A methodological proposal to research patients' demands and pre-test probabilities using paper forms in primary care settings

Uma proposta metodológica para pesquisar as demandas dos pacientes e probabilidades pré-teste através de formulários em papel na atenção primária

Una propuesta metodológica para investigar las demandas de los pacientes y las probabilidades pre-test a través de un formulario en papel en la atencion primaria

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Abstract

Objective: The purpose of this study is to present a methodology for assessing patients' demands and calculating pre-test probabilities using paper forms in Primary Care. **Method:** Most developing countries do not use Electronic Health Records (EHR) in primary care settings. This makes it difficult to access information regarding what occurs within the health center working process. Basically, there are two methodologies to assess patients' demands and problems or diagnosis stated by doctors. The first is based on single attendance at each appointment, while the second is based on episodes of care; the latter deals with each problem in a longitudinal manner. The methodology developed in this article followed the approach of confronting the 'reason for the appointment' and 'the problem registered' by doctors. Paper forms were developed taking this concept as central. All appointments were classified by the International Classification of Primary Care (ICPC). **Discussion:** Even in paper form, confrontation between 'reason for the appointment' and 'problem registered' is useful for measuring the pre-test probabilities of each problem-based appointment. This approach can be easily reproduced in any health center and enables a better understanding of population profile. Prevalence of many illnesses and diseases are not known in each reality, and studies conducted in other settings, such as secondary and tertiary care, are not adequate for primary health care. **Conclusion:** This study offers adequate technology for primary health care workers that have potential to transform each health center into a research-led practice, contributing directly to patient care.

Resumo

Objetivo: O propósito deste estudo é apresentar uma metodologia para avaliar as demandas dos pacientes e calcular probabilidades pré-teste utilizando formulário em papel na atenção primária. **Método:** A maioria dos países em desenvolvimento não usa registros eletrônicos de saúde (RES) em ambientes de cuidados primários. Isso dificulta o acesso a informações sobre o processo de trabalho dentro do centro de saúde. Existem basicamente duas metodologias para avaliar a demanda do paciente e problemas ou diagnósticos elaborados por médicos. A primeira se fundamenta em "encontro por encontro", enquanto a segunda, em "episódios de cuidados" de cada problema de uma forma longitudinal. A metodologia desenvolvida neste artigo foi a confrontação do "motivo da consulta" e do "problema registrado" pelos médicos. O formulário de papel que foi desenvolvido teve este conceito como central. Todas as consultas foram codificadas segundo a Classificação Internacional de Atenção Primária (CIAP). **Discussão:** Mesmo em formulário de papel, o confronto "motivo da consulta" e "problema registrado" pelos médicos é útil para medir as probabilidades pré-teste de cada problema com base em encontros. Essa abordagem pode facilmente ser reproduzida em qualquer centro de saúde e permite um melhor entendimento do perfil da população. A prevalência de muitas enfermidades e doenças não é conhecida em cada realidade e estudos feitos no contexto da atenção secundária e terciária não são adequados para os cuidados de saúde primários. **Conclusão:** Este artigo oferece uma tecnologia adequada aos trabalhadores de saúde de cuidados primários que tem potencial de transformar cada centro de saúde em um campo de pesquisa, contribuindo diretamente para o atendimento do paciente.

Resumen

Objetivo: el objetivo de este estudio es presentar una metodología para establecer las demandas de los pacientes y calcular las probabilidades *pre-test* utilizando formularios en la atención primaria. **Método:** La mayoría de los países en desarrollo no utilizan Registros Electrónicos de Salud (RES) en la asistencia primaria. Esto hace difícil acceder a la información sobre qué sucede durante el trabajo en un centro de salud. Hay básicamente dos metodologías para evaluar la demanda de los pacientes y los problemas o diagnósticos indicados por los médicos. La primera es "consulta a consulta", mientras que la segunda se basa en los "episodios de cuidado"; la última trata cada problema a largo plazo. La metodología desarrollada en este artículo adoptó el enfoque de enfrentarse a la "razón de la consulta" y el "problema" registrado por los médicos. El formulario fue desarrollado tomando esto concepto como central. Todas las consultas fueron codificadas por la Clasificación Internacional de Atención Primaria (CIAP). **Disción:** aún en el formulario en papel, la comparación entre la "razón de encuentro" y el "problema" registrado es útil para medir las probabilidades *pre-test* de cada consulta basada en un problema. Este enfoque puede ser fácilmente reproducido en cualquier centro de salud y puede permitir una mejor comprensión del perfil de la población. Las realidades de muchas enfermedades y su prevalencia no se conocen y estudios realizados en otros ámbitos, como la atención secundaria y terciaria de la salud, no son adecuados para la atención primaria **Conclusión:** el presente artículo ofrece una tecnología adecuada para los trabajadores de la atención primaria de la salud que tiene un potencial de transformar cada centro de salud en un campo de investigación, contribuyendo directamente con la atención del paciente.

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Introduction

Primary Health Care (PHC) became a better defined field during the second half of 20th century when health systems were more structured, especially after the Alma Ata Conference, in 1978. The work of Barbara Starfield was very important for this process[1-3]. She described PHC with four core attributes: access, longitudinality, comprehensive care and care coordination. It allowed governments to organize and better assess the primary health sector and to transform it in a cornerstone for health systems. However, to use health centre as a research field to evaluate the patients' demands for healthcare and working process is still incipient, even in developed countries with universal covered public health systems[4]. The advent of computerization and the use of Electronic Health Records (EHR) helped many countries and primary health professionals in this task; nevertheless EHR is not the reality in many developing countries. Most health centres in those places still work in a paper-based patient records and it is yet necessary the development of soft technologies for improving its use. In this regard, such technology might even help an adequate development of software for primary health care milieu.

In Brazil, Primary Health Care became more valued after the 1988 constitution that created the legal basis of Unified Health System (SUS), the Brazilian public health system of universal coverage[5]. In 1994 the government launched the Family Health Programme that settled teams of one general practitioner, one nurse, one or two assistant nurses and four to six health community agents in most cities which, currently covers more than fifty per cent of Brazilian population[6]. There are population-based studies showing positive outcomes such as the reduction of infant mortality,[7] but there are scarce studies focused on patients' demands and inherent issues to each health centre.

There are two ways to evaluate patients' demands in primary health care: the first one is based on "encounter by encounter" while the second is based on "episodes of care". In the first or Encounter Modality (EM) each consultation is evaluated as one single process. What is registered as patient complaint or "reason for encounter" usually is not linked to what the doctor has stated as problem or diagnosis*. This is the most common way to assess data in paper-based patient records in health centres[8,9]. However, to measure pre-test probabilities in a longitudinal and *Bayesian* manner, the best approach is to use the second one or Episode of Care Modality (ECM)[10]. Episode of Care is defined as "a health problem or disease from its first presentation to the health care provider to the last presentation for the same problem"[11] The strength of the ECM stems from this follow up process which cross-check the Reason For Encounter (RFE) with the final diagnosis. The Figure 1 exemplifies one episode of three encounters. Using this method it is possible to answer research questions such as "in a determined group of health centres what is the probability of one patient with weakness as main complaint to have a colon cancer?" In each encounter the problem (or diagnosis) labelled by one doctor might change or not. In the example, it changed from "weakness" to "unspecified anaemia" and then to "colon cancer". The disadvantage of the ECM is that in each consultation each episode (or problem) must be dealt separately or using what is called "sub-encounter". Another disadvantage is that it is difficult to incorporate this modality of recording medical information especially in paper-based patient records but in electronic format as well. However, it is possible to use some concepts of ECM and estimate pre-test probabilities of patients' demands for care in primary health centre. This article proposes a methodology for assessing patients' demands and to calculate the pre-test probabilities using paper form, based in the EM. Since it depends on the International Classification of Primary Care, what follows is a brief description of the ICPC and then the methodological approach will be discussed.

International Classification of Primary Care (ICPC): importance to research in primary care

Studies that use patient information in health centres require an appropriate classification system. Since the 50´s, general practitioner from many countries noted that the International Classification of Diseases (ICD) was not adequate to classify an encounter because around 50% of all patients' complaints are vague and cannot be classified as a disease[12] or they have spontaneous resolution[13,14]. Many groups started to research focusing in an appropriate classification system for using in primary care[15-17]. After many versions (Figure 2) and pilots, this group developed the International Classification of Primary Care (ICPC)[18-24]. It is available in many languages, including Brazilian Portuguese[25,26]. The ICPC has two axes of

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* Some demand studies call the doctor assessment "problem" and others "diagnosis".
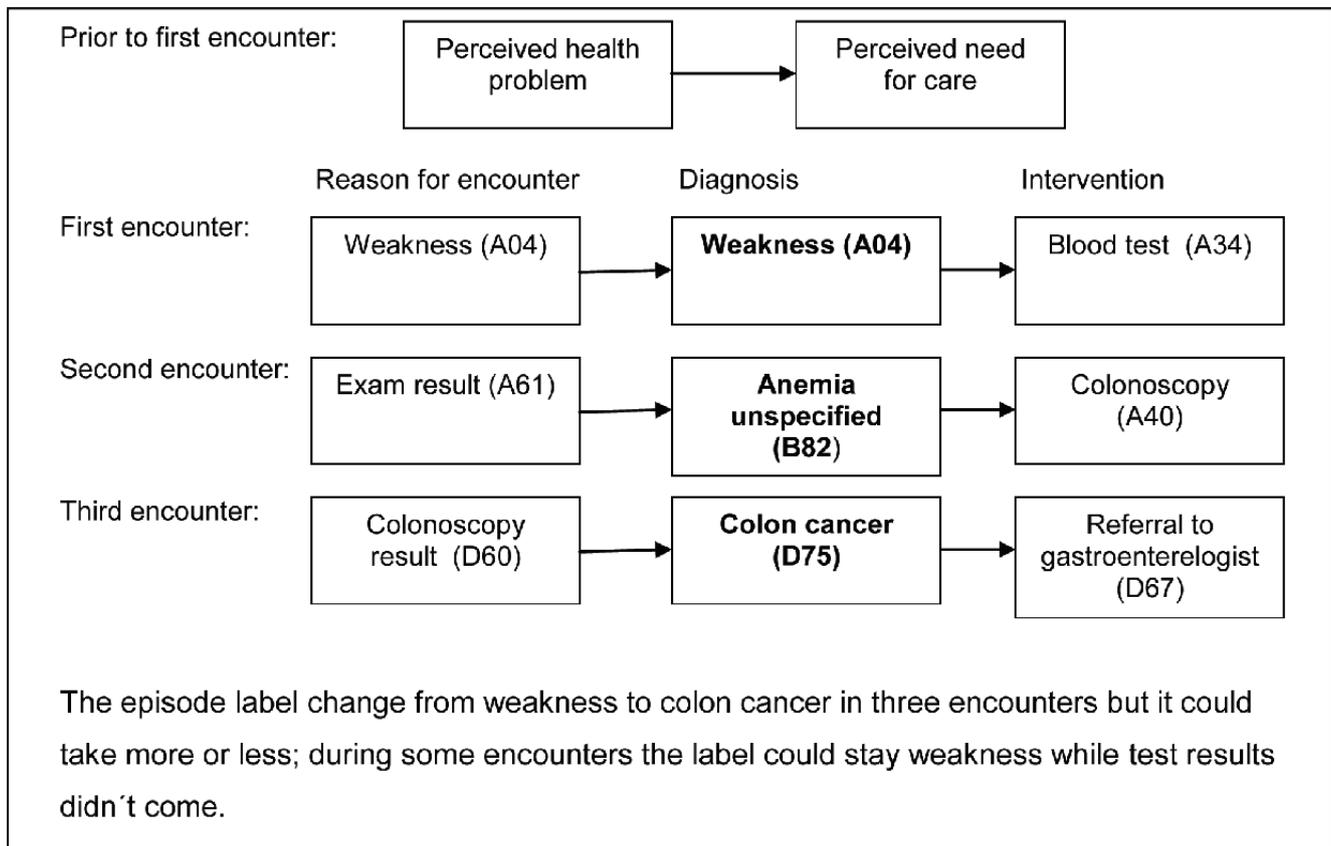
Prior to first encounter:

| Perceived health problem | → | Perceived need for care |

| | Reason for encounter | Diagnosis | Intervention |

First encounter:

| Weakness (A04) | → | **Weakness (A04)** | → | Blood test (A34) |

Second encounter:

| Exam result (A61) | → | **Anemia unspecified (B82)** | → | Colonoscopy (A40) |

Third encounter:

| Colonoscopy result (D60) | → | **Colon cancer (D75)** | → | Referral to gastroenterelogist (D67) |

The episode label change from weakness to colon cancer in three encounters but it could take more or less; during some encounters the label could stay weakness while test results didn´t come.

Figure 1. Example of one episode with three encounters (adapted from ICPC-2-R)[24].

| ICHPPC | ICHPPC - 2 | ICHPPC - 2 Defined | IC-Process-PC | ICPC -1 | ICPC -2 |

| 1965 | 1975 | 1979 | 1983 | 1986 | 1987 | 1989 | 1998 |

| ICD 8th | ICD 9 th | | | | ICD 10 th |

Legend:

ICD = International Classification of Diseases

ICHPPC = International Classification of Health Problems in Primary Care

IC-Process-PC = International Classification of Process in Primary Care

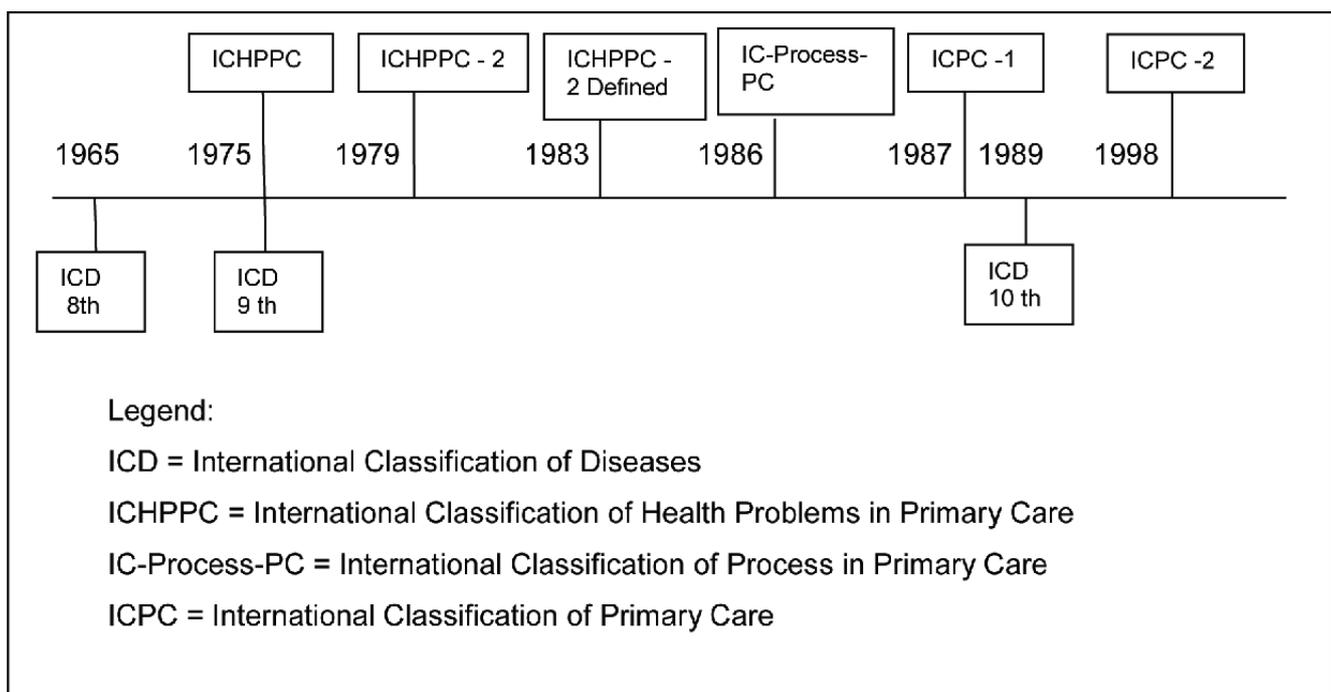ICPC = International Classification of Primary Care

Figure 2. Timeline – ICD and ICPC prior versions. ICD = International Classification of Diseases. ICHPPC = International Classification of Health Problems in Primary Care. IC-Process-PC = International Classification of Process in Primary Care. ICPC = International Classification of Primary Care.

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which the main has 17 chapters based on patient body that constitutes the major classification criteria, without information about the aetiology (Figure 3). The secondary axis has seven components: the first is related to signals and symptoms; from second to sixth are process codes (for example, blood test); and the seventh is related to diseases (with its aetiologies). This classification was designed to be used in primary care settings and can classify subjective (reason for encounter), assessment (problem, diagnosis or episode label) and plans (process). In the example of Figure 1 the codes in brackets belongs to ICPC. In order to code properly many basic rules must be followed, for example, it is allowed to use all components for reason for encounter but not process for problems[27].

chapters	A - general	B – blood, blood forming and	D – digestive	F – eye	H – ear	K – circulatory	L – músculoskeletal	N - neurological	P - psychological	R - respiratory	P - skin	T – endocrine, metabolic,nutritional	U - urological	W – pregnancy, child-bearing, family	X – female genital (X–chromossome)	Y – male genital (Y–chromossome)	Z – social problems
1 . complaint and symptoms component																	
2 – diagnostic, screening and preventive component																	
3 – medication, treatment, procedures component																	
4 – test results component																	
5 – administrative components																	
6 – referrals and other reason for encounter																	
7 - disease component: infectious diseases, neoplasms, injuries, congenital anomalies, other																	

(components for each chapter (standard))

Figure 3. ICPC biaxial structure.

Methods

The first challenge in this methodological approach was to develop a paper form that could be easily fulfilled by doctors during the consultation. It should be designed based on both concepts of EM and ECM. In the ECM, the confrontation of the reason for encounter (RFE) and the problem must be cross-checked (along the time) to enable the measurement of pre-test probabilities (Table 1). In a paper-based form it is difficult to use the longitudinality type of approach of the ECM, which requires continuing register of one problem in the forthcoming consultations in the same problem slot (called episode in the episode modality). For this reason, it was adopted the EM, since it is difficult to retrieve the same paper form in the subsequent consultation. Nevertheless, the paper form offers the possibility for confronting the RFE and the problem (or diagnosis) and this was the principal aim when the form was designed since the main questions were " (6) -which were the reasons for encounters that patient explained and (7) the problems or diagnosis that the doctor concluded for each reason for encounter" (Figure 4).

In paper forms are usually designed to be filled in free text by each family doctor. After that, one or more researchers, experts in classification, have to codify the information according to ICPC. When Electronic Health Record (EHR) is used to register the information instead of paper forms, each doctor have to code by him/herself and this involves a previous training in classification.

Table 1. Encounter and episode of care methods.

Encounter Modality (EM)	Episode of care Modality (ECM)
Lack of longitudinality	Longitudinal (analyze problems over time)
Easy in paper forms	Best with appropriate EHR
Not necessarily confronts reason for encounter and problem	Always confronts reason for encounter and problem
Registered as one single encounter	Need to split each problem in sub-encounters

1. Age (determine if years or months with y or m): _____ Ques _ _ _ _

2. Gender:
   (1) male   (2) female

   Idad _ _ _

   Gen _ _ _

3. Civil state:
   Child/ Adolescent (up to 18 years old) (1)   Single (2) Married (formally or informally) (3)   Estciv _ _ _
   Separated/ Divorced (4)   Widow (5)

4. Occupation:
   Student/ Child/ Adolescent (1)   Formal employment (2)   Informal employment (3)   Ocup _ _ _
   Unemployed (4)   Home worker (5)   Temporary work absence (6)   Retired/ Pensioner (7)

5. Nature of consultation: Natcons _ _ _
   A. Schedule consultation:
       Normal child (1)
       Pregnant (2)
       Hypertension/ DM2 control (3)
       Other special program (4)
       Schedule for other reason (5)
       Home visit (7)
   B. Same day consultation (6)

6. **Reasons for encounter- RFE** (same patient words):	7. **Problems/ Diagnosis** (diagnosed by FD; it might be same as RFE):
1.a	1.
1.b	
2.a	2.
2.b	
3.a	3.
3.b	

Motcons1 _ _ _
Motcons2 _ _ _
Motcons3 _ _ _

Diagn1 _ _ _ _
Diagn2 _ _ _ _
Diagn3 _ _ _ _

8. Plan:
   a. Referred to specialist?   Refspe _ _ _
       no (1)   yes (2)   Which? _____
                          _____
   b. Referred to another primary health care provider?   Refaphc _ _ _
       no (1)   yes (2)   Which? _____
                          _____
   c. Pathology: no (1) yes (2)   Pato _ _ _
       Blood (3)   Urine without culture (4)   Faeces (5)
       Culture (6)   Biopsy (7)   Other (8)
                                                                   Imag _ _ _
   d. Imaging: no (1) yes (2)
       X Ray (3)   ECG (4)   Endoscopy (5)   Colonoscopy (6)
       Ultrasound (7)   Echocardiography (8)   Tomography (9)   RMI(10) Other(11)

9. Medicine: Meduse _ _ _
       Prescribed drug?
       no (1)
       yes   Chronic use (2)
                      Drug used for a short period before or new drug (3)
                      Chronic use and new (4)

Figure 4. Form to be fulfilled by volunteer doctor.

In using this paper form, three main orientations should be given to doctors that will fill the form after consultations:
- Each consultation of the day has to be registered for posterior analyses, to minimize recall bias. One possibility is to ask doctors to fulfil the forms during five days each season, including one full typical day each week in five different weeks (one typical Monday per Winter, one typical Monday per summer and so on);
- In the "reason for encounter slot" (question 6 in Figure 4) doctors must write exactly what patient said without any interpretation; and

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- In the "diagnosis slot" (question 7 in Figure 4) doctors must only write down what is confirmed through clinical history, physical exams or complementary tests in the slot for "problems/ diagnoses", but never a hypothesis should be stated (in doubt leave it out, or better still repeat the 'patients word') .

In order to allow statistical software analysis, all International Classification of Primary Care 2ⁿᵈ edition (ICPC2) alphanumeric codes were transformed into numbers: chapter A became Chapter 1, Chapter B became Chapter 2, and so on. For example, code A01 was transformed in 101, A70 in 170, and K86 in 686. By definition, intervention codes (ranging from _30 to _69) are the same regardless the ICPC chapter. For example, if a blood test is requested for a cardiac problem it should be coded as K34, which means that in the paper form one should write down 634; if the same procedure is necessary to assess a patient with diabetes, the correct code is T34, but in the paper form should be marked 1234 (Table 2). All paper forms were codified and inserted in the database. The statistical analyses is simple, based only in frequencies, being possible to use excel or other software to calculate frequencies.

Table 2. Chapters transformed from alpha to numeric code.

1 – A: General and Unspecified
2 – B: Blood, Blood Forming Organs and Immune Mechanism
3 – D: Digestivo
4 – F: Eye
5 – H: Ear
6 – K: Cardiovascular
7 – L: Musculoskeletal
8 – N: Neurological
9 – P: Psychological
10 – R: Respiratory
11 – S: Skin
12 – T: Endocrine/Metabolic and Nutritional
13 – U: Urological
14 – W: Pregnancy, Childbearing, Family Planning
15 – X: Female Genital
16 – Y: Male Genital
17 – Z: Social Problems

In the proposed paper form, each line of questions 6ᵗʰ and 7ᵗʰ is coded by only one researcher who must be an expert in ICPC-2 and follow the guides, principles and rules set by WONCA International Classification Committee (WICC).

The base for the codification processes are two coloured sheets with ICPC-2 structure of codes and rubrics[27] and the criteria described in ICPC-2-R[12]. Because in this case codification is done without the presence of the patient but using the volunteer (doctors) notes, some situations requires interpretation of the real reason for encounter, especially to choose the best chapter. For instance, in chest pain as RFE, it can be used the correlated problem to decide if it was related to heart (K), lung (P), musculoskeletal (L) or even not specified (A). In other situations as "low weight" is important to check the age in the form to decide from 'weight loss" (T08) or "growth delay" (T10). The tools that might be used are:

- "ICPC2-ICD10 Thesaurus from Transition Project" (available in the CD Rom produced by "ICPC in the Amsterdam Transition Project"[28] that comes with ICPC-2-R): it has more than 80.000 concepts based on ICD10 terminology mapped to ICPC2 and ICD10;

- Medical Subject Headings (MeSH) or Bireme Health Science Descriptors (DeCS) if the research is in Portuguese[29]: to translate medical terms from Portuguese to English in order to research the respective ICPC-2 code in Thesaurus in the Transition Project; and

- Google translator[30]: to translate not specifically medical terms from Portuguese to English in order to looking for the respective code in the Thesaurus from the Transition Project.

In order to transform medical notes in codes many barriers must be transposed. If a translated ICPC is not available, it is important to translate at least the rubrics (translation of inclusions and exclusions criteria could be done in other moment).

During the codification process, sometimes it is important to use one Thesaurus (list of terms and its respective codes of one classification system)[28]. The Thesaurus available are in English and when there are doubts during the codification process the translation of terms to English to use the Thesaurus might be necessary. This method proposes Medical Subject Headings (MeSH)[29] and Google Translator[30] as tools, if they are available, but other tools can also be used. The following examples give a clear idea of how the codification task can be done and the solutions found using these tools. These examples are based on expressions and terms that can guide the classifier to reach the right code.

- Example of ICPC2/ ICD10 Thesaurus from the Transition Project used to achieve the right code: premature birth => A93 (premature newborn in ICPC);

- Example of Google translator plus ICPC2/ ICD10 Thesaurus from the Transition Project: reason for encounter = "coceira no olho" (portuguese) => coceira (Google translator) = itch => itch eye (ICPC2/ ICD10 thesaurus from the Transition Project) = F13 (eye sensation abnormal in ICPC); and

- Example of Medical Subject Headings (MeSH) plus ICPC2/ ICD10 Thesaurus from the Transition Project use: problem = "assadura" (portuguese) => exanthema (MeSH) = S06 (Rash localized in ICPC).

In the paper form, beside each slot, it is possible to put the codes of the software used for statistical analysis. For example, the encoder registered beside "premature birth" is 193 instead of ICPC code A93. Then all codes must be put in software used for the statistical analysis and it is possible to analyze data using frequencies. It is important to separate the reason for encounter 1a, 1b, 2a, 2b, 3a and 3b and the problem 1, 2 and 3 because reason for encounter 1a and 1b will be related to problem 1 and so on. A number of information can be retrieved from this methodology:

- Reason for encounters more frequent (joining 1a, 1b, 2a, 2b, 3a and 3b);

- Problems more frequent (joining 1, 2, 3);

- Reasons for encounters and problems according to the doctor;

- Reasons for encounters and problems by season;

- More frequent problems for one reason for encounter (example, main problems registered when reason for encounter was fever);

- More frequent reason for encounters for one problem (for example, reasons for encounter when problem was acute upper respiratory infection); and

- More frequent co-morbidity when problem was hypertension or other chronic diseases.

Most frequencies are measured using the most common reason for encounters or problems. As more consultations are analysed, the greater the possibilities for scrutinizing the results.

Discussion

The two main groups that study patients' demand in primary care are the Transition Project from Netherlands[28] and the Bettering the Evaluation And Care of Health (BEACH) from Australia[6]. The Transition Project is based on episodes of care applying software specially developed for this purpose. Ten to fifteen family doctors (some dropped off and some joined the group) use this device to classify all consultation since the 1990s. The Australian is a research group supported by pharmaceutical industry that uses different samples of family doctors each year. In their methodology, after each consultation, the volunteer must fulfil a paper form based on encounters but confronting just problem/diagnosis with the drug used but not with the reason for the encounter which constitutes a separated list. While in the Netherland's project each doctor puts the code based on ICPC during the consultation, the BEACH project uses research specialists in ICPC to classify what each doctor write as a free text.

The main methodological difference between BEACH and Transition Project is that the latter includes a longitudinal follow up (each problem is dealt separately again in the next consultation), as well as it confronts the RFEs with the problems or doctors' diagnosis. The Transition Project enables many possibilities of data analysis such as: how many consultations per

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year one diabetic patient makes on average for this problem specifically? What was the first signal or symptom of pneumonia? What are the main diagnoses when the RFE is fever? What are the main comorbidities of depressive patients? How seasonality affects the utilization of health care for each different problem? This approach enables a better understanding of prevalence of certain symptoms and problems in each health centre because, frequently, only prevalence from studies made in tertiary care are available. The main limitation in ECM is the necessity to split one consultation in two or three sub-encounters.

The method proposed here follows 'ECM' orientation allowing for up to three sub-encounters (questions 6 and 7 of Figure 4). For many family doctors and general practitioners it is not possible to split one consultation in sub-encounters because one sign or symptom might be linked with more than one problem and vice-versa. Software as TranHis[31] usually allows two different episodes to converge in one, as well as split one in two different ones in further consultations, but even using these tools it can be seen as artificial. However, the ECM is flexible and the recommendation is to leave the symptom as it is when the diagnosis is uncertain. On the other hand, ECM is more close to the way physicians think when needs to organize any individual history. Thus, the ECM is more precise, sophisticated and suitable for research purposes.

Brazil has not so much researches in this field[32-37]. Most of the studies evaluated only problems or diagnoses based on encounters and just two looked for the reason for the encounter[34,38]. The assessment of RFE, problems and pre-test probabilities is a fertile field of research in developing countries and the ICPC is adequate to be used in paper forms or in Electronic Health Record (EHR), either using the EM or the ECM.

Conclusion

The ECM, due to its complexity, can be used mainly in EHR as long as the register by episode, in each encounter, can be divided in sub-encounters (as more than one problem is dealt with separately). However, this approach might face great resistance from medical doctors as they may perceive it as an increase in their workload. The methodological approach presented in this article allows the collection of data from each consultation based on encounters, but incorporates the Episode of Care Modality reasoning. This gives possibilities for, even in a paper based practice to assess sophisticated data, as well as some pre-test probabilities. In summary, researchers should take this into account when choosing their research methodology.

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