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Qualitative Research

The search for person-related information in general practice: a qualitative study

Diego Schrans[a,*], Dirk Avonts[a], Thierry Christiaens[a], Sara Willems[a], Kaat de Smet[a], Kees van Boven[b], Pauline Boeckxstaens[a] and Thomas Kühlein[c]

[a]Department of Family Medicine and Primary Health Care, Ghent University, Ghent, Belgium, [b]Department of Primary and Community Care, Radboud University Nijmegen, Nijmegen, The Netherlands and [c]Allgemeinmedizinisches Institut, Universitätsklinikum Erlangen, Erlangen, Germany.

*Correspondence to Diego Schrans, Department of Family Medicine and Primary Health Care, UZ Gent 6K3, De Pintelaan 185, 9000 Gent, Belgium; E-mail: diego.schrans@ugent.be

Abstract

Background. General practice is person-focused. Contextual information influences the clinical decision-making process in primary care. Currently, person-related information (PeRI) is neither recorded in a systematic way nor coded in the electronic medical record (EMR), and therefore not usable for scientific use.
Aim. To search for classes of PeRI influencing the process of care.
Methods. GPs, from nine countries worldwide, were asked to write down narrative case histories where personal factors played a role in decision-making. In an inductive process, the case histories were consecutively coded according to classes of PeRI. The classes found were deductively applied to the following cases and refined, until saturation was reached. Then, the classes were grouped into code-families and further clustered into domains.
Results. The inductive analysis of 32 case histories resulted in 33 defined PeRI codes, classifying all personal-related information in the cases. The 33 codes were grouped in the following seven mutually exclusive code-families: 'aspects between patient and formal care provider', 'social environment and family', 'functioning/behaviour', 'life history/non-medical experiences', 'personal medical information', 'socio-demographics' and 'work-/employment-related information'. The code-families were clustered into four domains: 'social environment and extended family', 'medicine', 'individual' and 'work and employment'.
Conclusion. As PeRI is used in the process of decision-making, it should be part of the EMR. The PeRI classes we identified might form the basis of a new contextual classification mainly for research purposes. This might help to create evidence of the person-centredness of general practice.

Key words: Classification, electronic health records, general practice, illness behaviour, patient-centred care, quality of health care.

Introduction

Since its (re)introduction in the 1980s patient-centred care has moved from the periphery of medicine, as it was seen as a 'soft science', to a central role in health care (1). Patient-centred care can be defined as the care that honours and responds to individual patient preferences, needs, values and goals (2).

Evidence-based medicine (EBM) requires the integration of these unique values and circumstances with the best available research evidence and with clinical expertise (3). The integration of contextual factors in clinical practice is a hallmark of patient-centred care and a characteristic of good family medicine, as stated in the European definition of General Practice/Family Medicine (4). Attention to the

patient's context when planning care is associated with improved health care outcomes (5,6), and patient-centred decision-making is also associated with decreased health care utilization (7).

There is a distinction between patient-centred and person-focused care. Both are important but different since person-focused care is based on accumulated knowledge of people in a continuous relationship over time, while patient-centred care refers to interactions in single visits. Therefore, primary care is person-focused, not disease-focused care over time (8).

The medical knowledge that we have collected about our patients over time is nowadays largely available in an electronic health record (EHR). Recording and standardizing clinical information makes the content of patient care visible and interchangeable beyond the place of care. Classifying systems are developed to register clinical concepts, in a manner that facilitates recording and retrieval of clinical data (9). As a result, these data can be seen as resources for future clinical decision-making, audit, governance, research, education and training (10).

For this reason, the Wonca (World Organization of Family Physicians) International Classification Committee (WICC) developed and published the International Classification of Primary Care (ICPC) in 1987 (11). In family practice, ICPC takes the episode of care, including the patient's reason for encounter (RFE), the diagnostic label and the interventions, into account (12). The current version ICPC-2-R (13) is available in 36 languages and used in different countries as a classification tool for RFEs, and/or diagnoses or problems and/or processes of care (13,14). A first step in considering health issues more broadly than diagnoses, symptoms and processes was made with the inclusion of Chapter Z in the ICPC-2 (13) that defines social problems.

Beyond ICPC, the International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organization (WHO), describes health and health-related states of a person or a population in a biopsychosocial model. The framework maps and conceptualizes the relationship between six components of health: health condition, body functions and structures, activity, participation, environmental factors and personal factors. The component for personal factors is an empty placeholder at this moment.

Even if influencing the process of care, the person as a whole is not captured in the EHR yet. The ICPC-2 and the ICF are classifications developed to register interactions in a 'patient-centred way' and therefore lack the necessary vocabulary or structure to register and capture person-related aspects of care over time.

Some attempts have been made in order to gain an understanding of this contextual information. Stewart *et al.* (1) described in their famous book about patient-centred medicine proximal and distal factors. Weiner *et al.* (15) created a list of 10 contextual categories from theoretical concepts that were intended to serve as a useful differential for physicians when there are signs that a patient's life situation, or context, might interfere with health care services. These 10 contextual categories are: cognitive abilities, emotional state, cultural beliefs, spiritual beliefs, access to care, social support, caretaker responsibilities, attitude to illness, relationship with care providers and economic situation.

A recent systematic review of studies conducted to classify personal factors in relation to its use within the ICF (16) revealed that personal factors are relevant and useful in the application of the ICF in the clinical, administrative and research setting, and that there is a need of standardization of personal factors. None of the 79 eligible studies included were primary care based.

No tool or classification is currently available in primary care to register personal factors or contextual information. As a possible basis for adding the person focus to existing or future classifications, this study aimed to explore in an empiric way the person-related information (PeRI) that influences the care process in family medicine.

Methods

To know the person you must know something about the narrative or story (17). This is why PeRI was identified using the method of qualitative text analysis of narrative case histories collected from GPs (18).

Participants and data collection

Twelve WICC members were invited to this study. Nine agreed to participate as national coordinators, representing Austria, Belgium, Brazil, Germany, Ghana, Italy, Spain, The Netherlands and Vietnam. Representatives of Australia, South Africa and the USA did not participate because of the workload required to gain ethics approval. The national coordinators were asked to either recruit GPs as participants or to serve as participants themselves. Participants were asked to provide two to five case histories of consultations in which personal information of the patient played an important role in the decision-making process. All case histories were written down or translated by the national coordinators into English.

Data analysis

The written case histories were transferred into RQDA (19), a software package used for qualitative analysis.

First, three researchers (DS, TK and KdS) independently coded the first case history inductively creating classes of PeRI. Subsequently, the classes were discussed and defined among the three researchers together with a fourth researcher (KvB) until consensus was reached. This triangulation enhanced objectivity in data analysis and contributed to exhaustive exploitation of the data (20). The classes identified in the first case history were deductively applied to the content of the second case history. If necessary, the classes from the first case history were refined and emerging new codes and their definitions were discussed until consensus was reached. This process of independent coding, defining and discussing continued until no new classes were identified. The remaining case histories were subsequently coded by two of the authors (TK and KdS).

Secondly, the classes and their codes were independently grouped into 'code-families' by each of the three researchers (DS, TK and KdS). Again, these code-families were discussed and refined until consensus was reached.

Thirdly, each researcher independently clustered the code-families into code-domains. The clustering was subject of a final round of discussion and consensus.

Results

There were 32 case histories available for analysis (two to four case histories per country). Inductive analysis revealed 33 different defined classes of PeRI. After the analysis of case 25, no new classes emerged, and there was no more need to adapt or refine the definitions. These classes were grouped in seven clearly defined and mutually exclusive 'code-families'.

The seven code-families are: 'aspects between patient and formal care provider', 'social environment and family', 'functionality and behaviour', 'life history and non-medical experiences', 'contextual medical information', 'socio-demographics' and 'work- and employment-related information'.

The definitions of the code-families are displayed in Table 1.

Table 1. Definitions of the seven PeRI 'code-families'

Code-families	Definition
Social environment and family	All influences from the family or social background including cultural aspects, housing conditions, familial support and functionality of informal care that influence the process of care.
Socio-demographics	Objective data about the patient that influence for the process of care such as age, gender, marital status, ethnicity, profession, housing conditions and socio-economic status of the patient.
Aspects between patient and formal care provider	All aspects in the relationship of patient and physician including the functionality of the encounter from technical (home visit, out of hour) to communication aspects, ideas, concerns, expectations, former experiences with medical care and concordance that influence the process of care.
Contextual medical information	All aspects of personal medical history like co-morbidity, multi-morbidity or side effects that influence the process of care.
Functionality and behaviour	All physical, mental, social and spiritual aspects, beliefs and choices including emotions, coping, preferences, personality and lifestyle that influence the process of care.
Life history and non-medical experiences	All information that comes from the patients' life history that has an influence on the process of care.
Work- and employment-related information	All aspects concerning paid or unpaid work and employment of the patient (including unemployment) that influence the process of care.

In the final step, the seven code-families were clustered into four domains: 'individual', 'social environment and demographics', 'medicine' and 'work and employment'. Table 2 gives an overview of the final structure.

Discussion

Summary

We found that 33 PeRI classes covered all PeRI in our case histories. These 33 classes could be grouped into seven mutually exclusive code-families, which in turn could be clustered into four domains.

Strengths and limitations

For methodological reasons, it was not feasible to capture all possible PeRI in a qualitative study. Instead, we give a first approximate overview of what PeRI in primary care might consist of.

The method chosen, starting from case histories, ensured that we were able to categorize PeRI by active GPs. Since the story is told by the GP, some information might have been missed. On the other hand, it is the GPs' task to elicit, capture and use PeRI in decision-making. Hence, the way stories were told by the GPs is a very valuable source of this study. This 'empirical' approach was independent of existing frameworks or classification systems. To our knowledge, this is the first attempt to capture PeRI in this empiric way. We do realize that this is a first step and further research, with different methods, is needed to confirm the completeness and usefulness of the codes and classes we found and to add more if necessary.

We could have used other methods to identify classes of PeRI such as analysing videos of consultations. However, the act of videoing the consultation is visit based, whereas we were aiming at capturing the accumulated knowledge in a person-focused approach. Furthermore, the thought process of the physician would have been missed in a video approach.

PeRI classes found in existing frameworks and literature

Every contextual category in Weiner's list (15) is comparable but not similar to the PeRI code-families we found. They can all be mapped to the PeRI code-families or classes we found in this study. However, as there is overlap, there is not a one-to-one relationship, and it seems that the mapping of three PeRI code-families: contextual medical information, life history and non-medical experiences,

work- and employment-related information, is not straightforward. One can say that Weiner's 10 contextual categories were present in the case histories we received from GPs worldwide and even extra code-families were found. Further studies will identify what classes of PeRI might have been missed in our case histories.

ICPC-2 classifies three important elements of the patient–doctor encounter: the RFE, the process of care and the diagnoses or problems. The PeRI classes we identified sit beside such morbidity data because they are not necessarily related to a single specific problem or diagnosis. Thus, they are not related to a single episode of care and also transcend the different chapters of the ICPC. Just adding PeRI classes to Chapter Z is probably not the way to go. They will probably have to be recorded in an extra place of the EHR and tagged when they influence a care process.

As stated earlier, the component of personal factors in ICF is currently a 'placeholder'. However, it cannot simply be populated with the PeRI classes, as some of these can already be found in other components of ICF. A further study is required to identify which PeRI classes or code-families are already available in different classifications and nomenclatures, and whether it is possible to use them for registering contextual information.

Implications for research and/or practice

Knowing the patient, and by extension, understanding the whole person, is an important attribute of patient-centred care (2). Sweeney advocated to add personal significance as a third dimension on top of the statistical and clinical significance to transpose population-derived knowledge to the individual person (21). Coded registration of PeRI in the electronic medical record and analysis might be the way to render this personal significance visible for scientific reasons. Good doctors are not those who uniformly apply a standard to every patient, but those who correctly modify and adapt the best available knowledge to the circumstances, and to the preferences, needs and goals of the individual patient. This is the way Sackett (22) originally proposed EBM should be practiced. However, this contextual information—the personal factors—is usually not considered in clinical guidelines, which rely on randomized clinical trials (RCTs) as the 'gold standard' for the solution of health problems. In RCTs, specific patient characteristics are seen as confounding factors to be eliminated by the research design (23,24). This study revealed classes of PeRI that can be found in narrative case histories of GPs worldwide. Our PeRI classes might

Table 2. Found domains, code-families, classes and quotes of PeRI

Domains	Code-families	Classes	Reference, example, quotes
Social environment and demographics	Social environment and family	Cultural aspects	'started working as a pastor in a charismatic church'
		Family background	'father who started the farm 40 years ago as an immigrant'
		Functionality of informal care	'he had no contact with his family'
		Housing conditions	'patient lives alone in a detached house in a rural and isolated area'
		Influences of social context	'husband has insisted that she gets the lump removed as soon as possible'
	Socio-demographics	Age	'87 years old'
		Educational level	'highly educated lady'
		Family state	'she was a single parent of two children'
		Gender	'female'
		Socio-economic status	'no pension, no health insurance at all'
Medical	Aspects between patient and formal care provider	Communication aspects	'she speaks the local language perfectly'
		Concordance/adherence	'not had the blood tests and investigations (ECG) recently prescribed'
		Connectivity	'unable to drive and there is no public transport in that area'
		Experience with medical care	'afraid of …surgical procedure due to the bad experience she had'
		Feeling overwhelmed by medical demands	'He feels a bit overwhelmed by all this'
		Functionality of formal care	'the daughter thinks that the caregiver is inadequate…'
		Ideas, concerns, expectations (ICE)	'thinks something is wrong with her tensons…and asks for an X-ray'
		Kind of consultation	'brought by a neighbour'
		Relationship towards disease (underst./emot.)	'he cannot believe he has such a disease'
		Relationship towards health care provider	'know her since 2 years'
	Contextual medical information	Co-morbidity	'her osteoarthritis further complicated the situation'
		Multi-morbidity	'affected by cardiac failure (III NYHA), diabetes, hypertension'
		Side effect and contraindication	'make him go to the toilet to pass water quite frequently'
		Dependency	'sits in his chair and his wife is taking care of him'
Individual	Functionality and behaviour	(Dis)ability, mental/physical	'all long term and short term memories are reduced'
		Emotional aspects	'she is never cheerful when I see her'
		Health behaviour	'infrequent attender in the past'
		Legal problem	'seized by the police because she was caught…without insurance'
		Personality/lifestyle	'is an anxious boy and very demanding of himself'
		Preference	'Never did HIV and doesn't want to test for it'
	Life history and non-medical experiences	Personal history	'she was well till the above complaint started'
		Traumatic experience	'resulting from a dramatic event in the sixties, when he was a young…'
Work and employment	Work- and employment-related information	Work circumstances	'six months ago he was dismissed from one of his two jobs'

form the basis of a classification in the future or a basis to expend existing classifications. The classification then might be used in further research to collect data on patients' personal factors and circumstances that (together with research evidence) influence our decisions in primary care.

Acknowledgements

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