

What is patient-centered care as defined from the patient perspective?

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Background

Redesigning health and social care towards patient-centered care (PCC) is a topic on the political agenda in many countries. Various health care providers proclaim that they provide PCC. Even though several concepts of PCC exist, the concept remains diffuse. Additionally, existing models were either not developed in cooperation with patients or addressed only specific settings of care. The aim of this study was to provide a comprehensive understanding of the attributes characterizing PCC from the patients' perspective.

Methods

Semi-structured individual interviews were conducted with patients suffering from at least one chronic disease. Patients were recruited via newspaper advertisement, physician offices and nursing homes. Maximum variety sampling was used to represent different types of diseases, age groups, and personal life situations. The interviews were audiotaped, transcribed verbatim, and analyzed according to qualitative content analysis approach using MAXQDA. Coding schemes were developed deductively based on existing models of PCC and refined inductively through the analysis.

Results

25 patients with chronic diseases (e.g. diabetes mellitus, cancer, COPD, depression) participated in individual interviews with an average duration of 44 minutes. Participants' age ranged from 20-75 years, 32% were male, and 11 (44%) participants had a degree of disability of $\geq 40\%$. Based on data coding, participants' statements could broadly be clustered into three levels: micro, meso and macro level of attributes which characterize the implementation of PCC.

Macro Level (e.g. health care system, health policy, laws)

I have so many medical papers, sure, I sorted and stored them at home, but especially with these thrombosis things [coagulation disorder]. Yes, but there should be something uniform so that you can provide your physician with a complete medical file. Yes, because [...] often when I am asked about my medical records I cannot remember which year it was and I have to look it up [...] I do not know whether this [digital uniform medical record] would be possible regarding data protection laws.

I think it should be controlled by some institution and physicians should not be in competition [...] such a public health system where physicians are unbribable civil servants [...] then privately insured patients would not be abused as employment-creation measures.

And I like it more here in Germany, this freedom you have [for choosing a physician].

And that it really plays an important role what kind of insurance you have. Many (care provider) ask „which is your sickness fund?“ and this gives you a bad feeling.

So all these co-payments for the insurance, I have to say that it is a lot for me sometimes [...] There should be common rules, sometimes you have to make co-payments or almost always, sometimes it's more sometimes it's less. [...] I do not know what to change about this, but I really notice this, when I have to pay in addition to my insurance fee.

Meso Level (e.g. health care organisations)

It changes quickly. One day one person does the ward round, another day another person [...] For me personally it is very difficult to adjust to new people.

It is nice if there is some kind of routine and processes are clear and, well... it gets difficult, if routines are that rigid that there is no room for interruption or special cases.

I felt really well in this hospital, because I was already welcomed and looked after at the registration, advised in relation to surgery, anaesthesia and that they tried to relieve my fear. And then they also explained my situation afterwards, how follow-up care will work, in a way that I could also discuss this with my family.

I would like to have more of these larger health care centers, where they have everything, [...] all physicians, rehabilitation, physiotherapists, large centers, which need to have a really good network among each other, smooth, this is a challenge for developers.

[...] not in the operating theater, but a waiting room [...] but I was lying there all alone, they left me for four hours, my family was worried. I was supposed to be operated at 12am, but nothing happened and nobody told me [...] later a cleaning lady passed by and said „oh you are still here“. [...] They said there was an emergency case and I will be operated in the evening. And I was lying there all the time and then somebody came „No, it does not fit in our schedule anymore.“ And then I was operated the next day.

Micro Level (e.g. individual interactions between patient and care providers)

She is relaxed, she does not use physician jargon, well, she talks in an understandable way, this is what is pleasant and empathic [...] and she does this cautiously and explains and lets me know before she does something and how and why she does this.

[...] that he does not sit in front of you, handling his papers without looking at you.

A situation where I felt really lonely was when my breast cancer was diagnosed. [...] There was a young physician, I assume they sent her to present this diagnosis. [...] She said „you can sit here in this room until you feel better [...] Looking back, I think, this poor woman, this young woman, she was probably overwhelmed with my case.

It was very good, you had the feeling that you were informed very well. There were many forms. You had a lot of time to read them. And to ask questions. And you had the feeling that they really cared for you.

[Patient with coagulation disorder, having painful leg] He [Physician] checked the blood flow in my leg and said everything was normal. I said, that this can't be true since I did not do any sport or so [...] and the next day the vascular surgeon diagnosed a deep vein thrombosis.

So for me it is important that I, in case I realized that the medical competence is there, but I do not really get along with this person, then it is important for me to express this.

Discussion

Results illustrate that existing models of PCC include a variety of characteristics of PCC, but should be adapted as such that more actors are addressed including e.g. policy makers, insurance companies or self-help groups. In addition to the processes of care, providing effective care is a core element of PCC that is currently not emphasized sufficiently. The results provide starting points for health care redesign towards more PCC based on patients' suggestions.