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Original article

Development of a research tool to document self-reported chronic conditions in primary care

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Abstract

Background: Researchers interested in multimorbidity often find themselves in the dilemma of identifying or creating an operational definition in order to generate data. Our team was invited to propose a tool for documenting the presence of chronic conditions in participants recruited for different research studies. Objective: To describe the development of such a tool. Design: A scoping review in which we identified relevant studies, selected studies, charted the data, and collated and summarized the results. The criteria considered for selecting chronic conditions were: (1) their relevance to primary care services; (2) the impact on affected patients; (3) their prevalence among the primary care users; and (4) how often the conditions were present among the lists retrieved from the scoping review. Results: Taking into account the predefined criteria, we developed a list of 20 chronic conditions/categories of conditions that could be self-reported. A questionnaire was built using simple instructions and a table including the list of chronic conditions/categories of conditions. Conclusions: We developed a questionnaire to document 20 self-reported chronic conditions/categories of conditions intended to be used for research purposes in primary care. Guided by previous literature, the purpose of this questionnaire is to evaluate the self-reported burden of multimorbidity by participants and to encourage comparability among research studies using the same measurement.

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Introduction

The ongoing management of long-term or chronic conditions is an important aspect of the workload in primary care. These chronic conditions may also lead to many adverse health outcomes due to complications, unrecorded adverse drug interactions, inadequate

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management, or other situations. For these reasons, chronic conditions have become an important topic in primary care research. In many patients, the simultaneous presence of two or more chronic conditions can be observed, a situation generally known as "multimorbidity". Although it is reasonably simple to define or recognize multimorbidity in the clinical context, researchers interested in multimorbidity often find themselves in the dilemma of identifying or creating an operational definition in order to generate data. The simplest operational definition of multimorbidity has two components: the list of diagnoses that are considered and the cutoff for the number of diagnoses used to determine the presence of multimorbidity. A systematic review on multimorbidity indices [1] reported that the shortest list of diagnoses found in the literature was four

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[2], and the largest was 102 [3]. As well, an open list of diagnoses, considering all the conditions a patient has experienced, has been used to measure multimorbidity [4]. Regarding the cutoff for the number of diagnoses, the most frequently used are two or more and three or more diagnoses [5,6], but a cutoff of five or more diseases has also been used [7].

Chronic disease prevention and management are research priorities of the Community-Based Primary Health Care (CBPHC) Signature Initiative, in which 12 innovation teams were funded by the Canadian Institutes of Health Research to improve the delivery of appropriate and high-quality primary care in Canada (information available at: http://www.cihr-irsc.gc.ca/e/45817. html). Our research team (described at: http://www.paceinmm.recherche.usherbrooke.ca/), which is one of them, was invited to propose a tool that could be used across the 12 innovation teams for documenting the presence of chronic conditions in the participants recruited for the different research studies across Canada. This article describes the development of such a tool.

Methods

Scoping review

The first step in the development of the tool was to conduct a scoping review of publications on multimorbidity in which a list of conditions was described. The scoping review was conducted following the five stages of the framework described by Arksey and O'Malley [8]. These stages are: (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) charting the data; and (5) collating, summarizing, and reporting the results. We adopted this approach as this offered more flexibility for being more inclusive as compared with a systematic review.

The central research question of this scoping review was: what lists of chronic conditions have been used and reported in previous studies of multimorbidity? To identify relevant studies, we used a collection of publications on multimorbidity from the International Research Community on Multimorbidity website (available at: http://crmcspl-blog.recherche.usherbrooke.ca/) [9].

Currently, there are over 1,300 publications that have focused on some facet of multimorbidity in the collection, which is updated three or four times a year. Details of this search are available from the corresponding author by request. The collection includes publications of all types, sorted among categories, including review articles and protocols, definition and conceptualization studies, clinical and epidemiological studies, economic studies, qualitative studies, editorials, and opinion articles. At

the time of conducting the scoping review, the collection included articles published until 2015.

For the study selection, only review articles and research studies were considered. This way, we retrieved lists of conditions that were created for the purposes of conducting a research study and lists that were proposed as a result of a literature review. A total of 44 publications containing such lists were selected, including two systematic reviews [1–3,10–50].

The next step was to aggregate the different lists from these 44 publications into a single list. We looked for consistencies and differences among the lists in order to identify the conditions that were repeated. The result of this process was a single list in which the conditions were collated and included only once. The final list contained a total of 131 conditions (see Supplementary Table 1). The types of conditions that made up the final list were very diverse. This list includes imprecise symptoms or complaints (e.g. faints, forgetfulness), groups of conditions (e.g. liver problems, respiratory problems) and precise medical diagnoses (e.g. myocardial infarction, acquired immune deficiency syndrome).

Criteria for selection of conditions

Before providing the arguments that we used to justify the selection of conditions from the collated list, we want to acknowledge that this is an arbitrary process and, therefore, it is always prone to criticism. Indeed, this limitation is inherent to any list of chronic conditions made for research purposes. This limitation can be alleviated through the use of validity measures, such as face validity and construct validity measurements.

Firstly, to classify a condition as "chronic", we adopted the criterion of duration of 12 months or more. Our choice of considering conditions that usually last 12 months or more was based on the World Health Organization's definition of chronic conditions, i.e. "health problems that require ongoing management over a period of years or decades" [51]. As the tool to be constructed was intended to be used in research studies in which the presence of conditions would be documented by self-report, we considered that the length of the list was important. In a systematic review on the prevalence of multimorbidity, the prevalence was substantially underestimated in studies using short lists of conditions, whereas not much variation was observed in those that considered 12 diagnoses or more [52]. Extrapolating this information from studies on multimorbidity prevalence, we decided that the minimal number of conditions to be included in the list would be 12. To set an upper limit for the number of conditions, we reasoned that a list too long could be cumbersome for many patients for self-reporting. In this sense, we took into account our experience using a questionnaire to

measure self-reported disease burden, described by Bayliss and colleagues [53]. This previous questionnaire included a list of 21 conditions and it has been used by our team with meaningful and valid results in studies conducted in primary care settings. Based on the above information, we arrived at the criterion of including between 12 and about 20 chronic conditions/categories of conditions in our final list.

The criteria that we considered for selecting 20 chronic conditions/categories of conditions to be included in the tool were: (1) their relevance to primary care services; (2) the impact on affected patients; (3) their prevalence among the primary care clientele; and (4) how often the conditions were present among the lists retrieved from the scoping review. We thought that writing precise medical diagnoses from a professional perspective in a self-reported questionnaire could be confusing for lay persons. It would be better to present the conditions in a rather general, understandable, inclusive, and self-explanatory way. Many conditions affecting the same body system were grouped together. For example, angina,

myocardial infarction, atrial fibrillation, and other heart diseases were grouped under a single category named "Cardiovascular disease". Also, for the sake of simplicity, we grouped together related conditions that could be confusing for non-professional research participants who might not distinguish the difference between them. For example, reflux, heartburn, and gastric ulcer could be grouped under a single category named "Stomach problem".

A list of chronic conditions/categories of conditions was prepared by two experts working on multimorbidity, and the final version was approved after consultation and review by researchers of the 12 CBPHC innovation teams.

Results

Taking into account the predefined criteria outlined above, we developed a list of 20 chronic conditions/ categories of conditions that could be self-reported (Table 1). As displayed in the Table 1, each condition/

Table 1 List of 20 chronic conditions and corresponding International Classification of Disease, 10th Revision (ICD-10), and International Classification of Primary Care, 2nd Edition (ICPC-2).

Chronic condition/chronic condition category	ICD-10 codes	ICPC-2 codes
Hypertension (high blood pressure)	I10-I15	K86, K87
Depression or anxiety	F33, F40, F41	P74, P76
Chronic musculoskeletal conditions causing pain or limitation	M40–M54, M60–M63, M65–M68, M70–M79	L83, L84, L86, L87, L92, L93
Arthritis and/or rheumatoid arthritis	M05.9, M13.0, M13.9, M15–M19	L88-L91
Osteoporosis	M81	L95
Asthma, chronic obstructive pulmonary disease (COPD), or chronic bronchitis	J40-J46	R79, R95, R96
Cardiovascular disease (angina, myocardial infarction, atrial fibrillation, poor circulation in the lower limbs)	I20, I25, I48, I70–I79	K74–K76, K78–K80, K92
Heart failure (including valve problems or replacement)	I05–I09, I34–I39, I42, I43, I50	K77, K83, K84
Stroke and transient ischemic attack	G45, I62	K89-K91
Stomach problem (reflux, heartburn, or gastric ulcer)	K21, K25.7, K29.5	D84–D87
Colon problem (irritable bowel, Crohn's disease, ulcerative colitis, diverticulosis)	K50-K52, K57, K58	D92-D94
Chronic hepatitis	K70–K77	D72 (only chronic), D97 (only hepatitis)
Diabetes	E10-E14	T89,T90
Thyroid disorder	E00-E07	T81,T85,T86
Any cancer in the previous 5 years (including melanoma, but excluding other skin cancers)	C00–C97	A79, B72, D74–D77, F74 (only malignant), H75, K72, L71, N74, R84, R85, S77 (only melanoma), T71, U75–U77, X75–X77, Y77, Y78
Kidney disease or failure	N18, N19	U88, U99 (only kidneys)
Chronic urinary problem	N03, N11, N18, N20– N23, N25–N29, N30– N39, N40–N51	U99 (only urinary tract),Y85
Dementia or Alzheimer's disease	F00–F03	P70
Hyperlipidemia (high cholesterol)	E78	T93
Obesity (diagnosed through the calculation of the body mass index)	E/6 E66	T82

category of condition translated into a number of diagnostic codes from the International Classification of Diseases, 10th Revision (ICD-10) classification system [54], which ranged from 1 to 98. Not surprisingly, the condition category with the most ICD-10 codes was Cancer (C00-C97), given that cancer from any system could be included. Only three conditions (Obesity, Hyperlipidemia, and Osteoporosis) corresponded to a single diagnostic code. Conditions/ categories of conditions were also translated into diagnostic codes of the International Classification of Primary Care, 2nd Edition (ICPC-2) [55]. The purpose of these diagnostic codes is to facilitate a link between self-reported chronic conditions and chronic conditions within electronic medical record or administrative data. This list can also be adapted for use in research studies that use primary data collection and secondary data sources.

Using the final list of conditions/categories of conditions, we made the questionnaire shown in Supplementary Table 2. The questionnaire was built using simple instructions and a table including the list of chronic conditions/condition categories. The instruction for respondents presented at the beginning of the questionnaire is: "For each of the following conditions, please indicate if you have the condition "yes" or "no". Check "yes" only for conditions that have been confirmed by a doctor or for which you are taking prescribed drugs."

By asking the respondents to only check "yes" or "no" for each condition, we are trying to avoid or minimize the presence of missing values and to be sure that the line with the condition was read. If respondents are asked just to mark the conditions which are present in his/her case, unmarked conditions could result from unseen conditions. The presence of Obesity may be interpreted differently by respondents. This variation can be a source of bias in the process of data collection. It is important to correctly document the presence of Obesity because it is a condition that often co-occurs with other chronic conditions [56-58]. The diagnosis of Obesity was omitted from the questionnaire and replaced by the request of reporting the most current height and weight of the patient to calculate the body mass index [BMI=weight in kg/(height in meters)²]. The presence of Obesity is determined if the BMI exceeds the normal range. We consider the presence of obesity when the BMI exceeds 30 kg/m², but this criterion might be adjusted for ethnicity. These BMI calculations could also be conducted when using electronic medical data.

The questionnaire also includes an item named "Other" to let respondents add any other condition that may have been diagnosed and should be included, but that is not mentioned in the final questionnaire.

Discussion

We have developed a questionnaire for research purposes to document the presence of multimorbidity that includes 20 conditions/categories of conditions selected after a process that considered their relevance to primary care services, the impact on affected patients, and their prevalence among the primary care clientele.

The number of publications reporting the burden and consequences of multimorbidity rises every year. In many publications, multimorbidity has been measured in unique ways, which means that the results of similar studies of prevalence are frequently hard to compare. A systematic review on available methods to measure the presence of multiple chronic conditions conducted in 2003 identified 12 indices, in addition to the simple disease count [59]. In a most recent systematic review, published in 2011, the number of indices had increased to 39 [1]. A finding in the latter systematic review was that in 59.0% of the studies identified, the list of diseases to measure multimorbidity was presented without any selection criteria.

More than a decade ago, Extermann wrote [60]: "A first element influencing the design of comorbidity indexes is the setting to which it is to be applied. One can distinguish essentially three settings, population-based epidemiological studies; clinical studies on chronic diseases; and clinical studies on acute diseases (often within an intensive care unit or a hospital setting)." For developing an index to measure multimorbidity, both the population where it is intended to be used and the outcome of interest should be taken into account [59]. However, very often this is not observed when developing indices, and rarely taken into consideration when using them. The use of the Charlson Comorbidity Index is the most prominent example. The Charlson Comorbidity Index was developed to be applied prospectively and to evaluate the risk of mortality in longitudinal studies [12]. The conditions included in the index were chosen due to their weight on the risk of mortality. It would be too long to include here the vast number of publications in which the Charlson Comorbidity Index has been used for a variety of outcomes other than mortality, such as in the prediction of postoperative sepsis, hospital readmission risk, future costs, physical function, and quality of life [61-66].

The questionnaire developed in this work, which is meant to be used in primary care settings, includes items in which several diseases were grouped under the name of a single condition category, such as "Chronic musculoskeletal conditions causing pain or limitation". This was designed to enhance the ease of completion for respondents. Furthermore, while the list includes only 20 items, in fact the tool has been mapped to many more diagnostic codes from the ICD-10 and ICPC-2. The

description of the corresponding ICD-10 and ICPC-2 codes will reinforce the external validity of this study and facilitate future applications. This construction is similar to the approach used for the Cumulative Illness Rating Scale (CIRS) [67], which includes 13 relatively independent areas or domains that are grouped under body systems. The purpose of the CIRS was to assess only physical impairment, but in a more comprehensive manner. Recently, a list of 75 chronic conditions most relevant to multimorbidity in family medicine was proposed [68]. This list was the result of the work of a panel of family medicine experts. In the present work, we considered that a list too long could be cumbersome for many patients in self-reporting, and decided to agree on a shorter list that would still create reasonable estimates of multimorbidity.

It should be noted that although an operational definition of multimorbidity has two major components - the list of conditions considered and the cutoff for the number of diagnoses until multimorbidity is identified only the list of conditions was considered in this work. Indeed, once researchers in the field of multimorbidity have agreed on a list of conditions, more than one cutoff can be used for identifying those living with multimorbidity. Authors may choose to report results using one or more cutoffs. The use of a common list of conditions in different research studies makes their comparison feasible, when all crude frequencies of participants in each category are reported, even in the case that different cutoffs are ultimately used. This is because it is known that a higher cutoff value, such as three or more chronic conditions, produces a lower prevalence of multimorbidity. With a common process of identifying those living with multimorbidity, studies can be interpreted accordingly.

The next step in the process of developing the questionnaire is its validation within a study sample. We are presently carrying out a validation study that, once completed, will complement the present article. We have described here the need to develop the questionnaire,

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the criteria for its development, the steps followed, and the final product that will be used in national CBPHC research on chronic conditions. This questionnaire might be useful to other researchers who are interested in the study of multimorbidity in primary care, particularly from the patient perspective.

A limitation of the questionnaire is the arbitrary component accompanying the development of any list of chronic conditions. Another limitation of this work is that the validation of the tool is not presented here, but will be reported in a forthcoming publication.

Conclusions

We have developed a questionnaire to document selfreported chronic conditions/categories of conditions intended to be used for research purposes in primary care. The list includes 20 conditions/categories of conditions selected for their relevance, impact, and prevalence among the primary care clientele. Guided by previous literature, the purpose of this questionnaire is to evaluate the self-reported burden of multimorbidity by participants and to encourage comparability among research studies that have used the same measurement.

Conflicts of interest

All authors declare that they have no competing interests.

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