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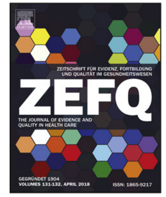

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The road to patient-centred care in Peru: The difficulties and opportunities to achieve participatory health care

Auf dem Weg zu einer patientenzentrierten Versorgung in Peru: Schwierigkeiten und Chancen bei der Realisierung von partizipativer Gesundheitsversorgung

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ABSTRACT

Patient-centred care (PCC) is a pillar of quality health services, where decision-making power is shared between the clinician and the patient. Although, this approach could be adopted with easiness in high income settings or in countries with unified health systems, in settings such as Peru, where universal access and other structural problems remain a challenge, the practice of PCC is not a priority. In Peru, research on PCC has been conducted for almost two decades, but this has not generated a need for development in academia, decision makers, health personnel or patients. Here, we give an overview of the road that PCC research has taken in Peru and the challenges that remain to translate it into clinical practice.

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ZUSAMMENFASSUNG

Patientenzentrierte Versorgung (PCC) ist eine der Säulen eines qualitativ hochwertigen Gesundheitssystems, in dem sich Arzt und Patient die Entscheidungsverantwortung teilen. Obwohl sich ein solches Konzept in einkommensstarken Gebieten oder in Ländern mit einheitlichen Gesundheitssystemen problemlos einführen ließe, wird der Umsetzung von PCC in Ländern wie Peru, in denen der allgemeine Zugang zur Gesundheitsversorgung sowie andere strukturelle Probleme nach wie vor eine Herausforderung darstellen, keine Priorität eingeräumt. In Peru wird seit beinahe zwei Jahrzehnten zu PCC geforscht, doch hat dies in der akademischen Welt sowie bei Entscheidungsträgern, Gesundheitsfachkräften oder Patienten bislang keinen Entwicklungsbedarf hervorgerufen. In diesem Beitrag geben wir einen Überblick über die bisherige Forschung zu PCC in Peru und skizzieren die Herausforderungen, die bei der Umsetzung von PCC in die klinische Praxis zu meistern sein werden.

Introduction

At the beginning of the century, the US Institute of Medicine called for patient centredness as a key to "cross the healthcare quality chasm" [1]. Patient Centred Care (PCC) is a model of healthcare where the patient is involved in the whole medical process, from assessing their needs, planning their care, and overall sharing the power of making decisions [2]. Shared decision making (SDM) is the cornerstone of PCC as opposed to other models where the physician monopolises power such as the paternalistic and clinician-as-perfect-agent approaches [3]. This concept goes hand in hand with the shift in health challenges brought by the

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epidemiological transition. If before, patients were passive subjects in the medical act and received care to cure acute infections, with the increase in life expectancy and the prevalence of chronic diseases, patients take a more active role in the disease [4]. Living with a condition makes a patient an expert in it, and chronic conditions have self-care as the basis of their management, so patient involvement is the key for best treatment outcomes.

Much of the evidence about the effectiveness of implementing this approach comes from countries with unified healthcare systems [4] or well-funded clinics and healthcare institutions [5]. These realities are far from the health systems of countries in the global south characterised by underfunding and structural problems that date back decades, which, in addition, must have been corroded by the ravages of the pandemic.

In fact, in low- and middle-income countries, these structural problems are perceived as the reason for the deficiency in incorporating evidence into public policy and decision-making [6]. There were initiatives in Peru to address this issue, specifically, the creation of a specialised unit for the generation of public health evidence within the National Institute of Health [7]. However, in the context of COVID-19, the country has shown unfortunate results for evidence-based medicine, reporting one of the world's worst record in excess death rates and COVID-19 mortality [8]. One of the main reasons for this include the lack of evidence behind governmental decisions. As such, the health authority published guidelines without proper evidence assessment including recommendations for drugs that were proven not effective [9]. This could show how the focus remains on the disease rather than in the patient who faces this disease.

In recent years Peru has experienced serious political and social crises that can be summarised as having 5 presidents in the last 5 years, an inflation rate of 6.4%[10] and, 95 active social conflicts by the beginning of 2022, 27 of which are at critical or imminent risk [11]. Despite facing concrete health challenges such as the COVID-19 pandemic, many structural changes in the health system are not seen as a priority in such circumstances by relevant stakeholders.

Here we argue that despite research being done in the matter, in Peru, something as fundamental as drawing attention to the need for the implementation of the SDM approach to medicine and its translation into clinical encounters where patient-centred care plays an essential role and, above all, where evidence is the bridge that links research, clinical practice, and public policy is yet to be achieved.

The Peruvian healthcare system

Peru's healthcare system is characterized by heavy fragmentation with intertwined healthcare models. According to national statistics, around 75% of the population have some type of healthcare insurance [12]. Almost 50% of the population has as its only insurance the Integral Health Insurance (SIS), a Beveridge-type healthcare model managed by the Ministry of Health and aimed at the economically vulnerable population. EsSalud is the main insurance of 22.7% of the population; EsSalud is administered by the Ministry of Labour and aims to provide health services to public and private workers and their families. It is financed by monthly payroll deductions. Similarly, the Armed Forces (FF.AA) and Police (PNP) have their own healthcare system for their active and retired personnel and their families. In the private system, there is a wide range of insurance companies for people with greater means [13]. It is important to note that the inequities between the different health care systems expressed in the long waiting times and the lack of some supplies or medicines in healthcare facilities in both models translates into patients having to resort to out-of-pocket expenses frequently despite the insurance system they belong to [14-16]. The consequence of this is a lack of continuity of care, a particularly sensitive situation for people living with chronic diseases.

Legislative efforts to promote PCC and SDM

Legislative efforts on PCC in Peru are scarce. The terms PCC and SDM are not included explicitly in the Clinical Practice Guidelines. Patient autonomy is recognised as a basic right of every patient according to the General Health Law, and its highest expression is the informed consent, which is defined as a written document that makes the information and decision-making process for medical procedures visible. However, in 2018, the National Superintendence of Health (SUSALUD) warned that this document was not being adequately applied in healthcare institutions and that numerous deficiencies had been detected, including as main concern the lack of information provided to the patient so they could make informed decisions. Interestingly, SUSALUD warned that this document should not be seen only as a way of practising medicine in a defensive manner hence, this would make the informed consent a manifestation of the loss of trust in the doctor-patient relationship. They conclude that there is a pressing need "to foster a culture of communication to inform the patient, so that in the current context, the informed consent does not become at all denatured of its fundamental purpose" [17].

The reasoning presented by the SUSALUD is considered a milestone as it identifies the major shortcoming of an informed consent, that is currently focusing on physician disclosure rather than in the patient understanding risks and benefits of the treatments [18]. This is particularly important in a culturally, ethnically, and linguistically diverse country as Peru, where values, beliefs and health literacy play a key role in the decision-making process.

Patient Centred Care and Shared decision making in Peru

Although little process has been achieved in the country to implement PCC and SDM, Peru has been the only Latin American country that has hosted the ISDM conference (2013). The focus of the ISDM 2013 conference was on the need to use an evidence-based medicine approach to inform PCC, thus promoting its adoption even though this was proving to be a painfully complicated and time-consuming process [19].

Kitson *et al* [17] identified three core elements of PCC in both research literature and policy: 1) patient participation, 2) relationship between the patient and the healthcare provider and 3) the context. In Peru, research has been done in these three areas but somehow, there is an imbalance. There are studies on the lack of training and the absence of PCC in national medical curricula and a small but growing number of articles on patient involvement: from choosing a course of pharmacological treatment among various options [20] to the identification of PCC as an essential factor in improving the patient experience [21]. However, there is a clear lack of research about how SDM and PCC could be implemented (Table 1). Given the inherently complex nature of the Peruvian Health System, research should be focused on assessing initiatives that follow a SDM approach in the different healthcare models available in the country. Stakeholders and decision makers should also be involved in these phases of research to properly ascertain the barriers and facilitators to implement PCC in Peru.

Efforts to generate evidence for the adoption of patient-centred approaches are still insufficient, even more so after seeing the devastating effects of policies that are not informed by evidence in health catastrophe contexts such as COVID-19. In Peru, the studies that have been carried out do not seem to have reached beyond a few research groups that have taken an incipient interest

Table 1
Summary of findings involving the three cores of PCC and SDM in Peru

Core	Objective	Results	Reference
Patient participation	Analysed SDM uptake in psoriasis patients following consecutive patient meetings	Higher satisfaction of patients who were given enough information about treatments. ~77% patients thought decisions should be made jointly but only ~39% did so	Tapia et al [22]
	Qualitative study assessing SDM practices in pregnant women with a prior C-section eligible for a trial of labour	9/17 women stated they were appropriately informed about all labour options, 6/17 did not received any information and 2/17 only received information about one delivery option	Lazo-Porras et al [23].
	Qualitative study assessing preference between several pharmacological treatment options for people with latent tuberculosis	People with latent TB (close contact and families of TB patients) prefer short, easy-to-remember, and non-disruptive treatments, as well as child friendly formulations	Yuen et al [20].
Relationship between the patient and healthcare provider (includes training resources and personnel)	Women with reproductive cancers and providers were interviewed to identify factors associated with positive cancer experiences	Genuine, individualised, patient centred care was identified as a core for positive cancer experiences	Nevin et al [21]
	Surveyed perceptions of medical students towards different approaches in decision making. By the time of this survey, no proper training in SDM was included in the national curricula	Half of the participants thought SDM is feasible in Peru and ~54% thought it should be the preferred approach towards decision making.	Zevallos Palacios et al [24].
Context	Compared clinician and patient involvement in decision making in Peru's private vs public settings.	No difference between PCC approaches in public vs private but patient involvement was diminished in public settings	Mongilardi et al [25]

in the topic. There has been no massive interest from educational institutions or medical associations in updating curricula to improve the skills of future health professionals in PCC. It seems as if the need to adopt this approach has not yet been generated at any level.

To achieve a measurable shift in this trend, we consider that future research is needed. Nevertheless, to be coherent with our advocacy for the involvement of patients in medical decisions concerning their health, we also believe patients should be involved in research concerning their health. This is by far a novelty; participatory research is increasingly being used in research practice nowadays and stems from the need to ensure patient involvement. This is much more than just reporting and disseminating research results. Rather, using the same principles of PCC, it involves the participant more directly in research that is done on them or their condition. However, this is more difficult to implement than to define. For a good participatory research project, people must be involved from the conception of the research idea, initial stages of question formulation that need not only time but also funding. Major funding bodies in the world require patient and public involvement as a core of any research proposal as it increases the chances of meaningful questions being asked and greater impact. In Peru, the main public funding body is the Council for Science Technology and Innovation (CONCYTEC). Schemes to fund earlier or formative stages of research proposals are not contemplated by CONCYTEC, especially not in health and social research. Participants need to be trained in basic scientific methods, ideally with a defined advisory group that can participate when necessary. And, above all, they should be adequately remunerated in the same way that an expert in a research topic is. This is not contemplated in CONCYTEC funding schemes.

Concluding remarks

Approaches that involve the patient in decision-making are essential to ensure quality health services and a humanised model of medical practice. In Peru, research projects that focused on PCC and SDM initiated more than 15 years ago and have intended to be the seed of a change in the way medicine is practised in the country. However, considering the fragmented health system and the difficulties to guarantee universal healthcare, the implementation of PCC and SDM is not perceived to be a necessity. Despite the efforts presented in this article, the uptake of PCC and SDM as training priorities by the academic community and as a clinical challenge for decision-makers remain insufficient. The future development of PCC in Peru is uncertain in a context of socio-political crisis, thus research efforts should consider a new road where PCC is presented (with local evidence) to advance in quality of healthcare for the Peruvian population.

Conflict of interest

All authors declare that there is no conflict of interest.

CRediT author statement

Dulce E. Alarcon-Yaquetto: Conceptualization, writing-original draft preparation. Aldo de Ferrari: Writing-Reviewing and Editing. German Malaga: Conceptualization, writing-original draft preparation, Supervision.

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