Learning from the Gothenburg model of person centred health care

Standfirst: Axel Wolf and colleagues discuss a groundbreaking initiative in Sweden that is redesigning health care in partnership with patients and achieving better clinical outcomes.

Authors: Britten, Nicky (Professor)[1,2]. Ekman, Inger (Professor)[2,3]. Naldemirci, Öncel (Senior Lecturer)[4]. Javinger, Mikaela. (Patient rep)[5], Hedman, Håkan. (Patient rep)[5,6]. & Wolf, Axel (Associate Professor),[2,3].

1. *Institute of Health Research, University of Exeter Medical School, Exeter, UK'*
2. *Institute of Health and Care Sciences, University of Gothenburg, Gothenburg Sweden*
3. *Gothenburg University Centre for Person-Centred Care (GPCC), Gothenburg, Sweden*
4. *Department of Social Work, Umeå University, Umeå, Sweden*
5. *Patient representative, Lund, Sweden*
6. *Swedish Kidney Association, Sweden*

Correspondence:
Axel Wolf RN, PhD
Institute of Health and Care Sciences, Sahlgrenska Academy
University of Gothenburg, Gothenburg, Sweden
E-mail: axel.wolf@gu.se

Providing person centred care (PCC) is a growing imperative across health care. The core component of person centred care is the co-creation of care and the partnership between patients, their families and carers, and health professionals[1]. It differs from patient centred care in having its roots in ethics. While much of the recent literature has focused on why we need to change to a more person centred approach, there is little information about how to do it and whether it makes any difference. Over the past 10 years, a model of PCC has been studied and implemented in Sweden and has shown promising results. By providing practical insights from a successful initiative that has spread both nationally and internationally, we hope to offer lessons for readers elsewhere.

The Gothenburg framework

The University of Gothenburg Centre for Person-Centred Care (GPCC) is funded by the Swedish government as part of a national initiative to stimulate research at Swedish universities. The government expects the centres it funds to conduct high quality research and to use this knowledge to change clinical practice. A multidisciplinary task force wrote a funding proposal with the goal of supporting cost-effective, sustainable and high-quality healthcare. The proposal aimed to address the lack of engagement with patients' own capacities, experiences and goals in both research and clinical practice. It specifically focused on the paucity of controlled clinical trials in PCC, the ethic and philosophy of the patient as a person, and the need to move research into everyday clinical practice. The Centre was inaugurated in 2010 and involves health professionals and researchers from several disciplines as well as a Person Council for patients and their relatives and carers. The Person Council includes 12 adults with a range of long term health conditions. From the start, the stakeholders had a clear vision about developing and testing the framework in controlled trials, as well as supporting the adoption of PCC, in different health care settings. The task force wrote a consensus white paper which set out the three routines in the partnership to be referred to as the gPCC framework, derived from best evidence, experience and practice (see Box 1). It is based on an explicit ethical approach that combines the relational aspects of collaboration with facilitating structures. The approach acknowledges the patient with needs but also as a capable and resourceful partner with expert knowledge about their everyday life, goals and motivation. It has some similarities with the NHS England policy on Personalised Care and Support Planning [2].

Box 1: The three routines of the Gothenburg framework [3 4]

1) Initiating the partnership: Narratives: The first routine involves eliciting the patient's narrative and their goals. These are goals arising from everyday life, for example the wish to return to paid employment or taking walks. This involves listening carefully to the patient's story to understand their condition, their capabilities and resources as well as obstacles to achieving good health, giving due consideration to diagnoses and treatments.
2) Working the partnership: The second routine uses this narrative or series of narratives with the patient and possibly their carer(s), used as the basis of partnership to co-creating a personal health plan consistent with identified resources and barriers and combined with medical and health research evidence. This partnership is intended to support the patient's self-efficacy and self-management by paying attention to their own priorities and building on their own capabilities.

3) Safe-guarding the partnership: Documentation: The third routine involves documenting the health plan, adapting it to changes in the patient's goals and/or other circumstances over time and in different settings, for example when moving from secondary to primary care, to support continuity of care[5]. It is documented in the patient´s record, which is accessible for the patient either in paper form or via the national patient-accessible electronic health record.

Putting research into practice

Over a ten year period implementation programmes started in Gothenburg and have spread to hospitals and primary care settings all over Sweden. The programmes build on co-production between clinicians, patients, researchers and managers. A series of clinical trials was designed to compare the PCC interventions to usual care, and have been conducted in a range of clinical specialties, including primary care and social care settings. For those in the intervention arm, the clinical trials provided deliberate and emergent strategies to help professionals create person centred partnerships with their patients. These strategies were co-created with professionals and patients to ensure relevance to the setting and specialty.

The early trials were supported by a 10 week education and implementation process[6] that was tested in five hospital wards in Gothenburg during 2012- 2014 (figure 1) and later in other settings. The process was influenced by Kotter's [7] change management ideas, and the notion of deliberate and emergent strategies i.e both top down and bottom up approaches [8]. It was co-designed with the management team, thus providing a change process at both management and individual levels. The management team strategically selected groups of participants representing different layers and roles in the organization (for example, a ward) to work autonomously to drive the change process.

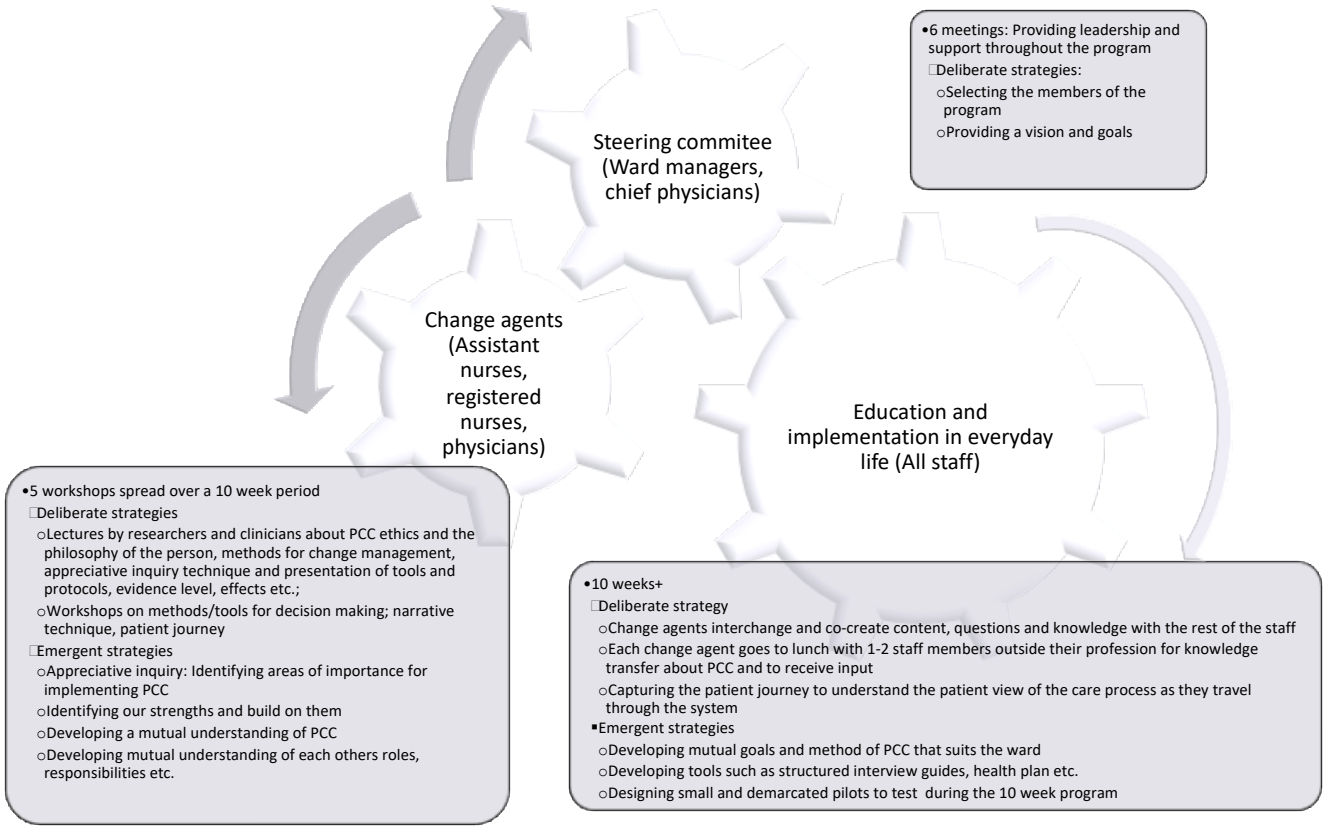

Figure 1Example of the 10 week implementation program/process that was tested during 2012-2014

Outcomes and evidence

Since 2010 over twenty studies have been published based on 15 controlled clinical trials (10 RCTs, 5 quasi-experimental design studies, see Table 1) in 11 different disease/clinical areas within primary care, secondary and tertiary settings, enrolling in total 2610 patients. All studies reported that the intervention was guided by PCC, using the patients' goals and resources in care planning. PCC requires ongoing and systematic engagement and co-creation, adapted to each patient and each context. Care plans need to be discussed and if necessary revised on a continuous basis. The intervention has evolved over time as it has been adapted to different patient groups and clinical contexts.

Table 1 shows that 9 out of the 15 controlled trials demonstrate statistically significant effects in favour of the GPCC intervention in a range of outcome measures in either ITT and/or PP analysis. These were: increased self-efficacy [9-13]; improved experience of health [14-16], improved satisfaction with care[17], improved symptom control [14 15 18-20]; improved physical function/capacity[14-16 21], improved ADL [22] fewer CHF/COPD related deteriorations [13], improved discharge planning [23]; shorter length of hospital stay [22 24-26]; and cost saving [27]. In 6 trials, results were non-significant [16 28-32].

Over time, the outcome measures in these trials have developed from mainly objective measurements into combined objective and subjective measures such as patient reported outcomes and process oriented outcomes. In general it seems that the more open and unhurried communication offered by the framework provided hospital patients with both information and confidence about co-creating the care process, and managing their own problems. This led to better understanding of the discharge process and readiness to return home with a greater sense of self-efficacy. The studies were not blinded; it was impossible to blind professionals or patients to the intervention as it required the active participation of both parties. As a complex intervention, composite outcome measures were sometimes warranted.

Although patients were engaged in designing several studies [10 22 24 30], they were not involved in the choice of outcome measures. Trial design requires pre-specified outcome variables but there is no reason that these variables could not reflect patients' priorities.

Lessons and insights: managing change by co-creation

Individual barriers and professional attitudes

We have learned a great deal during 10 years of researching and implementing PCC. We often hear from health care professionals either that they already practise PCC, that PCC isn't anything new, or that they would like to work person-centered but don't have the time or resources. We cannot agree more: many practitioners are person-centered yet aren't able to systematize it into a practice that enables PCC for most patients most of the time, regardless of who is caring for them. And yes, the notion of person centeredness has been around for ages, yet we still don't practise it systematically. We cannot talk about PCC if we aren't able to walk the talk. Walking the talk means co-creating a shared understanding of the barriers, resources, goals and responsibilities of all those involved.

We encountered professional attitudes including resistance, lack of understanding of the significance of the ethical approach, the difficulty of translating abstract principles into specific practices, and the risk of returning to old habits once the training was over[8 33]. These barriers were addressed by the change management programme already described, leaders who acted as role models, colleagues who supported PCC, multidisciplinary teamwork, and the flexibility to adapt to patients' circumstances. Other emergent strategies included lunch time discussion groups with professionals from different backgrounds to help differentiate PCC from usual practice, and the use of 'ambassadors' to convince unwilling colleagues. We also learned that you cannot implement PCC in an effective way if you aren't person-centered towards each other in the care team, which of course includes the patient.

In order to support the facilitation of person centredness by professionals, GPCC has developed a freely available an online implementation program in English and Swedish (www.mutualmeetings.org), as well as an educational gaming app for iOS App store and Android Google Play (The person centred care game).

Organisational barriers and strategies to overcome them

Each organisation has to develop PCC in its own way, which means working closely with professionals and patients, some of whom may already have great success stories about practising PCC.

Organisational barriers include hierarchical structures and traditional practices governing the roles of doctors and nurses in particular, time constraints, the challenges of transferring new working practices to new or temporary staff, and in some cases increased workloads resulting from reduced length of hospital stay. The documentation provides a particular challenge due to the incompatibility with traditional medical records[8 33]. Clear protocols can help to support and reinforce the adoption of new working practices. Health plans which are tailored to the patient population should be developed [8 33]. Patient and public engagement strategies are pivotal in practice, research and policy. For an optimal person centred process, researchers, health professionals and patients should have discussed and agreed the outcome measures as well as using a measure of goal attainment to assess the achievement of patients' goals [34]. We identified three particular successful strategies for addressing organizational barriers.

Firstly, the appointment of designated PCC nurses to introduce and manage the transition towards PCC. These nurses became ambassadors for PCC, facilitating training sessions, reflections and everyday questions concerning PCC practice, as well as continuous development of the PCC concept.

Secondly, it is important to implement PCC within the entire organization and not just a few wards, in order to share the burden of increased workload arising from reduced length of hospital stay in PCC wards. Managers may need to change the patient flow from the emergency room, to manage changed workloads. A different inequity, which also needs to be balanced, arises when PCC wards become more attractive for staff to work in.

Thirdly, it is important to systemize rather than simplify. For example, structured PCC health plans change the way in which professionals communicate with patients, sometimes using particular techniques such as particular open questions ('what do you wish to return to?') as a way of eliciting patients' goals. PCC health plans are written in collaboration with patients and made accessible to them. Patients said they felt informed about their condition and future care needs. It is safe to give patients responsibility for managing their health, even frail elderly patients receiving telephone based interventions. On hospital wards, patients noticed a sense of ease and commented that professionals treated each other in a person centred way[35].

In April 2020 a European standardization project initiated by GPCC was approved as a European standard by the European Committee for Standardization (CEN)[36], which aims to facilitate a more systematic and structured introduction of a "minimum level" of patient involvement in order to support a shift towards PCC on an organizational and policy level. This standard will support the wider implementation of PCC.

Conclusions

The work of the Gothenburg Centre provides an evidence base, in a range of clinical areas, for an ethically based yet practical framework for PCC. It shows that co-creation of care and person centeredness within the team itself, at the 'bedside' as well as within organisations, is crucial. While the framework will necessarily require adaptation to different contexts, clinical specialties, patient populations and organizational structures, fidelity is underpinned by the ethical approach rather than standardized guidelines. This implies continuity of care, and the involvement of different professionals to support patients´ goals. Perhaps the main challenge for those wishing to adopt this framework is to appreciate how it may differ from their own usual care.

Key Messages

- The Gothenburg framework for person centred care is an example of a complex intervention coproduced with patients that has been trialed and implemented at national scale
- The framework provides a structure for healthcare professionals, patients, carers, and families to develop person centred care plans that reflect the goals and values of the patient and guide future care, also working through mHealth/eHealth
- The change management programme involved a steering group, change agents, and education and implementation strategies in everyday practice
- Deliberate and emergent successful strategies have been developed to overcome individual and organizational barriers
- While change is never easy, it is easier to manage change if you are person centred with the rest of the team as well as with patients
- Controlled trials provide evidence of its effectiveness in several clinical areas, and it has now been implemented in primary care, secondary care, and social care settings across Sweden

Contributors and sources

All authors contributed to this manuscript. NB, ON and AW initiated the paper, and all authors contributed to the drafting and critical revision. The views expressed are their own. MJ and HH are patient representatives who are actively engaged in experience in debating patient advocacy and patient and public engagement issues. NB was partly supported by the UK National Institute for Health Research (NIHR) Applied Research Collaboration South West Peninsula (NIHR ARC South West Peninsula). This work was also supported by the Centre for Person-Centred Care at the University of Gothenburg (GPCC), Sweden. GPCC is funded by the Swedish Government's grant for Strategic Research Areas, Care Sciences (Application to Swedish Research Council no. 2009-1088) and co-funded by the University of Gothenburg, Sweden. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care. AW is the guarantor.

Conflict of interest

NB is a member of the Scientific Advisory Board of GPCC and a visiting professor at the Institute of Health and Care Sciences at Gothenburg University. IE was the centre director of GPCC until March 2019. AW has several research projects that are partially funded by GPCC. The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Author/Year/Design/ Disease	Population Control (CG) vs PCC	Primary outcome, Instrument, Follow-up	Intention to treat (ITT) & Per-Protocol (PP)
Öhlen et al 2020[29]/Quasi/Colorectal surgery	CG N=250 vs PCC N=238	Preparedness for Colorectal Cancer Surgery Questionnaire (PCSQ) HrQoL (EORTC QLQ-C30) and distress (NCCS Distress Thermometer)	NS in primary outcome. Significant differences in favour for PCC in two out of PCSQ domains.
Jakobsson et al 2019[17]/ Quasi/ Internal medicin	CG N = 204 vs PCC N = 177	Quality from the Patient Perspective questionnaire/EQ5D/ General Self-Efficacy Score (GSES)	Significant on item-level in some items regarding care satisfaction favors PCC. NS in EQ5D VAS mean(SD); PCC 63(24) vs CG 60(25), NS in self-efficacy at discharge (GSES>30 at discharge) PCC 64% vs CG 67%
Lange et al 2019[16]/RCT/RA	CC n=38 vs PCC n=36	Health Assessment - Disability Index (HAQ-DI),20 weeks follow up	NS differences in the primary outcome HAQ-DI (mean delta change (SD)), PCC(-0.063 (0.16) vs CG(0.0097(0.27)
Bergsten et al 2019[28]/RCT/RA	CG n=34 vs PCC n=36	DAS 28 (number of tender and swollen joints)/ 26 weeks	NS in ITT primary PCC in DAS 26 (Mean (95% CI)) 1.39 (0.97 – 1.82) vs CG 1.04(0.54 – 1.53. In PP PCC 1.50 (1.00 – 2.00) vs CG 1.07(0.56 – 1.57). Trial inclusion terminated in beforehand due to more patients in the interventions dropped out.
Fors et al 2018[13]/RCT/CHF, COPD	CG n=118 vs PCC n=103	Composite score: Self-efficacy, rehospitalization, death/GSES. Six-month follow up	NS in the composite score in the ITT PCC 57.6%(n = 68) vs. CG 46.6%(n = 48); OR = 1.6, 95 % CI: 0.9 – 2.7; P = 0.102. PP showed significant more patients deteriorated in the CG 57.6%(n = 68) vs. PCC 42.9%(n = 36); OR = 1.8, 95% CI 1.0–3.2; P = 0.039.
Barenfeld, E et al 2018[31]/RCT/Health promotion	CG n=75 vs PCC n=56	Activity of Daily living/6 and 12 months follow-up	NS: Maintained Activities of daily living in ADL staircase: 6 months PCC n(%) 42(75) vs CG 53(71), 0.583. 12 months PCC n(%) 38(68)) vs CG 54(72); P=0.608
Linden et al 2018/ RCT[30]/Diabetes during childbirth	CG n=91 vs PCC n=83	General wellbeing & self-efficiacy, Six-month follow up	NS differences in general well-being between the groups (1.04 (95% CI –1.28 to 3.37); P=0.68 or self-efficacy of diabetes management (0.08 (95% CI –0.12 to 0.28); P= 0.75
Hanson et al 2017[32]/RCT/Head & Neck Cancer	CG n=42 vs PCC n=54	HrQoL: (EORTC) QLQ-C30, EORTC QLQ-35, 12 months follow up	NS differences were found in HrQoL instruments. When testing longitudinal data, statistically significant results were found for head and neck cancer-specific problems, swallowing (p = 0.014), social eating (p = 0.048) and feeling ill (p = 0.021) in favors PCC.
Feldthusen, C. et al 2016[14 37]/RCT/RA	CG n=34 vs PCC n=36	General fatigue, 12 week / 6 months follow up.	Significant difference in General fatigue (delta VAS change, (SD): PCC (-23.5 (19.9) vs CG -15.3 (24.6); P=.042. NS at 6 months PCC -24.5 (27.3) vs CG -15.4 (22.7); P=.057.
Fors et al 2015[10]/RCT/ACS	CG n=105 vs PCC n=94	Composite score: Self-efficacy, rehospitalization, death/ GSES, Six-month follow up	Significantly more patients improved in PCC vs CG (22.3%(n = 21) versus 9.5%(n = 10); OR, 2.7; 95%, CI 1.2-6.2; P=0.015.
Larsson, A et al 2015[15]/RCT/ Fibromyalgi	CG n=63 vs PCC = 67	Isometric knee-extension force, 15 week program	NS difference in ITT primary outcome of isometric knee-extension force (delta mean (SD)) between the groups were found. PP analysis, significant differences in the primary outcome favoring PCC 30.4(71.9) vs CG −8.8(70.0), p=0.01.
	CG n=50		

Haby, K. et al 2015[21]/Quasi/Obesity during pregnancy	vs PCC n=50	Gestational weight gain (GWG)	Significant lower gestational weight gain for the PCC vs CG (8.6 kg versus 12.5 kg); p=0.001
Danielsson, L. et al 2014[20]/RCT/Major depression	PCC Exercise n=22, PCC Basic Body Awareness (BBAT) n=20, Control n=20	Anxiety/ Montgomery Asberg Depression Rating Scale (MADRS), 10-week program.	ITT: Significant improvements in MADRS score (mean change (SE)) in the PCC exercise -10.3 (1.6) vs. PCC BBAT -5.8(1.7) vs. CG -4.6(1.7); p=0.038. PP: Significant improvements for the PCC exercise (-12.8 (1.6) vs. PCC BBAT -8.4(1.8) vs. CG -5.1(1.8); p=0.012
Olsson, L. E. et al 2014[26]/QUASI/THA	CG n=138 vs. PCC n=128	Length of hospital stay (LOS)	Significantly shorter LOS in the PCC 5.3 days(SD 2.2) vs CG 7 days(SD 5.0);p <0.0005
Ekman, I. et al 2012[22]/QUASI/CHF	CG n=123 vs. PCC n=125	Length of hospital stay (LOS)	ITT: NS difference in LOS PCC 8.2 days (SD 4.4) vs CG 9.2 days (SD 7.4)(p=0.16). PP: LOS reduced in PCC to 6.7 days (SD 3.2); P = 0.01

Table 1 gPCC clinical trial: main trial data only of primary outcomes.. Rheumatoid arthritis (RA), Chronic Heart Failure (CHF), /Chronic Obstructive Pulmonary Disease (COPD), Acute Coronary Syndrome (ACS), Total hip arthroplasty (THA), Intention to treat (ITT), Per-Protocoll (PP), NS= Non significant,

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