UTS UNIVERSITY OF TECHNOLOGY SYDNEY

Self-care support needs and intervention differentiation across the heart failure illness trajectory

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Thesis submitted in fulfillment of the degree of

Doctor of Philosophy

under the supervision of

Professor Patricia Davidson and Professor Phillip Newton

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Certificate of original authorship

I, Glenn Paull declare that this thesis, is submitted in fulfilment of the requirements for the award of PhD Thesis Nursing, in the Faculty of Health at the University of Technology Sydney. This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis. This document has not been submitted for qualifications at any other academic institution. This research is supported by the Australian Government Research Training Program.

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''The most important practical lesson that can be given to nurses is to teach them what to observe - how to observe - what symptoms indicate improvement - what the reverse - which are of importance - which are of none. All of this is what ought to make part, and an essential part, of the training of every nurse"

Florence Nightingale - 1860

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Please note: an editor has not been used in the construction of this thesis.

Table of Contents

Acknowledgements iii

Table of Contents iv

List of Figures xii

List of Tables xiv

List of Appendices xv

Abstract xvi

List of outputs associated with this thesis xviii

List of abbreviations xix

Glossary of terms xx

Chapter 1 Introduction 1

1.1 Introduction 1

1.2 Background 1

1.3 Problem Statement 2

1.4 Thesis Aims 3

1.5 Research Questions 3

1.6 Heart Failure in Australia 3

1.6.1 Definition and Epidemiology of Chronic Heart Failure 4

1.6.2 Incidence 4

1.6.3 Ageing Population 5

1.6.4 Mortality 5

1.6.5 Symptoms 6

1.6.6 Comorbidities 7

1.6.7 Chronic Heart Failure Disease Trajectory 10

1.6.8 Disease Severity ... 12

1.6.9 Hospitalisation and Readmission ... 12

1.7 Self-Care ... 15

1.8 Chronic Heart Failure Disease Management ... 18

1.9 Outline of the Thesis ... 20

1.10 Significance of study ... 22

1.11 Conclusion ... 22

1.12 References ... 23

CHAPTER 2 CONCEPTUAL FRAMEWORK ... 38

2.1 Introduction ... 38

2.1.1 What is self-care? ... 38

2.1.2 Self-care in heart failure ... 38

2.1.3 Conceptual underpinnings of the self-care construct ... 39

2.2 Overview of theoretical models of self-care ... 39

2.2.1 Grand Theory: Orem's self-care deficit nursing theory ... 40

2.2.2 Middle Range Theory: Middle Range Theory of Self-Care in Chronic Illness ... 41

2.2.3 Situation Specific Theory: Situation-Specific Theory of Heart Failure Self-Care ... 43

2.2.4 Naturalistic decision-making ... 43

2.3 Illness trajectories over time and the concept of temporality ... 46

2.3.1 Patient perception of chronic disease - acute versus chronic illness framework ... 46

2.3.2 Temporal Dimensions in Chronic Illness ... 46

2.3.3 Temporal dimensions within heart failure models of care ... 48

2.3.4 Health trajectory of health and illness ... 51

2.3.5 Health trajectory in nursing research ... 54

2.3.6 The trajectory framework as a model for nursing ... 56

2.3.7 Temporality and philosophy ... *59*

2.3.8 Temporality and chronic disease models of care ... *60*

2.4 CONCLUSION ... 64

2.5 REFERENCES ... 65

CHAPTER 3 TEMPORALITY AS A CONSTRUCT IN SELF-CARE ... 69

3.1 INTRODUCTION ... 69

3.1.1 Patient-related ... *69*

3.1.2 Nursing related ... *70*

3.2 TEMPORAL DIMENSIONS WITHIN THE HEART FAILURE ILLNESS EXPERIENCE OF THE PATIENT ... 71

3.2.1 Care seeking decision-making for worsening symptoms ... *71*

3.2.2 Symptom Perception ... *73*

3.2.3 The Common-Sense Model of Self-Regulation ... *73*

3.2.4 Determinants of delay in seeking care ... *78*

3.2.5 Chronic illness as a temporal construct ... *80*

3.3 TEMPORAL DIMENSIONS IN NURSING ... 85

3.3.1 Nursing Surveillance ... *85*

3.3.2 Continuity of care ... *87*

3.3.3 Temporal continuity in nursing ... *89*

3.3.4 Tailoring strategies for patients with heart failure ... *92*

3.3.5 Time-varying adaptive interventions ... *93*

3.3.6 Summary ... *97*

3.4 CONCLUSION ... 98

3.5 REFERENCES ... 99

CHAPTER 4 METHODS ... 104

4.1 INTRODUCTION ... 104

4.2 THEORETICAL PERSPECTIVE 104

4.2.1 Pragmatism *104*

4.3 RESEARCH QUESTIONS 105

4.4 RESEARCH DESIGN 105

4.5 MIXED METHODS RESEARCH 105

4.6 DATA COLLECTION 107

4.6.1 Patient *107*

4.6.2 Carer *108*

4.6.3 Heart failure nurse specialist working in a disease management service *108*

4.7 LONGITUDINAL APPROACH EMBEDDED IN THE MIXED-METHOD DESIGN 109

4.8 LONGITUDINAL ASSESSMENT DESIGN 111

4.8.1 Longitudinal theoretical perspective *112*

4.9 STUDY SETTING AND POPULATION 112

4.10 PARTICIPANT RECRUITMENT 112

4.10.1 Specialist Heart Failure Nurses *112*

4.10.2 Patient and Carer *113*

4.11 QUANTITATIVE DATA COLLECTION AND STUDY MEASURES 115

4.11.1 Cognitive Function *116*

4.11.2 Depression *116*

4.11.3 Symptom Burden *117*

4.11.4 Self-care Competency *118*

4.11.5 Comorbidity Burden *118*

4.11.6 Health-Related Quality of Life *119*

4.11.7 Overall Health Status (carer) *119*

4.11.8 Functional Status *120*

4.12 Qualitative data collection 121
4.12.1 Interviews 121
4.12.2 Recruitment, retention, and attrition 123
4.12.3 Data collection and management of resources 124
4.13 Qualitative Data Analysis 124
4.14 Data Analysis 125
4.15 Quantitative Analysis 125
4.16 Qualitative Analysis 126
4.16.1 Analysis strategies 126
4.16.2 Analysing longitudinal qualitative data 126
4.16.3 Trajectory Analysis 127
4.16.4 Challenges in qualitative longitudinal data analysis 129
4.16.5 Ethical Issues of longitudinal qualitative research 129
4.17 Data integration 131
4.18 Ethical Considerations 131
4.18.1 Consolidated Criteria for Reporting qualitative research 132
4.18.2 Data management, storage, and retention 132
4.18.3 Positioning of the researcher 132
4.19 Conclusion 134
4.20 References 135
CHAPTER 5 NURSE SPECIALIST RESULTS 140
5.1 Introduction 140
5.2 Nurse Specialist Themes 143
5.2.1 Filling in the gaps: information, navigation, and troubleshooting 143
5.2.2 Assorted assessment and diligence 149

5.2.3 Differences in differentiating: intensity, frequency, and duration of service provision ... *157*

5.2.4 Transitions: clinical, social, spatial, over time ... *172*

5.3 CONCLUSION ... 177

CHAPTER 6 PATIENT RESULTS ... 178

6.1 INTRODUCTION ... 178

6.2 QUANTITATIVE FINDINGS ... 178

6.2.1 Participant Characteristics ... *178*

6.2.2 Montreal Cognitive Assessment (MoCA) ... *179*

6.2.3 Depression, Anxiety, Stress Scales (DASS 21) ... *179*

6.2.4 Heart Failure Somatic Perception Scale (HFSPS) ... *179*

6.2.5 Self-care of heart failure index (SCHFI) ... *179*

6.2.6 Charlson Comorbidity index ... *180*

6.2.7 Kansas City Cardiomyopathy Questionnaire (KCCQ) ... *180*

6.2.8 New York Heart Association (NYHA) ... *180*

6.3 QUALITATIVE FINDINGS ... 183

6.3.1 Context to analysis ... *183*

6.4 PATIENT THEMES ... 184

6.4.1 Unmet need for information ... *185*

6.4.2 Interacting with health care system and health care professionals can be stressful and challenging ... *187*

6.4.3 Unrecognised need: deficits in knowledge and self-care practice ... *192*

6.4.4 Change in the illness experience over time ... *205*

6.5 CONCLUSION ... 214

6.6 REFERENCES ... 215

CHAPTER 7 CARER RESULTS **216**

7.1 INTRODUCTION 216

7.2 QUANTITATIVE RESULTS 218

7.2.1 Quality of life *218*

7.2.2 Depression, anxiety, and stress *218*

7.3 QUALITATIVE RESULTS 221

7.4 CARER THEMES 221

7.4.1 Challenge of change and the need for information: navigating services and the need to be known *221*

7.4.2 The dyadic relationship: dependency, burden, conflict, frustration, and resignation….. .... *226*

7.4.3 The carer as a safety net: vigilance, negotiation, and agency *236*

7.4.4 Carer Support, transition, and change over time *241*

7.5 CONCLUSION 247

CHAPTER 8 DISCUSSION AND CONCLUSION **248**

8.1 HEART SUPPORT STUDY - SUMMARY OF KEY FINDINGS 248

8.1.1 Patient *248*

8.1.2 Care partner *249*

8.1.3 Nurse Specialist *249*

8.2 SYNTHESIS OF KEY FINDINGS 252

8.2.1 The need for information is a dynamic phenomenon and there is often a reluctance to seek help *252*

8.2.2 Interacting with the healthcare system and health care professionals can be stressful and challenging *252*

8.2.3 The patient and care partner dyad is complex with conflict and tensions evident…….. .... *252*

8.2.4 Temporal opportunities for care partner influence 253

8.2.5 The care partner needs a stronger voice: the need for support and respectful engagement............ 253

8.3 SUMMARY OF ANSWERS TO STUDY QUESTIONS 254

8.3.1 What are the self-care support needs of patients and carers across the heart failure illness trajectory?............ 254

8.3.2 How does self-care knowledge, attitudes and beliefs change over time? 254

8.3.3 How do chronic heart failure disease management services differentiate intensity, frequency, and duration of self-care support interventions across the heart failure illness trajectory? 255

8.4 DISCUSSION 255

8.4.1 The Theory of Dyadic Illness Management 256

8.4.2 Situation Specific Theory of Caregiver Contributions to Self-Care............ 258

8.4.3 Relevance of findings to theoretical framework 260

8.4.4 Heart Support Study and Transition Theory 262

8.4.5 Heart Support Study, Transition Theory and Complexity Science............ 263

8.5 LIMITATIONS............ 267

8.6 STRENGTHS OF THE STUDY 268

8.7 IMPLICATIONS FOR POLICY............ 269

8.8 IMPLICATIONS FOR PRACTICE 270

8.9 IMPLICATIONS FOR RESEARCH 271

8.9.1 Patient – care partner – dyad related 271

8.9.2 Provider related 271

8.10 CONCLUSION 272

8.11 REFERENCES 273

List of Figures

FIGURE 1.1 TYPICAL TRAJECTORY OF CHRONIC HEART FAILURE 11

FIGURE 1.2. CONCEPTUAL MODEL OF FACTORS THAT MAY INFLUENCE CHRONIC HEART FAILURE (CHF) SELF-CARE 17

FIGURE 2.1 LEVELS OF SELF-CARE NURSING THEORY WITH SELF-CARE EXEMPLAR 40

FIGURE 2.2 SELF-CARE CONCEPTS: SELF-CARE MAINTENANCE, SELF-CARE MONITORING, AND SELF-CARE MANAGEMENT 42

FIGURE 2.3 DIAGRAM OF THE SELF-CARE PROCESS 43

FIGURE 2.4 THE NATURALISTIC DECISION-MAKING INFLUENCE ON SELF-CARE PROCESS 44

FIGURE 2.5 THREE LEVELS OF NURSING THEORY DEMONSTRATING TEMPORAL DIMENSIONALITY 45

FIGURE 2.6 CONCEPTUAL FRAMEWORK OF FACTORS AFFECTING DECISION-MAKING AND SUBSEQUENT SELF-CARE IN PATIENTS WITH HEART FAILURE 48

FIGURE 2.7 FACTORS INFLUENCING THE ABILITY TO SELF-CARE IN PATIENTS WITH CHRONIC HEART FAILURE 49

FIGURE 2.8 CHANGE IN INFLUENCES AFFECTING SELF-CARE OVER TIME WITHIN THE CONCEPTUAL FRAMEWORK OF FACTORS AFFECTING DECISION-MAKING AND SUBSEQUENT SELF-CARE IN PATIENTS WITH HEART FAILURE 50

FIGURE 2.9 CHANGE IN INFLUENCES AFFECTING SELF-CARE OVER TIME WITHIN THE SITUATION-SPECIFIC THEORY OF HEART FAILURE SELF-CARE 51

FIGURE 2.10 HEALTH TRAJECTORY ALLOWS REFINEMENT IN THE TARGETING OF CLINICAL INTERVENTIONS 52

FIGURE 2.11 ADDITION OF TIME AS A CORE META CONCEPT IN NURSING 53

FIGURE 2.12 PHASES OF THE CHRONIC ILLNESS TRAJECTORY 56

FIGURE 2.13 KNIFE EDGE VERSUS TEMPORALLY EXTENDED PRESENT 60

FIGURE 2.14. HUSSERL'S TEMPORALLY EXTENDED PRESENT 60

FIGURE 2.15. PRESENT NOW ASSESSMENT WITH RETENTION AND PROTENTION INFLUENCE 61

FIGURE 2.16. HUSSERL'S TEMPORALLY EXTENDED PRESENT INCORPORATING SITUATION AND PROCESS ELEMENTS OF THE SITUATION-SPECIFIC THEORY OF HEART FAILURE SELF-CARE 62

FIGURE 3.1 COMMON SENSE MODEL OF SELF-REGULATION 75

Figure 3.2 Stages of delay 78
Figure 3.3 Decisions to seek or delay care in the three stages of an illness episode 79
Figure 4.1 Mixed methods research 106
Figure 4.2 Heart Support Study Data Collection 108
Figure 4.3 Fully longitudinal trajectory design 111
Figure 4.4 Reflexive process during Heart Support Study 134
Figure 7.1. Carer quality of life - SF 36 218
Figure 7.2 Carer Depression - DASS 219
Figure 7.3 Carer anxiety - DASS 219
Figure 8.1 Triadic chronic disease relationship 251
Figure 8.2 Relevance of Heart Support Study findings to the Situation Specific Theory of Heart Failure Self-Care 261
Figure 8.3. Dyadic relationship awareness within the heart failure self-care triad 262
Figure 8.4. Diagrammatic model of transition processes in heart failure self-care: representing continuous transition process of patient, care partner, nurse specialist, and within dyadic relationship during the heart failure experience to form a complex system 264
Figure 8.5. Transitions theory with complexity science concepts integrated 265
Figure 8.6 An example of a closed system 266
Figure 8.7 An example of an open system 267

List of Tables

TABLE 2.1. PHASES OF THE TRAJECTORY OF DISEASE 57

TABLE 2.2 POTENTIAL TEMPORAL INFLUENCE ON SITUATION AND PROCESS NATURALISTIC DECISION-MAKING FACTORS 62

TABLE 3.1 FIVE CORE CONSTRUCTS THAT COMPRISE ILLNESS REPRESENTATION 74

TABLE 3.2. SARTRE'S ANALYSIS OF PAIN AND ILLNESS 83

TABLE 3.3 THREE TYPES OF CONTINUITY 88

TABLE 4.1 HEART SUPPORT STUDY DATA COLLECTION 109

TABLE 4.2 PATIENT ASSESSMENT MEASURES 115

TABLE 4.3. CARER ASSESSMENT MEASURES 116

TABLE 4.4 DASS SEVERITY MEASURES 117

TABLE 4.5 NEW YORK HEART ASSOCIATION (NYHA) CLASSIFICATION 120

TABLE 4.6 COMPARISON OF RECURRENT CROSS-SECTIONAL AND TRAJECTORY ANALYSIS 127

TABLE 4.7 SAMPLE OF INDIVIDUAL MATRIX BASED ON THEMES IDENTIFIED 128

TABLE 4.8 SAMPLE OF A LONGITUDINAL ANALYSIS MATRIX 128

TABLE 5.1 CHARACTERISTICS OF NURSE SPECIALIST PARTICIPANTS 141

TABLE 5.2 SERVICE CHARACTERISTICS 142

TABLE 5.3 NURSE SPECIALIST PARTICIPANTS - KEY THEMES 143

TABLE 6.1 PARTICIPANT CHARACTERISTICS 180

TABLE 6.2 SUMMARY OF QUANTITATIVE PATIENT DATA 181

TABLE 6.3 SUMMARY OF PATIENT DATA FOR KANSAS CITY CARDIOMYOPATHY QUESTIONNAIRE 182

TABLE 6.4 ALL CAUSE HOSPITAL READMISSION 183

TABLE.6.5. PATIENT THEMES 184

TABLE 7.1 CARER DETAILS 217

TABLE 7.2 CARER THEMES 221

TABLE 8.1 QUALITATIVE FINDINGS SUMMARY TABLE 251

List of Appendices

APPENDIX 1 STUDY ADVERTISEMENT 276

APPENDIX 2 NURSE SPECIALIST PARTICIPANT INFORMATION SHEET 277

APPENDIX 3 NURSE SPECIALIST PARTICIPANT CONSENT FORM 278

APPENDIX 4 PATIENT INFORMATION FORM 283

APPENDIX 5 PATIENT PARTICIPANT CONSENT FORM 284

APPENDIX 6 CARER PARTICIPANT CONSENT FORM 289

APPENDIX 7 CARER INTERVIEW SCHEDULE GUIDE 294

APPENDIX 8 PATIENT INTERVIEW SCHEDULE GUIDE 295

APPENDIX 9 NURSE SPECIALIST INTERVIEW SCHEDULE GUIDE 296

APPENDIX 10 SESLHD HUMAN RESEARCH ETHICS APPROVAL 297

APPENDIX 11 UNIVERSITY OF TECHNOLOGY SYDNEY HUMAN RESEARCH ETHICS APPROVAL 299

Abstract

Purpose: Heart failure is a chronic, progressive condition requiring patients and their care partners to engage in self-care behaviours over time. This experience is a spatial entity as well as a temporal one. There are numerous factors contributing to the temporal dimensions of the heart failure illness experience, many of which influence the ability to self-care and are known to change over time. Disease severity, level of symptom burden, cognitive dysfunction, depression, anxiety, memory, comorbidity burden, and functional status are all patient level factors that can change over time and influence ability to carry out self-care activities.

While self-care support interventions are designed to support self-care, ongoing strategic differentiation of the timing and intensity of interventions to changing self-care support needs over time has been shown to be limited. Given the dynamic nature of disease progression, and the shifting challenges and support needs of patient and care partner relating to social, emotional, physical, and intellectual capacity, a greater understanding of the temporality of self-care support needs across the heart failure illness trajectory is essential. This thesis aimed to explore the self-care support needs and intervention differentiation across the heart failure illness trajectory.

Methods: This study utilised a prospective, longitudinal, mixed method study design to collect data from three study populations: patients with a diagnosis of heart failure; their care partners; and heart failure specialists working in a disease management program. For patient and care partner participants, a purposive sample of 16 patient/care partner dyads were recruited from a tertiary referral hospital in metropolitan Sydney, Australia. Serial, semi-structured interviews were conducted in conjunction with validated assessment measures with patients and identified care partners at two time points, 6 months apart. Descriptive statistics and interpretive longitudinal qualitative trajectory analysis were used to analyse the data.

For heart failure nurse specialist participants working in a disease management program, semi-structured in-depth interviews were conducted with sixteen (16) specialist heart failure nurses from fourteen (14) metropolitan and regional health care settings spanning eight Local Health Districts within New South Wales. Interviews explored service structure in addition to decision making relating to intervention differentiation and self-care support requirements across the heart failure illness trajectory. Interpretation of data was guided by thematic content analysis.

Results: Patient and care partner data revealed that heart failure self-care occurs within a dyadic context with pre-established relationship patterns. Cognitive impairment was common among patients (56%) with self-care engagement influenced by premorbid personality and remained largely unchanged across the two time points, regardless of structured intervention. This was a cause of concern and strain for care partners who often lacked the agency to influence decision-making. The quality of discharge planning and community based care altered care partners' support and capacity to adapt to changing needs over time.

Interviews with heart failure specialists revealed a wide variation in program structure, referral patterns and intervention focus relating to duration, content, and mode of delivery. Specialist heart failure nurses described the need for a highly insightful and nuanced assessment to inform self-care support priorities and strategies. Although considered to be important by all of the participants, formal assessment measures were not routinely applied, and service evaluation was limited.

Conclusion: To date, many of the approaches to heart failure self-care have been at an individualistic, linear level. The findings of the Heart Support Study demonstrate that care is delivered in a complex ecosystem with multiple factors that extend beyond the relationship between the nurse and the patient, and the patient and the care partner. There is a need to employ a multilevel approach that recognises the complexity of the environment and changes over time. This thesis has made a valuable contribution to the science of heart failure management. Importantly, it underscores that living with heart failure is a dynamic and evolving process with both the patient and care partner demonstrating an ongoing need for information as they undergo individual and dyadic processes of transition in response to living with heart failure as a chronic illness.

List of outputs associated with this thesis

Conference Proceedings

Cardiac Society of Australia and New Zealand ASM 2018 (Prize Finalist)

Self-care support needs of patients and their carers across the heart failure illness trajectory: a mixed methods longitudinal study

Glenn Paull, Phillip J Newton, Patricia M Davidson

Cardiac Society of Australia and New Zealand ASM 2018

Supporting self-care across the heart failure illness trajectory: exploring the clinical practice of specialist heart failure nurses across metropolitan and regional NSW

Glenn Paull, Phillip J Newton, Patricia M Davidson

Australian Cardiovascular Health and Rehabilitation Association ASM 2016

Influence of temporality on heart failure self-care support needs: opportunities for tailoring and targeting health service delivery

Glenn Paull, Phillip J Newton, Patricia M Davidson

Manuscripts in progress

Paull, G; Koirala, B; Newton, PJ; Davidson PM. *Temporality and self-care at the level of the individual: implications for heart failure model development.*

List of abbreviations

CNC: Clinical Nurse Consultant

CNS: Clinical Nurse Specialist

CSM: Common-sense model of self-regulation

DASS: Depression, Anxiety, Stress Scales

ED: Emergency department

GP: general practitioner

HCP: Healthcare provider

HF: Heart Failure

HFSPS: Heart Failure Somatic Perception Scale

HRQOL: Health Related Quality of Life

HSS: Heart Support Study

KCCQ: Kansas City Cardiomyopathy Questionnaire

MoCA: Montreal Cognitive Assessment

NHS: National Health Service

NHF: National Heart Foundation

NP: Nurse Practitioner

NYHA: New York Heart Association

OT: Occupational Therapist

SCHFI: Self Care of Heart Failure Index

Glossary of terms

Clinical nurse consultant (CNC): a type of advanced practice nurse modelled on the CNS role in the UK and USA. CNCs are required to function within five domains of practice: clinical service and consultancy, clinical leadership, research, education, and clinical services planning and management.

Clinical nurse specialist (CNS): a registered nurse who applies a high level of clinical nursing knowledge, experience, and skills in providing complex nursing care directed towards a specific area of practice, a defined population or defined service area, with minimum direct supervision.

Complexity science: concerned with complex systems and problems that are dynamic, unpredictable, multi-dimensional, and consisting of a collection of interconnected relationships and parts.

Complex adaptive system: characterised by dynamic relationships among multiple participants, the system being more complex than its individual parts

Constitution: occurring when a kind of stable unity is produced in experience

Dyad: a pair of individuals in an interpersonal situation

Health trajectory: the changing course of health and illness over time

Inner time: an internal experience that is not yet in need of another level of awareness. With inner time, time itself is no longer a measure but seems idle, with past and future dissolving into an everlasting present.

Naturalistic decision-making: how people make decisions and perform cognitively complex functions in demanding, real-world situations

Nurse practitioner (NP): an endorsed registered nurse (RN) who works at an advanced practice level with an extended role that allows them to request diagnostic investigations, prescribe medicines and receive/make referrals

Protention: rapidly arriving future

Reductionist: any approach to explanation that attempts to reduce complexities of structure for behaviour to less complex units

Retention: recently elapsed past

Spatial: relating to, occupying, or having the character of space

Temporal: relating to time

Temporal continuity in nursing: where nurses attend to the patient throughout the period in which they receive care

Temporality: the state of existing within or having some relationship with time

Temporally extended present: an awareness of what has been before and what is to come

Trajectory: the course of a chronical disease in its different stages and phases.

Transition theory: a middle range theory that allows the development of strategies to help people come to terms with new situations, demands, resources and relationships in their lives.

Transitions: processes which are both the result of and result in change in lives, health, relationships, and environments.