2019-06-24

Models of primary care for community dwelling adults with long term conditions- A scoping review protocol.

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Models of primary care for community-dwelling adults with long-term conditions: a scoping review protocol

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ABSTRACT

Objective

This scoping review aims to map primary care models designed to support adults with long-term conditions. The review will analyze the following in relation to the models identified: characteristics, impact reported, implications for practice and outcome measures.

Introduction

Robust solutions to support individuals with long-term conditions need to be established in order to increase health service capacity and provide cost-effective solutions while, most importantly, ensuring people receive the best services to live meaningful and productive lives.

Inclusion criteria

The concept to be mapped is primary care models used to support adults living with long-term conditions. This may also encompass services not solely designed for people with long-term conditions; however, they will be services that may be the first port of call for this group. Operational *a priori* criteria have been designed to assist with distinguishing appropriate literature.

Methods

Due to the nature of the scoping review, literature from a range of published and unpublished sources will be utilized from 1995 to 2019. Databases to be searched will include: MEDLINE, Embase, PsycINFO, HMIC, CINAHL, Cochrane Database of Systematic Reviews and Web of Science. Appropriate gray literature will be searched, alongside hand searching selected primary care journals, conference abstracts and professional and government bodies. Articles will be restricted to English. Titles and abstracts will be screened by two independent reviewers for assessment against the inclusion criteria. Charting of the data will include details about the population, concept, context, study methods and key findings relevant to the review objective.

Keywords Chronic disease; community health services; long-term conditions; primary health care

JBI Database System Rev Implement Rep 2019; 17(0):1–13.

Introduction

Worldwide, health is shaped by both the environment in which people live and the resources available.[1] For most, this has led to increased life expectancy over the last 10 years with little fluctuation. Adults in the United Kingdom (UK) who are currently 60 years of age are predicted to live for a further 20 years.[2] In addition to living longer, a significant percentage are also living with one or more long-term conditions.[3] Long-term conditions are defined as conditions that require ongoing management over a period of years or decades.[4] Also known as non-communicable diseases, conditions such as heart disease, stroke, cancer, chronic respiratory diseases and diabetes are the primary cause of mortality globally.[5] These conditions can fracture the economic development of countries and the number of individuals, groups and communities affected by the impact of long-term illness is increasing.[6] Advances in health care have led to conditions that were once thought to be life limiting becoming conditions that people live with for many years.[7] Although appearing to be an achievement

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There is no conflict of interest in this project.

DOI: 10.11124/JBISRIR-2017-004003

for humanity, this also presents a global challenge to healthcare systems, due to the increased prevalence of those living with complex and enduring conditions. People who live with these conditions often require high levels of health and social care due to the complexity that living with a long-term condition entails.[8]

It is well established that living with a long-term condition impacts on quality of life, health outcomes and the ability to carry out daily activities.[9] For example, research has highlighted experiencing fear, blame, struggling, fatalism and hidden disability as key themes for those affected by chronic obstructive pulmonary disease.[10] The risk of developing a mental health condition also increases with the number of physical illnesses a person experiences.[11] This demonstrates the need for services to be adequately equipped to support those with both physical and mental health conditions effectively. Generally, services are specialized to a single pathological condition and, therefore, the care and support provided to those with multi-factorial illnesses can be fragmented and disjointed, leading to errors and omissions.[12] Clinical evidence and guidelines are largely created for individual diseases and specialized to a single illness, demonstrating the lack of guidance for those supporting people with multiple long-term conditions. Likewise, most randomized trials exclude multi-morbidity and older people within their sampling strategies, thus limiting the evidence that could support the development of understanding within this areas of practice for many health professionals.[13]

Global impact of long-term conditions

In Australia, 35% of the population have a long-term condition, and an increasing number have multiple conditions, making care increasingly complex with input required from a range of health professionals.[14] Similarly, the health and social care systems within the UK are facing unprecedented pressures due to the high volumes of people who require support, compounded by the effects of long-term government austerity policies.[15] Many people with long-term conditions are frequent users of acute hospitals, primary care and social care services, thus increasing pressures on services that are already overwhelmed.[8] Within the United States, long-term conditions represent the leading cause of morbidity and mortality, with over 70% of all deaths being attributable to heart disease, cancer, stroke, chronic obstructive pulmonary disease and diabetes.[16] In New Zealand, long-term conditions account for 88% of healthy life lost due to factors including premature death, illness or impairment.[17]

Health systems globally are in need of strategic refocus due to the challenges stemming from how societies have developed. However, it is imperative not to ignore societies where the impact of long-term conditions is significant, despite some differences in their etiology, compared with the challenges posed by long-term conditions to Westernized society. An example might be Sub-Saharan Africa, which is stereotypically recognized as a region with high levels of malnutrition; however, due to growth in urbanization and Westernization, there is a rise in obesity.[18] Universally, the physical impact on the earth of global warming has had and will continue to have a significant impact on human health, especially for those with long-term conditions. This may occur through injury during natural disasters, malnutrition during famine or inability to cope physiologically with the effects of prolonged heat waves. The impact is amplified for those living in low-income countries.[19] Furthermore, direct exposure to natural disasters has an impact on mental health, and conflict has been reported as a major threat to public health. The lasting effects of conflict on health have yet to be studied in the context of developing countries.[20] In spite of developing countries representing the majority of the world's population and 90% of the worldwide burden of disease,[21] research and development is substantially inadequate.[22,23] Under-representation caused by lack of capacity and commercial viability hinders health improvement in regions where research-led resolutions could have the greatest impact to life.[24,25] The health and social care systems of developing countries require evidence to guide resolutions regarding the most efficient and cost effective interventions for those with long-term conditions.

Primary care

The World Health Organization's analysis of health systems[5] demonstrates gaps within health care, most noticeably within primary care, presenting barriers to the provision of equitable health care for people living with long term conditions. Primary care is the first point of contact with health systems and is also the point of access for people to receive care for most

of their everyday health and well-being needs.[26] Primary care services include health promotion, disease prevention, health maintenance, counselling, patient education, diagnosis and treatment of acute and chronic illnesses.[27] Over the past two decades, several countries worldwide have initiated reforms to improve their delivery of primary health care with the intention of supporting those with long-term conditions to manage their condition better and reduce the risk of unplanned hospital admissions.[7,17,28,29]

Long-term solutions to support those with long-term conditions need to be created to increase health service capacity and provide cost-effective solutions while, most importantly, ensuring people receive the best services to live meaningful and productive lives. Policy in the UK is focusing heavily on delivering care nearer to the patient with the aim of increasing self-care and improving management for those with more complex long-term conditions, preventing hospital admissions and improving quality of life for individuals.[7] However, it is imperative that new models of care consider that people with a long-term condition should be supported to live and not just exist.[15] Long-term conditions have a wide-reaching social impact, affecting every part of an individual's daily life, including family relationships, employment and everyday socialization. Models of health care often focus on symptom reduction, disease management and basic prevention, not on the pursuit of long-term health. Recent research has highlighted a rise of 41.3% in emergency readmissions for conditions that are classified as ''potentially preventable'' between 2010 and 2017. Such admissions are also contrary to many patients' preference to be cared for at home.[29]

Essentially, people with complex health needs are not properly supported.[30] More than a quarter of people who have long-term conditions say that they are not well cared for by their healthcare provider, and 40% expect their care to get worse in the future.[28] People report frustration due to using different services that do not communicate and share information, leaving them feeling that their conditions are treated in isolation.[28] Well-designed primary care has the potential to improve health and cost effectiveness; however, large gaps exist in the evidence base concerning care for patients with multi-morbidity.[31] A recent Cochrane review[32] found only 18 trials that evaluated models of care with two main strategies: the reorganization of care delivery through enhanced multidisciplinary working, and patient-oriented education or self-management. The review found limited evidence for the effectiveness of the models with a lack of agreement regarding the description of models of care for multimorbidity. However, the process of evidence building is hindered by incomplete descriptors of models within publications.[33] Without accurate descriptions of these developing models, researchers cannot replicate studies or identify components for success.

Producing a scoping review of the literature surrounding models of primary care for long-term conditions would allow researchers and healthcare professionals to further understand current and emerging models of practice in order to more effectively recognize what models of practice work for different individuals, communities and populations.[33] This information is likely to be critical, given the broad range of approaches and patient populations included under the umbrella of long-term conditions. Due to the heterogeneity of the research base and differing approaches for implementing primary care models to support those with long-term and complex conditions, a scoping review will provide a rigorous and transparent method of mapping this concept as a preliminary step to further research and evaluation. The objective of this review is to map the available evidence to provide an overview of the existing primary care models of practice that aim to improve clinical and mental health outcomes and patient-reported outcomes for community-dwelling adults with long-term conditions.

A preliminary search of PROSPERO, MEDLINE (Ovid), the Cochrane Database of Systematic Reviews and the *JBI Database of Systematic Reviews and Implementation Reports* was conducted and no current or proposed systematic reviews on the exact topic of this planned review were identified. However, a rapid review by Singh and Ham[34] conducted in 2005 was identified and, although the rapid review provides insight into frameworks for people with long-term conditions internationally, it was only able to capture readily available literature over a period of three weeks, thus not permitting systematic mapping of all of the evidence within this field. Due to the significant demographic and social changes and development of health care designed for those with long-term conditions over the

intervening 15 years, it is essential that this topic is explored comprehensively, examining the effectiveness of contemporary primary care models focused on those living with long-term conditions, which this scoping review aims to achieve.

Review questions

What primary care models exist globally for adults with long term conditions?

What are the characteristics, outcome measures, reported impact and the implications for practice of the models of primary care identified?

Inclusion criteria

Participants

The review will consider studies that include adults who live with long-term conditions. This will exclude evidence of those who have long-term conditions but are younger than 18 years. For the uniformity of this review, the term used throughout will be long-term conditions, although it has been noted that a multitude of definitions exist in the literature that encompass ''long-term conditions''. Interchangeable terms for long-term conditions include: chronic conditions, chronic illness and chronic disease, as well as a term identified by the World Health Organization[35]: noncommunicable disease. The Department of Health in England defined a long-term condition as: ''One that cannot currently be cured, but can be controlled with the use of medication and/or other therapies.''[4(p.3)] Long-term conditions are also defined as requiring ongoing management over a period of years or decades and cover a range of health conditions that go beyond the conventional definition of chronic illness, such as heart disease, diabetes and asthma.[36] Multi-morbidity is also a prevalent term within relevant literature, referring to the presence of two or more chronic medical conditions in an individual.[37] Long-term conditions also comprise some communicable diseases, such as the human immunodeficiency virus and the acquired immunodeficiency syndrome (HIV/AIDS) that, due to advances in medicine, have become controllable health problems although they are communicable. The term ''long-term condition'' also extends to mental health conditions such as depression, schizophrenia, disabilities and impairment, including blindness and musculoskeletal disorders.[36] While there remains some ambiguity regarding a sole definition, the common denominator is that they all require a complex approach to their care that is often over the course of the lifespan from the onset of the condition.

Concept

The concept being mapped within this scoping review will be primary care models used to manage individuals with long-term conditions. The concepts of interest are the characteristics (values, principles, components and suggested practical applications), outcome measures, impact and implications for practice of the models of primary care identified. Within the literature, a number of different terms such as service delivery models of care and service frameworks have been used interchangeably to articulate the way in which services are or should be conducted. For the purpose of this review, all characteristics of a model of service delivery, either in part or as a whole, will be considered; this may include services, models, interventions, frameworks that involve primary care of patients. This may also encompass services not solely designed for long-term conditions; however, they will be services that may be the first port of call for those with long-term conditions. Therefore, the focus of the search will include literature that involves specifically primary care models, interventions and similar concepts that are defined by similar boundaries of service design and implementation but lack use of the term, ''primary care intervention''. It is recognized that many service developments are not subjected to rigorous evaluation, but still may provide useful examples of the way in which primary care services have been developed. Therefore, the review will also encompass current developments in clinical practice in relation to long term primary and community care.

An operational *a priori* criteria has been developed in order to distinguish primary care models from similar community models:

i. The care provided is within a primary care setting (e.g. general practice (GP) surgery, community center or through adult social care).
ii. Care is longitudinally coordinated by health and social care professionals.
iii. Care may be delivered in the patients' home, through information technology or within a voluntary third sector setting.
iv. Care can include telecare and case managers; however, there must be clear and evident

oversight and integration of patient care by the primary care physician or team.

All four criteria need to be met for a paper to be included. Models that do not utilize the term ''primary care'', but met the four operational criteria, will be included in the review.

Context

This review will focus on the context of primary care. Therefore, this review will consider studies that examine primary care models within a global context, due to the scope of the literature available. The scoping review will take into consideration any evidence internationally that investigates primary care models for adults with long-term conditions. This is to capture all the evidence available to create a scoping review that has the potential to have international value for primary care. A preliminary review of the literature demonstrates that the development of primary care models will be of worldwide interest. Searching will be restricted to English as translation resources are not available.

Types of sources

This scoping review will consider both experimental and quasi-experimental study designs including randomized controlled trials, non-randomized controlled trials, before and after studies and interrupted time-series studies. In addition, analytical observational studies including prospective and retrospective cohort studies, case-control studies and analytical cross-sectional studies will be considered for inclusion. This review will also consider descriptive observational study designs including case series, individual case reports and descriptive cross-sectional studies for inclusion. Qualitative studies will also be considered that adopt methodologies including, but not limited to, phenomenology, grounded theory, ethnography, qualitative description, action research and feminist research. In addition, systematic reviews that meet the inclusion criteria will also be considered. Additionally, text and opinion papers, as well as other published material such as case studies and relevant academic presentations, such as theses and dissertations, will also be included. Official websites of organizations will be used (see Appendix I) together with international strategies on primary health and social care, including, but not limited to white papers, reports, position papers, policy papers, governmental guidance that are available in print or online from relevant websites listed in Appendix I.

Literature published from 1995 onward will be considered for the review. In 1995 Wagner published The Chronic Care Model,[38] a framework for describing the essential elements needed to provide the best quality care for those with long-term conditions. This model is frequently drawn upon in more contemporary evidence, so this date becomes a clear starting timeline for the development of the search for models for long-term health conditions.

Methods

Search strategy

The search strategy will aim to locate both published and unpublished studies. The proposed systematic review will be conducted in accordance with the Joanna Briggs Institute methodology for scoping reviews using a three-step process.[39] An initial limited search of MEDLINE will be undertaken to identify articles on the topic. An example search strategy has been appended (see Appendix II). The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles were used to develop a full search strategy. The search strategy, including all identified keywords and index terms will be adapted for each included information source. It is acknowledged that an iterative approach will be used and further search terms may be revealed and utilized within the search strategy.

The reference list of the identified articles will be reviewed to include other relevant studies and additional items. Duplicate sources and publications that do not directly relate to the research question will be eliminated. The title and abstract of each article will be reviewed thoroughly to select the most relevant sources.

Information sources

Searches will be undertaken using the following electronic databases: MEDLINE, Embase, PsycINFO, HMIC, CINAHL, Cochrane Database of Systematic Reviews and Web of Science.

Other searches will be undertaken through ProQuest Dissertations and Theses Global, and Google Scholar. A pragmatic decision to review only the Google Scholar articles from the first 50 pages was taken following consultation with an information specialist. In addition, EThOS (British Library

Theses online service) is accessible via ProQuest Dissertations and Theses Global. The appended search strategy will be employed to capture any grey literature using OpenGrey.

Supplementary searching will include hand searching of the data yielded and hand searching within relevant journals including but not limited to *Quality in Primary Care, Journal of Primary Care and Community Health, Journal of Family Medicine and Primary Care, Journal of Integrated Care, International Journal of Integrated Care, Journal of Primary Health Care, British Journal of General Practice* and *Canadian Family Physician*. It is predicted that these journals will form part of this search, and others will be searched according to their value to the research questions. Hand searching within relevant conference abstracts such as the primary care and public health conferences, white papers, reports, professional bodies, charities and news articles will also be utilized. Nexis library will be searched to capture any new articles of relevance. Further to this, the reviewers intend to contact authors of primary studies or reviews for further information, if necessary.

Study selection

Following the search, all identified citations will be collated and uploaded into the bibliographic citation management system, Endnote X8.2 (Clarivate Analytics, PA, USA) reference manager. Titles and abstracts will then be screened by two independent reviewers for assessment against the inclusion criteria for the review. Potentially relevant studies will be retrieved in full and their citation details imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI; JBI, Adelaide, Australia). The full text of the selected citations will be assessed in detail against the inclusion criteria by two independent reviewers. Reasons for exclusion of full-text studies that do not meet the inclusion criteria will be recorded and reported in the systematic review. Any disagreements that arise between the reviewers at each stage of the study selection process will be resolved through discussion or with a third reviewer. The results of the search will be reported in full in the final systematic review report and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram.[40]

Data extraction

Data will be extracted from papers included in the scoping review by two independent reviewers using a data extraction tool developed by the reviewers. The data extraction process may also be referred to as charting the results when utilized within a scoping review. Charting of the data will include specific details about the population, concept, context, study methods and key findings relevant to the review objective. A data extraction instrument has been created explicitly for this scoping review (see Appendix III). The data extraction instrument will be modified and revised as necessary during the process of extracting data from each included study. Modifications will be detailed in the full scoping review report. Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer. Authors of papers will be contacted to request missing or additional data, where required.

Data presentation

The extracted data will be presented in tabular form that aligns with the objective of this scoping review. A narrative summary will accompany the tabulated and/or charted results and will describe how the results relate to the reviews objective and questions.

Acknowledgments

The authors would like to acknowledge support from the PenCLAHRC Evidence Synthesis Team.

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Appendix I: List of websites to be included in search.

Australia

www.health.gov.au

www.aihw.gov.au

New Zealand

www.health.govt.nz

South Africa

www.health.gov.za

India

www.mohfw.gov.in

www.dhr.gov.in

Canada

www.canada.ca/en/health-canada

www.cihi.ca

www.cfpc.ca

www.cfhi-fcass.ca

United Kingdom

www.gov.uk/government/organisations/department-of-health-and-social-care

www.england.nhs.uk

www.scot.nhs.uk

https://health.gov.ie/

www.wales.nhs.uk

www.kingsfund.org.uk

www.nice.org.uk

www.napc.co.uk

www.hsj.co.uk

www.nhsconfed.org

https://digital.nhs.uk/

www.ageuk.org.uk

www.phc.ox.ac.uk

www.nuffieldtrust.org.uk

International

www.who.int/primary-health

www.improvingchroniccare.org

http://maccollcenter.org

www.ihi.org

www.rand.org

Appendix II: Search strategy for MEDLINE (via Ovid)

CONTEXT	
	Primary Health Care/
OR	(Primary adj2 care).tw.
OR	Family Practice/
OR	(general adj2 practi$).tw.
OR	family medicine.tw.
OR	(general adj1 practi$).tw.
AND	
CONCEPT	
	(care adj1 model*).tw.
OR	(model* adj1 service delivery).tw.
OR	(model* adj1 (healthcare or health care)).tw.
AND	
PARTICIPANTS	
	Comorbidity/
OR	Chronic Disease/
OR	Multimorbid*.tw.
OR	Multi-morbidity.tw.
OR	(Chronic* adj2 Disease*).tw.
OR	(Chronic* adj1 Ill*).tw.
OR	((persistent or long* term or ongoing or degenerative) adj3 (disease* or ill* or condition* or insufficienc* or disorder*)).tw.
OR	Diabetes Mellitus/
OR	(diabetes or diabetic).tw.
OR	(heart disease* or heart failure or myocardial ischemia or coronary disease* or coronary artery disease* or myocardial infarction or hypertension or high blood pressure).tw.
OR	Sickle cell.tw.
OR	Lung Diseases, Obstructive/
OR	(obstructive lung disease* or obstructive pulmonary disease* or copd or asthma or bronchitis).tw.

OR	emphysema.tw.
OR	emphysema/
OR	pulmonary emphysema/
OR	(cystic fibrosis or respiratory distress).tw.
OR	nervous system diseases/
OR	((brain adj disease*) or damage* or injur*).tw.
OR	(cerebrovascular or brain ischemia or cerebral infarction or carotid artery disease* or stroke or epilep* or seizure*).tw.
OR	(neurodegenerative or Huntingdon* or Parkinson* or amyotrophic lateral sclerosis or multiple sclerosis or motor neuron disease).tw.
OR	(paralys* or quadriplegi* or tetraplegi* or paraplegi* or locked-in syndrome).tw.
OR	((communication or learning or consciousness or perpetual or speech or voice or vision or hearing or psychomotor) adj disorder*).tw.
OR	(hearing loss or hearing aid* or deaf* or blind* or stutter*).tw.
OR	down* syndrome.tw.
OR	Cerebral Palsy/
OR	cerebral palsy.tw.
OR	gastrointestinal diseases/
OR	(gatroenter* or intestinal or bowel or colonic).tw.
OR	((renal or kidney) adj1 (failure* or insufficienc*)).tw.
OR	nutrition disorders/
OR	(underweight or malnutrition or malnourished or overweight or obes*).tw.
OR	arthritis/
OR	rheumatic diseases/
OR	(arthritis or osteoarthritis or rheumati* or fibromyalgia).tw.
OR	((back or neck) adj pain).tw.
OR	(chronic adj pain).tw.
OR	(musculoskeletal or MSK).tw.
OR	Osteoporosis/
OR	osteoporosis.tw.
OR	thyroid diseases/
OR	Thyroid Gland/
OR	thyroid.tw.

OR	hypersensitivity/
OR	(hypersensitivit* or allerg* or intolerance or anaphyla*).tw.
OR	neoplasms/
OR	(cancer* or oncolog* or neoplasm* or carcinom* or tumo?r* or malignan* or leuk?emia).tw.
OR	hiv infections/
OR	(hiv infect* or hiv disease*).tw.
OR	exp *mental disorders/
OR	behavioral symptoms/
OR	((mental* or psychiatr* or psychological*) adj1 (ill* or disorder* or disease* or distress* or disab* or problem* or health* or patient* or treatment)).tw.
OR	((personality or mood or dysthymic or cognit* or anxiety or stress or eating or adjustment or reactive or somatoform or conversion or behavior or perception or psycho* or impulse control or development* or attention deficit or hyperactivity or conduct or motor skills or movement or tic or substance related) adj disorder*).tw.
OR	(psychos#s or psychotic* or paranoi* or schizo* or neuros#s or neurotic* or delusion* or depression or depressive or bipolar or mania or manic or obsessi* or compulsi* or panic or phobic or phobia or anorexia or bulimia or neurastheni* or dissociative or autis* or Asperger* or Tourette or dyslex* or affective or borderline or narcissis* or suicid* or self injur* or self harm or adhd).tw.
OR	((substance or drug or alcohol) adj abuse).tw.
OR	((addict* or alcoholism or problem*) adj1 drinking).tw.
OR	Dementia/
OR	(Alzheimer adj Disease).tw.
OR	((sleep adj disease?) or disorder?).tw.
OR	hyperlipidem*.tw.
OR	Hypercholesterolemia*.tw.
OR	hypertriglyceridemia*.tw.
OR	((liver adj disease?) or disorder?).tw.
OR	Muscular Dystrophies/
AND	**limit 77 to yr="1995 -Current"**

Appendix III: Data extraction instrument

Author						
Year of publication						
Country of origin						
Model/ intervention						
Aim						
Study design						
Study population, sample size						
Characteristics of model/ intervention						
Outcomes assessed						
Results/findings/recommendations						
Implication for practice, further study						