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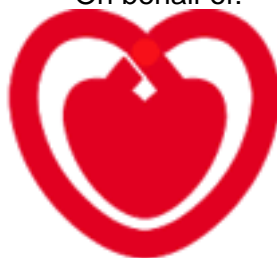
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Person-centered care — Ready for prime time

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Abstract

Long-term diseases are today the leading cause of mortality worldwide and are estimated to be the leading cause of disability by 2020. Person-centered care (PCC) has been shown to advance concordance between care provider and patient on treatment plans, improve health outcomes and increase patient satisfaction. Yet, despite these and other documented benefits, there are a variety of significant challenges to putting PCC into clinical practice. Although care providers today broadly acknowledge PCC to be an important part of care, in our experience we must establish routines that *initiate*, *integrate*, and *safeguard* PCC in daily clinical practice to ensure that PCC is systematically and consistently practiced, i.e. not just when we feel we have time for it. In this paper, we propose a few simple routines to facilitate and safeguard the transition to PCC. We believe that if conscientiously and systematically applied, they will help to make PCC the focus and mainstay of care in long-term illness.

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1. Introduction

In late 2009, fears of an impending swine influenza pandemic spurred a massive and highly visible mobilization of the international medical community to remedy, treat, and

contain the disease. While the eyes of the world were focused on the unfolding of this drama, another less sensational, but potentially more sinister pandemic was in progress and gaining ground. Denoted a silent pandemic, long term diseases are today the leading cause of mortality worldwide and are estimated to be the leading cause of disability by 2020 [1,2].

Making matters worse, already overburdened health care systems throughout the world are poorly prepared to meet this challenge and require extensive reform to realign traditional acute-care clinical practices and organizations to better accommodate illness management as a central goal of

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care and treatment [3]. Patients often must navigate through a fragmented health care system and adapt to the customs and usual procedures of health care organizations and professionals, rather than receiving care designed to focus on the individual patient's needs, preferences and values. As an alternative, Person-centered care (PCC) is today widely advocated as a key component of effective illness management [4–6].

1.1. Person-centered care vs. personalized medicine

Personalized medicine and PCC are two concepts which are often confused and conflated. This is partly due not only to the similarities in terminology but also to the fact that both approaches are intended to 'individualize care', or to compensate for our inability to predict and adapt care to exceptions from the medical norm. Evidence-based healthcare will always, by definition, apply standardized care models based on the response of cohorts to treatment; when these models fail to capture minority responses of individuals, personalized medicine and PCC are ways for us to help nuance the models and identify and properly respond to individual exceptions. Personalized medicine explains and predicts individual exceptions based on genetic or other phenotype variations; a person-centered approach to care can explain and predict individual exception based on who the person is: their context, their history, their family and loved ones, their individual strengths and weaknesses. There is a clear and obvious need in care for the advantages that both approaches can contribute, but we should take care that the adoption of personalized medicine does not reduce the role and importance of the person in the care process further, from their body to their genes, and takes responsibility, dignity, and autonomy away from the person. We need to understand the difference between personalized medicine and PCC, and the wider change and paradigmatic evolution that adopting PCC entails.

1.2. Person-centered care vs. patient-centered care

The notion of the person is crucial in legal matters. A person is legally responsible for his own acts and behaviors. One uses the concept of person in order to give somebody responsibility vis-à-vis a situation which concerns him or her [7]. PCC is the antithesis of reductionism. It asserts that patients are persons and should not be reduced to their disease alone, but rather that their subjectivity and integration within a given environment, their strengths, their future plans and their rights should also be taken into account [7]. PCC means a shift away from a model in which the patient is the passive target of a medical intervention to another model where a more contractual arrangement is made involving the patient as an active part in his or her care and the decision-making process [7]. Reasons for this lie in the fact that PCC has been shown to contribute to improved concordance between care provider and patient on treatment plans, better health outcomes and increased patient satisfac-

tion [8,9]. Yet, despite these and other documented benefits, there are a variety of significant challenges to putting PCC into clinical practice [8,10,11]. Studies have shown that despite the fact that care givers espouse person-centered values, care processes largely remain routinized, ritualistic and afford few opportunities for the formation of meaningful patient-provider relationships [9–11].

In this paper we propose a few simple routines to facilitate and safeguard the transition to PCC. We believe that if conscientiously and systematically applied, they will help to make PCC the focus and mainstay of care.

2. Point of departure

We have pointedly avoided the more widely used term '*patient-centered care*' and instead used what we feel is the more appropriate designation '*person-centered care*'. In our view, the word patient tends to objectify and reduce the *person* to a mere recipient of medical services, or to 'one who is acted on' [12]. Person-centered care highlights the importance of knowing the person behind the patient – as a human being with reason, will, feelings, and needs – in order to engage the person as an active partner in his/her care and treatment [13]. The challenge for the healthcare provider is to receive the person's self expression in such a way that confidence is strengthened and resources for healing identified. This can be understood from an ethical perspective as the health care provider's obligation to recognize and acknowledge the fragility of self and coherence in life [14]. When we become ill the meaning and coherence of our life project becomes threatened. Giving the patient the opportunity to present her/himself as a person in the form of an illness narrative is the starting point for building a collaborative, equalitarian provider (care and treatment expert)-patient (person expert) partnership that encourages and empowers patients to actively take part in finding solutions to their problems [15].

With grants from the Swedish government, we recently established the University of Gothenburg Centre for Person-centered Care (GPCC), an interdisciplinary research core center for the study of PCC in long-term illness. The center's overall aim is to systematically and comprehensively investigate PCC from the perspectives of the person with long-term illness, the health care professional involved in the care of that person, and the health care organization providing the structure for that care. At present, the Center is coordinating 10 large studies in these areas and several more are in the pipeline. Our experience from these studies is that although there are significant challenges to putting PCC into clinical practice, they are surmountable.

3. The challenges

In planning our studies we had anticipated that the staff at the hospital departments where the studies are being performed would be skeptical to the merits of PCC. We found instead that they considered PCC to be a self-evident

and important facet of care. In fact, our major challenge was not in persuading them to practice PCC, but rather in convincing them that they were not practicing PCC—at least not consistently or systematically. By following and documenting usual care at the departments, we were able to identify and discuss with the staff what we saw as departures from PCC. Generally, the staff members excused these lapses by explaining that when pressed for time they gave priority to performing medical work ups. The second challenge was thus that the staff felt it natural to relapse to disease-centered care—and hence implicitly placed the disease before the person.

We also noticed that PCC interactions were not generally documented in patient records – and in fact little was mentioned about the patients' preferences for, feelings, and beliefs about their illness or treatment – implying that this information was of lesser value than biomedical information. The third challenge was to convince the staff of the importance of documenting such information.

In short, although care providers today broadly acknowledge PCC to be an important part of care, they still often do not consider putting the person before the disease — see the person with the disease not just the disease. In our experience, to ensure that PCC is systematically and consistently practiced, i.e. not just when we feel we have time for it, we must establish routines that *initiate, integrate, and safeguard* PCC in daily clinical practice.

4. Routine 1: initiating the partnership: patient narratives

A person-centered approach to care sets the person's views about his/her life situation and condition irrefutably and always at the center of care. The patient narrative is the sick person's personal account of his/her illness, symptoms, and their impact on her/his life. It captures the person's suffering in an everyday context, in contrast to medical narratives that reflect the process of diagnosing and treating the disease. In our experience, the patient narrative constitutes the starting point for PCC and lays the ground for a partnership in care.

The mere invitation to relate a narrative sends a message to the patient that his/her experiences, feelings, beliefs, and preferences are important considerations. It is at this point that focus shifts from the disease to the person with the illness (needs and resources). In all of health practice the narrating of the patient's story is a therapeutically central act, because to find the words to describe the disorder and its attendant worries gives shape to and control over the chaos of illness [15].

Biological markers or images are important data, but as a basis for a care and treatment plan they are complementary to the patient's narrated experiences of his/her condition. The current norm in health care is to identify each patient's biological referents in order to diagnose, treat, and cure a disease. While these new methods are being developed, advanced biological and imaging diagnostic tools are being used in daily practice. We have found that these objective

data unfortunately dominate the basis for care and little consideration is given to patients' feelings, beliefs, and preferences, or to assessing and utilizing patients' resources for illness self management.

5. Routine 2: working the partnership: shared decision making

Narrative communication involves sharing experiences and learning from each other. Telling and listening is a way of creating a common understanding of the illness experience, which, together with signs of disease, give the professional a good basis for discussing and planning care and treatment with the patient [8,15]. Indeed, PCC starts with partnership building and includes sharing of information, shared deliberation, and shared decision making. Despite the availability of effective and safe treatments in long-term conditions (e.g., diabetes, chronic heart failure, hypertension) many patients do not achieve recommended target doses or optimal care. Given the progressive nature of long-term diseases and the need for extensive illness management, it is important that professionals and patients (often including relatives) develop a partnership to achieve commonly agreed goals. At diagnosis, the care team, including the patient, should evaluate all aspects of management, taking into account treatment options that are suited to the patient's lifestyle, preferences, beliefs, values, and health issues.

6. Routine 3: safeguarding the partnership: documenting the narrative

Documenting patient preferences, beliefs, and values, as well as involvement in care and treatment decision-making in patient records gives legitimacy to patient perspectives, makes the patient-provider interplay transparent, and facilitates continuity in care. The registration of such information must be considered equally mandatory as clinical and lab findings.

7. Case example

Mr. G is a 72 year old retired businessman and avid golfer who had had a small myocardial infarction 15 years ago. After recovery from the infarction he returned to playing golf and was in good health until one day he suddenly collapsed. Resuscitation was immediately initiated. An ambulance arrived shortly afterwards and he was defibrillated. A non-ST segment elevation myocardial infarction was later diagnosed at a local hospital and a percutaneous coronary intervention was performed. A significant coronary stenosis was left. He recovered well. Left ventricular dysfunction was diagnosed and treatment with an ACE-inhibitor and a beta-blocker was initiated. He was referred to a tertiary hospital for an Implantable Cardiac Defibrillator (ICD); however, a new angiography of his coronary lesion indicated the need for a coronary by-pass operation. The operation was scheduled to be performed a few months later.

7.1. Initiating the narrative

Sometime after being informed about the operation, Mr. G met with his district nurse and Dr. S for a yearly check-up. Mr. G explained that he did not feel well and was very worried about the upcoming surgery. He was so concerned about his condition that he did not dare to walk any distances and had given up golf. But from the illness narrative it was clear that Mr. G had no symptoms such as dyspnea or chest pain. When Mr. G was asked what he wanted to do, he became surprised, saying that none of his doctors had once asked him that question. Instead they had simply informed him that he was to be operated on and he assumed that he had no other option. However, he said that he would prefer not to go through with the operation.

7.2. Shared decision making

Mr. G was asked if he would mind if Dr. S and the care team took a closer look at his case. After reviewing Mr. G's records, Dr. S concluded that his condition did not clearly indicate by-pass surgery and that pharmacologic treatment was a viable option. None of the records made any reference to Mr. G's concerns about surgery or his preferences for treatment. Asked if he still preferred not to have surgery and instead continue with his medication as this was what guideline recommended, Mr. G answered that he did and that his wife supported him in this decision.

7.3. Documenting PCC

Mr. G expressed some concern about what his physicians at the tertiary hospital would say if he now declined the operation. Dr. S assured him that he would inform the physicians about their discussion and that Mr. G's decision about and preference for treatment would be documented in his patient record and that future options, e.g. an operation, would still be valid. After this talk, Mr. G became markedly relieved. During the three years since that time Mr. G has continued with pharmacologic treatment and has felt well and enjoyed an active life without any cardiac-related symptoms.

8. Conclusion

The paradigm shift that PCC represents will not be accomplished overnight. In our experience, the transition has already started—most care providers today appear to endorse a person-centered approach to care. But they need help to apply this approach systematically and consistently. We propose three simple routines to facilitate and safeguard the transition to PCC. The patient narrative is the first step in establishing a partnership with the patient. Shared decision-making builds on the partnership. Documentation in patient records not only sanctions the value of this information but also contributes to the continuity and transparency of the provider–patient partnership.

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Conflicts of interest

There are no conflicts of interest to be declared.

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