

Patient Experiences of Depression and Anxiety with Chronic Disease: A Systematic Review and Qualitative Meta-Synthesis

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Health Quality Ontario (HQO) is an arms-length agency of the Ontario government. It is a partner and leader in transforming Ontario's health care system so that it can deliver a better experience of care, better outcomes for Ontarians and better value for money.

Health Quality Ontario strives to promote health care that is supported by the best available scientific evidence. HQO works with clinical experts, scientific collaborators and field evaluation partners to develop and publish research that evaluates the effectiveness and cost-effectiveness of health technologies and services in Ontario.

Based on the research conducted by HQO and its partners, the Ontario Health Technology Advisory Committee (OHTAC) — a standing advisory sub-committee of the HQO Board — makes recommendations about the uptake, diffusion, distribution or removal of health interventions to Ontario's Ministry of Health and Long-Term Care, clinicians, health system leaders and policy-makers.

This research is published as part of Ontario Health Technology Assessment Series, which is indexed in CINAHL, EMBASE, MEDLINE, and the Centre for Reviews and Dissemination. Corresponding OHTAC recommendations and other associated reports are also published on the HQO website. Visit <http://www.hqontario.ca> for more information.

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To conduct its comprehensive analyses, HQO and/or its research partners reviews the available scientific literature, making every effort to consider all relevant national and international research; collaborates with partners across relevant government branches; consults with clinical and other external experts and developers of new health technologies; and solicits any necessary supplemental information.

In addition, HQO collects and analyzes information about how a health intervention fits within current practice and existing treatment alternatives. Details about the diffusion of the intervention into current health care practices in Ontario add an important dimension to the review. Information concerning the health benefits; economic and human resources; and ethical, regulatory, social, and legal issues relating to the intervention assist in making timely and relevant decisions to optimize patient outcomes.

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Abstract

Background

Depression and anxiety are highly prevalent in patients with chronic disease, but remain undertreated despite significant negative consequences on patient health. A number of clinical groups have developed recommendations for depression screening practices in the chronic disease population.

Objectives

The objective of this analysis was to review empirical qualitative research on the experiences of patients with chronic disease (e.g., COPD, diabetes, heart disease, stroke) and comorbid depression or anxiety, and to highlight the implications of the screening and management of anxiety and/or depression on chronic disease outcomes.

Review Methods

We performed literature searches for studies published from January 2002 to May 2012. We applied a qualitative mega-filter to nine condition-specific search filters. Titles and abstracts were reviewed by two reviewers and, for the studies that met the eligibility criteria, full-text articles were obtained. Qualitative meta-synthesis was used to integrate findings across relevant published primary research studies. Qualitative meta-synthesis produced a synthesis of evidence that both retained the original meaning of the authors and offered a new, integrative interpretation of the phenomenon through a process of comparing and contrasting findings across studies.

Results

The findings of 20 primary qualitative studies were synthesized. Patients tended to experience their chronic conditions and anxiety or depression as either independent or inter-related (i.e., the chronic disease lead to depression/anxiety, the depression/anxiety lead to the chronic disease, or the two conditions exacerbated each other). Potential barriers to screening for depression or anxiety were also identified.

Limitations

A wider array of issues might have been captured if the analysis had focused on broader psychological responses to the chronic disease experience. However, given the objective to highlight implications for screening for anxiety or depression, the more narrow focus seemed most relevant.

Conclusions

Chronic disease and anxiety or depression can be independent or inter-related. Patients may be reluctant to acknowledge depression or anxiety as a separate condition, or may not recognize that the conditions are separate because of overlapping physical symptoms. More qualitative research is needed to specifically address screening for depression or anxiety.

Plain Language Summary

Depression is a common complication of chronic disease. It may worsen the disease, and it may also affect the self-management of the disease. Screening for depression earlier, and then treating it, may reduce distress and improve symptoms of the chronic disease, leading to better quality of life.

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List of Abbreviations

CI	Confidence interval(s)
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COPD	Chronic obstructive pulmonary disease
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, version IV
GAD	Generalized anxiety disorder
HQO	Health Quality Ontario
MDD	Major depressive disorder
OHTAC	Ontario Health Technology Advisory Committee
SSCI	Social Sciences Citation Index
WHO	World Health Organization

Background

In July 2011, the Evidence Development and Standards (EDS) branch of Health Quality Ontario (HQO) began developing an evidentiary framework for avoidable hospitalizations. The focus was on adults with at least 1 of the following high-burden chronic conditions: chronic obstructive pulmonary disease (COPD), coronary artery disease (CAD), atrial fibrillation, heart failure, stroke, diabetes, and chronic wounds. This project emerged from a request by the Ministry of Health and Long-Term Care for an evidentiary platform on strategies to reduce avoidable hospitalizations.

After an initial review of research on chronic disease management and hospitalization rates, consultation with experts, and presentation to the Ontario Health Technology Advisory Committee (OHTAC), the review was refocused on optimizing chronic disease management in the outpatient (community) setting to reflect the reality that much of chronic disease management occurs in the community. Inadequate or ineffective care in the outpatient setting is an important factor in adverse outcomes (including hospitalizations) for these populations. While this did not substantially alter the scope or topics for the review, it did focus the reviews on outpatient care. HQO identified the following topics for analysis: discharge planning, in-home care, continuity of care, advanced access scheduling, screening for depression/anxiety, self-management support interventions, specialized nursing practice, and electronic tools for health information exchange. Evidence-based analyses were prepared for each of these topics. In addition, this synthesis incorporates previous EDS work, including *Aging in the Community* (2008) and a review of recent (within the previous 5 years) EDS health technology assessments, to identify technologies that can improve chronic disease management.

HQO partnered with the Programs for Assessment of Technology in Health (PATH) Research Institute and the Toronto Health Economics and Technology Assessment (THETA) Collaborative to evaluate the cost-effectiveness of the selected interventions in Ontario populations with at least 1 of the identified chronic conditions. The economic models used administrative data to identify disease cohorts, incorporate the effect of each intervention, and estimate costs and savings where costing data were available and estimates of effect were significant. For more information on the economic analysis, please contact either Murray Krahn at murray.krahn@theta.utoronto.ca or Ron Goeree at goereer@mcmaster.ca.

HQO also partnered with the Centre for Health Economics and Policy Analysis (CHEPA) to conduct a series of reviews of the qualitative literature on “patient centredness” and “vulnerability” as these concepts relate to the included chronic conditions and interventions under review. For more information on the qualitative reviews, please contact Mita Giacomini at giacomini@mcmaster.ca.

The Optimizing Chronic Disease Management in the Outpatient (Community) Setting mega-analysis series is made up of the following reports, which can be publicly accessed at <http://www.hqontario.ca/evidence/publications-and-ohtac-recommendations/ohtas-reports-and-ohtac-recommendations>.

- Optimizing Chronic Disease Management in the Outpatient (Community) Setting: An Evidentiary Framework
- Discharge Planning in Chronic Conditions: An Evidence-Based Analysis
- In-Home Care for Optimizing Chronic Disease Management in the Community: An Evidence-Based Analysis
- Continuity of Care: An Evidence-Based Analysis
- Advanced (Open) Access Scheduling for Patients With Chronic Diseases: An Evidence-Based Analysis
- Screening and Management of Depression for Adults With Chronic Diseases: An Evidence-Based Analysis
- Self-Management Support Interventions for Persons With Chronic Diseases: An Evidence-Based Analysis
- Specialized Nursing Practice for Chronic Disease Management in the Primary Care Setting: An Evidence-Based Analysis
- Electronic Tools for Health Information Exchange: An Evidence-Based Analysis
- Health Technologies for the Improvement of Chronic Disease Management: A Review of the Medical Advisory Secretariat Evidence-Based Analyses Between 2006 and 2011
- Optimizing Chronic Disease Management Mega-Analysis: Economic Evaluation
- How Diet Modification Challenges Are Magnified in Vulnerable or Marginalized People With Diabetes and Heart Disease: A Systematic Review and Qualitative Meta-Synthesis
- Chronic Disease Patients' Experiences With Accessing Health Care in Rural and Remote Areas: A Systematic Review and Qualitative Meta-Synthesis
- Patient Experiences of Depression and Anxiety With Chronic Disease: A Systematic Review and Qualitative Meta-Synthesis
- Experiences of Patient-Centredness With Specialized Community-Based Care: A Systematic Review and Qualitative Meta-Synthesis

Objective of Analysis

To review empirical qualitative research on the experiences of patients with chronic disease (i.e., chronic obstructive pulmonary disease (COPD), diabetes, heart disease, stroke) and comorbid depression or anxiety, and to highlight the implications of screening on the management of anxiety and/or depression.

Clinical Need and Target Population

Depression

Depression is recognized by the World Health Organization (WHO) as the leading cause of disability in the world, and the fourth leading contributor to the global burden of disease. (1) Projections by WHO suggest that, by 2020, depression will be the second leading public health concern, behind only cardiovascular disease. (2) Despite this, depression continues to be under-recognized and undertreated. (2)

Depressive illness can have a variety of presentations that can vary in both severity and chronicity. (3) According to criteria of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV), (4) major depressive disorder (MDD)—which consists of an episode of at least 2 weeks in which an individual has 5 of 9 specific depressive symptoms—is the most severe form of depression. One of these symptoms must be depressed mood or anhedonia (loss of interest or pleasure). (3) Also, these symptoms must cause clinically significant distress or impairment in social, occupational, or other important areas of functioning, a requirement that emphasizes the marked disability resulting from depressive illness.

Anxiety

Anxiety disorders are usually characterized by excessive fear and subsequent avoidance, typically in response to a specified object or situation and in the absence of true danger. (5, 6) Anxiety, like all emotions, has cognitive, neurobiological, and behavioural components. Although it is often comorbid with depressive mood, anxiety is a distinct emotion. (6) Anxiety becomes alarming and burdensome when it increases or persists to such a degree that the individual can no longer function effectively in everyday life. At this stage, anxiety can have negative consequences for the individual. Anxiety exists on a continuum from normal to pathological, and a number of anxiety disorders exist, such as panic disorder, phobic anxiety, generalized anxiety disorder (GAD), anxiety reactions, and chronic anxiety. (6)

Prevalence

Patients in the primary care setting often suffer from depression and anxiety. The 1994/1995 National Population Health Survey, a Canadian longitudinal study that included household residents in all provinces, reported a 1-year prevalence for major depressive disorder (MDD) of about 6% among Canadians aged 18 and older. (7) Point prevalence estimates of major depression range from 4.8% to 8.6% in primary care settings in the United States. (3) Anxiety disorders have a high prevalence as well, with a 12-month rate of 17.2% and lifetime rates of about 25% in the United States. (8)

Patten and colleagues (9) found in a large, prospective Canadian community-based study that subjects with chronic medical disorders had a higher risk of developing major depression than those without such disorders. A total of 4% (CI: 3.3-4.7) of those with one or more medical conditions versus 2.8% (CI: 2.2-3.4) of those without medical conditions developed major depression over a 2-year period. (9)

The 2005 Canadian Community Health Survey, cycle 3.1, measured the prevalence rates of comorbid mood disorders among individuals with various chronic physical conditions in Ontario. (10) The highest

prevalence (15.5%) was seen in those suffering from the effects of stroke, followed by cardiovascular disease (9.8%) and diabetes mellitus (9.3%). (10)

The estimated prevalence of anxiety and/or depression varies by the type and severity of chronic illness, and the setting and methodology for screening and diagnosis. However, rates are consistently higher across most chronic diseases compared to the general population, especially for people with stroke, cardiovascular disease, and diabetes.

Qualitative Evidence

Qualitative empirical studies can offer important information about how patients experience their conditions. This synthesis of qualitative literature offers insights into patients' perspectives on chronic disease and comorbid anxiety or depression, their needs, and how interventions such as screening might affect their experiences. The experiences of clinicians are also examined, where relevant.

Technology/Technique

Screening Instruments

Screening is defined as the systematic testing of asymptomatic individuals to detect a potential disease or condition. (11) The purpose of screening is to prevent or delay the development of advanced disease in the subset with preclinical disease through early detection and treatment. (11)

Screening for depression and/or anxiety identifies patients suffering from these conditions, allowing them to access care earlier in the course of their illness. Despite the potential benefits of screening, it is infrequently conducted and primary care physicians fail to identify an estimated 30% to 50% of patients suffering from depression. (3)

Several depression screening tools, called instruments, are currently available for use in the primary care setting. The tools differ primarily by the time frame to which they are applied, the time to administer the tools, and the discernment of levels of depression. (12) These tools have been designed to be administered in a variety of ways by a variety of health care providers. These instruments are composed of standardized questions that assess the number and severity of a patient's depression symptoms. The finding of a positive screen requires further diagnostic questioning by the clinician to establish an appropriate diagnosis and initiate a treatment plan and follow-up. (13)

Depression Screening for Adults With Chronic Diseases

Given the higher prevalence of depression among adults with chronic diseases, a number of clinical groups have developed recommendations on depression screening practices. There are guidelines on depression screening for the general population, as well as disease specific guidelines for those with diabetes, COPD, stroke, and coronary artery disease.

Evidence-Based Analysis

Research Question

What are the experiences of patients living with COPD, diabetes, heart disease, and stroke with comorbid depression or anxiety?

Research Methods

Literature Search

Search Strategy

We performed literature searches for studies published from January 1, 2002, to May 2012, on May 3, 2012, using OVID MEDLINE and EBSCO Cumulative Index to Nursing and Allied Health Literature (CINAHL), and on May 4, 2012, using ISI Web of Science Social Sciences Citation Index (SSCI). We developed a qualitative mega-filter by combining existing published qualitative filters. (14-16) The filters were compared and redundant search terms were deleted. We added exclusionary terms to the search filter that were likely to identify quantitative research and would reduce the number of false positives. We then applied the qualitative mega-filter to 9 condition-specific search filters (atrial fibrillation, diabetes, chronic conditions, chronic obstructive pulmonary disease, chronic wounds, coronary artery disease, heart failure, multiple morbidities, and stroke). Appendix 1 provides details of the search strategy. Titles and abstracts were reviewed by two reviewers and, for those studies meeting the eligibility criteria, full-text articles were obtained.

Inclusion Criteria

English language full-reports

- published between January 2002 and May 2012
- including adults (age ≥ 18) from Canada, Europe, Australia, New Zealand, and the United States
- primary qualitative empirical research (using any descriptive or interpretive qualitative methodology, including the qualitative component of mixed-methods studies) and secondary syntheses of primary qualitative empirical research
- studies addressing any aspect of the experience of comorbid anxiety or depression and chronic disease

Exclusion Criteria

- studies addressing topics other than the experience of comorbid anxiety or depression and chronic disease
- studies labelled “qualitative” but not using a qualitative descriptive or interpretive methodology (e.g., case studies, experiments, or observational analyses using qualitative categorical variables)
- quantitative research (i.e., using statistical hypothesis testing, using primarily quantitative data or analyses, or expressing results in quantitative or statistical terms)
- studies that did not pose an empirical research objective or question, or involve primary or secondary analysis of empirical data

Outcomes of Interest

- qualitative descriptions or interpretations (narrative or theoretical) of personal or social experiences of comorbid anxiety or depression.

Analytical Methods

We analyzed published qualitative research using techniques of integrative qualitative meta-synthesis. (17-19) Qualitative meta-synthesis, also known as qualitative research integration, is an integrative technique that summarizes research over a number of studies, with the intent of combining findings from multiple studies. Qualitative meta-synthesis has 2 objectives: first, summarizing the aggregate of a result should reflect the range of findings that exist while retaining the original meaning of the authors; second, through a process of comparing and contrasting findings across studies, a new integrative interpretation of the phenomenon should be produced. (20)

Predefined topic and research questions guided research collection, data extraction, and analysis. Topics were defined in stages, as available relevant literature was identified and the corresponding evidence-based analyses proceeded. First, we retrieved all qualitative research relevant to the conditions under analysis. Then, specific topics were chosen and a final search of the dataset was performed to retrieve papers relevant to these questions. This report examines the experience of comorbid anxiety or depression and chronic disease.

Data extraction focused on, and was limited to, findings relevant to this research topic. Qualitative findings are the "data-driven and integrated discoveries, judgments, and/or pronouncements researchers offer about the phenomena, events, or cases under investigation." (17) In addition to the researchers' findings, we also extracted original data excerpts (e.g., participant quotes, stories, or incidents) embedded in the findings, to help illustrate specific findings and, when useful, to facilitate the communication of our own meta-synthetic findings.

Through a staged coding process similar to that used in grounded theory (e.g., (21, 22)), we broke the studies' findings into their component parts (e.g., key themes, categories, concepts), which we then gathered across studies to regroup and relate to each other thematically. This process allowed us to organize and reflect upon the full range of interpretative insights across this body of research. (17, 23) These categorical groupings provided the foundation from which we synthesized interpretations of the social and personal phenomena addressed by the topic of comorbid anxiety or depression and chronic disease. A "constant comparative" and iterative approach was used, in which we repeatedly compared preliminary categories to the research findings, to raw data excerpts, and co-investigators' interpretations of the same studies, as well as to the original OHTAC-defined topic, the emerging evidence-based analyses of clinical evaluations of related technologies, and feedback from OHTAC deliberations and expert panels on issues emerging in relation to the topic.

Quality of Evidence

For valid epistemological reasons, the field of qualitative research lacks consensus on the importance, methods, and standards of critical appraisal. (24) Qualitative health researchers conventionally under-report procedural details, (25) and the quality of findings tends to rest less on methodological processes than on the conceptual prowess of the researchers. (24) Theoretically sophisticated findings are promoted as markers of study quality for making valuable theoretical contributions to social science academic disciplines. (26) However, theoretical sophistication is not necessary for contributing potentially valuable information to a synthesis of multiple studies, nor to inform questions posed by the interdisciplinary and interprofessional field of health technology assessment. Qualitative meta-synthesis researchers typically do not exclude qualitative research on the basis of independently appraised quality. This approach is common to multiple types of interpretive qualitative synthesis. (20, 27-29)

For this review, we relied on the academic peer review and publication process to eliminate scientifically unsound studies according to current standards. Beyond this, we included all topically relevant, accessible research studies using any qualitative interpretive or descriptive methodology. We appraised the value of the research findings solely in terms of their relevance to our research questions and the presence of data that supported the authors' findings.

Results of Systematic Review

Applying the qualitative research filter to the HQO search strategy for all chronic disease topics yielded 49,676 citations published between January 1, 2002, and May 2, 2012 (including some duplicates). Articles were excluded based on information in the title and abstract. Two reviewers reviewed all titles and abstracts to refine the database to qualitative research relevant to any of the chronic diseases (N=1937). Figure 1 shows the breakdown of when and for what reason citations were excluded from the analysis.

From the database of relevant studies, titles and abstracts were searched for their relevance to depression or anxiety, including a keyword search for "anxi*" and "depress*". Twenty-four citations were retrieved. Based on full-text review, 9 were excluded because they did not relate to experiences of anxiety or depression. Five additional studies were identified from systematic reviews and reference lists of retrieved papers.

A total of twenty papers met the inclusion criteria for this analysis.

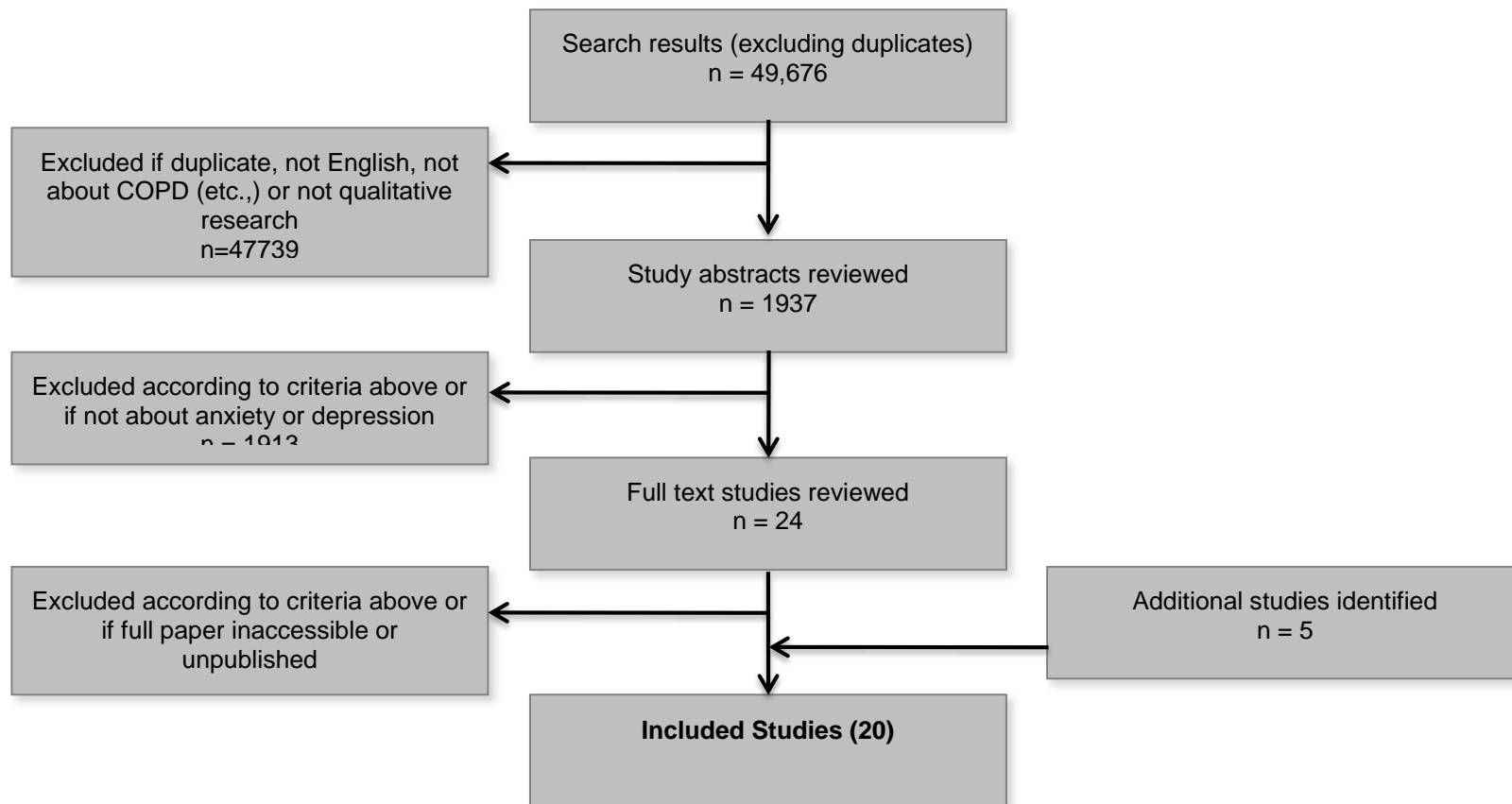


Figure 1: Citation Flow Chart

Table 1: Body of Evidence Examined According to Condition

Chronic Disease	Comorbid Disease		
	Anxiety	Depression	Anxiety and Depression
COPD	2	0	1
Diabetes	0	5	1
Heart Failure	0	3	2
Stroke	0	3	1
Various	0	1	1

For each included study, the study design was identified and is summarized below in Table 2.

Table 2: Body of Evidence Examined According to Study Design

Study Design	Number of Eligible Studies
Qualitative Studies	
Content Analysis	6
Ethnography	1
Grounded Theory/Constant Comparative Analysis	6
Framework Analysis	1
Other	3
Qualitative (otherwise unspecified)	3
Total	20

For each included study, the study location was identified and is summarized below in Table 3.

Table 3: Body of Evidence Examined According to Study Context

Study Context	Number of Eligible Studies
Australia and New Zealand	3
Europe	8
Canada (Ontario)	1
United States	8
Total	20

Results

A central theme that emerged from this body of research was the relationship between the chronic conditions and depression or anxiety (see Figure 2 for an illustration of perceived relationships between depression/anxiety and chronic disease). In the synthesized research, patients reported experiencing their chronic conditions and these mental health states in two main ways: 1) as two co-incident problems, or 2) as independent conditions, with no relationship between the chronic disease and their depression or anxiety. Where patients did experience a relationship between their chronic condition and depression or anxiety, some believed they experienced a progression from chronic disease to depression or anxiety (Figure 2, pathway 1). Others described experiencing the reverse, with the depression or anxiety leading to the chronic disease (Figure 2, pathway 2). While most research reports identified one or two types of experiences (pathway 1 or 2), (30-36) a minority of reports identified both types of experienced relationships, a cyclical relationship we describe as pathway 3 (Figure 2). (37-39) As a whole, this body of qualitative research sheds light on the various patient experiences of the relationships between their physical and mental health, and the cyclical reasoning used to make sense of these. From this evidence, some potential barriers to screening for depression or anxiety can also be identified.

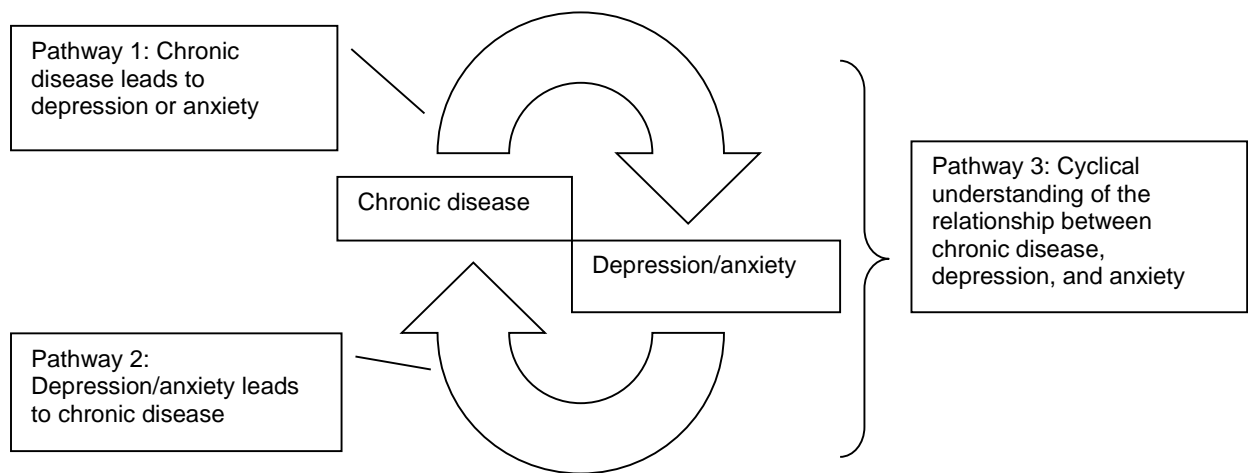


Figure 2: Patient-Experienced Pathways Between Depression/Anxiety and Chronic Disease

Patient-Experienced Pathway 1: Chronic Disease Leads to Depression or Anxiety

The majority of papers found that patients tended to experience depression or anxiety as a consequence of being diagnosed with a chronic disease. (30-37, 39) Multiple consequences of a chronic disease diagnosis can contribute to depression or anxiety: the loss of a sense of self, anxiety and uncertainty about the future, loss of relationships and social isolation, and feelings of guilt.

Loss of self pervades experiences of chronic disease. Many patients expressed sadness and distress at the changes to their lives as a result of the chronic disease. They felt “trapped in a different life” (31) because the limitations of the disease, such as fatigue and a lack of energy, (31, 40-42) kept them from pursuing their normal activities. Functional limitations also lead to feelings of frustration and sadness. (30) Conversely, patients noted a reduction in symptoms of depression when they felt that they were able to participate in and contribute to daily life, and if they were able to regain certain functions (e.g., regain a driver’s licence or return to work). (31)

Chronic disease can socially isolate people. The experience of chronic disease often resulted in reduced contact with friends and family and sometimes the loss of relationships. (30-32, 36) Contact with friends might be limited because of friends' fears about the condition, (32) the patients' lack of energy, (32, 33) or a reluctance to engage with friends because days were uneventful and "there's nothing to talk about." (32)

Some patients reported that they avoided social situations because of their chronic disease. With COPD, patients worried that exertion would lead to breathlessness, possibly triggering a panic attack. (37) Stroke survivors reported uncertainty in social settings because of sensitivity to noise and feelings of confusion. (31) Willgoss et al (37) reported that symptoms of anxiety such as sweating and incontinence in COPD patients led to social isolation and that some patients were "effectively housebound."

Anxiety and uncertainty about the future often accompanies chronic disease. Patients described concern about the prognosis of their chronic disease and uncertainty about their future, often experienced as anxiety and depression. (33, 35, 37, 39) Some patients reported relatively sudden episodes of panic, such as waking up at night and being unable to sleep because they were worrying about their chronic disease while others described a more subtle and constant feeling of uncertainty. (33, 35) Patients attributed their uncertainty to the fact that their chronic disease was incurable (39), that the course of the disease was unpredictable, (35) and that they had fears about death. (33)

Feelings of guilt concerning the chronic illness can heighten feelings of depression. Some patients reported feeling that they were to blame for the development of their chronic condition. (30) Patients who had experienced a stroke described "paying the price" for a variety of factors such as drinking and stress. (30) Patients also experienced guilt for not feeling grateful for being alive. (40)

Patient-Experienced Pathway 2: Depression or Anxiety Lead to Chronic Disease

While most qualitative studies find that patients interpret their chronic condition as contributing to depression or anxiety (30-37, 39), fewer studies find patients expressed the belief that anxiety or depression led to their chronic disease. (33, 38, 39) For example, patients may attribute their heart disease to depression having caused a "heavy heart," (39) or heart attacks to high blood pressure triggered by "high emotions," (39) or diabetes to high blood sugar caused by constant worry. (33)

Patient-Experienced Pathway 3: Chronic Disease and Depression or Anxiety Each Worsen the Other

Sometimes, the relationship between the depression or anxiety and the chronic disease could be described as cyclical. Most notably, patients with COPD described a breathlessness/anxiety/breathlessness cycle, where patients perceived breathlessness as a sign of an impending panic attack, while the panic in turn exacerbated the feeling of breathlessness. (37, 38) Bogner et al (39) highlighted the interconnectedness of depression and heart failure, with one patient suggesting that the only way to deal with heart problems was to seek treatment for depression. The relationships between social isolation and depression or anxiety can be perceived as cyclical because symptoms of the latter may prevent patients from engaging in social activities, which in turn leads to increased distress.

Ultimately, the majority of papers addressing anxiety or depression in patients with chronic disease focused on the causal pathway from chronic disease to anxiety or depression. (30-36) Some addressed the opposite pathway, and others highlighted the recurring relationship between the two. (37-39)

Patient-Experienced (Non) Pathway 4: Chronic Disease and Depression or Anxiety are Independent

Some studies found that patients experience chronic disease and anxiety or depression as coincidental. (33, 35, 43) Depression might be pre-existing, with chronic disease simply adding to the patient's burden. (35) Anxiety and depression sometimes arose because of unrelated issues such as financial difficulties, (43) family problems, (35) health issues unrelated to the chronic disease, (35) or grief over the loss of a loved one. (33, 35)

Barriers to Screening

Because screening for anxiety and depression is a technology under assessment for the optimal management of patients with chronic disease, we also reviewed these qualitative studies for findings potentially relevant to the practice of screening. A few reports provided insight into barriers to screening for anxiety or depression in patients with chronic disease. (33, 34, 44) A major barrier to identifying anxiety or depression is that there is often overlap between the physical symptoms of the chronic disease, such as fatigue in heart failure (35) or heart palpitations in COPD. (37) Common symptoms can make it difficult for both clinicians and patients to recognize anxiety or depression as a separate disease and not simply a manifestation of the chronic disease. (43)

Some papers described a normalization of symptoms of anxiety or depression by both patients and clinicians. (33, 44) Clinicians tend to highlight the common link between chronic disease and feelings of anxiety or depression, which in turn can make it difficult for the patient to recognize them as separate conditions and not just an “inevitable” and expected part of the chronic disease experience. (44) In fact, some patients felt that a formal diagnosis of depression underplayed the experience of the chronic disease. (33)

Finally, patients may be reluctant to acknowledge a formal diagnosis of anxiety or depression because of the stigma associated with mental illness. (33, 34, 44, 45) One patient's concerns about taking anti-depressant medication illustrates the reluctance to accept a mental health problem (versus a chronic disease): “I said that is being *loco*, taking medicines for depression. I'm not depressed... depression is a mental problem... I don't have that, I have diabetes. I have other problems, but not a mental problem.” (34) Clinicians also raised the issue of stigma, and reluctance to diagnose and label patients as a result. (44)

Limitations

We focused our review on papers that addressed diagnosis of comorbid anxiety or depression with chronic disease. It is possible that a wider array of issues might have been captured if we had focused on broader psychological responses to the chronic disease experience. However, given our OHTAC-related objective to highlight the implications of screening for anxiety or depression, the more narrow focus seemed most relevant for this report.

Conclusions

The relationship between the chronic conditions and depression or anxiety can be experienced as independent or inter-related (with either one causing the other). The majority of papers find that patients tend to experience depression or anxiety as a consequence of being diagnosed with a chronic disease, some studies highlight the experience from anxiety or depression to chronic disease, and others describe a cyclical relationship between the two. Some patients with chronic disease sense no relationship between their chronic disease and mental health conditions.

Patients may be reluctant to acknowledge depression or anxiety as a separate condition. Clinicians' tendency to highlight the link between chronic disease and depression or anxiety can lead to the normalization of these experiences and make it more difficult for patients to recognize anxiety or depression as separate conditions. The overlapping physical symptoms of chronic disease and depression or anxiety also make formal diagnosis difficult.

More qualitative research is needed to specifically address screening for depression or anxiety, and the effect of depression or anxiety (and their treatments) on the chronic disease and its outcomes.

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Expert Panel for Health Quality Ontario: Optimizing Chronic Disease Management in the Community (Outpatient) Setting

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Shirlee Sharkey (chair)	President & CEO	Saint Elizabeth Health Care
Theresa Agnew	Executive Director	Nurse Practitioners' Association of Ontario
Onil Bhattacharrya	Clinician Scientist	Li Ka Shing Knowledge Institute, St. Michael's Hospital, University of Toronto
Arlene Bierman	Ontario Women's Health Council Chair in Women's Health	Department of Medicine, Keenan Research Centre in the Li Ka Shing Knowledge Institute, St. Michael's Hospital, University of Toronto
Susan Bronskill	Scientist	Institute for Clinical Evaluative Sciences
Catherine Demers	Associate Professor	Division of Cardiology, Department of Medicine, McMaster University
Alba Dicenso	Professor	School of Nursing, McMaster University
Mita Giacomini	Professor	Centre of Health Economics & Policy Analysis, Department of Clinical Epidemiology & Biostatistics
Ron Goeree	Director	Programs for Assessment of Technology in Health (PATH) Research Institute, St. Joseph's Healthcare Hamilton
Nick Kates	Senior Medical Advisor	Health Quality Ontario – QI McMaster University Hamilton Family Health Team
Murray Krahn	Director	Toronto Health Economics and Technology Assessment (THETA) Collaborative, University of Toronto
Wendy Levinson	Sir John and Lady Eaton Professor and Chair	Department of Medicine, University of Toronto
Raymond Pong	Senior Research Fellow and Professor	Centre for Rural and Northern Health Research and Northern Ontario School of Medicine, Laurentian University
Michael Schull	Deputy CEO & Senior Scientist	Institute for Clinical Evaluative Sciences
Moira Stewart	Director	Centre for Studies in Family Medicine, University of Western Ontario
Walter Wodchis	Associate Professor	Institute of Health Management Policy and Evaluation, University of Toronto

Appendices

Appendix 1: Literature Search Strategies

Mega Filter: OVID MEDLINE

1. Interviews+
2. (theme\$ or thematic).mp.
3. qualitative.af.
4. Nursing Methodology Research/
5. questionnaire\$.mp.
6. ethnological research.mp.
7. ethnograph\$.mp.
8. ethnonursing.af.
9. phenomenol\$.af.
10. (grounded adj (theor\$ or study or studies or research or analys?s)).af.
11. (life stor\$ or women* stor\$).mp.
12. (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).af. or (data adj1 saturat\$).tw. or participant observ\$.tw.
13. (social construct\$ or (postmodern\$ or post- structural\$) or (post structural\$ or poststructural\$) or post modern\$ or post-modern\$ or feminis\$ or interpret\$).mp.
14. (action research or cooperative inquir\$ or co operative inquir\$ or co- operative inquir\$).mp.
15. (humanistic or existential or experiential or paradigm\$).mp.
16. (field adj (study or studies or research)).tw.
17. human science.tw.
18. biographical method.tw.
19. theoretical sampl\$.af.
20. ((purpos\$ adj4 sampl\$) or (focus adj group\$)).af.
21. (account or accounts or unstructured or open-ended or open ended or text\$ or narrative\$).mp.
22. (life world or life-world or conversation analys?s or personal experience\$ or theoretical saturation).mp
23. (lived or life adj experience\$.mp
24. cluster sampl\$.mp.
25. observational method\$.af.
26. content analysis.af.
27. (constant adj (comparative or comparison)).af.
28. ((discourse\$ or discurs\$) adj3 analys?s).tw.
29. narrative analys?s.af.
30. heidegger\$.tw.
31. colaizzi\$.tw.
32. spiegelberg\$.tw.
33. (van adj manen\$).tw.

34. (van adj kaam\$.tw.
35. (merleau adj ponty\$.tw
36. .husserl\$.tw
37. foucault\$.tw.
38. (corbin\$ adj2 strauss\$.tw
39. glaser\$.tw.

NOT

40. p =.ti,ab.
41. p<.ti,ab.
42. p>.ti,ab.
43. p =.ti,ab.
44. p<.ti,ab.
45. p>.ti,ab.
46. p-value.ti,ab.
47. retrospective.ti,ab.
48. regression.ti,ab.
49. statistical.ti,ab.

Mega Filter: EBSCO Cumulative Index to Nursing & Allied Health Literature (CINAHL)

1. Interviews+
2. MH audiorecording
3. MH Grounded theory
4. MH Qualitative Studies
5. MH Research, Nursing
6. MH Questionnaires+
7. MH Focus Groups (12639)
8. MH Discourse Analysis (1176)
9. MH Content Analysis (11245)
10. MH Ethnographic Research (2958)
11. MH Ethnological Research (1901)
12. MH Ethnonursing Research (123)
13. MH Constant Comparative Method (3633)
14. MH Qualitative Validity+ (850)
15. MH Purposive Sample (10730)
16. MH Observational Methods+ (10164)
17. MH Field Studies (1151)
18. MH theoretical sample (861)
19. MH Phenomenology (1561)
20. MH Phenomenological Research (5751)
21. MH Life Experiences+ (8637)
22. MH Cluster Sample+ (1418)
23. Ethnonursing (179)
24. ethnograph* (4630)

25. phenomenol* (8164)
26. grounded N1 theor* (6532)
27. grounded N1 study (601)
28. grounded N1 studies (22)
29. grounded N1 research (117)
30. grounded N1 analys?s (131)
31. life stor* (349)
32. women's stor* (90)
33. emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$ (2305)
34. data N1 saturat* (96)
35. participant observ* (3417)
36. social construct* or postmodern* or post-structural* or post structural* or poststructural* or post modern* or post-modern* or feminis* or interpret* (25187)
37. action research or cooperative inquir* or co operative inquir* or co-operative inquir* (2381)
38. humanistic or existential or experiential or paradigm* (11017)
39. field N1 stud* (1269)
40. field N1 research (306)
41. human science (132)
42. biographical method (4)
43. theoretical sampl* (983)
44. purpos* N4 sampl* (11299)
45. focus N1 group* (13775)
46. account or accounts or unstructured or open-ended or open ended or text* or narrative* (37137)
47. life world or life-world or conversation analys?s or personal experience* or theoretical saturation (2042)
48. lived experience* (2170)
49. life experience* (6236)
50. cluster sampl* (1411)
51. theme* or thematic (25504)
52. observational method* (6607)
53. questionnaire* (126686)
54. content analysis (12252)
55. discourse* N3 analys?s (1341)
56. discours* N3 analys?s (35)
57. constant N1 comparative (3904)
58. constant N1 comparison (366)
59. narrative analys?s (312)
60. Heidegger* (387)
61. Colaizzi* (387)
62. Spiegelberg* (0)
63. van N1 manen* (261)
64. van N1 kaam* (34)
65. merleau N1 ponty* (78)
66. husserl* (106)

- 67. Foucault* (253)
- 68. Corbin* N2 strauss* (50)
- 69. strauss* N2 corbin* (88)
- 70. glaser* (302)

NOT

- 71. TI statistical OR AB statistical
- 72. TI regression OR AB regression
- 73. TI retrospective OR AB retrospective
- 74. TI p-value OR AB p-value
- 75. TI p< OR AB p<
- 76. TI p< OR AB p<
- 77. TI p= OR AB p=

Mega Filter: ISI Web of Science, Social Science Citation Index

- 1. TS=interview*
- 2. TS=(theme*)
- 3. TS=(thematic analysis)
- 4. TS=qualitative
- 5. TS=nursing research methodology
- 6. TS=questionnaire
- 7. TS=(ethnograph*)
- 8. TS= (ethnonursing)
- 9. TS=(ethnological research)
- 10. TS=(phenomenol*)
- 11. TS=(grounded theor*) OR TS=(grounded stud*) OR TS=(grounded research) OR TS=(grounded analys?s)
- 12. TS=(life stor*) OR TS=(women's stor*)
- 13. TS=(emic) OR TS=(etic) OR TS=(hermeneutic) OR TS=(heuristic) OR TS=(semiotic) OR TS=(data saturat*) OR TS=(participant observ*)
- 14. TS=(social construct*) OR TS=(postmodern*) OR TS=(post structural*) OR TS=(feminis*) OR TS=(interpret*)
- 15. TS=(action research) OR TS=(co-operative inquir*)
- 16. TS=(humanistic) OR TS=(existential) OR TS=(experiential) OR TS=(paradigm*)
- 17. TS=(field stud*) OR TS=(field research)
- 18. TS=(human science)
- 19. TS=(biographical method*)
- 20. TS=(theoretical sampl*)
- 21. TS=(purposive sampl*)
- 22. TS=(open-ended account*) OR TS=(unstructured account) OR TS=(narrative*) OR TS=(text*)
- 23. TS=(life world) OR TS=(conversation analys?s) OR TS=(theoretical saturation)
- 24. TS=(lived experience*) OR TS=(life experience*)
- 25. TS=(cluster sampl*)
- 26. TS=observational method*
- 27. TS=(content analysis)
- 28. TS=(constant comparative)
- 29. TS=(discourse analys?s) or TS =(discurs* analys?s)

30. TS=(narrative analys?s)
31. TS=(heidegger*)
32. TS=(colaizzi*)
33. TS=(spiegelberg*)
34. TS=(van manen*)
35. TS=(van kaam*)
36. TS=(merleau ponty*)
37. TS=(husserl*)
38. TS=(foucault*)
39. TS=(corbin*)
40. TS=(strauss*)
41. TS=(glaser*)

NOT

42. TS=(p-value)
43. TS=(retrospective)
44. TS=(regression)
45. TS=(statistical)

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