

**Title of Systematic Review**

*A qualitative review on the experiences of people, their families and carers living with one or more long term condition (LTC) being supported by the nurses in the community.*

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**Expected Completion date**

April 2010

## Background

The burden of Long Term Conditions (LTC) is growing globally and in Scotland, and as in many parts of the world, the demographic picture shows an increasing number of older people in the next 20-30 years many of whom will be living with one or more LTC <sup>(1, 2, 3)</sup>. Factors such as longevity, successful medical and pharmacological interventions and the increased exposure to chronic disease risk factors through unhealthy/risky lifestyle choices, contributes to increasing number of people with LTCs and the subsequent impact on health systems <sup>(4)</sup>. As a result, increasing numbers of people are now living with one or more LTC many of them receiving care and support in the community. The World Health Organisation <sup>(3)</sup> characterises LTC or chronic conditions as they are often termed, as being those which require “ongoing management over a period of years or decades”.

Recent Government policy indicates several aspects vital for supporting and caring for those with LTC include care that is co-ordinated in primary care, holistic in nature, involves people in their own planning and care, using community and voluntary resources well, and includes support for family and carers <sup>(2)</sup>. LTC's require care and support over a sustained period of time and never achieve a cure. Supporting older people, their families and carers with their health is seen as part of the ‘core businesses’ for nurses and allied Health Professionals (AHP's) in the community <sup>(5)</sup> and the needs of older people and those with LTC's must be at the centre of attention in a patient focused service.

A shift away from a reactive medical model of caring and supporting LTC's has meant that a more proactive approach to managing LTC's is needed that includes strategies to improve patient outcomes <sup>(6)</sup>. Individuals require better control, management and ongoing monitoring of their LTC to maximise their independence and quality of life. There is a clear need for caring and supporting people with LTC's in their own homes and communities though this is not monopolised by nurses and patients themselves, family members and paid and unpaid carers contribute to patient experiences and health outcomes. This ongoing care and support in this context is therefore a ‘caring partnership’ with a focus on promoting self care and self management. Enhancing self care is important for a number of reasons including people with LTC ‘gaining a sense of control’ and ‘enjoying a better quality of life’ <sup>(7)</sup>. Thus, there is a growing need for an increased focus on understanding the experiences and perceptions of those at the

'coal face' of this 'caring partnership' and to explore further the 'lived' experiences and perceptions of all parties involved.

Kennedy et al <sup>(8)</sup> recently reinforces that nurses working in the community are fundamental to improving patient satisfaction and effectiveness and that patients value interactions with nurses, in part, due to the humanistic approach taken to caring and supporting those with LTC. The humanistic approach is consequently bound up in a patient-centred perspective of caring. The World Health Organisation <sup>(9)</sup>, lists patient centred care as a core competency when describing new education models for nurse training. This aims at enhancing basic nurse caring skills for patients living with chronic illness. However, genuine patient-centred care and support can only be achieved when we are able to look into the patients' world and experiences of living with a condition from their perspective <sup>(10)</sup>.

Lundman and Jansson <sup>(11)</sup> note that in several studies the perspectives on illness and disease between professionals and patients has been discussed which points to their 'separate worlds'. Some recent research has shifted the gaze from illness perspectives from an outsider approach (that of health care professionals) to that of an 'insider' perspective in an attempt to understand the impact of diseases on peoples daily living and functioning <sup>(11)</sup>. The literature to date on the experiences of patients, their carers and nurses has neither been comprehensive (looking at one supporters perspective for example) nor recently systematically reviewed.

This proposal seeks to add to the qualitative evidence base for supporting individuals and optimising their experiences and quality of life with LTC by looking at common and shared experiences and perceptions of those in the 'caring partnership'. This would be achieved through taking an 'insider' perspective of those with LTC and those directly involved in their ongoing care and support.

It is anticipated that the systematic review will uncover literature encompassing the following long term conditions: Chronic Obstructive Pulmonary Disease (COPD), Coronary Heart Disease (CHD), Diabetes (D), Cerebrovascular Disease (CVD) and Neurological Diseases (N). This list however, is not exhaustive or exclusive and will be dictated by the literature base and those selected.

## **Objectives**

This review seeks to establish the nature of care and support in the community for those people who have one or more long term condition. The review will consider any qualitative research that describes or analyses the experiences of adult patients, families, carers and members of the community nursing team involved in managing long term conditions.

## **Criteria for considering studies for this review**

### **Types of studies**

The study types to be considered in the review will be qualitative research studies which address the question of care and support of adults with one or more long term condition as described above.

The studies may consist of but not limited to: phenomenology, grounded theory, ethnography, ethnomethodology, phenomenography and action research. The review will also consider relevant government and non government reports, conference papers and proceedings.

### **Types of participants**

The review will consider older adult participants with one or more long term condition being supported by family, carers and members of the community nursing team. The perspectives of the family may be from a variety of points of view, for example, spousal support as differing from the support of offspring. The viewpoint of the community nursing team may be through, for example District Nurses, Family Health Nurses or Community Matrons.

### **Phenomenon of Interest**

This review will examine the phenomenon of care and support in LTC whilst living at home. This will include the perspectives of the person with a LTC, the families and or carers and community nurses. The interventions may consider but not be limited to the following:

- Support
- Self-care

- Symptom control
- Communication
- Quality of life
- Activities
- Spirituality

### **Anticipated Outcomes**

The anticipated outcome will be a synthesis of themes/categories that relate to the perspectives of the main players (patient, carer or nurse) in the care and support of Long Term Conditions. Whilst at this stage it is not possible to identify differences between these, the review will seek to identify differences and similarities across the three groups.

### **Search strategy for identification of studies**

An initial scoping phase would be undertaken to identify relevant MeSH terms and keywords. The literature search will identify a broad range of evidence from a wide range of sources including peer and non-peer reviewed journals, conference proceedings, dissertations, reports and policy documents, publications from patient and voluntary organisations, websites, meetings and local initiative reports. Grey literature will be included and resources such as non health and social care journals may be identified to establish the extent to which support for LTC has been reported or investigated within the broader public domain. In addition the network of collaborating centres of the Joanna Briggs institute will be utilised to identify any work that is currently underway to seek other literature that may not be accessible through other routes. JBI centres number 54 and are situated in Australasia, Europe, South Africa and North America.

The aim of the literature search will be to find both published and unpublished material in the English language. The review will include literature from 1990 onwards to the present, date although any seminal papers and work identified from prior to this cut off date would be included in the report narrative. With changes to health care systems the cut off date of 1990 would be appropriate. 'Refworks' referencing management tool will be employed to organise the list of references.

The search strategy will involve a number of elements, notably:

- The identification of keywords
- A search of relevant abstracts and indexes
- A search of relevant conference proceedings and databases such as 'ZETOC'
- Consultation of full text documents for verification purposes

- Identification of individual authors and follow up using citation analysis
- Identification of relevant theses and dissertations
- A search of relevant sources of 'grey' literature
- A search of relevant Web pages

The keywords that would inform the initial review include:

Managing long term conditions, chronic disease\*, support, carer\*, family, primary care, self care, symptoms, communication, quality of life, spirituality, patient care, nurse-led, long term care, nurse\*

## Databases

Examples of the range of information sources that will be consulted are as follows:

- ASSIA
- AMED
- CAB HEALTH
- CINHAL
- Cochrane Library
- Embase
- ERIC
- Medline
- PASCAL
- PsychINFO
- Sociological Abstracts
- Web of Science

## Grey Literature

- 'Google Scholar'
- ZETOC
- Index to Theses
- CAREDATA
- Subject Gateways and Directories (e.g. OMNI and SOSIG)
- Directory of Open Access journals
- Networked Digital Library of Theses

In addition broader strategies will include :

- Hand searching of journals in health and social care CLIP database for local projects
- Use of CHAIN network
- Contact with key individuals who have researched and written on long term conditions.
- RCN library
- ISD
- King's Fund
- Government health department websites
- University departments, particularly those where long term conditions is a specific focus
- Voluntary organisations and charities

All identified material will be assessed for relevance to the review and if necessary a full report will be retrieved for studies that meet the inclusion criteria. Studies identified from reference list searches will be assessed for relevance on the study title. Wherever possible, personal contact will be made with individuals and organisations for recommendation of literature.

## **Methods of the review**

### **Critical Appraisal**

Papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using the standardised critical appraisal instruments from the Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information package (SUMARI) (Appendix I and II). Any disagreements that arise between the reviewers will be resolved through discussion with a third reviewer. For this review the primary reviewer will be PK with EW acting as a secondary reviewer with support from PW.

### **Data extraction:**

Data will be extracted from papers included in the review using the standardised data extraction tool from the Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information package (SUMARI). For qualitative research this will be through QARI and if appropriate NOTARI for text and opinion (Appendix I and II).

### **Data synthesis:**

Where meta-synthesis is possible, qualitative research findings will be pooled using the Qualitative Assessment and Review Instrument (QARI). This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings rated according to their quality, and categorising these findings on the basis of similarity in meaning. This will be carried out separately for each of the main themes identified as patients, carers and families and nurses. These categories are then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesised findings that can be used as a basis for evidence-based practice.

If appropriate any text and opinion papers will be pooled using the Narrative, Opinion and Text Assessment Review Instrument (NOTARI). See Appendix II for appraisal and extraction format.

### **Acknowledgements**

The review would be carried out in conjunction with the Joanna Briggs Collaborating Centre at The Robert Gordon University in Aberdeen

### **Potential conflict of interest**

No conflicts of interest noted.

### **References**

1. Scottish Executive: NHS Scotland. *Building a Health Service fit for the future*. Edinburgh: Scottish Executive; 2005a.
2. Scottish Executive: NHS Scotland. *Delivering for Health*. Edinburgh: Scottish Executive; 2005b.
3. World Health Organisation. *Innovative Care for Chronic Conditions: building blocks for action*. Geneva: World Health Organisation; 2002.
4. Nolte, E. & McKee, M. *Caring for People with Chronic Conditions: A health system perspective*. Maidenhead: Open University Press; 2008.
5. Scottish Executive: NHS Scotland. *Delivering Care: Enabling Health*. Edinburgh: Scottish Executive; 2006.
6. Presho, M. *Managing Long Term Conditions: A social model for community practice*. Chichester: Wiley –Blackwell; 2008.
7. Koch, T., Jenkin, P and Kralik, D. Chronic Illness self-management: locating the 'self'. *Journal of Advanced Nursing*. 2004; 48 (5), 484-492.
8. Kennedy, C., Christie, J., Harbison, J., Maxton, F., Rutherford, I. and Moss, D. Establishing the contribution of nursing in the community to the health of the people of Scotland: integrative literature review. *Journal of Advanced Nursing*. 2008; 64 (5), 416-439.
9. World Health Organisation. *Preparing a Health Care Workforce for the 21<sup>st</sup> Century: The challenge of chronic conditions*. Geneva: World Health Organisation; 2005.
10. Astin, F. and Closs, S. J. Guest Editorial: Chronic Disease Management and self-care support for people living with long-term conditions: is the nursing workforce prepared? *Journal of Clinical Nursing*. 2007; 16 (7b), 105-106.
11. Lundman, B. and Jansson, L. The meaning of living with a long-term disease. To revalue and be revalued. *Journal of Nursing and Healthcare of Chronic Illness*. 2007; 16, 7b, 109-115.

# **Appendix 1**

Qualitative Research Appraisal and Extraction Tool

## JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer \_\_\_\_\_

Date \_\_\_\_\_

Author \_\_\_\_\_

Year \_\_\_\_\_

Record Number \_\_\_\_\_

	Yes	No	Unclear
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal:      Include       Exclude       Seek further info.

Comments (Including reasons for exclusion)

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# JBI QARI Data Extraction Form

## for Interpretive & Critical Research

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Reviewer _____	Date _____
Author _____	Year _____
Journal _____	Record Number _____

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### Study Description

Methodology \_\_\_\_\_  
\_\_\_\_\_

Method \_\_\_\_\_  
\_\_\_\_\_

Intervention \_\_\_\_\_  
\_\_\_\_\_

Setting \_\_\_\_\_  
\_\_\_\_\_

Geographical \_\_\_\_\_  
\_\_\_\_\_

Cultural \_\_\_\_\_  
\_\_\_\_\_

Participants \_\_\_\_\_  
\_\_\_\_\_

Data analysis \_\_\_\_\_  
\_\_\_\_\_

### Authors Conclusions

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

### Comments

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



## **Appendix 2**

Text and Opinion Research Appraisal and Extraction Tool

# JBI NOTARI Critical Appraisal Checklist for text and opinion

Reviewer:

Date:

Author:

Record Number:

	Yes	No	Unclear
1. Is the source of the opinion clearly identified?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Does the source of the opinion have standing in the field of expertise?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Are the interests of patients / clients the central focus of the opinion?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is the opinion's basis in logic / experience clearly argued?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is the argument developed analytical?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there reference to the extant literature / evidence and any incongruence with it logically defended?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the opinion supported by peers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal:

Include

Exclude

Seek further info.

Comments (Including reasons for exclusion)

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**Study Description**

Type of Text	
Those Represented	
Stated Allegiance/Position	
Setting	
Geographical	
Cultural	
Logic of Argument	

**Author's Conclusions**

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**Reviewer's Comments**

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