Faculty of Health: Medicine, Dentistry and Human Sciences

School of Psychology

2022-04-08

Exploring Documentation in Person-Centred Care: A Content Analysis of Care Plans

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http://hdl.handle.net/10026.1/18928

10.1111/opn.12461 International Journal of Older People Nursing Wiley

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International Journal of Older People Nursing

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| Journal: | International Journal of Older People Nursing |
|--------------------------|---|
| Manuscript ID | OPN-2021-2070.R3 |
| Wiley - Manuscript type: | Original Article (Direct Via EEO) |
| Keywords: | Person-Centred Care, documentation, goals, Content Analysis |
| | |

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| Editorial/peer review comment | Response | Changes made and where to find them |
|---|---|---|
| Editor's comment | | |
| The reviewer makes very helpful suggestions for final revisions. I ask you to make those revisions so I can accept the manuscript for publication. | Thank you for your feedback. We made all minor changes as suggested by the reviewer. | All changes are highlighted yellow in the paper. Please see our responses below for details. |
| Reviewer's comments | | |
| The quality of the paper has improved significantly after this revision. I have only three minor comments: Regarding the ethical considerations: Were the nurses who wrote the care plans informed about this stud and did they agree to participate? | Thank you taking the time to review the manuscript again thoroughly. We appreciate your positive comments and valuable suggestions for minor revisions. The ethical approval for this study comprised interviews with nurses and analyses of the patient journal. The ethical approval obtained for the initial study comprised a secondary analysis of patient journals. | We added at statement that this secondary analysis of nursing documentation was included in the initial ethics application. (see page 8) |
| On page 17 in the discussion section, you start to discuss the issue of resources. Three sentences later, however, you turn again to the issue of goals. This is not logical, and you should consider rewriting this paragraph. | Thank you for your astute observation. | We reorganized the paragraph to ensure a logical flow of the discussion. (see pages 14/15) |
| One final comment on your terminology is: it might be clearer if you replaced the term medical/lifestyle goals and resources with medical/health goals and resources. Readers might misunderstand the term health as being related to fashion. | Thank you for your suggestion, which we accepted. | We replaced the term medical/lifestyle goals with medical/health goals throughout the manuscript and in all tables and figures. All changes are highlighted yellow. |

Exploring Documentation in Person-Centred Care: A Content Analysis of Care Plans

Abstract

Background

Person-centred care is a growing imperative in healthcare, but the documentation of person-centred care is challenging. According to the Gothenburg Framework of Person-centred Care, care should be documented in continuously revised care plans and based on patients' personally formulated *goals* and *resources* to secure a continuous partnership.

Aim

This study aimed to examine care plans produced within a randomised controlled trial that tested a person-centred care intervention in older people with acute coronary syndrome. Nurses with training in the theory and practice of person-centred care had written the care plans.

Methods

We conducted a secondary analysis of care plans developed in a randomised controlled trial for assessing person-centred care in patients with acute coronary syndrome (Myocardial infarct (MI) or unstable angina pectoris). The study sample included 84 patients, with three care plans for each patient from inpatient (T1), outpatient (T2) and primary care (T3), i.e., a total of 252 care plans. We conducted a descriptive quantitative content analysis of the care plans to examine the reported patients' life-world and medical/ health resources and goals.

Results

The analysis illustrates the differences and overlaps between life-world and medical/health goals and resources. We found that documented goals and resources change over time. Life-world goals and resources decreased with time as medical/health goals and resources documentation increased.

Conclusions

This paper illustrates that in the setting of a randomised controlled trial, nurses with training in person-centred care recorded fewer life-world and more medical/health goals over time. Placing life-world goals at the top of the goal hierarchy enables alignment with medical/health goals. Further research should explore whether the goals and resources documented in care plans accurately reflect patients' wishes as they transition along the care chain.

What does this research add to existing knowledge in gerontology?

The documentation of life-world and medical/health goals and resources is variable and changes over the course of a patient's journey.

What are the implications of this new knowledge for nursing care with older people?

The differences between life-world and medical/health goals require more consideration. Patients' resources that support their recovery and goal attainment should also receive more attention.

How could the findings be used to influence policy or practice or research or education?

Person-centred care training should highlight the differences between goals and resources and how to record these more clearly and assertively.

Keywords:

Person-centred care, documentation, goals, content analysis

Introduction

Internationally and across all healthcare settings, providing person-centred care is a growing imperative (Author, date), not least in older people nursing (Dewing, 2008; Kindblom et al., 2021; Sundler et al., 2020). Tailoring care to the patient's individual wants and needs and jointly setting goals are essential to person-centred care (Ekman et al., 2011).

The Gothenburg Framework for Person-centred Care (gPCC) was developed by researchers at the University of Gothenburg (Sweden) in 2011 (Ekman et al., 2011) and has been widely implemented (Author, date; Ekman et al., 2021; Håkansson Eklund et al. 2018). The gPCC consists of three routines that facilitate the initiation, integration, and safeguarding of person-centred care in daily clinical practice. The first routine involves initiating a partnership with the patient by eliciting the patient narrative, i.e. the person's account of their illness, symptoms, and impact on their life. Especially important for this routine is identifying the patient's own resources (Ekman et al., 2011). The second routine concerns working the partnership through shared decision-making and establishing *personally* formulated and commonly agreed goals. Person-centred care represents a shift from solely medically oriented goals as it includes the patient's personal goals in shared care planning (Ekman et al., 2011; Jansson et al., 2018). These personal goals are life-world goals based on the everyday world shared with others. The life-world includes family life, culture, and social life; but excludes organised or institution-driven aspects (Author, date). A qualitative interview study with researchers working with the gPCC found that healthcare professionals often heard patients speak more about life-world goals than biomedical goals (Author, year). Life-world goals included, for example, activities like picking mushrooms in the forest, digging a potato patch, or walking the dog, as well as personal goals such as having a job or a partner.

The third gPCC routine safeguards the partnership by documenting the narrative, the resources and the agreed goals in a shared care plan (Ekman et al., 2011). Care planning should be based on patients' own personally formulated *goals* and *resources* and needs to be discussed and, if necessary, revised continuously (Author, date). Indeed, Berntsen et al. (2015) argue that patients have the moral and legal

right to have their life-world goals placed at the top of the 'goal hierarchy'. Goal documentation should be adapted to changes in the patient's goals over time and across different care settings, for example, when moving from hospital to outpatient care. Reviewing and adjusting patient goals support continuity of care. Goal documentation can also enable a discussion of care on a 'new level' that actively includes the patient's expertise and resources (Author, date). Arguably, the role of documentation is essential to person-centred care.

Yet research shows that person-centred documentation is a substantial challenge because patient records are legal records firmly embedded in healthcare structures and rooted in biomedical traditions. Current patient records comprise patient diagnosis, treatment and care planning, delivery, and outcomes (Blair & Smith, 2012). Their primary purpose is to ensure communication between healthcare professionals rather than patient-healthcare professional communication.

Although person-centredness is a quality criterion in documentation (Jefferies et al., 2010), integrating person-centred care aspects such as goal setting challenges current medical and nursing documentation (Dellenborg et al., 2019, Author, date, Author, date, Sefcik et al., 2020). Existing documentation systems and structures often fail to prompt and support person-centred documentation (Gyllensten et al., 2020, Broderick et al., 2012). Structured, template-style documentation that focuses on the medical problem contributes to improving patient care (Björvell et al., 2003) because it facilitates clinical auditing and evaluation (Saranto & Kinnunen, 2009). However, the dialogical or narrative elicitation (Ekman et al., 2011) that is essential in person-centred care is often less structured. Person-centred care elicitation includes the patient's personal experience and exceeds the focus on medical problems. As a result, person-centred care documentation is often fragmented, poorly developed, and lacking in various settings, including, for example, older people out of hospital settings, ageing migrant communities or coronary care (Ebrahimi et al. 2021, Author, date).

Moreover, nursing documentation often fails to go beyond the descriptions of the routine aspects of care (Frank-Stromborg & Christensen, 2001). Patients' psychosocial concerns and the details of the clinical communication are often lacking (Broderick et al., 2012). In a similar vein, medical

documentation in shared patient records lacked person-centred content, and physicians often used terminology and abbreviations that were inaccessible to patients (Author, date). This is particularly problematic in collaborative goal setting and its documentation, which are essential in person-centred care (Ekman et al., 2011; Jansson et al., 2018). Person-centred goals combine medical and patients' personal goals and resources, documented in plain language. Continued collaborative goal setting is important for patients with chronic conditions yet to date an under-researched area that requires further development (Vermunt et al., 2017). To our knowledge, there are no previous studies examining goal documentation across the patient trajectory, yet the continuity of care is essential, particularly in chronic illness. This study broadens the knowledge base about longitudinal goal-setting documentation through a secondary analysis of nursing care plans. Registered Nurses (RNs) who had received person-centred care training developed the care plans within a randomised controlled trial. The trial assessed the effects of a person-centred care intervention in patients with acute coronary syndrome (ACS) (myocardial infarction or angina pectoris), which is most common in older patients (Fors et al., 2015). The analysis enabled us to investigate longitudinal, person-centred goals and resource documentation in a clinical trial.

Methods

Study context

The data for this secondary analysis derives from a clinical trial conducted by researchers affiliated with the Gothenburg Centre for Person-Centred Care (Fors et al., 2015). The trial enrolled 199 participants with ACS treated at two coronary care units at Sahlgrenska University Hospital between June 2011 and February 2014. The intervention group comprised 89 patients who received a personcentred care plan in addition to usual care. The care plan was co-created during their hospital stay (T1), updated in outpatient care (4 weeks after discharge) (T2) and in primary care (8 weeks after discharge) (T3).

"Usual" care for acute heart disease in Sweden follows the Socialstyrelsens (National Board of Health and Welfare) evidence-based guidelines for cardiac care (Socialstyrelsen, 2018a). In addition to pharmacological and medical measures, the guidance includes recommendations for changing health-related risk factors. Patient education through specially trained nurses ('heart school') is vital to ensure that the patient follows the treatment, undergoes regular weight checks and can participate in decisions about the diuretics (Socialstyrelsen, 2018a).

Registered nurses and patients developed the first person-centred care plan (T1) within 24 hours after admission to the hospital ward. At T2 and T3, RNs and physicians trained in person-centred interviewing reviewed the initial care plan and updated it in collaboration with the patient. The care plans included information on (a) medical/health and personal (life-world) patient goals, (b) how to achieve these goals, (c) patients' resources, and (d) support needs (see figure 1).

Figure 1

The person-centred training comprised lectures, seminars and workshops about the theory and practice of the Gothenburg framework for Person-centred Care (gPCC). In addition, healthcare professionals learned about formulating and executing gPCC plans. In addition, RNs participated in four three-hour sessions with case examples and tutoring to ensure they adhered to the gPCC approach during the intervention (Fors et al., 2015).

Sampling and analysis

The intervention arm of the RCT included 89 patients; however, care plans for five patients were missing from the data set. Therefore, our study sample included 84 patients, with three care plans per patient from inpatient, outpatient, and primary care visits, giving a total of 252 care plans.

and transcribed the care plans into excel spreadsheets and repeatedly read them to familiarise themselves with the content. All authors met three times to discuss and review a deductive coding

framework. The coding framework comprised two of the key aspects of the gPCC: resources and goals. (See table 1)

We built on the definition and operalization of the concept 'life-world' by Author (date) to define codes for medical/health and life-world goals and resources. Medical/health goals were biomedical and not connected to the patient's life-world.

Based on the coding framework, we conducted a deductive quantitative content analysis. The codes were treated as categorical variables and each entry was assigned value (medical/health = 1, lifeworld = 2, missing = 0). Data were imported into SPSS for a descriptive analysis of goals and to examine shifts over time.

Table 1

Ethics

The Regional Ethical Review Board (DNr 275-11) approved the original RCT study. The application included the option to conduct secondary analyses of the documentation material. The study conformed to the principles of the Declaration of Helsinki. When extracting the data, we assigned anonymous Case-IDs to all patients. Identifying information such as name or social security number were excluded from the dataset.

Results

The results are presented in two sections: goals and resources. We provide a quantitative summary of the data over three time points followed by qualitative data extracts that illustrate the nature of the goals or resources.

Section one: Goals

The RNs had written the care plans. There was no indication of whether patients confirmed the stated goals as reflective of their own narrative, wishes and needs. The goals were documented in plain

language, with little use of medical jargon. Still, there were abbreviations such as VC (vårdcentral = Primary Healthcare Centre) or FaR (fysisk aktivitet på recept = Physical activity on prescription).

These abbreviations are standard and widely used in Swedish healthcare.

Figure 2

The descriptive analysis of the longitudinal data showed that the reporting of goals decreased over time. At T1, the RNs had recorded either life-world or medical/health goals in most care plans (n= 84). At T3, the number of missing goals had increased (n=12). Still, most care plans contained goals (n=72). The focus of the reported goals shifted with fewer life-world goals over time (n=56 at T1; n=43 at T2; n=32 at T3) and more medical/health goals (n=28 at T1; n=30 at T2; n=40 at T3) (Figure 2).

We found that many medical/health goals were in line with evidence-based guidelines and concerned health factors such as smoking, weight loss, physical activity, and stress (Socialstyrelsen, 2018a, 2018b). In contrast, life-world goals concerned areas such as the patients' social role or family, ethical or spiritual issues (Schellinger et al., 2018) and thus extend beyond the realm of medical/health, guideline-driven goals. However, medical/health goals may represent life-world goals when connected to the patients' social life or role.

In the following paragraphs, we provide examples of documentation of both kinds of goals for older persons.

Life-world goals

The excerpt below illustrates the integration of life-world and medical/health goals. This patient wished to resume his social role as a bookbinder and return to his previous hobbies. The medical/health goal (physical exercise) was linked to the patient's life-world goals: returning to cycling. Across all time points, the focus in care planning remained on life-world goals.

Table 2

This example illustrates the maintenance of life-world goals and medical/health goals across all time points.

Table 3

This example shows that medical/health and life-world perspectives can exist parallel and seemingly disconnected throughout this patient's care trajectory.

The focus on life-world goals was not maintained in all care plans, as shown in figure 2. The example below illustrates how the focus on life-world goals vanished as time passed.

From life-world to medical/ health goals

Table 4

At T1, we found a mix of life-world (writing a book, living a long life, travelling with the son) and medical/health goals (being more physically active). At T2, the documentation became scant, and the focus shifted towards medical/health goals. The care plan stated that goals were 'as previously', and there was no follow up on the progress towards the previously stated life-world goals. Instead, the health goal – to increase physical activity, was revisited.

The shift towards medical/health goals became more evident at T3, where the sole documented goal concerns a return to previous physical strength.

Medical/health goals

Some care plans did not include a life-world goal but featured medical/health goals from T1 through to T3. The example below illustrates this sole focus on medical/health goals (weight reduction and physical fitness). In these cases, the RNs possibly paid less attention to life-world goals, or the patient had no desire to share their life-world goals.

Table 5

Section two: Resources

The RNs documented patient resources that supported the agreed goals. About half (n=48) of the reported resources had a connection to the patient's life-world at T1. However, the focus of the reported resources shifted towards fewer life-world resources and more medical/health resources from T1 to T3. (See figure 3)

Figure 3

We found that many of the documented resources were medical/health resources concerning the patient's efforts and abilities to achieve their goals. These included physical activities and abilities (e.g. living a healthy health) and mental abilities or states (e.g. a positive attitude towards recovery). Life-world resources pertained to the patient's social support network (for example, a general sense of feeling supported by a spouse or friends). Some care plans reported a lack of physical or mental resources, preventing goal achievement. These included physical barriers such as pain and fatigue or negative /unresourceful mental states such as feelings of depression, anxiety, and stress.

The following paragraph provides examples of patients' life-world and medical/health resources.

Life-world resources

The example below illustrates the link between life-world and health resources, which we commonly found in our analysis. The documented resources depict a patient with a positive attitude (with "no depressive thoughts") and a tight social network consisting of children and grandchildren. This link between life-world and health resources is seen at T1 and T2, while the care plan at T3 only includes 'being positive' as a health resource.

Table 6

The following example includes more details about the patient's social network. The patient has comprehensive support and previous experience of mutual support in difficult times.

Table 7

Medical/health resources

Some care plans featured medical/health resources from T1 through to T3.

Table 8

Many patients wish to get better and return to life before a disruptive event, such as getting ill (Bury, 1982). However, the example above does not connect to the patient's life-world, and the resources are more 'standalone'.

Discussion

This article offers two important insights about life-world and medical/health goals and resource documentation in person-centred care plans for older people with acute coronary syndrome. First, the analysis illustrates the overlaps and differences between life-world and medical/health goal and resource reporting. Second, it demonstrates that documented goals and resources change over time.

Our analysis showed that many medical/health goals aligned with evidence-based guidelines (Socialstyrelsen, 2018a, 2018b). However, these goals do not necessarily reflect the person's own wishes and preferences, and RNs may have steered patients towards these practical guideline-based goals. This is reflective of two issues. First, our findings confirm a lack of knowledge regarding collaborative goal setting (Vermunt et al. 2017) and documentation, even in staff trained in personcentred care. Second, healthcare professionals prioritise medical/health goal setting because it is a legal obligation. Healthcare professionals who fail to set medical/health goals may be liable to legal prosecution (Berntsen et al., 2015). Accordingly, it is currently in the healthcare professional's self-interest to comply with legal-professional requirements rather than prioritise person-centred principles (Berntsen et al., 2015). This might explain RNs tendency to uphold stable and familiar routines rather than test newly acquired practices (Author, date).

This article reports a secondary analysis of care plans from a randomised controlled trial. Since RNs trained in person-centred care wrote the care plans, they may not reflect routine clinical practice settings. Notwithstanding the controlled nature of the setting, our analysis demonstrated that the documentation of life-world goals decreased over time, and the documentation of medical/health goals increased. RCT studies are designed to show the effect of an intervention between selected study groups. The controlled nature of the study context and the selected study population often precludes the direct transfer of RCT results to real-world settings. Previous research shows that patients recruited to clinical trials usually have better outcome measures than non-participants, as it has been shown that adherence to the study protocol (regardless if intervention or placebo) is independently associated with outcomes (Granger et al., 2005; Rogers et al., 2021). This, combined with the attention of carefully trained RNs, might suggest that in non-trial settings, the analysis of care plans might reveal similar results, if not greater attrition of life-world goals. This assumption supports previous research that underscores the difficulty in sustaining person-centred care over time (Author, year; Ekman et al., 2021).

Life-world goals may relate to patients' social, cultural or personal lives. Therefore, they are more difficult to describe as they extend beyond the realm of the more clearly defined medical/health goals. However, the boundaries are fluid: medical/health goals may become life-world goals if they are aligned with the patient's wishes, needs or preferences. This alignment is indeed critical: Berntsen et al. (2015), who propose a goal hierarchy, argue that goals can be aligned by prioritising the patient's health rather than medical goals. Our analysis shows evidence of this type of aligned goal setting that places health goals at the top of the 'goal hierarchy'. For example, the evidence-based recommendation to pursue regular physical exercise becomes a life-world goal if the patient can connect it with a favourite pastime, such as cycling. Still, our analysis also demonstrates that medical/health and lifeworld goals do not always overlap. This may point towards a need to discuss goal hierarchies in person-centred care training.

Our analysis shows that the reporting of resources followed the same pattern as the reporting of the goals. From T1 to T3, fewer life-world resources were recorded, while medical/health resource

reporting increased. The biomedical paradigm regards the patient in isolation, while person-centred care sees the patient as an individual in a social context of relationships with family, friends, and colleagues (Dewing, 2008; Kitwood 1997). However, life-world resources such as a supportive partner or a strong social network can play an important role in achieving desired goals.

We can only speculate why goal and resource reporting shifted over time. The care plans were our sole data source, and we did not have access to additional data about the communication between patients and the RNs. However, the shifts may point to a changing tone in the communication and they may not necessarily be related to fading person-centred care and life-world orientation. Previous research shows that once a sense of ease and trust is established (Author, date; Edvardsson et al., 2015), patients tend to be more receptive to clinicians' guidance in setting goals; therefore more medicalised language and content may occur. In contrast, Broderick et al., (2012) saw an increase in personcentred documentation over time. This may be due to different settings. Our study analysed patient records from different settings (inpatient, outpatient clinic and primary care clinic), while Broderick et al. (2012) examined care records from a long-term setting. Long-term care offers patients and staff the time and space to get to know each other as 'persons'; this might be more difficult on a care trajectory that includes several settings.

In our analysis of the care plans, we did not know whether the life-world goals and resources were recorded in the patients' own words or whether the RNs interpreted the patients' narratives. Nursing documentation may feature the patient's voice, the nurses' view of the patient's thoughts or situation, or the mutual view of the relationship (Laitinen et al., 2010). Our sample does not enable us to draw conclusions about the mutual view of the relationship between patients and RNs, and the relationship and discussion of goals and resources may have been more person-centred than the notes reveal. Patients may not be used to or encouraged to talk about life-world goals, as healthcare professionals struggle to elicit these (Author, date). Likewise, patient-related factors can hamper life-world goal elicitation. Person-centred care encourages healthcare professionals to see patients as persons, to talk to them like partners, rather than talking about or above them (Author, date). However, patients may have been socialised into taking a passive role or may not be familiar with collaborative goal setting

(Author, date). Other patients may prefer to leave the care decisions to clinicians (Chewning et al., 2012) or agree with clinicians to avoid challenging their authority or make undue demands on their time (Joseph-Williams, Elwyn, & Edwards, 2014).

In a previous study (Author, date), we underscored that narrative-inducing questions did not immediately lead to the eliciation of life-world goals, since many patients were not used to telling stories and setting goals. Patients tended to articulate generic goals like "being healthy". However, we also observed that nurses who asked follow-up questions such as "Ok, what would you like to do when you are healthy again?" "Would you like to be able to spend more time in your garden when you go home?" could identify specific life-world goals more easily (Author, date). However, the concept of 'resources' is even less well-established than 'goals' in healthcare. 'Resources' are a distinctive aspect of person-centred care, as the patient is regarded as a 'capable person' (Ekman et al., 2011). To date, patients' resources are rarely considered in clinical communication (Author, date), and what exactly could and should be considered a patient resource is not defined in previous literature.

Our analysis shows that even under the controlled conditions of an RCT testing person-centred care, the alignment of goals with resources was unclear and inconsistent. This emphasises the value of asking follow-up questions such as "What can help you to achieve this goal?" to help patients identify the resources they need. Our findings indicate that the elicitation of goals and resources should be more strongly emphasised in person-centred care training.

Ekman et al., (2021:3) propose that future research in person-centred care ought to "describe and evaluate different forms of health plans, including those recorded and written only by patients and relatives". This is one of the first papers to make a secondary analysis of the content of care plans over time (an exception is Jansson et al., 2018). Whatever their limitations, care plans are the basis for ongoing care. As such, they should reflect the perspectives of both healthcare professionals and patients alike (Author, date).

Limitations and recommendations

This study builds on an analysis of care plans generated within an RCT and written by RNs trained in person-centred care. Therefore, the documentation may not be representative of usual care as it was part of a clinical trial pathway. We were unable to interview RNs and patients to triangulate our results. Moreover, it was impossible for us to explore whether the life-world goals and resources we identified were mutually agreed upon or merely based on the RNs' interpretation of the patient narrative. In particular, the study highlights that further research is needed to achieve continued person-centred care documentation along a care pathway that involves different care levels.

This study raises questions regarding person-centred care documentation, such as what prevents healthcare professionals from focusing on the life-world of their patients, or, at a more abstract level, to which degree the concept of person-centredness is compatible within the current framework of medical treatment. Future qualitative studies should address these questions. Despite its limitations, our analysis adds much insight as there are few studies addressing the actual content of person-centred care plans.

Conclusion

This paper reports a secondary analysis of care plans for older persons. from a randomised controlled trial evaluating a person-centred care intervention in patients with acute coronary syndrome. Nurses with training in the theory and practice of person-centred care had written the care plans. We found both overlaps and differences between life-world and medical/health goals and resources. We also demonstrated that documented goals and resources change over time. However, we need to know more about whether the goals and resources documented in care plans accurately reflect the wishes of older patients and if similar results can be found in real world data. Placing life-world goals at the top of the 'goal hierarchy' will enable alignment with medical/health goals, as this will tap into people's motivation and increase chances that supportive behaviours will be adopted during the recovery after a cardiac event

References:

Author

Berntsen, G. K. R., Gammon, D., Steinsbekk, A., Salamonsen, A., Foss, N., Ruland, C. & Fønnebø, V. (2015). How do we deal with multiple goals for care within an individual patient trajectory? A document content analysis of health service research papers on goals for care *BMJ Open* 5:e009403. https://doi: 10.1136/bmjopen-2015-009403

Björvell, C., Wredling, R. & Thorell-Ekstand, I. (2003). Improving documentation using a nursing model. *Journal of Advanced Nursing* **43**(4): 402-10.

Blair, W. & Smith, B. (2012). Nursing documentation: Frameworks and barriers, *Contemporary Nurse*, 41:2, 160-168.

Broderick, M.C., Coffey, A.. (2012) Person-centred care in nursing documentation. *International Journal of Older People Nursing* 8, 309–318. https://doi.org/10.1111/opn.12012

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of health & illness*, *4*(2), 167-182. https://doi.org/10.1111/1467-9566.ep11339939

Chewning, B., Bylund, C. L., Shah, B., Arora, N. K., Gueguen, J. A., & Makoul, G. (2012). Patient preferences for shared decisions: a systematic review. *Patient education and counseling*, 86(1), 9-18. https://doi.org/10.1016/j.pec.2011.02.004

Dewing, J. (2008), Personhood and dementia: revisiting Tom Kitwood's ideas. *International Journal of Older People Nursing*, 3: 3-13. https://doi.org/10.1111/j.1748-3743.2007.00103.x

Dellenborg, L., Wikström, E., & Erichsen, A. A. (2019). Factors that may promote the learning of person-centred care: an ethnographic study of an implementation programme for healthcare professionals in a medical emergency ward in Sweden. *Advances in Health Sciences Education*, 24(2), 353-381. https://doi.org/10.1007/s10459-018-09869-y

Edvardsson, J. D., Sandman, P. O., & Rasmussen, B. H. (2005). Sensing an atmosphere of ease: a tentative theory of supportive care settings. *Scandinavian journal of caring sciences*, *19*(4), 344-353. https://doi.org/10.1111/j.1471-6712.2005.00356.x

Ebrahimi, Z., Patel, H., Wijk, H., Ekman, I., & Olaya-Contreras, P. (2021). A systematic review on implementation of person-centered care interventions for older people in out-of-hospital settings. Geriatric nursing (New York, N.Y.), 42(1), 213–224. https://doi.org/10.1016/j.gerinurse.2020.08.00

Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., ... & Sunnerhagen, K. S. (2011). Person-centered care—ready for prime time. *European journal of cardiovascular nursing*, *10*(4), 248-251. https://doi.org/10.1016/j.ejcnurse.2011.06.008

Ekman, I., Ebrahimi, Z., & Olaya Contreras, P. (2021). Person-centred care: looking back, looking forward. *European Journal of Cardiovascular Nursing*, *20*(2), 93-95. https://doi.org/10.1093/eurjcn/zvaa025

Fors, A., Ekman, I., Taft, C., Björkelund, C., Frid, K., Larsson, M. E., ... & Swedberg, K. (2015). Person-centred care after acute coronary syndrome, from hospital to primary care—a randomised controlled trial. *International journal of cardiology*, *187*, 693-699. https://doi.org/10.1016/j.ijcard.2015.03.336

Frank-Stromborg, M., Christensen, A., & Elmhurst, D. (2001). Nurse documentation: not done or worse, done the wrong way--Part I. *Oncology nursing forum*, 28(4), 697–702.

Granger, B. B., Swedberg, K., Ekman, I., Granger, C. B., Olofsson, B., McMurray, J. J., ... & Pfeffer, M. A. (2005). Adherence to candesartan and placebo and outcomes in chronic heart failure in the CHARM programme: double-blind, randomised, controlled clinical trial. *The Lancet*, *366*(9502). https://doi.org/10.1016/S0140-6736(05)67760-4

Gyllensten, H., Björkman, I., Jakobsson Ung, E., Ekman, I., & Jakobsson, S. (2020). A national research centre for the evaluation and implementation of person-centred care: Content from the first interventional studies. *Health expectations: an international journal of public participation in health care and health policy*, 23(5), 1362–1375. https://doi-org.ezproxy.ub.gu.se/10.1111/hex.13120

Håkansson Eklund, J., Holmström, I. K., Kumlin, T., Kaminsky, E., Skoglund, K., Höglander, J., ... & Summer Merenius, M. (2019). Same same or different? A review of reviews of person-centred and patient-centred care. *Patient education and counseling*, (1), 3-11. https://doi.org/10.1016/j.pec.2018.08.029

Heckemann, B., Chaaya, M., Jakobsson Ung, E., Olsson, D. S., & Jakobsson, S. (2020). Finding the Person in Electronic Health Records. A Mixed-methods Analysis of Person-centered Content and Language. *Health communication*, 1–7. Advance online publication. https://doiorg.ezproxy.ub.gu.se/10.1080/10410236.2020.1846275

Jansson, I., Fors, A., Ekman, I., & Ulin, K. (2018). Documentation of person-centred health plans for patients with acute coronary syndrome. *European Journal of Cardiovascular Nursing*, *17*(2), 114-122. https://doi.org/10.1177/1474515117718415

Jefferies, D., Johnson, M., & Griffiths, R. (2010). A meta-study of the essentials of quality nursing documentation. International Journal of Nursing Practice, 16(2), 112–124. doi:10.1111/j.1440-172x.2009.01815.x sa

Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education And Counseling*, 94(3), 291-309. https://doi.org/10.1016/j.pec.2013.10.031

Kindblom, K., Edvardsson, D., Boström, A. M., & Vikström, S. (2021). A learning process towards person-centred care: A second-year follow-up of guideline implementation. *International Journal of Older People Nursing*, e12373. https://doi.org/10.1111/opn.12373

Kitwood, T.M. (1997). *Dementia reconsidered: the person comes first*. Buckingham: Open University Press.

Laitinen, H., Kaunonen, M., & Astedt-Kurki, P. (2010). Patient-focused nursing documentation expressed by nurses. *Journal of clinical nursing*, *19*(3-4), 489–497. https://doiorg.ezproxy.ub.gu.se/10.1111/j.1365-2702.2009.02983.x

Rogers, J. R., Liu, C., Hripcsak, G., Cheung, Y. K., & Weng, C. (2021). Comparison of Clinical Characteristics Between Clinical Trial Participants and Nonparticipants Using Electronic Health Record Data. *JAMA network open*, *4*(4), e214732-e214732. https://doi.org/10.1001/jamanetworkopen.2021.4732

Saranto, K & Kinnunen, U. (2009). Evaluating nursing documentation-research designs and methods: systematic review. *Journal of Advanced Nursing* 65(3): 464-76.

Sefcik, J. S., Madrigal, C., Heid, A. R., Molony, S. L., Van Haitsma, K., Best, I., Kolanowski, A. (2020). Person-centered care plans for nursing home residents with behavioral and psychological symptoms of dementia. Journal of Gerontological Nursing, 46(11), 17–27. https://doi.org/10.3928/00989134-20201012-03

Schellinger, S. E., Anderson, E. W., Frazer, M. S., & Cain, C. L. (2018). Patient self-defined goals: essentials of person-centered care for serious illness. *American Journal of Hospice and Palliative Medicine*®, *35*(1), 159-165. https://doi.org/10.1177/1049909117699600

Socialstyrelsen (2018a). *Nationella riktlinjerför hjärtsjukvård. Stöd för styrning och ledning.* [National guidelines for cardiac care. Support for management.] Stockholm, Sweden: Socialstyrelsen.

Socialstyrelsen (2018b). Nationella riktlinjerför hjärtsjukvård. Vetenskapligt underlag. Bilaga. [National guidelines for cardiac care. Scientific evidence]. Stockholm: Socialstyrelsen.

Sundler, A. J., Hjertberg, F., Keri, H., & Holmström, I. K. (2020). Attributes of person-centred communication: A qualitative exploration of communication with older persons in home health care. *International journal of older people nursing*, *15*(1), e12284. https://doi.org/10.1111/opn.12284

Vermunt, N., Harmsen, M., Westert, G. P., Olde Rikkert, M., & Faber, M. J. (2017). Collaborative goal setting with elderly patients with chronic disease or multimorbidity: a systematic review. *BMC geriatrics*, 17(1), 167. https://doi-org.ezproxy.ub.gu.se/10.1186

| Person-Centred Care Plan: Resources/Barriers – Motivation – Personal Goal | | |
|---|--|--|
| Goal setting (return to desired activity): | | |
| What and how should I do this? When? | | |
| My own resources and capabilities (How can I use these to achieve my goal?) | | |
| My need for support: | | |

| Team Decision (Patient Narrative): To be completed by physician, nurse and patient | | | | | |
|--|---------------------|-------|-------------|----|--|
| PCC plan prepared and agreed as per patient's requests and wishes | | | Yes | No | |
| Discharge planning, anticipated discharge date: | | | | | |
| Next of kin informed about PCC plan in accordance with patient's requests and wishes | | | Yes | No | |
| Are there any anticipated complications in the PCC planning? | | | Yes | No | |
| Anticipated Complications | | | | | |
| Signature Patient: | Signature Physician | Signa | ture Nurse: | | |

| Wellbeing | Wellbeing (Symptom Monitoring): Symptoms assessed by patient every 48 hours | | | | |
|------------------------|---|-------|-------|-------|------------------|
| | Day 1 | Day 3 | Day 5 | Day 7 | Discharge Day |
| Date | | | | | |
| Dyspnoea (1-5) | | | | | |
| Fatigue (1-5) | | | | | |
| Health (0-10) | | | | | |
| Pain (0-10) | | | | | |
| Sleeping well (yes/no) | | | | | |
| Depression (0-10) | | | | | |
| Anxiety (0-10) | | | | | |
| Other symptoms | | | | | |

| Evaluation (Evaluation/Discharge Planning): by patient | | | | |
|--|-----|----|--|--|
| I was involved in my care planning Yes No | | | | |
| I was involved in discharge planning in a satisfactory way | Yes | No | | |

| Continued PCC Plan (Evaluation/Discharge Planning) Patient keeps PCC care plan and brings it to appointment | | | |
|---|--|--|--|
| Two days after discharge the patient will be contacted by primary care centre | | | |
| Contact at primary care centre: Telephone Number: | | | |

Figure 1: Person-Centred Care Plan

| Category | Codes | Examples |
|----------|--|--|
| 1. Goals | a) Medical/health (medication adherence, smoking, diet etc.) b) Life-world (goals that concern the patients' social or life situation. Long/mid-term and immediate goals.) c) Missing (no goal documented) | a) Medical goal: "Increase physical activity to 10.000 steps a day. Stop smoking" b) Long-term life-world goal: "Planning to retire next year.". Midterm life-world goal: "Return to previous activity-level with fishing, gardening, basketry and painting". Immediate life-world goal: "work in allotment garden, be with grand-kids, dance". |

- Resources
 a) Medical/health perspective (standard resources, not socially contextualised but mostly consisting of motivational language)
 b) Life-world perspective (socially contextualised resources)
- Table 1 Coding frame for goals and resources

- a) "Is willing to stop smoking"
- b) "Family members are very supportive"

| Time | T1 | T2 | T3 |
|-------|---|---|---|
| Goals | Return to your work as a bookbinder. Engage in their hobbies that were out in nature, museums, music, cultural history, antiques, archeology, etc. Continue cycling a couple of miles / day. Diet as low cholesterol, in the future has his own studio. | Getting started with cycling and other interests. Has started with the goal that was set at the hospital. | Cycles daily. About 2 hours / day. Desires - find a place to develop bookbinding, paper marbling. |

Table 2: Life-world goals of a male patient 61 years old.

| Time | T1 | T2 | Т3 |
|-------|--|--------------|--|
| Goals | Being able to go on a holiday trip to Turkey in March, as well as losing weight. | See earlier. | Lose weight. Be able to go to Turkey in March. |

Table 3: Lifeworld and health goals of a male patient 74 years old.

| Time | T1 | T2 | T3 |
|-------|---|--|---------------------------------------|
| Goals | Live a long life like his mother (106 years). Write a book. Return to physical activity: 3 times/week walk + gym. Get out and fly with his son. | As previously. Starts going to the gym tomorrow. | Return to previous physical strength. |

Table 4: Changing goals of a male patient 74 years old

| Time | T1 | T2 | Т3 | |
|------|----|----|----|--|

| level as before the illness. Reduce weight to 74 kg. | weight, has 2 left. | | |
|---|---------------------|---------|--|
| | | - 6 - 7 | |

Table 5: Health goals of a male patient 72 years old

| Time | T1 | T2 | T3 |
|-----------|---|--|---|
| Resources | Tight social network, feels good, doesn't experience any hindrance to achieve goals | Doesn't see any hinders. Good contact with children and grandchildren. | Positive – no worries – no depressive thoughts |

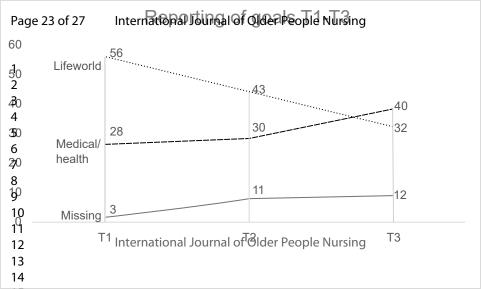
Table 6: Lifeworld and health resources of a male patient 72 years

| Time | T1 | T2 | T3 |
|-----------|---|--|---|
| Resources | Has a positive view on life, support of husband and family/friends. Has previous experiences of getting through and supporting each other in difficult times. | Has a strong will of her own and is motivated. Has closeness to support. | See above. Knows that the most important thing is to decrease stress. |

Table 7: Life-world resources of a female patient 64 years

| Time | T1 | T2 | Т3 |
|-----------|--|--|--|
| Resources | Have always wanted to be physically active and have a strong will. Good at finding information about her illness, exercise, and diets. Feels hindered by shortness of breath and fatigue but hope this will improve after medical procedure and medication adjustment. | Is very motivated to return to the physical abilities she had before the infarction. | Is motivated to "get well" and to "feel well". |

Table 8: Health resources of female patient 70 years





| Category | Codes | Examples |
|--------------|---|---|
| 1. Goals | a) Medical/health (medication adherence, smoking, diet etc.) b) Lifeworld (goals that concern the patients' social or life situation. Long/mid-term and immediate goals.) c) Missing (no goal documented) | a) Medical goal: "Increase physical activity to 10.000 steps a day. Stop smoking" b) Long-term lifeworld goal: "Planning to retire next year.". Mid-term lifeworld goal: "Return to previous activity-level with fishing, gardening, basketry and painting". Immediate lifeworld goal: "work in allotment garden, be with grandkids, dance". |
| 2. Resources | a) Medical/health perspective (standard resources, not socially contextualized but mostly consisting of motivational language) b) Lifeworld perspective (socially contextualized resources) | a) "Is willing to stop smoking"b) "Family members are very supportive" |

contextualized resources)

Table 1 Coding frame for goals and resources

| Time | T1 | T2 | T3 |
|-------|--|---|---|
| Goals | Return to your work as a bookbinder. Engage in their hobbies that were out in nature, museums, music, cultural history, antiques, archaeology, etc. Continue cycling a couple of miles / day. Diet as low cholesterol, in the future has his own studio. | Getting started with cycling and other interests. Has started with the goal that was set at the hospital. | Cycles daily. About 2 hours / day. Desires - find a place to develop bookbinding, paper marbling. |

Table 2: Lifeworld goals of a male patient 61 years old.

| Time | T1 | T2 | Т3 |
|-------|-------------------------------|--------------|----------------------------|
| Goals | Being able to go on a holiday | See earlier. | Lose weight. Be able to go |
| | trip to Turkey in March, as | | to Turkey in March. |
| | well as losing weight. | | |

Table 3: Lifeworld and health goals of a male patient 74 years old.

| Time | T1 | T2 | T3 | |
|------|----|----|----|--|

| Goals | Live a long life like his | As previously. | Return to previous physical |
|-------|--------------------------------|-------------------------|-----------------------------|
| | mother (106 years). | Starts going to the gym | strength. |
| | Write a book. | tomorrow. | |
| | Return to physical activity: 3 | | |
| | times/week walk + gym. | | |
| | Get out and fly with his son. | | |
| | | | |

Table 4: Changing goals of a male patient 74 years old

| Time | T1 | T2 | T3 |
|-------|---|---|-------------|
| Goals | Return to the same physical level as before the illness. Reduce weight to 74 kg. | See earlier. Has lost 2 kg in weight, has 2 left. | See earlier |

Table 5: Health goals of a male patient 72 years old

| Time | T1 | T2 | Т3 |
|-----------|---|---|----------------------------|
| Resources | Tight social network, feels | Doesn't see any hinders. | Positive – no worries – no |
| | good, doesn't experience any hindrance to achieve goals | Good contact with children and grandchildren. | depressive thoughts |

Table 6: Lifeworld and health resources of a male patient 72 years

| Time | T1 | T2 | Т3 |
|-----------|---|--|---|
| Resources | Has a positive view on life, support of husband and family/friends. Has previous experiences of getting through and supporting each other in difficult times. | Has a strong will of her own and is motivated. Has closeness to support. | See above. Knows that the most important thing is to decrease stress. |

Table 7: Lifeworld resources of a female patient 64 years

| Time | T1 | T2 | T3 |
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| Resources | Have always wanted to be physically active and have a strong will. Good at finding information about her illness, exercise, and diets. Feels hindered by shortness of breath and fatigue but hope this will improve after medical procedure and medication adjustment. | Is very motivated to return to the physical abilities she had before the infarction. | Is motivated to "get well" and to "feel well". |

Table 8: Health resources of female patient 70 years

