

## Chronic Patients' Values Associated to Continuity of Care – the Results of Qualitative Study

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The aim of this paper is to identify chronic patients' experiences and values associated to continuity in care in integrated health care settings in Poland. The author answers two major research questions: (1) what variables do patients perceive to be significant in the continuity of care?, (2) how can the isolated elements be grouped in order to establish a model of evaluating patient care quality in the respect of continuity of care? Applying the qualitative study, focus group interview with 10 chronic ill patients has been carried. Collected responses were analysed thematically and grouped into dimensions of continuity of care. A patient-based framework for evaluating continuity of care was developed. 8 central categories and 36 sub-dimensions were constructed, that allow quality of integrated health care to be examined holistically. The following central dimensions of experienced continuity of care were identified: patients' involvement, decision-making support, cross-boundary continuity, coordination of activities, communication with the patient, problem solving, flexibility and availability, and patient-centeredness. This study develops a patient-based framework for evaluating continuity of care. It also identifies key transition points with problems of lack of continuity.

**Keywords:** continuity of care, patient perceptions, chronic care, quality indicators, Poland.

## Wartości przypisywane ciągłości opieki przez pacjentów przewlekle chorych – wyniki badania jakościowego

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Celem niniejszego artykułu jest identyfikacja doświadczeń pacjentów przewlekle chorych i wartości przypisywanych przez tych pacjentów ciągłości opieki w polskich podmiotach leczniczych. Autorka odpowiada na dwa główne pytania badawcze: (1) jakie czynniki pacjenci postrzegają jako istotne dla ciągłości opieki?, (2) w jaki sposób można te elementy pogrupować w celu stworzenia modelu oceny jakości opieki nad pacjentem w kontekście ciągłości opieki? Stosując analizę jakościową, przeprowadzono zogniskowany wywiad grupowy z 10 pacjentami przewlekle chorymi. Zebrane odpowiedzi pogrupowano tematycznie w wymiary ciągłości opieki. Na podstawie doświadczeń pacjentów nakreślono model oceny ciągłości opieki. Wyróżniono 8 kategorii centralnych i 36 sub-wymiarów, które umożliwiają całościową ewaluację postrzeganej jakości w opiece nad pacjentem w stanach przewlekłych. Zidentyfikowano następujące wymiary centralne: aktywacja pacjentów, wsparcie przy podejmowaniu decyzji, ciągłość relacyjna, koordynacja działań, komunikacja z pacjentem, rozwiązywanie problemów, elastyczność i dostępność oraz orientacja na pacjenta. Praca stanowi wstęp do koncepcyjnego modelu oceny ciągłości opieki. Identyfikuje zarazem newralgiczne punkty braku owej ciągłości.

**Słowa kluczowe:** ciągłość opieki, percepcja pacjentów, opieka w chorobach przewlekłych, wskaźniki jakości, Polska.

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## 1. Introduction

contemporary healthcare faces a broad spectrum of challenges with the issue of how to define and assess quality of care being one of the most crucial ones. The focus on quality is highlighted by a wide body of research reflecting a longstanding gap between actual practice and best practice standards. For example, Asch (2006) estimates that half of patients in the United States do not receive the care they should. Studies analyzing specific incidents suggest that poor design of healthcare delivery processes and fragmentation, rather than technical incompetence of doctors, underpins the majority of problems (Organization of Economic Co-operation and Development, 2010). The issue of quality becomes even more apparent when considering the health care of chronically ill patients such as in Poland. As they consume a lot of continuous healthcare services, the quality control issue is accompanied by strong cost pressures.

Health care is becoming more patient-centred and, as a result, the experience of users of care and evaluation of their experience are considered seriously, and used to evaluate the delivery of care (Vrijhoef et al., 2009; Wagner et al., 2005). There is considerable amount of literature about patient satisfaction and experience (Linder-Pelz, 1982; Pascoe, 1983), but it is not clear how to appropriate the instruments are to measure patient experience with care in integrated health care settings. The issue becomes even more important when, quality and satisfaction tools validated by health plans are implemented as a marketing instrument. This is especially the case in current policies towards the integration of health care in Poland.

The quality of healthcare has become a priority on the agenda to improve the healthcare systems (Schröder-Bäck, 2012; Jakab and Tsouros, 2014) also in Poland. Evaluating quality is the first step towards improving quality and thus value in healthcare. Therefore, the purpose of this paper is to identify chronic patients' experiences and values associated to continuity in care. Apart from the theoretical background this article is divided as follows: the research methodology is presented in the section 2, in the following point the research findings are described, in order to discuss them in section 4, indicate the value of the study in section 5 and to finish with the conclusions.

## 2. Theoretical Framework

The idea of integrated healthcare is associated with the provision of healthcare services through the co-ordination of different activities (diagnostics, therapy, rehabilitation, health promotion), with the patient being the final beneficiary (Stranberg-Larsen and Krasnik, 2009). We define thus integration of care after WHO as “bringing together inputs, delivery, management and organization of services related to diagnosis, treatment, care,

rehabilitation and health promotion wherein integration is regarded as a means to improve the services in relation to access, quality, user satisfaction and efficiency” (Gröne and Garcia-Barbero, 2001). Considering patients’ perspective in this integrated care approach, a measurement instrument is needed to appropriately evaluate the experience of chronically ill people.

World Health Organization defines chronic disease as any disorder or deviation from standards that have one or more of the following characteristics: it is permanent, leads to disability, is caused by irreversible, pathological changes, requires special treatment or rehabilitation and requires a long period of supervision, observation and care (Gröne and Garcia-Barbero, 2001).

Continuity of care becomes a crucial issue in terms of chronic illnesses. The term of continuity of patient care appears in numerous discussions as a fundamental aim of integrating the process of health care service provision in Europe (Antunes and Moreira, 2001). In turn, patient satisfaction is a reflection of the problems occurring during a service provision process. Any loopholes in the process coordination, be it between service providers themselves, or between patients and care providers, can thus be treated as threats to continuity of patient care, which impacts on the achieved treatment results (Weinberg, 2007). The term of continuity of care is not in itself an innovative attribute that can be assigned to patient care only in integrated health care. The first signs of interest in the concept in health care date back to the 1950’s, initially as an element of general practitioner’s care (as a synonym of treatment provided by one physician), only to focus in the 1970’s on the relativity of the past and the future in patient care (one related to the other). The 1980’s shifted the interest to measurement of the construct by way of Continuity of Care Index, and Index of Sequential Continuity (Uijen et al., 2012). The weakness of those indicators is their one-dimensional approach to the analysed phenomenon.

In the context of integrated health care, continuity of patient care is understood as a qualitative dimension concerning seamlessness of health care process provision. The legacy that the 1990’s left behind is the perception of continuity of care from the patient’s perspective, as the patient’s experience of a coordinated and seamless progress/development of care (Cowie et al., 2009). Therefore, continuity of care does not refer to the attitude of care providers, but to patients’ perception in the course of their experience of service coordination and integration (Rodríguez and Riveres-Pigeon, 2007).

Currently, researchers use multi-dimensional models to describe the discussed concept. One such model is Haggerty’s team interpretation, treating continuity of care as a combination of (Haggerty et al., 2003):

- informational continuity – ability of a service provider, from the patient’s perspective, to take the right decisions based on sufficient information source regarding patient’s medical history;

- management continuity – ability of a service provider/network of service providers, from the patient's perspective, to establish a cohesive care management plan;
- relational continuity – ability of a service provider, from the patient's perspective, to continue the provision of care by medical professionals the patient is familiar with.

What is crucial in this interpretation for further consideration is adding long-term relations to continuity as well as concentrating on an individual patient and his/her needs. In turn, concentration on an individual patient lies close to the concept of patient/client-oriented care, and more broadly to human-oriented care (Kodner, 2003). Patient/client orientation is becoming one of the key characteristics of contemporary health care systems, one of the critical spheres of quality, and measuring patient experience is therefore becoming a significant component of health care services evaluation. Shaping health care through the prism of patient's/client's needs and preferences increases patient's satisfaction and improves therapeutic results, thereby contributing to greater efficiency of thus-operating system. These conclusions have been drawn from the observation of the British health care system, where improvements recommended in the report "Crossing the Quality Chasm" have been implemented. Key among those improvements include better care coordination and integration, health information and education, guarantees that ensure patient's physical comfort during treatment as well as emotional support for informal care providers (Madhok, 2001).

Furthermore, management continuity (also understood as organizational continuity) as well as informational continuity concern the process of health care delivery, while relational continuity refers rather to the patient's experience of care. That last aspect is strongly emphasized in another multi-dimensional concept of continuity established by G.K. Freeman's team, which differentiated experienced continuity (Freeman, 2000), defined as experiencing a coordinated and smooth sequence of health services. In order to achieve it, according to G. Freeman (Freeman, Olesen and Hjortdahl, 2000), a health care system needs to feature:

- continuity of information – ensuring information transfer following the patient in the system,
- cross-boundary and team continuity – ensuring effective communication between professionals and services and with patients,
- flexible continuity – ensuring adjustments to patient's needs over time,
- longitudinal continuity – minimizing the number of physicians treating a given patient in a given health care unit (such as family physician practice),
- relational continuity – assigning one or more individuals with whom the patient can establish and maintain a relationship in the therapeutic process.

From the adopted perspective of integrated health care one more interpretation of continuity merits a reference. Namely, a definition established by the American Academy of Family Physicians (AAFP), which emphasizes a long-term cooperation of physicians and patients oriented at care management which aims to achieve high quality and cost effective care at the same time (Naithani, Gulliford and Morgan, 2006). Cooperation of the patients with service deliverers is thus – according to the interpretation proposed by the AAFP – a condition necessary to sustain continuity of care. Emphasis placed in this element seems to be of great import in the concept of disease self-management, supporting, involving and inspiring patients to take responsibility for their own health. Both messages are strongly accentuated in the Wagner’s Model (Wagner, 2004) which constitutes a theoretical foundation for these deliberations. The approach does not aim to treat the patient as a passive recipient of educational and health-promoting activities, but as an active co-creator of his/her own health. In such a point of view, the patient is not only entitled to health care, but he/she has also got obligations resulting from the responsibility for the condition of his/her own health. Consequently, the patient joins in the creation of health care – perceived holistically – as the establishment of conditions for continued good health and its improvement through individual’s conduct. Continuity of care can thus be treated as a determinant of quality of patient service provision, which penetrates other elements of assessment of health care system operation that uses the concept of integrated health care.

### 3. Purpose, Material and Method

The main purpose of this paper is to identify chronic patients’ experiences and values associated to continuity in care. To accomplish it a qualitative study was used. The qualitative study comprised of a focus group interview (FGI) conducted in the form of an open discussion with patients suffering from a chronic condition, who may be treated as informants. The procedure of the focus group interview followed the guidelines set forth for that type of study (Krueger, 2004).

The study was guided by two research questions:

- what variables do patients perceive to be significant in the continuity of care?,
- how can the isolated elements be grouped in order to establish a model of evaluating patient care quality in the respect of continuity of care?

Potential participants of the pilot patients’ panel were intentionally selected through a community interview. The criteria of participants’ selection for the focus group interview were as follows: the patient is an adult, the patient suffers from a chronic medical condition

- on account of a chronic illness the patient has frequent (over 7 times a year) contact with the health care system, the patient is able to participate in a meeting lasting approximately 2 hours.

The community interview enabled identifying several dozen chronically ill patients, out of which 12 people, fulfilling the afore-specified criteria, were invited by phone or directly to participate in the study. 10 of them consented to attend an interview. On the eve of the meeting all the patients were reminded of the time and place of the study to be conducted via a text message. The selection of respondents in the sample of FGI was targeted.

The structure of patients partaking in the FGI is presented in Table 1.

| No. | Age | Gender | Condition                        |
|-----|-----|--------|----------------------------------|
| 1   | 63  | F      | glaucoma                         |
| 2   | 62  | F      | hypertension, thyroid condition  |
| 3   | 82  | M      | ischaemic heart disease          |
| 4   | 41  | M      | organic heart disease            |
| 5   | 79  | F      | chronic urologic disease         |
| 6   | 61  | F      | Diabetes                         |
| 7   | 65  | F      | Diabetes                         |
| 8   | 61  | F      | neoplastic disease               |
| 9   | 59  | F      | spondylosis deformans            |
| 10  | 40  | F      | spondylosis deformans, hemopathy |

Table 1. Structure of FGI participants. Source: authors' research.

The FGI has been conducted using an open discussion with the gathered patients. Although the moderator tried to keep the discussion structured by raising the following specific issues:

1. What are the difficulties you face in treating health care in Poland?
2. Do you see any solutions that could contribute to better patient care?
3. How would you rate the communication/contact with a doctor?
4. Are patients in our country, suffering from certain disease have knowledge of the methods of therapy, the latest methods of diagnosis and treatment, its effectiveness?
5. Traditional medicine is a lot, but usually not all that lets the patient get well, sometimes you need a diet, exercise, etc. Do you get any guides, instructions on how to support the treatment?
6. Does it ever happen that you yourself seek such information, for example, in other doctors, the Internet?

The FGI was carried out in February 2013 at the Faculty of Economics and Management at Szczecin University. During the focus group interview the researcher faced some unpredictable methodological situations regarding divergent interpretation of the same content by different patients. It referred mainly to the term "relationship with a doctor/general practitioner". Therefore, the moderator needed to explain it more precisely and carefully.

#### 4. Results of the Study

An analysis of transcripts of the gathered material allowed identifying 56 comments defining patients' needs, feelings, preferences and experiences in respect of health care in chronic conditions. Subsequently, the statements were entered into ATLAS.ti computer program for management of qualitative study data. Preliminary analysis involved encoding the comments from the transcript of the FGI. Then the author assigned the encoded comments to several central categories by applying Strauss' and Corbin's method of comparison in pairs (Glaser and Strauss, 2009). The names of sets were identified on the basis of the literature of the subject dedicated to integrated health care (Antunes and Moreira, 2001; Raak et al., 2003; Delnoij, Klazinga i van der Velden, 2003; Uijen et al., 2012; Mur-Veeman et al., 2003). Their understanding and interpretation were also submitted to discussion with patients during the group interview. The central categories (sets) comprised: patient involvement, decision-making support, flexibility and availability, communication, organization and coordination of the service provision process, continuity, problem resolution and focus on the patient. As a result, a schedule of central categories and sub-categories was compiled describing the dimensions of service quality provided to chronically ill patients, which can be treated as indicators and sub-indicators in the evaluation of service quality delivered to the analysed patient segment (Table 2).

| <b>Groups of indicators identified in the literature and confirmed by the FGI – main category (in brackets – reference to the Freeman's model)</b> | <b>Contents of indicator groups identified via the FGI – sub-indicators</b> | <b>Examples of authentic comments delivered by patients during the FGI</b>                                                                                                                                                                                                                                 |
|----------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. Patient's involvement (Freeman's et al. team continuity)                                                                                        | patient's opinion                                                           | "my GP did not even ask about my opinion"                                                                                                                                                                                                                                                                  |
|                                                                                                                                                    | time devoted to hear the patient                                            | "a lot depends on the nurses, but they do not have time to give information, because they run from one patient to another, and then they do the paperwork"                                                                                                                                                 |
|                                                                                                                                                    | information on subsequent stages of therapy, action scenarios               | "I asked the physician what if any complications appear after the surgery, but he did not respond"                                                                                                                                                                                                         |
|                                                                                                                                                    | history taken by the physician with extended patient's involvement          | "I regularly take painkillers. I was registered for rehabilitation and nobody had asked me about it earlier, and when I came to the first rehabilitation procedure they asked me: are you taking any pain medication? YES, I replied, to which they said: in that case rehabilitation cannot be conducted" |

cont. Table 2

|                                                                      |                                                                    |                                                                                                                                                                                                                                                                                                                                                                                                                   |
|----------------------------------------------------------------------|--------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                      | patient's involvement in decision making                           | <p>"no one asked me what I was thinking of the therapy"</p> <p>"I trust my physician, whatever he tells me I accept it"</p>                                                                                                                                                                                                                                                                                       |
| 2. Decision-making support – (Freeman's continuity of information)   | guidelines concerning patient's conduct                            | <p>"when I was using the German health care system I received a lot of information, e.g. firstly I was informed how long it would take me to get to the nearest hospital. I was told which doctor I was supposed to specify as my primary care physician, so that the information regarding my chronic condition could reach him as soon as possible. I was instructed what to eat, what to do in case (...)"</p> |
|                                                                      | consultations conducted by other means than the traditional method | <p>"I would like to be able to contact over the phone instead of waiting for an appointment with a primary care physician for 3 or 5 days, when I already feel better"</p> <p>"I have my family doctor's mobile telephone number"</p>                                                                                                                                                                             |
|                                                                      | provision of printed material                                      | <p>"I read informational leaflets of medication, but they contain all possible diseases"</p>                                                                                                                                                                                                                                                                                                                      |
|                                                                      | organized community support                                        | <p>"when I was waiting for an oncology board review I found out such things from other patients that I wanted to run. Patients scare one another."</p> <p>„I go to my breast cancer peer support group and it helps me a lot, chiefly the psychological support, [the sense] of not being alone with the disease"</p>                                                                                             |
| 3. Cross-boundary continuity – (Freeman's cross-boundary continuity) | relational continuity                                              | <p>"in my case a diabetologist is changed each year"</p> <p>"intervals between visits [are] 9, 10 months – I believe that it is too rarely. It is hard to refer to a doctor you see so seldom as your attending physician"</p>                                                                                                                                                                                    |
|                                                                      | organizational continuity                                          | <p>"if a patient is under the care of a specialist, then they should not be required to visit a family doctor only to get a referral – it is a waste of time and unnecessary cost"</p>                                                                                                                                                                                                                            |
|                                                                      | informational continuity                                           | <p>"when I am leaving an examination room with a referral here and here, the attending physician says: please come back and see me after those visits. Yet, when I do come back, the doctor does not ask me about the results of the examinations conducted by the specialists"</p>                                                                                                                               |



cont. Table 2

|                                                                                                     |                                                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|-----------------------------------------------------------------------------------------------------|-------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 4. Organization of care provision and activities coordination – (Freeman's longitudinal continuity) | action coordinator, case manager                      | “there should be a person who would be in charge of my treatment. I have three different diseases and I sometimes get disoriented”                                                                                                                                                                                                                                                                                                                                                                                      |
|                                                                                                     | standardization of care over chronically ill patients | “I would expect more attention from a diabetologist: taking my sugar level, examining my legs; but he does none of that, does not talk about it. All he does is prescribe medication and recommend a follow-up in six months' time”                                                                                                                                                                                                                                                                                     |
|                                                                                                     | cohesion of medical advice                            | “I went to my family doctor and told her that I was feeling pain in the bladder. She, knowing that I suffer from diabetes, prescribed me Furagin. After a week I went to see a diabetologist who asked me: who prescribed that to you? You cannot take the medication if you have diabetes”                                                                                                                                                                                                                             |
|                                                                                                     | information exchange between physicians               | “a physician sent my x-ray for consultation with another doctor, a radiologist. I was pleasantly surprised”                                                                                                                                                                                                                                                                                                                                                                                                             |
|                                                                                                     | comprehensive care                                    | „I would expect that my attending physician should recommend additional tests checking my condition, and not merely ask how I am feeling. But he does not do that. That is why every six months I go to a clinic in Warsaw, where the development of defect is comprehensively checked. Then I show the results of those tests to my doctor. Since I am under the care of a specialist in Szczecin these tests ought to be done here, but my physician is of the opinion that it is not necessary. It should not be so” |
|                                                                                                     | diagnostics                                           | “a family doctor should recommend that a patient of a particular age (i.e. an elderly patient) take the tests that the patient is entitled to on account of his/her age”                                                                                                                                                                                                                                                                                                                                                |
|                                                                                                     | timely services (time coordination)                   | “on the day of an appointment I had not yet received test results, because the laboratory was late. I went to see the specialist, and he asked me: why did you come without the test results?”                                                                                                                                                                                                                                                                                                                          |
|                                                                                                     | multi-disciplinary teams                              | “I think that a psychologist would have helped me solve my problems sooner”<br>“leaving after chemotherapy I received no psychological support”                                                                                                                                                                                                                                                                                                                                                                         |

cont. Table 2

|                                                                     |                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                          |
|---------------------------------------------------------------------|-------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 5. Communication with the patient (Freeman's relational continuity) | communication with the patient regarding purpose of care                            | "the attending physician was not very communicative"                                                                                                                                                                                                                                                                                                                                                     |
|                                                                     | communication with the patient regarding health promoting conduct and prophylactics | "too few test are done on the spot; patients need to have them done on their own, if they are aware of what test can be done in a given case. A physician shows no interest, he is satisfied with the fact that I am feeling fine. And it should be about prophylactics"                                                                                                                                 |
|                                                                     | standardization of gathering patient's history                                      | "I had previously undergone orthopaedic surgeries and had screws fitted in the ankle. Then, when I was taking various physiotherapy procedures for my spine, already after a series of such procedures, I found out from patients waiting their turn in line that I absolutely cannot have such procedures having had metal elements installed in the body. No one has ever mentioned that to me before" |
|                                                                     | explaining the therapeutic process and its expected results to the patient          | "I only knew chemotherapy from television. When I was taking it myself, none of the doctors, none of the nurses told me what I could expect, what I should do, what to eat. I found all of that from other patients, basically groping in the dark. When the chemotherapy was coming to an end and I was recovering, I still did not know anything, what I can and cannot do"                            |
| 6. Problem resolution                                               | therapy planning                                                                    | "my urologists discusses the next stages of treatment with me"<br>"during my stay at a cardiology clinic, the attending physician came and explained in detail the particular steps of treating my condition"                                                                                                                                                                                            |
|                                                                     | impact of a disease on life quality                                                 | "I received contradictory information from different doctors as to whether plaster was going to be necessary after the surgery. It would mean I would be immobilised for 6 weeks"                                                                                                                                                                                                                        |
|                                                                     | emergency cases and exacerbation of a disease                                       | "when my condition deteriorates, I go to a cardiology clinic, describe my symptoms and I assume that they will squeeze me in somewhere, at the end of the line. I only assume so, since I do not know if they actually will. To top it all, it does not necessarily have to be my doctor [that I will see]"                                                                                              |

cont. Table 2

|                                                                 |                                                                    |                                                                                                                                                                                                                  |
|-----------------------------------------------------------------|--------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                 | continuity of care and treatment                                   | “when I left the hospital I would have liked to be visited at home, for instance by the nurse I selected. But it is only theoretically possible”                                                                 |
| 7. Flexibility and availability (Freeman’s flexible continuity) | sensitivity of the system to patient’s suggestions                 | „after a surgery of my bunion deformity I wanted to put on an orthopaedic shoe I had bought on my own, but I was told that it was not the practice allowed there, that they only used plaster”                   |
|                                                                 | availability of various services at one location                   | “every six months I regularly visit a cardiologist, who checks the operation of a stimulator; additionally, I also have [visits at] an urologist, but in a different place – I have to run there and back again” |
|                                                                 | possibility of choice                                              | “I would appreciate a possibility of having a doctor making a house call when I am bed-ridden”<br>“I have a regular cardiologist, however not the one I would have liked, but the one I had to choose”           |
|                                                                 | therapy waiting time                                               | “it is about the time needed to get to a primary care physician, it is getting longer”                                                                                                                           |
| 8. Focus on the patient                                         | availability of information as to where and how to arrange matters | “I would like to have an advisor who would tell me what steps I should take and in what order”                                                                                                                   |
|                                                                 | empathy demonstrated by the personnel                              | “what bothers me the most in the system is lack of interest demonstrated by the personnel”                                                                                                                       |
|                                                                 | respecting patient’s rights                                        | “I wanted to register for a house call, but I was refused. I did not dare to ask why”                                                                                                                            |
|                                                                 | evaluation of the system from a patient’s perspective              | “there is a complaints and suggestions book at my outpatient clinic, but I have never used it”                                                                                                                   |

Table 2. Central categories and their detailed dimensions of continuity of care delivered to chronically ill patients identified in the FGI. Source: author’s research.

Most of the indicators (central categories) identified above, such as patient involvement, decision-making support, problem resolution, communication with the patient, activities organization and coordination, flexibility and availability refer to the process of service provision to patients with chronic conditions. The remaining ones, i.e. ensuring continuity in its various dimensions, focus on the patient, are of structural nature.

The obtained results can be compared with Freeman's model. He distinguished six dimensions of continuity of care. Our research confirmed eight of them, adding two new central categories, i.e. Problem resolution and Focus on the patient.

## 5. Discussion and Findings

Analysing the results obtained through the FGI, it is worth emphasizing that the chronically ill patients themselves rarely use terms such as: "continuity of care", "coordination", "therapy planning", "integration of care" to describe their experience, needs and feelings with regard to systematic use of health services. Furthermore, assigning a particular experience or need expressed in a patient's comment to one of the eight main categories was problematic at times on account of mutual interrelation of individual dimensions and possibility of illustrating a number of various sub-categories with a single comment at the same time.

Patients described their previous experience with health care system in regard to continuity as the care they have been receiving since the diagnosis identifying their chronic condition was made. They were referring to check-ups and systematically repeated tests related to a given chronic disease. Some declared that "patients need to demand the tests from their doctors," "the patient more often than not reminds the doctor of it," or they articulated their needs for such tests by saying: "a family doctor should recommend that a patient of a particular age (i.e. an elderly patient) take the tests that the patient is entitled to on account of his/her age". The respondents were also referring to the significance of continuity of care by demonstrating their concern resulting from deficiency of care:

- "intervals between visits [are] 9, 10 months – I believe that it is too rarely. It is hard to refer to a doctor you see so seldom as your attending physician"

High frequency of visits and consultations resulting from exacerbation of condition symptoms seems to be the parameter describing the quality of care delivered to a chronically ill patient. This component acquires particular significance at the start of therapy, where the patient's ignorance is confronted with the need to deal with a chronic condition on an everyday basis. Hence patients particularly value extensive consultations with numerous specialists at initial episodes of chronic diseases, which improve their understanding of the circumstance they are in. The effect of such an attitude to the service recipient, which in fact constitutes an indicator of the focus on the patient (patient in the centre), involves closer adherence to therapy regime and acceptance of any related inconveniences.

Furthermore, the FGI participants linked longitudinal continuity with individual approach to the patient, understood as adapting medical advice to a particular case:

- “when I come, my doctor always remembers that I do not tolerate large-sized pills and tries to prescribe me soothing easier to swallow”.

Experience of longitudinal continuity may be perceived as a pre-condition necessary for the establishment of relational continuity. Patients appreciate the situations in which they are recognizable. It builds their sense of security, which may contribute to achieving better therapeutic results: “when I come to the outpatient clinic, everyone knows me, greets me and it is very pleasing”.

A significant characteristic of a chronically ill patient-physician relation is not only the former knowing the latter, but it also encompasses recognition of the service recipient’s needs and preferences, understanding the latter as a human being. The patients relate it in the following accounts, stressing the impact of an interpersonal attitude of a medical practitioner to the patient:

- “I changed my family physician and it was the right thing to do. The new doctor understands me, knows what I need.”
- “It simply depends on the person, it seems to me. I had an operation, it happened to be in Police, and there was a doctor, the best one ever. He explained everything to me in detail.”

Sometimes patients deeply feel the loss or change of a physician which did not result from their initiative. If so far they have been satisfied with the relation with a representative of the service provider and they were forced to end that relation, they are clearly concerned:

- “my oculist who treated me for 13 years has left the clinic. It is a pity... Now I will have to start explaining what’s what anew, to adapt to a new one ...”.
- “Even if a patient has an appointment at the clinic, you never know which doctor you are going to end up seeing.”

Lack or loss of a personal relation with an attending physician may result in patient’s lower involvement in the therapeutic process, poorer compliance with the diagnosis and therapy, reduced satisfaction from health services, or even severing the relation altogether. The following response coming from one of the FGI’s participant is proof of that:

- “I for instance (would like) that a specialist treated one given person. I was referred to a vascular specialist at Pomorzany. The physician examined me, told me what to do, I was very satisfied. Then I come, and today I am seeing a completely different doctor. Eventually, I withdrew from the treatment”.

The focused group interview additionally proves that patients expect a certain standardization of care in case of chronic illnesses, as well as in age-related conditions. Erosion of patient care quality perceived in such a manner typically involves insufficient amount of time devoted to the patient and poor communication. Patients complain that doctors keep visits short, superficial, that they do not look for details, do not engage in

conversations. Patients wait months for an appointed visit, hoping that it will entail a comprehensive examination and that it will clarify many issues. Meanwhile the visit lasts only a few minutes, e.g.:

- “The question of prophylactics. When I go to see a cardiologist, I expect that at the very least I will have some tests done. [And] not that he will [merely] ask “how are you feeling?”- a conversation is just not enough. The condition needs to be monitored, after all,”
- “I would like to be taken care of. For instance, when I go to see a diabetologist, the first thing she should do is take my sugar level, but there is no mention of it, just medication.”

The above-quoted patients' accounts lead to a conclusion that relational continuity is not only limited to the degree of service provider's friendliness to the patient, but it also encompasses familiarity with the patient's case history, the ability to listen closely to the patient's needs and willingness to clarify any of the patient's doubts. These elements build institutional trust in doctor-patient relations and they contribute to the service recipient's greater involvement in the therapeutic process. Stability and regularity of contact a chronically ill patient has with the same attending physician play a crucial role.

However, the FGI study demonstrates that relational continuity is upset by lack of systematic, frequent contacts with an attending physician. A systemic solution which would impose standards of care over the chronically ill patient, which would, for instance, recommend the number of visit in a year necessary on account of an existing chronic condition, would create favourable conditions for building the sense of security among the patients of that segment, and it would furthermore increase the degree of patient's compliance with medical recommendations and orders. The present situation presents a limited possibility of respecting patients' preferences, excessively long intervals between visits and the requirement of obtaining referrals to secondary care physicians. From the patients' perspective the most serious problems concern:

- lack of possibility of selecting the specialist of the patient's own choice: “I have a regular cardiologist, however not the one I would have liked, but the one I had to choose.”
- too long intervals between visits: “I believe that it is too rarely, because I go every 9-10 months or sometimes even longer between individual visits. I think that it is a little too seldom, which is why it hard to really refer to your attending physician as one.”
- the need to go to a first care physician every six months in order to receive a referral to a specialist, when it has already been established that the patient is chronically ill: “Yes, yes, that is the worst, exactly that. If someone requires a specialist, it should not be necessary to go and get a referral from a family doctor, because it is a waste of time and an unnecessary cost.”

The element of continuity of care in chronic diseases that the patients value is the possibility of obtaining assistance/consultation in emergencies. Since the needs of chronically ill patients change over time, they find it important that medical professionals react quickly enough. Such situations may thus be related to flexible continuity, which involves adaptation of a service to the patients' needs. One such option is provision of services by medical professionals selected by the patient. Here is how one of the interview participants perceives the phenomenon: "I have a regular cardiologist, however not the one I would have liked, but the one I had to choose." In this context the responses given by some of the patients regarding the course of action they would take if there was an emergency and they needed to contact their physician are surprising:

- "I'd call my family doctor's mobile,"
- "If the situation was tragic, I would call the ambulance."

The nature of the patients' responses clearly demonstrates lack of any systemic approach in this respect. Overall, in an emergency, patients are left with only one option – ambulance service, unless they have some other contacts, be it with their family practitioner or specialist physicians. A call for ambulance assistance is an obvious choice in case of a dramatic deterioration of health condition or a risk to life. Unfortunately, there are no solutions to a situation when the patient feels ill and the next doctor's appointment is in several months' time. Patients' comments demonstrate that they themselves do not know what to do in such circumstances:

- "I know that then I can go to a cardiology clinic, describe my conditions, my symptoms, what is wrong with me and I assume that they will squeeze me in somewhere, that they will add this one more patient. I only assume so, since I do not know if it is really so."

The patients propose home care as a way of improving continuity of care, e.g.: "Above all, I would like it if some form of home care was available. When I was enrolling as a patient with my outpatient clinic, there was a mention that there might be some house calls from primary care doctor, or even a nurse. And she was sitting there and I even registered with her."

Flexible continuity also manifests itself through service provider's readiness to change appointment dates suitably to patients' preferences. Here is an account of one of the FGI's participants describing her experience in this regard: "they have their schedules, and I have mine."

A majority of patients experience lack of flexible continuity, especially with respect to the waiting time for scheduled consultations and delays in making appointments. Here are several responses recorded during the FGI:

- "there was no problem with issuing a referral, however there was one with actually making use of it."

- “it is about the time needed to get to a primary care physician, it is getting longer! And it is not a question of getting [an appointment] in three or five days.”

The difficulties described above may contribute to the erosion of the perceived patient care quality in the system and a decrease of institutional trust in patient-physician relation. Nevertheless, the patients who enjoy a satisfactory relation with their attending physician find it easier to adapt to such unfavourable situations, assigning any encountered inconvenience to systemic problems.

Communication and its continuity appear to be yet another important component of patient care in patient-service provider relation. The quality of communication is chiefly defined as the ability to listen to the other party and to convey a certain amount of information, including on the course of therapy, any possible adverse effects, any risk related to a procedure, expected results. Patients' experience in this respect related during the group interview was rather negative. The following patients' accounts are symptomatic:

- “I had no idea that [if] I take Eutyrox it will cause diabetes. No one has informed me of that.”
- „The doctor just whizzed by”
- “I am not surprised, since they (nurses) have no time to take care of the patient, come by even just for a moment, sit down and say “listen, you need to do this and that, behave like that,” because she has no time, she runs around administering chemo, filling in patient' charts, since each patient needs to [have everything] documented, which leaves them with no time to spare. [They could] possibly do it in the evenings, but still.”

What is more, a serious complaint that patients reported with regard to communication with a physician is lack of thoroughly finding out case history prior to prescribing medication or therapy. The following accounts confirm the issue:

- “No doctor told me to stop taking my medication before rehabilitation, because it is not going to help, [that it is] just a waste of time, waste of everything.”
- “I went to my family doctor and told her that I was feeling pain in the bladder. She, knowing that I suffer from diabetes, prescribed me Furagin. After a week I went to see a diabetologist who asked me: who prescribed that to you? You cannot take the medication if you have diabetes.”

It needs to be strongly emphasised that communication, appearing in numerous empirical studies (Aldana, Al-Sabir and Piechulek, 2001; Johnston, 1995; Johnson, 1995; Zifko-Baliga and Krampf, 1997) as an indicator of patient care quality, should – in the author's view – be perceived as an intrinsic, and not instrumental value. It means that its objective is supporting patients in a decision-making process, building the sense of security, involving the patient, planning therapy, solving medical and non-medical problems (organizational, informational ones) of the population to whom services are delivered.



An issue of import that the patients note the burden of paperwork resting on physicians, thereby limiting their time devoted to patient care. One of the FGI's participants comments:

- “Bureaucracy, they have too much to write down, too many documents. They need to document everything, every case history, every survey,” „One patient is leaving, I am entering, while the doctor keeps writing, keeps typing.”

Patients are convinced that nurses could do more activities, both medical and non-medical ones, which would facilitate service provision:

- “But a nurse could prepare all the documents before an appointment,”
- “Today I also was at the outpatient clinic in Police and many people, half of them came to have stiches removed. People are waiting for a surgeon, and a treatment room is right next door, where a nurse could be taking those stiches off.”

Considering the above comments, it is worth emphasising that administrative functions could be handled, at least partially, by properly trained non-medical personnel. The position of a Health Service Administrator exists in many health care systems.

## 6. Originality and Value

The paper contributes to the discussion concerning the methodology of evaluation of perceived quality in integrated health care and extends the work done by Freeman et al. (2003). The adopted approach can be treated as a promising framework for developing a quality management tool also in other service sectors. It offers quality managers a chance to see the quality process in an innovative way and to boost the satisfaction of customers of their businesses.

The study contributes also to theory building. It adds value because it creates a conceptual framework of a complex concept such as continuity of care, by identifying perceived quality items and segmenting them in several dimensions. The proposed model is well-suited for the health sector in Poland. It extends existing quality concepts by adding new central categories, i.e. *Problem resolution* and *Focus on the patient*.

## 7. Conclusions and Practical Implications

The results of the conducted qualitative study constitute an important premise for the construction of a methodological tool, comprising a set of indicators describing continuity of care from the perspective of the patient. Identification of the dimensions of health care continuity over chronically ill patients as well as identification of any possible loopholes in such continuity constitutes a vital cognitive value of this stage of methodological procedure.

Erosion of continuity may occur at any stage of the process of patient care provision, although the greatest risk of it appearing exists in the course of a patient's transfer from one stage of health care to another, for instance from primary health care to secondary specialist outpatient care, from outpatient care to hospital-based setting, or from hospital-based setting to primary care. Transition of the patient from one stage of care to another typically involves exacerbation of symptoms; it necessitates more extensive diagnostics or a hospital discharge. All of the above situations generate a different demand for health care and different intensity of health care services consumption. The loopholes in the continuity of health care may therefore result in delays of care provision, misinformation, or problems of a communicative nature. Consequently, the patient may seek alternative solution to the medical problem, disregard medical advice, or even decide to discontinue treatment.

The research findings leads us to the conclusion that in the competitive environment in which Polish health care providers now operate, it is essential to understand the quality indicators that encompass the holistic approach towards patient service, especially in chronic conditions. The proposed study exhibits new dimensions that strongly focus on effective collaboration with chronic patients in integrated health care settings.

Polish managers of integrated health care plans could use the identified dimensions and indicators of continuity of care as a useful tool for quality management. The model has thus a potential to serve evaluation and improvement purposes in integrated health care settings and to make more informed managerial decisions. The above presented findings provide the basis upon which health care managers could design effective quality strategies and tactics.

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