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Étude du concept de trajectoires de soins chez les personnes âgées vivant avec un trouble neurocognitif majeur, à l'aide du modèle multidimensionnel des trajectoires de soins « 6W » : un protocole de revue systématique mixte

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Résumé de l'article

Introduction : L'utilisation des services de santé par les personnes vivant avec un trouble neurocognitif majeur (TNCM) varie tout au long de la maladie. S'intéresser aux trajectoires de soins, définies comme le schéma d'utilisation des soins sur une période donnée, permet de mieux comprendre l'évolution des individus dans le système de santé. Objectifs : 1) À l'aide du modèle multidimensionnel « 6W » sur les trajectoires de soins, évaluer comment les trajectoires de soins sont mesurées et définies chez les personnes âgées vivant avec un TNCM et, 2) Examiner comment les facteurs socio-économiques sont considérés dans les études portant sur les trajectoires de soins. Critères d'inclusion : Cette revue portera sur les personnes âgées vivant avec un TNCM, dans la communauté. Composante quantitative : études considérant les trajectoires de soins, portant sur un minimum de 2 services de santé différents et 3 temps de mesure. Composante qualitative : études portant sur les trajectoires de soins du point de vue des patients ou de proches aidants. Méthodes : Cette revue systématique utilise la méthode proposée par l'Institut Joanna Briggs. Nous rechercherons des articles (anglais ou français) dans 5 bases de données bibliographiques. Des évaluateurs indépendants procéderont au choix des articles à inclure, à l'extraction des données et à l'évaluation de la qualité. Une approche intégrée convergente permettra l'intégration et la synthèse des données. Discussion et conclusion : Les résultats pourront alimenter les initiatives visant à améliorer l'adéquation des services et des besoins des personnes vivant avec un TNCM, ainsi que de comprendre les inégalités liées aux soins de cette population.

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Keywords

major neurocognitive disorder; healthcare; systematic review; trajectories; older adults

Abstract

Introduction: The use of healthcare services by older adults with major neurocognitive disorder (MNCD) varies significantly throughout the disease process. The evaluation of healthcare trajectories, defined as the pattern of care use over time, allows for a better understanding of how people move through the healthcare system and facilitates the identification of potentially modifiable risk factors for suboptimal care trajectories. **Objectives:** The objectives of the review are to: 1) critically appraise and synthesize evidence on how healthcare trajectories of older adults with MNCD are measured and defined, using the '6W' multidimensional model of care trajectories, and 2) examine how socioeconomic factors are considered in studies reporting on healthcare trajectories. **Inclusion criteria:** This review will consider community-dwelling older adults diagnosed with MNCD. The quantitative component will include studies reporting on healthcare trajectories, including at least 2 different care services and at least 3 time-points. The qualitative component will include studies reporting on healthcare trajectories from the perspective of patients or their informal caregivers. **Methods:** This review will follow the Joanna Briggs Institute mixed methods review approach. We will search EMBASE, MEDLINE, CINAHL, PsycINFO, and the Web of Science Core Collection for English or French articles. Independent reviewers will identify articles for inclusion, extract data, and assess quality. A convergent integrated approach to synthesis and integration will be used. **Discussion and conclusion:** The results will help anticipate patients' needs, improve patient care, service planning and coordination, and understand inequities in MNCD care.

Résumé

Introduction : L'utilisation des services de santé par les personnes vivant avec un trouble neurocognitif majeur (TNCM) varie tout au long de la maladie. S'intéresser aux trajectoires de soins, définies comme le schéma d'utilisation des soins sur une période donnée, permet de mieux comprendre l'évolution des individus dans le système de santé. **Objectifs :** 1) À l'aide du modèle multidimensionnel « 6W » sur les trajectoires de soins, évaluer comment les trajectoires de soins sont mesurées et définies chez les personnes âgées vivant avec un TNCM et, 2) Examiner comment les facteurs socio-économiques sont considérés dans les études portant sur les trajectoires de soins. **Critères d'inclusion :** Cette revue portera sur les personnes âgées vivant avec un TNCM, dans la communauté. Composante quantitative : études considérant les trajectoires de soins, portant sur un minimum de 2 services de santé différents et 3 temps de mesure. Composante qualitative : études portant sur les trajectoires de soins du point de vue des patients ou de proches aidants. **Méthodes :** Cette revue systématique utilise la méthode proposée par l'Institut Joanna Briggs. Nous rechercherons des articles (anglais ou français) dans 5 bases de données bibliographiques. Des évaluateurs indépendants procéderont aux choix des articles à inclure, à l'extraction des données et à l'évaluation de la qualité. Une approche intégrée convergente permettra l'intégration et la synthèse des données. **Discussion et conclusion :** Les résultats pourront alimenter les initiatives visant à améliorer l'adéquation des services et des besoins des personnes vivant avec un TNCM, ainsi que de comprendre les inégalités liées aux soins de cette population.

Mots-clés

trouble neurocognitif majeur; services de santé; revue systématique; trajectoires; personnes âgées

INTRODUCTION

Worldwide, as many as 47.5 million people live with major neurocognitive disorder (MNCD), the most common being Alzheimer's disease. This number is projected to reach 75 million by 2030 (Prince, 2015; World Health Organization [WHO], 2017). MNCD is defined as the occurrence of progressive, irreversible and chronic impairments in memory and cognitive function beyond what would be expected in the context of normal aging (Chambers et al., 2016). As a result of their complex medical and long-term care needs, healthcare utilization and costs for community-dwelling, older adults living with MNCD are high across the full spectrum of healthcare services, including specialized MNCD care, home care, and community resources (Daras et al., 2017; Public Health Agency of Canada, 2017). Indeed, they often present a high burden of chronic illness, complex pharmacological treatment, behavioral challenges, and extensive assistance and social needs (Daras et al.; WHO). However, these people often report fragmentation and lack of continuity of care with poor communication between different healthcare professionals (Canadian Academy of Health Sciences, 2019). This represents a significant barrier to receive optimal care as older adults with MNCD are more likely to transition between multiple healthcare settings during their healthcare trajectory. This puts them at higher risk of emergency department visits, hospital admission, and decreased quality of life (Parker et al., 2020).

Healthcare use by older adults with MNCD varies throughout the course of the disease. Their patterns of care use over time can be operationalized using the concept of healthcare trajectories, defined as the patterns of care use over time (Bronskill et al., 2020; Vanasse et al., 2018). A systematic review by Pinaire et al. (2017) aimed to investigate how the concept of trajectory is defined, studied, and what it contributes, using myocardial infarction as a motivating example. They conclude that studies oriented toward healthcare trajectories "[...] may be highly informative regarding the medico-economic aspects so as to be able to streamline the patient's

care management to avoid treatment dispersion" (Pinaire et al., p. 13). For example, a study by Bronskill et al. aimed to determine the long-term trajectories of health system use by individuals with MNCD. Amongst others, their findings add value to care planning: they showed that this population uses more healthcare services over time, with home care services being used more frequently throughout the disease progression.

Healthcare trajectories are tightly influenced by health factors and personal characteristics, including socioeconomic status. Socioeconomic inequalities contribute to health gaps among older adults living with MNCD and play a significant role in social inequalities in MNCD care (Deckers et al., 2019). Lower socioeconomic status is associated with insufficient access to care services and less favourable health behaviors, resulting in a higher risk of adverse health outcomes (van de Vorst et al., 2016). However, the effect of socioeconomic disparities on healthcare trajectories is not well understood in this population.

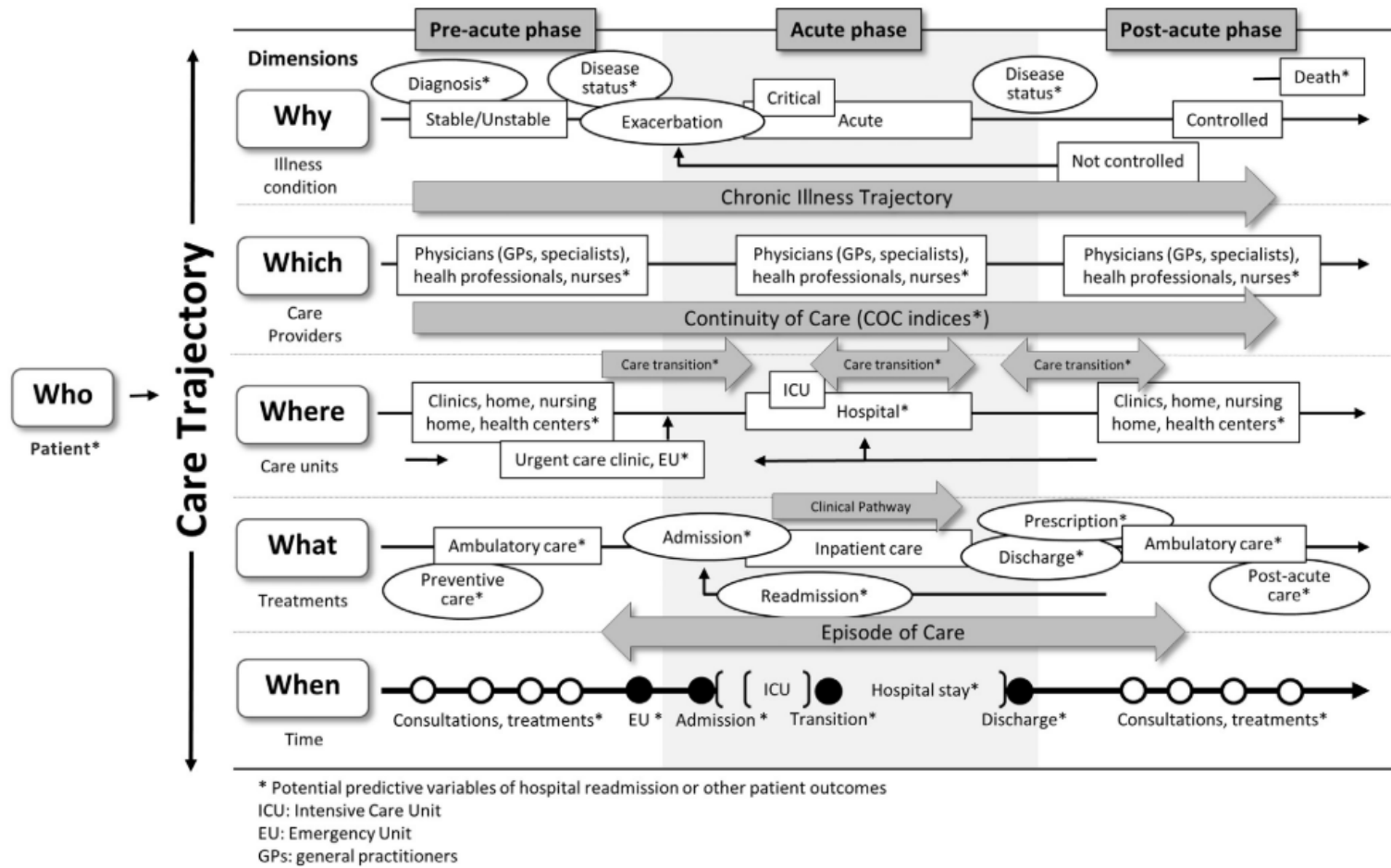
As healthcare trajectories are an emerging topic encompassing broad and varied concepts, it can be challenging to define and consolidate. To promote cohesion, Vanasse et al. (2018) developed a comprehensive model of healthcare trajectories based on concepts related to patterns or processes of care analyses. They include concepts such as continuity of care, clinical pathways, and episodes of care, which, when examined separately, do not offer a complete understanding of care patterns (Vanasse et al.).

The '6W' multidimensional model of care trajectories highlights six key components to describe whether quantitatively or qualitatively, how:

The patient (**who**), through the course of his/her chronic illness (**why**), will likely consult family physicians, specialists and other types of care providers (**which**) either at an ambulatory care clinic, an emergency department or in a hospital (**where**). The patient will follow a sequence of preventive care, tests and treatments in ambulatory care and inpatient care settings (**what**), over specific periods (**when**). (Vanasse et al., 2018, p. 57) (see Figure 1).

Figure 1

The '6W' multidimensional model of care trajectory by Vanasse et al. (2018)



Using a comprehensive approach, the proposed '6W' multidimensional model of care trajectories gathers these critical dimensions into a single framework and is transferable to various populations.

A preliminary search of PROSPERO, MEDLINE, the Cochrane Database of Systematic Reviews and the Joanna Briggs Institute (JBI) Evidence Synthesis was conducted, and no current or underway systematic reviews on the topic were identified. Most studies related to healthcare trajectories were purely descriptive or used complex analysis approach, such as sequence analysis (Nguena Nguetack et al., 2020). Developing knowledge based on healthcare trajectories could help to contextualize the experiences of older adults living with MNCD across the healthcare system, identify opportunities to improve care for the individuals, and reveal where inequities arise in MNCD care (Pinaire et al., 2017).

OBJECTIVES

Thus, the objectives of the review are to critically appraise and synthesize evidence on how healthcare trajectories are measured and defined, using the '6W' multidimensional model of care trajectories, and examine how socioeconomic factors are considered in studies reporting on healthcare trajectories in older adults living with MNCD. We will apply the '6W' model to each study and examine the specific dimensions they report on. We will then be able to assess the completeness of included studies regarding healthcare trajectories.

The use of a mixed methods approach allows for a comprehensive synthesis of evidence (qualitative and quantitative), improving the usefulness of the findings for clinical, policy and organizational applications. It is also helpful to determine how both perspectives address a phenomenon of interest (Lizarondo et al., 2020). In literature, healthcare trajectories are frequently measured through quantitative analysis, but less is known on how they are defined using a qualitative approach. A mixed method systematic review will give a novel insight and help understand how different approaches complement each other.

REVIEW QUESTIONS

Guided by the '6W' multidimensional model of care trajectories, we aimed to answer these questions: 1) How are healthcare trajectories of people with MNCD measured and defined, and 2) How socioeconomic factors are considered in studies reporting on healthcare trajectories in this population.

INCLUSION CRITERIA

1) POPULATION

The review will consider studies that include community-dwelling people 65 years and older, living with MNCD. We will exclude studies targeting individuals with mild cognitive impairment (defined as impairment in a single cognitive domain, or moderate impairment in several cognitive domains, that do not meet criteria for MNCD) or living in institutionalized settings (Tang, Brayne, Albanese, & Stephan, 2015). As the term MNCD encompasses a range of specific disorders, we will include studies on these conditions, including, but not limited to, Alzheimer's disease, Lewy body dementia, and vascular dementia.

2) PHENOMENA OF INTEREST

The quantitative component of this review will consider studies reporting on healthcare trajectories, defined as the pattern of care use over time (Vanasse et al., 2018). Healthcare trajectories imply using a sequence of services, revealing use trends over time. Thus, we will include studies examining at least two different health and social care services, including formal and informal care, across at least three time-points.

The qualitative component of this review will also consider studies reporting on healthcare trajectories of older adults living with MNCD. We will include studies examining trajectories from the perspective of our population of interest, or their informal caregivers (defined as individuals who provide some type of unpaid assistance for activities of daily living (ADL) and instrumental ADL) (Plöthner et al., 2019).

3) TYPES OF STUDIES

This review will consider mixed method, qualitative, and quantitative studies. Mixed method studies will only be considered if data from the qualitative and quantitative components can be clearly extracted. Qualitative studies will be included regardless of design and method. Quantitative studies will include observational studies (cohort, case-control).

We will exclude non-empirical studies, including editorials, opinion pieces, and methodological papers. We will also exclude abstracts, posters, dissertations, case studies (case series or case reviews), clinical guides, and reviews. Relevant reviews identified by the search will be used to help enrich the discussion. Studies published in English or in French will be included. Studies published from inception to the present will be included, to capture the evolution and trends of the measurement of healthcare trajectories.

METHODS

Our approach for this study will be conducted in accordance with the JBI Methodology for Mixed Methods Systematic Reviews (MMSR) (Lizarondo et al., 2020).

This systematic review protocol is registered in the Prospective Register of Systematic Reviews (PROSPERO) database (registration number: CRD42021225798).

SEARCH STRATEGY

A preliminary search of MEDLINE and CINAHL was undertaken to identify articles on this topic. Key words from the titles and abstracts of relevant articles as well as index terms used to describe the articles were used to develop a full search strategy, for EMBASE (Ovid), MEDLINE (Ovid), Cumulative Index to Nursing and Allied Health Literature (CINAHL) (EBSCO), PsycINFO (Ovid), Web of Science Core Collection, from inception to December 2020 (See Appendix I). The search strategy, including all identified keywords and index terms, are adapted for each database. To

enhance the search strategy and examine additional sources, we included hand searching through reference lists in pertinent studies. We will keep a detailed record of our search strategy to ensure transparency and replicability throughout the process.

STUDY SELECTION

Following the systematic database search, all identified literature will be imported into EndNote X8.2 to facilitate organization. The de-duplication process developed by Bramer, Giustini, de Jonge, Holland, and Bekhuis (2016) will be used to remove duplicates. We will use Covidence© (Veritas Health Innovation, 2013), an online citation screening tool, to facilitate and monitor study selection. This software allows for independent screening, flagging discrepancies for discussion and consensus decision, and clearly displays differences in reviewers' ratings.

Two independent reviewers will screen all titles and abstracts, and review all the full text for assessment against the inclusion criteria. Reasons for the 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 review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram (Moher et al., 2009).

ASSESSMENT OF METHODOLOGICAL QUALITY

The same two reviewers will independently assess the risk of bias in individual studies using the Mixed Methods Appraisal Tool (MMAT) (Hong, Pluye et al., 2018). The MMAT was designed for mixed methods systematic reviews, allowing for the use of a single harmonized tool to concomitantly appraise the risk of bias across the most common types of empirical studies: qualitative studies, randomized controlled trials, non-randomized studies, quantitative descriptive studies, and mixed methods studies, according to seven criteria relating to the most important

sources of potential bias in each study design. The MMAT does not include a validated cut-off value that can be used to characterize low vs. high-quality studies (Hong, Gonzalez-Reyes, et Pluye, 2018). However, for the purposes of our analysis, we developed criteria to categorize studies quality based on their score on each of the seven MMAT criteria: 'high' (6 or 7 criteria achieved), 'moderate' (3 to 5 criteria achieved) or 'low' (0 to 2 criteria achieved).

Authors of papers will be contacted to request missing or additional data for clarification, where required. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. The results of critical appraisal will be reported in narrative form and in a table including the MMAT items.

All studies, regardless of the results of their methodological quality, will undergo data extraction and synthesis (where possible). A sensitivity analysis will be performed to evaluate the impact on the study's conclusions of removing the studies considered as having 'low' quality.

DATA EXTRACTION

Two reviewers will independently extract the data, using a modified version of the standardized JBI data extraction tool in Covidence© (Lizarondo et al., 2020; Veritas Health Innovation, 2013). For quantitative and mixed methods studies (quantitative component only), the data extracted will include specific details about the study method, population, phenomena of interest, context, and aspect relevant to the review question. For studies where people living with MNCD are a subset of the study population, participant characteristics will be extracted only for this group.

For qualitative and mixed methods studies (qualitative component only), the data extracted will include specific details about the population, context, culture, geographical location, study methods and the phenomena of interest relevant to the review objective. Findings and their illustrations will be extracted and assigned a level of credibility.

For all studies, we will assess which dimensions of the '6W' model and what variables

are considered in healthcare trajectories development (Vanasse et al., 2018). Secondly, we will report on the use of socioeconomic factors, including dimensions of income, education, and social class (Darin-Mattsson et al., 2017). Any disagreement will be resolved through discussion, or with a third reviewer.

DATA TRANSFORMATION, SYNTHESIS AND INTEGRATION

This review will follow a convergent integrated approach, as per JBI methodology for questions that both quantitative and qualitative research designs can address. The quantitative data will be converted into 'qualitized data', as codifying quantitative data is less error-prone than attributing numerical values to qualitative data. This will involve transforming the quantitative results into textual descriptions or narrative interpretation to respond to the review questions directly. At its most basic level, 'qualitized' data will consist of a sample description based on descriptive statistics. For quantitative data with a longitudinal or temporal component and those exploring associations, the process will entail identifying the variables included in the data analysis through textual descriptions and transformation of the numerical data. The 'qualitized data' will then be assembled with the qualitative data. Grounded in the '6W' multidimensional model of healthcare trajectories, assembled data will be categorized and pooled together based on similarity in meaning to produce a set of integrated findings in the form of a line of action statements (Lizarondo et al., 2020). Where textual pooling is impossible, the findings will be presented in narrative form.

DISCUSSION

The impacts of MNCD are widespread, representing substantial human costs to individuals, families, and societies, as well as significant financial burden for health systems. The degenerative nature of MNCD and the lack of effective treatments underscore the need for effective care planning. However, as the use of

healthcare by people living with MNCD varies significantly throughout the disease process, ensuring access to timely and appropriate care represents a critical challenge (Bronskill et al., 2020).

This mixed methods systematic review is designed to enhance understanding of healthcare trajectories for people living with MNCD. This would allow the assessment of the healthcare service adequacy for these individuals compared to current standards, thereby contributing to the strategic improvement of care organizations. The results of this review will contribute significantly to the knowledge base in MNCD care.

From a public health perspective, understanding how trajectories are defined and measured will contribute to the efforts of health organizations, increasingly moving to a trajectory-based management approach. Understanding the impact of socioeconomic factors is also an essential element in addressing health inequalities.

LIMITATIONS

Preliminary searches suggest potential limitations of the review. First, the measurement and conceptualization of studies reporting on healthcare trajectories for people living with MNCD are heterogeneous, which may present a challenge during data synthesis. Second, as healthcare trajectories are a multifaceted concept, our search strategy may not capture all relevant studies. To mitigate these difficulties, we constructed a representative and comprehensive definition of healthcare trajectories based on the '6W' multidimensional model of care trajectory to strengthen our systematic search strategy. Grounding our work in this conceptual model will also help us organize and deepen our data synthesis process. Finally, due to language barrier, relevant studies written in a language other than English, or French will be excluded, potentially resulting in the exclusion of relevant studies.

CONCLUSION

Various approaches allow for an innovative examination of the concept of healthcare

trajectory. This mixed methods systematic review will provide a detailed account of the healthcare trajectories of people living with MNCD, using the '6W' multidimensional model of care trajectories, and examine how included studies report on socioeconomic factors. The results of this review will provide insightful information to support public health and policy action. The results will highlight gaps in trajectory studies at the research level and offer insight into future research development. Understanding care trajectories is also of great interest for improving nursing interventions, patient follow-up, and care management for MNCD. Thus, understanding patient care patterns offer an opportunity to improve care quality across the care continuum.

Authors' contribution: ID, IV, AQV, and CBF developed the systematic-review concept. The search strategy was implemented by ID and CBF. ID, IV, AQV and CBF helped draft the article and approved its final version. All four authors revised and approved the final version of the manuscript.

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Appendix I

Search strategy

Database	Search details	Records retrieved
EMBASE Classic+Embase (Ovid)	<ol style="list-style-type: none"> 1. (dementia or alzheimer*).mp. 2. dementia/ or alzheimer disease/ 3. Neurocognitive Disorder*/ 4. 1 or 2 or 3 5. (Trajector* or pathway? or path? or pattern? or "care network?").ti,ab,kw. or longitudinal*.ti. 6. patient care/ 7. 5 or 6 8. Health Services/ 9. Community Health Services/ 10. (healthcare or "health care" or "health service*" or "health system*" or "dementia care").ti,ab,kw. 11. 8 or 9 or 10 12. 4 and 7 and 11 13. limit 12 to (english or french) 	2,044