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The person-centred approach to an ageing society

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Abstract

Modern care is often based on investigations such as laboratory markers and imaging - for example, X-ray or ultrasound. The results contribute to a diagnosis and, if judged necessary, treatment is initiated. This diseased-oriented approach is the prevailing mode of management in modern medicine. In contrast, person-centered care (PCC) takes the point of departure from each person´s subjective experience of illness and its impact on daily life. A patient is considered as a *person* with emotions and feelings. PCC is considered present within clinical care according to a definition articulated by the Centre for Person Centred Care at the University of Gothenburg (GPCC) when three core components are present: elicitation of a detailed patient narrative; formulated partnership between caregiver and patient and documentation of the partnership in the patient record. Accordingly, when there is an illness requiring care and the person is attended using these components, PCC is being applied. In most situations today, PCC is not applied in terms of the narrative and is not fully elicited or the partnership and/or the documentation are not included. It is proposed that the challenge to Society arising from changing demographics can be addressed by implementing PCC and creating an alternative to existing healthcare. The importance and benefits of such an approach on a wider scale is not yet clear as research has been limited to date. Studies in selected patient populations (heart failure and hip fractures), however, have shown promising results. As the population ages, there will be a dramatic increase in healthcare consumption. Even with technological developments, there will be a need for tremendous resources to be dedicated to care. A new organization and attitude from healthcare policymakers and providers above and beyond the present model appears required in order to respond to this demand. As part of such change, person-centred care, with the interaction between healthcare providers and the person of the patient, can facilitate, compensate and develop more effective healthcare services for the future.

Keywords
Ageing, patient-centred medicine, partnership, person-centred care, personalized medicine, shared decision-making, utilization

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Accepted for publication: 29 June 2012

Introduction

In the current paper we argue that a new and growing generation of elderly people, technological developments and the growth of individualized care, all require the development and evaluation of a new model for the care of the sick: person-centred healthcare. We base our discussions on the proceedings of a meeting on "Ageing and Society" and person-centred care (PCC) organised by the University of Gothenburg Centre for Person Centred Care (GPCC) on November 24, 2011. The objectives of the meeting were to review current thinking and practice related to PCC in this context. How can PCC implemented in Society contribute to and help to address the future challenges posed by an ageing population?

It is commonly accepted that current demographic trends and the increasing global population will result in a major increase of the elderly population in general and in the Western world in particular [1]. This will inevitably result in major changes in healthcare utilization. For example, in present-day Sweden there is one old person per four working people, but in 2050 this will have changed to one old person for every two working people**.** In Sweden, by the age of 65, current life expectancy is on average another 20 years; 14.7 of which will be in good health and 5 of which will be in poor health. By the age of 65, 40% need some kind of assistance, in ages over 85 it is 75% [1].

This increase in the elderly population will lead to an increasing demand for healthcare services as a proportion of the older population experiences increasing morbidity with impairments of function such as cognitive decline and increasing limitations in activities reflecting higher levels of dependency and associated costs. Consequently, the number of households receiving elderly care in Sweden will increase sharply in the future, by 40% up to 2030 and by 60% up to 2050. The need for care of the elderly, in particular for special housing, will therefore increase more than the need for healthcare in all the scenarios, assuming the same pattern of care as today. The simulation shows that the consumption of elderly care increases on average by around 1.3 – 1.4% per year up to 2050, depending on the health scenario [1].

The World Health Organization (WHO) has summarized the situation. The world population is rapidly ageing. Between 2000 and 2050, the proportion of the world's population over 60 years will double from about 11% to 22%. The absolute number of people aged 60 years and over is expected to increase from 605 million to 2 billion over the same period [2]. The increased demand for care will require an estimated tax increase by 42% by 2035 which has been considered not politically possible [3]. Thus, health services around the world are struggling increasingly to meet the increased demands placed upon them.

There is also increased heterogeneity among elderly people as many elderly demonstrate more differences in desires and interests, different skills and a high degree of resiliency. In addition, cultural differences add to complexity as research indicates that ethnic minorities perceive that they are not listened to or involved in decisions, that they are not respected and that they are sometimes unfairly treated [4]. This marked change in demography and heterogeneity will most probably influence the attitude to ageing. This cultural change has already influenced future retirement and nursing home practice where residents can now be seen in partnership with providers [5]. The so called 'Baby Boom' generation is changing stereotypes of the elderly and this suggests that previous models of elderly care may not be appropriate for them. Another possible scenario might be a polarization between the older and the younger population. Within the next 20 years, the elderly may be viewed by younger people as having consumed enormous resources during their productive years, leaving environmental problems for the younger to resolve. Thus, there are many reasons to call for plans and actions. The Institute of Medicine's report on re-tooling for an ageing America recently emphasized the need for fundamental reform in healthcare training and implementation to meet the needs of the older population [6]. "The nation needs to move quickly and efficiently," the report states. Such changes are also being recognized as necessary within the medical community where, for example, a human systems model approach is being proposed within Clinical Rehabilitation, shifting the focus towards relationships, enabling rehabilitation problems to be seen as provisional and context dependent [7]. In a recent review in the *New England Journal of Medicine* Fineberg, from the Institute of Medicine, highlighted that partnership with patients in the future changes of healthcare need to reduce the expenditures in healthcare costs in the US [8].

Person-centered care in the ageing society

The modern care of people is most often based on a symptomatic initiation when a subject is seeking care

following the experience of specific symptoms [9]. The caregiver, usually a physician, requisitions investigations based on laboratory markers and imaging by, for example, X-ray or ultrasound. The results contribute to a diagnosis and, if judged necessary, treatment is initiated. In addition, multimorbodity will increase in the ageing population [10]. This disease-oriented approach is the prevailing model of management in modern medicine. In contrast, person-centered care refers to the behavior or attitudes of health professionals when a patient is considered as a *person* who is conscious and has feelings. Other essential traits in being a person are a sense of self-worth, dignity, selfhood, self-knowledge and self-direction [11]. This means that every human being has the right to be treated according to these principles. One example of a well-known Personalist is Martin Luther King, who argued that all people, including Afro-Americans, have the right to be treated as people with dignity, self-knowledge and self-direction [12]. Similar arguments can be made concerning patients since the dominant biomedical model of disease today leaves little or no room within its framework for viewing the patient as a person with social and existential dimensions having her/his own thoughts and ideas of their illness [13]. Person-Centred Care (PCC) is the antithesis of reductionistic biomedicine. It asserts that patients are persons and should not be reduced to their disease alone, but rather that their subjectivity and situation within a given environment, their strengths, their future plans and their rights, should be taken fully into account. PCC is considered present according to the definition by the Centre for Person Centred Care at the University of Gothenburg (GPCC) when three core components are practised: elicitation of a detailed patient narrative, formulated partnership between caregiver and patient and documentation of the partnership in the patient record [14]. Accordingly, when there is an illness requiring care and the person is attended by these components, PCC can be described as being applied. In most clinical situations today, PCC is not being practised as the narrative is not fully elicited or the partnership and/or the documentation are not included.

We propose that the challenge to Society arising from the changing demographics we have described above can be addressed by implementing PCC and creating an alternative to existing healthcare models. The importance of such an approach on a wider scale is not yet known as research has been limited to date. Studies in selected patient populations (heart failure and hip fractures) have, however, shown promising results [15,16].

Which possibilities can be provided by technological developments and progress?

Healthcare has been associated with enormous technical developments over the last 20-30 years. Major advances in imaging, biomarkers and treatments have reduced mortality and morbidity resulting in increased longevity and ageing. Technical developments will continue and partially contribute to better care and solutions which will reduce morbidity. However, sooner or later, the ageing person will demand increased care, which will require resources corresponding to the changing demography as discussed. In this context, it is interesting to observe that technical solutions have resulted in increased involvement of the patient and increased feedback between the provider of service and user. The original IKEA model was a transfer of assembly of furniture to the customer. More recently, the transfer of bank service from the bank office to the customer has, during a short period, that is, in less than 10 years, made the customer - banking service interaction completely different. Such solutions are cost-effective for providers, while also giving customers the opportunity to shape the services they receive. It is reasonable to believe that developments such as these will also impact on models of healthcare provision. Such developments have resulted in new possibilities to collect information on health status, for example, monitoring of heart function by pacemakers and other monitoring equipment. However, the increased information has resulted in a paradoxical need for care [17]. A Cochrane Review has demonstrated that TeleMonitoring / TeleHealth is associated with significant decrease in mortality and hospital admissions / length of stay, in heart failure [18]. However, more recent experiences from randomized studies with monitoring of patients with heart failure have not translated into reduced morbidity [19,20], reflecting the need to assess and design studies appropriately.

In healthcare, the need for person to person communication can either increase the burden on health services or, alternatively, it can provide the possibility for developing less resource-intensive models of care. Such possibilities can, for example, consist of the identification of each individual's resources (self-knowledge, self-direction) and the usage of the interaction to increase the person's (and her/his family's) capacity for self-management. PCC appears as an attractive option as the patient and the family are expected to be actively involved in future care.

Personalized (individualized) medicine

Personalized medicine is another development of modern medicine where technical progress has increased the possibility for individualising the patient´s diagnosis and treatment. Solutions are based on individual profiles from, typically, biomarkers. More advanced applications of personalized medicine determine the individual's genomic profile as part of individualizing therapies. The solutions can offer tailoring of drug treatment (pharmacogenomics). However, so far there has been more hope than actual results in this area. Diseases are often multifactorial and genomic solutions to therapies are mostly based on alterations of only a few genes.

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 persons are: their context, their history, their family and loved ones, their individual strengths and weaknesses, their own experiential knowledge of their condition and their own treatment goals. There is a clear and obvious need in clinical 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.

Person-centred care

Central to the concept of person-centred care (PCC) is the view that care is a collaborative process between patients and healthcare providers. As such, it involves the joint development of care plans with goals which are documented in the patient's notes, targets and implementation strategies, providing self-management training and support services and active, sustained follow-up. It is care that is coordinated across settings and over time.

WHO has identified PCC as one of five core competencies that clinicians must develop to deliver quality healthcare in the 21st century [21]. Unfortunately, there are very few studies that have evaluated fully implemented PCC and, of the published studies, it is evident that implementing a systematic and structured PCC is very difficult. In a review of PCC, only 10 studies that had actually implemented and evaluated PCC according to the definition discussed above, in a controlled design (RCTs or before and after measurements), could be identified [22]. Both objective (HbA1c, BMI, cost of care and length of hospital stay) and subjective (wellbeing, quality of care and patient satisfaction) outcomes showed positive effects of PCC, one example being that hospital stay was shortened by 50% [15]. Accurately implemented, PCC means more satisfying care for the individual patient as well as effective and cost-saving care for Society.

How can PCC be implemented?

Management by PCC is planned by patient representatives, physicians, nurses and other care professionals. The aim is to establish a working consensus in order to facilitate and safeguard the implementation of PCC in the designated hospital ward or healthcare unit. Nevertheless, only 60% of patients received the entire PCC intervention in one of the most recently performed PCC studies [16]. Public healthcare organizations are considered to be extremely difficult to change and there are several examples of how professional territorialism and organizational inertia cause and sustain ineffective routines [8,23,24]. Organizational culture is the "normative glue" which holds individuals together in an organization and new working models have often been hindered by healthcare cultures that resist change [25]. The need for a change in healthcare culture towards a stronger person orientation instead of disease-centredness seems self-evident. However, healthcare professionals still tend to focus on the disease within the person, rather than the person with the disease [14]. Biomedical knowledge continues to take precedence in multi-professional dialogue and even when physicians are not present, other professionals such as nurses, act as 'deputies for medicine' [14]. It appears that the shift from traditional, disease-centred care towards PCC is complicated and slow, but with the present challenge that is facing healthcare systems throughout the world, to meet the complex and costly care needs of the large and growing population of persons with long-term illnesses, it is vital that healthcare systems realign traditional clinical practices and organizations as soon as possible [8,26,27]. Such transformations could be facilitated by leaders who seriously and thoroughly initiate the organizational and cultural transformation processes towards PCC. In order to provide PCC to patients, healthcare personnel themselves need to be treated as persons, that is, there is a need of person-centred supervision and management in healthcare.

PCC and Industry

Despite groundbreaking advancements in medicine and biotechnology over the last few decades, approximately 50% of symptoms are medically unexplained [28]. The accuracy in diagnoses and medical treatments is at the same time negatively correlated with increased disease complexity. Guidelines for professionals tend to cover single conditions, although the multimorbid individual has to manage all of his/her problems in his/her own life world [29]. This inevitably involves trade-offs between 'best treatment' for any single condition and the person's own experience and goals [30]. A growing market of multimorbid elderly patients is thus presenting a major challenge for the current system [10]. Person-centered care, with its strong focus on the subject and his/her symptoms and narrative as the starting-point, is likely to hold large potential as a key to be able to effectively

manage this trend. Person-centered care should thus present an interesting marketing opportunity for Industry.

The global pharmaceutical industry, with its decreasingly efficient business model, is looking partly in this direction in a process where all the major players are trying to 're-invent' themselves and find new sources for innovation and new business models. One major path includes so-called open innovation models, where assessments of drug effects are moving away from biomarkers and genomics, given that these have not translated into new markets and instead involve patients in product development by collecting patient feedback through patient-reported outcome (PRO) solutions. The Industry is also looking 'beyond the pill'; investigating business models around more integrated and customized care solutions with a stronger element of choice for the patient. Over several years, trends in care consumable products have developed in this way and are rapidly moving from products to complete care solutions resting on a PCC fundament where the subjective perceptions of the end-consumer (patient) such as wellbeing, quality and satisfaction are central.

The most promising areas for large-scale deployment of commercial investment with a person-centered care basis may, however, be e-health and medical technology. Information technology solutions have opened up almost infinite possibilities for the development of ubiquitous care solutions. However, these solutions have to be adapted to the needs of the elderly, their self-care processes and coping strategies and to support new ways of healthcare delivery under close surveillance of patient safety, legal and ethical issues. This will require an active involvement of the patient in the product development process. In particular, it will require the products and services to capture and process the subjective experiences and perceptions of its user (the patient), while allowing the user to be an active partner in his/her care process.

Summary and Conclusions

As the population is ageing, there will be a dramatic increase in healthcare consumption. Even with technological developments, there will be a need for tremendous resources to be dedicated to care. A new organization and attitude from healthcare policymakers and providers and beyond the present situation appears required in order to respond effectively to this demand. As part of such changes, person-centred care, with the interaction between healthcare provider and the patient, can facilitate, compensate and develop healthcare for the future.

Conflicts of Interest

The authors report no conflicts of ineterst.

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