al.* 2015 Adzic *et al.* 2008, Skarbalienė *et al.* 2019 and Chan *et al.* 2019). In this older population, functional capability (i.e., biological age) as indicated by frailty was more influential than chronological age in predicting enablement. This implies that enablement in an older population should be viewed in the context of a person's level of multimorbidity and functional capability rather than age alone. Interventions should focus on active ageing and health promotion to delay or reverse frailty (HSE 2015).

7.4.3 Formal & Informal Supports

In this study, 35% of participants lived alone, which is higher than the 27% identified in the Irish census (Central Statistics Office, 2017). Patients who lived alone were more likely to report low enablement than people who lived with a family member. The Irish Longitudinal Study on Ageing demonstrated that the prevalence of frailty among people aged 50 and over who lived alone was approximately twice that of older people who lived with other people (Roe *et al.* 2017). There is limited research on enablement and social networks, but Batterham *et al.* (2017) suggested that individuals need higher levels of personal knowledge, skills, energy, and confidence where social supports are reduced. In this research, 67% of respondents stated that the health professional discussed their home care needs. For the remaining 33%, it may have been previously discussed or irrelevant due to functional independence.

The involvement of a public health nurse and receipt of home help was also identified as a significant influencing factor on low enablement. These factors are surrogate markers of frailty indicative of those who were more dependent on others for help. Higher home help utilisation was associated with a higher prevalence of frailty (Kelly *et al.* 2017). In response to an open-ended question, respondents made some suggestions for additional supports that may help, such as exercise and social activities, additional therapy, day care places and respite facilities. Enablement is likely to be influenced by unmet social and physical needs reflecting support for social engagement and social prescribing as part of the national Slaintecare Health strategy (Dept of Health, 2019).

7.4.4 Chronic Disease / Multiple Comorbidities

There was a high prevalence of chronic disease in this population that was associated with lower enablement. Mead et al. (2008) identified that patients reporting longstanding illness and those with above-average health care contact in the previous 12 months had lower enablement scores. Similarly, Al Momen *et al.* (2015) found that the presence of chronic disease negatively influenced enablement scores. The personal burden of chronic illness and the cumulative impact of comorbidities and treatment is well recognised (May *et al.* 2009, Greenglass *et al.* 2006). Ageing and reduced physical reserves and social supports add greater complexity to patient management. Concurring with the principles of enablement, the National Institute of Clinical Evidence (2017) has published best practice guidelines on multimorbidity. The guideline aims to reduce the impact of treatment burden by focusing on the person's individual needs, preferences, health priorities, lifestyle choices, goals and promoting proactive healthcare management to improve quality of life, reduce adverse events and unplanned care (Kernick *et al.* 2017). Enablement through patient education shifts the locus of control from professional to patient and family carers (Funnell 2000).

7.4.5 Self-reported Health

Self-reported health was associated with enablement ($p=0.027$), and those who reported their health as poor, or fair were more likely to have low enablement. This concurs with other research (Adzic *et al.* 2008, Mead *et al.* 2008, Pawlikowska *et al.* 2010, Simmons & Winefield 2002) where perceptions of poor personal health and reduced quality of life were associated with lower enablement scores.

It is recognised that subjective perception of health is a powerful predictor of morbidity and mortality (Borglin *et al.* 2005). Adzic *et al.* (2008) found that 35% of respondents reported

their health as poor or fair. In this study, 28% of the study sample reported their health as poor or fair, which corresponds with findings of TILDA where 25% rated their health as fair and 6% as poor (Turner et al. 2010). Self-reported health does not necessarily relate to the severity of symptoms or the number of chronic diseases but to coping and resilience levels (Tkatch *et al.* 2017). While those with lower levels of self-rated health have possibly most to gain from the enabling interventions of health professionals, enablement is likely to require more than one consultation in this population.

7.4.6 Psychological Morbidity

Psychological morbidity was associated with enablement (p=0.037) in the univariate analysis. Respondents with more depressive symptoms and higher anxiety were more likely to have low enablement. Other researchers have reported similar findings (Pawlikowska *et al.* 2010. Mercer *et al.* 2012 Small *et al.* 2013, Weenick *et al.* 2014). In TILDA cohort study, 1 in 20 older people had a major depressive disorder in the last 12 months (McGarrigle *et al.* 2017). In this research, 30% of respondents indicated depressive symptoms frequently or nearly every day, yet less than 1% (n =3) identified mood or anxiety as an issue for discussion with the health professional. Roman and Callen (2008) reported that older people were less likely to report depressive symptoms to a healthcare professional than their younger counterparts. There is a misperception that depression is a normal feature of ageing; thus, it is often under-recognised and inadequately treated (Katona 2000, World Health Organisation 2017).

The findings in this research support the importance of health professionals proactively inquiring about mood as a standard part of an enabling health care consultation (Pawlikowska 2011, Goodrich & Cornwell 2008). The importance of health professionals' therapeutic engagement and eliciting information on mood in a caring and compassionate manner encourages patients to be more forthcoming about their symptoms and concerns.

7.5 Measurement of Enablement

An important question to address in this concluding chapter is the adequacy of the PEI as a research measure of the dependent variable, low enablement. This research supports the validity and reliability of the PEI to measure enablement post consultation and to identify independent predictors. However, the number of influencing factors identified as patient and

context-specific affirms that the PEI should not be used alone as a quality outcome measure of health services or health professional enabling skills.

The brevity of the 6-item instrument facilitated the inclusion of the PEI in a questionnaire that addressed broader contextual elements (figure 7.1). As intended by Howie *et al.* 1997, 1998), the focus was on enablement as an outcome measure of health gains post engagement with a health professional, addressing understanding, confidence, coping, ability to care for oneself and engage in healthy behaviours. This is meaningful in the context of chronic disease management, community-based health initiatives and the development of ambulatory services that sustain older people in the community (Department of Health 2019). It is important to note that the PEI is not a measure of a person's enablement status. It addresses a pivotal point of health service engagement which may positively influence longer term healthcare outcomes. Much depends on patient needs, available resources (personal or external), and the health professional's enabling skills.

International use of the PEI (Frost *et al.* 2015) facilitated comparative analysis of mean PEI scores, although the non-normative distribution of PEI scores is problematic. In this research, the PEI scores ranged from 0 (19%, n=52), indicating no change in enablement to 12 (8%, n = 21) maximum gain in enablement. The PEI may be a useful quality indicator in relation to chronic disease and best practice guidelines (HSE 2017). In this study, the range of PEI scores in comparison with high satisfaction rates (99%) confirms that enablement is a more discerning measure than satisfaction in demonstrating the benefits of healthcare engagement.

As a transitional scale measure, the PEI has recognised limitations (Weenick *et al.* 2014, Murphy *et al.* 2018, Bedford *et al.* 2020). Measuring health gains and the efficacy of enabling interventions at a single point in time can be challenging, particularly in an older population with multiple consultations for various health conditions. Comments suggest that some ratings were based on cumulative experiences. In response to an open-ended question, one 87-year-old participant remarked, *'.some of the questions are not relevant as it is just continuous assessment of the same condition'.* For this person, what was important was that *'the courtesy and care is second to none and I am treated like a fully functioning adult despite my very advanced years' (PEI score 8).*

It is acknowledged that the PEI may be more suitable for specific populations with newly diagnosed chronic disease who have greater potential for a positive shift in PEI scores regarding the understanding of illness and coping with a potentially life-limiting disease (Roost

et al. 2015). The research did not identify first or follow-up appointments as a significant variable. In an older adult population with chronic disease, it is not easy to capture the full value of healthcare engagement in a quantitative study (Knäuper *et al.* 2016). The research findings presented confirm that the PEI can make a valuable contribution to research and understanding enablement, but it should not be used as a stand-alone quality indicator in clinical practice, and both researchers and clinicians need to be discerning when interpreting evidence.

7.6 Application of the Enablement Model

A review of the theoretical literature identified the Consumer Enablement Model (Batterham *et al.* 2017) as the best fit for this research as it places the patient centre stage and acknowledges the contexts in which people seek healthcare. Batterham *et al.* (2017) developed the original model following an extensive review of the literature and case review of enablement in patients with chronic disease. The dearth of evidence, particularly concerning patients with low enablement, has in part been addressed by this research.

The synthesis of the theoretical and empirical evidence generated common themes, which aided the identification of a best-fit model (Carroll *et al.* 2013, Booth and Carroll 2015). The scoping review of the empirical literature identified potential influencing factors on enablement following consultation with an HCP. These factors were aligned under the broad categories proposed in the CEM: external and personal determinants, patient components (characteristics) and dynamic determinants (persons' positive or negative experience of healthcare). At the end of chapter 4, there is a diagrammatic representation of the synthesis of the theoretical and empirical literature on enablement (Figure 4.4). Conscious of the burden of questionnaire completion, it was necessary to prioritise potential influencing factors identified in the enablement literature. Therefore, some external and personal determinants (e.g., health literacy, economic factors) were not measured.

The results of this research have added to the body of knowledge on enablement. Deeper analysis and synthesis of the information and model development was aided by academic supervisors and external advisors (appendix II). It was also enhanced by personal knowledge and clinical experience as an advanced nurse practitioner in rehabilitation and engagement with

key stakeholders. The following section reconsiders the model fit in terms of factors influencing low enablement in an older adult population living with chronic disease.

The CEM is amended in Figure 7.1 specifically to low enablement and incorporates independent and influencing factors based on the univariate and multivariate analysis. As demonstrated in Figure 7.1, the factors that emerged as important in this research fell predominately under patient components (age, gender, chronic disease, frailty, activation etc.). Dynamic determinants mainly concerned the HCP skills and unidisciplinary versus multidisciplinary consultation. The adaptation to the model is specific to gains in enablement following consultation as measured by the PEI; it is possible that using a different measure of enablement may identify other significant influencing factors.

Batterham *et al.* (2017) advised that the CEM required further development for different groups. The title of the re-worked model (Figure 7.2) remains unchanged but is extended to include older people. The word 'consumer' may not be meaningful, with evidence suggesting that 'patient' is the preferred term (Costa *et al.* 2019). The term 'consumer' is increasingly used in strategic healthcare documents (Phelan *et al.* 2019), there are concerns that consumerism comes from a perspective that may not align well with a supportive enablement approach (Lattimer *et al.* 2017, Sage Advocacy 2019). The title 'Person Enablement Model' may be more universally acceptable.

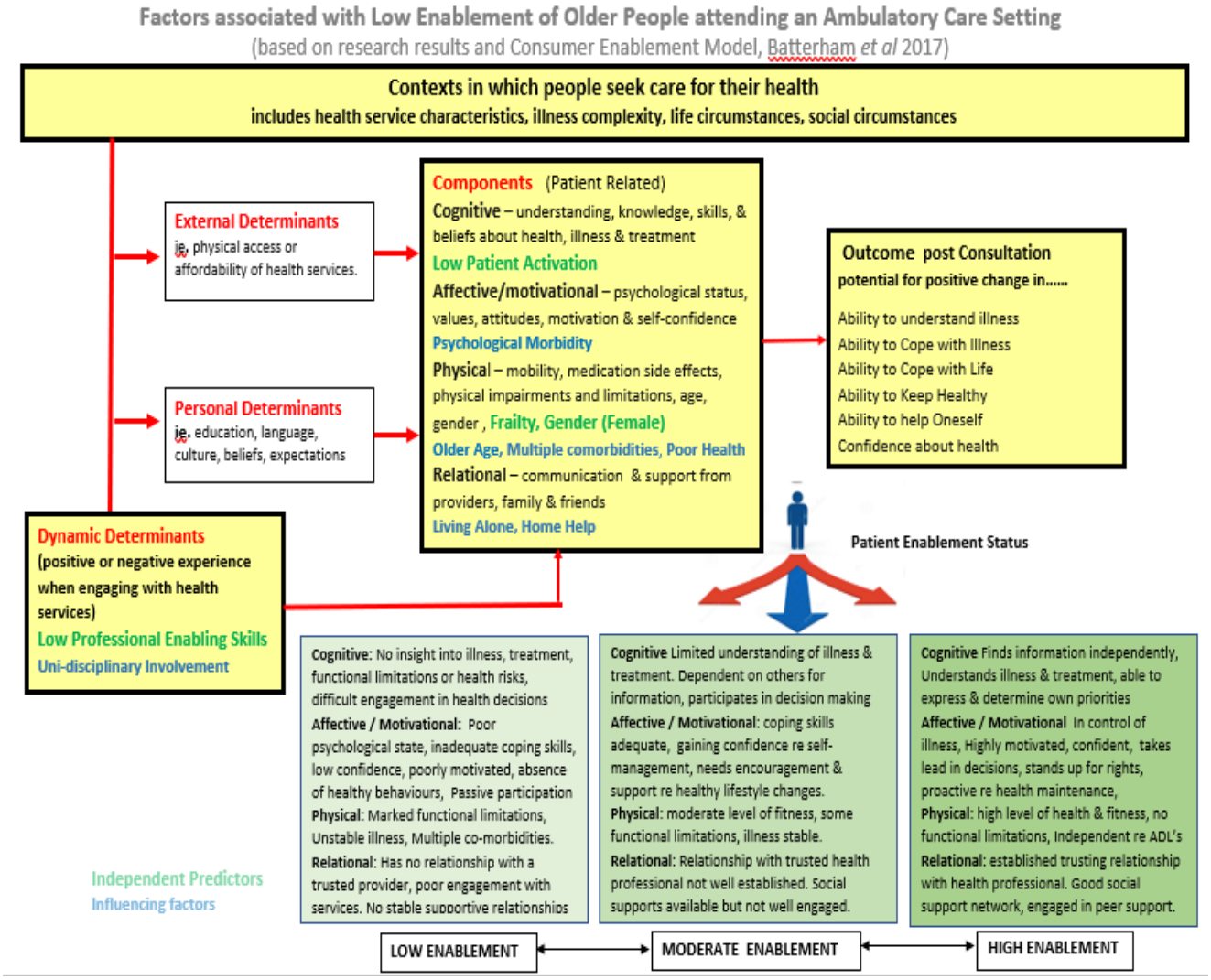


Figure 7.1 Influencing factors on low enablement post Consultation with a health professional.

The Consumer Enablement Model for Older People (CEMOP) (Figure 7.2) has similar constructs to Figure 7.1 but has broader clinical application as it provides a framework for the promotion of enablement of older people. The CEMOP facilitates a more positive narrative and a person centred, strengths-based approach that takes cognisance of a patient's individual strengths and weaknesses and the need for tailored healthcare interventions.

In accordance with Batterham *et al.* (2017), enabling strategies should promote a positive shift in components of the patient's enablement status (towards a higher level of enablement status) considering life context and optimising patient experience and health gains. Model fit is further discussed under the heading's dynamic determinants, patient components and outcome.

7.6.1 Dynamic Determinants

The dynamic determinants of enablement are based on an individuals' positive or negative experience when attending to their health (Batterham *et al.* 2017). This includes health service engagement and interactions with health professionals, which can potentially enhance or undermine a patients' knowledge, confidence, coping and self-management. Multivariate analysis identified the enabling skills of the health professional as an independent predictor of enablement in older people and reinforced the dynamic nature of enablement. Positive engagement with health professionals who have effective consultation skills and are proactive in addressing the needs of patients is of particular importance in caring for older people who may have difficulty expressing their needs. The importance of a person-centred therapeutic relationship is well supported in the literature (Hudon *et al.* 2011a, Pawlikowska *et al.* 2012, Banergee *et al.* 2012, Little *et al.* 2001) and was evident in the narrative of participants.

Multidisciplinary involvement was also as an influencing factor and was added to the CEMOP under dynamic determinants of enablement. Supporting older people to live well with multimorbidity requires a continuum of healthcare services spanning health promotion, prevention, self-management, and timely access to specialist expertise (HSE 2012, 2015, 2017). This requires a coordinated, integrated approach centred on the needs of the individual. It is recognised that the most effective self-management support interventions are individualised and multifaceted (Richardson *et al.* 2014), requiring enabling health professional skills, collaborative, trusting relationships and continuity of care to minimize the impact of chronic illness on quality of life.

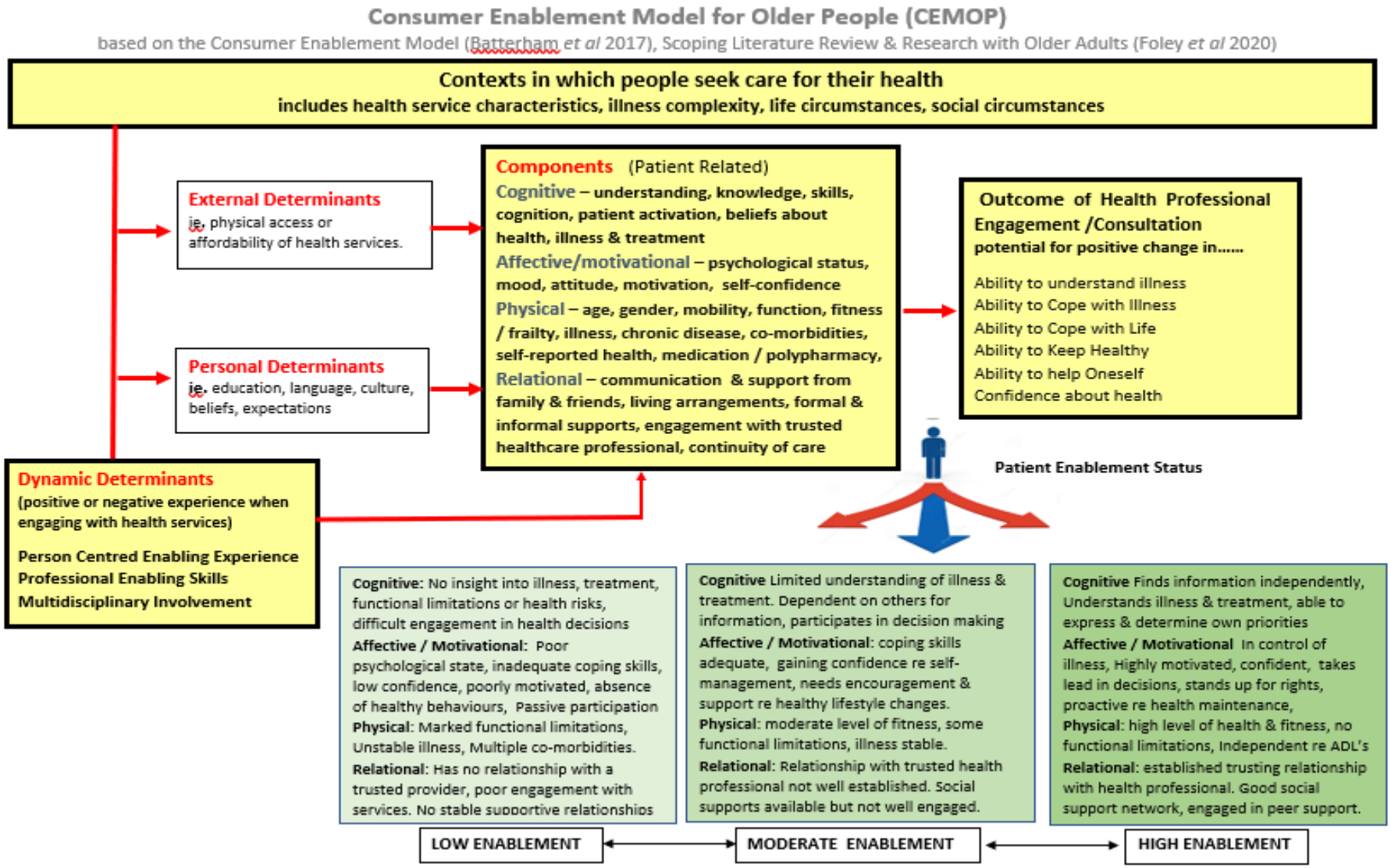


Figure 7.2 Consumer Enablement Model for Older People

As per the original CEM, the CEMOP acknowledges that a patients' experience of health care shapes their response to illness. Thematic analysis of respondents' comments identified the importance of the person-centred welcoming atmosphere in the ambulatory care centre, holistic approach, thorough assessment, multidisciplinary and multi-agency involvement, information, and reassurance. This concurs with other models (Stamler 1996, Pawlikowska 2011, Hudon *et al.* 2011a, Desborough *et al.* 2016, 2018, Frost *et al.* 2017a). Unlike other models, the CEMOP more accurately reflects the synergy between the dynamic determinants and patient components, which influence enablement and modify gains post engagement with health services. Batterham *et al.* (2017) outline strategies for enablement with different levels of self-management capacity (Table 7.1). This requires 'working with' rather than 'doing for' the patient (consumer) who is involved in decisions and personal goal setting.

7.6.2 Components of Enablement

According to the CEM, patient enablement components directly affect a person's overall enablement status, their ability to care for their health and manage the impact of illness in their lives (Batterham *et al.* 2017). As demonstrated in figure (7.1), factors associated with low enablement map onto the CEM components: Cognitive (low patient activation), Affective / Motivational (psychological morbidity), Physical (age, frailty, chronic disease, and poor self-reported health) and Relational (living alone and receipt of home help). These results concur with Batterham *et al.* (2017), who identified risk factors for low enablement as complex health problems and life circumstances, cognitive impairment, physical dependency, psychological morbidity, and social vulnerability. These, in turn, lead to a 'typical profile' of a person with a low level of enablement (poor insight, low levels of activation, poorly motivated etc.) (Figure 7.2). An important finding in this research is that older people living with multimorbidity, including frailty, retained the capability to become more enabled. Enablement is not static and can be influenced by the positive or negative experience of healthcare engagement and the enabling skills of the health professional who conducts a holistic assessment, building on strengths and working collaboratively with the patient and family to address areas of weakness.

Cognitive: Cognitive components relate to knowledge and skills, insight, and ability to self-manage, beliefs about illness, treatment, and health (PAM-13). As measured by the PAM-13, nearly 40% of respondents were in the lower activation category with knowledge gaps and poor problem solving and self-management skills. The relationship between patient enablement and

activation is likely to be a bidirectional flow rather than linear (one influences the other), and both should be measured.

Affective / Motivational: This component includes psychological morbidity and self-efficacy as measured by the PAM-13). Greater levels of patient activation reduced the risk of low enablement while psychological morbidity tended to increase low enablement. This supports the CEM and current evidence that depression or emotional distress has a negative impact on enablement (Batterham *et al.* 2017). In a larger study, psychological morbidity may have retained significance in the multivariate model.

Physical: In the CEM, the physical components include age, gender, illness, function, mobility, physical impairment, and polypharmacy (Batterham *et al.* 2017). All but polypharmacy was identified as influencing enablement. Frailty is included as a new descriptor under physical components in the CEMOP and is an important consideration in focusing on enabling interventions and evaluating enablement as an outcome measure post consultation. Hendry *et al.* (2018) distinguished chronic disease from frailty in that the latter is more often associated with functional deficits and physical inactivity that require a restorative enabling approach beyond the scope of a traditional chronic care model. Age-attuned health services such as the ambulatory care centre provide an important 'safety net' for older people with chronic disease.

Relational: According to the CEM, relationships, social connection and engagement is viewed as critical enabling factors. This incorporates formal and informal supports, relationships with family, health professionals, outings, and involvement with support groups. In this study, living alone and receiving home help were identified as influencing factors on enablement. The growing evidence base on social prescribing (Smith *et al.* 2019) and the synergy between health and social well-being also need to be considered to enable health care consultations. Research findings identified a socially vulnerable subgroup with (21%) who did not always have someone to call on when they needed help and who did not have regular social outings (29%).

Another aspect of the relational component is the study population is the high level of trust invested in the health professional (99.5%). This is viewed as a central component of enabling healthcare partnerships (Jones and Barry 2011). The enabling skills of health professionals identify a person-centred approach, active listening, empathetic engagement, and patient involvement in decision making that is suggestive of reciprocal respectful relationships and informed flexibility as advocated by Pawlikowska (2011). It is recognised that synergistic

solutions require meaningful collaboration between the health professional and patient (Stamler, 1996, Anden *et al.* 2006, Pawlikowska *et al.* 2012, Desborough *et al.* 2017, Frost *et al.* 2017a). The directional flow of the CEMOP reflects this synergy and acknowledges that outcomes are improved by the enabling partnership between the health professional and patient.

7.6.3 Enablement as an Outcome

The scoping review of the theoretical and empirical literature informed the following definition of enablement: 'an outcome of healthcare engagement which reflects a positive change in a person's ability to understand, manage or cope with his or her illness and which is influenced by individual needs and resources and the enabling skills of the health professional'.

The research findings provide evidence of the enabling role of the HCP, with 81% of participants indicating a positive gain (PEI score > 0). Most gains were in relation to the understanding of health and illness (88%). As measured by the PEI, there were lower gains in coping with illness (67%), coping with life (58%), ability to help oneself (68%), ability to keep healthy (59%) and confidence about health (56%) suggesting that there may be missed opportunities for health promotion, coping and confidence-boosting strategies.

Outcome measures need to address the quality of healthcare engagement and the core constructs of enablement. The PEI is meaningful in the context of older people with chronic disease managing self-management, understanding, engagement in healthy behaviours, confidence and coping with life and illness. The CEMOP provides a directional flow arrow from the outcome of health engagement to enablement status, which may result in a positive, negative or no shift in patient enablement status (low, moderate, or high). This is meaningful in the context of older people with chronic illness who are susceptible to functional decline post an acute illness. Much depends on the enabling skills of the health professional and multidisciplinary engagement who optimises functional gains and bolster coping strategies, putting the necessary supports in place.

The model accommodates a diverse population with individual characteristics (components) that may not fit neatly into a single category (i.e., low physical (functional dependency) with high relational (good family and homecare support). This has meaningful clinical application with older people with varying levels of physical and cognitive abilities and deficits, motivational and relational circumstances that shape their illness experience. The bi-directional

flow between the CEMOP components demonstrates that a person can move from low to high enablement and back again due to changing circumstances. Each healthcare engagement is a pivotal encounter with the onus on health professionals to make every contact count.
A weakness of the CEM and CEMOP is the lack of a specific measurement tool capable of measuring all its construct elements. Batterham *et al.* (2017) advise that outcome measures need to be adapted and developed to meet the needs of those presenting with chronic disease.

7.7 Implications of Research on Clinical Practice

It is recognised that optimal chronic care management is achieved when a prepared, proactive healthcare team interacts with an informed activated patient, and when the healthcare system interacts productively with the community (Wagner 1998, Darker *et al.* 2015). Accessing healthcare can be challenging for older people, particularly if services are fragmented. Managing multiple appointments, polypharmacy and complex treatment regimens can be overly burdensome (Eton *et al.* 2012, Sheehan *et al.* 2019) and may lead to unnecessary duplication and confusion (Darker *et al.* 2014). Ambulatory care centres with specialist clinics and multidisciplinary input are recognised as pivotal in sustaining older people in the community (HSE 2018, Burke *et al.* 2018). Bridges *et al.* (2019) point to the urgent need for responsive health service with the capacity to meet the diverse needs of the older adult throughout their ageing and illness experience.

The CEMOP helps to conceptualise what a responsive service means in terms of the multiple factors that can enable or dis-able an older person. Optimising patient outcomes requires more than a person-centred approach responsive to the individual. It requires the enabling skills of the health professional and the combined efforts of the multidisciplinary team, motivational and rehabilitative strategies, and tailoring treatments (pharmacological and non-pharmacological) to individual patient needs (Araújo-Soares *et al.* 2019, Araújo-Soares *et al.* 2019). Best practice in chronic disease management occurs when the person with chronic disease is enabled and supported regarding self-care, healthy behaviours and coping with illness and life (HSE 2015, 2018). The CEMOP duly considers that rehabilitation goals may be limited in more frail older people, but there are gains to be made concerning confidence and coping with life and illness.

Much depends on the quality of the consultation and the therapeutic interaction between the patient and the health professional. Health care professional enabling skills include listening,

communication, empathy, holistic assessment, advocacy, and interdisciplinary engagement. In this research, there was some disparity between key issues that patients wished to discuss with the health professional (e.g., reduced mobility, memory difficulties, anxiety and depression, urinary incontinence, constipation, and pain) and what was discussed in the consultation. The gold standard is a patient-led consultation as an enablement strategy (Pawlikowska 2011), but it is likely that older patients require confidence-building and the facilitating presence of an 'enabling' health professional.

Healthcare engagement has the potential to bolster or undermine the older person's knowledge, confidence, coping skills, and relationships. In this research, over 80% demonstrated a positive change in PEI scores because of engagement with a health professional. Modifiable risk factors associated with low enablement, such as frailty and patient activation, require more prolonged interventions beyond a single consultation (Hibbard & Gilburt 2014, Putt et al. 2017). Multicomponent interventions are required that address cognitive, physical, psychological, motivational, and relational modifiable risk factors for low enablement. As presented in table 7.1, Batterham *et al.* (2017) identify that those with lower levels of enablement require specific strategies that consider life circumstances (relationships, daily activities, and physical and social environments), bite-sized information and manageable goals, consideration of enablers and barriers and how people gain or lose confidence in themselves and health services. To date, there is very little development and testing of such interventions in older adult populations living with chronic disease.

The CEMOP, depicts enablement as a complex, multifaceted and fluctuating phenomenon with potential for strengths in one area to compensate for weaknesses in another. It provides a guiding framework for comprehensive geriatric assessment and person-centred enabling interventions. The impact of chronic illness and functional decline may be offset by a trusting relationship with a health professional and engagement of formal and informal supports. Viewing enablement in this way allows greater scope for targeted interventions at both the health professional and patient level. It requires a flexible approach and enabling skills of the health professional, capable of responding to changing circumstances and levels of enablement. There needs to be heightened awareness that older people are a heterogeneous population in a dynamic state of transition (physical, function, health and social) that requires psychological adjustment and adaptation. Consultations take place in this context with enablement based on the premise that the client (consumer) is an expert in their own lives and needs to be involved in decisions and goal setting.

Quality measurement tools and interpretation of research findings require cognisance of the diversity of factors that can impact patient gains and enablement as an outcome measure. Both clinicians and researchers need to be discerning when interpreting findings in the context of diverse influential factors in an older adult population. Key principles of patient enablement should underpin health professional education, health policy and research with an ageing population (Bridges *et al.* 2019).

Table 7.1 Strategies for enablement for people with different levels of self-management capacity

Level of self-management capability	Strategies from original case studies	Additional strategies from this evidence check
(Classic 'self-manager') Largely independent in looking after health at least between acute health episodes. Some regular health improvement activities. Initiates engagement with health and related providers when necessary or when they consider it beneficial.	• Classic health education	• On-line learning • Interactive technology • Providing up to date health information
(Supported 'self-manager') Able to set and commit to personal goals, but requires assistance with arrangements to meet these. May have periods of significant personal discouragement and require assistance to overcome setbacks.	• Health education • Coaching • Referral • Linkage to services • Some monitoring • Relapse planning	• Periodic follow up
(Prompted 'self-manager') Able to express wishes and preferences, and understands how health services and personal actions can contribute to these. Actively participates in health service decisions and cooperates to the best of their ability. Piecemeal approach to personal health care actions.	• Coaching • Organise environmental stimuli • Assist to establish routines • Work with families	• Provide periodic follow-up and prompt feedback • Encourage shared-decision making
(Reactive co-operator) Some capacity to express aspirations and wishes and understand health implications. Willing to participate in health decisions, but easily swayed off track and has difficulty maintaining personal effort.	• Assist to establish routines • Address crises • Address mental health conditions • Assist families	• Provide periodic follow-up and prompt feedback • Promote social-connectedness • Respond and be flexible to needs • Tailor information to needs
(Non-co-operator) Very little understanding of what is done to them and no emotional buy-in or commitment. Cooperation is piecemeal and reactive if given at all.	• Find something they LOVE to do • Ensure crisis needs are met • Ensure that any mental health conditions are treated • Assist families or carers • Try to establish a relationship with one or two care providers	• Address modifiable structural/physical barriers • Try to establish positive relationship with person/client (re-build trust)

Published in Batterham *et al.* (2017), p. 50.

7.8 Summary

Enablement is described as a person-centred quality outcome measure of patients understanding of their health condition and ability to cope with life, illness, and ability to help oneself (Howie et al. 1997, 1998). As such, it is pertinent to older people with chronic disease and quality-driven ambulatory care services. The research findings reported herein demonstrated that the majority of older people achieve some positive changes in enablement post consultation with a health professional in an ambulatory care centre. It highlighted the importance of professional enabling skills and multidisciplinary involvement, which affirm the relationship between the CEM patient components and dynamic determinants of enablement.

The consultation is a pivotal exchange between a health professional and a patient, so it is vital to optimising its quality (Al Momen *et al.* 2015, Pawlikowska & Marinowicz 2015). Research findings demonstrated that the PEI is a useful measure of enablement in older people with chronic illness and is a more discriminating outcome measure than satisfaction. The PEI can detect a positive shift in patients' knowledge of their condition, independence and self-management ability and coping with illness and life post consultation. However, measures of enablement and interpretation of results need to be cognisant of the diversity of factors that can impact enablement. It is counterproductive to assume that all patients will respond to interventions in the same way. Previous studies on enablement were often poorly representative of older people and focused more on health professionals than patient characteristics. This led to the over-simplification of a linear relationship between enabling healthcare interventions and enablement as a patient outcome measure. Batterham *et al.* (2017) were critical of the predominant focus on those with higher levels of enablement who tend to have better physical and psychological health, are informed, confident, and actively participate in treatment decisions, self-management, and healthy lifestyle behaviours.

This research has addressed a knowledge gap and the dearth of information relating to the concept of low enablement in an older adult population attending an ambulatory care centre. The research confirms that older people are a heterogeneous population in a dynamic state of transition (social, health, psychological) with vulnerable subgroups characterised by higher levels of frailty, low activation, and limited social support (30-40%). This research identified female gender, frailty, low activation, and perceived low HCP enabling skills as independent predictors of low enablement. The univariate analysis also identified other influencing factors,

including older age, multi-morbidity, chronic disease, reduced self-reported health and psychological morbidity.

The Consumer Enablement Model has shaped this research and provided a pragmatic framework for the interpretation of the research findings. The factors influencing enablement post-consultation align with the CEM patient components (cognitive, affective/motivational, physical, and relational) and dynamic determinants (professional enabling skills and multidisciplinary input). These findings have informed further development of the CEM specific to older people (CEMOP).

The CEMOP supports a person-centred enabling approach based on insight into the older person's personal context for seeking healthcare and internal and external characteristics. It provides a framework for individual assessment and focused interventions. Health services need to shift to a proactive rather than a reactive approach that increases patient knowledge and confidence, optimises health and functional gains, and sustains older people in their community (HSE 2018, Allegrante *et al.* 2019).

While the CEMOP is a strengths-based model, it also provides a rationale for realistic expectations regarding what is possible in the context of life-limiting conditions such as advanced frailty and the limitations of using the PEI as a simple measure of the quality of patient consultation. Batterham *et al.* (2017) acknowledge that enablement is a fluctuating state and that the burden of chronic disease is multidimensional, requiring a supportive framework that extends beyond the healthcare setting. The CEMOA is person centred and addresses the diverse, often complex needs of older people who present with multiple comorbidities, varying states of resilience, different home circumstances and supports. The final model (CEMOP) was informed by a synthesis of the literature and research results. It builds on a limited knowledge base and provides a solid foundation for further research (Pawlikowska 2020, appendix II). The constructs of the CEMOP require further research in different health care settings and with other older adult populations.

7.9 Conclusion

Enablement has become an important concept in supporting patients to self-manage chronic disease and optimise their health outcomes. Older people living with chronic conditions are underrepresented in many fields of research, including enablement. This research project addresses this gap in the literature. The focus of the study is the exchange between the patient and HCP during the clinical consultation as it is a pivotal opportunity to influence a patient's attitude and health outcomes; thus, it is vital to optimise the quality and effectiveness of this exchange (Pawlikowska & Marinowicz 2015). Enablement is identified as a person-centred outcome measure that is pertinent to quality-driven health care services for older people with chronic disease (Al Momen *et al.* 2015). Enablement is achieved when patients demonstrate increased understanding, confidence, coping with illness and life and ability to care for oneself and engage in healthy behaviours (Howie *et al.* 1997, 1998). It is evident from the current and previous research (Hudon *et al.* 2013, 2015) that the enabling skills of the health professional and the quality of the therapeutic relationship impacts enablement. The significance of multidisciplinary input as an enabling factor is one of the unique contributions of this research.

Guided by the CEM, this is the first study to adopt a comprehensive examination of influencing factors on enablement, examining variables related to consultation, health professional and patient characteristics. The study addresses a gap in the literature in identifying factors associated with low enablement specific to an older adult population attending an ambulatory centre. The results provide insight into the mechanism by which enablement is increased and characteristics of those who have little if any gains following a consultation with a health professional. Independent predictors of low enablement were identified as patient activation, gender (female), frailty and health professional enabling skills, with an additional eight factors that were likely to influence enablement. The dynamic determinants of enablement affirm the importance of making every patient contact count and aligns with the key principles of chronic disease management.

Although faced with more challenges, older people should be afforded the same opportunities to increase enablement as younger populations. Equally, there need to be realistic expectations of the extent of self-management in older people with chronic disease given demographic, health, psychological and social factors.

The research has reaffirmed five overarching principles: 1) Older people with long term conditions have the capacity to become more enabled despite health, psychological and social challenges, 2) HCP with appropriate consultation skills act as a catalyst to increase patients enablement, 3) Enablement requires an informed flexible approach responsive to individual patient needs, 4) The influence of the enabling skills of the professional are moderated by patient characteristics such as frailty, multimorbidity and patient activation, and 5) Ambulatory care and clinics such as the ATC play an important role in enabling older people to continue to live in their community. The research results support constructs of the CEM and offer new insights into the dynamic determinants of enablement (healthcare experience) and components (patient characteristics) which informed the development of the CEMOP.

The literature identifies enablement as a meaningful concept in the context of quality-driven services. However, Batterham et al. (2017) acknowledged that enablement is a complex concept with varied definitions and perspectives. The constructs of the model operationalise enablement as a process, experience, outcome, and fluctuating state. The CEMOP captures bio-psycho-social aspects of care, the often-fluctuating chronic disease trajectory, varied symptom presentation and diverse functional capacity of an older adult population.

Overview of Thesis

Chapter 1 provided a background for this research, highlighting its importance within the context of an ageing population with an increased prevalence of chronic disease and demand for services. Chronic diseases account for two-thirds of emergency medical admissions to hospitals. Integrated and ambulatory care is viewed as a cost-effective person-centred approach that facilitates timely interventions in the community and proactive management of chronic diseases. (NCPOP 2012, Dept of Health 2017). The researcher drew on the literature and her own experience as an Advanced Nurse Practitioner in the Rehabilitation of Older People to provide a rationale for undertaking this research.

Chapter 2 traced the origins of enablement back to the concept of empowerment which first appeared in the 1950's when power and control dominated the healthcare literature (Hudon *et al.* 2011a). Enablement is described as having a *'clinically useful and narrower definition than empowerment* (Fumagalli *et al.* 2015, Siegel *et al.* 2019) that has broad application underpinning person centred (Howie *et al.* 1997, 1998) and collaborative care (Valentin-Hjorth *et al.* 2018). It has a close association with other concepts such as patient activation (Hibbard

et al. 2004, 2005, 2010). The justification was made for choosing enablement as an important outcome measure within the context of quality-driven services for older people with chronic disease.

Chapter 3 focused on the theoretical literature in relation to enablement to gain clarity regarding the constructs of enablement, operational definition, and measurement parameters. Two previous conceptual analyses by Hudon *et al.* (2011a) and Stamler (1996) differed in their focus. Hudon *et al.* (2011a) focused on the enabling skills of the health professional ('contribution to the therapeutic relationship', 'broadening of the possibilities', implication and support to decision-making' 'valorization of the persons' strengths', 'facilitation of learning' and 'consideration of the person as a whole'). In contrast, Stamler (1996) identified the key attributes of enablement as the reciprocal interaction between the health professional and patient, identification of the enablement goal, requiring the existence of a deficit in patient means, abilities or opportunities to meet this goal. The latter is supported by Pawlikowska (2011) who described consultation variables at the patient and health professional level that impact on the outcome of enablement. Both Frost *et al.* (2017a, b) and Desborough *et al.* (2016, 2017, 2018) represented the dynamic interplay of factors which include the trusting relationship between patient and health professional, nurse's scope of practice, enabling skills (knowledge transference, promoting self-efficacy, building on strengths) and contextual variables (continuity of care and adequate time). There was a consensus that the outcome of enablement is a patient's coping, managing, and understanding (Stamler 1996, Howie *et al.* 1998, Pawlikowska 2011, Desborough *et al.* 2016, 2018, Frost *et al.* 2017).

The consumer enablement model (CEM) (Batterham *et al.* 2017) was introduced and identified as the best model fit for the research. The model identified external, personal, and dynamic determinants of enablement and provided a comprehensive, multilevel framework for the measurement of enablement. The CEM identified patient components and enablement as a dynamic construct with multiple influencing factors. It places the patient (consumer) centre-stage and challenges assumptions about vulnerable groups and their potential for enablement.

Chapter 4. presented the scoping review of the empirical literature on enablement in community and ambulatory care (non-inpatient) settings. Forty papers were included in the scoping review. There was a variation in the definition of enablement used across studies. The most widely used definition was 'an outcome that reflects a patient's ability to understand, manage & cope with his or her illness after a consultation with a health professional' (Howie

et al. 1997, 1998). There were different perspectives in the research: enablement as a process i.e., the enabling skills of the health professional (Hudon et al. (2011a, 2015), the experience of enablement (Frost et al. 2017a, 2017b), enablement as an outcome measure following patient consultation with a health professional (Howie et al. 1997, 1998, 1999, Pawlikowska 2011, Desborough *et al.* 2016) and finally, enablement as a complex, fluctuating patient state (Batterham *et al.* 2017).

The research was largely concentrated in general practice and primary care settings and was dominated by use of the Patient Enablement Instrument (PEI) based on the seminal work of Howie *et al.* (1997, 1998. 1999). Research tended to focus on comparing PEI scores between different groups and identifying factors that were associated with low or high enablement (though there were no standardised cut-offs). The scoping review of the literature identified influencing factors on enablement which were related to consultation (i.e., length, first or follow-up appointment, receipt of a prescription), health professional characteristics (i.e., health professional enabling skills, empathy) and patient characteristics (i.e., age, gender, chronic disease, self-reported health, psychological morbidity). The dearth of evidence examining influencing factors on enablement of older people provided justification for this research.

Chapter 5. outlined the main aim of this research study: to examine enablement of older people with chronic disease post consultation with a health professional in an ambulatory care setting and identify influencing factors for low enablement.

The research design was a descriptive cross-sectional survey. Following ethical approval, a convenience sample of 300 older people attending a single ambulatory care centre were recruited. The questionnaire design was guided by the literature search and the Consumer Enablement Model. Data was collected using a 72-item questionnaire. In addition to demographic questions, it contained the validated instruments Patient Enablement Instrument (PEI) (Howie *et al.* 1997), Patient Activation Measure (Hibbard *et al.* 2005) and Clinical Frailty Scale (Rockwood *et al.* 2005) and modified Physician Enabling Skills Questionnaire (Hudon *et al.* 2015). Expert review and cognitive interviews with older people informed questionnaire design and layout. Descriptive and inferential statistics were used to identify patterns and statistically significant relationships in the data using SPSS and STATA.

Chapter 6. Data analyses were carried out on 273 respondents (27 incomplete questionnaires excluded). The study population mean age was 79.7 years (52% female, 48% male). Sixty-one

percent of participants had three or more chronic conditions, 35% described their health as fair or poor. Post consultation, 81% of respondents reported some positive change in enablement post consultation. The population mean PEI score was 4.48 (SD 3.5). With guidance from a statistician, univariate and multivariate logistic regression was used to examine the associations between low enablement (PEI 0-4) and the independent variables.

Four independent predictors of low enablement were identified: gender, clinical frailty, patient activation and professional enabling skills. Hypothesis testing provided confirmatory evidence of these relationships. There were an additional eight variables that were significant in the univariate analysis but were not significant in the multivariate model: age, living alone, receipt of home help, visits from a PHN, number of chronic diseases, self-reported health, psychological morbidity and seen by two or more disciplines. Although these research findings are specific to the Assessment & Treatment Centre, instruments used and population surveyed, it provides a solid foundation for further research on enablement of older people.

Chapter 7 presents a discussion on the findings and situates them in the wider literature. This is the first study to examine enablement in Ireland and provides a unique contribution to the international literature focusing on enablement of older people post consultation with a multidisciplinary team in an ambulatory care centre. The results provide insight into the demographic and health profile of older people and enabling characteristics of an ambulatory care centre. The research results align well with the CEM and informed further development of the model specific to an older population, CEMOP.

7.9.1 Strengths of the Research

The strengths of this research are presented below:

- The research topic focusing on enablement of older people with chronic disease is apt in the context of an ageing population and health system reform to promote self-management.
- It is the first study on enablement using the PEI to focus solely on an older adult population living with chronic disease and accessing ambulatory care services and provides insight into the characteristics of this group.
- The study addresses a gap in research on factors that influence low enablement in an older population.

- A detailed theoretical and empirical review of the literature underpinned the study methodology, instruments used and interpretation of the results.
- The expected sample size was achieved and a comprehensive suite of evidence-based tools with established psychometric properties were used in the data collection.
- To date, much of the research on enablement has focused on general practice. This study is the first to focus on an ambulatory care setting with general and specialist clinics offering insight into the enabling skills of a multidisciplinary team.
- The researcher is an Advanced Nurse Practitioner in this ambulatory care centre. It is recognised that health professionals working within a healthcare organisation are in an excellent position to carry out research due to their close access to patients and opportunity for clinically driven research questions (Pager *et al.* 2012).
- Potentially modifiable enabling factors were identified, which can act as a basis for intervention design targeting healthcare professionals and patients.
- This research informed the development of the Consumer Enablement Model for Older People providing a solid foundation for research in this area.

7.9.2 Limitations of the Research

There are limitations to this research which are listed below.

- This research was conducted in a single ambulatory care centre therefore, results may not be generalisable to other settings.
- The cross-sectional design provides a snapshot in time and is not reflective of changes in enablement over time.
- Some health professional disciplines were not well represented (one ANP, no speech and language therapist) therefore, comparative analysis is limited.
- As participants were an older adult population, assistance with the completion of the questionnaire was provided by a family member who may have influenced results.
- The sample may not be truly representative of older people attending an ambulatory care centre as people who were acutely medically unstable or had a diagnosis of dementia were excluded from participation.
- Diagnoses and frailty levels were self-reported and therefore may not represent an accurate estimate of chronic disease and frailty.

- There are some reservations about the reliability of the PAM-13 as a measure of activation in multimorbid, older and low-literacy patients (Napoles *et al.* 2017)
- The PEI as a measure of enablement is open to hypothesis-guessing and may lack face-validity for a longer episode of care (e.g., in patients with chronic conditions). Transitional scales can be inconsistently completed with some patients forgetting during completion that they are measuring a change from baseline (Murphy *et al.* 2018).
- Data analysis using logistic regression forces categorisation into dichotomous groups, enablement is a complex concept, and rarely do respondents fit neatly into simple groupings (Batterham *et al.* 2017).
- A larger sample size would have provided greater statistical power to identify other variables that may have a statistically significant impact on enablement in this population.
- A quantitative methodology alone cannot explain the nuanced relationships between enablement and influencing factors. Future research involving qualitative methodologies can help expand understanding of enablement in this population.

7.9.3 Recommendations

Based on the results of this research study the following recommendations are made for clinical practice, education, and further research.

Clinical Practice

- This research affirms that older people have the capacity for health gains and are responsive to the enabling skills of the health professional a proactive co-ordinated multidisciplinary approach.
- There is a need for targeted interventions to address modifiable predictors of low enablement- frailty, low patient activation & influencing factors- chronic disease, poor self-reported health, psychological morbidity.
- This research has identified the diversity of an older adult population with chronic disease. It highlights the need for a comprehensive geriatric assessment with identification of biopsychosocial as well as health factors that influence enablement.

- Patient activation was a significant predictor of low enablement, highlighting the importance of considering motivation, self-efficacy, and engagement in health consultations.
- Frailty as a predictor of low enablement needs to be prioritised for clinical screening and proactive management strategies.
- In line with the CEM, this research identified 12 variables that impact on enablement to a greater or lesser extent. Enablement is a dynamic phenomenon that fluctuates with changes in a patient's health or social circumstances as well as dynamic factors such as the enabling skills of the health professional. This points to the need for individualised and tailored approaches to optimise engagement in health and self-management.
- Health Professionals' enabling skills were identified as a significant enabling factor. The research findings reinforce the importance of the therapeutic trusting relationship between a patient and the health professional. A therapeutic enabling relationship involves developing an ongoing partnership, starting from the person's situation, legitimizing the illness experience, acknowledging patient expertise in their own life, offering realistic hope, providing advocacy for the person in the health system.
- Patient-led consultation needs to be encouraged; however, health professionals need to be cognisant that some patients may be reluctant or unable to articulate key issues such as anxiety or incontinence.
- The dynamic determinants of enablement presented in the CEMOP identify factors that enhance the enabling experience, such as the welcoming environment, person centred approach and the enabling skills of the health professional. It reinforces the importance of health promotion and making 'every contact count'.
- With increasing demands on existing services, it may be prudent to further examine patient enablement and the value of repeated follow-up appointments in specialist ambulatory centres.
- The needs of older people with chronic disease require continuity of care and a responsive, integrated, co-ordinated person-centred approach.

Education

- Healthcare professional enabling skills was identified as an independent predictor of enablement and as such needs to be reinforced in undergraduate and postgraduate education curricula.
- The CEM model is already influencing education programmes and models of care in both rehabilitation and ambulatory care settings (Agency for Clinical Innovation 2013) providing a person-centred framework for targeted interventions of health professionals. The CEMOP can help refine the model for an older population.
- Educational programmes need to highlight the significance of patient activation while recognising that patients may be disengaged or overwhelmed. Such patients require tailored interventions delivered by health professionals with enhanced enabling skills.
- This research supports the need for an educated age-attuned workforce who are equipped with knowledge and skills regarding ageing, chronic disease and frailty syndromes combined with motivation and enablement approaches outside of the traditional biomedical focus (Rodríguez-Laso *et al.* 2014).

Research

- This research produced a final parsimonious (12 factors down to 4) model which identified three potentially modifiable factors of enablement as frailty, patient activation and enabling skills of the health professional. A larger-scale study may identify other significant variables such as psychological morbidity.
- Three significant research questions on enablement in this population have emerged:
    - How do we sustain enablement in older people as their chronic disease and physical function decline as aging progresses?
    - How do we improve enablement of older people with low levels of activation and low enablement?
    - Is the PEI an adequate measure of enablement over time and can it be used to assess the effectiveness of enabling interventions (pre-post)
- Frailty is increasingly recognised as a public health priority due to the associated demand for acute and longer-term health and social care support and the impact on the lives of individuals, caregivers, and families. There is limited data on outcomes to

prevent and manage frailty, further research underpinned by the concept of enablement has the potential to fill this gap.

- The PESQ was shortened and modified through expert review and cognitive interviews with older people. More research is needed to determine the psychometric properties of this instrument.
- Variations in patients' PEI scores for different health professions suggest the need for further investigation around the specific consultation characteristics and HCP skills. The researcher has a particular interest in the contribution of the ANP role in the older adult population.
- The open-ended questions provided insight into the experience of ageing with chronic disease and perceptions of enabling interventions. This warrants further qualitative research in an older adult population attending ambulatory community healthcare services.
- The research findings support the stance that enablement is influenced by patient internal and external factors and dynamic determinates, which include HCP skills. The generalisability of these findings needs to be assessed in different populations of older people in different settings.
- Constructs of the CEMOP require further testing, which would be enhanced by development of a specific measurement instrument.

Strategy

- Quality measures demonstrating the value of clinic consultations is apt in the context of healthcare reform of community services in Ireland (Department of Health 2019).
- The HSE is investing in community based ambulatory specialist services to provide an integrated model of care that reduces crisis hospital admissions (HSE 2018).
- This research illustrates the need to provide ongoing support and chronic disease management for older people who are more vulnerable and rely on the current ambulatory care model and contact with experts to avoid or reduce hospital admissions.
- Consumer enablement supports the political and strategic paradigm shift towards sustaining older people in the community through healthy ageing, self-management of chronic disease & making every contact count.

Plans for Dissemination.

- AIGNA masterclass November 2018
- HSE Quality Improvement Workshop Oct 2019
- INMO masterclass for Nurses Jan 2020
- HSE multidisciplinary education workshop Feb 2020
- UCC Older Person Regional Quality Improvement 'What Matters' Conference

Abstracts will be submitted for conference / poster presentation to Irish Gerontological Society, British Gerontological Society, European Geriatric Medicine Society, All Ireland Gerontological Nurses Association.

Publication plan:

Article Topics may include:

- Factors influencing enablement of older people with chronic disease.
- Patient Activation, Frailty & Enablement.
- The Enabling Skills of Health Professionals
- The Consumer Enablement Model for Older People
- Enablement of Older People attending an Ambulatory Care Centre

Potential Journals:

International Journal of Nursing Studies

International Journal of Nursing Older People

Journal of Rehabilitation Medicine.

Age and Ageing Journal.

In conclusion, this research dissertation provides valuable insight into the concept of enablement in older adults and includes modifiable factors that can be targeted to improve the quality of life for older people. The CEMOP model can act as a basis for future interdisciplinary research to inform the development and testing of effective enabling skills of health care professionals. The model can also inform the design of service models that keep older people at the heart of shared decision-making and accommodate the complexity of individual's health and social circumstances.

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Appendix I Research Setting



St. Finbarr's Hospital
Assessment & Treatment Centre
GP Referral Criteria

The Assessment & Treatment Centre provides for assessment, diagnosis, treatment and rehabilitation of older adults presenting with uncertain diagnosis or complex case management issues. For all referrals a detailed GP letter is required, stating purpose of review and relevant history, investigations and medications.

Referral may be made directly to one of the speciality clinics overleaf, alternatively it may be directed to named Consultant if patient previously under their care.

Specialist Clinic	Referral Criteria	Exclusion Criteria In relation to any of the issues below, Consultants are happy to receive telephone calls and offer general advice.
Rapid Access Clinic (For Urgent Complex Case Management Referrals)	Symptom presentation requiring urgent review by Consultant Geriatrician.	Symptoms requiring acute hospital admission. Non-urgent medical review.
Comprehensive Geriatric Assessment	Symptom Presentation requiring comprehensive geriatric assessment.	Symptoms requiring acute hospital admission or rapid access appointment.
Memory Clinic Professor Molloy	Cognitive Changes, short term memory loss,word finding etc. Decreased function due to cognitive changes i.e.difficulty shopping, paying bills etc.	Advanced Dementia in Nursing Home Settings.
Old Age Psychiatry Dr Eleanor Mullan	New onset, Functional Psychiatric illnesses (depression, psychosis) South Lee (Catchment area). Early memory or cognitive Problems (South Lee). Limited access (diagnostic assessment only). North Lee & North Cork.	Engaged with general adult psychiatry.
Cognitive Impairment Clinic Dr Aoife Ni Chorcorain	Any person over 60 years old from the Cork and Kerry region may be referred.	Engaged with general adult psychiatry.
Movement Disorder Dr Suzanne Timmons	Complex gait and movement disorders requiring specialist intervention to assist diagnosis or treatment of Parkinson's.	Already under the care of a Neurologist or Consultant Geriatrician.
Falls & Syncope Dr Kieran O'Connor	Single or Recurrent Unexplained Fall(s) requiring further investigation / intervention.	Fall(s) previously investigated with known cause.
Continence Advisory Clinic Mary J. Foley Advanced Nurse Practitioner	Urine / Incontinence / Frequency / Retention / Trial of Voiding. Constipation / Faecal Incontinence.	Under care of Urologist / Continence Advisor Within scope of PHN. Sinister presentation.

THE FOLLOWING CLINICS ARE AVAILABLE VIA THE CONSULTANT GERIATRICIAN:

- **Dexa- Bone Densitometry**
- **Infusions/ Transfusions / Investigations including Blood Transfusions**
- **Therapy** (where needs cannot be met by Primary Care Team)
- **Pre-driving Skills Assessment**
- **Warfarin / Anticoagulation**
- **Stroke Follow-Up / Review**
- **Complex Case Management / Community Liaison Support** (frailty, wound care, pain management, carer support etc)
- **Memory Intervention & Support Clinic**

Appendix II Communication with Published Experts

From: Teresa Pawlikowska [mailto:tpawlikowska@rcsi.ie]
Sent: 02 July 2020 12:21
To: Mary J. Foley (Advanced Nurse Practitioner)
Subject: Your thesis

Dear Mary,

Thank you for taking me through your doctoral thesis and its conclusions today.

I am very impressed by the form it has taken as you have progressed through your study and the analysis. It was always going to be a labour of love as it springs from your work and your detailed observation of it and your desire to make it better for your patients. Importantly your PhD has actionable conclusions, which is an outcome that not everyone can claim!

I have always felt that researching this domain is complex, the variables, and variability, that one needs to encompass and consider is huge: patient (and your older people have complex multi-system and biopsycho-social needs), health care provider (multi-professional, individual? team?) , the issue of the day, and the context! You are to be congratulated on not only working with this , but also making sense of it.

Importantly for me you have shown that its dynamic and older people's enablement can be moved. You have also provided another instance of when 'able to cope with life' is relevant and indeed achievable. You have developed interesting models which can inform practice. Last , but not least I feel that you have built on my PEI work in a very valuable manner to move it on. I look forward to discussing that with you later and wish you all the best for your PhD defence.

Best wishes

Teresa

Prof. Teresa Pawlikowska BSc (Pharmacol) MB BS MSc PhD MRCP DRCOG FRCPI
Director

UNIVERSITY OF MEDICINE AND HEALTH SCIENCES
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Transforming Healthcare Education, Research and Service: RCSI Strategic Plan 2018-2022

From: Jane Desborough [mailto:Jane.Desborough@anu.edu.au]
Sent: 22 September 2016 01:28

To: Mary J. Foley (Advanced Nurse Practitioner)
Subject: Re: Clinical Doctorate Student Research on Enablement

Dear Mary,

Please accept my apology for a tardy reply to your email. I have had the flu and am just now catching up on emails. Your project sounds very interesting and yes, I believe the PESS could be used in a day hospital setting and patients with Parkinson's Disease. A number of the people in my study were carers of people with conditions such as Parkinson's and it was, they who completed the survey and reported being enabled as a result of nursing care.

The instrument hasn't been validated outside of Australia, although the enablement section of the survey is based on Howie's Patient Enablement Instrument (PEI) (http://fampra.oxfordjournals.org/content/15/2/165.full.pdf+html), which has been validated in the UK and several other countries. One question from this instrument (able to cope with life) was deleted in the PESS at the request of patients during focus groups. You might like to consider creating a new version of the PESS, which includes this question. This would look after the validity issue in terms of the enablement section of the survey and at the same time, I think this question might be important for people with Parkinson's Disease and their carers.

You might like to consider conducting a focus group with patients from your clinic to get their feedback on the tool - this would strengthen your study and confirm the validity of the tool you use. You could include other disciplines, although the satisfaction section of the PESS is based on a nursing framework and validated for nursing care. Despite this, it has parallels with the GPAS/ GPAQ, which are used for both doctors and nurses - they all basically examine areas of importance to patients, such as access, decisional control, knowledge provision/ exchange, technical skills, time. You could consider just using the PEI and framing the question specifically to the health professional you want patients to evaluate. I have also attached the PESS v.2, which I used for my PhD. It has questions that I was specifically interested in and some important demographic questions. I am hoping to have the findings from this study published in the near future.

Your project sounds very interesting and I am happy to discuss it further with you if I can be of any help.

Best wishes, Jane.

Dr Jane Desborough
Postdoctoral Fellow
Department of Health Services Research and Policy
Research School of Population Health
College of Medicine, Biology, and the Environment
Australian National University
ACT 0200
http://www.anu.edu.au/aphcri/
Ph: +61 2 6125 6545
M: +61 407 897 066

Mary J. Foley (Advanced Nurse Practitioner)

From: Catherine Hudon [Catherine.Hudon@USherbrooke.ca]
Sent: 14 June 2017 19:09
To: Mary J. Foley (Advanced Nurse Practitioner)
Cc: a.coffey@ucc.ie; Hartigan, Irene
Subject: Re: Research Enablement, Query regarding Conceptual Framework

Dear Mary,

Thank you very much for you interest in my work!
I will try to explain a little bit more my process...

The conceptual framework for Enablement in a Care Relationship was first developed following a concept analysis method of the literature.
In this article, I tried to keep a broad focus considering literature of many disciplines (nursing, medicine...).
The conceptual framework concerns enablement in care relationship in general (without a focus on a particular discipline).

In family medicine, the patient-centered care model is very popular and a concept near from enablement...
So I developed a framework of enablement using my previous model and patient-centered care literature.
The Physician Enabling Skills Questionnaire was developed based on this model and interviews with patients (yellow in your e-mail):

- develop a partnership with patients by building a relationship

based on trust and by finding common Ground;

• promote their interests in the health care system by fostering continuity, accessibility, and safety;

• start from their personal situation by knowing about their feelings, expectations, and context;

• legitimize their illness experience by recognizing their Suffering;

• acknowledge their strengths and promote their expertise by encouraging self-care and fostering self-confidence;
And

• help maintain hope by supporting them

FACILITATION OF LEARNING is now included in "acknowledge their strengths and promote their expertise **by encouraging self-care** and fostering self-confidence ».

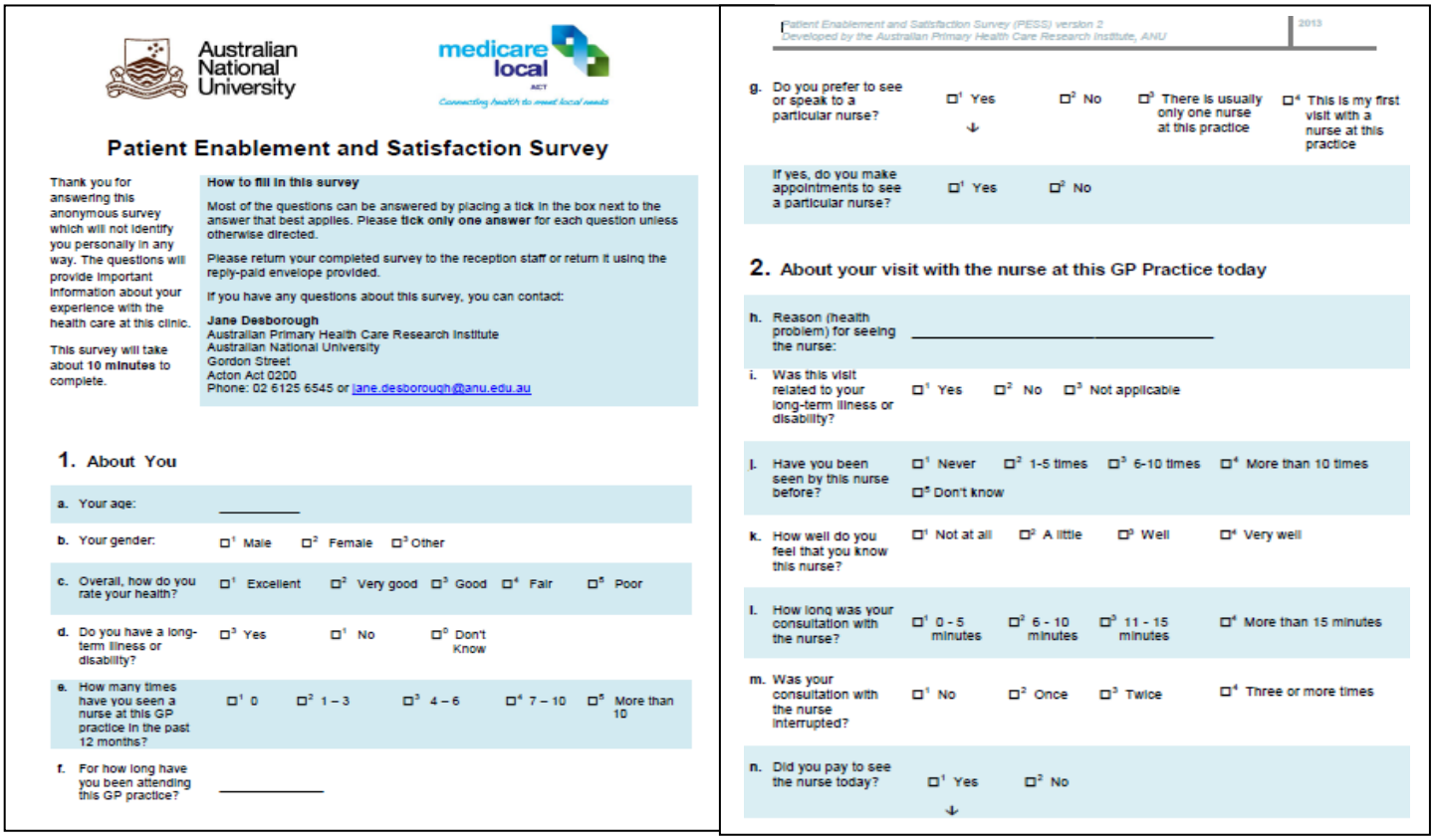
I think that this model could be used for your research into enablement of older adults with chronic disease with particular focus on the enabling role of the nurse in an ambulatory / primary care setting. I know that it has already been used by nurses in Australia (I think that the paper is not published yet).

Feel free to ask if you have other questions and good luck with your project!

Catherine

Appendix III Patient Enablement & Satisfaction Survey

(Desborough *et al.* 2016)



Australian National University

medicare local ACT
Connecting health to meet local needs

Patient Enablement and Satisfaction Survey

Thank you for answering this anonymous survey which will not identify you personally in any way. The questions will provide important information about your experience with the health care at this clinic.

This survey will take about **10 minutes** to complete.

How to fill in this survey

Most of the questions can be answered by placing a tick in the box next to the answer that best applies. Please **tick only one answer** for each question unless otherwise directed.

Please return your completed survey to the reception staff or return it using the reply-paid envelope provided.

If you have any questions about this survey, you can contact:

Jane Desborough
Australian Primary Health Care Research Institute
Australian National University
Gordon Street
Acton Act 0200
Phone: 02 6125 6545 or jane.desborough@anu.edu.au

1. About You

a. Your age: _____

b. Your gender: ☐1 Male ☐2 Female ☐3 Other

c. Overall, how do you rate your health? ☐1 Excellent ☐2 Very good ☐3 Good ☐4 Fair ☐5 Poor

d. Do you have a long-term illness or disability? ☐3 Yes ☐1 No ☐0 Don't Know

e. How many times have you seen a nurse at this GP practice in the past 12 months? ☐1 0 ☐2 1 – 3 ☐3 4 – 6 ☐4 7 – 10 ☐5 More than 10

f. For how long have you been attending this GP practice? _____

g. Do you prefer to see or speak to a particular nurse? ☐1 Yes ☐2 No ☐3 There is usually only one nurse at this practice ☐4 This is my first visit with a nurse at this practice

If yes, do you make appointments to see a particular nurse? ☐1 Yes ☐2 No

2. About your visit with the nurse at this GP Practice today

h. Reason (health problem) for seeing the nurse: _____

i. Was this visit related to your long-term illness or disability? ☐1 Yes ☐2 No ☐3 Not applicable

j. Have you been seen by this nurse before? ☐1 Never ☐2 1-5 times ☐3 6-10 times ☐4 More than 10 times ☐5 Don't know

k. How well do you feel that you know this nurse? ☐1 Not at all ☐2 A little ☐3 Well ☐4 Very well

l. How long was your consultation with the nurse? ☐1 0 - 5 minutes ☐2 6 - 10 minutes ☐3 11 - 15 minutes ☐4 More than 15 minutes

m. Was your consultation with the nurse interrupted? ☐1 No ☐2 Once ☐3 Twice ☐4 Three or more times

n. Did you pay to see the nurse today? ☐1 Yes ☐2 No

3. Satisfaction with your visit with the nurse at this GP practice today

Please respond to the following statements by ticking one box on each line:

	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree	No applic
a. The nurse was understanding of my personal health concerns	☐1	☐2	☐3	☐4	☐5	☐
b. The nurse gave me encouragement in regard to my health problem	☐1	☐2	☐3	☐4	☐5	☐
c. I felt comfortable to ask the nurse questions	☐1	☐2	☐3	☐4	☐5	☐
d. My questions were answered in an individual way	☐1	☐2	☐3	☐4	☐5	☐
e. I was included in decision-making	☐1	☐2	☐3	☐4	☐5	☐
f. I was included in the planning of my care	☐1	☐2	☐3	☐4	☐5	☐
g. The treatment I received was of a high quality	☐1	☐2	☐3	☐4	☐5	☐
h. Decisions regarding my health care were of high quality	☐1	☐2	☐3	☐4	☐5	☐
i. The nurse was available when I needed him/ her	☐1	☐2	☐3	☐4	☐5	☐
j. The nurse appointment time was when I needed it	☐1	☐2	☐3	☐4	☐5	☐
k. The nurse spent enough time with me	☐1	☐2	☐3	☐4	☐5	☐
l. I was confident with the nurse's skills	☐1	☐2	☐3	☐4	☐5	☐
m. The nurse was very professional	☐1	☐2	☐3	☐4	☐5	☐
n. Overall, I was satisfied with my health care	☐1	☐2	☐3	☐4	☐5	☐
o. The care I received from the nurse was of high quality	☐1	☐2	☐3	☐4	☐5	☐

3. As a result of seeing the nurse today, do you feel you are:

Please respond to the following statements by ticking one box on each line:

	Same or less	Better	Much better	Not applicable
p. Able to understand your illness	☐0	☐1	☐2	☐0
q. Able to cope with your illness	☐0	☐1	☐2	☐0
r. Able to keep yourself healthy	☐0	☐1	☐2	☐0
	Same or less	**More**	**Much more**	**Not applicable**
s. Confident about your health	☐0	☐1	☐2	☐0
t. Able to help yourself	☐0	☐1	☐2	☐0

4. Do you have any further comments?

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

Appendix IV Original Physician Enabling Skills Questionnaire (Hudon *et al.* 2015)

11. My family doctor listens to me.				
☐ Strongly disagree	☐ Disagree	☐ Uncertain	☐ Agree	☐ Strongly agree
12. I feel that my family doctor is interested in me.				
☐ Strongly disagree	☐ Disagree	☐ Uncertain	☐ Agree	☐ Strongly agree
13. My family doctor asks about my life context (family, work, etc.)				
☐ Never/very rarely	☐ Rarely	☐ Sometimes	☐ Often	☐ Always/very often
14. My family doctor knows how I react to various life events.				
☐ Strongly disagree	☐ Disagree	☐ Uncertain	☐ Agree	☐ Strongly agree
15. My family doctor knows what to say to reassure me.				
☐ Never/very rarely	☐ Rarely	☐ Sometimes	☐ Often	☐ Always/very often
16. My family doctor understands me.				
☐ Strongly disagree	☐ Disagree	☐ Uncertain	☐ Agree	☐ Strongly agree
17. My family doctor takes me seriously.				
☐ Strongly disagree	☐ Disagree	☐ Uncertain	☐ Agree	☐ Strongly agree
18. My family doctor helps me obtain the care I need.				
☐ Never/very rarely	☐ Rarely	☐ Sometimes	☐ Often	☐ Always/very often
19. I have developed a connection with my family doctor.				
☐ Strongly disagree	☐ Disagree	☐ Uncertain	☐ Agree	☐ Strongly agree
20. I trust my family doctor.				
☐ Strongly disagree	☐ Disagree	☐ Uncertain	☐ Agree	☐ Strongly agree
21. My family doctor helps me become aware of certain situations that can be harmful to my health.				
☐ Never/very rarely	☐ Rarely	☐ Sometimes	☐ Often	☐ Always/very often

22. My family doctor helps me see what I am capable of doing to improve my health.

☐ Never/very rarely ☐ Rarely ☐ Sometimes ☐ Often ☐ Always/very often

23. My family doctor helps (or would help) me access more urgent care when necessary.

☐ Strongly disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly agree

24. My family doctor looks after my interests in the health care system.

☐ Strongly disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly agree

25. My family doctor encourages me to adopt a healthy lifestyle (to exercise, eat well, not smoke, etc.).

☐ Strongly disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly agree

26. My family doctor knows (or would know) how to provide encouragement if I need it.

☐ Never/very rarely ☐ Rarely ☐ Sometimes ☐ Often ☐ Always/very often

27. My family doctor encourages me to ask questions.

☐ Never/very rarely ☐ Rarely ☐ Sometimes ☐ Often ☐ Always/very often

28. My family doctor takes my preferences into account.

☐ Never/very rarely ☐ Rarely ☐ Sometimes ☐ Often ☐ Always/very often

29. I am satisfied with the way my family doctor involves me in decision-making.

☐ Strongly disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly agree

30. My family doctor congratulates me on my accomplishments.

☐ Never/very rarely ☐ Rarely ☐ Sometimes ☐ Often ☐ Always/very often

31. I feel that my family doctor and I are a team.

☐ Strongly disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly agree

32. My family doctor seems to collaborate well with other health professionals.

☐ Strongly disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly agree

33. My family doctor asks about my hobbies and interests.

☐ Never/very rarely ☐ Rarely ☐ Sometimes ☐ Often ☐ Always/very often

34. My family doctor finds (or would find) the right words to give me hope if I am discouraged.

☐ Never/very rarely ☐ Rarely ☐ Sometimes ☐ Often ☐ Always/very often

Thank you! Your participation is greatly appreciated. The information you provide is very important to us.

Appendix V Study Protocol

Title: Enablement of Older People with Chronic Disease attending Ambulatory Care Service

Details of the Purpose of the Study:

Enablement is defined as an intervention by which the health care professional recognizes, promotes, and enhances patients' ability to control their health and their life (Hudon *et al.* 2011). Enablement is viewed as an important person-centred outcome measure of patient consultations (Pawlikowska and Marcinowicz, 2015) particularly in the context of chronic disease management (Small *et al.* 2013). Research evidence on enablement poorly represents older people and those with advanced chronic disease and multiple comorbidities.

The overarching aim of this study was to examine enablement of older people attending an ambulatory care centre and identify influencing factors associated with low enablement.

The specific objectives of the study were to:

- describe the study population characteristics (demographic, health profile and patient activation) attending ambulatory care.
- describe the health care profession enabling skills using the modified PESQ.
- describe the patient enablement scores using the PEI.
- examine the association between patient characteristics and the PEI.
- examine the association between health care profession enabling skills and the PEI.
- identify factors associated with low enablement (PEI ≤ 4)
- identify univariate and independent predictors of low enablement in the study population.

Details of the Procedures to which humans will be subjected:

The study uses a cross sectional quantitative survey design.

Research procedure

Patients attending clinics in the Assessment & Treatment Centre will be given the opportunity to participate. The nurse manager will have screened patient caseload in advance (i.e., reviewed referral or last clinic letter to identify those who do not meet inclusion criteria). When patients report to the clinic reception, they will be given a research patient information leaflet with attached questionnaire.

Participants will be asked to complete the first sections of the questionnaire in private waiting area and the final section following their consultation (therapeutic engagement / treatment intervention) with the healthcare professional. If the person is seeing more than one health professional, they will be asked to complete the questionnaire after their final clinic consultation. If required patients will be supported with completion by a family member (if present) or staff.

Completed questionnaires will be placed in collection box in the Assessment & Treatment Centre. MJF will be present to address questions should they arise. If patients wish, they will be provided with a stamped address envelope to return questionnaires in their own time. As names and address will not be recorded there will be no patient follow-up.

Research Sample and Access

Following receipt of ethical approval, permission to access the study site will be sought from the gatekeepers (i.e., Director of Nursing, Nurse Managers, Consultants and Therapy Managers) who will be provided with information. The researcher is an Advanced Nurse Practitioner working in this setting and is very familiar with how the Centre runs. An information session will be facilitated in the Assessment & Treatment Centre to advise all staff of research requirements.

Population

A convenience sample of patients (n= 300) attending a ranged of clinics at the Assessment and Treatment Centre will be recruited over a two-to- three-month period. However, patients with a diagnosis of dementia or attending memory services will be excluded, as the instruments are not validated in this population. Formal tests of cognition will not be undertaken as part of the survey. The nurse manager will have screened patient notes in advance and identified those who meet the exclusion criteria. It is standard practice that clinic staff are aware of which patients have a diagnosis of dementia. When patients report to the clinic reception, eligible patients will be given the introductory letter and research patient information leaflet. The receptionist/ Nurse Manager will give the questionnaire to patients who identify themselves as willing to participate.

Inclusion Criteria:

- Willingly agree to participate.
- Patients attending the assessment & treatment centre.
- Older People > than 60 years of age
- Presenting with at least 1 chronic disease.
- Physically able to complete questionnaire with assistance.
- Cognitively able to participate and give consent (MMSE / MOCA > 20/30)

Exclusion Criteria:

- Patients who do not wish to participate.
- Patients < 60 years
- Patients who are acutely unwell
- Patients who are in the terminal phase of their illness & in receipt of palliative care.
- Patients attending memory or psychiatric clinics or with a diagnosis of cognitive impairment recorded.

Data Analysis

Data obtained from completed questionnaires will be entered into SPSS version 18 for windows. Descriptive analysis will include frequency, mean, median and percentages. Binary logistic regression will be used to predict the association between variables. The dependent variable is enablement (measured by the Patient Enablement Instrument), and the independent variables will include age, gender, marital status, living arrangements, home supports, chronic illness, frailty scale and health professional enabling skills.

Ethical considerations

This research is of social value as it will assist in understanding enablement from the perspective of older people with chronic disease. Results will inform clinical practice, education, and research.

There are three primary ethical principles based on the Belmont report (1945), namely autonomy, beneficence, and justice. Autonomy is the right of an individual to make their own decisions, beneficence relates to improving the situation of others and justice is to treat all persons equally and fairly. (NMBI 2015). The researcher will operationalise these principles within the research study as follows: An information leaflet will be provided which will give a description of the planned research, invitation to partake in completing the questionnaire and contact details of the researcher. The data collection period will take place over a two-month period. During this time, the researcher will be present to offer support as required. Participation will be voluntary, and all patients will be assured that non-participation will not impact negatively on their care.

The research questionnaire will not seek any identifying details therefore ensuring anonymity and patient confidentiality. A sealed collection box will be available in reception for completed questionnaires. Data will be encrypted and stored securely for ten years as per university regulations.

Consent:

Completion of the questionnaire will constitute consent to take part in the proposed study. The research assistant will explain that participation is voluntary. Potential participants will be provided with an information leaflet explaining that non-participation will not impact negatively on their care.

Data storage:

Data storage and informed consent will comply with new General Data Protection Regulation (2018).Paper based questionnaire data will be entered into an electronic spreadsheet on a password protected computer in UCC. Once data cleaning and verification is complete paper questionnaires will be destroyed. Electronic files will be stored in UCC One Drive which allows for secure file storage and sharing between the research team. Files will be password protected.

Research Integrity:

The researcher will seek to promote accuracy, honesty and rigor throughout the steps outlined for this study.

Potential benefits to subjects and/or society:

Enabling strategies are associated with improved patient outcomes including increased self-efficacy, coping and healthier lifestyles (Hudon *et al.* 2011 Lawn *et al*. 2013). This research will give an insightful perspective of older people with chronic illness attending ambulatory care services and will inform enabling strategies of healthcare professionals.

Potential risks to subjects and precautions taken to minimise risk:

There are no foreseen risks anticipated in this study. Participants will be advised of their right to refuse to partake or withdraw from the study at any stage with no adverse repercussions. Instrument used in this study will not seek any identifying details therefore ensuring anonymity and confidentiality. Completion of the questionnaire will constitute consent to take part in the proposed study by participants. Participation will be voluntary. Participation or non-participation will not impact on the quality of patient care received. Research burden will be minimized as patients will complete the questionnaire while waiting to see practitioners and immediately after consultation. If patients wish, they will be provided with a stamped addressed envelope to return questionnaires in their own time.

Appendix VI Research Ethical Approval

UCC

Tel: + 353-21-490 1901
Fax: + 353-21-490 1919

Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

COISTE EITICE UM THAIGHDE CLINICIÚIL
Clinical Research Ethics Committee

Lancaster Hall,
6 Little Hanover Street,
Cork,
Ireland.

ECM 4 (l) 16/10/18

Date: 12th September 2018

Professor Corina Naughton
School of Nursing & Midwifery
University College Cork
Brookfield Health Sciences Complex
College Road
Cork

Study Title: Enablement of older adults with chronic disease attending ambulatory care services.

Dear Professor Naughton

Approval is granted to carry out the above study at:

- St Finbarr's Hospital, Cork.

The following documents have been approved:

Submission Document	Approved	Version	Date
Cover Letter	Yes		25/07/18 (received 23/08/18)
Application Form	Yes		09/07/18
Study Protocol	Yes	1	
Data Collection Sheet	N/A		
Study Advertisements	N/A		
Questionnaire/Surveys	Yes		
Invitation Letter	Yes		
CV for Chief Investigator	Yes		
Evidence of Insurance	Yes		
Participant Information Leaflet	Yes		
Consent Form	N/A		

Appendix VII Review of Research Instrument

Assessment & Treatment Centre,

St Finbarr's Hospital,

Douglas Rd,

Cork

26/05/18

Re: Review of Research Instrument

Dear Colleague,

I am currently undertaking research as part requirements for a Doctorate in Nursing at University College Cork under the supervision of Prof Corina Naughton (UCC) and Dr. Irene Hartigan (UCC). The main objectives of this study is to examine the quality of health professional consultations and its relationship with patient enablement and to identify independent predictors of enablement in an older adult population with chronic disease.

I would appreciate your review of the attached questionnaire which includes the Patient Enablement Instrument and a modified version of the Physician Enabling Skills Questionnaire in addition to the Patient Activation Measure and additional descriptive questions based on a scoping review of the literature.

The questionnaire is divided into 5 sections, Part 1 (sections 1 – 4) is completed pre-consultation with the health professional and Part 2 (section 5) is completed post consultation. Older adults attending the Assessment & Treatment Centre will be invited to partake in the study with assistance from family member or research assistance if required.

The purpose of this expert review is to ensure that the final questionnaire is **clear**, **concise** and contains **relevant** items relating to enablement of older adults with chronic disease. I have enclosed a reviewer's copy of the items (questions) for you to evaluate together with instructions. Your review may be returned by email or in the envelope provided.

Thank you for your assistance with this study which will inform enabling skills of health professionals and provide insight into predictors of enablement in older adults with chronic disease.

Kind Regards,

Mary J. Foley

MaryJ.Foley@hse.ie 086 7871999

Instructions for Reviewers

There are 2 sections for you to review. Contained within each section is 4 columns; A, B, C, D

Column A: Contains a list of items taken from the questionnaire, you are not required to fill in anything in Column A.

Column B: Item clarity; please read each item in Column A and indicate whether the item is clear or unclear by placing a circle around your choice.

Column C: Content validity; please read each item again in Column A and indicate whether the item is relevant to what is being measured by placing a circle around your choice.

Column D: Apparent internal consistency: please review all the items in Column A and indicate whether the items collectively appear to measure the same thing by placing a circle around your choice.

See below example of how to compete each section:

Section 1			
A Item	B Clarity	C Relevance	D Consistency
1. Number of years since first registration as a nurse	(Clear) / Unclear	Not relevant / Somewhat relevant/ Quite relevant/ (Very relevant)	Please indicate whether the items overall appear to measure appropriate demographics for the sample in question. (Yes) / no
2. In which county do you currently reside?	(Clear) / Unclear	Not relevant / Somewhat relevant/ (Quite relevant)/ Very relevant	
3. What was the highest staff grade you worked at prior to entering the Nursing Service in CUH?	Clear / (Unclear)	(Not relevant)/ Somewhat relevant/ Quite relevant/ Very relevant	

PART 1 Sections (1 – 4)

SECTION 1: About You & Your Living Arrangements

No	A Item	B Clarity	C. Relevance
1a	**Your Age: (years)**_____	Clear / Unclear	Not relevant / Somewhat relevant/ Quite relevant/ Very relevant
1b	**Your Gender:** Male Female Other Prefer not to Say	Clear / Unclear	Not relevant / Somewhat relevant/ Quite relevant/ Very relevant
1c	**Relationship Status:** Single Married Widow(er) Other	Clear / Unclear	Not relevant / Somewhat relevant/ Quite relevant/ Very relevant
1d	**Living arrangements:** Alone with spouse or partner with family other ____	Clear / Unclear	Not relevant / Somewhat relevant/ Quite relevant/ Very relevant
1e	**Do you receive home help visits?** Yes or No	Clear / Unclear	Not relevant / Somewhat relevant/ Quite relevant/ Very relevant
1f	**When you need help, can you count on someone who is willing and able to meet your needs?** Always Sometimes Never	Clear / Unclear	Not relevant / Somewhat relevant/ Quite relevant/ Very relevant
1g	**Do you have regular (weekly) social outings (ie coffee with friends, day centre or support / active retirement group)?** Yes or No	Clear / Unclear	Not relevant / Somewhat relevant/ Quite relevant/ Very relevant

RN Psychologist, RD Occupational Therapist, RD Physiotherapist RN Professor Expert Advisor, RD Dietician

Item	Clear	Unclear	Not Relevant	Somewhat Relevant	Quite Relevant	Very Relevant	Consistency	Comment
1a	**8**					**8**		
1b	**8**					**8**		
1c	**8**					**8**		R2:Insert long term relationship
1d	**8**					**8**		
1e	**7**	**1**			**2**	**6**		R1:Should home help hours be added
1f	**7**	**1**		**1**				R2:Help could mean a number of things. R3: good question, some not able to voice
1g	**8**				**1**	**7**	**Yes**	
2a	**8**					**8**		
2b	**8**					**8**		
2c	**8**			**2**	**1**	**5**		
2d	**8**					**8**		
2e	**8**					**8**		
2f	**8**					**8**		
2g	**8**					**8**	Yes	
3a	**8**					**8**		R4: Format changes recommended
3b	**8**					**8**		
3c	**7**	**1**				**8**	Yes / No(1)	R2: some items do not fit under title. R3: important question about mental health R4: ? add question on anti-depressant medication
4a	**8**				**1**	**7**	Yes	
5a	**8**					**8**		
5b	**7**	**1**				**8**		R2: How do they rate 2 health professionals
5c	**7**	**1**			**1**	**7**		
5d	**8**					**8**		R5: Add fatigue
5e	**8**					**8**		
5f	**8**			**1**	**2**	**5**		R2: Not sure if a prescription is important
5g	**8**					**8**	**Yes**	
5h1	**8**				**1**	**7**		
5h2	**8**					**8**		
5h3	**8**			**1**		**7**		R2: Depends on the context
5h4	**8**					**8**		
5h5	**8**					**8**		

5h6	**8**					**8**		
5h7	**8**					**8**		
5h8	**8**				**1**	**7**		
5h9	**8**					**8**		
5h10	**6**	**2**				**8**		R2: Not always possible R4: May not be relevant to a therapist. R6: Broad statement, ? needs to be clearer
5h11	**8**				**1**	**7**		
5h12	**8**				**1**	**7**		
5h13	**8**					**8**		
5h14	**8**					**8**		
5h15	**8**			**1**		**7**		
5h16	**8**					**8**		
5h17	**8**					**8**		
5h18	**8**					**8**		
5h19	**8**					**8**		
5h20	**8**					**8**		
5h21	**8**					**8**		
5h22	**8**			**1**	**1**	**6**		R2: Not as relevant to enabling. R8: Not sure a patient would know this
5h23	**8**				**1**	**7**		
5h24	**8**					**8**	**Yes**	R1: would have reservation re length of questionnaire but all relevant questions
51	**8**					**8**		
5j	**8**					**8**		R2: comments may not relate to topic

Questionnaire Piloted with 10 older people, Cognitive Interviews carried out (pilot participants asked to reflect on the last time they consulted with the Doctor)

Index: Non-Response (NR), Clarification Sought (CS), Delayed Answer (DA), Relevance Considered (RC)

Item	**Pilot Participant Comments**	
1e	P10 'This is a good question, people not always able to voice this'	
1f	P6 'the stroke support group is my lifeline now, enjoy Wednesday activities'	
2a	P8. 'I go to my GP for my 3-month prescription and get my blood pressure checked'	
2b	P10 'would I put the Gastroenterologist in here'	**CS**
2d	P1 'Sharon (PHN) is great and checks in on me regularly'.	

	P3 ‘I don’t know who my community nurse is, but I haven’t needed that service’	
2e	P7 ‘ I get 2 visits Monday to Friday and 1 Saturday and Sunday so guess that is 12’	**HR**
2f	P1. ‘I had to re-apply for my medical card, this should be an automatic entitlement when you have a disability so that you can get equipment and services that are needed’.	**DA (3)**
	P4. ‘The Parkinson’s Association offer exercise, dance classes and choir, not sure if there is anything else I need’.	
	P6. ‘I enjoy hydrotherapy sessions with stroke support group but wish heated pools were more accessible’.	
	P7. ‘Wheelchair taxis are expensive, should be more support with transport for appointments.	
	P8. ‘I enjoy the active retirement group and meeting up with friends’	
3a	P10 ‘I have diverticulitis, would that go in here’	**CS**
3d	P1. ‘I take a lot of tablets, would prefer to take less not more’.	**RC (2)**
	P8. ‘When I go for my routine check-up, I don’t expect to receive a prescription’	
3e	P1. ‘I feel nervous if I am out in case someone knocks me over …… didn’t realise I was meant to tick all 6 options’.	**NR**
	P2. ‘It is easier to say that everything is grand and put a smile on your face’.	
	P6. ‘My husband passed away 3 years ago; I have had recurring thoughts of death myself but am not fearful of it’.	
	P.10 ‘these are important questions; your mental health is everything’	
3f	P1. ‘I went on an antidepressant after my stroke’	
3 h 8	P10. ‘I have an irregular heartbeat and fluid builds up in my legs, so I am on a diuretic’	
3 h 9	P10. ‘Trust the Doctor has the answers to this’	
3h10	P7. ‘I do my best, but I am limited in this wheelchair’	
3h11	P3. ‘ I now eat healthier and take more exercise based on my doctors advise’	
3h13	P1. ‘Not sure how to answer this one’.	**DA (2)**
	P9. ‘If I am stressed, I take to the roads.	
	P10. ‘I don’t get stressed often but when I do, my appetite goes, and I stay indoors’	
3i	P1. ‘ I go for a swim daily and am fit considering I have had a stroke and need a stick to walk, is 4 the right category’.	**DA (3)**
	P4 ‘I need the wheels (rollator) now to get around and my walking has slowed down a lot in the last year’.	**CS**
	P7. ‘Have to put down for a 6 here, I can transfer in and out of the wheelchair by myself’	
4c	P1. ‘We discussed my blood pressure and the pains in my legs, would have liked more discussion about the spasticity in my hand but perhaps this is something I need to talk to the physio about’.	
	P5. ‘We talked about reducing the steroids for my arthritic joints’.	
	P10. ‘The doctor is busy and doesn’t have time to listen to all my woes, I have to identify what is most important’	
4e	P3. ‘I had a routine check-up; it gave me confidence to know that my blood pressure was controlled. There was no need for further information, I have no symptoms that affect my life’.	**RC**
	P4. ‘The GP s friendly and gives me a repeat prescription however he leaves decisions regarding my medication to the specialist’.	
	P5, ‘She (doctor) gives me confidence regarding management of my condition and how to cope with it, we have a good relationship’.	
	P7. ‘The last time the Doctor came out to my house to review my tablets, he went through everything, unfortunately there is no magic pill to get me walking again’.	
	P10. ‘My rating is generally good, however some days he is rushed off his feet and I come away not having not addressed what I went in for’	
4g2	P1. ‘At this stage, the doctor knows me and has a record my history in his file’.	

	P10. the junior doctors in the clinic are very thorough but the Consultant knows me better'	
4g4	P1. 'My mood is variable, so this always comes up'.	
	P10. 'He always asks how I am but presume this is more to do with physical than emotional feelings'	
4g5	P8. 'He gave me an information leaflet on osteoporosis with useful advice regarding nutrition and exercise'	
4g6	P1. 'Despite all the medication changes, I still have pains in my feet'	
	P7. 'He knows me well now and adjusts medication to suit my needs'	
4g7	P7. 'I don't get up until 11am so we agreed that my tablets could be taken later'	
4g8	P2. 'The hospital organised a girl to come in every morning to assist me'	
	P3. 'I don't need home help'.	
	P5. 'I am managing okay without home help, so the issue was not discussed'.	
	P7. 'The doctor recognised I was struggling and asked the community nurse to increase my hours'	
4g9	P.1 'sometimes he appears distracted and more interested in the computer screen than me'.	
	P5 'she always gives me her full attention and responds to my concerns'	
4g10	P1. 'He often asks about the family, many of them attend him also'.	
	P7. 'The therapists came out to my home to make sure I could get around in my wheelchair'	
4g11	P5. 'We have a good rapport and I always feel better after a clinic visit'.	
	P8. 'I now feel reassured that treatment and lifestyle changes, the condition may improve'	
4g12	P1. 'I have asked the Doctor to send a referral for more physiotherapy'.	
	P4. 'The GP contacted the Specialist when I needed an earlier appointment'.	
	P7 ' the doctor organised for my home help to be increased'	
4g13	P4 'I trust my doctor but have more confidence in the Parkinson's' Disease Specialist regarding adjusting my medication'.	
	P10 'where would we be if we didn't trust the GP'	
4g14	P3. 'I have followed his advice and now take more exercise and follow a healthy diet'	
4g15	P1. 'The GP makes sense of my medical issues which are complex, he understands when I need further medical opinion or hospital admission'.	
	P7. 'I would be lost without my GP; he organises services and he put me in touch with the support group which has been a valuable life-line'.	
4g16	P3. 'I have a quick visit to check my blood pressure, not sure hope comes into it'.	
	P7. 'He encourages me although my expectations are realistic regarding recovery'	
4g 17	P1. 'Yes, but sometimes feels rushed'	
4g18	P7. 'The doctor organised respite and we have discussed the possibility of going into a Nursing Home full-time. He recognises that this is my decision, and he will support me'	
4g19	P1 'yes as I have to go through him to access most services.	**CS**
	P3 'I presume so, I haven't had much experience of it'.	
	P4. ' The GP knows who to contact regarding management of my Parkinson's Disease'?	
	P7. 'I appreciate the doctor linking me in with the Stroke Support Group	
4g20	P4 'changes to my medication improved my mobility and ability to care for myself'.	
	P6 'physio sessions increased my confidence to go out more'.	
	P7. 'Unfortunately, I am stuck in this wheelchair since the stroke'	

4g21	P1. ‘Sometimes, guess he knows what I get up to now’.
	P5. ‘can’t remember being asked this but maybe it is not that relevant to me’
4h	No additional comments made. Content of questionnaire deemed relevant & clear.

Participant	Age	Gender	Diagnosis	Self-reported health	CFS
1	66	Male	Hypertension, Stroke, Diabetes, Cardiac, Respiratory	Good	4
2	86	Female	Stroke, problems with legs	Poor	5
3	68	Female	Hypertension	Good	3
4	79	Male	Parkinson’s Disease	Very Good	5
5	73	Female	Arthritis	Good	4
6	79	Female	Stroke, Cardiac	Poor	5
7	80	Male	Stroke, Diabetes	Good	6
8	70	Female	Arthritis, Osteoporosis	Good	4
9	67	Male	Hypertension	Good	4
10	71	Female	Cardiac, Hypertension, Diverticulitis	Good	5

Appendix IX Study Research Questionnaire

Instructions for Completion of the Survey

Thank you for agreeing to participate in this survey. Your participation is voluntary and will not impact on any aspect of your health care at the clinic today. Please respond as honestly and fully as you can, there are no right or wrong answers.

If you require help with completing the questionnaire, a family or staff member will assist you if required.

Indicate if this survey is being completed by:

Patient alone ☐

Patient supported by family member ☐ (answers is the patients)

Patient supported by nursing staff. ☐

Please complete.

Part 1 (sections 1 – 3) **BEFORE** your consultation [colour code **Pink**]

Part 2 (section 4) **AFTER** your consultation [colour code **Yellow**]

During the consultation with the health professional, we ask that you conceal the questionnaire and do not discuss its contents.

When completed, place the questionnaire in the labelled sealed box in reception.

If you have any questions, speak to a member of the nursing staff or

you can contact the Researcher (UCC) on 086 7871999

PART 1. PRE-CONSULTATION

Section 1: About You & Your Living Arrangements

(1a) Your **Age** (years): _____

(1b) Your **Gender**: Male ☐ Female ☐ Other ☐ Prefer not to say ☐

(1c) Relationship Status: Single ☐ Married ☐ Widow(er) ☐ Partners ☐

(1d) Living Arrangements: Alone ☐ with Spouse or Partner ☐ with Family ☐

Other ☐ please specify_____

(1e) When you need help, can you count on someone who is willing and able to meet your needs? Always ☐ Sometimes ☐ Never ☐

(1f) Do you have regular (weekly) social outings (i.e. coffee with friends, day centre or support / active retirement group or meeting friends / family)? Yes ☐ No ☐

Section 2: About Service Engagement.

(2a) In the **last 6 months**, how often did you see a general practitioner / GP?

Not at all ☐ 1 – 3 times ☐ 4 – 6 times ☐ more than 6 times ☐

(2b) Are you attending **other health professionals / services**? No ☐ Yes ☐

(Please state i.e. Neurologist, Cardiologist, Geriatrician, Physiotherapist)

_____

(2c) In the past **year**, how many times have you been admitted to hospital?

0 ☐ 1 – 2 times ☐ more than 2 times ☐

(2d) In the **last 6 months**, how often did the Public Health (community) Nurse visit ?

Not at all ☐ 1 – 3 times ☐ 4 – 6 times ☐ more than 6 times ☐

(2e) Do you receive **home help visits**? No ☐ Yes ☐ visits per week _____

(2f) Are there **additional community services** (i.e. day care, exercise class) that would help you manage / cope with your health condition? **No** ☐ **Yes** ☐
If yes, please specify_____

_____

Section 3 Your Health & Fitness

(3a) What **health condition(s)** do you have (tick relevant options below)

Hypertension (blood pressure) ☐ Diabetes ☐ Stroke ☐
Respiratory (Breathing) Problems ☐ Arthritis ☐ Dementia ☐
Heart / Cardiac Problems ☐ Depression / Anxiety ☐ Parkinson's ☐
Other ☐ (please specify) _____

_____

(3b) What is the **main issue / health complaint / symptom** that you wish to discuss with the health professional today ? _____

_____

(3c) Do you use **5 or more different prescription medications** on a regular basis?

Yes ☐ No ☐ Unsure ☐

(3d) Do you expect to receive a **prescription** today?

Yes ☐ No ☐ Unsure ☐

(3e) Over the **last month**, how often have you been bothered by the following.

*Tick answer opposite **ALL** options 1 – 6 below*	**Not at all**	**Occasionally 1 or 2 times month**	**Frequently / Several days**	**Nearly every day**
1. **Feeling nervous, anxious or on edge**				
2. **Feeling down, depressed, or hopeless**				
3. **Little interest or pleasure in doing things**				
4. **Feeling Worthless**				
5. **Having poor concentration**				
6. **Recurring thoughts of death / dying**				

(3f) Are you taking medication to help your **mood** ? Yes, ☐ No ☐ ☐ Unsure

(3g) In general, would you describe your **health** (tick 1 option only)
Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐

(3h) Select the appropriate response that reflects your view regarding **your own role in managing your health**. There are no right or wrong answers.

Tick opposite **ALL** options 1 - 13	**Agree Strongly**	**Agree**	**Disagree**	**Disagree Strongly**	**Not Applicable**
1. When all is said and done, I am the person who is responsible for managing my health condition					
2. Taking an active role in my own health care is the most important factor in determining my health & ability to function					
3. I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition					
4. I know what each of my prescribed medications does					
5. I am confident I can tell when I need to get medical care & when I can handle a health problem myself					
6. I am confident I can tell the health professional concerns I have even when he or she does not ask					
7. I am confident that I can follow through on medical treatments I need to do at home					
8. I understand the nature and causes of my health condition(s)					
9. I know the different medical treatment options available for my health condition					
10. I have been able to maintain the lifestyle changes I have made for my health					
11. I know how to prevent further problems with my health condition					
12. I am confident I can find a solution when new situations or problems arise with my health condition					
13. I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress.					

(3i) Select **<u>one description</u>** below that most accurately reflects your activity and how you manage daily.

1	**Very Fit** –robust, active, energetic, and motivated. I exercise regularly and I am fit for my age		
2	**Well** –no active disease symptoms but I am not very fit, I exercise occasionally.		
3	**Managing Well** – my medical problems are well controlled. I am not regularly active beyond routine walking. I do not need any help with daily activities,		
4	**Managing OK-** I am not dependent on others for daily help, but often symptoms limit activities. I feel I have "slowed up" a bit and feel tired during the day. I may use a stick		
5	**Just managing** – I am slowing up a good bit, I have difficulty walking outside alone and may need help with shopping, finances, transport, heavy housework, medications, meal preparation and housework. I may use a zimmer frame.		
6	**Managing with help** –I need help (standby, cueing) with washing, dressing, toileting, showering, keeping house and all outside activities. I have problems with stairs and rely on my Zimmer frame to walk.		
7	**Managing with a lot of help** – Completely dependent on others to assist with personal care (getting dressed, going to the toilet). Health is relatively stable, I mostly use a wheelchair to get around especially if going outside.		
8	**Dependent -** I am unable to walk now, I am tired, lethargic and spend a lot of time in bed. I need help with everything. My health condition is unstable.		

Thank You for Completing Part 1 (please conceal questionnaire and attend consultation with the health professional).

PART 2: Please complete AFTER Your Clinic Appointment(s) today

Section 4. Your Consultation Experience

(4a) Including today, how many times have you attended the Assessment & Treatment Centre ? 1st time ☐ 2-3 times ☐ 4 – 6 times ☐ more than 6 times ☐

(4b) What health care professional(s) did you attend at the clinic today

Consultant ☐ Doctor ☐ Nurse ☐ Nurse Practitioner ☐

Physiotherapist ☐ Occupational Therapist ☐ Dietician ☐

(4c) During your visit today, what did you discuss with the health professional ?

(Tick all that apply)

Unsteady / Slow Walking ☐ Falls ☐ Difficulty with personal care ☐

Difficulty Breathing ☐ Pain ☐ Bladder or Bowel ☐

Symptoms ☐ Blood Pressure ☐ Weight ☐

Warfarin / INR ☐ Memory ☐ Sleep ☐

Fatigue / Energy Levels ☐ Mood ☐ Tremor ☐

Other ☐ (write) _____

(4d) Did you consider the length of your consultation (tick 1 option below)

Just right ☐ Too Long ☐ Too Short ☐

(4e) As a result of your visit to the health professional(s) today, do you feel you are

	*Tick relevant option after **ALL** statements 1-6*	**Much Better**	**Better**	**Same or less**	**Not Applicable**
1	Able to **cope with life**				
2	Able to **understand your illness**				
3	Able to **cope with your illness**				
4	Able to **keep yourself healthy**				
		Much More	**More**	**Same or less**	**Not Applicable**
5	**Confident about your health**				
6	Able to **help yourself**				

(4f) Did you receive a **prescription** today? Yes ☐ No ☐

(4g) Thinking about your **consultation with the health professional(s)** today, please rate your level of agreement with **ALL** the following statements

		Agree Strongly	Agree	Unsure	Disagree	Disagree Strongly
1	The health professional(s) made me feel at ease					
2	The health professional discussed my medical history					
3	The health professional(s) asked about my health problems & how it affects my life					
4	The health professional(s) asked about my feelings					
5	The health professional(s) gave me useful information & advice					
6	The health professional(s) understood and addressed my symptoms.					
7	I feel that the health professional(s) respected my choices					
8	The health professional(s) discussed home help and my care needs.					
9	The health professional(s) listened to me and appeared interested.					
10	The health professional(s) asked about my home environment & family					
11	The health professional(s) reassured me & helped me see things more positively					
12	The health professional(s) helped me obtain the care I need					
13	I trust the health professional(s)					

14	The health professional(s) helped me see what I can do to improve my health.					
15	The health professional(s) looks after my interests in the health system					
16	The health professional(s) gave me hope and encouragement.					
		Agree Strongly	**Agree**	**Unsure**	**Disagree**	**Disagree Strongly**
17	The health professional(s) provided an opportunity to ask questions.					
18	The health professional(s) involved me in decisions					
19	The health professional(s) links well with other professionals & agencies					
20	The health professional helped me become more independent.					
21	The health professional(s) asked about my interests & social activities					

(4h) Are there additional comments you would like to make regarding your

experience of the service here in the Assessment & Treatment Centre?

No all covered ☐ **Yes see** below ☐

_____

_____

_____

(4i) Indicate your level of agreement with the following statement.

'Today I was satisfied with my consultation with the health professional(s)' ☐

strongly agree ☐ agree ☐ unsure ☐ disagree ☐ strongly disagree.

Thank you for completing this Survey, please place in the box in Reception.

Appendix X mPESQ Confirmatory & Exploratory Factor Analysis

Confirmatory Factor Analysis (CFA)

The original Physician Enabling Skills Questionnaire (PESQ) containing 34 items was validated with the Cronbach's alpha for the 6 subscales .69 - .82 (Hudon *et al.* 2015). The input of professional and patient expertise assisted in the reduction of items from 34 to 24. As outlined in the previous chapter, cognitive interviews with older people aided further reduction of items to 21.

Confirmatory factor analysis was carried out on the 5 factors that had more than 1 item (excluding legitimising the illness experience which had only 1 item). Analysis involved the 5 remaining factors: a) developing an ongoing partnership, b) starting from the patients' personal situation, c) acknowledging the patients' expertise regarding their own lives, d) providing advocacy for the patient in the health system and e) providing realistic hope. The five-factor structure of the modified mPESQ scale was examined using a confirmatory factor analysis (CFA). Maximum likelihood estimation was used, and the factors were allowed to correlate freely. The fit of the model was evaluated using the chi-square test and fit indices including the Comparative Fit Index (CFI), the Standardized Root Mean Square Residual (SRMR) and the Root Mean Square Error of Approximation (RMSEA). SRMR values less than 0.055 are considered ideal. CFI values between 0.90 and 0.94, suggest adequate fit, but values greater than 0.94 are ideal. As a rule of thumb, RMSEA values less than 0.05 indicate a good fit, values between 0.05 and 0.08 suggest acceptable model fit, values between 0.08 and 0.1 suggest marginal model fit, and values greater than 0.1 suggest poor model fit. CFA was performed using Stata (Version 13.0, StataCorp LP, College Station, Texas, USA).

Results of CFA

All items loaded significantly ($p<0.001$ for all) on to their respective factors with standardised factor loadings ranging from 0.489 to 0.838. The factor loadings are reported in Table 1. However, the chi-square test was statistically significant ($p<0.001$), and the fit indicated that the proposed 5-factor structure was not an adequate fit to the data (CFI=0.866, RMSEA=0.098, SRMR=0.055). Despite the inadequate model fit for the 5-factor structure, the factors had good internal reliability with Cronbach alpha values ranging from 0.737 (factor 3) to 0.845 (factor 1).

Factor loadings of items for the 5-factor model, n = 273

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
PESQ1	0.489				
PESQ7	0.743				
PESQ9	0.653				
PESQ13	0.667				
PESQ17	0.621				
PESQ18	0.763				
PESQ19	0.726				
PESQ2		0.599			
PESQ3		0.752			
PESQ4		0.712			
PESQ8		0.639			
PESQ10		0.745			
PESQ21		0.684			
PESQ5			0.726		
PESQ14			0.805		
PESQ11				0.831	
PESQ16				0.838	
PESQ12					0.723
PESQ15					0.773
PESQ20					0.705
Cronbach's alpha	0.845	0.837	0.737	0.813	0.764

*p<0.001 for all factor loadings

Exploratory Factor Analysis (EFA)

As the proposed 5-factor structure was not an adequate fit to the data, an exploratory factor analysis was performed to examine the factor structure of the 21 items. Prior to performing EFA, the suitability of the data for factor analysis was assessed using Bartlett's test of sphericity, the Kaiser-Myer-Olkin (KMO) statistic, and the correlation and anti-image correlation matrices. As the items were measured on a Likert scale, EFA was performed using the polychoric correlation matrix. Principal component analysis (PCA) was used to extract the factors. Kaiser's criterion (eigenvalues>1) was used for determining the number of factors to retain. To aid interpretability of the retained factors, an oblimin (delta=0) rotation was used. Oblique rotation was used as it was hypothesised that the factors would be correlated. EFA was performed using IBM SPSS Statistics (Version 24, IBM Corp, Armonk, USA).

Results of EFA

The data was suitable for exploratory factor analysis. All 21 items had a minimum correlation of 0.3 with at least one other item. None of the correlations were greater than 0.9, indicating that multicollinearity was not an issue. The Kaiser-Meyer-Olkin value was 0.94 (above the

recommended minimum of 0.6) and Bartlett' test of sphericity was statistically significant ($p<0.001$). The diagonals of the anti-image correlation matrix were all over 0.5, supporting the inclusion of each item in the factor analysis.

In the initial principal component analysis, 3 factors had eigenvalues greater than 1, explaining 62.0%, 5.8% and 5.0% of the variance, respectively. The total explained variance was 72.8%. PCA using an oblimin rotation of the 3-factor solution was conducted and inspection of the pattern matrix showed that four of the items (PESQ3, PESQ5, PESQ9 and PESQ13) cross-loaded onto two factors and two items (PESQ6, PESQ7) cross-loaded onto all three factors. Item PESQ6 was removed and the EFA repeated. Again, a three-factor solution was supported and the pattern matrix of the 3-factor solution after an oblimin rotation was examined. Five items (PESQ3, PESQ5, PESQ7, PESQ9 and PESQ13) cross-loaded onto two factors. The smallest difference in factor loadings was for PESQ7. Hence, the EFA steps were repeated with this item removed. Again, a three-factor solution was supported and the pattern matrix of the 3-factor solution after an oblimin rotation was examined. Four items (PESQ3, PESQ5, PESQ9 and PESQ13) cross-loaded onto two factors. The smallest difference in factor loadings was for PESQ5. Hence, the EFA steps were repeated with this item removed. Again, a three-factor solution was supported and the pattern matrix of the 3-factor solution after an oblimin rotation was examined. One item (PESQ9) cross-loaded onto two factors. The EFA steps were repeated with this item removed. Again, a three-factor solution was supported and the pattern matrix of the 3-factor solution after an oblimin rotation was examined. One item (PESQ13) cross-loaded onto two factors. The EFA steps were repeated with this item removed. This time, a two-factor solution was supported and the pattern matrix of the 2-factor solution after an oblimin rotation was examined. Each item loaded on to one factor only with a loading of at least 0.3. The results of the final 2-factor solution are presented in Table 5.5. The first factor had 10 items (Cronbach's alpha = 0.914) and the second factor had 6 items (Cronbach's alpha = 0.807). There was a strong correlation between the two factors ($r=0.750$).

Therefore, the EFA suggests a 2-factor structure, explaining 67.7% of the variance overall. Factor 1 explains 61.2% and Factor 2 explains 6.5%.

Results of EFA with PCA and oblimin rotation of two-factor solution, n=273

Items	Factor 1		Factor 2		Communalities
	Pattern	Structure	Pattern	Structure	
PESQ20	**0.949**	**0.814**	-0.180	0.532	0.676
PESQ18	**0.878**	**0.862**	-0.020	0.638	0.744
PESQ19	**0.829**	**0.841**	0.015	0.637	0.707
PESQ14	**0.826**	**0.846**	0.027	0.646	0.716
PESQ15	**0.819**	**0.859**	0.053	0.667	0.738
PESQ12	**0.797**	**0.807**	0.014	0.612	0.652
PESQ16	**0.770**	**0.875**	0.140	0.717	0.774
PESQ11	**0.768**	**0.847**	0.105	0.681	0.722
PESQ17	**0.710**	**0.785**	0.101	0.633	0.621
PESQ21	**0.697**	**0.779**	0.109	0.632	0.611
PESQ3	0.010	0.688	**0.903**	**0.910**	0.829
PESQ2	-0.102	0.557	**0.879**	**0.802**	0.648
PESQ4	0.115	0.671	**0.741**	**0.827**	0.690
PESQ8	0.055	0.584	**0.704**	**0.746**	0.558
PEQ1	0.023	0.530	**0.676**	**0.693**	0.481
PESQ10	0.236	0.705	**0.625**	**0.802**	0.667
Percentage of total variation accounted for	61.2		6.5		
Factor intercorrelations					
Factor 1	1		0.750		
Factor 2	0.750		1		

mPESQ Factor 1 & Factor 2 items and dimensions

Item	**Factor 1**	**Dimension**
21	The health professional(s) asked about my interests & social activities	Starting from the patient's personal situation
14	The health professional(s) helped me see what I can do to improve my health.	Acknowledging the patient's expertise regarding their own lives
17	The health professional(s) provided an opportunity to ask questions.	Developing an ongoing partnership
18	The health professional(s) involved me in decisions	Developing an ongoing partnership

19	The health professional(s) links well with other professionals & agencies	Developing an ongoing partnership
12	The health professional(s) helped me obtain the care I need	Providing advocacy for the patient in health care system
15	The health professional(s) looks after my interests in the health system	Providing advocacy for the patient in health care system
20	The health professional helped me become more independent.	Providing advocacy for the patient in health care system
16	The health professional(s) gave me hope and encouragement.	Offering Realistic Hope
11	The health professional(s) reassured me & helped me see things more positively	Offering Realistic Hope
	Factor 2	
3	The health professional(s) asked about my health problems & how it affects my life	Starting from the patient's personal situation
2	The health professional discussed my medical history	Starting from the patient's personal situation
4	The health professional(s) asked about my feelings	Starting from the patient's personal situation
8	The health professional(s) discussed home help and my care needs.	Starting from the patient's personal situation
10	The health professional(s) asked about my home environment & family	Starting from the patient's personal situation
1	The health professional(s) made me feel at ease	Developing an ongoing partnership
	Redundant Items	
5	The health professional(s) gave me useful information & advice	Acknowledging the patient's expertise regarding their own lives
6	The health professional(s) understood and addressed my symptoms.	Legitimizing the illness experience
7	I feel that the health professional(s) respected my choices	Developing an ongoing partnership
9	The health professional(s) listened to me and appeared interested.	Developing an ongoing partnership
13	I trust the health professional(s)	Developing an ongoing partnership

Appendix XI Participant Information Letter

PARTICIPANT INFORMATION LETTER

Study Information Sheet

This study is part of a doctoral study undertaken by Mary J. Foley under the supervision of Professor Corina Naughton, University College Cork. Participation is voluntary. **Before you decide whether to take part in this survey, please read the information below.**

What is the purpose of this study?

The purpose of this study is to examine participants perception of enablement (managing and coping with health issues) and how the consultation with a health professional, impacts on enablement.

Who is invited to participate?

Patients with a long-term condition (such as high blood pressure , arthritis, Parkinson's disease) attending the Assessment & Treatment Centre, St Finbarr's Hospital.

What does participation involve?

You will be asked to complete a questionnaire which is in two parts. Part A will be completed before you visit with the doctor/nurse or therapist and will take about 15 minutes. The questions related to your current health status and how well you manage your condition.

Part B will be completed after your last visit (prior to leaving the clinic today) and it will take about 10 minutes to complete. The questions ask you about your clinic visit and how it impacts on your ability to manage your condition. Please ask for help from the nursing staff if you need it. Once completed, please place the questionnaire in a sealed collection box in reception.

Benefits of participation?

There are no direct benefits to participation however, the information you provide will help us evaluate our service and inform further research and education on enablement.

Risks of participation?

There are no risks associated with participation or non-participation. Whether you decide to participate or not will not impact on the care you receive. Participation is voluntary. We appreciate the concentration and physical effort required to complete a questionnaire. If the questions raise any personal issues, please discuss with a member of staff. If you become tired during completion, please ask for help.

Will my participation be kept confidential?

All information will be treated in a confidential manner.
You will not be asked to provide your name or identifying details therefore anonymity will be protected (nobody will know you completed the survey). The information will be used in the doctoral dissertation and published in academic journals and conference. Nothing identifying you will be published. Data obtained from this study will be stored securely in UCC for 5 years as per university regulations.

Further Information

If you have any questions, please discuss with the nurse manager or nurse practitioner. Alternatively, you can contact
Mary J. Foley – 086-7871999 Email MaryJ.Foley@hse.ie or
Prof Corina Naughton, Principal Investigator, University College Cork. Phone: 021 490215