# BMJ Open

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|---|---|
| Journal: | *BMJ Open* |
| Manuscript ID | bmjopen-2017-016491 |
| Article Type: | Research |
| Date Submitted by the Author: | 17-Feb-2017 |
| Complete List of Authors: | Wolf, Axel; Health and Care Sciences, Sahlgrenska academy, University of Gothenburg; Centre for Person-Centred Care (GPCC), University of Gothenburg<br>Moore, Lucy; University of Exeter Medical School<br>Lydahl, Doris; Department of Sociology and Work Science, University of Gothenburg<br>Naldemirci, Öncel; Department of Sociology and Work Sciences, University of Gothenburg<br>Elam, Mark; Department of Sociology and Work Science, University of Gothenburg,<br>Britten, Nicky; University of Exeter Medical School, PenCLAHRC: National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for the South West Peninsula; University of Exeter Medical School, Institute for Health Service Research |
| <b>Primary Subject Heading</b>: | Health services research |
| Secondary Subject Heading: | Qualitative research, Nursing, Medical management, Evidence based practice |
| Keywords: | person-centred care, patient participation, partnership, patient-centered care |

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# The realities of partnership in person-centred care: a qualitative interview study with patients and professionals

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**ABSTRACT**

**Objective:** Although conceptual definitions of person-centred care (PCC) vary, most models value the active involvement of patients through patient-professional partnerships. However, while this may increase patients' sense of responsibility and control, relational, contextual and affective aspects of partnership are increasingly emphasised. The aim of this study is to explore the realities of partnership and participation as perceived by patients and health professionals in everyday PCC practice.

**Design**: Qualitative study employing an interpretive approach using semi-structured interviews with professionals and patients.

**Setting:** Four internal medicine wards and 2 primary care centres in western Sweden.

**Participants:** 20 patients admitted to hospital wards delivering person-centred care and 16 health professionals based on these wards and primary care centres.

**Results:** Our findings identified both informal and formal aspects of partnership in the delivery of person-centred care. Informal aspects incorporated proximity and receptiveness of professionals, and building a close connection and confidence. This epitomised a caring, respectful relationship congruent across accounts. Formal aspects and descriptions of partnership were more dichotomous. Professionals described collaborating with patients to encourage participation, capture personal goals, plan and document care. However, although patients felt listened to and informed, they were content to ask questions and felt less involved in care planning, documentation or exploring lifeworld goals. They commonly perceived participation as informed discussion and agreement, deferring to professional knowledge and expertise in the presence of an empathetic and trusting relationship.

**Conclusions**:

In our study patients appear to value a process of human connectedness above and beyond formalised aspects of documenting agreed goals and care planning. The PCC pathway or mechanism increases patients' confidence in professionals who are competent and able to make them feel safe and secure. Informal elements of partnership provide the conditions for communication and mutual co-operation upon which formal relations of partnership can be constructed.

Keywords:

Person-Centred Care, Patient-Centred Care, Patient Participation, Healthcare service

**Strengths and limitations of this study:**

- This studyreports the experiences of both patients and professionals in hospital settings which have implemented an evidence based model of person centred care .

- The study population consisted of professionals with a broad range of clinical experience and patients with diverse medical signs and symptoms.

- Our sample was not designed to be statistically representative, nor can we claim to have reached data saturation.

**INTRODUCTION**

Increasingly clinicians are encouraged to engage, inform and involve patients [1][2] and support health policies that promote patient led care through 'activated' patients trained in self-management skills [3][4]. Health professionals and policy makers aspire towards person centred care (PCC) [5-7] and recent models of PCC prioritise a whole systems approach that places patients at the centre [8-10]. It is clear that with professional support, patients can become active partners in their care [11-15] and can benefit from opportunities to take part [16][17][18]. However, despite the development of PCC and the push towards patient professional

partnerships [8], there is much talk and little action [7] [19-21]. Substantial organisational and cultural barriers exist [20] [22] [23] [24] and in order to overcome these barriers, both patients and professionals need to feel engaged, respected and treated as equals [2] [11] [12] [25] [14] [26] [27]. To date, there are numerous care concepts such as patient-centred care, individualized care and narrative medicine that touch upon patient involvement and partnership, all including some sort of reciprocity and shared knowledge [28] [29], self management [30] [31] participation in decision making [32]. Different PCC frameworks lift patient involvement toward an enhanced therapeutic relationship that requires sharing power and responsibility [6]. Yet, as patients are increasingly offered more choice and involvement, researchers also describe circumstances where patients choose to decline participation, defer decisions or feel unable to participate [33] [34]. It seems that the notion of the patient as an active partner in care requires empirical understanding and clarity.

Cribb and Entwistle (2011) draw attention to the importance of an emotionally supportive patient-professional partnership to aid 'meaningful participation' and shared decision-making [14]. Relationships that are open ended and conversational are prioritised as well as professional virtues and patient capabilities. This approach takes into account the relational aspects of partnership, which pay attention to the mindfulness of professionals and the unique aspects of patients' lives [5] [35] [36]. However, although power sharing implies an egalitarian and meaningful patient-professional relationship [29], the literature describes a hierarchy of relationships depicting the different levels of engagement, responsibility and shared goals [31] [37]. This moves from the lowest level i.e. involvement towards participation and the highest level i.e. partnership [32] [37]. Thoransdottir & Kristjansson (2014) elaborate on informal and formal relationships; the former describing the importance of human connectedness on the bottom tier and the latter involving shared agreements on decisions and documentation at the top [31].

In this paper we use a Swedish initiative for implementing an evidence-based PCC model as a case study. The University of Gothenburg Centre for PCC (GPCC)

has introduced a new evidence based model[38-41], supported by a programme of training and research, which has changed clinical practice.[42] This model consists of three 'routines' of PCC namely narrative, partnership and documentation [39 42 43]. Partnership in the GPCC framework is the main routine that drives the PCC process. The patient's narrative paves the way for collaboration, and documentation safeguards this collaboration. The aim of this study is to explore the realities of partnership as perceived by patients and health professionals in everyday PCC practice.

METHODS

**Sample and design**

This study adopted an interpretive approach employing qualitative semi-structured interviews. We used a purposive sampling strategy aiming at representation of several professional categories and patients (table 1). Four hospital wards at a large teaching hospital in west Sweden were chosen; these varied in size (18 to 36 hospital beds), specialization and patient group (patients with chronic and/or acute illness and from self-managing to bed-confined).

*Table 1 Description of practitioners and patient demography*

Each ward manager was contacted with information about the study and gave their consent. They were then asked to recruit a nurse, an assistant nurse and a physician, with experience of working with PCC, from their ward.

Patients were eligible for enrolment into the study if they were cognisant, able to communicate in Swedish and admitted to a reference ward where PCC was being implemented. The patients were admitted for symptoms of chronic heart failure, chronic obstructive lung disease, infections, iron deficit, colorectal diseases such as ulcerative colitis, Crohn's disease, colon surgery and hepatological disease.

This reference ward had implemented PCC systematically following a 10 week extensive training course facilitated by GPCC following the PCC routines [38].

A nurse coordinator working on the ward provided eligible patients with the study information. Twenty-one patients volunteered to participate and gave

their informed consent to be contacted by the study team after discharge and to be interviewed about the care they had received. One patient was excluded when transferred from another ward to the reference ward, which hampered recall.

**Data collection**

The interview guide for practitioners included questions how PCC related to the everyday work of healthcare practitioners and its implementation. The interview guide used for patient interviews intended to elicit patients' experiences of care on the ward and their understanding of PCC (table 2).

*Table 2 Interview guide practitioners and patients*

DL conducted 12 interviews with professionals, AW conducted 2, and a trained research assistant conducted 3 interviews with practitioners and all interviews with patients.

All interviews were audio recorded, transcribed verbatim, anonymised and translated from Swedish into English. All interviewees were given a pseudonym to maintain anonymity (P for Patient, N for Nurses, M for Manager and MD for Physician). The regional ethics committee approved the study and all participants, prior to their interview, gave informed consent.

### Analysis

Interviews were thematically analysed, adopting some basic features of grounded theory. Interviews were analysed initially employing line-by-line coding and an inductive, intuitive reading of the transcripts. A combination of computer software (NVivo 9) and hand written methods were used and mind mapping to assist with the development of themes [44]. We then followed a deductive process to explore how the characteristics and components of partnership were experienced by professionals and patients. Transcripts were independently coded by LM, ON & DL, and discussed with the whole team in order to address differences and reach a consensus.

### Results

Two main themes were found: firstly informal aspects of partnership comprising two subthemes, proximity & receptiveness and building a personal connection/ confidence. The second main theme was formal aspects of partnership having two subthemes, aspects of goal setting and care planning, and documentation.

### Informal aspects of partnership

*Proximity and receptiveness*

Professionals described engaging patients in conversation with the intention of respecting and listening to the patient dialogue, understanding the patient's situation, making a good start and building a close connection.  Assistant nurses followed this process each morning and described feeling 'closer' to the patient, seeing and hearing aspects of the patient from a social, psychological and physical perspective and becoming their 'eyes and ears'. Professionals described using communication techniques such as posing open, straightforward questions, talking without distractions and not judging.  A number of professionals felt this process aided partnership in subsequent meetings.

> I think that I and the nurse get a great response from the patients, straight away, that they feel very comfortable in this. They know who to turn to. That they feel like they've been given a lot of time, even if it´s not that long time, but the content of the appointment gives them that feeling. (MD1)

Many patients described positive feelings towards the receptiveness of staff and the atmosphere of the ward. Accounts of unhurried and immediate support with care provided in a caring and close manner were common.

> Not everyone sits down at your bedside, just a few of them do. Mostly they pull out chair or something to sit on. They are not on their way to another patient when they do that. It's more of a good opening; that we are sitting here now, talking, until we are finished doing that. (P1)

Available and reliable professionals increased patients' comfort, with professionals described as thoughtful, open and warm, leading to patients feeling a sense of humanity, security, familiarity and trust.

> They say "Hi Paula!" and then they present themselves with their name and then the title comes. Already there they create an opportunity for dialogue. It's not "I'm nurse, good day." So at that point it feels like an openness and they simply and easily describe how my life will be in this room. (P2)

*Building a close connection and confidence*

Professionals described listening in a more engaged way to patients' wishes and needs. They emphasised the importance of knowing how patients felt, what they thought, aspects of their personality and personal knowledge, described by one professional as 'life-luggage'. Patients were prompted to discuss personal interests and common topics. For most professionals finding common ground built trust, security and a collaborative relationship on a person-to-person level.

> You may talk about books or music, or common interests so that you're not only... You establish a relationship beyond the nurse-patient, and it becomes more like person to person. (N1)

In keeping with professionals' aspirations, many patients felt listened to and acknowledged. Several felt known personally, for who they were and their individual needs.

They could ask ordinary questions about the everyday life. We could talk about summer houses, and pets, and kind of on that level. And that's... I think that's very important. I think so at least... one is feeling more as if you aren't just a patient among others. (P3)

**Formal partnership**

*Goal setting and care planning*

Professionals reported working in partnership with patients in formal ways by giving and exchanging information, updating, summarizing and care planning. For example, patients are encouraged to discuss aspects of their symptoms, treatment, diagnosis and discharge plans. A number of professionals described making a 'team decision', alternatively known as a health plan, in collaboration with patients. This acknowledged a person's capabilities and personal goals that were agreed, documented and given to the patient. This is in line with the PCC routine of safeguarding the partnership through agreed goals.

The patient when at the hospital together with the nurse and the doctor decided what are the main issues: is it losing weight, is it anxiety, is it stop smoking or getting better medication or is it more training, physical activities, is it fear of training?  And so on.  So when they left the hospital they had this sheet where they had described their problem and it was just, it was their problem it was not a standard formula – the formula was standard but the questions and the wishes from the patient was personal (MD2)

Informal aspects of partnership led to an environment where it became possible for patients to ask questions, learn about their condition and treatment. Professionals believed patients had the inclination to begin caring for themselves, follow suggestions and instructions. Formal aspects such as discussing goals facilitated self-care such as getting dressed, mobilising on the ward, preparing for discharge and following advice post discharge.

Several professionals described the need to encourage, 'push' or 'pass' on competence to the patient, enabling the patient to become well informed, knowledgeable and take responsibility.

> There is a more practical understanding that the patient also carries a responsibility, and also is responsible for the process. I tend to think that my ward is at this stage of the process – to get the patient to understand the significance of his or her participation to activity, to rehabilitation. (M1)

Professionals noticed a change, where patients who were well informed, knew they had an impact, influence and could handle themselves. They seemed satisfied and more willing to help themselves and 'buy the whole concept'.

> We look at what the patient usually does in their everyday life outside the hospital, and what the patient does right now, and what we can do to improve and to support that the patient becomes their ordinary self again. And that you really try to understand how they can use their own resources and train themselves. (N2)

However from the patient perspective some remembered taking part in developing a health plan but few mentioned goals and when discussed, these were invariably described in medicalised terms or framed around home circumstances for discharge. Personal information was elicited and described, but not necessarily orientated towards 'lifeworld' goals.

> I don't actually know if the goal has been mentioned, but that might be the goal with the illness I have, that the goal is to be free from relapses. Because everything would then be as good as they can be. One wouldn't suffer from the disease then. As long as one eats medications that doesn't give side-effects and isn't suffering from relapses, then everything will be okay. And I know that has been mentioned, that it might be the goal after all. But that, as I said, that has to do with the disease. (P4)

Patients felt they contributed when they discussed choices with professionals, helped themselves, used their initiative and became knowledgeable. There were opportunities to question, decline treatment and contribute to discharge planning. For some, participation involved discussing test results, investigations and medication management that helped them 'feel' (our emphasis) they were committed to taking part in their care. For example discussing an ultrasound test, a transfusion or a colonoscopy procedure. They received explanations and felt they knew what to do, how to deal with medication and treatments.

> I know much more about my illness now and why it has become the way it has, I think I understand that better now. And that I can see in hindsight that I haven't been feeling well for a very long time, which has been connected to this. So now I have got a much clearer picture of my condition. (P5)

Others felt they participated by listening to professionals, agreeing and accepting professionals' decision-making. They felt confident, comfortable and treated as equals, described by one patient as 'horizontal communication'. A few patients described themselves as 'experienced', 'verbal' even when very ill and able to 'demand and ask questions'. Yet for patients in this study, participating was described in terms of informed discussion, acceptance and agreement, participating up to a point or as far as they felt able. Several felt comfortable 'submitting' and 'not being in the driving seat'.

> Many times one might feel like one is participating... one sometimes may be silent, but still feel a fellowship. Do you understand what I mean? And that's probably what I felt with the ward. That I didn't need to ask or I didn't need to ask them, the nurses I mean, since I knew in some way that the community still was there. (P6)

*Documentation*

Professionals described writing care plans with patients, eliciting biomedical information and discussing social and discharge planning. Decisions and plans were agreed and documented.

> You should make a plan together with the patient and that you discuss with the patient and so on, but the difference of having it in this way is that you have more of a structure of it. You create a framework for what it means to work like this, so that what you're doing becomes more concrete. (MD3)

> In some way the patient gets what we've done on paper, and we get a proof of that we understand it in the right way, so that the patient can say "Yes, this is how it was" or "I don't agree with this." The important thing is that you agree, so that you are on the same page so to speak. (N1)

In this respect professionals described 'a new practice' where patients were encouraged to actively participate, become more involved and take part in decisions about their care.

> Documentation acted as a reminder for patients to discuss care on 'a new level'. (N3)

> You must create a care plan for the patient within 48 hours and then you should write why they have sought care and what we have planned for them and this should be addressed at the round with the patient, and it is written down and then it's a little investigation to see what the patients can do themselves. (N4)

Professionals encouraged patients to use their own resources and expertise. For example patients were encouraged to prepare for conversations with the team and write down thoughts or questions.

Patients felt informed about their condition, discharge and future care needs, felt they were listened to and some felt they were participating in their care plan.

I think, that it felt like it was a team. Decisions where I participated in, and the care plan and such things. How much you actually were that, I don't know, but at least you had a picture of it, so. But I can't decide how I'm going to be treated or taken care of, but at least you can be a part of it and have opinions, you were able to do that. (P8)

Although patients remembered receiving written information and some described opportunities to write down thoughts, questions and contribute to their care, they did not remember the written information in any detail. Nevertheless, patients saw this documentation in 'simple' terms whereby they felt taken care of and in receipt of sufficient information.

Discussion

In our study, interviewees' accounts reflect levels of mutuality, self-expression and respect that lay the groundwork for PCC and indicate a move from disease focused models of care [19]. In keeping with the literature we suggest that informal elements of partnership provide the conditions for communication and mutual co-operation upon which formal relations of partnership can be constructed [27 31 36]. Professional and patient perspectives highlight the importance of the informal elements of partnership for ultimately determining the level of shared decision making which is possible to aspire to and practically achieve [14]. Informal elements in our study depict emotionally supportive relationships that pave the way for patients to participate, once the scene is set and the circumstances feel right.

However, in our findings patients were content to be able to ask questions and receive information. They perceived participation as informed discussion and agreement, deferring to professional knowledge and expertise and not necessarily describing opportunities for empowerment and activation. Perceived competence of professionals seemed enough for patients and whilst patients prioritised the informal processes where 'good care' may have been interpreted as PCC, professionals prioritised outcomes that were formal and documented. Patients described participating in plans for discharge but did not describe notions of enablement or control. As with other studies, patients were satisfied

with a personal approach and a positive partnership with professionals who communicated empathetically and effectively [45] with professionals acting as educators, building mutual and collaborative partnerships [46]. Measurements of optimum patient-professional relationships and person-centredness need to consider patients' emotional and personal responses that highlight the process rather than the outcome of interactions with health professionals [5 14 27 35]. Aspects of informal and formal partnership appeared to act as antecedents of patient participation. Yet overall, most patients portrayed a taken-for-granted pragmatism, trusting professionals with expertise and competence to make overall decisions in a caring environment. For patients in this study, PCC was not explicitly understood or described as an opportunity to formalize a partnership with professionals in order to actively participate in their care. There were relational, contextual and emotional factors for partnership that took precedence in patients' minds. In addition, professionals may have considered PCC as a particular professional approach rather than a systematic endeavour to "invite" patients to participate in the PCC routines and explicate the model.

Aspects of partnership, particularly informal aspects, led patients to leave some decisions to the professionals since they felt cared for and well informed. In this respect patients' interpretation of participation can be viewed, not as passive submission or deferment to professional expertise and knowledge, but a common understanding reached through a therapeutic relationship. Our interpretation of the present study points toward the importance of human connectedness and the feeling of being listen to and acknowledged as a person (informal aspect) for patients, while routines and formal aspects of care came more into the foreground for the practitioners. It seems as if in order to integrate the patient into clinical practice, there seems to be a balancing act that practitioners as well as patients need to reflect upon: recognition of the patient as a person (informal aspects) needs to balance the specific practical routines (formal aspects)[42]. The risk could otherwise be that the patient as a person becomes a "check box" in a routine, which in many aspects would entrench profession-centred care rather than person-centredness.

This study has some limitations.  Patients did not necessarily perceive their care in the context of a PCC model and our study depended upon patients remembering events and perhaps perceiving the relevance of information and care strategies. Secondly, because the study took place in an particular institutional context (GPCC) in Sweden, the findings may not be transferable to other settings.  Moreover, formal aspects of partnership, for example, documented care plans and decisions, could have provided patients with opportunities to revisit decisions in written form, and maintain a sense of confidence and trust during their admission that was taken for granted. Moreover, most interviewees were older perhaps predisposing them to comply with professional expertise or feel knowledgeable but not necessarily empowered [47].

Conclusion

In our study patients appear to value a process of human connectedness above and beyond formal aspects of taking part and feeling activated and capable. These findings may point to the need for professionals to acknowledge the importance of the human connectedness that is as crucial as formal aspects for PCC to be fully realised in practice.

Author contributions

LM and AW contributed equally to the study as first authors. All authors contributed to the study design, conception and development. DL and AW conducted the interviews together with research assistant Marie Hammer. LM, DL and ÖN initially analysed the data, and all authors met face to face and over skype as a group to discuss, revise and confirm the findings.  All authors were responsible for critical revision and finalising the manuscript.

Competing interest

Nicky Britten is a member of the Scientific Advisory Board of GPCC. The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data sharing statement

No additional unpublished data is available

Wordcount 3560

References

1. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for
   clinical practice. *J Gen Intern Med* 2012;27(10):1361-7. doi:
   10.1007/s11606-012-2077-6 [published Online First: 2012/05/24]
2. Elwyn G, Lloyd A, May C, et al. Collaborative deliberation: a model for patient
   care. *Patient Educ Couns* 2014;97(2):158-64. doi:
   10.1016/j.pec.2014.07.027 [published Online First: 2014/09/02]
3. Department of Health. Long term conditions compendium of information,
   2012.
4. Eaton S, Roberts S, Turner B. Delivering person centred care in long term
   conditions. *Bmj* 2015;350:h181. doi: 10.1136/bmj.h181 [published
   Online First: 2015/02/12]
5. Epstein RM, Street RL, Jr. The values and value of patient-centered care. *Ann
   Fam Med* 2011;9(2):100-3. doi: 10.1370/afm.1239 [published Online
   First: 2011/03/16]
6. Harding E, Wait S, Scrutton J. The state of play in person-centred care:
   pragmatic review of how person-centred care is defined, applied and
   measured, featuring selected key contributors and case studies across the
   field.: The Health Foundation, 2015:1-140.
7. Hawkes N. Seeing things from the patients' view: what will it take? *Bmj*
   2015;350:g7757. doi: 10.1136/bmj.g7757 [published Online First:
   2015/02/12]
8. Health Foundation. Helping people help themselves, 2011.
9. King's Fund. People in control of their own health and care, 2014.

10. NHS England. Enhancing the quality of life for people living with long term conditions-the house of care, 2014.

11. Coulter A. Patient engagement--what works? *J Ambul Care Manage* 2012;35(2):80-9. doi: 10.1097/JAC.0b013e318249e0fd [published Online First: 2012/03/15]

12. Coulter A, Collins A. Making shared decision-making a reality; no decision about me, without me. London: The King's Fund, 2011:1-40.

13. Coulter A, Safran D, Wasson JH. On the language and content of patient engagement. *J Ambul Care Manage* 2012;35(2):78-9. doi: 10.1097/JAC.0b013e31824a5676 [published Online First: 2012/03/15]

14. Cribb A, Entwistle VA. Shared decision making: trade-offs between narrower and broader conceptions. *Health Expect* 2011;14(2):210-9. doi: 10.1111/j.1369-7625.2011.00694.x

15. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Educ Couns* 2006;60(3):301-12. doi: 10.1016/j.pec.2005.06.010

16. Amin F. Commentary: Becoming a person centred practice. *Bmj* 2015;350:h269. doi: 10.1136/bmj.h269 [published Online First: 2015/02/12]

17. National Voices. Principles of care and support planning, 2013.

18. Coulter A, Entwistle VA, Eccles A, et al. Personalised care planning for adults with chronic or long-term health conditions. *Cochrane Database Syst Rev* 2015;3:CD010523. doi: 10.1002/14651858.CD010523.pub2 [published Online First: 2015/03/04]

19. Ekman I, Swedberg K, Taft C, et al. Person-centered care--ready for prime time. *Eur J Cardiovasc Nurs* 2011;10(4):248-51. doi: 10.1016/j.ejcnurse.2011.06.008 [published Online First: 2011/07/19]

20. Frosch DL. The patient is the most important member of the team. *Bmj* 2015;350:g7767. doi: 10.1136/bmj.g7767 [published Online First: 2015/02/12]

21. Frosch DL, May SG, Rendle KA, et al. Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Aff (Millwood)* 2012;31(5):1030-8. doi: 10.1377/hlthaff.2011.0576 [published Online First: 2012/05/09]

22. Moore L, Britten N, Lydahl D, et al. Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. *Scand J Caring Sci* 2016 doi: 10.1111/scs.12376

23. Naldemirci O, Lydahl D, Britten N, et al. Tenacious assumptions of person-centred care? Exploring tensions and variations in practice. *Health (London)* 2016 doi: 10.1177/1363459316677627

24. Alharbi TS, Ekman I, Olsson LE, et al. Organizational culture and the implementation of person centered care: results from a change process in Swedish hospital care. *Health Policy* 2012;108(2-3):294-301. doi: 10.1016/j.healthpol.2012.09.003

25. Gravel K, Legare F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. *Implement Sci* 2006;1:16. doi: 10.1186/1748-5908-1-16 [published Online First: 2006/08/11]

26. Entwistle VA. Considerations of 'fit' and patient involvement in decision making. *Health Expect* 2006;9(2):95-7. doi: 10.1111/j.1369-7625.2006.00397.x

27. Entwistle VA, Watt IS. Patient involvement in treatment decision-making: the case for a broader conceptual framework. *Patient Educ Couns* 2006;63(3):268-78. doi: 10.1016/j.pec.2006.05.002

28. Hudon C, Fortin M, Haggerty J, et al. Patient-centered care in chronic disease management: a thematic analysis of the literature in family medicine. *Patient Educ Couns* 2012;88(2):170-6. doi: 10.1016/j.pec.2012.01.009

29. Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med* 2000;51(7):1087-110.

30. Sahlsten MJ, Larsson IE, Sjostrom B, et al. An analysis of the concept of patient participation. *Nurs Forum* 2008;43(1):2-11. doi: 10.1111/j.1744-6198.2008.00090.x

31. Thorarinsdottir K, Kristjansson K. Patients' perspectives on person-centred participation in health care: A framework analysis. *Nursing ethics* 2013 doi: 10.1177/0969733013490593

32. Frank C, Asp M, Dahlberg K. Patient participation in emergency care - a phenomenographic analysis of caregivers' conceptions. *J Clin Nurs* 2009;18(18):2555-62. doi: 10.1111/j.1365-2702.2008.02477.x

33. Eldh AC, Ehnfors M, Ekman I. The phenomena of participation and non-participation in health care--experiences of patients attending a nurse-led clinic for chronic heart failure. *Eur J Cardiovasc Nurs* 2004;3(3):239-46. doi: 10.1016/j.ejcnurse.2004.05.001

34. Eldh AC, Ekman I, Ehnfors M. Conditions for patient participation and non-participation in health care. *Nursing ethics* 2006;13(5):503-14.

35. Epstein RM. Making communication research matter: what do patients notice, what do patients want, and what do patients need? *Patient Educ Couns* 2006;60(3):272-8. doi: 10.1016/j.pec.2005.11.003

36. Epstein RM, Franks P, Fiscella K, et al. Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. *Soc Sci Med* 2005;61(7):1516-28. doi: 10.1016/j.socscimed.2005.02.001

37. Cahill J. Patient participation: a concept analysis. *J Adv Nurs* 1996;24(3):561-71.

38. Ekman I, Wolf A, Olsson LE, et al. Effects of person-centred care in patients with chronic heart failure: the PCC-HF study. *Eur Heart J* 2012;33(9):1112-9. doi: 10.1093/eurheartj/ehr306 [published Online First: 2011/09/20]

39. Fors A, Ekman I, Taft C, et al. Person-centred care after acute coronary syndrome, from hospital to primary care - A randomised controlled trial. *International journal of cardiology* 2015;187:693-9. doi: 10.1016/j.ijcard.2015.03.336 [published Online First: 2015/04/29]

40. Feldthusen C, Dean E, Forsblad-d'Elia H, et al. Effects of person-centered physical therapy on fatigue-related variables in persons with rheumatoid arthritis: a randomized controlled trial. *Arch Phys Med Rehabil* 2016;97(1):26-36.

41. Olsson LE, Hansson E, Ekman I. Evaluation of person-centred care after hip replacement-a controlled before and after study on the effects of fear of

movement and self-efficacy compared to standard care. *BMC nursing* 2016;15(1):53. doi: 10.1186/s12912-016-0173-3

42. Britten N, Moore L, Lydahl D, et al. Elaboration of the Gothenburg model of person-centred care. *Health Expect* 2016 doi: 10.1111/hex.12468 [published Online First: 2016/05/20]

43. Ekman I, Hedman H, Swedberg K, et al. Commentary: Swedish initiative on person centred care. *Bmj* 2015;350:h160. doi: 10.1136/bmj.h160 [published Online First: 2015/02/12]

44. Miles MB, Huberman AM, Saldana J. Qualitative data analysis: A methods sourcebook. Third ed. London: Sage Publications 2014.

45. Little P, Everitt H, Williamson I, et al. Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *BMJ* 2001;323(7318):908-11. [published Online First: 2001/10/23]

46. Roter D. The enduring and evolving nature of the patient-physician relationship. *Patient Educ Couns* 2000;39(1):5-15.

47. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns* 2014;94(3):291-309. doi: 10.1016/j.pec.2013.10.031 [published Online First: 2013/12/07]

*Table 1*

|                      | Practioners (n=17) |
|----------------------|--------------------|
| Women (n)            | 14                 |
| Profession           |                    |
| Registered nurse     | 5                  |
| Assistant nurse      | 4                  |
| Manager              | 4                  |
| Physician            | 4                  |
| Interview range      | 29-60 minutes      |
| Place for interview  |                    |
| Hospital             | 13                 |
| Primary care center  | 2                  |
| University           | 2                  |

|                      | Patient (n=20)     |
|----------------------|--------------------|
| Women (n)            | 11                 |
| Age median (range)   | 69, 35-88 years    |
| Interview range      | 19-83 minutes      |
| Place for interview  |                    |
| Home                 | 13                 |
| Hospital             | 2                  |
| University           | 1                  |
| Telephone            | 4                  |

**Table 2**

| Interview guide: Practitioners | Interview guide: Patients |
|--------------------------------|---------------------------|
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- To start with, could you tell me a bit about this ward/clinic/centre?

**Prompts**: Size? Practical work? Team?

- How did you start working with PCC?

**Prompts**: First contact with PCC? When did you first hear about it? Where did the idea come from? Did you have a special training?

- How did you implement PCC in the ward/clinic/centre? What did the implementation look like?
- Could you tell me about a regular day at work with PCC?
- Tell me about your practice and experiences with PCC on this ward/clinic/centre?
- How would you describe PCC to someone who is coming to work with you on your ward/center?

**Prompts**: How would you describe or define PCC?

- How did patients react to PCC?
- Would you tell me about any changes to your practice since you started working with PCC?

**Prompts**: Were there any changes in your ways of working? Relations with patients? Routines? Division of labour? Any changes-adaptions?

- What kind of documentation do you use when you work with PCC? Do you use any tools, diaries, notebooks, written material as part of PCC during your day? Can you describe this for me? How do you use this documentation for PCC in your work?
- What kinds of conditions do you think are required for PCC?
- What kinds of things do you think helped PCC and what kinds of things made PCC difficult in your experience?
- Is there anything else you would like to add?

- Could you tell me about your experience of the care you received? How would you describe the care and treatment?

**Prompts**: Can you give examples of the kind of care you received? What did the routines look like?

- How have you experienced the relationship between you and the staff? How did you experience the communication between you and the staff?

**Prompts:** In which ways, did you receive information? Did you discuss your care and treatment with the staff? Did the staff listen to your concerns and questions?

- What has been important to you in the care that you got?

**Prompts:** How did you you participate in decisions, have you been seen and listened to, information and communication about your care and treatment? Do you think that your resources/knowledge have been utilized?

- Do you think that the care you received was different from that of the care experience you have had in the past and ( if applicable) the care that you received later?

**Prompts:** In what way did they differ? What changes have you noticed?

- Are you familiar with the term person-centered care?

**Prompts:** If so, how would you describe PCC?

- During the care process, which part(s) of the care and treatment received do you perceive were person-centred?

- Which parts of PCC meant the most to your experience of involvement / partnership

**Prompts:** Could you give some examples? Procedures? Documentation? How staff looked after you? Something else?

- Do you think that health professionals have been interested in you as a person?
- Did you use an electronic health diary via the app or the web?

**Prompts:** How important was it for you? If not, did you use any other form of documentation tools or aids that had meaning for you?

- Is there anything else you would like to add?

# COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|---|---|---|---|
| **Domain 1: Research team and reflexivity** | | | |
| *Personal characteristics* | | | |
| Interviewer/facilitator | 1 | Which author/s conducted the interview or focus group? | P. 6) DL, AW |
| Credentials | 2 | What were the researcher's credentials? E.g. PhD, MD | N/A |
| Occupation | 3 | What was their occupation at the time of the study? | N/A |
| Gender | 4 | Was the researcher male or female? | P. 1) 50% of th |
| Experience and training | 5 | What experience or training did the researcher have? | N/A |
| *Relationship with participants* | | | |
| Relationship established | 6 | Was a relationship established prior to study commencement? | P 5) |
| Participant knowledge of the interviewer | 7 | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | N/A |
| Interviewer characteristics | 8 | What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | N/A |
| **Domain 2: Study design** | | | |
| *Theoretical framework* | | | |
| Methodological orientation and Theory | 9 | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | P 7) Interviews |
| *Participant selection* | | | |
| Sampling | 10 | How were participants selected? e.g. purposive, convenience, consecutive, snowball | P. 5) a purposi |
| Method of approach | 11 | How were participants approached? e.g. face-to-face, telephone, mail, email | P 20 Table 1) |
| Sample size | 12 | How many participants were in the study? | P 6) 37 respon |
| Non-participation | 13 | How many people refused to participate or dropped out? Reasons? | P 6) One patie |
| *Setting* | | | |
| Setting of data collection | 14 | Where was the data collected? e.g. home, clinic, workplace | P 20, Table 1) |
| Presence of non-participants | 15 | Was anyone else present besides the participants and researchers? | N/A |
| Description of sample | 16 | What are the important characteristics of the sample? e.g. demographic data, date | P20, Table 1) A |
| *Data collection* | | | |
| Interview guide | 17 | Were questions, prompts, guides provided by the authors? Was it pilot tested? | P 21, Table 2) |
| Repeat interviews | 18 | Were repeat inter views carried out? If yes, how many? | N/A |
| Audio/visual recording | 19 | Did the research use audio or visual recording to collect the data? | P.6) Audio reco |
| Field notes | 20 | Were field notes made during and/or after the inter view or focus group? | N/A |
| Duration | 21 | What was the duration of the inter views or focus group? | P20, Table 1) E |
| Data saturation | 22 | Was data saturation discussed? | N/A |
| Transcripts returned | 23 | Were transcripts returned to participants for comment and/or | N/A |

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| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|---|---|---|---|
| | | correction? | |
| **Domain 3: analysis and findings** | | | |
| *Data analysis* | | | |
| Number of data coders | 24 | How many data coders coded the data? | P 15) |
| Description of the coding tree | 25 | Did authors provide a description of the coding tree? | N/A |
| Derivation of themes | 26 | Were themes identified in advance or derived from the data? | P 7) Derived fr |
| Software | 27 | What software, if applicable, was used to manage the data? | P 7) |
| Participant checking | 28 | Did participants provide feedback on the findings? | N/A |
| *Reporting* | | | |
| Quotations presented | 29 | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | P7-P13) |
| Data and findings consistent | 30 | Was there consistency between the data presented and the findings? | N/A |
| Clarity of major themes | 31 | Were major themes clearly presented in the findings? | P 7) |
| Clarity of minor themes | 32 | Is there a description of diverse cases or discussion of minor themes? | N/A |

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**

# BMJ Open

## The realities of partnership in person-centred care: a qualitative interview study with patients and professionals

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# The realities of partnership in person-centred care: a qualitative interview study with patients and professionals

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**ABSTRACT**

**Objective:** Although conceptual definitions of person-centred care (PCC) vary, most models value the active involvement of patients through patient-

professional partnerships. However, while this may increase patients' sense of responsibility and control, research is needed to further understand how this partnership is created and perceived. The aim of this study is to explore the realities of partnership and participation as perceived by patients and health professionals in everyday PCC practice.

**Design**: Qualitative study employing a thematic analysis of semi-structured interviews with professionals and patients.

**Setting:** Four internal medicine wards and 2 primary care centres in western Sweden.

**Participants:** 20 patients admitted to hospital wards delivering person-centred care and 16 health professionals based on these wards and primary care centres.

**Results:** Our findings identified both informal and formal aspects of partnership. Informal aspects, emerging during the interaction between healthcare professionals and patients, without any prior guidelines or regulations incorporated proximity and receptiveness of professionals, and building a close connection and confidence. This epitomised a caring, respectful relationship congruent across accounts. Formal aspects, including structured ways of sustaining partnership were experienced differently. Professionals described collaborating with patients to encourage participation, capture personal goals, plan and document care. However, although patients felt listened to and informed, they were content to ask questions and felt less involved in care planning, documentation or exploring lifeworld goals. They commonly perceived participation as informed discussion and agreement, deferring to professional knowledge and expertise in the presence of an empathetic and trusting relationship.

**Conclusions**:

In our study patients appear to value a process of human connectedness above and beyond formalised aspects of documenting agreed goals and care planning. PCC increases patients' confidence in professionals who are competent and able to make them feel safe and secure. Informal elements of partnership provide the

conditions for communication and mutual co-operation upon which formal relations of partnership can be constructed.

Keywords:

Person-Centred Care, Patient-Centred Care, Patient Participation, Healthcare service

**Strengths and limitations of this study:**

- This study reports the experiences of both patients and professionals in hospital settings which have implemented an evidence based model of person centred care .

- The study population consisted of professionals with a broad range of clinical experience and patients with diverse medical signs and symptoms.

- Our sample was not designed to be statistically representative, nor can we claim to have reached data saturation.

**INTRODUCTION**

Increasingly clinicians are encouraged to engage, inform and involve patients [1][2] and support health policies that promote patient led care through 'activated' patients trained in self-management skills [3][4]. Health professionals and policy makers aspire towards person centred care (PCC) [5-7] and recent models of PCC prioritise a whole systems approach that places patients at the centre [8-10]. It is clear that with professional support, patients can become active partners in their care [11-15] and can benefit from opportunities to take part [16][17][18]. However, despite the development of PCC and the push towards patient professional partnerships [8], there is much talk and little action [7][19-21]. Substantial organisational and cultural barriers exist [20][22][23][24] and in order to overcome these barriers, both patients and professionals need to feel engaged, respected and treated as equals [2][11][12][25][14][26][27]. To date, there are numerous care concepts such

as patient-centred care, individualized care and narrative medicine that touch upon patient involvement and partnership, all including some sort of reciprocity and shared knowledge [28] [29], self management [30] [31] participation in decision making [32]. Different PCC frameworks lift patient involvement toward an enhanced therapeutic relationship that requires sharing power and responsibility [6]. Yet, as patients are increasingly offered more choice and involvement, researchers also describe circumstances where patients choose to decline participation, defer decisions or feel unable to participate [33] [34]. It seems that the notion of the patient as an active partner in care requires empirical understanding and clarity.

Cribb and Entwistle (2011) draw attention to the importance of an emotionally supportive patient-professional partnership to aid 'meaningful participation' and shared decision-making [14]. Relationships that are open ended and conversational are prioritised as well as professional virtues and patient capabilities. This approach takes into account the relational aspects of partnership, which pay attention to the mindfulness of professionals and the unique aspects of patients' lives [5] [35] [36]. However, although power sharing implies an egalitarian and meaningful patient-professional relationship [29], the literature describes a hierarchy of relationships depicting the different levels of engagement, responsibility and shared goals [31] [37]. This moves from the lowest level i.e. involvement towards participation and the highest level i.e. partnership [32] [37]. Thoransdottir & Kristjansson (2014) elaborate on informal and formal relationships; the former describing the fundamental importance of human connectedness and the latter involving shared agreements on decisions and documentation [31]. Thoransdottir & Kristjansson suggest that the ethics of care, meaning the informal aspects of human connectedness, is fundamental to the establishment of a partnership. However, it is important to acknowledge that both aspects are equally crucial for partnership.

In this paper we use a Swedish initiative for implementing an evidence-based PCC model as a case study. The University of Gothenburg Centre for PCC (GPCC) has introduced a new evidence based model[38-41], supported by a programme of training and research, which has changed clinical practice.[42] This model consists

of three 'routines' of PCC namely narrative, partnership and documentation [39 42 43]. Partnership in the GPCC framework is the main routine that drives the PCC process. The patient's narrative paves the way for collaboration, and documentation safeguards this collaboration. The aim of this study is to explore the realities of partnership as perceived by patients and health professionals in everyday PCC practice.

METHODS

**Sample and design**

This study adopted an interpretive approach employing qualitative semi-structured interviews. We used a purposive sampling strategy to capture several professional categories and a convenience sampling approach for patients (table 1). Four hospital wards at a large teaching hospital in west Sweden were chosen; these varied in size (18 to 36 hospital beds), specialization and patient group (patients with chronic and/or acute illness and from self-managing to bed-confined). Each ward took part in a 10 week PCC change management/training program, incorporating both lectures and workshops regarding the ethics of PCC, research findings from PCC studies as well as training in using different tools such as care plans and interview techniques. The ward manager chose members of staff (RN, AN, Physicians) as designated change agents in the training program and to implement PCC to their colleagues on each ward.

*Table 1 Description of practitioners and patient demography*

Each ward manager was contacted with information about the study and gave their consent. They were then asked to recruit a nurse, an assistant nurse and a physician, with experience of working with PCC and from the training program, from their ward.

Patients were eligible for enrolment into the study if they were cognisant, able to communicate in Swedish and admitted to a reference ward where PCC was being implemented at the hospital. The patients were admitted for symptoms of chronic heart failure, chronic obstructive lung disease, infections, anemia,

colorectal diseases such as Ulcerative Colitis, Crohn's disease, colon surgery and hepatological disease.

This reference ward had implemented PCC systematically using a 10 week extensive training course facilitated by GPCC following the PCC routines [38].

A nurse coordinator working on the ward provided eligible patients with the study information. Twenty-one patients volunteered to participate and gave their informed consent to be contacted by the study team after discharge and to be interviewed about the care they had received. One patient was excluded when transferred from another ward to the reference ward, which hampered recall.

**Data collection**

The interview guide for practitioners included questions about how PCC related to the everyday work of healthcare practitioners and its implementation. The interview guide for patients intended to elicit patients' experiences of care on the ward and their understanding of PCC (table 2).

*Table 2 Interview guide practitioners and patients*

DL conducted 12 interviews with professionals, AW conducted 2, and a trained research assistant conducted 3 interviews with practitioners and all interviews with patients.

All interviews were audio recorded, transcribed verbatim, anonymised and translated from Swedish into English. All interviewees were given a numbered pseudonym to maintain confidentiality (P for Patient, N for Nurses, M for Manager and MD for Physician). All participants were told that they were free to withdraw their consent at any time during the study. Patients were interviewed after their hospital stay, in a place of their choosing to ensure that they felt comfortable talking about the care episode. All interviews with patients were performed by researchers without a clinical background or connection to the

hospital. The regional ethics committee in Gothenburg approved the study and all participants, prior to their interview, gave informed consent. If the patients wanted to talk to a healthcare professional regarding general or specific topics that came up during the interviews, they were able to talk to a nurse about their concern or thoughts.

**Analysis**

Interviews were thematically analysed, adopting some basic features of grounded theory. Interviews were analysed initially employing line-by-line coding and an inductive, intuitive reading of the transcripts. Transcripts were independently coded by LM, ON & DL, summarised and then discussed by online and face-to-face meetings. A combination of computer software (NVivo 9) and hand written methods were used and mind mapping to assist with the development of themes [44]. We then followed a deductive process to explore how the characteristics and components of partnership were experienced by professionals and patients. Early analysis identified categories associated with providing comfort, creating confidence and finding common ground through everyday informal interactions. In contrast, other categories revealed formalised care provided by professionals such as exchanging information, planning, evaluating and documenting care. However, when these were compared with patient transcripts patients described a simplified and practical process such as receiving some form of paperwork and knowing what was done. As analysis progressed we categorized these findings under two main themes: informal and formal aspects of partnership. These findings were discussed with the whole team in order to address differences and reach a consensus.

**Results**

Two main themes were found: firstly informal aspects of partnership comprising two subthemes, proximity & receptiveness and building a personal connection/ confidence. Informal aspects of partnership were interpreted as those emerging during the interaction between healthcare professionals and patients. The second main theme was formal aspects of partnership having two subthemes,

aspects of goal setting and care planning, and documentation. Formal partnership is about the structured ways of sustaining the relationship between the health professionals and the patients via deciding goals, care planning and documentation. The results are presented below to allow comparison between the 2 groups.

**Informal aspects of partnership**

*Proximity and receptiveness*

Professionals described engaging patients in conversation with the intention of respecting and listening to the patient dialogue, understanding the patient's situation, making a good start and building a close connection.  Assistant nurses followed this process each morning and described feeling 'closer' to the patient, seeing and hearing aspects of the patient from a social, psychological and physical perspective and becoming their 'eyes and ears'. Professionals described using communication techniques such as posing open, straightforward questions, talking without distractions and not judging.  A number of professionals felt this process aided partnership in subsequent meetings.

> I think that I and the nurse get a great response from the patients, straight away, that they feel very comfortable in this. They know who to turn to. That they feel like they've been given a lot of time, even if it´s not that long time, but the content of the consultation gives them that feeling. (MD1)

Many patients described positive feelings towards the receptiveness of staff and the atmosphere of the ward. Accounts of unhurried and immediate support with care provided in a caring and close manner were common.

> Not everyone sits down at your bedside, just a few of them do. Mostly they pull out chair or something to sit on. They are not on their way to another patient when they do that. It's more of a good opening; that we are sitting here now, talking, until we are finished doing that. (P1)

Available and reliable professionals increased patients' comfort, with professionals described as thoughtful, open and warm, leading to patients feeling a sense of humanity, security, familiarity and trust.

> They say "Hi Paula!" and then they present themselves with their name and then the title comes. Already there they create an opportunity for dialogue. It's not "I'm nurse, good day." So at that point it feels like an openness and they simply and easily describe how my life will be in this room. (P2)

*Building a close connection and confidence*

Professionals described listening in a more engaged way to patients' wishes and needs. They emphasised the importance of knowing how patients felt, what they thought, aspects of their personality and personal knowledge, described by one professional as 'life-luggage'. Patients were prompted to discuss personal interests and common topics. For most professionals finding common ground built trust, security and a collaborative relationship on a person-to-person level.

> You may talk about books or music, or common interests so that you're not only... You establish a relationship beyond the nurse-patient, and it becomes more like person to person. (N1)

In keeping with professionals' aspirations, many patients felt listened to and acknowledged. Several felt known personally, for who they were and their individual needs.

> They could ask ordinary questions about the everyday life. We could talk about summer houses, and pets, and kind of on that level. And that's... I think that's very important. I think so at least... one is feeling more as if you aren't just a patient among others. (P3)

Some patients reported that they noticed changes in professionals' receptiveness.

> 'I was thinking that I should ask him to sit down, but you know how it is, no. But I can think that it's a different situation. He stands there taller than me who's sitting on the bedside. I don't like that….But what I regret is that I wasn't able to look at my x-rays on CT-abdomen. I had asked for that previously, but I didn't receive an answer to that. Well, I might have said that I wanted to see my x-rays. It can be interesting to look with a physician, because I know nothing about… I can't do it myself. So I asked for that the last day, but she said that she was much stressed, the assistant physician, and she had had very much to do. I would have wanted that. I'm sure I will get them to my home. I have requested everything and my medical records, but I can't examine things like those. It wasn't anything, but it would have been interesting to look at it. Sit with a doctor and review it (P4)

However other patients paid less attention to this change in professionals' receptiveness since they considered their hospitalisation as brief and requiring straightforward treatment.

**Formal partnership**

*Goal setting and care planning*

Professionals reported working in partnership with patients in formal ways by giving and exchanging information, updating, summarizing and care planning. For example, patients are encouraged to discuss aspects of their symptoms, treatment, diagnosis and discharge plans. A number of professionals described making a 'team decision', alternatively known as a health plan, in collaboration with patients. This acknowledged a person's capabilities and personal goals that were agreed, documented and given to the patient. This is in line with the PCC routine of safeguarding the partnership through agreed goals.

> The patient when at the hospital together with the nurse and the doctor decided what are the main issues: is it losing weight, is it anxiety, is it stop smoking or getting better medication or is it more training, physical activities, is it fear of training? And so on. So when they left the hospital

> they had this sheet where they had described their problem and it was
> just, it was their problem it was not a standard formula – the formula was
> standard but the questions and the wishes from the patient was personal
> (MD2)

Informal aspects of partnership led to an environment where it became possible for patients to ask questions, learn about their condition and treatment. Professionals believed patients had the inclination to begin caring for themselves, follow suggestions and instructions. Formal aspects such as discussing goals facilitated self-care such as getting dressed, mobilising on the ward, preparing for discharge and following advice post discharge.

Several professionals described the need to encourage, 'push' or 'pass' on competence to the patient, by letting the patient ask questions and take part in the care planning, hence enabling the patient to become well informed, knowledgeable and take responsibility.

> There is a more practical understanding that the patient also carries a
> responsibility, and also is responsible for the process. I tend to think that
> my ward is at this stage of the process – to get the patient to understand
> the significance of his or her participation to activity, to rehabilitation.
> (M1)

Professionals noticed a change, where patients who were well informed, knew they had an impact, influence and could handle themselves. They seemed satisfied and more willing to help themselves and 'buy the whole concept'.

> We look at what the patient usually does in their everyday life outside the
> hospital, and what the patient does right now, and what we can do to
> improve and to support that the patient becomes their ordinary self again.
> And that you really try to understand how they can use their own
> resources and train themselves. (N2)

However from the patient perspective some remembered taking part in developing a health plan but few mentioned goals and when discussed, these

were invariably described in medicalised terms or framed around home circumstances for discharge. Personal information was elicited and described, but not necessarily orientated towards 'lifeworld' goals.

> I don't actually know if the goal has been mentioned, but that might be the goal with the illness I have, that the goal is to be free from relapses. Because everything would then be as good as they can be. One wouldn't suffer from the disease then. As long as one takes medicine that doesn't give side-effects and isn't suffering from relapses, then everything will be okay. And I know that has been mentioned, that it might be the goal after all. But that, as I said, that has to do with the disease. (P5)

Patients felt they contributed when they discussed choices with professionals, helped themselves, used their initiative and became knowledgeable. There were opportunities to question, decline treatment and contribute to discharge planning. For some, participation involved discussing test results, investigations and medication management that helped them 'feel' (our emphasis) they were committed to taking part in their care, for example by discussing an ultrasound test, a transfusion or a colonoscopy procedure. They received explanations and felt they knew what to do, how to deal with medication and treatments.

> I know much more about my illness now and why it has become the way it has, I think I understand that better now. And that I can see in hindsight that I haven't been feeling well for a very long time, which has been connected to this. So now I have got a much clearer picture of my condition. (P6)

Others felt they participated by listening to professionals, agreeing and accepting professionals' decision-making. They felt confident, comfortable and treated as equals, described by one patient as 'horizontal communication'. A few patients described themselves as 'experienced', 'verbal' even when very ill and able to 'demand and ask questions'. Yet for patients in this study, participating was described in terms of informed discussion, acceptance and agreement, participating up to a point or as far as they felt able. Several felt comfortable 'submitting' and 'not being in the driving seat'.

Many times one might feel like one is participating… one sometimes may be silent, but still feel a fellowship. Do you understand what I mean? And that's probably what I felt with the ward. That I didn't need to ask or I didn't need to ask them, the nurses I mean, since I knew in some way that the community still was there. (P7)

When I say no to something, they listen to me. Whatever it might be; the discharge or anything. Or some kind of examination… I said no to an examination, and I said that: "You did that examination just six months ago, and it's very painful. Is it really necessary to do it again?" "No, then we won't do it." (P1)

Since you are part of the treatments, and you know how they are doing the plan for the treatment and are explaining in a good way. So even when you return home, you know approximately about… Well, now I know how I will deal with the medications and the treatment and everything, in a completely different way. (P7)

Documentation

Professionals described writing care plans with patients, eliciting biomedical information and discussing social and discharge planning. Decisions and plans were agreed and documented.

You should make a plan together with the patient and that you discuss with the patient and so on, but the difference of having it in this way is that you have more of a structure of it. You create a framework for what it means to work like this, so that what you're doing becomes more concrete. (MD3)

In some way the patient gets what we've done on paper, and we get a proof of that we understand it in the right way, so that the patient can say "Yes, this is how it was" or "I don't agree with this." The important thing is that you agree, so that you are on the same page so to speak. (N1)

In this respect professionals described 'a new practice' where patients were encouraged to actively participate, become more involved and take part in decisions about their care.

> Documentation acted as a reminder for patients to discuss care on 'a new level'. (N3)

> You must create a care plan with the patient within 48 hours and then you should write why they have sought care and what we have planned for them and this should be addressed at the round with the patient, and it is written down and then it's a little investigation to see what the patients can do themselves. (N4)

Professionals encouraged patients to use their own resources and expertise. For example patients were encouraged to prepare for conversations with the team and write down thoughts or questions.

Patients felt informed about their condition, discharge and future care needs, felt they were listened to and some felt they were participating in their care plan.

> I think, that it felt like it was a team. Decisions where I participated in, and the care plan and such things. How much you actually were that, I don't know, but at least you had a picture of it, so. But I can't decide how I'm going to be treated or taken care of, but at least you can be a part of it and have opinions, you were able to do that. (P8)

Although patients remembered receiving written information and some described opportunities to write down thoughts, questions and contribute to their care, they did not remember the written information in any detail. Nevertheless, patients saw this documentation in 'simple' terms whereby they felt taken care of and in receipt of sufficient information.

Discussion

In our study, interviewees' accounts reflect levels of mutuality, self-expression and respect that lay the groundwork for PCC and indicate a move from disease focused models of care [19]. In keeping with the literature we suggest that informal elements of partnership provide the conditions for communication and mutual co-operation upon which formal relations of partnership can be constructed [27] [31] [36]. Professional and patient perspectives highlight the importance of the informal elements of partnership for ultimately determining the level of shared decision

making which is possible to aspire to and practically achieve [14]. Informal elements in our study depict emotionally supportive relationships that pave the way for patients to participate, once the scene is set and the circumstances feel right.

However, in our findings patients were content to be able to ask questions and receive information. They perceived participation as informed discussion and agreement, deferring to professional knowledge and expertise and not necessarily describing opportunities for empowerment and activation. Perceived competence of professionals seemed enough for patients and whilst patients prioritised the informal processes where 'good care' may have been interpreted as PCC, professionals prioritised outcomes that were formal and documented. Patients described participating in plans for discharge but did not describe notions of enablement or control. As with other studies, patients were satisfied with a personal approach and a positive partnership with professionals who communicated empathetically and effectively [45] with professionals acting as educators, building mutual and collaborative partnerships [46]. Measurements of optimum patient-professional relationships and person-centredness need to consider patients' emotional and personal responses that highlight the process rather than the outcome of interactions with health professionals [5 14 27 35]. Aspects of informal and formal partnership appeared to act as antecedents of patient participation. Yet overall, most patients portrayed a taken-for-granted pragmatism, trusting professionals with expertise and competence to make overall decisions in a caring environment. For patients in this study, PCC was not explicitly understood or described as an opportunity to formalize a partnership with professionals in order to actively participate in their care. There were more formal aspects of partnership that took precedence in patients' minds, which is in line with the description of the fundamentals of human connectedness described by Thoransdottir & Kristjansson (2014), pointing toward the ethical dimension of partnership and PCC. In addition, professionals may have considered PCC as a particular professional approach rather than a systematic endeavour to "invite" patients to participate in the PCC routines and explicate the model.

Aspects of partnership, particularly informal aspects, led patients to leave some decisions to the professionals since they felt cared for and well informed. Patients were not forced to make a choice, but they were rather given guidance and information. In this respect patients' interpretation of participation can be viewed, not as passive submission or deferment to professional expertise and knowledge, but a common understanding reached through a therapeutic relationship. Our interpretation of the present study points toward the importance of human connectedness and the feeling of being listen to and acknowledged as a person (informal aspect) for patients, while routines and formal aspects of care came more into the foreground for the practitioners. It seems as if in order to integrate the patient into clinical practice, there seems to be a balancing act that practitioners as well as patients need to reflect upon: recognition of the patient as a person (informal aspects) needs to balance the specific practical routines (formal aspects)[42]. The risk could otherwise be that the patient as a person becomes a "tickbox" in a routine, which in many aspects would entrench profession-centred care rather than person-centredness.

This study has some limitations. Patients did not necessarily perceive their care in the context of a PCC model and our study depended upon patients remembering events and perhaps perceiving the relevance of information and care strategies. Secondly, because the study took place in a particular institutional context (GPCC) in Sweden, the findings may not be transferable to other settings. Moreover, formal aspects of partnership, for example, documented care plans and decisions, could have provided patients with opportunities to revisit decisions in written form, and maintain a sense of confidence and trust during their admission that was taken for granted. Moreover, most interviewees were older perhaps predisposing them to comply with professional expertise or feel knowledgeable but not necessarily empowered [47]. However, Ekdalh et al (2011) suggest that older peoples' preferences for information and decision making are not associated with age, and that the majority of patients wanted more information, not less [48].

 Another limitation in this study is that patients were first contacted by a nurse coordinator and after agreeing to be part of the study, participants were contacted by the researchers after their discharge within the first 7 days to schedule a interview. Patients who agreed to participate in the interview study might have been more attentive to the particular aspects of PCC and eager to talk about their experience. This might have led to the tendency for positive accounts about the informal parts of partnership. However, it is equally important for the objective of the study to capture positive comments about partnership.

Conclusion

In our study patients appear to value a process of human connectedness above and beyond formal aspects of taking part and feeling activated and capable. These findings may point to the need for professionals to acknowledge the importance of the human connectedness that is as crucial as formal aspects for PCC to be fully realised in practice.

Author contributions

LM and AW contributed equally to the study as first authors. All authors contributed to the study design, conception and development. DL and AW conducted the interviews together with research assistant Marie Hammer. LM, DL and ÖN initially analysed the data, and all authors met face to face and over skype as a group to discuss, revise and confirm the findings.  All authors were responsible for critical revision and finalising the manuscript.

Data sharing statement

No additional unpublished data is available

Wordcount 4756

References

1. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med* 2012;27(10):1361-7. doi: 10.1007/s11606-012-2077-6 [published Online First: 2012/05/24]
2. Elwyn G, Lloyd A, May C, et al. Collaborative deliberation: a model for patient care. *Patient Educ Couns* 2014;97(2):158-64. doi: 10.1016/j.pec.2014.07.027 [published Online First: 2014/09/02]
3. Department of Health. Long term conditions compendium of information, 2012.
4. Eaton S, Roberts S, Turner B. Delivering person centred care in long term conditions. *Bmj* 2015;350:h181. doi: 10.1136/bmj.h181 [published Online First: 2015/02/12]
5. Epstein RM, Street RL, Jr. The values and value of patient-centered care. *Ann Fam Med* 2011;9(2):100-3. doi: 10.1370/afm.1239 [published Online First: 2011/03/16]
6. Harding E, Wait S, Scrutton J. The state of play in person-centred care: pragmatic review of how person-centred care is defined, applied and measured, featuring selected key contributors and case studies across the field.: The Health Foundation, 2015:1-140.
7. Hawkes N. Seeing things from the patients' view: what will it take? *Bmj* 2015;350:g7757. doi: 10.1136/bmj.g7757 [published Online First: 2015/02/12]
8. Health Foundation. Helping people help themselves, 2011.
9. King's Fund. People in control of their own health and care, 2014.
10. NHS England. Enhancing the quality of life for people living with long term conditions-the house of care, 2014.
11. Coulter A. Patient engagement--what works? *J Ambul Care Manage* 2012;35(2):80-9. doi: 10.1097/JAC.0b013e318249e0fd [published Online First: 2012/03/15]
12. Coulter A, Collins A. Making shared decision-making a reality; no decision about me, without me. London: The King's Fund, 2011:1-40.
13. Coulter A, Safran D, Wasson JH. On the language and content of patient engagement. *J Ambul Care Manage* 2012;35(2):78-9. doi: 10.1097/JAC.0b013e31824a5676 [published Online First: 2012/03/15]

14. Cribb A, Entwistle VA. Shared decision making: trade-offs between narrower and broader conceptions. *Health Expect* 2011;14(2):210-9. doi: 10.1111/j.1369-7625.2011.00694.x

15. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Educ Couns* 2006;60(3):301-12. doi: 10.1016/j.pec.2005.06.010

16. Amin F. Commentary: Becoming a person centred practice. *Bmj* 2015;350:h269. doi: 10.1136/bmj.h269 [published Online First: 2015/02/12]

17. National Voices. Principles of care and support planning, 2013.

18. Coulter A, Entwistle VA, Eccles A, et al. Personalised care planning for adults with chronic or long-term health conditions. *Cochrane Database Syst Rev* 2015;3:CD010523. doi: 10.1002/14651858.CD010523.pub2 [published Online First: 2015/03/04]

19. Ekman I, Swedberg K, Taft C, et al. Person-centered care--ready for prime time. *Eur J Cardiovasc Nurs* 2011;10(4):248-51. doi: 10.1016/j.ejcnurse.2011.06.008 [published Online First: 2011/07/19]

20. Frosch DL. The patient is the most important member of the team. *Bmj* 2015;350:g7767. doi: 10.1136/bmj.g7767 [published Online First: 2015/02/12]

21. Frosch DL, May SG, Rendle KA, et al. Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Aff (Millwood)* 2012;31(5):1030-8. doi: 10.1377/hlthaff.2011.0576 [published Online First: 2012/05/09]

22. Moore L, Britten N, Lydahl D, et al. Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. *Scand J Caring Sci* 2016 doi: 10.1111/scs.12376

23. Naldemirci O, Lydahl D, Britten N, et al. Tenacious assumptions of person-centred care? Exploring tensions and variations in practice. *Health (London)* 2016 doi: 10.1177/1363459316677627

24. Alharbi TS, Ekman I, Olsson LE, et al. Organizational culture and the implementation of person centered care: results from a change process in Swedish hospital care. *Health Policy* 2012;108(2-3):294-301. doi: 10.1016/j.healthpol.2012.09.003

25. Gravel K, Legare F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. *Implement Sci* 2006;1:16. doi: 10.1186/1748-5908-1-16 [published Online First: 2006/08/11]

26. Entwistle VA. Considerations of 'fit' and patient involvement in decision making. *Health Expect* 2006;9(2):95-7. doi: 10.1111/j.1369-7625.2006.00397.x

27. Entwistle VA, Watt IS. Patient involvement in treatment decision-making: the case for a broader conceptual framework. *Patient Educ Couns* 2006;63(3):268-78. doi: 10.1016/j.pec.2006.05.002

28. Hudon C, Fortin M, Haggerty J, et al. Patient-centered care in chronic disease management: a thematic analysis of the literature in family medicine. *Patient Educ Couns* 2012;88(2):170-6. doi: 10.1016/j.pec.2012.01.009

29. Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med* 2000;51(7):1087-110.

30. Sahlsten MJ, Larsson IE, Sjostrom B, et al. An analysis of the concept of patient participation. *Nurs Forum* 2008;43(1):2-11. doi: 10.1111/j.1744-6198.2008.00090.x

31. Thorarinsdottir K, Kristjansson K. Patients' perspectives on person-centred participation in health care: A framework analysis. *Nursing ethics* 2013 doi: 10.1177/0969733013490593

32. Frank C, Asp M, Dahlberg K. Patient participation in emergency care - a phenomenographic analysis of caregivers' conceptions. *J Clin Nurs* 2009;18(18):2555-62. doi: 10.1111/j.1365-2702.2008.02477.x

33. Eldh AC, Ehnfors M, Ekman I. The phenomena of participation and non-participation in health care--experiences of patients attending a nurse-led clinic for chronic heart failure. *Eur J Cardiovasc Nurs* 2004;3(3):239-46. doi: 10.1016/j.ejcnurse.2004.05.001

34. Eldh AC, Ekman I, Ehnfors M. Conditions for patient participation and non-participation in health care. *Nursing ethics* 2006;13(5):503-14.

35. Epstein RM. Making communication research matter: what do patients notice, what do patients want, and what do patients need? *Patient Educ Couns* 2006;60(3):272-8. doi: 10.1016/j.pec.2005.11.003

36. Epstein RM, Franks P, Fiscella K, et al. Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. *Soc Sci Med* 2005;61(7):1516-28. doi: 10.1016/j.socscimed.2005.02.001

37. Cahill J. Patient participation: a concept analysis. *J Adv Nurs* 1996;24(3):561-71.

38. Ekman I, Wolf A, Olsson LE, et al. Effects of person-centred care in patients with chronic heart failure: the PCC-HF study. *Eur Heart J* 2012;33(9):1112-9. doi: 10.1093/eurheartj/ehr306 [published Online First: 2011/09/20]

39. Fors A, Ekman I, Taft C, et al. Person-centred care after acute coronary syndrome, from hospital to primary care - A randomised controlled trial. *Int J Cardiol* 2015;187:693-9. doi: 10.1016/j.ijcard.2015.03.336 [published Online First: 2015/04/29]

40. Feldthusen C, Dean E, Forsblad-d'Elia H, et al. Effects of person-centered physical therapy on fatigue-related variables in persons with rheumatoid arthritis: a randomized controlled trial. *Arch Phys Med Rehabil* 2016;97(1):26-36.

41. Olsson LE, Hansson E, Ekman I. Evaluation of person-centred care after hip replacement-a controlled before and after study on the effects of fear of movement and self-efficacy compared to standard care. *BMC nursing* 2016;15(1):53. doi: 10.1186/s12912-016-0173-3

42. Britten N, Moore L, Lydahl D, et al. Elaboration of the Gothenburg model of person-centred care. *Health Expect* 2016 doi: 10.1111/hex.12468 [published Online First: 2016/05/20]

43. Ekman I, Hedman H, Swedberg K, et al. Commentary: Swedish initiative on person centred care. *Bmj* 2015;350:h160. doi: 10.1136/bmj.h160 [published Online First: 2015/02/12]

44. Miles MB, Huberman AM, Saldana J. Qualitative data analysis: A methods sourcebook. Third ed. London: Sage Publications 2014.

45. Little P, Everitt H, Williamson I, et al. Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *BMJ* 2001;323(7318):908-11. [published Online First: 2001/10/23]

46. Roter D. The enduring and evolving nature of the patient-physician relationship. *Patient Educ Couns* 2000;39(1):5-15.

47. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns* 2014;94(3):291-309. doi: 10.1016/j.pec.2013.10.031 [published Online First: 2013/12/07]

48. Ekdahl AW, Andersson L, Wirehn AB, et al. Are elderly people with co-morbidities involved adequately in medical decision making when hospitalised? A cross-sectional survey. *BMC geriatrics* 2011;11:46. doi: 10.1186/1471-2318-11-46 [published Online First: 2011/08/20]

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*Table 1*

|                          | Practitioners (n=17) |
|--------------------------|:--------------------:|
| Women (n)                | 14                   |
| Profession               |                      |
|   Registered nurse  | 5               |
|   Assistant nurse   | 4               |
|   Manager           | 4               |
|   Physician         | 4               |
| Interview range          | 29-60 minutes        |
| Place for interview      |                      |
|   Hospital          | 13              |
|   Primary care center | 2             |
|   University        | 2               |

|                          | Patient (n=20)       |
|--------------------------|:--------------------:|
| Women (n)                | 11                   |
| Age median (range)       | 69, 35-88 years      |
| Interview range          | 19-83 minutes        |
| Place for interview      |                      |
|   Home              | 13              |
|   Hospital          | 2               |
|   University        | 1               |
|   Telephone         | 4               |

**Table 2**

| Interview guide: Practitioners | Interview guide: Patients |
|--------------------------------|---------------------------|
|                                |                           |

- To start with, could you tell me a bit about this ward/clinic/centre?

**Prompts**: Size? Practical work? Team?

- How did you start working with PCC?

**Prompts**: First contact with PCC? When did you first hear about it? Where did the idea come from? Did you have a special training?

- How did you implement PCC in the ward/clinic/centre? What did the implementation look like?
- Could you tell me about a regular day at work with PCC?
- Tell me about your practice and experiences with PCC on this ward/clinic/centre?
- How would you describe PCC to someone who is coming to work with you on your ward/center?

**Prompts**: How would you describe or define PCC?

- How did patients react to PCC?
- Would you tell me about any changes to your practice since you started working with PCC?

**Prompts**: Were there any changes in your ways of working? Relations with patients? Routines? Division of labour? Any changes-adaptions?

- What kind of documentation do you use when you work with PCC? Do you use any tools, diaries, notebooks, written material as part of PCC during your day? Can you describe this for me? How do you use this documentation for PCC in your work?
- What kinds of conditions do you think are required for PCC?
- What kinds of things do you think helped PCC and what kinds of things made PCC difficult in your experience?
- Is there anything else you would like to add?

- Could you tell me about your experience of the care you received? How would you describe the care and treatment?

**Prompts**: Can you give examples of the kind of care you received? What did the routines look like?

- How have you experienced the relationship between you and the staff? How did you experience the communication between you and the staff?

**Prompts:** In which ways, did you receive information? Did you discuss your care and treatment with the staff? Did the staff listen to your concerns and questions?

- What has been important to you in the care that you got?

**Prompts:** How did you participate in decisions, have you been seen and listened to, information and communication about your care and treatment? Do you think that your resources/knowledge have been utilized?

- Do you think that the care you received was different from the care you have experience in the past and (if applicable) the care that you received later?

**Prompts:** In what way did they differ? What changes have you noticed?

- Are you familiar with the term person-centered care?

**Prompts:** If so, how would you describe PCC?

- During the care process, which part(s) of the care and treatment received do you perceive were person-centred?

- Which parts of PCC meant the most to your experience of involvement / partnership

**Prompts:** Could you give some examples? Procedures? Documentation? How staff looked after you? Something else?

- Do you think that health professionals have been interested in you as a person?
- Did you use an electronic health diary via the app or the web?

**Prompts:** How important was it for you? If not, did you use any other form of documentation tools or aids that had meaning for you?

- Is there anything else you would like to add?

# COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|---|---|---|---|
| **Domain 1: Research team and reflexivity** | | | |
| *Personal characteristics* | | | |
| Interviewer/facilitator | 1 | Which author/s conducted the interview or focus group? | P. 6) DL, AW |
| Credentials | 2 | What were the researcher's credentials? E.g. PhD, MD | N/A |
| Occupation | 3 | What was their occupation at the time of the study? | N/A |
| Gender | 4 | Was the researcher male or female? | P. 1) 50% of th |
| Experience and training | 5 | What experience or training did the researcher have? | N/A |
| *Relationship with participants* | | | |
| Relationship established | 6 | Was a relationship established prior to study commencement? | P 5) |
| Participant knowledge of the interviewer | 7 | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | N/A |
| Interviewer characteristics | 8 | What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | N/A |
| **Domain 2: Study design** | | | |
| *Theoretical framework* | | | |
| Methodological orientation and Theory | 9 | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | P 7) Interviews |
| *Participant selection* | | | |
| Sampling | 10 | How were participants selected? e.g. purposive, convenience, consecutive, snowball | P. 5) a purposi |
| Method of approach | 11 | How were participants approached? e.g. face-to-face, telephone, mail, email | P 20 Table 1) |
| Sample size | 12 | How many participants were in the study? | P 6) 37 respon |
| Non-participation | 13 | How many people refused to participate or dropped out? Reasons? | P 6) One patie |
| *Setting* | | | |
| Setting of data collection | 14 | Where was the data collected? e.g. home, clinic, workplace | P 20, Table 1) |
| Presence of non-participants | 15 | Was anyone else present besides the participants and researchers? | N/A |
| Description of sample | 16 | What are the important characteristics of the sample? e.g. demographic data, date | P20, Table 1) / |
| *Data collection* | | | |
| Interview guide | 17 | Were questions, prompts, guides provided by the authors? Was it pilot tested? | P 21, Table 2) |
| Repeat interviews | 18 | Were repeat inter views carried out? If yes, how many? | N/A |
| Audio/visual recording | 19 | Did the research use audio or visual recording to collect the data? | P.6) Audio rec |
| Field notes | 20 | Were field notes made during and/or after the inter view or focus group? | N/A |
| Duration | 21 | What was the duration of the inter views or focus group? | P20, Table 1) [ |
| Data saturation | 22 | Was data saturation discussed? | N/A |
| Transcripts returned | 23 | Were transcripts returned to participants for comment and/or | N/A |

| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|---|---|---|---|
| | | correction? | |
| **Domain 3: analysis and findings** | | | |
| *Data analysis* | | | |
| Number of data coders | 24 | How many data coders coded the data? | P 15) |
| Description of the coding tree | 25 | Did authors provide a description of the coding tree? | N/A |
| Derivation of themes | 26 | Were themes identified in advance or derived from the data? | P 7) Derived fr |
| Software | 27 | What software, if applicable, was used to manage the data? | P 7) |
| Participant checking | 28 | Did participants provide feedback on the findings? | N/A |
| *Reporting* | | | |
| Quotations presented | 29 | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | P7-P13) |
| Data and findings consistent | 30 | Was there consistency between the data presented and the findings? | N/A |
| Clarity of major themes | 31 | Were major themes clearly presented in the findings? | P 7) |
| Clarity of minor themes | 32 | Is there a description of diverse cases or discussion of minor themes? | N/A |

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**

# BMJ Open

## The realities of partnership in person-centred care: a qualitative interview study with patients and professionals

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1  The realities of partnership in person-centred care: a qualitative interview study
2  with patients and professionals

3

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22  **ABSTRACT**

23  **Objective:** Although conceptual definitions of person-centred care (PCC) vary,

24  most models value the involvement of patients through patient-professional

25  partnerships. While this may increase patients' sense of responsibility and

26  control, research is needed to further understand how this partnership is created

27  and perceived. This study aims to explore the realities of partnership as
28  perceived by patients and health professionals in everyday PCC practice.

29  **Design**: Qualitative study employing a thematic analysis of semi-structured
30  interviews with professionals and patients.

31  **Setting:** Four internal medicine wards and 2 primary care centres in western
32  Sweden.

33  **Participants:** 20 patients admitted to hospital wards delivering person-centred
34  care and 16 health professionals based on these wards and primary care centres.

35  **Results:** Our findings identified both informal and formal aspects of partnership.
36  Informal aspects, emerging during the interaction between healthcare
37  professionals and patients, without any prior guidelines or regulations
38  incorporated proximity and receptiveness of professionals, and building a close
39  connection and confidence. This epitomised a caring, respectful relationship
40  congruent across accounts. Formal aspects, including structured ways of
41  sustaining partnership were experienced differently. Professionals described
42  collaborating with patients to encourage participation, capture personal goals,
43  plan and document care. However, although patients felt listened to and
44  informed, they were content to ask questions and felt less involved in care
45  planning, documentation or exploring lifeworld goals. They commonly perceived
46  participation as informed discussion and agreement, deferring to professional
47  knowledge and expertise in the presence of an empathetic and trusting
48  relationship.

49  **Conclusions**:

50  In our study patients appear to value a process of human connectedness above
51  and beyond formalised aspects of documenting agreed goals and care planning.
52  PCC increases patients' confidence in professionals who are competent and able
53  to make them feel safe and secure. Informal elements of partnership provide the
54  conditions for communication and co-operation upon which formal relations
55  of partnership can be constructed.

56  Keywords:

57　Person-Centred Care, Patient-Centred Care, Patient Participation, Healthcare

58　service, Qualitative

59　**Strengths and limitations of this study:**

60　　• This study reports the experiences of both patients and professionals in

61　　　hospital settings which have implemented an evidence based model of

62　　　person centred care .

63　　• The study population consisted of professionals with a broad range of

64　　　clinical experience and patients with diverse medical signs and

65　　　symptoms.

66　　• Our sample was not designed to be statistically representative

67

68　**INTRODUCTION**

69　Increasingly clinicians are encouraged to engage, inform and involve patients [1] [2]

70　and support health policies that promote patient led care through 'activated'

71　patients trained in self-management skills [3] [4]. Health professionals and policy

72　makers aspire towards person centred care (PCC) [5-7] and recent models of PCC

73　prioritise a whole systems approach that places patients at the centre [8-10]. It is

74　clear that with professional support, patients can become active partners in their

75　care [11-15] and can benefit from opportunities to take part [16] [17] [18]. However,

76　despite the development of PCC and the push towards patient professional

77　partnerships [8], there is much talk and little action [7] [19-21]. Substantial

78　organisational and cultural barriers exist [20] [22] [23] [24] and in order to overcome

79　these barriers, both patients and professionals need to feel engaged, respected

80　and treated as equals [2] [11] [12] [25] [14] [26] [27]. To date, there are numerous care concepts

81　such as patient-centred care, individualized care and narrative medicine that

82　touch upon patient involvement and partnership, all including some sort of

83　reciprocity and shared knowledge [28] [29], self management [30] [31] participation in

84　decision making [32]. Different PCC frameworks lift patient involvement toward an

85　enhanced therapeutic relationship that requires sharing power and

86　responsibility [6]. Yet, as patients are increasingly offered more choice and

87 involvement, researchers also describe circumstances where patients choose to

88 decline participation, defer decisions or feel unable to participate [33][34]. It seems

89 that the notion of the patient as an active partner in care requires empirical

90 understanding and clarity.

91

92 Cribb and Entwistle (2011) draw attention to the importance of an emotionally

93 supportive patient-professional partnership to aid 'meaningful participation' and

94 shared decision-making [14]. Relationships that are open ended and conversational

95 are prioritised as well as professional virtues and patient capabilities. This

96 approach takes into account the relational aspects of partnership, which pay

97 attention to the mindfulness of professionals and the unique aspects of patients'

98 lives [5][35][36]. However, although power sharing implies an egalitarian and

99 meaningful patient-professional relationship [29], the literature describes a

100 hierarchy of relationships depicting the different levels of engagement,

101 responsibility and shared goals [31][37]. This moves from the lowest level i.e.

102 involvement towards participation and the highest level i.e. partnership [32][37].

103 Thoransdottir & Kristjansson (2014) elaborate on informal and formal

104 relationships; the former describing the fundamental importance of human

105 connectedness and the latter involving shared agreements on decisions and

106 documentation [31].

107

108 In this paper we use a Swedish initiative for implementing an evidence-based

109 PCC model as a case study. The University of Gothenburg Centre for PCC (GPCC)

110 has introduced a new evidence based model[38-41], supported by a programme of

111 training and research, which has changed clinical practice.[42] This model consists

112 of three 'routines' of PCC namely narrative, partnership and documentation [39][42]

113 [43]. Partnership in the GPCC framework is the main routine that drives the PCC

114 process. The patient's narrative paves the way for collaboration, and

115 documentation safeguards this collaboration. The aim of this study is to explore

116 the realities of partnership as perceived by patients and health professionals in

117 everyday PCC practice.

118

119 METHODS

120   **Sample and design**

121   This study adopted an interpretive approach employing qualitative semi-

122   structured interviews. We used a purposive sampling strategy to capture  several

123   professional categories and a convenience sampling approach for patients (table

124   1). Four hospital wards at a large teaching hospital in west Sweden were chosen;

125   these varied in size (18 to 36 hospital beds), specialization and patient group

126   (patients with chronic and/or acute illness and from self-managing to bed-

127   confined). Each ward took part in a 10 week PCC change management/training

128   program, incorporating both lectures and workshops regarding the ethics of PCC,

129   research findings from PCC studies as well as training in using different tools

130   such as care plans and interview techniques.  The ward manager chose members

131   of staff (Registered Nurse (RN), Assistant Nurse (AN), Physicians) as designated

132   change agents in the training program and to implement PCC to their colleagues

133   on each ward.

134   *Table 1 Description of practitioners and patient demography*

135   Each ward manager was contacted with information about the study and gave

136   their consent. They were then asked to recruit a nurse, an assistant nurse and a

137   physician, with experience of working with PCC and from the training program,

138   from their ward.

139   Patients were eligible for enrolment into the study if they were cognisant, able to

140   communicate in Swedish and admitted to a reference ward where PCC was being

141   implemented at the hospital. The patients were admitted for symptoms of

142   chronic heart failure, chronic obstructive lung disease, infections, anaemia,

143   colorectal diseases such as Ulcerative Colitis, Crohn's disease, colon surgery and

144   hepatological disease.

145   This reference ward had implemented PCC systematically using a 10 week

146   extensive training course facilitated by GPCC following the PCC routines [38].

147   A nurse coordinator working on the ward provided eligible patients with the

148   study information. Twenty-one patients volunteered to participate and gave

149   their informed consent to be contacted by the study team after discharge and to

150  be interviewed about the care they had received. One patient was excluded when

151  transferred from another ward to the reference ward, which hampered recall.

152  **Data collection**

153

154  The interview guide for practitioners included questions about how PCC related

155  to the everyday work of healthcare practitioners and its implementation. The

156  interview guide for patients was intended to elicit patients' experiences of care

157  on the ward and their understanding of PCC (table 2).

158

159  *Table 2 Interview guide practitioners and patients*

160

161  DL conducted 12 interviews with professionals, AW conducted 2, and a trained

162  research assistant conducted 3 interviews with practitioners and all interviews

163  with patients.

164  All interviews were audio recorded, transcribed verbatim, anonymised and

165  translated from Swedish into English. They were then read and checked by the

166  team to ensure accuracy and fluency. Translation was literal, yet for specific

167  idioms in Swedish which are not easy to translate, native English speakers in the

168  research team suggested alternatives which would do better justice to the

169  content and bilingual team members checked their accuracy. Any potential

170  misinterpretations were clarified and agreed. All interviewees were given a

171  numbered pseudonym to maintain confidentiality (P for Patient, N for Nurses, M

172  for Manager and MD for Physician). All participants were told that they were free

173  to withdraw their consent at any time during the study. Patients were

174  interviewed after their hospital stay, in a place of their choosing to ensure that

175  they felt comfortable talking about the care episode. A research assistant (MH)

176  without a clinical background or connection to the hospital performed all patient

177  interviews. However, she is trained sociology and had previous experience of

178  conducting patient interviews. She received guidance from the team concerning

179  the interview guide, qualitative interview techniques and the use of probing

180   questions throughout the present study.  Probing questions were used to follow

181   up a topic of discussion, to obtain a better illustration of the discussed topics and

182   facilitate the dialogue in a way that the interviewees felt comfortable responding

183   to questions.  If interviewees did not want to talk more about a particular issue,

184   the interviewer skipped the related probing questions and asked the following

185   question in the guide.

186   The regional ethics committee in Gothenburg approved the study and all

187   participants, prior to their interview, gave informed consent. If the patients

188   wanted to talk to a healthcare professional about general or specific topics that

189   came up during the interviews, they were able to talk to a nurse about their

190   concern or thoughts.

191   **Analysis**

192   Interviews were thematically analysed, adopting some basic features of

193   grounded theory.  The interviews were analysed initially employing line-by-line

194   coding and an inductive, intuitive reading of the transcripts. Transcripts were

195   independently coded by LM, ON & DL, summarised and then discussed by online

196   and face-to-face meetings. A combination of computer software (NVivo 9) and

197   hand written methods were used and mind mapping to assist with the

198   development of themes [44]. We then followed a deductive process to explore how

199   the characteristics and components of partnership were experienced by

200   professionals and patients. Early analysis identified categories associated with

201   providing comfort, creating confidence and finding common ground through

202   everyday informal interactions.  In contrast, other categories revealed formalised

203   care provided by professionals such as exchanging information, planning,

204   evaluating and documenting care.  However, when these were compared with

205   patient transcripts patients described a simplified and practical process such as

206   receiving some form of paperwork and knowing what was done. As analysis

207   progressed we categorized these findings under two main themes: informal and

208   formal aspects of partnership.  These findings were discussed with the whole

209   team in order to address differences and reach a consensus.

210

211   **Results**

212   Two main themes were found: firstly informal aspects of partnership comprising

213   two subthemes, proximity & receptiveness and building a personal connection/

214   confidence. Informal aspects of partnership were interpreted as those emerging

215   during the interaction between healthcare professionals and patients. The

216   second main theme was formal aspects of partnership having two subthemes,

217   aspects of goal setting and care planning, and documentation. Formal

218   partnership is about the structured ways of sustaining the relationship between

219   the health professionals and the patients via deciding goals, care planning and

220   documentation. The results are presented below to allow comparison between

221   the 2 groups.

222   **Informal aspects of partnership**

223   *Proximity and receptiveness*

224   Professionals described engaging patients in conversation with the intention of

225   respecting and listening to the patient, understanding the patient's situation,

226   making a good start and building a close connection.  Assistant nurses followed

227   this process each morning and described feeling 'closer' to the patient, seeing

228   and hearing aspects of the patient from a social, psychological and physical

229   perspective and becoming their 'eyes and ears'. Professionals described using

230   communication techniques such as posing open, straightforward questions,

231   talking without distractions and not judging.  A number of professionals felt this

232   process aided partnership in subsequent meetings.

233         I think that I and the nurse get a great response from the patients, straight

234         away, that they feel very comfortable in this. They know who to turn to.

235         That they feel like they've been given a lot of time, even if it´s not that long

236         time, but the content of the consultation gives them that feeling. (MD1)

237   Many patients described positive feelings towards the receptiveness of staff and

238   the atmosphere of the ward. Accounts of unhurried and immediate support with

239   care provided in a caring and close manner were common.

240         Not everyone sits down at your bedside, just a few of them do. Mostly

241         they pull out chair or something to sit on. They are not on their way to

242   another patient when they do that. It's more of a good opening; that we

243   are sitting here now, talking, until we are finished doing that. (P1)

244

245 Available and reliable professionals increased patients' comfort, with

246 professionals described as thoughtful, open and warm, leading to patients feeling

247 a sense of humanity, security, familiarity and trust.

248   They say "Hi Paula!" and then they present themselves with their name

249   and then the title comes. Already there they create an opportunity for

250   dialogue. It's not "I'm nurse, good day." So at that point it feels like an

251   openness and they simply and easily describe how my life will be in this

252   room. (P2)

253

254 *Building a close connection and confidence*

255 Professionals described listening in a more engaged way to patients' wishes and

256 needs. They emphasised the importance of knowing how patients felt, what they

257 thought, aspects of their personality and personal knowledge, described by one

258 professional as 'life-luggage'. Patients were prompted to discuss personal

259 interests and common topics. For most professionals finding common ground

260 built trust, security and a collaborative relationship on a person-to-person level.

261   You may talk about books or music, or common interests so that you're

262   not only... You establish a relationship beyond the nurse-patient, and it

263   becomes more like person to person. (N1)

264 In keeping with professionals' aspirations, many patients felt listened to and

265 acknowledged. Several felt known personally, for who they were and their

266 individual needs.

267

268   They could ask ordinary questions about the everyday life. We could talk

269   about summer houses, and pets, and kind of on that level. And that's... I

270   think that's very important. I think so at least... one is feeling more as if

271   you aren't just a patient among others. (P3)

272    Some patients reported that they noticed changes in professionals' receptiveness.

273             'I was thinking that I should ask him to sit down, but you know how it is,

274             no. But I can think that it's a different situation. He stands there taller

275             than me who's sitting on the bedside. I don't like that....But what I regret

276             is that I wasn't able to look at my x-rays on CT-abdomen. I had asked for

277             that previously, but I didn't receive an answer to that. Well, I might have

278             said that I wanted to see my x-rays. It can be interesting to look with a

279             physician, because I know nothing about... I can't do it myself. So I asked

280             for that the last day, but she said that she was much stressed, the assistant

281             physician, and she had had very much to do. I would have wanted that.

282             I'm sure I will get them to my home. I have requested everything and my

283             medical records, but I can't examine things like those. It wasn't anything,

284             but it would have been interesting to look at it. Sit with a doctor and

285             review it (P4)

286

287    However other patients paid less attention to this change in professionals'

288    receptiveness since they considered their hospitalisation as brief and requiring

289    straightforward treatment.

290

291    **Formal partnership**

292    *Goal setting and care planning*

293    Professionals reported working in partnership with patients in formal ways by

294    giving and exchanging information, updating, summarizing and care planning.

295    For example, patients are encouraged to discuss aspects of their symptoms,

296    treatment, diagnosis and discharge plans. A number of professionals described

297    making a 'team decision', alternatively known as a health plan, in collaboration

298    with patients. This acknowledged a person's capabilities and personal goals that

299    were agreed, documented and given to the patient. This is in line with the PCC

300    routine of safeguarding the partnership through agreed goals.

301             The patient when at the hospital together with the nurse and the doctor

302             decided what are the main issues: is it losing weight, is it anxiety, is it stop

303   smoking or getting better medication or is it more training, physical

304   activities, is it fear of training?  And so on.  So when they left the hospital

305   they had this sheet where they had described their problem and it was

306   just, it was their problem it was not a standard formula – the formula was

307   standard but the questions and the wishes from the patient was personal

308   (MD2)

309   Informal aspects of partnership led to an environment where it became possible

310   for patients to ask questions, learn about their condition and treatment.

311   Professionals believed patients had the inclination to begin caring for themselves,

312   follow suggestions and instructions. Formal aspects such as discussing goals

313   facilitated self-care such as getting dressed, mobilising on the ward, preparing

314   for discharge and following advice post discharge.

315   Several professionals described the need to encourage, 'push' or 'pass' on

316   competence to the patient, by letting the patient ask questions and take part in

317   the care planning, hence enabling the patient to become well informed,

318   knowledgeable and take responsibility.

319   There is a more practical understanding that the patient also carries a

320   responsibility, and also is responsible for the process. I tend to think that

321   my ward is at this stage of the process – to get the patient to understand

322   the significance of his or her participation to activity, to rehabilitation.

323   (M1)

324

325   Professionals noticed a change, where patients who were well informed, knew

326   they had an impact, influence and could handle themselves. They seemed

327   satisfied and more willing to help themselves and 'buy the whole concept'.

328   We look at what the patient usually does in their everyday life outside the

329   hospital, and what the patient does right now, and what we can do to

330   improve and to support that the patient becomes their ordinary self again.

331   And that you really try to understand how they can use their own

332   resources and train themselves. (N2)

333

334  However from the patient perspective some remembered taking part in
335  developing a health plan but few mentioned goals and when discussed, these
336  were invariably described in medicalised terms or framed around home
337  circumstances for discharge. Personal information was elicited and described,
338  but not necessarily orientated towards 'lifeworld' goals.

339      I don't actually know if the goal has been mentioned, but that might be the
340      goal with the illness I have, that the goal is to be free from relapses.
341      Because everything would then be as good as they can be. One wouldn't
342      suffer from the disease then. As long as one takes medicine that doesn't
343      give side-effects and isn't suffering from relapses, then everything will be
344      okay. And I know that has been mentioned, that it might be the goal after
345      all. But that, as I said, that has to do with the disease. (P5)

346  Patients felt they contributed when they discussed choices with professionals,
347  helped themselves, used their initiative and became knowledgeable. There were
348  opportunities to question, decline treatment and contribute to discharge
349  planning. For some, participation involved discussing test results, investigations
350  and medication management that helped them 'feel' (our emphasis) they were
351  committed to taking part in their care, for example by discussing an ultrasound
352  test, a transfusion or a colonoscopy procedure. They received explanations and
353  felt they knew what to do, how to deal with medication and treatments.

354      I know much more about my illness now and why it has become the way
355      it has, I think I understand that better now. And that I can see in hindsight
356      that I haven't been feeling well for a very long time, which has been
357      connected to this. So now I have got a much clearer picture of my
358      condition. (P6)

359

360  Others felt they participated by listening to professionals, agreeing and accepting
361  professionals' decision-making. They felt confident, comfortable and treated as
362  equals, described by one patient as 'horizontal communication'. A few patients
363  described themselves as 'experienced', 'verbal' even when very ill and able to
364  'demand and ask questions'. Yet for patients in this study, participating was
365  described in terms of informed discussion, acceptance and agreement,

366    participating up to a point or as far as they felt able. Several felt comfortable

367    'submitting' and 'not being in the driving seat'.

368        Many times one might feel like one is participating… one sometimes may

369        be silent, but still feel a fellowship. Do you understand what I mean? And

370        that's probably what I felt with the ward. That I didn't need to ask or I

371        didn't need to ask them, the nurses I mean, since I knew in some way that

372        the community still was there. (P7)

373

374        When I say no to something, they listen to me. Whatever it might be; the

375        discharge or anything. Or some kind of examination… I said no to an

376        examination, and I said that: "You did that examination just six months

377        ago, and it's very painful. Is it really necessary to do it again?" "No, then

378        we won't do it." (P1)

379

380        Since you are part of the treatments, and you know how they are doing

381        the plan for the treatment and are explaining in a good way. So even when

382        you return home, you know approximately about… Well, now I know how

383        I will deal with the medications and the treatment and everything, in a

384        completely different way. (P7)

385

386    Documentation

387    Professionals described writing care plans with patients, eliciting biomedical

388    information and discussing social and discharge planning. Decisions and plans

389    were agreed and documented.

390        You should make a plan together with the patient and that you discuss

391        with the patient and so on, but the difference of having it in this way is

392        that you have more of a structure of it. You create a framework for what it

393        means to work like this, so that what you're doing becomes more

394        concrete. (MD3)

395        In some way the patient gets what we've done on paper, and we get a

396        proof of that we understand it in the right way, so that the patient can say

397    "Yes, this is how it was" or "I don't agree with this." The important thing is

398    that you agree, so that you are on the same page so to speak. (N1)

399  In this respect professionals described 'a new practice' where patients were

400  encouraged to actively participate, become more involved and take part in

401  decisions about their care.

402    Documentation acted as a reminder for patients to discuss care on 'a new

403    level'. (N3)

404    You must create a care plan with the patient within 48 hours and then

405    you should write why they have sought care and what we have planned

406    for them and this should be addressed at the round with the patient, and

407    it is written down and then it's a little investigation to see what the

408    patients can do themselves. (N4)

409  Professionals encouraged patients to use their own resources and expertise. For

410  example patients were encouraged to prepare for conversations with the team

411  and write down thoughts or questions.

412  Patients felt informed about their condition, discharge and future care needs, felt

413  they were listened to and some felt they were participating in their care plan.

414    I think, that it felt like it was a team. Decisions where I participated in, and

415    the care plan and such things. How much you actually were that, I don't

416    know, but at least you had a picture of it, so. But I can't decide how I'm

417    going to be treated or taken care of, but at least you can be a part of it and

418    have opinions, you were able to do that. (P8)

419  Although patients remembered receiving written information and some

420  described opportunities to write down thoughts, questions and contribute to

421  their care, they did not remember the written information in any detail.

422  Nevertheless, patients saw this documentation in 'simple' terms whereby they

423  felt taken care of and in receipt of sufficient information.

424  Discussion

425    In our study, interviewees' accounts reflect levels of mutuality, self-expression

426    and respect that lay the groundwork for PCC and indicate a move from disease

427    focused models of care [19]. In keeping with the literature we suggest that informal

428    elements of partnership provide the conditions for communication and mutual

429    co-operation upon which formal relations of partnership can be constructed [27 31

430    36]. Professional and patient perspectives highlight the importance of the informal

431    elements of partnership for ultimately determining the level of shared decision

432    making which is possible to aspire to and practically achieve [14]. Informal

433    elements in our study depict emotionally supportive relationships that pave the

434    way for patients to participate, once the scene is set and the circumstances feel

435    right.

436

437    However, in our findings patients were content to be able to ask questions and

438    receive information. They perceived participation as informed discussion and

439    agreement, deferring to professional knowledge and expertise and not

440    necessarily describing opportunities for empowerment and activation. Perceived

441    competence of professionals seemed enough for patients and whilst patients

442    prioritised the informal processes where 'good care' may have been interpreted

443    as PCC, professionals prioritised outcomes that were formal and documented.

444    Patients described participating in plans for discharge but did not describe

445    notions of enablement or control. As with other studies, patients were satisfied

446    with a personal approach and a positive partnership with professionals who

447    communicated empathetically and effectively [45] with professionals acting as

448    educators, building mutual and collaborative partnerships [46]. Measurements of

449    optimum patient-professional relationships and person-centredness need to

450    consider patients' emotional and personal responses that highlight the process

451    rather than the outcome of interactions with health professionals [5 14 27 35].

452    Aspects of informal and formal partnership appeared to act as antecedents of

453    patient participation. Yet overall, most patients portrayed a taken-for-granted

454    pragmatism, trusting professionals with expertise and competence to make

455    overall decisions in a caring environment. For patients in this study, PCC was not

456    explicitly understood or described as an opportunity to formalize a partnership

457    with professionals in order to actively participate in their care. There were more

458    informal aspects of partnership that took precedence in patients' minds, which is

459    in line with the description of the fundamentals of human connectedness

460    described by Thoransdottir & Kristjansson (2014), pointing toward the ethical

461    dimension of partnership and PCC. In addition, professionals may have

462    considered PCC as a particular professional approach rather than a systematic

463    endeavour to "invite" patients to participate in the PCC routines and explicate

464    the model.

465    Aspects of partnership, particularly informal aspects, led patients to leave some

466    decisions to the professionals since they felt cared for and well informed.

467    Patients were not forced to make a choice, but they were rather given guidance

468    and information. In this respect patients' interpretation of participation can be

469    viewed, not as passive submission or deferment to professional expertise and

470    knowledge, but a common understanding reached through a therapeutic

471    relationship. Our interpretation of the present study points toward the

472    importance of human connectedness and the feeling of being listen to and

473    acknowledged as a person (informal aspect) for patients, while routines and

474    formal aspects of care came more into the foreground for the practitioners.  It

475    seems as if in order to integrate the patient into clinical practice, there seems to

476    be a balancing act that practitioners as well as patients need to reflect upon:

477    recognition of the patient as a person (informal aspects) needs to balance the

478    specific practical routines (formal aspects)[42]. The risk could otherwise be that

479    the patient as a person becomes a  "tickbox" in a routine, which in many aspects

480    would entrench profession-centred care rather than person-centredness.

481

482    This study has some limitations.  Patients did not necessarily perceive their care

483    in the context of a PCC model and our study depended upon patients

484    remembering events and perhaps perceiving the relevance of information and

485    care strategies. Secondly, because the study took place in a particular

486    institutional context (GPCC) in Sweden, the findings may not be transferable to

487    other settings. Formal aspects of partnership, for example, documented care

488    plans and decisions, could have provided patients with opportunities to revisit

489    decisions in written form, and maintain a sense of confidence and trust during

490  their admission that was taken for granted. Most interviewees were older

491  perhaps predisposing them to comply with professional expertise or feel

492  knowledgeable but not necessarily empowered [47]. Ekdahl et al[48] suggest that

493  older peoples' preferences for information and decision making aren't fully

494  acknowledge and/or acted upon by the healthcare professional. Patients aged 75

495  years and above may want more information relating to their care, without

496  having to ask. Therefore healthcare professionals need to be receptive and

497  responsive to patients' preferences and tailor the information and decision

498  making process accordingly.

499   Another limitation in this study is that patients were first contacted by a nurse

500  coordinator and after agreeing to be part of the study, participants were

501  contacted by the researchers after their discharge within the first 7 days to

502  schedule a interview. Patients who agreed to participate in the interview study

503  might have been more attentive to the particular aspects of PCC and eager to talk

504  about their experience. This might have led to the tendency for positive accounts

505  about the informal parts of partnership. However, it is equally important for the

506  objective of the study to capture positive comments about partnership.

507  Conclusion

508  In our study patients appear to value a process of human connectedness above

509  and beyond formal aspects of taking part and feeling activated and capable.

510  These findings may point to the need for professionals to acknowledge the

511  importance of the human connectedness that is as crucial as formal aspects for

512  PCC to be fully realised in practice.

513

514  Author contributions

515  LM and AW contributed equally to the study as first authors. All authors

516  contributed to the study design, conception and development. DL and AW

517  conducted the interviews together with research assistant Marie Hammer. LM,

518  DL and ÖN initially analysed the data, and all authors met face to face and over

519  skype as a group to discuss, revise and confirm the findings.  All authors were

520  responsible for critical revision and finalising the manuscript.

536 Data sharing statement

537 No additional unpublished data is available

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539 Wordcount 4913

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541 References

542 1. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for
543     clinical practice. *J Gen Intern Med* 2012;27(10):1361-7. doi:
544     10.1007/s11606-012-2077-6 [published Online First: 2012/05/24]
545 2. Elwyn G, Lloyd A, May C, et al. Collaborative deliberation: a model for patient
546     care. *Patient Educ Couns* 2014;97(2):158-64. doi:
547     10.1016/j.pec.2014.07.027 [published Online First: 2014/09/02]
548 3. Department of Health. Long term conditions compendium of information,
549     2012.
550 4. Eaton S, Roberts S, Turner B. Delivering person centred care in long term
551     conditions. *Bmj* 2015;350:h181. doi: 10.1136/bmj.h181 [published
552     Online First: 2015/02/12]
553 5. Epstein RM, Street RL, Jr. The values and value of patient-centered care. *Ann
554     Fam Med* 2011;9(2):100-3. doi: 10.1370/afm.1239 [published Online
555     First: 2011/03/16]

556    6. Harding E, Wait S, Scrutton J. The state of play in person-centred care:
557        pragmatic review of how person-centred care is defined, applied and
558        measured, featuring selected key contributors and case studies across the
559        field.: The Health Foundation, 2015:1-140.
560    7. Hawkes N. Seeing things from the patients' view: what will it take? *Bmj*
561        2015;350:g7757. doi: 10.1136/bmj.g7757 [published Online First:
562        2015/02/12]
563    8. Health Foundation. Helping people help themselves, 2011.
564    9. King's Fund. People in control of their own health and care, 2014.
565    10. NHS England. Enhancing the quality of life for people living with long term
566        conditions-the house of care, 2014.
567    11. Coulter A. Patient engagement--what works? *J Ambul Care Manage*
568        2012;35(2):80-9. doi: 10.1097/JAC.0b013e318249e0fd [published Online
569        First: 2012/03/15]
570    12. Coulter A, Collins A. Making shared decision-making a reality; no decision
571        about me, without me. London: The King's Fund, 2011:1-40.
572    13. Coulter A, Safran D, Wasson JH. On the language and content of patient
573        engagement. *J Ambul Care Manage* 2012;35(2):78-9. doi:
574        10.1097/JAC.0b013e31824a5676 [published Online First: 2012/03/15]
575    14. Cribb A, Entwistle VA. Shared decision making: trade-offs between narrower
576        and broader conceptions. *Health Expect* 2011;14(2):210-9. doi:
577        10.1111/j.1369-7625.2011.00694.x
578    15. Makoul G, Clayman ML. An integrative model of shared decision making in
579        medical encounters. *Patient Educ Couns* 2006;60(3):301-12. doi:
580        10.1016/j.pec.2005.06.010
581    16. Amin F. Commentary: Becoming a person centred practice. *Bmj*
582        2015;350:h269. doi: 10.1136/bmj.h269 [published Online First:
583        2015/02/12]
584    17. National Voices. Principles of care and support planning, 2013.
585    18. Coulter A, Entwistle VA, Eccles A, et al. Personalised care planning for adults
586        with chronic or long-term health conditions. *Cochrane Database Syst Rev*
587        2015;3:CD010523. doi: 10.1002/14651858.CD010523.pub2 [published
588        Online First: 2015/03/04]
589    19. Ekman I, Swedberg K, Taft C, et al. Person-centered care--ready for prime
590        time. *Eur J Cardiovasc Nurs* 2011;10(4):248-51. doi:
591        10.1016/j.ejcnurse.2011.06.008 [published Online First: 2011/07/19]
592    20. Frosch DL. The patient is the most important member of the team. *Bmj*
593        2015;350:g7767. doi: 10.1136/bmj.g7767 [published Online First:
594        2015/02/12]
595    21. Frosch DL, May SG, Rendle KA, et al. Authoritarian physicians and patients'
596        fear of being labeled 'difficult' among key obstacles to shared decision
597        making. *Health Aff (Millwood)* 2012;31(5):1030-8. doi:
598        10.1377/hlthaff.2011.0576 [published Online First: 2012/05/09]
599    22. Moore L, Britten N, Lydahl D, et al. Barriers and facilitators to the
600        implementation of person-centred care in different healthcare contexts.
601        *Scand J Caring Sci* 2016 doi: 10.1111/scs.12376
602    23. Naldemirci O, Lydahl D, Britten N, et al. Tenacious assumptions of person-
603        centred care? Exploring tensions and variations in practice. *Health*
604        *(London)* 2016 doi: 10.1177/1363459316677627

605 24. Alharbi TS, Ekman I, Olsson LE, et al. Organizational culture and the
606     implementation of person centered care: results from a change process in
607     Swedish hospital care. *Health Policy* 2012;108(2-3):294-301. doi:
608     10.1016/j.healthpol.2012.09.003
609 25. Gravel K, Legare F, Graham ID. Barriers and facilitators to implementing
610     shared decision-making in clinical practice: a systematic review of health
611     professionals' perceptions. *Implement Sci* 2006;1:16. doi: 10.1186/1748-
612     5908-1-16 [published Online First: 2006/08/11]
613 26. Entwistle VA. Considerations of 'fit' and patient involvement in decision
614     making. *Health Expect* 2006;9(2):95-7. doi: 10.1111/j.1369-
615     7625.2006.00397.x
616 27. Entwistle VA, Watt IS. Patient involvement in treatment decision-making: the
617     case for a broader conceptual framework. *Patient Educ Couns*
618     2006;63(3):268-78. doi: 10.1016/j.pec.2006.05.002
619 28. Hudon C, Fortin M, Haggerty J, et al. Patient-centered care in chronic disease
620     management: a thematic analysis of the literature in family medicine.
621     *Patient Educ Couns* 2012;88(2):170-6. doi: 10.1016/j.pec.2012.01.009
622 29. Mead N, Bower P. Patient-centredness: a conceptual framework and review
623     of the empirical literature. *Soc Sci Med* 2000;51(7):1087-110.
624 30. Sahlsten MJ, Larsson IE, Sjostrom B, et al. An analysis of the concept of patient
625     participation. *Nurs Forum* 2008;43(1):2-11. doi: 10.1111/j.1744-
626     6198.2008.00090.x
627 31. Thorarinsdottir K, Kristjansson K. Patients' perspectives on person-centred
628     participation in health care: A framework analysis. *Nursing ethics* 2013
629     doi: 10.1177/0969733013490593
630 32. Frank C, Asp M, Dahlberg K. Patient participation in emergency care - a
631     phenomenographic analysis of caregivers' conceptions. *J Clin Nurs*
632     2009;18(18):2555-62. doi: 10.1111/j.1365-2702.2008.02477.x
633 33. Eldh AC, Ehnfors M, Ekman I. The phenomena of participation and non-
634     participation in health care--experiences of patients attending a nurse-led
635     clinic for chronic heart failure. *Eur J Cardiovasc Nurs* 2004;3(3):239-46.
636     doi: 10.1016/j.ejcnurse.2004.05.001
637 34. Eldh AC, Ekman I, Ehnfors M. Conditions for patient participation and non-
638     participation in health care. *Nursing ethics* 2006;13(5):503-14.
639 35. Epstein RM. Making communication research matter: what do patients
640     notice, what do patients want, and what do patients need? *Patient Educ
641     Couns* 2006;60(3):272-8. doi: 10.1016/j.pec.2005.11.003
642 36. Epstein RM, Franks P, Fiscella K, et al. Measuring patient-centered
643     communication in patient-physician consultations: theoretical and
644     practical issues. *Soc Sci Med* 2005;61(7):1516-28. doi:
645     10.1016/j.socscimed.2005.02.001
646 37. Cahill J. Patient participation: a concept analysis. *J Adv Nurs* 1996;24(3):561-
647     71.
648 38. Ekman I, Wolf A, Olsson LE, et al. Effects of person-centred care in patients
649     with chronic heart failure: the PCC-HF study. *Eur Heart J*
650     2012;33(9):1112-9. doi: 10.1093/eurheartj/ehr306 [published Online
651     First: 2011/09/20]
652 39. Fors A, Ekman I, Taft C, et al. Person-centred care after acute coronary
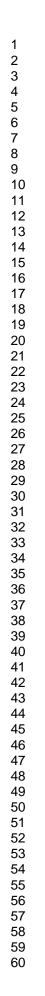653     syndrome, from hospital to primary care - A randomised controlled trial.

654        *Int J Cardiol* 2015;187:693-9. doi: 10.1016/j.ijcard.2015.03.336
655        [published Online First: 2015/04/29]
656    40. Feldthusen C, Dean E, Forsblad-d'Elia H, et al. Effects of person-centered
657        physical therapy on fatigue-related variables in persons with rheumatoid
658        arthritis: a randomized controlled trial. *Arch Phys Med Rehabil*
659        2016;97(1):26-36.
660    41. Olsson LE, Hansson E, Ekman I. Evaluation of person-centred care after hip
661        replacement-a controlled before and after study on the effects of fear of
662        movement and self-efficacy compared to standard care. *BMC nursing*
663        2016;15(1):53. doi: 10.1186/s12912-016-0173-3
664    42. Britten N, Moore L, Lydahl D, et al. Elaboration of the Gothenburg model of
665        person-centred care. *Health Expect* 2016 doi: 10.1111/hex.12468
666        [published Online First: 2016/05/20]
667    43. Ekman I, Hedman H, Swedberg K, et al. Commentary: Swedish initiative on
668        person centred care. *Bmj* 2015;350:h160. doi: 10.1136/bmj.h160
669        [published Online First: 2015/02/12]
670    44. Miles MB, Huberman AM, Saldana J. Qualitative data analysis: A methods
671        sourcebook. Third ed. London: Sage Publications 2014.
672    45. Little P, Everitt H, Williamson I, et al. Observational study of effect of patient
673        centredness and positive approach on outcomes of general practice
674        consultations. *BMJ* 2001;323(7318):908-11. [published Online First:
675        2001/10/23]
676    46. Roter D. The enduring and evolving nature of the patient-physician
677        relationship. *Patient Educ Couns* 2000;39(1):5-15.
678    47. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for
679        patients: a systematic review and thematic synthesis of patient-reported
680        barriers and facilitators to shared decision making. *Patient Educ Couns*
681        2014;94(3):291-309. doi: 10.1016/j.pec.2013.10.031 [published Online
682        First: 2013/12/07]
683    48. Ekdahl AW, Andersson L, Wiréhn A-B, et al. Are elderly people with co-
684        morbidities involved adequately in medical decision making when
685        hospitalised? A cross-sectional survey. *BMC geriatrics* 2011;11(1):46.

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688

689   *Table 1*

| | Health professionals (n=17) |
|---|---|
| Women (n) | 14 |
| Profession | |
| Registered nurse | 5 |
| Assistant nurse | 4 |
| Manager | 4 |
| Physician | 4 |
| Interview range | 29-60 minutes |
| Place for interview | |
| Hospital | 13 |
| Primary care center | 2 |
| University | 2 |

| | Patient (n=20) |
|---|---|
| Women (n) | 11 |
| Age median (range) | 69, 35-88 years |
| Interview range | 19-83 minutes |
| Place for interview | |
| Home | 13 |
| Hospital | 2 |
| University | 1 |
| Telephone | 4 |

690

691   **Table 2**

692

| Interview guide: Health professionals | Interview guide: Patients |
|---|---|
| | |

- To start with, could you tell me a bit about this ward/clinic/centre?

**Prompts**: Size? Practical work? Team?

- How did you start working with PCC?

**Prompts**: First contact with PCC? When did you first hear about it? Where did the idea come from? Did you have a special training?

- How did you implement PCC in the ward/clinic/centre? What did the implementation look like?
- Could you tell me about a regular day at work with PCC?
- Tell me about your practice and experiences with PCC on this ward/clinic/centre?
- How would you describe PCC to someone who is coming to work with you on your ward/center?

**Prompts**: How would you describe or define PCC?

- How did patients react to PCC?
- Would you tell me about any changes to your practice since you started working with PCC?

**Prompts**: Were there any changes in your ways of working? Relations with patients? Routines? Division of labour? Any changes-adaptions?

- What kind of documentation do you use when you work with PCC? Do you use any tools, diaries, notebooks, written material as part of PCC during your day? Can you describe this for me? How do you use this documentation for PCC in your work?
- What kinds of conditions do you think are required for PCC?
- What kinds of things do you think helped PCC and what kinds of things made PCC difficult in your experience?
- Is there anything else you would like to add?

- Could you tell me about your experience of the care you received? How would you describe the care and treatment?

**Prompts**: Can you give examples of the kind of care you received? What did the routines look like?

- How have you experienced the relationship between you and the staff? How did you experience the communication between you and the staff?

**Prompts:** In which ways, did you receive information? Did you discuss your care and treatment with the staff? Did the staff listen to your concerns and questions?

- What has been important to you in the care that you got?

**Prompts:** How did you participate in decisions, have you been seen and listened to, information and communication about your care and treatment? Do you think that your resources/knowledge have been utilized?

- Do you think that the care you received was different from the care you have experience in the past and (if applicable) the care that you received later?

**Prompts:** In what way did they differ? What changes have you noticed?

- Are you familiar with the term person-centered care?

**Prompts:** If so, how would you describe PCC?

- During the care process, which part(s) of the care and treatment received do you perceive were person-centred?

- Which parts of PCC meant the most to your experience of

|  | involvement / partnership |
|---|---|
|  | **Prompts:** Could you give some examples? Procedures? Documentation? How staff looked after you? Something else? |
|  | • Do you think that health professionals have been interested in you as a person? |
|  | • Did you use an electronic health diary via the app or the web? |
|  | **Prompts:** How important was it for you? If not, did you use any other form of documentation tools or aids that had meaning for you? |
|  | • Is there anything else you would like to add? |

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