

Chapter 2

Person-Centred Care, Theory, Operationalisation and Effects



Inger Ekman and Karl Swedberg

Abstract In healthcare systems patient engagement and care satisfaction are less than optimal. Different solutions have been proposed to recognise the patient in health care, including person-centred care. The University of Gothenburg Centre for Person-Centred Care (GPCC) steering committee formulated three ‘simple routines’ to initiate, integrate and safeguard person-centred care in daily clinical practice. These routines are: the patient narrative followed by an agreed health plan which is then safeguarded by documentation. Health care professionals need to know how health processes are strengthened in a relationship where patients are accepted as persons with their own will and emotions and in which individual responsibilities and capabilities are highlighted. A person-centred perspective uses ethics as a springboard. Such an ethical view can briefly be formulated by: “To aim for the good life, with and for others in just institutions”. When the starting point is ethics and each person is understood as a unique individual, care actions will never be the same for each patient. By asking for the patients’ understanding of the condition and treatment relative to their lives in general, professionals can understand what health, illness, treatment and care convey to patients and their relatives. The patient narratives are obviously very important in formulating the health plan. Controlled studies have found several benefits from implementing person-centred practices, including improved quality of life, maintained self-efficacy and reduced health costs.

Keywords Person-centred care · Patient narratives · Health plan

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2.1 Introduction

Healthcare systems need to be re-organized to provide high-quality care without increased costs to an ageing population with a high prevalence of chronic and long-term disorders [1, 2].

Currently, patient engagement and care satisfaction are less than optimal. Different solutions have been proposed to recognise the patient in health care, including person-centred care (PCC) initiatives.

Researchers and clinicians noted that PCC, emphasising patient-professional partnerships, has not been implemented in health care to a significant extent. Thus, in 2010, intending to test and implement PCC, an interdisciplinary group of clinical and non-clinical academics in Sweden created a research centre for the study of PCC in long-term illness: the University of Gothenburg Centre for Person-Centred Care (GPCC) [3, 4].

The GPCC steering committee formulated a position paper with three ‘simple routines’ to initiate, integrate and safeguard person-centred care in daily clinical practice [5].

The first routine serves to initiate a partnership by eliciting patient narratives, defined as the sick person’s account of his or her perception of the illness and its impact on life.

In sharp contrast to medical narratives that reflect the process of diagnosing and treating the disease, the first routine captures the patients’ suffering in the context of their daily lifeworld. The second routine implements the partnership principle using a commonly agreed personal health plan so that professionals, patients and relatives can work collaboratively to achieve the patients’ goals. The third routine safeguards the partnership by documenting the health plan accessible to both professionals and patients. This plan is often shown in the patient record. These three routines represent clinical tasks that professionals embark on and that patients and relatives perform in daily life. This PCC model is distinguished from other models by incorporating patient wishes and capabilities with care team support.

Such an approach is rooted in philosophical literature on [6–8].

2.2 The Patient—A Person

Health care professionals routinely understand and explain the patient from a medical perspective that focuses almost exclusively on biological and physiological factors. With this knowledge, the complex biology of human beings can be explained. However, even if this knowledge is important, health care professionals need to know more about how health processes are strengthened in a relationship in which patients are accepted as persons with their own will and emotions and in which individual responsibilities and capabilities are highlighted.

To understand another person, we must listen to what that person has to say. If the listening process in the communication is effective, the target person feels acknowledged and respected. Professionals must therefore listen to and understand patient needs and concerns. Such an approach implies that the professional must see patients as persons with a lifeworld (experiences and contacts that make up an individual's world), different but also similar to the professionals' in many ways.

Having such a perspective on understanding entails sensing, grasping or feeling the patient's experiences. In this context human vulnerability means being mindful and deeply affected by the suffering of others. This ability to have empathy may sometimes be painful to clinicians because a patient's suffering can be overwhelming, especially when there is insufficient time to meet each patient's needs. It could even mean attempts to abandon these feelings of vulnerability. However, vulnerability constitutes the notion of being human and postulates human capabilities. Human value is a concept of relationships: to understand and trust that one has a value one must be confirmed and recognised by another person.

The patient role can be part of an objective context as a closed system, i.e. the patient is reduced to only representing objective data of disease instead of an open system. In an open system the patient is a subject with autonomy and something important to contribute- the person is someone. Being a person and human being implies different roles, such as patient, teacher or beggar. Whatever position, the individual is treated as a person with dignity and respect. If only a diagnosis or objective data from tests serve as the starting point, no system allows the person to be introduced. If the health professional receives information (age, diagnosis, etc.) that a patient is to be admitted to a hospital ward, such information contains only objective information.

The patient's personal story can then bridge the gap between the objective perspective and a unique individual. Hence, people and lifeworld become attainable and can help understand and explain their particular illness. The story can sometimes be without words, but by meeting and communicating through the body (smiles, glances, actions), caregivers and patients can connect and build a more authentic relationship.

Similarly, a person can initiate a relationship with a beggar who is always found sitting outside the local shop and you start to worry about this person who, without verbalising it, asks for your help. The beggar's apparent suffering affects your vulnerability, causing concern and frustration. The verbal story may diminish or help comprehend these feelings because the narrative enhances understanding.

2.3 Ethics as the Basis for Health Care

A person-centred perspective on health and care uses ethics as a springboard. Such an ethical view can briefly be formulated by citing the French philosopher Paul Ricoeur: "To aim for the good life, with and for others in just institutions" [7]. This ethics guide people who often face moral dilemmas that must be resolved about ethics in

every care situation or for every person seeking help. When writing about the good life, Ricoeur refers to what is good for us, namely a ‘flourishing’ life characterised by meaning and harmony.

Human capabilities, including those of patients, can be noted or neglected and strengthened or diminished by fellow human beings, particularly evident in situations characterised by asymmetric relationships, such as those that often occur in health care. In such cases care staff need to be aware of the importance of the relationship and how it is expressed in different situations. When the starting point is ethics and each person is understood as a unique individual, care actions will never be the same for each patient, although diagnosis and treatment are included as determining aspects.

By recognising the patients and understanding their needs and capabilities, care and treatment can be tailored to different patients and their unique needs [3, 5]. Suffering is sometimes reduced to physical or mental pain. In contrast, the most challenging suffering is a lack of recognition of a person’s human capabilities, i.e. individuals are reduced to only a fraction of their potential. A capable person is vulnerable in the sense that vulnerability is not a defect in need of elimination but a constituent part of human beings that unlocks their sensitivity to the suffering of others.

2.4 Understanding the Patient’s World

The jumping-off point for understanding the patient’s world is that professional caregivers share the same world with the patient but that the health professional has different ways to approach and understand it. The lifeworld consists of all the immediate experiences and contacts that influence our world. Thus, all people develop their ways of understanding themselves and others, with the ultimate goal of achieving harmony and living in coexistence with others. In addition, our way of understanding things is in rapid and constant change. Accordingly, the lifeworld is a realm of both unique and shared experiences. By asking for the patients’ understanding of the condition and treatment relative to their lives in general, professionals can understand what health, illness, treatment and care convey to patients and their relatives.

Our pre-understanding is based on our lifetime experiences and can be a valuable asset when we navigate the world in the presence of others. Even so, such a pre-conception can hinder further understanding as it creates certain expectations. If something is different from what we expect if something is not usual or common understanding can be greatly obscured. Everyday life would not work well and much would become complicated without the daily conversation lubricant as ‘the natural setting’ implies. Nevertheless, it is important to be self-critical and not take our understanding for granted, i.e. critical reflection is necessary, something that thoughtful people (such as health care practitioners) incorporate into their life. Subtle shifts in the tone of a person’s voice may be observed that make us wonder if this person likes the situation as he or she claims.

Such attention that leads to reflection must always be included in health care situations. In particular, health care professionals have to listen to the premise that they do not know what the patient knows, needs, desires or is willing to disclose. Listening this way is time-consuming and a complicated process but it is essential when seeking to gain a fuller understanding of the patient's narrative. In the quest to understand the patient professionals need to be responsive, subtle and flexible.

To penetrate what strengthens a patients' vitality and help them find ways to recover an 'insider' perspective is needed [9]. This insider concept refers to gaining insight into the patient's life, where staff use their humanity to understand the patient's humanity. It is not enough to use cognitive skills. As professionals, we need emotional and bodily competence to grasp patients' deeper existential layers and their current situation. Incorporating such strategies in today's health care environment can be challenging but necessary to attain a more humanised care.

2.5 The Personal Health Plan

Establishing a health plan for care or rehabilitation requires health workers to include medical data (e.g., signs and symptoms) related to the particular condition or diagnosis. Still, the patient narratives are important in formulating such a plan but have not been given adequate space or significance in today's health care environment [10]. Patient narratives are not just one long story told by a patient on one occasion, rather, they are often a series of conversations between a patient and a health professional (perhaps with other professional or family members present) [11]. These conversations and narratives intend to clarify the context and the patient's life situation. Patients, close relatives and professionals can agree on what is relevant and what should be emphasised in the health plan. However, underscoring the value of stories is not just about verbal narratives in that patients cannot always express their story in words.

For various reasons, people may have problems expressing themselves verbally (e.g., a person with a stroke or similar disease, small children who have not yet developed their language or those who have a different first language from the caregiver). In such situations, where linguistic capacity is inadequate or non-existent, alternative strategies are needed.

As Gadamer notes, the tough thing is not finding the 'good' answers but asking the right questions [12]. The right questions are marked by the fact that we do not know the answers. We may have encountered patients with a disease that we know about as professional caregivers. However, we still lack an understanding of how the specific patient experiences the disorder, cope with daily life activities, wishes and needs. Transparency and questioning are limited by context (e.g., hospital or municipality care, emergency illness or health promotion). Consequently, there needs to be insight into how, for example, the patient's context affects both the patient and the professional's understanding of a current care situation.

2.6 An Example of a Person-Centred Care Intervention

The person-centred intervention, consisting of a combined digital platform and structured telephone support system, was provided for 6 months in addition to usual care. The structured telephone support programme included an optional number of phone calls with a health plan co-created and followed up by patients and health care professionals consistent with person-centred principles. The digital platform was built to support communication between phone calls and provide access to shared documentation (health plans and self-ratings) and reliable information sources.

In the first telephone conversations the health care professionals encouraged the patients to talk about their beliefs, thoughts and feelings.

The professionals established a partnership using communication skills such as listening to participants' narratives about daily life events and the effects of their condition. The next step entailed co-creating a health plan based on patient narratives, including patient goals, resources and needs.

The health plan typically contained information about what they had talked about, how the participants felt, what goals they had and what they hoped to achieve. Participants' capacities and resources to help them achieve their respective health goals were also included in the health plan.

Health care professionals and patients collaborated to schedule follow-up meetings. The health plan was then uploaded to the digital platform with help from health care professionals if participants chose to write the plan themselves. The health plan served as a leading source for impending talks and communication via the platform. All participants and health care professionals had access to the platform during the 6-month study period. The health plan was revised during each follow-up phone call and when needed (e.g., if the participants spontaneously contacted the health care professionals).

The platform contained:

- (1) functionalities for two-way communication through private messages or calls,
- (2) the possibility to rate daily symptoms to be visualised as trend graphs and
- (3) an archive of the health plan.

The participants could invite and give customised access to the platform to any person they wanted, such as informal carers, family or friends. They also could access links to relevant websites containing information and services about their diseases. This information was provided by patient organisations and the Swedish national support guide (1177.se) as to an online peer-to-peer support group. A detailed description of the intervention has been published elsewhere [13].

2.7 Evaluation of Person-Centred Care Interventions

From a person-centred perspective, health care professionals recognise patients as partners in planning and performing the care process. Moreover, person-centred care comprises shared responsibility, co-ordinated care and treatment [3, 5, 11, 14]. Early research has shown that an intervention based on person-centred principles after surgery has successfully improved daily living activities, improved care satisfaction and reduced hospital admissions [15].

Based on these findings, Ekman et al. illustrated how the ethics of person-centredness could be operationalised in practice through person-centred care, where the theoretical framework encompasses the philosophy of personhood manifested through the patient narrative, partnership and coherent documentation. One of the first controlled studies based on this framework showed reduced hospital stay for patients with CHF without worsening functional performance or increasing readmission risk [16].

Previous evaluations have reported how health professionals translate person-centred care into clinical practice and how well participants understand the established partnership and co-operation created when using this model [4, 17]. In these studies, health care professionals had to interpret how to apply person-centred care in their setting and that some aspects of the partnership created through person-centred care are not directly linked to the content of the health plan. Because a person-centred care intervention contains several interacting components, it is a complex and challenging objective [18, 19].

For example, the intervention's elements should be tailored to each participant and different clinical contexts given that the potential outcomes can be multiple and dispersed rather than linear. The design and evaluation of complex interventions need to be handled according to the complexity involved, including understanding how interventions are produced and affect participants and the settings in which they are tested and later implemented.

2.8 Effects of Person-Centred Care Measured by Controlled Studies

In a study evaluating PCC in an older patient group with CHF the length of hospital stay was reduced by 30%, activities in daily living were better preserved, uncertainty about the disease and treatment was reduced and the discharge process was more effective and less costly [16, 20].

In a randomised controlled trial, with follow-up in outpatient and primary care, PCC implementation after hospitalisation for acute coronary syndrome was evaluated. Results showed a significant, three-fold higher chance of improved self-efficacy and a return to work (or previous activity level). Moreover, the execution of PCC has proven to be efficient and cost-effective [21–23].

Another study found that using an eHealth tool combined with a person-centred approach resulted in a significant four-fold higher prospect of improved self-efficacy [24]. With regard to the ethical basis in PCC, an important finding was that patients with lower than a university education significantly improved their self-efficacy compared to those with academic degrees.

This finding confirms that person-centeredness supports equal access to care and actively reduces social disparities in health care [21]. A randomised controlled study evaluating PCC in patients with severe CHF in palliative care at home showed significant differences in reducing symptoms, increasing quality of life and decreasing rehospitalisation rates [25].

In a recent randomised controlled study person-centred care in people with chronic heart failure and/or chronic obstructive pulmonary disease was evaluated using person-centred telephone-contacts.

Results showed that only three calls were made during 6 months, on average, and self-efficacy significantly worsened in the control group and showed no change in the intervention group [26]. The significance of these studies, based on person-centred ethics and consecutive clinical trials to study practical application, is so profound that their results have been embraced by the Swedish health and social care sector and embedded in the strategic focus of the Swedish Association of Local Authorities and Regions.

The relevance and impact of the performed and supported studies have proven to be high. In addition, two EU-funded projects on PCC has been conducted.

First, within the 7th frame programme, the WE CARE project, a road map for future health in Europe, was developed by key players representing different countries and disciplines [1].

Second, a COST initiative that included 28 countries was established with three test-beds for testing and researching PCC on cost containment and quality of care in different systems [27].

Recently, a European standard has been approved for minimal patient involvement in person-centred care [28].

2.9 Conclusion

The principle of person-centred care is presented as the antithesis of reductionism. The doctrine maintains that patients are persons and should not be reduced to their disease alone. Instead, the subjectivity and integration of patients within a given environment should also be considered, including their strengths, plans and patient rights, a subset of human rights. Person-centred care implies a shift away from a model in which the patient is the passive target of medical intervention to a more contractual arrangement involving patients having an active part in their care and the decision-making process. Person-centred care includes active collaboration with the patient as a person based on the patient's narratives. Moreover, a readily accessible, tailored health plan is formulated and documented together with each patient. The main

difference between person-centred care and diagnostic medicine is that the patient is accepted as a subject in person-centred care. In contrast, in conventional medicine the patient is a biological object identified by a series of diagnostic measurements. Controlled studies have found several benefits from implementing person-centred practices, including improved quality of life, self-esteem maintenance and reduced health costs.

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