

Chronic Care Research: Issues and Directions

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in the Asian & Western Pacific Region**

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Definitions

- Chronic disease - any condition that requires ongoing adjustments by the affected person and interactions with the health care system
- Chronic care management encompasses the oversight and education activities conducted by health care professionals to help patients with chronic diseases
- Chronic care research – a systematic inquiry about any aspect of chronic disease

Some issues in chronic care management

- Patient related concerns:
 - Patients inadequately trained to manage their illnesses
- Health caregiver concerns:
 - Practitioners do not follow established practice guidelines
- Health system concerns:
 - Lack of care coordination and planned care
 - Lack of active follow-up to ensure the best outcomes

Need for chronic care research

- Rising prevalence of chronic diseases
- Incidence of multiple chronic diseases/ co-morbidities
- Reactive health care system (curative vs. preventive)
 - reacting to a person who is sick
 - rather than preventing incidence of chronic diseases
- Need for good evidence as basis for good interventions (evidence based practice in a knowledge era)

Chronic care management system

Elements

- Health system (MOH policy and infrastructure)
- Community resources (local infrastructure)
- Health organization (patient groups)
- Self-management support
- Delivery system design
- Decision support
- Clinical information systems

The Chronic Care Model



Developed by The MacColl Institute
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Research on the role of nurses

- ‘Nurses, not doctors, are the key to implementing the chronic care model in a patient centered care team’
- Interaction between an informed, activated patient and a prepared, proactive practice team
- Better communication between patient and nurse

Areas for research

Systems improvement

- Fragmentation of chronic health care components towards an integrated system
- Absence of policy to support a good system
- Need for patient education
- Need for adequate training of health care givers
- Linking effective health care practice to health outcomes

Areas of research

- Role of primary health care unit for prevention and management of chronic diseases
 - Facility (e.g. adequate infrastructure)
 - Personnel (e.g. nurse, caregiver, etc.)
 - Interaction with patients (e.g. satisfaction surveys)

Areas of research

Investigational medicinal products (IMP) to develop effective interventions for chronic diseases

- New generation drugs (e.g. combination drugs)
- Effective interventions to relieve symptoms
- Effective diagnostic tools (e.g. medical device)
- New vaccines
- Traditional and complementary products/interventions
- Effective delivery system (access)

Areas of research

Patient – Caregiver interaction

- Knowledge, attitudes and practice (KAP) of patients and caregivers
- Socio-demographic factors
- Identification of behavioral barriers
- Utilization of cognitive behavioral therapy measures
- Development of good models

Directions in Nursing Research

- Methods Used
- Quantitative methods: make use of statistical tools to arrive at a conclusion
 - Follows a linear model from a general theory to hypothesis testing towards application to a given situation to arrive at a conclusion
- Qualitative methods make use of iterative interviews to provide in-depth analysis
 - Uses particular views to arrive at good analysis
- Mixed methods

Quantitative Research

- ❑ Aims to generate generalizable information/ conclusions
- ❑ Uses statistical methods
- ❑ Checks validity and reliability of data
- ❑ States the data analysis plan
- ❑ Uses simple/ stratified random sampling methods in surveys

Quantitative Research

Quantitative – makes use of quantitative data for precise measurement of social phenomena.

- General patterns are described.
- Statistics are used to make statements of relationships of variables across many cases.
- Statistical tools include percentage, frequency distribution, measures of central tendency (arithmetic mean, median, mode and standard deviation)

Qualitative Research

Emphasize particular context and settings

- Use methods (ethnography, KII, etc.) capable of providing sufficient detailed account or analysis
- Outcome is capable of enabling others to determine the application of the findings to other circumstances
- Provides in-depth insights about specific situations

Based on Australian National Statement on Ethical Conduct in Human Research (Sec.3.1.4 -3.1.8)

Qualitative Research

- ❑ Capable of generating quality and credible data based on its data collection techniques and analysis plan
- ❑ No intention to generalize
- ❑ Its rigor cannot be judged based on sample size

Based on Australian National Statement on Ethical Conduct in Human Research (Sec.3.1.4 -3.1.8)

Grounded Theory

- A systematic qualitative research methodology in the social sciences emphasizing generation of theory from data in the process of conducting research.
- This contradicts the traditional model of research, where the researcher chooses a theoretical framework, and only then applies this model to the studied phenomenon.

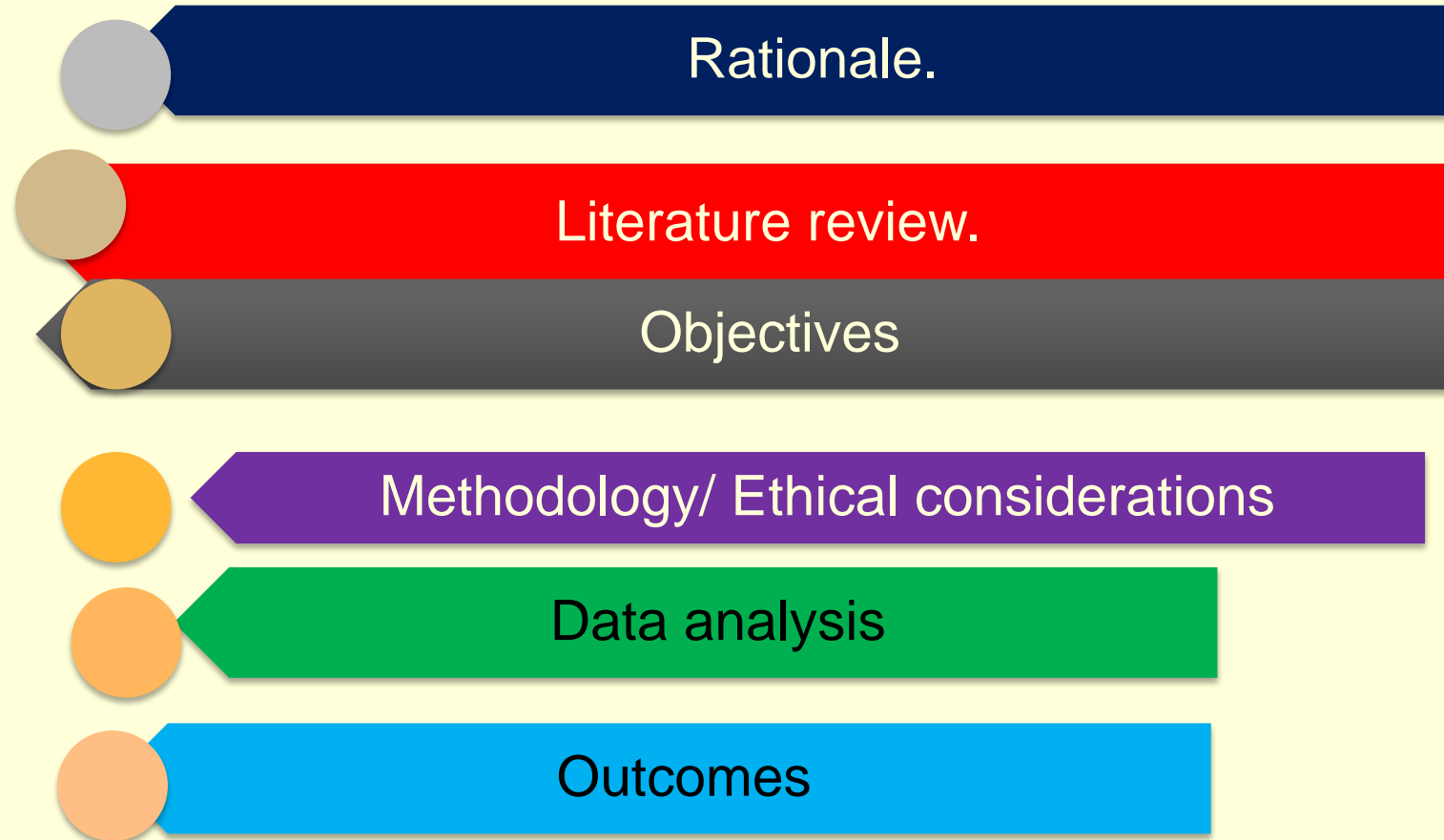
Research in Alternative Pain Management

- Approaches to Management of Chronic Pain
- The primary goal of caring for the patient with chronic pain is not the elimination of pain but the improvement of function.
- Pain as a self-reported symptom cannot be directly measured by the clinician, but the substantial effects of chronic pain on sleep quality, work and home role disability, and social connectivity are more readily measurable.
- Patients may have experienced the failure of prior treatment approaches and are seeking a simple pharmacologic resolution to their pain.
- Education and support of the patient during this process is critical.
- A new repertoire of treatment modalities such as psychological, self-management, educational, and complementary and alternative therapies

Jill Schneiderhan, MD et al, *Primary Care of Patients with Chronic Pain*, JAMA, May 18, 2017



Ensuring scientific protocols: Standard protocol sections



Some ethical questions in chronic care research

- Which patient issues in chronic care should be a priority topic in research?
- What types of vulnerabilities will you encounter among chronic care patients in your research?
- What are the types of risks?
- What protections must be provided for patients and/or providers to reduce the risks?
- Under what circumstances are informed consent or other forms of disclosure or permission needed?
- What are the best practices for addressing privacy and confidentiality issues?
- Are there any potential direct or indirect benefits to, or incentives for, participating in chronic care research?

Ethical Consideration Section

Defines the relationship between scientific characteristics of the study and its effects on human participants

- Identifies possible risks the study would entail
- States what benefits may be derived by the participant, community, or the larger society
- Explains how vulnerability issues will be addressed
- Explains how the ICF will address the ethical issues
- Submission to an Ethics Committee for further review and suggestions

Ethical Review

University of Edinburgh School of Social and Political Studies

1. Project details

2. Type of participants

3. Risk to participants

4. Confidentiality and handling of data

5. Information and consent form

6. Conflict of interest

Responsibility of researchers

- Scientific integrity
- Ethical compliance
- Technical soundness
- Good documentation
- Publication
- Application/ translation



Institutional responsibilities

- Establishment of good research governance system
 - Support for good ethics review system (IRB)
 - Biosafety committee
 - Institutional animal care and use and committee (IACUC)
 - Office of research integrity
- Mentoring
- Assistance to investigators

Role of Research Ethics Committee

Characteristics of good ethics review

- Comprehensive and integrated review of scientific and ethical issues
- Specific to protocol related documents
- Ensures social relevance of study topic
- Ensures scientific integrity of persons conducting research
- Minimizes risks to humans
- Maximizes human benefits

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