

Lang suggests her daughter's experience in medicine is a world away from her own. 'Things are much better now in terms of teaching materials and methods and obviously technology has developed so things like imaging are much better than in my time, but the commitment remains the same. You still need to have the same dedication to your work and to care for patients'.

Her final piece of advice is to have several areas of interest in life to cross-fertilise your ideas and ensure that all is not lost if the first goal falls by the wayside.



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Engaging patients in their medical care

The return of the clinician is an essential prerequisite to competently involve patients in their medical care for best outcomes. A reflection by Karl Swedberg

At the beginning of the 20th century, technical development made it possible for clinicians to measure organ function in patients e.g. by X-ray and echocardiogram (ECG). Until then the patient narrative had been the foundation to evaluate illness and disease, and clinicians needed to be very skilful to discover what was wrong with a patient who felt unwell. It took many years for the new techniques to markedly change practice but eventually clinical practice had changed to such a degree and influenced the evaluation of a sick person that there were reminders needed that patients were people with biopsychosocial functions which should be considered as well.¹

I started my clinical practice around 1970 and I joined cardiology in 1974. I have since then been fortunate to experience the fantastic development of the diagnostic and treatment options, which have developed during the last 50 years. All these have translated into patient benefits reflected by a reduction in morbidity and mortality. During the same time, I have observed a transition in clinical practice, away from the patient history (narrative), to a description of patients as objects, by describing them in laboratory values including biomarkers, and by results from imaging e.g. ECGs and coronary angiography. These are all important but they cannot distract our focus away from the patient person and his or her burden of a disease.

Because this development has been particularly obvious with the success of modern cardiology, I started some years ago to reflect on this development. I experienced that physicians have left more and more of care management to other health professionals, primarily nurses, while focusing on the objective findings from biomarkers and imaging. Based on this information, diagnostic and therapeutic decisions have been formed.

Patients have been reduced to objects, which can be managed based on such information. I think this is an unfortunate development. The importance to penetrate the patient's narrative must not be forgotten as an introduction to engage the patient in his/her disease. In order to change this development, I believe that it is of importance that physicians return to the roots of clinical medicine and to listening to patients.

At the University of Gothenburg Centre for Person Centred Care (GPCC www.gpcc.gu.se) we have realized that in order to involve the patient in his/her care, we need to first of all understand the person behind the patient. We are all patients during some time in our lives but we are always persons. The starting point to person-centred care (PCC) is the narrative where the story is expressed in addition to an understanding of each person's resources and capability to reach well-being and health. Based on this, a personal health plan is developed together with the patient where goals and actions to reach the goals are defined. The plan is then documented and made accessible for the health professionals and the patient. Based on this definition of PCC (gPCC),² we have developed a network of researchers within medicine, care sciences, health economics, and social sciences. We have supported approximately 60 research-projects and performed 25 controlled studies. The first clinical proof of the viability of gPCC was achieved in the care of patients with hip fractures. Data showed that length of hospital stay was reduced by 50%,³ costs of care were reduced by 40%,⁴ and there were less medical complications after surgery, better pain management, improved activities of daily living (ADL) recovery, and a more effective discharge process.⁵

In a second study on gPCC the average length of hospital stay for patients with worsening chronic heart failure was reduced by 30%,⁶ ADL were better preserved,⁶ uncertainty about the disease and treatment was reduced⁷ and the discharge process was more effective⁸ and less costly.⁹ Other randomized controlled studies from University of Gothenburg have demonstrated effects by the gPCC approach on symptom relief in rheumatoid arthritis¹⁰ and fibromyalgia in addition to improved muscle strength.¹¹

In a randomized controlled study in 72 patients with advanced heart failure, Boman and co-workers at the University of Umeå, Sweden, found that the gPCC approach was associated with 15 rehospitalizations (103 days), compared with 53 (305 days) in the control group where standard care was applied.¹² In addition, health related quality of life was significantly improved together with the use of target doses of life-prolonging medication and a significant cost reduction in patients was demonstrated. They concluded that PCC combined with active

heart failure and palliative care at home has the potential to substantially improve quality of life and morbidity in patients with severe chronic heart failure.

In a recent randomized controlled trial with follow-up of outpatients in primary care, implementation of gPCC *after hospitalization* for acute coronary syndrome was evaluated and shown to result in a significant, three-fold higher chance of improved self-efficacy in combination with return to work (or previous activity level) without increased risk of re-admission or death¹³ as well as improved confidence to manage symptoms.¹⁴ In addition, using an eHealth tool in combination with the gPCC approach resulted in a significant four-fold higher chance of improved self-efficacy.¹⁵ Last but not least, when studying the impact of gPCC on self-efficacy, significantly better results were found in patients with education below university level, which confirms that gPCC not only supports equal access to care but also actively contributes to reducing social inequality in health care.¹⁶

These research results together with an increasing interest in patient engagement in Swedish health care, have translated into a major movement in a transformation of health care into implementing PCC.¹⁷

The application of PCC will by definition, result in major effects for the health care professional: listening carefully to patients and patient involvement which in combination will result in better clinicians.

In summary, patient engagement is of central importance in the management of patients in health care as developed into PCC, which is a care model, that will have increasing impact in future health care.



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References

References are available as [supplementary material](#) at *European Heart Journal* online.

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The GPCC

The Gothenburg University Centre for Person Centred Care (GPCC) has been involved in individualized patient care for almost a decade, with noticeably improved outcomes for participating patients.

At present, organization of healthcare is focused on diagnosing and treating patients and optimizing the efficiency of the care process. Although this is a valid approach, the patient's own capabilities and resources are not sufficiently taken into account.¹ The patient is not stimulated to optimize his/her own resources and take more responsibility for self-management and prevention.

Gothenburg University, Centre for Person Centred Care (GPCC)

The Centre for Person-Centred Care at University of Gothenburg (GPCC) was inaugurated in 2010 and involves researchers from several different disciplines such as medicine, nursing, health sciences, health economics, pedagogics, and philosophy. Gothenburg University Centre for Person Centred Care is funded mainly by the Swedish Government (€10 m the first 5 years and then €2 annually) as part of a broad initiative to stimulate research at Swedish universities. The centre conducts research, develops and distributes educational resources such as courses for health professionals and students, and helps to facilitate implementation of person centred care programs in hospitals, and primary care centres by providing guidance on reshaping services and ongoing support.

The core component in person-centred care (PCC) is acknowledging the patient as a person in order to engage that person as an active partner in her/his own care and treatment.^{2,3} Patients (often with the help of relatives) present themselves as persons by their individual narratives which includes how their daily life is being affected by the condition and treatment, this is added to by results from the medical examination and tests. A person-centred approach not only means identifying health barriers, but also recognizing a patient's capabilities and resources in their home and local environment.

At the basis of PCC is the Capability Approach, which has been used as a theoretical frame of reference in several research disciplines, for example in economics by the Nobel laureate Amartya Sen.⁴ A central component of PCC is that the professional and patient jointly develop a health plan based on each patient's capabilities and health barriers. In PCC the role of health professional's changes from taking the lead and being dominant in care, to supporting the patient to take as much responsibility as possible for his/her own condition.

Gothenburg University Centre for Person Centred Care has described an approach to PCC, consisting of three main components:

- (1) Initiating the partnership through a narrative in order to get to know the patient and to identify the patient's experiences, present situation, needs, capabilities, and resources.
- (2) Co-creating a health plan in line with identified resources and barriers combined with medical and health research evidence.
- (3) Documenting and monitoring the health plan, adapting it to changes in the patient's goals and/or other circumstances.