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

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8 ABSTRACT

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11 **Objective:** Although conceptual definitions of person-centred care (PCC) vary,
12 most models value the active involvement of patients through patient-
13 professional partnerships. However, while this may increase patients' sense of
14 responsibility and control, relational, contextual and affective aspects of
15 partnership are increasingly emphasised. The aim of this study is to explore the
16 realities of partnership and participation as perceived by patients and health
17 professionals in everyday PCC practice.
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22 **Design:** Qualitative study employing an interpretive approach using semi-
23 structured interviews with professionals and patients.
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28 **Setting:** Four internal medicine wards and 2 primary care centres in western
29 Sweden.
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32 **Participants:** 20 patients admitted to hospital wards delivering person-centred
33 care and 16 health professionals based on these wards and primary care centres.
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37 **Results:** Our findings identified both informal and formal aspects of partnership
38 in the delivery of person-centred care. Informal aspects incorporated proximity
39 and receptiveness of professionals, and building a close connection and
40 confidence. This epitomised a caring, respectful relationship congruent across
41 accounts. Formal aspects and descriptions of partnership were more
42 dichotomous. Professionals described collaborating with patients to encourage
43 participation, capture personal goals, plan and document care. However,
44 although patients felt listened to and informed, they were content to ask
45 questions and felt less involved in care planning, documentation or exploring
46 lifeworld goals. They commonly perceived participation as informed discussion
47 and agreement, deferring to professional knowledge and expertise in the
48 presence of an empathetic and trusting relationship.
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57 **Conclusions:**
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3 In our study patients appear to value a process of human connectedness above
4 and beyond formalised aspects of documenting agreed goals and care planning.
5 The PCC pathway or mechanism increases patients' confidence in professionals
6 who are competent and able to make them feel safe and secure. Informal
7 elements of partnership provide the conditions for communication and mutual
8 co-operation upon which formal relations of partnership can be constructed.
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14 Keywords:

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16 Person-Centred Care, Patient-Centred Care, Patient Participation, Healthcare
17 service
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21 **Strengths and limitations of this study:**

- 22 • This study reports the experiences of both patients and professionals in
23 hospital settings which have implemented an evidence based model of
24 person centred care .
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- 27 • The study population consisted of professionals with a broad range of
28 clinical experience and patients with diverse medical signs and
29 symptoms.
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- 32 • Our sample was not designed to be statistically representative, nor can we
33 claim to have reached data saturation.
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44 **INTRODUCTION**

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46 Increasingly clinicians are encouraged to engage, inform and involve patients ¹²
47 and support health policies that promote patient led care through 'activated'
48 patients trained in self-management skills ^{3 4}. Health professionals and policy
49 makers aspire towards person centred care (PCC) ⁵⁻⁷ and recent models of PCC
50 prioritise a whole systems approach that places patients at the centre ⁸⁻¹⁰. It is
51 clear that with professional support, patients can become active partners in their
52 care ¹¹⁻¹⁵ and can benefit from opportunities to take part ^{16 17 18}. However,
53 despite the development of PCC and the push towards patient professional
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3 partnerships ⁸, there is much talk and little action ^{7 19-21}. Substantial
4 organisational and cultural barriers exist ^{20 22 23 24} and in order to overcome these
5 barriers, both patients and professionals need to feel engaged, respected and
6 treated as equals ^{2 11 12 25 14 26 27}. To date, there are numerous care concepts such
7 as patient-centred care, individualized care and narrative medicine that touch
8 upon patient involvement and partnership, all including some sort of reciprocity
9 and shared knowledge ^{28 29}, self management ^{30 31} participation in decision
10 making ³². Different PCC frameworks lift patient involvement toward an
11 enhanced therapeutic relationship that requires sharing power and
12 responsibility ⁶. Yet, as patients are increasingly offered more choice and
13 involvement, researchers also describe circumstances where patients choose to
14 decline participation, defer decisions or feel unable to participate ^{33 34}. It seems
15 that the notion of the patient as an active partner in care requires empirical
16 understanding and clarity.

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

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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)

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3 has introduced a new evidence based model³⁸⁻⁴¹, supported by a programme of
4 training and research, which has changed clinical practice.⁴² This model consists
5 of three 'routines' of PCC namely narrative, partnership and documentation ^{39 42}
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8 ⁴³. Partnership in the GPCC framework is the main routine that drives the PCC
9 process. The patient's narrative paves the way for collaboration, and
10 documentation safeguards this collaboration. The aim of this study is to explore
11 the realities of partnership as perceived by patients and health professionals in
12 everyday PCC practice.

16 METHODS

18 **Sample and design**

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

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37 Each ward manager was contacted with information about the study and gave
38 their consent. They were then asked to recruit a nurse, an assistant nurse and a
39 physician, with experience of working with PCC, from their ward.
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43 Patients were eligible for enrolment into the study if they were cognisant, able to
44 communicate in Swedish and admitted to a reference ward where PCC was being
45 implemented. The patients were admitted for symptoms of chronic heart failure,
46 chronic obstructive lung disease, infections, iron deficit, colorectal diseases such
47 as ulcerative colitis, Crohn's disease, colon surgery and hepatological disease.
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52 This reference ward had implemented PCC systematically following a 10 week
53 extensive training course facilitated by GPCC following the PCC routines ³⁸.
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57 A nurse coordinator working on the ward provided eligible patients with the
58 study information. Twenty-one patients volunteered to participate and gave
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3 their informed consent to be contacted by the study team after discharge and to
4 be interviewed about the care they had received. One patient was excluded when
5 transferred from another ward to the reference ward, which hampered recall.
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8 9 **Data collection**

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12 The interview guide for practitioners included questions how PCC related to the
13 everyday work of healthcare practitioners and its implementation. The interview
14 guide used for patient interviews intended to elicit patients' experiences of care
15 on the ward and their understanding of PCC (table 2).
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19 20 *Table 2 Interview guide practitioners and patients*

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24 DL conducted 12 interviews with professionals, AW conducted 2, and a trained
25 research assistant conducted 3 interviews with practitioners and all interviews
26 with patients.
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30 All interviews were audio recorded, transcribed verbatim, anonymised and
31 translated from Swedish into English. All interviewees were given a pseudonym
32 to maintain anonymity (P for Patient, N for Nurses, M for Manager and MD for
33 Physician). The regional ethics committee approved the study and all
34 participants, prior to their interview, gave informed consent.
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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 themes⁴⁴. 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)

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3 Many patients described positive feelings towards the receptiveness of staff and
4 the atmosphere of the ward. Accounts of unhurried and immediate support with
5 care provided in a caring and close manner were common.
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9 Not everyone sits down at your bedside, just a few of them do. Mostly
10 they pull out chair or something to sit on. They are not on their way to
11 another patient when they do that. It's more of a good opening; that we
12 are sitting here now, talking, until we are finished doing that. (P1)
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18 Available and reliable professionals increased patients' comfort, with
19 professionals described as thoughtful, open and warm, leading to patients feeling
20 a sense of humanity, security, familiarity and trust.
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24 They say "Hi Paula!" and then they present themselves with their name
25 and then the title comes. Already there they create an opportunity for
26 dialogue. It's not "I'm nurse, good day." So at that point it feels like an
27 openness and they simply and easily describe how my life will be in this
28 room. (P2)
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35 *Building a close connection and confidence*

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37 Professionals described listening in a more engaged way to patients' wishes and
38 needs. They emphasised the importance of knowing how patients felt, what they
39 thought, aspects of their personality and personal knowledge, described by one
40 professional as 'life-luggage'. Patients were prompted to discuss personal
41 interests and common topics. For most professionals finding common ground
42 built trust, security and a collaborative relationship on a person-to-person level.
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48 You may talk about books or music, or common interests so that you're
49 not only... You establish a relationship beyond the nurse-patient, and it
50 becomes more like person to person. (N1)
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54 In keeping with professionals' aspirations, many patients felt listened to and
55 acknowledged. Several felt known personally, for who they were and their
56 individual needs.
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5 They could ask ordinary questions about the everyday life. We could talk
6 about summer houses, and pets, and kind of on that level. And that's... I
7 think that's very important. I think so at least... one is feeling more as if
8 you aren't just a patient among others. (P3)
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13 **Formal partnership**

14 *Goal setting and care planning*

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16 Professionals reported working in partnership with patients in formal ways by
17 giving and exchanging information, updating, summarizing and care planning.
18 For example, patients are encouraged to discuss aspects of their symptoms,
19 treatment, diagnosis and discharge plans. A number of professionals described
20 making a 'team decision', alternatively known as a health plan, in collaboration
21 with patients. This acknowledged a person's capabilities and personal goals that
22 were agreed, documented and given to the patient. This is in line with the PCC
23 routine of safeguarding the partnership through agreed goals.
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33 The patient when at the hospital together with the nurse and the doctor
34 decided what are the main issues: is it losing weight, is it anxiety, is it stop
35 smoking or getting better medication or is it more training, physical
36 activities, is it fear of training? And so on. So when they left the hospital
37 they had this sheet where they had described their problem and it was
38 just, it was their problem it was not a standard formula - the formula was
39 standard but the questions and the wishes from the patient was personal
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45 (MD2)
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47 Informal aspects of partnership led to an environment where it became possible
48 for patients to ask questions, learn about their condition and treatment.
49 Professionals believed patients had the inclination to begin caring for themselves,
50 follow suggestions and instructions. Formal aspects such as discussing goals
51 facilitated self-care such as getting dressed, mobilising on the ward, preparing
52 for discharge and following advice post discharge.
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3 Several professionals described the need to encourage, 'push' or 'pass' on
4 competence to the patient, enabling the patient to become well informed,
5 knowledgeable and take responsibility.
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9 There is a more practical understanding that the patient also carries a
10 responsibility, and also is responsible for the process. I tend to think that
11 my ward is at this stage of the process – to get the patient to understand
12 the significance of his or her participation to activity, to rehabilitation.
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15 (M1)
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19 Professionals noticed a change, where patients who were well informed, knew
20 they had an impact, influence and could handle themselves. They seemed
21 satisfied and more willing to help themselves and 'buy the whole concept'.
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25 We look at what the patient usually does in their everyday life outside the
26 hospital, and what the patient does right now, and what we can do to
27 improve and to support that the patient becomes their ordinary self again.
28 And that you really try to understand how they can use their own
29 resources and train themselves. (N2)
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36 However from the patient perspective some remembered taking part in
37 developing a health plan but few mentioned goals and when discussed, these
38 were invariably described in medicalised terms or framed around home
39 circumstances for discharge. Personal information was elicited and described,
40 but not necessarily orientated towards 'lifeworld' goals.
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45 I don't actually know if the goal has been mentioned, but that might be the
46 goal with the illness I have, that the goal is to be free from relapses.
47 Because everything would then be as good as they can be. One wouldn't
48 suffer from the disease then. As long as one eats medications that doesn't
49 give side-effects and isn't suffering from relapses, then everything will be
50 okay. And I know that has been mentioned, that it might be the goal after
51 all. But that, as I said, that has to do with the disease. (P4)
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3 Patients felt they contributed when they discussed choices with professionals,
4 helped themselves, used their initiative and became knowledgeable. There were
5 opportunities to question, decline treatment and contribute to discharge
6 planning. For some, participation involved discussing test results, investigations
7 and medication management that helped them 'feel' (our emphasis) they were
8 committed to taking part in their care. For example discussing an ultrasound
9 test, a transfusion or a colonoscopy procedure. They received explanations and
10 felt they knew what to do, how to deal with medication and treatments.
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15 I know much more about my illness now and why it has become the way
16 it has, I think I understand that better now. And that I can see in hindsight
17 that I haven't been feeling well for a very long time, which has been
18 connected to this. So now I have got a much clearer picture of my
19 condition. (P5)
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28 Others felt they participated by listening to professionals, agreeing and accepting
29 professionals' decision-making. They felt confident, comfortable and treated as
30 equals, described by one patient as 'horizontal communication'. A few patients
31 described themselves as 'experienced', 'verbal' even when very ill and able to
32 'demand and ask questions'. Yet for patients in this study, participating was
33 described in terms of informed discussion, acceptance and agreement,
34 participating up to a point or as far as they felt able. Several felt comfortable
35 'submitting' and 'not being in the driving seat'.
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42 Many times one might feel like one is participating... one sometimes may
43 be silent, but still feel a fellowship. Do you understand what I mean? And
44 that's probably what I felt with the ward. That I didn't need to ask or I
45 didn't need to ask them, the nurses I mean, since I knew in some way that
46 the community still was there. (P6)
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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.

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3 I think, that it felt like it was a team. Decisions where I participated in, and
4 the care plan and such things. How much you actually were that, I don't
5 know, but at least you had a picture of it, so. But I can't decide how I'm
6 going to be treated or taken care of, but at least you can be a part of it and
7 have opinions, you were able to do that. (P8)
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12 Although patients remembered receiving written information and some
13 described opportunities to write down thoughts, questions and contribute to
14 their care, they did not remember the written information in any detail.
15 Nevertheless, patients saw this documentation in 'simple' terms whereby they
16 felt taken care of and in receipt of sufficient information.
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20 21 Discussion

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23 In our study, interviewees' accounts reflect levels of mutuality, self-expression
24 and respect that lay the groundwork for PCC and indicate a move from disease
25 focused models of care¹⁹. In keeping with the literature we suggest that informal
26 elements of partnership provide the conditions for communication and mutual
27 co-operation upon which formal relations of partnership can be constructed^{27 31}
28³⁶. Professional and patient perspectives highlight the importance of the informal
29 elements of partnership for ultimately determining the level of shared decision
30 making which is possible to aspire to and practically achieve¹⁴. Informal
31 elements in our study depict emotionally supportive relationships that pave the
32 way for patients to participate, once the scene is set and the circumstances feel
33 right.
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44 However, in our findings patients were content to be able to ask questions and
45 receive information. They perceived participation as informed discussion and
46 agreement, deferring to professional knowledge and expertise and not
47 necessarily describing opportunities for empowerment and activation. Perceived
48 competence of professionals seemed enough for patients and whilst patients
49 prioritised the informal processes where 'good care' may have been interpreted
50 as PCC, professionals prioritised outcomes that were formal and documented.
51 Patients described participating in plans for discharge but did not describe
52 notions of enablement or control. As with other studies, patients were satisfied
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3 with a personal approach and a positive partnership with professionals who
4 communicated empathetically and effectively⁴⁵ with professionals acting as
5 educators, building mutual and collaborative partnerships⁴⁶. Measurements of
6 optimum patient-professional relationships and person-centredness need to
7 consider patients' emotional and personal responses that highlight the process
8 rather than the outcome of interactions with health professionals^{5 14 27 35}.
9
10 Aspects of informal and formal partnership appeared to act as antecedents of
11 patient participation. Yet overall, most patients portrayed a taken-for-granted
12 pragmatism, trusting professionals with expertise and competence to make
13 overall decisions in a caring environment. For patients in this study, PCC was not
14 explicitly understood or described as an opportunity to formalize a partnership
15 with professionals in order to actively participate in their care. There were
16 relational, contextual and emotional factors for partnership that took precedence
17 in patients' minds. In addition, professionals may have considered PCC as a
18 particular professional approach rather than a systematic endeavour to "invite"
19 patients to participate in the PCC routines and explicate the model.
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31 Aspects of partnership, particularly informal aspects, led patients to leave some
32 decisions to the professionals since they felt cared for and well informed. In this
33 respect patients' interpretation of participation can be viewed, not as passive
34 submission or deferment to professional expertise and knowledge, but a
35 common understanding reached through a therapeutic relationship. Our
36 interpretation of the present study points toward the importance of human
37 connectedness and the feeling of being listen to and acknowledged as a person
38 (informal aspect) for patients, while routines and formal aspects of care came
39 more into the foreground for the practitioners. It seems as if in order to
40 integrate the patient into clinical practice, there seems to be a balancing act that
41 practitioners as well as patients need to reflect upon: recognition of the patient
42 as a person (informal aspects) needs to balance the specific practical routines
43 (formal aspects)⁴². The risk could otherwise be that the patient as a person
44 becomes a "check box" in a routine, which in many aspects would entrench
45 profession-centred care rather than person-centredness.
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3 This study has some limitations. Patients did not necessarily perceive their care
4 in the context of a PCC model and our study depended upon patients
5 remembering events and perhaps perceiving the relevance of information and
6 care strategies. Secondly, because the study took place in an particular
7 institutional context (GPCC) in Sweden, the findings may not be transferable to
8 other settings. Moreover, formal aspects of partnership, for example,
9 documented care plans and decisions, could have provided patients with
10 opportunities to revisit decisions in written form, and maintain a sense of
11 confidence and trust during their admission that was taken for granted.
12 Moreover, most interviewees were older perhaps predisposing them to comply
13 with professional expertise or feel knowledgeable but not necessarily
14 empowered ⁴⁷.

24 Conclusion

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

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

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

No additional unpublished data is available

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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
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<p>1</p> <p>2</p> <p>3</p> <p>4</p> <p>5</p> <p>6</p> <p>7</p> <p>8</p> <p>9</p> <p>10</p> <p>11</p> <p>12</p> <p>13</p> <p>14</p> <p>15</p> <p>16</p> <p>17</p> <p>18</p> <p>19</p> <p>20</p> <p>21</p> <p>22</p> <p>23</p> <p>24</p> <p>25</p> <p>26</p> <p>27</p> <p>28</p> <p>29</p> <p>30</p> <p>31</p> <p>32</p> <p>33</p> <p>34</p> <p>35</p> <p>36</p> <p>37</p> <p>38</p> <p>39</p> <p>40</p> <p>41</p> <p>42</p> <p>43</p> <p>44</p> <p>45</p> <p>46</p> <p>47</p> <p>48</p> <p>49</p> <p>50</p> <p>51</p> <p>52</p> <p>53</p> <p>54</p> <p>55</p> <p>56</p> <p>57</p> <p>58</p> <p>59</p> <p>60</p> <ul style="list-style-type: none"> • To start with, could you tell me a bit about this ward/clinic/centre? <p>Prompts: Size? Practical work? Team?</p> <ul style="list-style-type: none"> • How did you start working with PCC? <p>Prompts: First contact with PCC? When did you first hear about it? Where did the idea come from? Did you have a special training?</p> <ul style="list-style-type: none"> • 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? <p>Prompts: How would you describe or define PCC?</p> <ul style="list-style-type: none"> • How did patients react to PCC? • Would you tell me about any changes to your practice since you started working with PCC? <p>Prompts: Were there any changes in your ways of working? Relations with patients? Routines? Division of labour? Any changes-adaptions?</p> <ul style="list-style-type: none"> • 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? 	<ul style="list-style-type: none"> • Could you tell me about your experience of the care you received? How would you describe the care and treatment? <p>Prompts: Can you give examples of the kind of care you received? What did the routines look like?</p> <ul style="list-style-type: none"> • How have you experienced the relationship between you and the staff? How did you experience the communication between you and the staff? <p>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?</p> <ul style="list-style-type: none"> • What has been important to you in the care that you got? <p>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?</p> <ul style="list-style-type: none"> • 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? <p>Prompts: In what way did they differ? What changes have you noticed?</p> <ul style="list-style-type: none"> • Are you familiar with the term person-centered care? <p>Prompts: If so, how would you describe PCC?</p> <ul style="list-style-type: none"> • 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 <p>Prompts: Could you give some examples? Procedures? Documentation? How staff looked after you? Something else?</p> <ul style="list-style-type: none"> • 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? <p>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?</p> <ul style="list-style-type: none"> • Is there anything else you would like to add?
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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			
<i>Personal characteristics</i>			
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
<i>Relationship with participants</i>			
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			
<i>Theoretical framework</i>			
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
<i>Participant selection</i>			
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
<i>Setting</i>			
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) 4
<i>Data collection</i>			
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 recd
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

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
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
<i>Reporting</i>			
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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Primary Subject Heading:	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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Manuscripts

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-

1
2
3 professional partnerships. However, while this may increase patients' sense of
4 responsibility and control, research is needed to further understand how this
5 partnership is created and perceived. The aim of this study is to explore the
6 realities of partnership and participation as perceived by patients and health
7 professionals in everyday PCC practice.
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12 **Design:** Qualitative study employing a thematic analysis of semi-structured
13 interviews with professionals and patients.
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16 **Setting:** Four internal medicine wards and 2 primary care centres in western
17 Sweden.
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21 **Participants:** 20 patients admitted to hospital wards delivering person-centred
22 care and 16 health professionals based on these wards and primary care centres.
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25 **Results:** Our findings identified both informal and formal aspects of partnership.
26 Informal aspects, emerging during the interaction between healthcare
27 professionals and patients, without any prior guidelines or regulations
28 incorporated proximity and receptiveness of professionals, and building a close
29 connection and confidence. This epitomised a caring, respectful relationship
30 congruent across accounts. Formal aspects, including structured ways of
31 sustaining partnership were experienced differently. Professionals described
32 collaborating with patients to encourage participation, capture personal goals,
33 plan and document care. However, although patients felt listened to and
34 informed, they were content to ask questions and felt less involved in care
35 planning, documentation or exploring lifeworld goals. They commonly perceived
36 participation as informed discussion and agreement, deferring to professional
37 knowledge and expertise in the presence of an empathetic and trusting
38 relationship.
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49 **Conclusions:**

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

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9 Person-Centred Care, Patient-Centred Care, Patient Participation, Healthcare
10 service
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14 **Strengths and limitations of this study:**

- 15 • This study reports the experiences of both patients and professionals in
16 hospital settings which have implemented an evidence based model of
17 person centred care .
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- 19 • The study population consisted of professionals with a broad range of
20 clinical experience and patients with diverse medical signs and
21 symptoms.
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- 23 • Our sample was not designed to be statistically representative, nor can we
24 claim to have reached data saturation.
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37 **INTRODUCTION**

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39 Increasingly clinicians are encouraged to engage, inform and involve patients ^{1 2}
40 and support health policies that promote patient led care through ‘activated’
41 patients trained in self-management skills ^{3 4}. Health professionals and policy
42 makers aspire towards person centred care (PCC) ⁵⁻⁷ and recent models of PCC
43 prioritise a whole systems approach that places patients at the centre ⁸⁻¹⁰. It is
44 clear that with professional support, patients can become active partners in their
45 care ¹¹⁻¹⁵ and can benefit from opportunities to take part ^{16 17 18}. However,
46 despite the development of PCC and the push towards patient professional
47 partnerships ⁸, there is much talk and little action ^{7 19-21}. Substantial
48 organisational and cultural barriers exist ^{20 22 23 24} and in order to overcome these
49 barriers, both patients and professionals need to feel engaged, respected and
50 treated as equals ^{2 11 12 25 14 26 27}. To date, there are numerous care concepts such
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3 as patient-centred care, individualized care and narrative medicine that touch
4 upon patient involvement and partnership, all including some sort of reciprocity
5 and shared knowledge ^{28 29}, self management ^{30 31} participation in decision
6 making ³². Different PCC frameworks lift patient involvement toward an
7 enhanced therapeutic relationship that requires sharing power and
8 responsibility ⁶. Yet, as patients are increasingly offered more choice and
9 involvement, researchers also describe circumstances where patients choose to
10 decline participation, defer decisions or feel unable to participate ^{33 34}. It seems
11 that the notion of the patient as an active partner in care requires empirical
12 understanding and clarity.
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21 Cribb and Entwistle (2011) draw attention to the importance of an emotionally
22 supportive patient-professional partnership to aid 'meaningful participation' and
23 shared decision-making ¹⁴. Relationships that are open ended and conversational
24 are prioritised as well as professional virtues and patient capabilities. This
25 approach takes into account the relational aspects of partnership, which pay
26 attention to the mindfulness of professionals and the unique aspects of patients'
27 lives ^{5 35 36}. However, although power sharing implies an egalitarian and
28 meaningful patient-professional relationship ²⁹, the literature describes a
29 hierarchy of relationships depicting the different levels of engagement,
30 responsibility and shared goals ^{31 37}. This moves from the lowest level i.e.
31 involvement towards participation and the highest level i.e. partnership ^{32 37}.
32 Thoransdottir & Kristjansson (2014) elaborate on informal and formal
33 relationships; the former describing the fundamental importance of human
34 connectedness and the latter involving shared agreements on decisions and
35 documentation ³¹. Thoransdottir & Kristjansson suggest that the ethics of care, meaning
36 the informal aspects of human connectedness, is fundamental to the establishment of a
37 partnership. However, it is important to acknowledge that both aspects are equally crucial for
38 partnership.
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53 In this paper we use a Swedish initiative for implementing an evidence-based
54 PCC model as a case study. The University of Gothenburg Centre for PCC (GPCC)
55 has introduced a new evidence based model³⁸⁻⁴¹, supported by a programme of
56 training and research, which has changed clinical practice.⁴² This model consists
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3 of three 'routines' of PCC namely narrative, partnership and documentation ^{39 42}
4 ⁴³. Partnership in the GPCC framework is the main routine that drives the PCC
5 process. The patient's narrative paves the way for collaboration, and
6 documentation safeguards this collaboration. The aim of this study is to explore
7 the realities of partnership as perceived by patients and health professionals in
8 everyday PCC practice.
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13 14 15 METHODS

16 17 **Sample and design**

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19 This study adopted an interpretive approach employing qualitative semi-
20 structured interviews. We used a purposive sampling strategy to capture several
21 professional categories and a convenience sampling approach for patients (table
22 1). Four hospital wards at a large teaching hospital in west Sweden were chosen;
23 these varied in size (18 to 36 hospital beds), specialization and patient group
24 (patients with chronic and/or acute illness and from self-managing to bed-
25 confined). Each ward took part in a 10 week PCC change management/training
26 program, incorporating both lectures and workshops regarding the ethics of PCC,
27 research findings from PCC studies as well as training in using different tools
28 such as care plans and interview techniques. The ward manager chose members
29 of staff (RN, AN, Physicians) as designated change agents in the training program
30 and to implement PCC to their colleagues on each ward.
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40 41 *Table 1 Description of practitioners and patient demography*

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43 Each ward manager was contacted with information about the study and gave
44 their consent. They were then asked to recruit a nurse, an assistant nurse and a
45 physician, with experience of working with PCC and from the training program,
46 from their ward.
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51 Patients were eligible for enrolment into the study if they were cognisant, able to
52 communicate in Swedish and admitted to a reference ward where PCC was being
53 implemented at the hospital. The patients were admitted for symptoms of
54 chronic heart failure, chronic obstructive lung disease, infections, anemia,
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3 colorectal diseases such as Ulcerative Colitis, Crohn's disease, colon surgery and
4 hepatological disease.
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6
7 This reference ward had implemented PCC systematically using a 10 week
8 extensive training course facilitated by GPCC following the PCC routines ³⁸.
9

10
11 A nurse coordinator working on the ward provided eligible patients with the
12 study information. Twenty-one patients volunteered to participate and gave
13 their informed consent to be contacted by the study team after discharge and to
14 be interviewed about the care they had received. One patient was excluded when
15 transferred from another ward to the reference ward, which hampered recall.
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20 **Data collection**

21
22 The interview guide for practitioners included questions about how PCC related
23 to the everyday work of healthcare practitioners and its implementation. The
24 interview guide for patients intended to elicit patients' experiences of care on the
25 ward and their understanding of PCC (table 2).
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34 *Table 2 Interview guide practitioners and patients*

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38 DL conducted 12 interviews with professionals, AW conducted 2, and a trained
39 research assistant conducted 3 interviews with practitioners and all interviews
40 with patients.
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44 All interviews were audio recorded, transcribed verbatim, anonymised and
45 translated from Swedish into English. All interviewees were given a numbered
46 pseudonym to maintain confidentiality (P for Patient, N for Nurses, M for
47 Manager and MD for Physician). All participants were told that they were free to
48 withdraw their consent at any time during the study. Patients were interviewed
49 after their hospital stay, in a place of their choosing to ensure that they felt
50 comfortable talking about the care episode. All interviews with patients were
51 performed by researchers without a clinical background or connection to the
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3 hospital. The regional ethics committee in Gothenburg approved the study and
4 all participants, prior to their interview, gave informed consent. If the patients
5 wanted to talk to a healthcare professional regarding general or specific topics
6 that came up during the interviews, they were able to talk to a nurse about their
7 concern or thoughts.
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11 **Analysis**

12
13 Interviews were thematically analysed, adopting some basic features of
14 grounded theory. Interviews were analysed initially employing line-by-line
15 coding and an inductive, intuitive reading of the transcripts. Transcripts were
16 independently coded by LM, ON & DL, summarised and then discussed by online
17 and face-to-face meetings. A combination of computer software (NVivo 9) and
18 hand written methods were used and mind mapping to assist with the
19 development of themes ⁴⁴. We then followed a deductive process to explore how
20 the characteristics and components of partnership were experienced by
21 professionals and patients. Early analysis identified categories associated with
22 providing comfort, creating confidence and finding common ground through
23 everyday informal interactions. In contrast, other categories revealed formalised
24 care provided by professionals such as exchanging information, planning,
25 evaluating and documenting care. However, when these were compared with
26 patient transcripts patients described a simplified and practical process such as
27 receiving some form of paperwork and knowing what was done. As analysis
28 progressed we categorized these findings under two main themes: informal and
29 formal aspects of partnership. These findings were discussed with the whole
30 team in order to address differences and reach a consensus.
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49 **Results**

50 Two main themes were found: firstly informal aspects of partnership comprising
51 two subthemes, proximity & receptiveness and building a personal connection/
52 confidence. Informal aspects of partnership were interpreted as those emerging
53 during the interaction between healthcare professionals and patients. The
54 second main theme was formal aspects of partnership having two subthemes,
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3 aspects of goal setting and care planning, and documentation. Formal
4 partnership is about the structured ways of sustaining the relationship between
5 the health professionals and the patients via deciding goals, care planning and
6 documentation. The results are presented below to allow comparison between
7 the 2 groups.
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11 **Informal aspects of partnership**

12 *Proximity and receptiveness*

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17 Professionals described engaging patients in conversation with the intention of
18 respecting and listening to the patient dialogue, understanding the patient's
19 situation, making a good start and building a close connection. Assistant nurses
20 followed this process each morning and described feeling 'closer' to the patient,
21 seeing and hearing aspects of the patient from a social, psychological and
22 physical perspective and becoming their 'eyes and ears'. Professionals described
23 using communication techniques such as posing open, straightforward questions,
24 talking without distractions and not judging. A number of professionals felt this
25 process aided partnership in subsequent meetings.
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33 I think that I and the nurse get a great response from the patients, straight
34 away, that they feel very comfortable in this. They know who to turn to.
35 That they feel like they've been given a lot of time, even if it's not that long
36 time, but the content of the consultation gives them that feeling. (MD1)
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40 Many patients described positive feelings towards the receptiveness of staff and
41 the atmosphere of the ward. Accounts of unhurried and immediate support with
42 care provided in a caring and close manner were common.
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46 Not everyone sits down at your bedside, just a few of them do. Mostly
47 they pull out chair or something to sit on. They are not on their way to
48 another patient when they do that. It's more of a good opening; that we
49 are sitting here now, talking, until we are finished doing that. (P1)
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3 Available and reliable professionals increased patients' comfort, with
4 professionals described as thoughtful, open and warm, leading to patients feeling
5 a sense of humanity, security, familiarity and trust.
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9 They say "Hi Paula!" and then they present themselves with their name
10 and then the title comes. Already there they create an opportunity for
11 dialogue. It's not "I'm nurse, good day." So at that point it feels like an
12 openness and they simply and easily describe how my life will be in this
13 room. (P2)
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20 *Building a close connection and confidence*

21
22 Professionals described listening in a more engaged way to patients' wishes and
23 needs. They emphasised the importance of knowing how patients felt, what they
24 thought, aspects of their personality and personal knowledge, described by one
25 professional as 'life-luggage'. Patients were prompted to discuss personal
26 interests and common topics. For most professionals finding common ground
27 built trust, security and a collaborative relationship on a person-to-person level.
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33 You may talk about books or music, or common interests so that you're
34 not only... You establish a relationship beyond the nurse-patient, and it
35 becomes more like person to person. (N1)
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39 In keeping with professionals' aspirations, many patients felt listened to and
40 acknowledged. Several felt known personally, for who they were and their
41 individual needs.
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46 They could ask ordinary questions about the everyday life. We could talk
47 about summer houses, and pets, and kind of on that level. And that's... I
48 think that's very important. I think so at least... one is feeling more as if
49 you aren't just a patient among others. (P3)
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3 Some patients reported that they noticed changes in professionals' receptiveness.
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6 'I was thinking that I should ask him to sit down, but you know how it is, no.
7 But I can think that it's a different situation. He stands there taller than me
8 who's sitting on the bedside. I don't like that....But what I regret is that I
9 wasn't able to look at my x-rays on CT-abdomen. I had asked for that
10 previously, but I didn't receive an answer to that. Well, I might have said that
11 I wanted to see my x-rays. It can be interesting to look with a physician,
12 because I know nothing about... I can't do it myself. So I asked for that the
13 last day, but she said that she was much stressed, the assistant physician, and
14 she had had very much to do. I would have wanted that. I'm sure I will get
15 them to my home. I have requested everything and my medical records, but I
16 can't examine things like those. It wasn't anything, but it would have been
17 interesting to look at it. Sit with a doctor and review it (P4)
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27 However other patients paid less attention to this change in professionals' receptiveness since
28 they considered their hospitalisation as brief and requiring straightforward treatment.
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32 **Formal partnership**

33 *Goal setting and care planning*

34
35 Professionals reported working in partnership with patients in formal ways by
36 giving and exchanging information, updating, summarizing and care planning.
37 For example, patients are encouraged to discuss aspects of their symptoms,
38 treatment, diagnosis and discharge plans. A number of professionals described
39 making a 'team decision', alternatively known as a health plan, in collaboration
40 with patients. This acknowledged a person's capabilities and personal goals that
41 were agreed, documented and given to the patient. This is in line with the PCC
42 routine of safeguarding the partnership through agreed goals.
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52 The patient when at the hospital together with the nurse and the doctor
53 decided what are the main issues: is it losing weight, is it anxiety, is it stop
54 smoking or getting better medication or is it more training, physical
55 activities, is it fear of training? And so on. So when they left the hospital
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3 they had this sheet where they had described their problem and it was
4 just, it was their problem it was not a standard formula – the formula was
5 standard but the questions and the wishes from the patient was personal
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8 (MD2)
9

10 Informal aspects of partnership led to an environment where it became possible
11 for patients to ask questions, learn about their condition and treatment.
12 Professionals believed patients had the inclination to begin caring for themselves,
13 follow suggestions and instructions. Formal aspects such as discussing goals
14 facilitated self-care such as getting dressed, mobilising on the ward, preparing
15 for discharge and following advice post discharge.
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21 Several professionals described the need to encourage, 'push' or 'pass' on
22 competence to the patient, by letting the patient ask questions and take part in
23 the care planning, hence enabling the patient to become well informed,
24 knowledgeable and take responsibility.
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29 There is a more practical understanding that the patient also carries a
30 responsibility, and also is responsible for the process. I tend to think that
31 my ward is at this stage of the process – to get the patient to understand
32 the significance of his or her participation to activity, to rehabilitation.
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36 (M1)
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39 Professionals noticed a change, where patients who were well informed, knew
40 they had an impact, influence and could handle themselves. They seemed
41 satisfied and more willing to help themselves and 'buy the whole concept'.
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45 We look at what the patient usually does in their everyday life outside the
46 hospital, and what the patient does right now, and what we can do to
47 improve and to support that the patient becomes their ordinary self again.
48 And that you really try to understand how they can use their own
49 resources and train themselves. (N2)
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56 However from the patient perspective some remembered taking part in
57 developing a health plan but few mentioned goals and when discussed, these
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3 were invariably described in medicalised terms or framed around home
4 circumstances for discharge. Personal information was elicited and described,
5 but not necessarily orientated towards 'lifeworld' goals.
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9 I don't actually know if the goal has been mentioned, but that might be the
10 goal with the illness I have, that the goal is to be free from relapses.
11 Because everything would then be as good as they can be. One wouldn't
12 suffer from the disease then. As long as one takes medicine that doesn't
13 give side-effects and isn't suffering from relapses, then everything will be
14 okay. And I know that has been mentioned, that it might be the goal after
15 all. But that, as I said, that has to do with the disease. (P5)
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21 Patients felt they contributed when they discussed choices with professionals,
22 helped themselves, used their initiative and became knowledgeable. There were
23 opportunities to question, decline treatment and contribute to discharge
24 planning. For some, participation involved discussing test results, investigations
25 and medication management that helped them 'feel' (our emphasis) they were
26 committed to taking part in their care, for example by discussing an ultrasound
27 test, a transfusion or a colonoscopy procedure. They received explanations and
28 felt they knew what to do, how to deal with medication and treatments.
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36 I know much more about my illness now and why it has become the way
37 it has, I think I understand that better now. And that I can see in hindsight
38 that I haven't been feeling well for a very long time, which has been
39 connected to this. So now I have got a much clearer picture of my
40 condition. (P6)
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46 Others felt they participated by listening to professionals, agreeing and accepting
47 professionals' decision-making. They felt confident, comfortable and treated as
48 equals, described by one patient as 'horizontal communication'. A few patients
49 described themselves as 'experienced', 'verbal' even when very ill and able to
50 'demand and ask questions'. Yet for patients in this study, participating was
51 described in terms of informed discussion, acceptance and agreement,
52 participating up to a point or as far as they felt able. Several felt comfortable
53 'submitting' and 'not being in the driving seat'.
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3 Many times one might feel like one is participating... one sometimes may
4 be silent, but still feel a fellowship. Do you understand what I mean? And
5 that's probably what I felt with the ward. That I didn't need to ask or I
6 didn't need to ask them, the nurses I mean, since I knew in some way that
7 the community still was there. (P7)
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13 When I say no to something, they listen to me. Whatever it might be; the discharge or
14 anything. Or some kind of examination... I said no to an examination, and I said that:
15 "You did that examination just six months ago, and it's very painful. Is it really
16 necessary to do it again?" "No, then we won't do it." (P1)
17
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20
21 Since you are part of the treatments, and you know how they are doing the plan for
22 the treatment and are explaining in a good way. So even when you return home, you
23 know approximately about... Well, now I know how I will deal with the medications
24 and the treatment and everything, in a completely different way. (P7)
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28 Documentation

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30 Professionals described writing care plans with patients, eliciting biomedical
31 information and discussing social and discharge planning. Decisions and plans
32 were agreed and documented.
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36 You should make a plan together with the patient and that you discuss
37 with the patient and so on, but the difference of having it in this way is
38 that you have more of a structure of it. You create a framework for what it
39 means to work like this, so that what you're doing becomes more
40 concrete. (MD3)
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45 In some way the patient gets what we've done on paper, and we get a
46 proof of that we understand it in the right way, so that the patient can say
47 "Yes, this is how it was" or "I don't agree with this." The important thing is
48 that you agree, so that you are on the same page so to speak. (N1)
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53 In this respect professionals described 'a new practice' where patients were
54 encouraged to actively participate, become more involved and take part in
55 decisions about their care.
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3 Documentation acted as a reminder for patients to discuss care on 'a new
4 level'. (N3)
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7 You must create a care plan with the patient within 48 hours and then
8 you should write why they have sought care and what we have planned
9 for them and this should be addressed at the round with the patient, and
10 it is written down and then it's a little investigation to see what the
11 patients can do themselves. (N4)
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16 Professionals encouraged patients to use their own resources and expertise. For
17 example patients were encouraged to prepare for conversations with the team
18 and write down thoughts or questions.
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22 Patients felt informed about their condition, discharge and future care needs, felt
23 they were listened to and some felt they were participating in their care plan.
24
25

26 I think, that it felt like it was a team. Decisions where I participated in, and
27 the care plan and such things. How much you actually were that, I don't
28 know, but at least you had a picture of it, so. But I can't decide how I'm
29 going to be treated or taken care of, but at least you can be a part of it and
30 have opinions, you were able to do that. (P8)
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36 Although patients remembered receiving written information and some
37 described opportunities to write down thoughts, questions and contribute to
38 their care, they did not remember the written information in any detail.
39 Nevertheless, patients saw this documentation in 'simple' terms whereby they
40 felt taken care of and in receipt of sufficient information.
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45 Discussion

46
47 In our study, interviewees' accounts reflect levels of mutuality, self-expression
48 and respect that lay the groundwork for PCC and indicate a move from disease
49 focused models of care¹⁹. In keeping with the literature we suggest that informal
50 elements of partnership provide the conditions for communication and mutual
51 co-operation upon which formal relations of partnership can be constructed^{27 31}
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3 making which is possible to aspire to and practically achieve ¹⁴. Informal
4 elements in our study depict emotionally supportive relationships that pave the
5 way for patients to participate, once the scene is set and the circumstances feel
6 right.
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11 However, in our findings patients were content to be able to ask questions and
12 receive information. They perceived participation as informed discussion and
13 agreement, deferring to professional knowledge and expertise and not
14 necessarily describing opportunities for empowerment and activation. Perceived
15 competence of professionals seemed enough for patients and whilst patients
16 prioritised the informal processes where 'good care' may have been interpreted
17 as PCC, professionals prioritised outcomes that were formal and documented.
18 Patients described participating in plans for discharge but did not describe
19 notions of enablement or control. As with other studies, patients were satisfied
20 with a personal approach and a positive partnership with professionals who
21 communicated empathetically and effectively ⁴⁵ with professionals acting as
22 educators, building mutual and collaborative partnerships ⁴⁶. Measurements of
23 optimum patient-professional relationships and person-centredness need to
24 consider patients' emotional and personal responses that highlight the process
25 rather than the outcome of interactions with health professionals ^{5 14 27 35}.
26 Aspects of informal and formal partnership appeared to act as antecedents of
27 patient participation. Yet overall, most patients portrayed a taken-for-granted
28 pragmatism, trusting professionals with expertise and competence to make
29 overall decisions in a caring environment. For patients in this study, PCC was not
30 explicitly understood or described as an opportunity to formalize a partnership
31 with professionals in order to actively participate in their care. There were more
32 formal aspects of partnership that took precedence in patients' minds, which is
33 in line with the description of the fundamentals of human connectedness
34 described by Thoransdottir & Kristjansson (2014), pointing toward the ethical
35 dimension of partnership and PCC. In addition, professionals may have
36 considered PCC as a particular professional approach rather than a systematic
37 endeavour to "invite" patients to participate in the PCC routines and explicate
38 the model.
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3 Aspects of partnership, particularly informal aspects, led patients to leave some
4 decisions to the professionals since they felt cared for and well informed.
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6 Patients were not forced to make a choice, but they were rather given guidance
7 and information. In this respect patients' interpretation of participation can be
8 viewed, not as passive submission or deferment to professional expertise and
9 knowledge, but a common understanding reached through a therapeutic
10 relationship. Our interpretation of the present study points toward the
11 importance of human connectedness and the feeling of being listen to and
12 acknowledged as a person (informal aspect) for patients, while routines and
13 formal aspects of care came more into the foreground for the practitioners. It
14 seems as if in order to integrate the patient into clinical practice, there seems to
15 be a balancing act that practitioners as well as patients need to reflect upon:
16 recognition of the patient as a person (informal aspects) needs to balance the
17 specific practical routines (formal aspects)⁴². The risk could otherwise be that
18 the patient as a person becomes a "checkbox" in a routine, which in many aspects
19 would entrench profession-centred care rather than person-centredness.
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33 This study has some limitations. Patients did not necessarily perceive their care
34 in the context of a PCC model and our study depended upon patients
35 remembering events and perhaps perceiving the relevance of information and
36 care strategies. Secondly, because the study took place in a particular
37 institutional context (GPCC) in Sweden, the findings may not be transferable to
38 other settings. Moreover, formal aspects of partnership, for example,
39 documented care plans and decisions, could have provided patients with
40 opportunities to revisit decisions in written form, and maintain a sense of
41 confidence and trust during their admission that was taken for granted.
42 Moreover, most interviewees were older perhaps predisposing them to comply
43 with professional expertise or feel knowledgeable but not necessarily
44 empowered⁴⁷. However, Ekdal et al (2011) suggest that older peoples'
45 preferences for information and decision making are not associated with age,
46 and that the majority of patients wanted more information, not less⁴⁸.
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3 Another limitation in this study is that patients were first contacted by a nurse
4 coordinator and after agreeing to be part of the study, participants were
5 contacted by the researchers after their discharge within the first 7 days to
6 schedule a interview. Patients who agreed to participate in the interview study
7 might have been more attentive to the particular aspects of PCC and eager to talk
8 about their experience. This might have led to the tendency for positive accounts
9 about the informal parts of partnership. However, it is equally important for the
10 objective of the study to capture positive comments about partnership.
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17 Conclusion

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

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

43 Nicky Britten is a member of the Scientific Advisory Board of GPCC. The
44 author(s) declared no potential conflicts of interest with respect to the research,
45 authorship, and/or publication of this article.
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3 the NIHR or the Department of Health. The authors are grateful to the
4 interviewees for their willingness to participate in the study.
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7 Data sharing statement

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9 No additional unpublished data is available
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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
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<p>1</p> <p>2</p> <p>3</p> <p>4</p> <p>5</p> <p>6</p> <p>7</p> <p>8</p> <p>9</p> <p>10</p> <p>11</p> <p>12</p> <p>13</p> <p>14</p> <p>15</p> <p>16</p> <p>17</p> <p>18</p> <p>19</p> <p>20</p> <p>21</p> <p>22</p> <p>23</p> <p>24</p> <p>25</p> <p>26</p> <p>27</p> <p>28</p> <p>29</p> <p>30</p> <p>31</p> <p>32</p> <p>33</p> <p>34</p> <p>35</p> <p>36</p> <p>37</p> <p>38</p> <p>39</p> <p>40</p> <p>41</p> <p>42</p> <p>43</p> <p>44</p> <p>45</p> <p>46</p> <p>47</p> <p>48</p> <p>49</p> <p>50</p> <p>51</p> <p>52</p> <p>53</p> <p>54</p> <p>55</p> <p>56</p> <p>57</p> <p>58</p> <p>59</p> <p>60</p> <ul style="list-style-type: none"> To start with, could you tell me a bit about this ward/clinic/centre? <p>Prompts: Size? Practical work? Team?</p> <ul style="list-style-type: none"> How did you start working with PCC? <p>Prompts: First contact with PCC? When did you first hear about it? Where did the idea come from? Did you have a special training?</p> <ul style="list-style-type: none"> 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? <p>Prompts: How would you describe or define PCC?</p> <ul style="list-style-type: none"> How did patients react to PCC? Would you tell me about any changes to your practice since you started working with PCC? <p>Prompts: Were there any changes in your ways of working? Relations with patients? Routines? Division of labour? Any changes-adaptions?</p> <ul style="list-style-type: none"> 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? 	<ul style="list-style-type: none"> Could you tell me about your experience of the care you received? How would you describe the care and treatment? <p>Prompts: Can you give examples of the kind of care you received? What did the routines look like?</p> <ul style="list-style-type: none"> How have you experienced the relationship between you and the staff? How did you experience the communication between you and the staff? <p>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?</p> <ul style="list-style-type: none"> What has been important to you in the care that you got? <p>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?</p> <ul style="list-style-type: none"> 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? <p>Prompts: In what way did they differ? What changes have you noticed?</p> <ul style="list-style-type: none"> Are you familiar with the term person-centered care? <p>Prompts: If so, how would you describe PCC?</p> <ul style="list-style-type: none"> 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 <p>Prompts: Could you give some examples? Procedures? Documentation? How staff looked after you? Something else?</p> <ul style="list-style-type: none"> 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? <p>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?</p> <ul style="list-style-type: none"> Is there anything else you would like to add?
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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			
<i>Personal characteristics</i>			
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
<i>Relationship with participants</i>			
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			
<i>Theoretical framework</i>			
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
<i>Participant selection</i>			
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
<i>Setting</i>			
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) 4
<i>Data collection</i>			
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 recd
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

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
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
<i>Reporting</i>			
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

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BMJ Open

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

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3 1 The realities of partnership in person-centred care: a qualitative interview study
4 2 with patients and professionals

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49 22 **ABSTRACT**

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52 23 **Objective:** Although conceptual definitions of person-centred care (PCC) vary,
53 24 most models value the involvement of patients through patient-professional
54 25 partnerships. While this may increase patients' sense of responsibility and
55 26 control, research is needed to further understand how this partnership is created

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3 27 and perceived. This study aims to explore the realities of partnership as
4
5 28 perceived by patients and health professionals in everyday PCC practice.
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7 **Design:** Qualitative study employing a thematic analysis of semi-structured
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9 30 interviews with professionals and patients.
10

11 **Setting:** Four internal medicine wards and 2 primary care centres in western
12
13 32 Sweden.
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15 **Participants:** 20 patients admitted to hospital wards delivering person-centred
16
17 34 care and 16 health professionals based on these wards and primary care centres.
18

19
20 35 **Results:** Our findings identified both informal and formal aspects of partnership.
21
22 36 Informal aspects, emerging during the interaction between healthcare
23
24 37 professionals and patients, without any prior guidelines or regulations
25
26 38 incorporated proximity and receptiveness of professionals, and building a close
27
28 39 connection and confidence. This epitomised a caring, respectful relationship
29
30 40 congruent across accounts. Formal aspects, including structured ways of
31
32 41 sustaining partnership were experienced differently. Professionals described
33
34 42 collaborating with patients to encourage participation, capture personal goals,
35
36 43 plan and document care. However, although patients felt listened to and
37
38 44 informed, they were content to ask questions and felt less involved in care
39
40 45 planning, documentation or exploring lifeworld goals. They commonly perceived
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42 46 participation as informed discussion and agreement, deferring to professional
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44 47 knowledge and expertise in the presence of an empathetic and trusting
45
46 48 relationship.
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49 **Conclusions:**

50 In our study patients appear to value a process of human connectedness above
51
52 51 and beyond formalised aspects of documenting agreed goals and care planning.
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54 52 PCC increases patients' confidence in professionals who are competent and able
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56 53 to make them feel safe and secure. Informal elements of partnership provide the
57
58 54 conditions for communication and co-operation upon which formal relations
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60 55 of partnership can be constructed.

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56 Keywords:

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3 57 Person-Centred Care, Patient-Centred Care, Patient Participation, Healthcare
4 58 service, Qualitative

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

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- 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

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 centre⁸⁻¹⁰. It is
74 clear that with professional support, patients can become active partners in their
75 care¹¹⁻¹⁵ 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 partnerships⁸, 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 making³². Different PCC frameworks lift patient involvement toward an
85 enhanced therapeutic relationship that requires sharing power and
86 responsibility⁶. Yet, as patients are increasingly offered more choice and

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3 87 involvement, researchers also describe circumstances where patients choose to
4 88 decline participation, defer decisions or feel unable to participate ^{33 34}. It seems
5 89 that the notion of the patient as an active partner in care requires empirical
6 90 understanding and clarity.
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11 92 Cribb and Entwistle (2011) draw attention to the importance of an emotionally
12 93 supportive patient-professional partnership to aid 'meaningful participation' and
13 94 shared decision-making ¹⁴. Relationships that are open ended and conversational
14 95 are prioritised as well as professional virtues and patient capabilities. This
15 96 approach takes into account the relational aspects of partnership, which pay
16 97 attention to the mindfulness of professionals and the unique aspects of patients'
17 98 lives ^{5 35 36}. However, although power sharing implies an egalitarian and
18 99 meaningful patient-professional relationship ²⁹, the literature describes a
19 100 hierarchy of relationships depicting the different levels of engagement,
20 101 responsibility and shared goals ^{31 37}. This moves from the lowest level i.e.
21 102 involvement towards participation and the highest level i.e. partnership ^{32 37}.
22 103 Thoransdottir & Kristjansson (2014) elaborate on informal and formal
23 104 relationships; the former describing the fundamental importance of human
24 105 connectedness and the latter involving shared agreements on decisions and
25 106 documentation ³¹.
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31 108 In this paper we use a Swedish initiative for implementing an evidence-based
32 109 PCC model as a case study. The University of Gothenburg Centre for PCC (GPCC)
33 110 has introduced a new evidence based model³⁸⁻⁴¹, supported by a programme of
34 111 training and research, which has changed clinical practice.⁴² This model consists
35 112 of three 'routines' of PCC namely narrative, partnership and documentation ^{39 42}
36 113 ⁴³. Partnership in the GPCC framework is the main routine that drives the PCC
37 114 process. The patient's narrative paves the way for collaboration, and
38 115 documentation safeguards this collaboration. The aim of this study is to explore
39 116 the realities of partnership as perceived by patients and health professionals in
40 117 everyday PCC practice.
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57 119 METHODS
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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 routines³⁸.

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

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3 150 be interviewed about the care they had received. One patient was excluded when
4 151 transferred from another ward to the reference ward, which hampered recall.

7 152 **Data collection**

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10 154 The interview guide for practitioners included questions about how PCC related
11 155 to the everyday work of healthcare practitioners and its implementation. The
12 156 interview guide for patients was intended to elicit patients' experiences of care
13 157 on the ward and their understanding of PCC (table 2).

18 158

20 159 *Table 2 Interview guide practitioners and patients*

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23 161 DL conducted 12 interviews with professionals, AW conducted 2, and a trained
24 162 research assistant conducted 3 interviews with practitioners and all interviews
25 163 with patients.

26 164 All interviews were audio recorded, transcribed verbatim, anonymised and
27 165 translated from Swedish into English. They were then read and checked by the
28 166 team to ensure accuracy and fluency. Translation was literal, yet for specific
29 167 idioms in Swedish which are not easy to translate, native English speakers in the
30 168 research team suggested alternatives which would do better justice to the
31 169 content and bilingual team members checked their accuracy. Any potential
32 170 misinterpretations were clarified and agreed. All interviewees were given a
33 171 numbered pseudonym to maintain confidentiality (P for Patient, N for Nurses, M
34 172 for Manager and MD for Physician). All participants were told that they were free
35 173 to withdraw their consent at any time during the study. Patients were
36 174 interviewed after their hospital stay, in a place of their choosing to ensure that
37 175 they felt comfortable talking about the care episode. A research assistant (MH)
38 176 without a clinical background or connection to the hospital performed all patient
39 177 interviews. However, she is trained sociology and had previous experience of
40 178 conducting patient interviews. She received guidance from the team concerning
41 179 the interview guide, qualitative interview techniques and the use of probing

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3 180 questions throughout the present study. Probing questions were used to follow
4 181 up a topic of discussion, to obtain a better illustration of the discussed topics and
5 182 facilitate the dialogue in a way that the interviewees felt comfortable responding
6 183 to questions. If interviewees did not want to talk more about a particular issue,
7 184 the interviewer skipped the related probing questions and asked the following
8 185 question in the guide.

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13 186 The regional ethics committee in Gothenburg approved the study and all
14 187 participants, prior to their interview, gave informed consent. If the patients
15 188 wanted to talk to a healthcare professional about general or specific topics that
16 189 came up during the interviews, they were able to talk to a nurse about their
17 190 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 themes⁴⁴. 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.

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211 **Results**

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3 212 Two main themes were found: firstly informal aspects of partnership comprising
4 213 two subthemes, proximity & receptiveness and building a personal connection/
5 214 confidence. Informal aspects of partnership were interpreted as those emerging
6 215 during the interaction between healthcare professionals and patients. The
7 216 second main theme was formal aspects of partnership having two subthemes,
8 217 aspects of goal setting and care planning, and documentation. Formal
9 218 partnership is about the structured ways of sustaining the relationship between
10 219 the health professionals and the patients via deciding goals, care planning and
11 220 documentation. The results are presented below to allow comparison between
12 221 the 2 groups.

20 222 **Informal aspects of partnership**

21 223 *Proximity and receptiveness*

22 224 Professionals described engaging patients in conversation with the intention of
23 225 respecting and listening to the patient, understanding the patient's situation,
24 226 making a good start and building a close connection. Assistant nurses followed
25 227 this process each morning and described feeling 'closer' to the patient, seeing
26 228 and hearing aspects of the patient from a social, psychological and physical
27 229 perspective and becoming their 'eyes and ears'. Professionals described using
28 230 communication techniques such as posing open, straightforward questions,
29 231 talking without distractions and not judging. A number of professionals felt this
30 232 process aided partnership in subsequent meetings.

31 233 I think that I and the nurse get a great response from the patients, straight
32 234 away, that they feel very comfortable in this. They know who to turn to.
33 235 That they feel like they've been given a lot of time, even if it's not that long
34 236 time, but the content of the consultation gives them that feeling. (MD1)

35 237 Many patients described positive feelings towards the receptiveness of staff and
36 238 the atmosphere of the ward. Accounts of unhurried and immediate support with
37 239 care provided in a caring and close manner were common.

38 240 Not everyone sits down at your bedside, just a few of them do. Mostly
39 241 they pull out chair or something to sit on. They are not on their way to

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3 242 another patient when they do that. It's more of a good opening; that we
4 243 are sitting here now, talking, until we are finished doing that. (P1)

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9 245 Available and reliable professionals increased patients' comfort, with
10 246 professionals described as thoughtful, open and warm, leading to patients feeling
11 247 a sense of humanity, security, familiarity and trust.

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15 248 They say "Hi Paula!" and then they present themselves with their name
16 249 and then the title comes. Already there they create an opportunity for
17 250 dialogue. It's not "I'm nurse, good day." So at that point it feels like an
18 251 openness and they simply and easily describe how my life will be in this
19 252 room. (P2)

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24 254 *Building a close connection and confidence*

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28 255 Professionals described listening in a more engaged way to patients' wishes and
29 256 needs. They emphasised the importance of knowing how patients felt, what they
30 257 thought, aspects of their personality and personal knowledge, described by one
31 258 professional as 'life-luggage'. Patients were prompted to discuss personal
32 259 interests and common topics. For most professionals finding common ground
33 260 built trust, security and a collaborative relationship on a person-to-person level.

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39 261 You may talk about books or music, or common interests so that you're
40 262 not only... You establish a relationship beyond the nurse-patient, and it
41 263 becomes more like person to person. (N1)

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45 264 In keeping with professionals' aspirations, many patients felt listened to and
46 265 acknowledged. Several felt known personally, for who they were and their
47 266 individual needs.

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52 268 They could ask ordinary questions about the everyday life. We could talk
53 269 about summer houses, and pets, and kind of on that level. And that's... I
54 270 think that's very important. I think so at least... one is feeling more as if
55 271 you aren't just a patient among others. (P3)

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3 272 Some patients reported that they noticed changes in professionals' receptiveness.

4
5 273 'I was thinking that I should ask him to sit down, but you know how it is,
6
7 274 no. But I can think that it's a different situation. He stands there taller
8
9 275 than me who's sitting on the bedside. I don't like that....But what I regret
10
11 276 is that I wasn't able to look at my x-rays on CT-abdomen. I had asked for
12
13 277 that previously, but I didn't receive an answer to that. Well, I might have
14
15 278 said that I wanted to see my x-rays. It can be interesting to look with a
16
17 279 physician, because I know nothing about... I can't do it myself. So I asked
18
19 280 for that the last day, but she said that she was much stressed, the assistant
20
21 281 physician, and she had had very much to do. I would have wanted that.
22
23 282 I'm sure I will get them to my home. I have requested everything and my
24
25 283 medical records, but I can't examine things like those. It wasn't anything,
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27 284 but it would have been interesting to look at it. Sit with a doctor and
28
29 285 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

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2
3 303 smoking or getting better medication or is it more training, physical
4 304 activities, is it fear of training? And so on. So when they left the hospital
5
6 305 they had this sheet where they had described their problem and it was
7
8 306 just, it was their problem it was not a standard formula – the formula was
9
10 307 standard but the questions and the wishes from the patient was personal
11 308 (MD2)

12
13
14 309 Informal aspects of partnership led to an environment where it became possible
15 310 for patients to ask questions, learn about their condition and treatment.
16
17 311 Professionals believed patients had the inclination to begin caring for themselves,
18
19 312 follow suggestions and instructions. Formal aspects such as discussing goals
20
21 313 facilitated self-care such as getting dressed, mobilising on the ward, preparing
22
23 314 for discharge and following advice post discharge.

24
25 315 Several professionals described the need to encourage, 'push' or 'pass' on
26
27 316 competence to the patient, by letting the patient ask questions and take part in
28
29 317 the care planning, hence enabling the patient to become well informed,
30
31 318 knowledgeable and take responsibility.

32
33 319 There is a more practical understanding that the patient also carries a
34
35 320 responsibility, and also is responsible for the process. I tend to think that
36
37 321 my ward is at this stage of the process – to get the patient to understand
38
39 322 the significance of his or her participation to activity, to rehabilitation.
40
41 323 (M1)

42
43 324
44 325 Professionals noticed a change, where patients who were well informed, knew
45
46 326 they had an impact, influence and could handle themselves. They seemed
47
48 327 satisfied and more willing to help themselves and 'buy the whole concept'.

49
50 328 We look at what the patient usually does in their everyday life outside the
51
52 329 hospital, and what the patient does right now, and what we can do to
53
54 330 improve and to support that the patient becomes their ordinary self again.
55
56 331 And that you really try to understand how they can use their own
57
58 332 resources and train themselves. (N2)

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3 334 However from the patient perspective some remembered taking part in
4 335 developing a health plan but few mentioned goals and when discussed, these
5 336 were invariably described in medicalised terms or framed around home
6 337 circumstances for discharge. Personal information was elicited and described,
7 338 but not necessarily orientated towards 'lifeworld' goals.

11
12 339 I don't actually know if the goal has been mentioned, but that might be the
13 340 goal with the illness I have, that the goal is to be free from relapses.
14 341 Because everything would then be as good as they can be. One wouldn't
15 342 suffer from the disease then. As long as one takes medicine that doesn't
16 343 give side-effects and isn't suffering from relapses, then everything will be
17 344 okay. And I know that has been mentioned, that it might be the goal after
18 345 all. But that, as I said, that has to do with the disease. (P5)

21
22 346 Patients felt they contributed when they discussed choices with professionals,
23 347 helped themselves, used their initiative and became knowledgeable. There were
24 348 opportunities to question, decline treatment and contribute to discharge
25 349 planning. For some, participation involved discussing test results, investigations
26 350 and medication management that helped them 'feel' (our emphasis) they were
27 351 committed to taking part in their care, for example by discussing an ultrasound
28 352 test, a transfusion or a colonoscopy procedure. They received explanations and
29 353 felt they knew what to do, how to deal with medication and treatments.

32
33 354 I know much more about my illness now and why it has become the way
34 355 it has, I think I understand that better now. And that I can see in hindsight
35 356 that I haven't been feeling well for a very long time, which has been
36 357 connected to this. So now I have got a much clearer picture of my
37 358 condition. (P6)

38
39 359
40
41 360 Others felt they participated by listening to professionals, agreeing and accepting
42 361 professionals' decision-making. They felt confident, comfortable and treated as
43 362 equals, described by one patient as 'horizontal communication'. A few patients
44 363 described themselves as 'experienced', 'verbal' even when very ill and able to
45 364 'demand and ask questions'. Yet for patients in this study, participating was
46 365 described in terms of informed discussion, acceptance and agreement,

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3 366 participating up to a point or as far as they felt able. Several felt comfortable
4
5 367 'submitting' and 'not being in the driving seat'.
6

7 368 Many times one might feel like one is participating... one sometimes may
8
9 369 be silent, but still feel a fellowship. Do you understand what I mean? And
10
11 370 that's probably what I felt with the ward. That I didn't need to ask or I
12
13 371 didn't need to ask them, the nurses I mean, since I knew in some way that
14
15 372 the community still was there. (P7)
16

17 373

18 374 When I say no to something, they listen to me. Whatever it might be; the
19
20 375 discharge or anything. Or some kind of examination... I said no to an
21
22 376 examination, and I said that: "You did that examination just six months
23
24 377 ago, and it's very painful. Is it really necessary to do it again?" "No, then
25
26 378 we won't do it." (P1)
27

28 379

29 380 Since you are part of the treatments, and you know how they are doing
30
31 381 the plan for the treatment and are explaining in a good way. So even when
32
33 382 you return home, you know approximately about... Well, now I know how
34
35 383 I will deal with the medications and the treatment and everything, in a
36
37 384 completely different way. (P7)
38

39 385

40 386 Documentation

41 387 Professionals described writing care plans with patients, eliciting biomedical
42
43 388 information and discussing social and discharge planning. Decisions and plans
44
45 389 were agreed and documented.

46 390 You should make a plan together with the patient and that you discuss
47
48 391 with the patient and so on, but the difference of having it in this way is
49
50 392 that you have more of a structure of it. You create a framework for what it
51
52 393 means to work like this, so that what you're doing becomes more
53
54 394 concrete. (MD3)

55 395 In some way the patient gets what we've done on paper, and we get a
56
57 396 proof of that we understand it in the right way, so that the patient can say
58
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1
2
3 397 “Yes, this is how it was” or “I don’t agree with this.” The important thing is
4 398 that you agree, so that you are on the same page so to speak. (N1)

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6
7 399 In this respect professionals described ‘a new practice’ where patients were
8 encouraged to actively participate, become more involved and take part in
9 400 decisions about their care.
10 401

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13 402 Documentation acted as a reminder for patients to discuss care on ‘a new
14 403 level’. (N3)

15
16
17 404 You must create a care plan with the patient within 48 hours and then
18 405 you should write why they have sought care and what we have planned
19 406 for them and this should be addressed at the round with the patient, and
20 407 it is written down and then it's a little investigation to see what the
21 408 patients can do themselves. (N4)

22
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26
27 409 Professionals encouraged patients to use their own resources and expertise. For
28 410 example patients were encouraged to prepare for conversations with the team
29 411 and write down thoughts or questions.

30
31
32 412 Patients felt informed about their condition, discharge and future care needs, felt
33 413 they were listened to and some felt they were participating in their care plan.

34
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36
37 414 I think, that it felt like it was a team. Decisions where I participated in, and
38 415 the care plan and such things. How much you actually were that, I don’t
39 416 know, but at least you had a picture of it, so. But I can’t decide how I’m
40 417 going to be treated or taken care of, but at least you can be a part of it and
41 418 have opinions, you were able to do that. (P8)

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46 419 Although patients remembered receiving written information and some
47 420 described opportunities to write down thoughts, questions and contribute to
48 421 their care, they did not remember the written information in any detail.
49 422 Nevertheless, patients saw this documentation in ‘simple’ terms whereby they
50 423 felt taken care of and in receipt of sufficient information.

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55 424 Discussion
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3 425 In our study, interviewees' accounts reflect levels of mutuality, self-expression
4 426 and respect that lay the groundwork for PCC and indicate a move from disease
5 427 focused models of care ¹⁹. In keeping with the literature we suggest that informal
6 428 elements of partnership provide the conditions for communication and mutual
7 429 co-operation upon which formal relations of partnership can be constructed ^{27 31}
8 430 ³⁶. Professional and patient perspectives highlight the importance of the informal
9 431 elements of partnership for ultimately determining the level of shared decision
10 432 making which is possible to aspire to and practically achieve ¹⁴. Informal
11 433 elements in our study depict emotionally supportive relationships that pave the
12 434 way for patients to participate, once the scene is set and the circumstances feel
13 435 right.

14 436
15 437 However, in our findings patients were content to be able to ask questions and
16 438 receive information. They perceived participation as informed discussion and
17 439 agreement, deferring to professional knowledge and expertise and not
18 440 necessarily describing opportunities for empowerment and activation. Perceived
19 441 competence of professionals seemed enough for patients and whilst patients
20 442 prioritised the informal processes where 'good care' may have been interpreted
21 443 as PCC, professionals prioritised outcomes that were formal and documented.
22 444 Patients described participating in plans for discharge but did not describe
23 445 notions of enablement or control. As with other studies, patients were satisfied
24 446 with a personal approach and a positive partnership with professionals who
25 447 communicated empathetically and effectively ⁴⁵ with professionals acting as
26 448 educators, building mutual and collaborative partnerships ⁴⁶. Measurements of
27 449 optimum patient-professional relationships and person-centredness need to
28 450 consider patients' emotional and personal responses that highlight the process
29 451 rather than the outcome of interactions with health professionals ^{5 14 27 35}.

30 452 Aspects of informal and formal partnership appeared to act as antecedents of
31 453 patient participation. Yet overall, most patients portrayed a taken-for-granted
32 454 pragmatism, trusting professionals with expertise and competence to make
33 455 overall decisions in a caring environment. For patients in this study, PCC was not
34 456 explicitly understood or described as an opportunity to formalize a partnership
35 457 with professionals in order to actively participate in their care. There were more

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3 458 informal aspects of partnership that took precedence in patients' minds, which is
4
5 459 in line with the description of the fundamentals of human connectedness
6
7 460 described by Thoransdottir & Kristjansson (2014), pointing toward the ethical
8
9 461 dimension of partnership and PCC. In addition, professionals may have
10
11 462 considered PCC as a particular professional approach rather than a systematic
12
13 463 endeavour to "invite" patients to participate in the PCC routines and explicate
14
15 464 the model.

16 465 Aspects of partnership, particularly informal aspects, led patients to leave some
17
18 466 decisions to the professionals since they felt cared for and well informed.
19
20 467 Patients were not forced to make a choice, but they were rather given guidance
21
22 468 and information. In this respect patients' interpretation of participation can be
23
24 469 viewed, not as passive submission or deferment to professional expertise and
25
26 470 knowledge, but a common understanding reached through a therapeutic
27
28 471 relationship. Our interpretation of the present study points toward the
29
30 472 importance of human connectedness and the feeling of being listen to and
31
32 473 acknowledged as a person (informal aspect) for patients, while routines and
33
34 474 formal aspects of care came more into the foreground for the practitioners. It
35
36 475 seems as if in order to integrate the patient into clinical practice, there seems to
37
38 476 be a balancing act that practitioners as well as patients need to reflect upon:
39
40 477 recognition of the patient as a person (informal aspects) needs to balance the
41
42 478 specific practical routines (formal aspects)⁴². The risk could otherwise be that
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44 479 the patient as a person becomes a "checkbox" in a routine, which in many aspects
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46 480 would entrench profession-centred care rather than person-centredness.

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482 This study has some limitations. Patients did not necessarily perceive their care
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484 in the context of a PCC model and our study depended upon patients
485
486 remembering events and perhaps perceiving the relevance of information and
487
488 care strategies. Secondly, because the study took place in a particular
489
490 institutional context (GPCC) in Sweden, the findings may not be transferable to
491
492 other settings. Formal aspects of partnership, for example, documented care
493
494 plans and decisions, could have provided patients with opportunities to revisit
495
496 decisions in written form, and maintain a sense of confidence and trust during

1
2
3 490 their admission that was taken for granted. Most interviewees were older
4 491 perhaps predisposing them to comply with professional expertise or feel
5 492 knowledgeable but not necessarily empowered⁴⁷. Ekdahl et al⁴⁸ suggest that
6 493 older peoples' preferences for information and decision making aren't fully
7 494 acknowledge and/or acted upon by the healthcare professional. Patients aged 75
8 495 years and above may want more information relating to their care, without
9 496 having to ask. Therefore healthcare professionals need to be receptive and
10 497 responsive to patients' preferences and tailor the information and decision
11 498 making process accordingly.

12
13 499 Another limitation in this study is that patients were first contacted by a nurse
14 500 coordinator and after agreeing to be part of the study, participants were
15 501 contacted by the researchers after their discharge within the first 7 days to
16 502 schedule a interview. Patients who agreed to participate in the interview study
17 503 might have been more attentive to the particular aspects of PCC and eager to talk
18 504 about their experience. This might have led to the tendency for positive accounts
19 505 about the informal parts of partnership. However, it is equally important for the
20 506 objective of the study to capture positive comments about partnership.

21 507 Conclusion

22 508 In our study patients appear to value a process of human connectedness above
23 509 and beyond formal aspects of taking part and feeling activated and capable.
24 510 These findings may point to the need for professionals to acknowledge the
25 511 importance of the human connectedness that is as crucial as formal aspects for
26 512 PCC to be fully realised in practice.

27 513 28 514 Author contributions

29 515 LM and AW contributed equally to the study as first authors. All authors
30 516 contributed to the study design, conception and development. DL and AW
31 517 conducted the interviews together with research assistant Marie Hammer. LM,
32 518 DL and ÖN initially analysed the data, and all authors met face to face and over
33 519 skype as a group to discuss, revise and confirm the findings. All authors were
34 520 responsible for critical revision and finalising the manuscript.

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2
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4 522 Nicky Britten is a member of the Scientific Advisory Board of GPCC. The
5
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7
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24
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26
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30 536 **Data sharing statement**

31
32 537 No additional unpublished data is available
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36 539 **Wordcount 4913**
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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

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691 **Table 2**

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Interview guide: Health professionals	Interview guide: Patients

<p>1</p> <p>2</p> <p>3</p> <p>4</p> <p>5</p> <p>6</p> <p>7</p> <p>8</p> <p>9</p> <p>10</p> <p>11</p> <p>12</p> <p>13</p> <p>14</p> <p>15</p> <p>16</p> <p>17</p> <p>18</p> <p>19</p> <p>20</p> <p>21</p> <p>22</p> <p>23</p> <p>24</p> <p>25</p> <p>26</p> <p>27</p> <p>28</p> <p>29</p> <p>30</p> <p>31</p> <p>32</p> <p>33</p> <p>34</p> <p>35</p> <p>36</p> <p>37</p> <p>38</p> <p>39</p> <p>40</p> <p>41</p> <p>42</p> <p>43</p> <p>44</p> <p>45</p> <p>46</p> <p>47</p> <p>48</p> <p>49</p> <p>50</p> <p>51</p> <p>52</p> <p>53</p> <p>54</p> <p>55</p> <p>56</p> <p>57</p> <p>58</p> <p>59</p> <p>60</p> <ul style="list-style-type: none"> To start with, could you tell me a bit about this ward/clinic/centre? <p>Prompts: Size? Practical work? Team?</p> <ul style="list-style-type: none"> How did you start working with PCC? <p>Prompts: First contact with PCC? When did you first hear about it? Where did the idea come from? Did you have a special training?</p> <ul style="list-style-type: none"> 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? <p>Prompts: How would you describe or define PCC?</p> <ul style="list-style-type: none"> How did patients react to PCC? Would you tell me about any changes to your practice since you started working with PCC? <p>Prompts: Were there any changes in your ways of working? Relations with patients? Routines? Division of labour? Any changes-adaptions?</p> <ul style="list-style-type: none"> 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? 	<ul style="list-style-type: none"> Could you tell me about your experience of the care you received? How would you describe the care and treatment? <p>Prompts: Can you give examples of the kind of care you received? What did the routines look like?</p> <ul style="list-style-type: none"> How have you experienced the relationship between you and the staff? How did you experience the communication between you and the staff? <p>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?</p> <ul style="list-style-type: none"> What has been important to you in the care that you got? <p>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?</p> <ul style="list-style-type: none"> 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? <p>Prompts: In what way did they differ? What changes have you noticed?</p> <ul style="list-style-type: none"> Are you familiar with the term person-centered care? <p>Prompts: If so, how would you describe PCC?</p> <ul style="list-style-type: none"> 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
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	<p style="text-align: right;">involvement / partnership</p> <p>Prompts: Could you give some examples? Procedures? Documentation? How staff looked after you? Something else?</p> <ul style="list-style-type: none"> • 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? <p>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?</p> <ul style="list-style-type: none"> • Is there anything else you would like to add?
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For peer review only

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