BMJ Open

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Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2015-009403
Article Type:	Research
Date Submitted by the Author:	15-Jul-2015
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Primary Subject Heading:	Health services research
Secondary Subject Heading:	Health services research
Keywords:	Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Change management < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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

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Keywords:

Quality of health care, Patient-Centered Care, Continuity of patient care, Evidence-based practice, Goal oriented care

Word count, excluding title page, abstract, references, figures and tables: 3785

ABSTRACT

Objectives: Patients with complex long-term needs experience multiple parallel care processes, which may have conflicting or competing goals, within their individual Patient Trajectory (iPT). The alignment of multiple goals of is often implicit or non-existent, and has received little attention in the literature. Research questions: 1) What goals for care, relevant for the iPT can be identified from the literature? 2) What goal typology can be proposed based on goal characteristics? 3) How can professionals negotiate a consistent set of goals for the iPT?

Design: Document content analysis of health service research papers, on the topic of "goals for care".

Setting: With increasing prevalence of multimorbidity, guidance regarding the identification and alignment of goals for care across organizations and disciplines is urgently needed.

Participants: 70 papers that describe "goals for care", "health" or "the good health care process" relevant to a general iPT, identified in a step wise structured search of Medline, Web of Science and Google Scholar.

Results: We developed a goal typology with four categories: Three are professionally defined:1) Functional, 2) Biologic/ Disease and 3) Adaptive goals. The fourth is the patient's personally defined goals. Professional and personal goals may conflict, in which case goal prioritization by creation of a goal hierarchy can be useful. We argue that the patient has the moral and legal right to determine the goals at the top of such a goal hierarchy. Professionals can then translate personal goals into realistic professional goals such as standardized health outcomes linked to evidence based guidelines. Thereby, goals are aligned with one another, the iPT will be truly patient centered, and care follows professional guidelines.

Conclusion: Personal goals direct professional goals and define the success criteria of the iPT. However, making personal goals count require brave and wide-sweeping attitudinal, organizational and regulatory transformation of care delivery.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Multiple care processes within the individual Patient Trajectory (iPT) are often guided by implicit and possibly conflicting goals for care.
- The health service research literature is the key arena for professional discussion regarding what the goals of care are or ought to be, yet goal-conflict within the iPT has received scant attention.
- As no formal set of keywords define this set of papers, we may have missed papers that could have met our inclusion criteria.
- We made a document content analysis of health service research documents that describe "goals for care", "health" or "the good health care process" relevant to the general iPT and on the basis of this developed a goal-hierarchy for goal alignment in iPTs.
- This paper work is mainly theoretical. Further research should test the usefulness of a goal-

hierarchy in care for patients with complex long-term needs.

INTRODUCTION

The individual Patient Trajectory (iPT) for persons with multiple long-term conditions (LTCs) consists of multiple parallel care processes.[1] Ideally, the iPT for a patient with multi-morbidity is guided by the patient's priorities and an alignment of all professionally driven care processes and their goals. However, in an increasingly fragmented and specialized health care system, each specialist tends to take responsibility for only one care process. In addition patients and informal caregivers contribute to the care process according to personal goals, which may or may not be aligned with professional goals.[2] As goals for care are often implicit, patients with multiple LTCs at best, experience a confusing iPT due to many unaligned goals for care. At worst, the iPT might grind to a deadlock between hidden, unclear, overwhelming and conflicting goals.[2-4].

Understanding the problem is half of the answer.

The following case story is but one in a larger case series of patients with multiple LTCs, all displaying the same deep system disconnects.[3] Alfred, a 75-year old widower, suffers from five potentially life-threatening conditions: generalized atherosclerosis including an aortal aneurysm, atrial fibrillation, congestive heart failure, renal failure and recurrent duodenal ulcers. Alfred had 34 separate encounters with the health care services (GP visits, out-patient visits and hospital admissions) the last year, including 98 days in hospital over 4 emergency admissions. Figure 1 outlines the health services involved in his care and their focus:

In our interview with him, Alfred expressed appreciation for the care he had received, but had two main concerns:

- **Transport**: Alfred became a widower 3 years ago, but has recently found a lady friend whom he wishes to visit. However, Aflred's has lost his driver's license due to health issues and public transport is unavailable. No one has addressed Alfred's need for disabled transport.
- **Medications**: Alfred said, "*I take 20 tablets a day. I don't understand what they are all good for. (...) If I am not careful, 15 or 30 min after I take them, I will either vomit or have diarrhea*." This happens every 2nd to 3rd day. The medical records at the hospital or GP does not mention this problem.

Alfred is surrounded by specialist, nursing services and a GP working towards the common goal of improving Alfred's overall health. However, they are addressing his intertwined problems through parallel series of consultations where each service limit their focus to their area of expertise and their professional standardized goals. None of the specialists have a dialogue with each other about Alfred's health issues. Alfred's two personal goals: to be able to visit his sweetheart and to solve the digestion problems which disrupt his medication regime, are effectively ignored. His providers tailor his care neither to his multi-morbidity nor to his personal preferences. The key questions are: Which overarching goals should have guided the overall process of Alfred's care, and who gets to prioritize between them?

Previous research on goal setting in care processes

The general goal of care is according to the WHO "*to promote, restore or maintain health*".[5] Consequently, the operationalization of the "health" concept by each contributor to an iPT, is fundamental to goal setting in health care. A rich literature outlines the variations in the concept of health across individuals, professions, organizations and culture.[6 7] Essays, editorials or individual opinions,[8 9] have articulated these variations, but they neglect to address how they influence the goal-setting practices of everyday care in an iPT-context. Tensions between the perspectives of health care professionals have been reported describing disagreement both within the professional context and between patients and professionals regarding the choice of goals.[10-16] Why these goals come to differ or contradict each other has not been explored, and none of these publications discuss how these tensions can be resolved in the context of an iPT.

There is an urgent need to for health professionals to understand the variation in the nature of goals for care and the process of goal setting within context of an iPT. We have found no other studies that examine this subject. The explicit research questions of this study are:

- What goals for care, that are relevant for the iPT, can be identified from the literature?
- What typology of goals can be proposed based on goal attributes?
- How can professionals negotiate a consistent set of goals for the iPT?

METHODS AND MATERIAL

Material

This is a document content analysis of selected health service research papers, according to methods described by Prior [17 18], Krippendorf and Tjora.[19 20] The health service research literature is the most important knowledge base for health care professionals in Western countries, and the key arena for professional discussion regarding what the goals of care are or ought to be. These documents provide the basis for our interpretative analysis of health researcher's views of what "health care's" goals are or should be.

Individualized care goals are operationalizations of the general goal: "*to promote, restore or maintain health*".[5] Included documents, hereafter called "goal papers", were therefore articles in scientific journals that describe "goals for care", "health" or "the good health care process" relevant to the general iPT seen from the perspective of one or more roles/ disciplines involved in the iPT. Papers relevant only for episodes of care or specific types of iPTs (i.e. a narrow condition specific iPT) were excluded. There is no cross-disciplinary set of "key-words" that uniformly identify "goal-papers". For example medical ethicists discuss goals of care in terms of "beneficence" and "autonomy", while the medical field uses terms like "outcomes" and "quality". We defined goals described by similar goal-terminology as separate "goal-concepts". Our aim was not to perform exhaustive searches to flush out all goal-concepts or even all papers within a concept. Rather we aim to identify a broad set of examples of distinct goal-concepts that form the basis for development of a goal-typology. We therefore devised our own step-wise iterative search strategy, where we identified as many different distinct goal-concepts as possible until additional searches no longer contributed to our ongoing goal-typology analysis (saturation). The steps of the search were:

- Three books which review the terms "health", "medicine", and "disease" respectively.[6 7 21]
- A set of seminal papers defining goals for care already familiar to the authors: WHO health definitions, works of Donabedian and the Institute of medicine.[22-25]
- Systematic searches performed in 2013-14 in Medline and Web of Science (ISI), which cover most health disciplines journals,[26] on the terms: "concepts of health", "goals for care/health" and "quality of care", limited to English language, Reviews and "health service research".
- A snowballing process: When additional goal-concepts were identified, we made supplementary searches in Google Scholar, Medline and/ or Web of Science® to uncover more papers describing it. Searches ended when we had enough material to make a description of the essential characteristics and typical examples of goals linked to the goal-concept. These searches continued until manuscript submission in 2015.

We included 70 "Goal-papers", (see appendix B) of which 34 focused on the goals for care, 17 focused on the process of care and 19 focused on both. The first paper is from 1927, but more than half are published in 2000-12. The authors of these papers represent either WHO or locations with a predominant Western cultural background (North America, Australia, Europe).

Analyses

The included papers were subjected to stepwise deductive – inductive content analysis using Nvivo software (v10, from QSR ®). All authors contributed to and commented on analyses to ensure the development of meaningful categories across professional boundaries. We developed a two level analysis:

Identifying goal-concepts: The unstructured papers were coded to reflect the underlying goal terminology, using the paper's own vocabulary.[19 20] We applied no theoretical framework at this stage. We contrasted and compared the identified codes so that all papers sharing the same terminology were grouped, thereby identifying a goal-concept. A goal-concept guide, (enclosed as appendix A) described a goal's' defining feature, the typical goals, and examples references, ensured coding consistency across papers.

Developing a goal-typology and goal relationships: The following theoretical lenses were applied to the goal-concepts identified in the first level analysis:

- **Disablement model**: Based on Verbrugge and Jette's disablement model we created a goal typology which we applied to our set of goal-concepts.[27-29]
- **The ethics of authenticity**,[30] and specifically Taylor's work describes the emphasis that Western culture places on the person.[31] With reference to this framework, we grouped goal-concepts in terms of how well they accommodate the patient's personalized goal setting in the iPT.
- **Goal theory was used to create** a model for goal alignment within the iPT.[32-34]

Ethics and authors' roles.

The first author, who is a physician and health service researcher and is the guarantor of the study, performed all searches and analyses in dialogue with the co-authors. The co-authors represent a multi-

professional background (medicine, psychology, nursing, electronic-health, medical sociology and medical anthropology). Some authors had considerable patient experience.

All authors helped formulate the original research questions, had full access to the data and provided input for the work in terms of relevant papers, critical review of drafts and methodology, and contributions to the final manuscript. We comply with the Equator network's recommendation of "Standards for reporting Qualitative research" developed by O'Brien.[35] Data did not include sensitive material. Ethics or data privacy approvals were therefore unnecessary.

RESULTS

What goals for care that are relevant for the iPT, can be identified from the literature?

We developed a set of 14 concepts of goals for health care in our first level analysis, each defined by a common terminology. For each concept, we made a statement that describes the goal-concept by use of the goal's affiliated goal terminology. (see Table 1and Appendix A).

Table 1: Concepts of goals for care identified in first-level coding.

1. Health is balance and homeostasis
2. Biomedical health
3. Health is to achieve desired health outcomes
4. Health is disease prevention
5. Bio-psycho-social health
6. Health is freedom of disability
7. Health is a resource for wellbeing
8. Health is a resource for everyday life
9. Health is a resource for self-care
10. Health is a resource for autonomy
11. Health is a resource for personhood
12. Health is a resource for spirituality
13. Health is socially constructed
14. Health is determined by supernatural powers. (This is perhaps the oldest human health model, but is untenable within a health care context. Excluded from further analyses)

What typology of goals can be proposed based on goal attributes?

Goal framework I – based on Disablement model:

According to theories of Disability, ability or functional goals, is the result of meeting relevant Biologic, Adaptive Personal coping and Adaptive Environmental goals.[27-29 36 37] A negative development in these goals produce disability, while strengthening supports function and ability.

- **Functional goals**: Health is a resource for a desired functional ability in a social context. (Goals 6 - 12), and the goal of care is to restore function. Goals range from biologic function (i.e. urinary continence) at one end, to highly personalized skills (i.e. mountain climbing) that define a person's identity at the other.
- **Biological goals**: Health is absence of biological malfunction or disease. (Goals 1-5) Diseases have a biological basis or etiology for symptomatology and signs. The goal for care is to remove the cause of disease and relieve symptoms through biologic manipulation.
- **Social Adaptive goals**: Health is a social construct. (Goal 13, from Table 1) Social goals reduce the impact of a health condition and prevent or create opportunities for health through social action. These goals can be further sub-divided into goals to enhance "Adaptive personal coping skills" and goals that create an "Adaptive environment".

With the exception of the papers on the Disablement model (Goal 6), we found that authors neither discuss nor try to envision how they would position their goal relative to other goals. Most authors focus on isolated care goals and processes that lie firmly within their professional domain, giving little occasion to recognize or discuss a potential "clash" with other goals in an iPT. The disablement model however, views "Functional ability" as an overarching goal that is supported by Disease/ Biologic and Adaptive measures as shown in Fig 2.

Goal framework II - based on the ethics of authenticity

Although the Goal typology I incorporates all relevant goal-concepts of Table 1, it does not really accommodate the essence of the three "person-centered" goal-concepts (Goals 10-12). Western culture places a strong emphasis on the person and the person's duty and a right to exercise his/ her free-will to create a "life project" for oneself. Individuals build and communicate their identities through words and actions that reflect their current values and commitments.[38] Although the individual is considered the author of his/ her identity, identity is developed in a social context which shapes and sets boundaries to individual pursuits. An identity is in constant development, contingent on dialogue, interactions, and re-actions to who he/she is. Ignoring the individuality of the person, depersonalization, is experienced as deeply hurtful.[38] Through the lens of Authenticity ethics, we established two new goal groups:

1) **The patient's personal goals:** honor the patient's right to make decisions about his/ her personal matters, which includes health matters. The "autonomy", "personhood" and "spirituality" goals (goals 10-12) belong here. They amount to a personal construction of what "health» means to the individual and health care's role is to support them as far as realistically possible.
2) **The professional goals**: are the remaining goals from Table 1, defined and set by professionals in terms of Function, Biology and Adaptive goals (Goals 1-9 and 13).

We have now set the patient's "personal goals" apart from the "functional" goals, but otherwise Goal-framework I is unchanged. To understand how "personal" goals can be grafted onto this framework it is necessary to examine personally and professionally set goals closer.

The tension between personal and professional goals:

Professionals are highly specialized in solving a relatively narrow set of biological or functional problems.

Most professionals are not at all prepared to solve the fluctuating broad personal goals linked to a "life project", as a professional by definition focuses on a limited set of problems. Specialization requires a grouping of similar "problems" (i.e. patients with similar diagnoses). All problems within a "group" share the same essential attributes. A diagnosis, such as appendicitis, represents a group of patients with the same condition. All members of the "appendicitis" group share the same cause for disease and will benefit from the same set of interventions.

The professional mode of operation is thus strongly "depersonalized" in the sense that professionals gain experience, test and develop their knowledge and tools in the context of groups of people. In order to identify the correct course of action, a professional's primary task is to place the patient in the correct group. Once the professional has classified the patient's problem, the specialist can draw upon a wealth of knowledge, from past and current patients, from personal experience and the experience of other specialists that applies to the group in question. The bottom line is that health professionals regularly treat individuals as representatives of a "group". Any professional who fails to aim for professionally set goals could face legal prosecution. It follows that it is in the professional's self-interest to satisfy "professional" requirements.

The pain of being ignored as a person

Thus, it happens, that patients who are already experiencing vulnerability in terms of bad health, may in addition experience the pain of "disappearing" as persons with a unique identity. The institutionalized trappings of health-care treats them as an anonymous representative of a group of patients. The most extreme examples of this tension comes from palliative care, where professionals feel compelled to promote professionally set goals even when it is acknowledged that the patient is dying and further treatment is in contradiction with the patient's written "living will".[39] The traumatizing effects of depersonalization has been well described by many patients.[2 4]

The alignment of multiple goals - general goal theory

It seems intuitively difficult to respect both professionalism and personal goals at the same time, but goal-setting theory shows how consistent set of goals are created. Goals represent the desired future state of affairs. They serve to direct resources towards activities that support the desired state, and away from irrelevant activities.[34] Both in case of conflicting goals or complementary goals that compete for resources, an explicit prioritization of goals is called for.[32-34] This is done by creating a goal hierarchy, where the highest level goal invokes a vision of the desired future, which is then broken down into sub-goals and tasks.[32 33] We have previously argued that professional's skills and knowledge pertain to groups. Only the individual can provide a legitimate "vision" for the future desired state of the individual. We propose that Personal goals legitimize which professional goals to pursue, and how to pursue them. This is a value-based choice sustained by the ethics of authenticity described above and by:

- **Western legislation**: Human rights declaration and national legislations support the individual's right to make their personal choices count in all aspects of life, including health.
- **Ethics**: The balance between "paternalistic beneficence" and "patient autonomy" challenges health personnel with two moral duties: "*The first is to respect the self-determination or autonomy of the patient. The second, often neglected duty, is to help restore that autonomy or help establish*

it when it is absent."[40 41]

- **Effectiveness studies**. There is evidence that patient involvement and engagement in care, i.e. care where the patient's own priorities are heeded, have better health and functional outcomes.[42 43]

By putting the patient's personal goals on top of the goal-hierarchy, the tension between personal and professional goals effectively disappears. Professional goals are the Lego-blocks that build the iPT in accordance with personal goals. The tension between personal and professional goals surfaces only when personal goals are held equal or subordinate to professional goals. The resulting goal-framework is depicted in figure 3:

DISCUSSION

Main findings

Based on document analysis of 70 health service research papers on health concepts and goals for care, we created a goal typology and goal hierarchy relevant for the iPT. The individual's personal goals are at the top of the goal-hierarchy. Health professionals then translate personal goals into realistic professional goals within Functional, Biological and Adaptive domains. Such a goal hierarchy clarifies the relationships between personal and professional goals. Goal attainment at the personal level both defines and guides successful care.

Strengths and Limitations:

We have not found other papers that examine and analyze the variation of goals for care across relevant disciplines and its implications in an iPT context. Thus, this appears to be an original contribution to the discussion of how to achieve continuity of care, high quality care and personalized care. Our multi-professional background was vital to both identifying and understanding the epistemological and professional implications of differing goals across professional and lay roles, and the trustworthiness of our analysis.

We may have missed papers that could have met our inclusion criteria, however, our aim was not an exhaustive search for all possible goals for care, but rather a large enough sample of goal papers that could serve as a basis for the development of a goal-typology. Our goal typology seems robust, as publications identified late in the search process did not bring new goal-types, indicating a saturation of the material.

Previous research

The person centered care literature has long underlined the importance of the patient's personal goals in all care decisions.[44 45] A goal-oriented approach, where goals are set by the patient was proposed already in 1968 and was recently re-visited by Reuben.[46 47][45] However, the person-centered care movement has failed to merge the strengths of disease- and person-centered care practices. Understanding the relationships between personal and professional goals, where personal goals are the overarching guide to the setting of professional goals, is key to the delivery of truly personalized care.

Implications for practice

Already in 1927 Peabody berated his colleagues for losing sight of the patient's personal needs.[48] Although the call for personalized care has only grown, it still seems out of reach in modern health care.[1 2 4 49]. In light of our findings, this is not surprising, since the tensions between personalized and professional goals are inherent to professionalism and specialization, and is still poorly understood. The care system is, currently designed to deliver single disease episodic care that supports professional goals.[1] Specialists presently have no benefit from changing their scope and goals from a relatively tidy professional focus, which may be challenging and complex enough in and of itself, and add on to it the personal fuzzy unspecific cross-disciplinary personal goals of patients. Turning care processes around so that professionals truly start with and adhere to personal goals will require wide-sweeping, brave and visionary efforts on the part of health managers.

While this paper underlines the importance of personal goals for care, this paper is not an argument for a unilateral patient command of health care decisions and resources. The operationalization of goals of care must take place in a shared decision making process, where the professional duty is to translate the personal goals into goals that are realistic professional goals aligned with clinical, financial, ethical and regulatory boundaries.[44 50] Situations where professional goals and means are incompatible with the personal goals will remain a dilemma.[51] However, a goal-hierarchy may be an appropriate tool to identify and discuss openly and nonjudgmentally the clashes of interest that occur when patients find that professional advice is in contradiction to their wishes.

Health personnel routinely experience situations that are too urgent, patients who are too ill, too cognitively impaired, too emotionally upset or feel too un-informed to make confident judgments about their goals. We realize that personal goals might not be available to guide care at these times. However, health professionals are well taught regarding which professional goals to move towards first in such situations. The challenge is perhaps the opposite: As soon as the emergency is over, in the transition from acute care to follow-up care, patients must be actively engaged in re-assessing professionally set goals.

Implications for future research.

Many issues emerge from the findings in this study. There is a need to test whether goal concepts, which were not included here, could have changed our analytic results. Scholars from other cultural contexts are invited to reflect on the validity of our goal hierarchy. This is a theoretical piece of work, and the proposed goal-setting model needs testing in real care settings to assess if better alignment between personalized goals and professional goals improves continuity and quality of care across professional and organizational borders.

This model of goal-setting does not solve the delicate and difficult issue of gaining insight into "what is important" for the individual patient. Nor does it relieve professionals of the duty of translating "what is important" into professional goals that are realistic. It does however give professionals a clear and unambiguous guide to the primary goal for care: to improve and maintain health, where health is defined by "what is important to the patient". Personalized goals are not "nice to have", they are at the core of what health care is about. Care should be evaluated in terms of meeting the personal goals set by patients. Making personal goals set the course for care, can be likened to a paradigmatic shift that requires

require brave wide-sweeping regulatory, organizational and attitudinal reformation within our care systems.

ACKNOWLEDGEMENTS

We are grateful to the Norwegian Research Council and Regional health authorities, Northern Norway for their financial support.

COMPETING INTERESTS

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare that (1) GKRB, AS, DG, AS. NF, CR and VF have no support from any company for the submitted work; (2) GKRB, AS, DG, AS. NF, CR and VF have no relationships with any companies that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) GKRB, AS, DG, AS. NF, CR and VF have no non-financial interests that may be relevant to the submitted work.

FUNDING AND TRANSPARENCY DECLARATION:

This study was supported by research grants from the Regional health authorities, Northern Norway (grant # HST1024-11 5396), and the Norwegian research council (grants # 213973, and # 232184). The authors have no conflicts of interest that could influence the contents of this paper. Data sharing of full list of publications included in analyses are available from the corresponding author at request. The lead author (the manuscript's guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained

AUTHOR'S CONTRIBUTIONS

All authors developed the initial research question. GKRB, VF, DG, CR and AS secured support and funding for data-collection and analyses. GKRB is responsible for data-collection, primary analyses and first draft of manuscript. All authors had full access to the data and provided input for in terms of relevant additional papers, critical review of drafts and methodology, and contributions to the final manuscript. All authors read, edited and approved the final manuscript.

DATA SHARING STATEMENT

The empirical data on which this paper is based are the selection of health service literature papers included in our document analysis. The full list of publications are given in appendix B.

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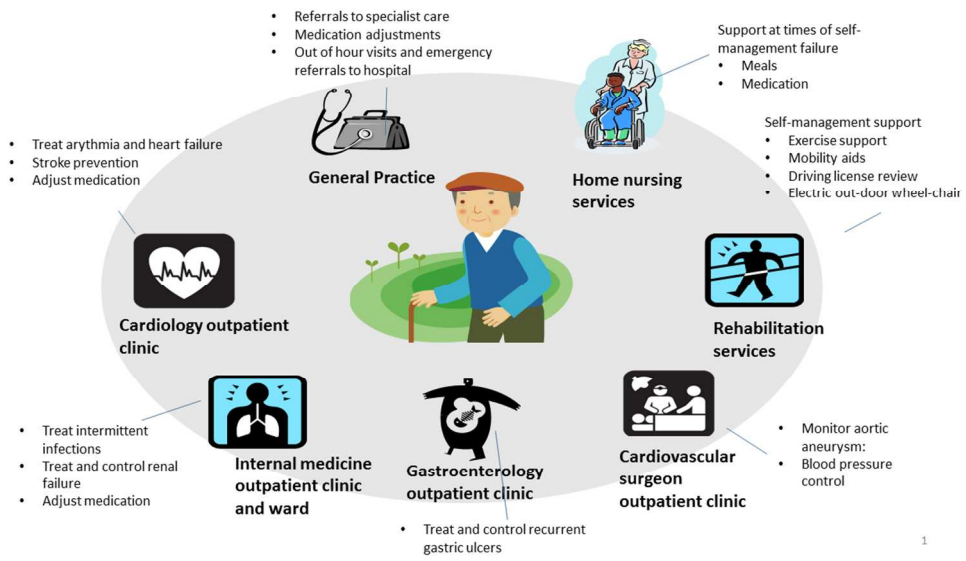
LEGENDS for FIGURES

Figure 1: The health services involved in Alfred's individual Patient Trajecotory (iPT) and their main focus of care according to the electronic medcial record at hospital and GP, Tromsø Norway, 2012

Figure 2: Goal framework I, inspired by Verbrugge and Jette[27-29]

Figure 3: Goal framework II - The personalized hiearchical health care goal model.



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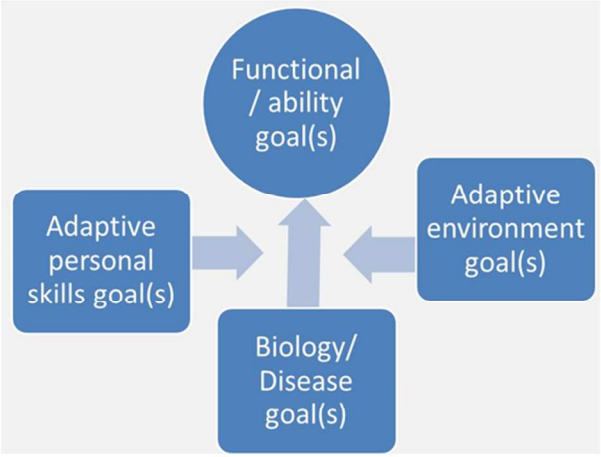

254x190mm (96 x 96 DPI)

APPENDIX A

Presentation of goals for care, their defining characteristics and typical concrete goals associated with them.

Concepts of goals for care	Defining features	Typical goal of care is…
1. Balance and homeostasis	Health is a balance between external/ internal forces, bodily components or bodily physiological processes. Characterized by words like balance, equilibrium, homeostasis, allostasis, holistic.	...is to re-establish balance or homeostasis.(1)
2. Biomedical	Health is absence of disease. Diseases are caused by natural forces, which disturb biological -anatomical structures, -biochemical and/or -physiological processes. Disease definitions are agreed upon by the medical profession.	...is to provide the Evidence Based Medicine (EBM) that is likely to remove root cause of disease.(2-4)
3. Health outcomes	Health is the observable presence/ absence of a health outcome defined as relevant for any given disease.	...is to provide EBM likely to produce desired outcome and minimize risks.(5-7)
4. Disease prevention	Health is absence of disease, and depends on disease prevention through identification of increased risk for-, and/or early signs of a disease.	...is to provide EBM likely to postpone disease onset/ deterioration.(8, 9)
5. Bio-psycho-social	Health is absence of disease. Builds on bio-medical concept, but emphasizes that disease is experienced and observed in terms of human dysfunction, within the unique biological, psychological and social context of each human being.	...is to provide EBM likely to remove cause of disease and/or improve function in the personalized context.(4)
6. Disability	Health is defined by the person's ability to perform "*the necessary, usual, expected and personally desired functions*". (10, 11) Disability arises from the condition itself, and ability is modified by personal coping skills and social- or environmental adaptions to disease.	...is to restore functional ability through treatment of condition, enhancement of coping skills and/ or manipulation of environment.(10-12)

7. Health is a resource for wellbeing	Health is understood as wellbeing, in bio-, psycho- , emotional-, social- and spiritual terms. Texts are unspecific in terms of how to recognize poor health.	...is to restore wellbeing.(13, 14)
8. Health is a resource for everyday life	Health is understood as bio-psycho-social functioning which supports activities of everyday life.	...is to recognize and address deficits in activities of daily life.(2, 15, 16)
9. Health is a resource for self-care	Health is the ability or capacity for self-care.	...is to recognize compromised self-care and to support self-management.(16-18)
10. Health is a resource for autonomy	Health is the ability to function autonomously, in terms of making decisions, to pursue decisions within social context and ability to execute decisions.	...is to recognize and act to remove factors, which restrict individual autonomy.(16, 19, 20)
11. Health is a resource for personhood	Health is the foundation for defining who we are, our identity, our «personhood», including our spiritual beliefs. Threats or damage to our identity causes **suffering**, which is akin to poor health.	...is to detect the effects of poor health on identity and understand the suffering this produces in the individual, and then act to alleviate suffering.(21-24)
12. Health is a resource for spirituality	Health both supports a spiritual belief, and health supports the individual's spiritual activities. Spirituality connects the individual to a larger cause or religious belief. Spiritual beliefs can also support health by creating frameworks for sense and meaning in times of suffering.	...is to restore ability to align life choices and actions with beliefs, and/ or to understand health and suffering in terms of the belief system.(21, 25-27)

13. Health is socially constructed	Health is a social construct, which we understand in terms of the cultural, regulatory and historical context of the society in question. The impact of a condition depends on the society's ability to make resources for health available to the individual.	… is to make social- and environmental resources available to the person, such as health care, information, social support and physical aids which can support the person's ability to manage health.(3, 10)
14. Supernatural	Health is thought to be caused and maintained by supernatural or religious forces.. Supernatural health is perhaps the oldest health model in human history. Typical interventions appeal to higher religious or supernatural forces, via institutions found outside of health-care systems. While we recognize its existence, we position our analysis within a health care context, which is why we have excluded this health-concept from further analyses	…is to release religious/ supernatural forces.(3, 28)

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Appendix B – Papers included in primary analyses

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Standards for reporting Qualtitative research(1)

	Name	Description	Application to Submitted manuscript
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus .group) is recommended	Done see title
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Done – see abstract
S3	Introduction	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Done – see introduction
S4	Research Q	Purpose of the study and specific objectives or questions	Done – See research questions
S5	Approach	·Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale	Document content analysis. Inductive – deductive theoretical approach. Interpretative and theory driven approach See methods,
S6	Researcher characteristics	·Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research .questions, approach, methods, results, and/or transferability	Described, see methods
S7	Context	Setting/site and salient contextual factors; rationale	Described, see introduction
S8	Sampling	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale	Described, see methods
S9	Ethics	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Described, see methods
S10	Data collectoin	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures	Described, see methods

		in response to evolving study findings; rationale	
S11	Data collection instruments	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Not applicable
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Described: Goal papers > goal terminology > goals > goal typologies
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	Described, Nvivo
S14	Data analysis	·Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale b	Described, see methods
S15	Techniques of trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	Described – use of multiprofessional author group
S16	Synthesis and interpretations	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Described - see results.
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	See appendix
S18	Integration with prior work, implictations, transferabiltiy and contributions to the field	·short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field	See discussion
S19	Limitations	Trustworthiness and limitations of findings	See discussion
S20	conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Not applicable
S21	Funding	Sources offunding and other support; role offunders in data collection,	Reported.

		interpretation, and reporting	

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BMJ Open

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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2015-009403.R1
Article Type:	Research
Date Submitted by the Author:	20-Oct-2015
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Primary Subject Heading:	Health services research
Secondary Subject Heading:	Health services research, Ethics, Health policy, Patient-centred medicine, Qualitative research
Keywords:	Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Change management < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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

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Keywords:

Quality of health care, Patient-Centered Care, Continuity of patient care, Evidence-based practice, Goal oriented care

Word count, excluding title page, abstract, references, figures and tables: 3785

ABSTRACT

Objectives: Patients with complex long-term needs experience multiple parallel care processes, which may have conflicting or competing goals, within their individual Patient Trajectory (iPT). The alignment of multiple goals of is often implicit or non-existent, and has received little attention in the literature. Research questions: 1) What goals for care, relevant for the iPT can be identified from the literature? 2) What goal typology can be proposed based on goal characteristics? 3) How can professionals negotiate a consistent set of goals for the iPT?

Design: Document content analysis of health service research papers, on the topic of "goals for care".

Setting: With increasing prevalence of multimorbidity, guidance regarding the identification and alignment of goals for care across organizations and disciplines is urgently needed.

Participants: 70 papers that describe "goals for care", "health" or "the good health care process" relevant to a general iPT, identified in a step wise structured search of Medline, Web of Science and Google Scholar.

Results: We developed a goal typology with four categories: Three are professionally defined:1) Functional, 2) Biologic/ Disease and 3) Adaptive goals. The fourth is the patient's personally defined goals. Professional and personal goals may conflict, in which case goal prioritization by creation of a goal hierarchy can be useful. We argue that the patient has the moral and legal right to determine the goals at the top of such a goal hierarchy. Professionals can then translate personal goals into realistic professional goals such as standardized health outcomes linked to evidence based guidelines. Thereby, goals are aligned with one another, the iPT will be truly patient centered, and care follows professional guidelines.

Conclusion: Personal goals direct professional goals and define the success criteria of the iPT. However, making personal goals count require brave and wide-sweeping attitudinal, organizational and regulatory transformation of care delivery.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Multiple care processes within the individual Patient Trajectory (iPT) are often guided by implicit and possibly conflicting goals for care.
- Goal-conflict within the iPT has received scant attention. By use of "Goal-hierarchies" we show that when personal goals are set above professional goals, this may clarify and resolve tension between potentially conflicting goals.
- Reflecting upon how professionals ought to engage with patients in vulnerable situations about their personal goals is a topic of its own right, but lies outside the scope of this paper.
- We identified potential goals from the health service research literature, but as no formal set of keywords define this topic, we may have missed papers that could have met our inclusion criteria.
- This paper work is mainly theoretical. Further research should test the usefulness of a goal-hierarchy in care for patients with complex long-term needs.

INTRODUCTION

The individual Patient Trajectory (iPT) for persons with multiple long-term conditions (LTCs) consists of multiple parallel care processes.[1] Ideally, the iPT for a patient with multi-morbidity is guided by the patient's priorities and an alignment of all professionally driven care processes and their goals. However, in an increasingly fragmented and specialized health care system, each specialist tends to take responsibility for only one care process. In addition patients and informal caregivers contribute to the care process according to personal goals, which may or may not be aligned with professional goals.[2] As goals for care are often implicit, patients with multiple LTCs at best experience a confusing iPT due to many unaligned goals for care. At worst, the iPT might grind to a deadlock between hidden, unclear, overwhelming and conflicting goals.[2-4].

Understanding the problem is half of the answer.

The following pseudonymised case story, published with patient consent by Berntsen et al, is but one in a larger case series of patients with multiple LTCs, all displaying the same deep system disconnects.[3] "Alfred", a 75-year old widower, suffers from five potentially life-threatening conditions: generalized atherosclerosis including an aortal aneurysm, atrial fibrillation, congestive heart failure, renal failure and recurrent duodenal ulcers. "Alfred" had 34 separate encounters with the health care services (GP visits, out-patient visits and hospital admissions) the last year, including 98 days in hospital over 4 emergency admissions. Figure 1 outlines the health services involved in his care and their focus:

In our interview with him, «Alfred» expressed appreciation for the care he had received, but had two main concerns:

- **Transport**: «Alfred» became a widower 3 years ago, but has recently found a lady friend whom he wishes to visit. However, Alfred has lost his driver's license due to health issues and public transport is unavailable. No one has addressed «Alfred»'s need for disabled transport.
- **Medications**: «Alfred» said, "*I take 20 tablets a day. I don't understand what they are all good for. (...) If I am not careful, 15 or 30 min after I take them, I will either vomit or have diarrhea*." This happens every 2nd to 3rd day. The medical records at the hospital or GP does not mention this problem.

«Alfred» is surrounded by specialist, nursing services and a GP working towards the common goal of improving «Alfred»'s overall health. However, they are addressing his intertwined problems through parallel series of consultations where each service limit their focus to their area of expertise and their professional standardized goals. None of the specialists have a dialogue with each other about «Alfred»'s health issues. «Alfred»'s two personal goals: to be able to visit his sweetheart and to solve the digestion problems which disrupt his medication regime, are effectively ignored. His providers tailor his care neither to his multi-morbidity nor to his personal preferences. The key questions are: Which overarching goals should have guided the overall process of «Alfred»'s care, and who gets to prioritize between them?

Previous research on goal setting in care processes

The general goal of care is according to the WHO "*to promote, restore or maintain health*".[5] Consequently, the operationalization of the "health" concept by each contributor to an iPT, is fundamental to goal setting in health care. A rich literature outlines the variations in the concept of health across individuals, professions, organizations and culture.[6, 7] Essays, editorials or individual opinions,[8, 9] have articulated these variations, but they neglect to address how they influence the goal-setting practices of everyday care in an iPT-context. Tensions between the perspectives of health care professionals have been reported describing disagreement both within the professional context and between patients and professionals regarding the choice of goals.[10-16] Why these goals come to differ or contradict each other has not been explored, and none of these publications discuss how these tensions can be resolved in the context of an iPT.

There is an urgent need to for health professionals to understand the variation in the nature of goals for care and the process of goal setting within context of an iPT. We have found no other studies that examine this subject. The explicit research questions of this study are:

- What goals for care, that are relevant for the iPT, can be identified from the literature?
- What typology of goals can be proposed based on goal attributes?
- How can professionals negotiate a consistent set of goals for the iPT?

METHODS AND MATERIAL

Material

This is a document content analysis of selected health service research papers, according to methods described by Prior [17, 18], Krippendorf and Tjora.[19, 20] The health service research literature is the most important knowledge base for health care professionals in Western countries, and the key arena for professional discussion regarding what the goals of care are or ought to be. These documents provide the basis for our interpretative analysis of health researcher's views of what "health care's" goals are or should be.

Individualized care goals are operationalizations of the general goal: "*to promote, restore or maintain health*".[5] Included documents, hereafter called "goal papers", were therefore articles in scientific journals that describe "goals for care", "health" or "the good health care process" relevant to the general iPT seen from the perspective of one or more roles/ disciplines involved in the iPT. Papers relevant only for episodes of care or specific types of iPTs (i.e. a narrow condition specific iPT) were excluded. There is no cross-disciplinary set of "key-words" that uniformly identify "goal-papers". For example medical ethicists discuss goals of care in terms of "beneficence" and "autonomy", while the medical field uses terms like "outcomes" and "quality". We defined goals described by similar goal-terminology as separate "goal-concepts". Our aim was not to perform exhaustive searches to flush out all goal-concepts or even all papers within a concept. Rather we aim to identify a broad set of examples of distinct goal-concepts that form the basis for development of a goal-typology. We therefore devised our own step-wise iterative search strategy, where we identified as many different distinct goal-concepts as possible until additional searches no longer contributed to our ongoing goal-typology analysis (saturation).

The first author, who is a physician and health service researcher and is the guarantor of the study,

performed all literature searches. The co-authors represent a multi-professional background (medicine, psychology, nursing, electronic-health, medical sociology and medical anthropology). Some authors had considerable patient experience.

The steps of the search were:

- Three books which review the terms "health", "medicine", and "disease" respectively.[6, 7, 21]
- A set of seminal papers defining goals for care already familiar to the authors: WHO health definitions, works of Donabedian and the Institute of medicine.[22-25]
- Systematic searches performed in 2013-14 in Medline and Web of Science (ISI), which cover most health disciplines journals,[26] on the terms: "concepts of health", "goals for care/health" and "quality of care", limited to English language, Reviews and "health service research".
- A snowballing process: When additional goal-concepts were identified, we made supplementary searches in Google Scholar, Medline and/ or Web of Science® to uncover more papers describing it. Searches ended when we had enough material to make a description of the essential characteristics and typical examples of goals linked to the goal-concept. These searches continued until manuscript submission in 2015.

We included 70 "Goal-papers", (see appendix A) of which 34 focused on the goals for care, 17 focused on the process of care and 19 focused on both. The first paper is from 1927, but more than half are published in 2000-12. The authors of these papers represent either WHO or locations with a predominant Western cultural background (North America, Australia, Europe).

Analyses

The included papers were subjected to stepwise deductive – inductive content analysis using Nvivo software (v10, from QSR ®). All authors contributed to and commented on analyses to ensure the development of meaningful categories across professional boundaries. We developed a two level analysis:

Identifying goal-concepts: The unstructured papers were coded to reflect the underlying goal terminology, using the paper's own vocabulary.[19, 20] We applied no theoretical framework at this stage. We contrasted and compared the identified codes so that all papers sharing the same terminology were grouped, thereby identifying a goal-concept. A goal-concept guide, (enclosed as appendix B) described a goal's' defining feature, the typical goals, and examples references, ensured coding consistency across papers.

Developing a goal-typology and goal relationships: The following theoretical lenses were applied to the goal-concepts identified in the first level analysis:

- **Disablement model**: Based on Verbrugge and Jette's disablement model we created a goal typology which we applied to our set of goal-concepts.[27-29]
- **The ethics of authenticity**,[30] and specifically Taylor's work describes the emphasis that Western culture places on the person.[31] With reference to this framework, we grouped goal-

concepts in terms of how well they accommodate the patient's personalized goal setting in the iPT.

- **Goal theory was used to create** a model for goal alignment within the iPT.[32-34]

Ethics and authors' roles.

All authors helped formulate the original research questions. The work progressed in iterative collaborative cycles between the first author and co-authors. All authors had full access to included papers and co-authors were iteratively provided with both written and oral presentation of coding and analytic results as these were developed regarding goal-typology, identification of relevant theoretical frameworks and the analytic results of their application. Co-authors then provided feedback in terms of insights and critical review in bilateral discussions, workshops and written feedback. All authors have read and approved the final manuscript.

We comply with the Equator network's recommendation of "Standards for reporting Qualitative research" developed by O'Brien.[35] Data did not include sensitive material. Ethics or data privacy approvals were therefore unnecessary.

RESULTS

What goals for care that are relevant for the iPT, can be identified from the literature?

We developed a set of 14 concepts of goals for health care in our first level analysis, each defined by a common terminology. For each concept, we made a statement that describes the goal-concept by use of the goal's affiliated goal terminology. (see Table 1and Appendix B).

Table 1: Concepts of goals for care identified in first-level coding.

1. Health is balance and homeostasis
2. Biomedical health
3. Health is to achieve desired health outcomes
4. Health is disease prevention
5. Bio-psycho-social health
6. Health is freedom of disability
7. Health is a resource for wellbeing
8. Health is a resource for everyday life
9. Health is a resource for self-care
10. Health is a resource for autonomy
11. Health is a resource for personhood
12. Health is a resource for spirituality
13. Health is socially constructed
14. Health is determined by supernatural powers. This view is in direct contradiction to modern health care foundations, which assume that human interventions affect health. Excluded from further analyses.

What typology of goals can be proposed based on goal attributes?

Goal framework I – based on Disablement model:

According to theories of Disability, ability or functional goals, is the result of meeting relevant Biologic, Adaptive Personal coping and Adaptive Environmental goals.[27-29, 36, 37] A negative development in these goals produce disability, while strengthening supports function and ability.

- **Functional goals**: Health is a resource for a desired functional ability in a social context. (Goals 6 - 12), and the goal of care is to restore function. Goals range from biologic function (i.e. urinary continence) at one end, to highly personalized skills (i.e. mountain climbing) that define a person's identity at the other.
- **Biological goals**: Health is absence of biological malfunction or disease. (Goals 1-5) Diseases have a biological basis or etiology for symptomatology and signs. The goal for care is to remove the cause of disease and relieve symptoms through biologic manipulation.
- **Social Adaptive goals**: Health is a social construct. (Goal 13, from Table 1) Social goals reduce the impact of a health condition and prevent or create opportunities for health through social action. These goals can be further sub-divided into goals to enhance "Adaptive personal coping skills" and goals that create an "Adaptive environment".

With the exception of the papers on the Disablement model (Goal 6), we found that authors neither discuss nor try to envision how they would position their goal relative to other goals. Most authors focus on isolated care goals and processes that lie firmly within their professional domain, giving little occasion to recognize or discuss a potential "clash" with other goals in an iPT. The disablement model however, views "Functional ability" as an overarching goal that is supported by Disease/ Biologic and Adaptive measures as shown in Fig 2.

Goal framework II - based on the ethics of authenticity

Although the Goal framework I incorporates all relevant goal-concepts of Table 1, it does not really accommodate the essence of the three "person-centered" goal-concepts (Goals 10-12). Western culture places a strong emphasis on the person and the person's duty and a right to exercise his/ her free-will to create a "life project" for oneself. Individuals build and communicate their identities through words and actions that reflect their current values and commitments.[38] Although the individual is considered the author of his/ her identity, identity is developed in a social context which shapes and sets boundaries to individual pursuits. An identity is in constant development, contingent on dialogue, interactions, and re-actions to who he/she is. Ignoring the individuality of the person, depersonalization, is experienced as deeply hurtful.[38] Through the lens of Authenticity ethics, we established two new goal groups:

1) **The patient's personal goals:** honor the patient's right to make decisions about his/ her personal matters, which includes health matters. The "autonomy", "personhood" and "spirituality" goals (goals 10-12) belong here. They amount to a personal construction of what "health» means to the individual and health care's role is to support them as far as realistically possible.
2) **The professional goals**: are the remaining goals from Table 1, defined and set by professionals in terms of Function, Biology and Adaptive goals (Goals 1-9 and 13).

We have now set the patient's "personal goals" apart from the "functional" goals, but otherwise Goal-framework I is unchanged. To understand how "personal" goals can be grafted onto this framework it is necessary to examine personally and professionally set goals closer.

The tension between personal and professional goals:

Professionals are highly specialized in solving a relatively narrow set of biological or functional problems. Most professionals are not at all prepared to solve the fluctuating broad personal goals linked to a "life project", as a professional by definition focuses on a limited set of problems. Specialization requires a grouping of similar "problems" (i.e. patients with similar diagnoses). All problems within a "group" share the same essential attributes. A diagnosis, such as appendicitis, represents a group of patients with the same condition. All members of the "appendicitis" group share the same cause for disease and will benefit from the same set of interventions.

The professional mode of operation is thus strongly "depersonalized" in the sense that professionals gain experience, test and develop their knowledge and tools in the context of groups of people. In order to identify the correct course of action, a professional's primary task is to place the patient in the correct group. Once the professional has classified the patient's problem, the specialist can draw upon a wealth of knowledge, from past and current patients, from personal experience and the experience of other specialists that applies to the group in question. The bottom line is that health professionals regularly treat individuals as representatives of a "group". Any professional who fails to aim for professionally set goals could face legal prosecution. It follows that it is in the professional's self-interest to satisfy "professional" requirements.

The pain of being ignored as a person

Thus, it happens, that patients who are already experiencing vulnerability in terms of bad health, may in addition experience the pain of "disappearing" as persons with a unique identity. The institutionalized trappings of health-care treats them as an anonymous representative of a group of patients. The most extreme examples of this tension comes from palliative care, where professionals feel compelled to promote professionally set goals even when it is acknowledged that the patient is dying and further treatment is in contradiction with the patient's written "living will".[39] The traumatizing effects of depersonalization has been well described by many patients.[2, 4]

The alignment of multiple goals - general goal theory

It seems intuitively difficult to respect both professionalism and personal goals at the same time, but goal-setting theory shows how consistent set of goals are created. Goals represent the desired future state of affairs. They serve to direct resources towards activities that support the desired state, and away from irrelevant activities.[34] Both in case of conflicting goals or complementary goals that compete for resources, an explicit prioritization of goals is called for.[32-34] This is done by creating a goal hierarchy, where the highest level goal invokes a vision of the desired future, which is then broken down into sub-goals and tasks.[32, 33] We have previously argued that professional skills and knowledge pertain to groups. Thus, only the individual can provide a legitimate "vision" for the future desired state for the individual. We propose that Personal goals legitimize which professional goals to pursue, and how to

pursue them. This is a value-based choice sustained by the ethics of authenticity described above and by:

- **Western legislation**: Human rights declaration and national legislations support the individual's right to make their personal choices count in all aspects of life, including health.
- **Ethics**: The balance between "paternalistic beneficence" and "patient autonomy" challenges health personnel with two moral duties: "*The first is to respect the self-determination or autonomy of the patient. The second, often neglected duty, is to help restore that autonomy or help establish it when it is absent.*"[40, 41]
- **Effectiveness studies**. There is evidence that patient involvement and engagement in care, i.e. care where the patient's own priorities are heeded, have better health and functional outcomes.[42, 43]

By putting the patient's personal goals on top of the goal-hierarchy, the tension between personal and professional goals effectively disappears. Professional goals are the Lego-blocks that build the iPT in accordance with personal goals. The tension between personal and professional goals surfaces only when personal goals are held equal or subordinate to professional goals. The resulting goal-framework is depicted in figure 3:

DISCUSSION

Main findings

Based on document analysis of 70 health service research papers on health concepts and goals for care, we created a goal typology and goal hierarchy relevant for the iPT. The individual's personal goals are at the top of the goal-hierarchy. Health professionals can then translate personal goals into realistic professional goals within Functional, Biological and Adaptive domains. Such a goal hierarchy clarifies the relationships between personal and professional goals. Goal attainment at the personal level both defines and guides successful care.

Strengths and Limitations:

Strengths: We have not found other papers that examine and analyze the variation of goals for care across relevant disciplines and its implications in an iPT context. Thus, this appears to be an original contribution to the discussion of how to achieve continuity of care, high quality care and personalized care. Our multi-professional background was vital to both identifying and understanding the epistemological and professional implications of differing goals across professional and lay roles, and the trustworthiness of our analysis.

Limitations: We may have missed papers that could have met our inclusion criteria. As the first author, who has a medical background, performed all literature searches, there may be clusters of relevant papers in other domains that were missed. However, our aim was not an exhaustive search for all possible goals for care, but rather a large enough sample of goal papers that could serve as a basis for the development of a goal-typology. Our goal typology seems robust, as publications identified late in the search process did not bring new goal-types, indicating a saturation of the material.

Our results makes the exploration of personal goals mandatory, a practice that may be especially difficult for patients in a vulnerable situation. However, the challenges of this task, including the involvement of family and/ or informal caregivers in the goal-setting process, are topics in their own right, which lie outside the scope of this paper.

The exclusion of goal 14, which holds that health, is caused and maintained by supernatural or religious forces, could be viewed as a limitation. This is perhaps the oldest health model in human history. Typical interventions would appeal to higher religious or supernatural forces, via institutions mostly found outside of health-care systems. While we recognize its legitimate existence, we position our analysis to be useful within a health care context, which is why we excluded this goal from further analyses.

Previous research

The person centered care literature has long underlined the importance of the patient's personal goals in all care decisions.[44, 45] A goal-oriented approach, where goals are set by the patient was proposed already in 1968 and was recently re-visited by Reuben.[45-47] However, the person-centered care movement has failed to merge the strengths of disease- and person-centered care practices. Understanding the relationships between personal and professional goals, where personal goals are the overarching guide to the setting of professional goals, is key to the delivery of truly personalized care.

Of the many interventions directed at better service coordination, neither integrated care, case-management, nor clinical pathways pay much attention to personal goals or goal alignment [48-51]. The Chronic Care Model does emphasize "the informed active patient", but does not really extend this into goal oriented care.[52] However, exciting examples do exist where personal goals are used to guide service coordination. The health and social services partnership in Scotland explicitly uses the formulation of desired personal outcomes as a tool for both service integration and ensuring value for the service user. [53, 54]

Implications for practice

Already in 1927 Peabody berated his colleagues for losing sight of the patient's personal needs.[55] Although the call for personalized care has only grown, it still **seems** out of reach in modern health care.[1, 2, 4, 56]. In light of our findings, this is not surprising, since the tensions between personalized and professional goals are inherent to professionalism and specialization, and are still poorly understood. The care system is currently designed to deliver single disease episodic care that supports professional goals.[1] Specialists presently have no benefit from changing their scope and goals from a relatively tidy professional focus, which may be challenging and complex enough in and of itself, and add on to it the fuzzy unspecific cross-disciplinary personal goals of patients. Turning care processes around so that professionals truly start with and adhere to personal goals will require wide-sweeping, brave and visionary efforts on the part of health managers.

While this paper underlines the importance of personal goals for care, this paper is not an argument for a unilateral patient command of health care decisions and resources. The operationalization of goals of care must take place in a shared decision making process, where the professional duty is to translate the personal goals into realistic professional goals aligned with clinical, financial, ethical and regulatory

boundaries.[44, 57] Situations where professional goals and means are incompatible with the personal goals will remain a dilemma.[58] However, a goal-hierarchy may be an appropriate tool to identify and discuss openly and nonjudgmentally the clashes of interest that occur when patients find that professional advice is in contradiction to their wishes.

The goal-hierarchy depends heavily on an appropriate identification of personal goals. However, learning and understanding what is important to another human being, is not a "check-box" activity. Health personnel routinely experience situations that are too urgent, patients who are too ill, too cognitively impaired, too emotionally upset or feel too un-informed to make confident judgments about their goals. We have not touched upon the challenges of engaging patients in a sensitive manner about their goals when these barriers occur. This is a huge and important topic of its own right, which has been reviewed and examined by many other authors. [44, 59, 60] However, even though we realize that personal goals might not be available to guide care at all times, we argue that health professionals are well taught regarding which professional goals to move towards first in such unclear situations. The challenge is perhaps the opposite: As soon as the emergency is over, in the transition from acute care to follow-up care, patients must be actively engaged in re-assessing professionally set goals.

Implications for future research.

Many issues emerge from the findings in this study. There is a need to test whether goal concepts, which were not included here, could have changed our analytic results. Scholars from other cultural contexts are invited to reflect on the validity of our goal hierarchy. How goal-setting practices vary with respect to professional background and care context is yet largely unexplored in the research literature. This is a theoretical piece of work, and the proposed goal-setting model needs testing in real care settings to assess if better alignment between personalized goals and professional goals improves continuity and quality of care across professional and organizational borders.

This model of goal-setting does not solve the delicate and difficult issue of gaining insight into "what is important" for the individual patient. Nor does it relieve professionals of the duty of translating "what is important" into professional goals that are realistic. It does however give professionals a clear and unambiguous guide to the primary goal for care: to improve and maintain health, where health is defined by "what is important to the patient". Personalized goals are not "nice to have", they are at the core of what health care is about. Care should be evaluated in terms of meeting the personal goals set by patients. Making personal goals set the course for care, can be likened to a paradigmatic shift that requires require brave wide-sweeping regulatory, organizational and attitudinal reformation within our care systems.

ACKNOWLEDGEMENTS

We are grateful to the Norwegian Research Council and Regional health authorities, Northern Norway for their financial support.

COMPETING INTERESTS

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and

declare that (1) GKRB, AS, DG, AS. NF, CR and VF have no support from any company for the submitted work; (2) GKRB, AS, DG, AS. NF, CR and VF have no relationships with any companies that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) GKRB, AS, DG, AS. NF, CR and VF have no non-financial interests that may be relevant to the submitted work.

FUNDING AND TRANSPARENCY DECLARATION:

This study was supported by research grants from the Regional health authorities, Northern Norway (grant # HST1024-11 5396), and the Norwegian research council (grants # 213973, and # 232184). The authors have no conflicts of interest that could influence the contents of this paper. Data sharing of full list of publications included in analyses are available from the corresponding author at request. The lead author (the manuscript's guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained

AUTHOR'S CONTRIBUTIONS

All authors developed the initial research question. GKRB, VF, DG, CR and AS secured support and funding for data-collection and analyses. GKRB is responsible for data-collection, primary analyses and first draft of manuscript. All authors had full access to the data and provided input for in terms of relevant additional papers, critical review of drafts and methodology, and contributions to the final manuscript. All authors read, edited and approved the final manuscript.

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LEGENDS for FIGURES

Figure 1: The health services involved in «Alfred»'s individual Patient Trajecotory (iPT) and their main focus of care according to the electronic medcial record at hospital and GP, Tromsø Norway, 2012

Figure 2: Goal framework I, inspired by Verbrugge and Jette[27-29]

Figure 3: Goal framework II - The personalized hiearchical health care goal model.

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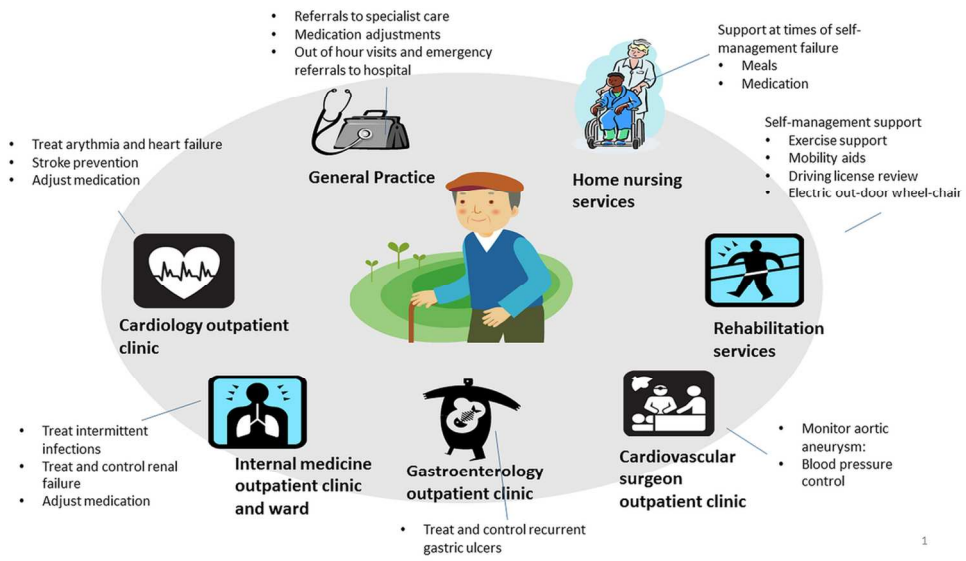

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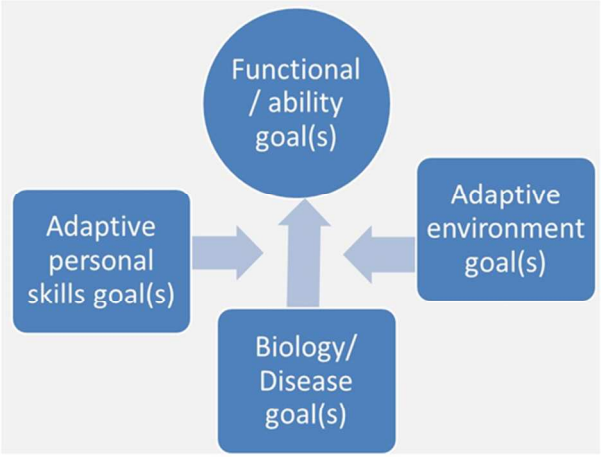

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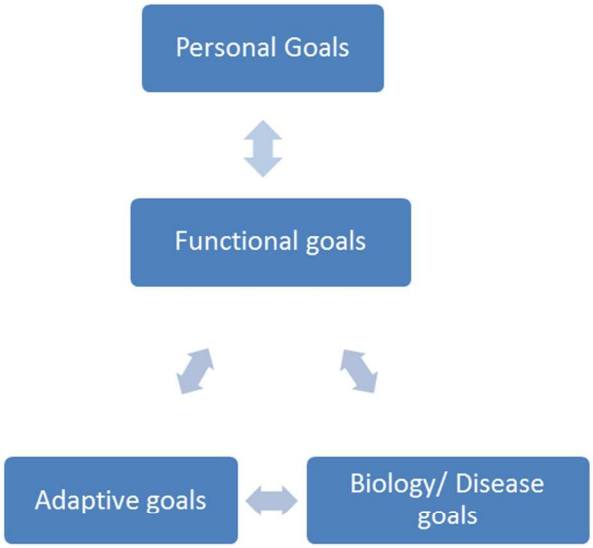

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APPENDIX B

Presentation of goals for care, their defining characteristics and typical concrete goals associated with them.

Concepts of goals for care	Defining features	Typical goal of care is…
1. Balance and homeostasis	Health is a balance between external/ internal forces, bodily components or bodily physiological processes. Characterized by words like balance, equilibrium, homeostasis, allostasis, holistic.	...is to re-establish balance or homeostasis.(1, 2).
2. Biomedical	Health is absence of disease. Diseases are caused by natural forces, which disturb biological -anatomical structures, -biochemical and/or -physiological processes. Disease definitions are agreed upon by the medical profession.	...is to provide the Evidence Based Medicine (EBM) that is likely to remove root cause of disease.(2-4)
3. Health outcomes	Health is the observable presence/ absence of a health outcome defined as relevant for any given disease.	...is to provide EBM likely to produce desired outcome and minimize risks.(5-7)
4. Disease prevention	Health is absence of disease, and depends on disease prevention through identification of increased risk for-, and/or early signs of a disease.	...is to provide EBM likely to postpone disease onset/ deterioration.(8, 9)
5. Bio-psycho-social	Health is absence of disease. Builds on bio-medical concept, but emphasizes that disease is experienced and observed in terms of human dysfunction, within the unique biological, psychological and social context of each human being.	...is to provide EBM likely to remove cause of disease and/or improve function in the personalized context.(4)
6. Disability	Health is defined by the person's ability to perform "*the necessary, usual, expected and personally desired functions*". (10, 11) Disability arises from the condition itself, and ability is modified by personal coping skills and social- or environmental adaptions to disease.	...is to restore functional ability through treatment of condition, enhancement of coping skills and/ or manipulation of environment.(10-12)

7. Health is a resource for wellbeing	Health is understood as wellbeing, in bio-, psycho- , emotional-, social- and spiritual terms. Texts are unspecific in terms of how to recognize poor health.	...is to restore wellbeing.(13, 14)
8. Health is a resource for everyday life	Health is understood as bio-psycho-social functioning which supports activities of everyday life.	...is to recognize and address deficits in activities of daily life.(2, 15, 16)
9. Health is a resource for self-care	Health is the ability or capacity for self-care.	...is to recognize compromised self-care and to support self-management.(16-18)
10. Health is a resource for autonomy	Health is the ability to function autonomously, in terms of making decisions, to pursue decisions within social context and ability to execute decisions.	...is to recognize and act to remove factors, which restrict individual autonomy.(16, 19, 20)
11. Health is a resource for personhood	Health is the foundation for defining who we are, our identity, our «personhood», including our spiritual beliefs. Threats or damage to our identity causes **suffering**, which is akin to poor health.	...is to detect the effects of poor health on identity and understand the suffering this produces in the individual, and then act to alleviate suffering.(21-24)
12. Health is a resource for spirituality	Health both supports a spiritual belief, and health supports the individual's spiritual activities. Spirituality connects the individual to a larger cause or religious belief. Spiritual beliefs can also support health by creating frameworks for sense and meaning in times of suffering.	...is to restore ability to align life choices and actions with beliefs, and/ or to understand health and suffering in terms of the belief system.(21, 25-27)

13. Health is socially constructed	Health is a social construct, which we understand in terms of the cultural, regulatory and historical context of the society in question. The impact of a condition depends on the society's ability to make resources for health available to the individual.	… is to make social- and environmental resources available to the person, such as health care, information, social support and physical aids which can support the person's ability to manage health.(2, 10)
14. Supernatural	Health is thought to be caused and maintained by supernatural or religious forces.. Supernatural health is perhaps the oldest health model in human history. Typical interventions appeal to higher religious or supernatural forces, via institutions found outside of health-care systems. While we recognize its existence, we position our analysis within a health care context, which is why we have excluded this health-concept from further analyses	…is to appease religious/ supernatural forces.(3, 28)

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Standards for reporting Qualtitative research(1)

	Name	Description	Application to Submitted manuscript
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus .group) is recommended	Done see title
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Done – see abstract
S3	Introduction	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Done – see introduction
S4	Research Q	Purpose of the study and specific objectives or questions	Done – See research questions
S5	Approach	·Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale	Document content analysis. Inductive – deductive theoretical approach. Interpretative and theory driven approach See methods,
S6	Researcher characteristics	·Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research .questions, approach, methods, results, and/or transferability	Described, see methods
S7	Context	Setting/site and salient contextual factors; rationale	Described, see introduction
S8	Sampling	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale	Described, see methods
S9	Ethics	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Described, see methods
S10	Data collectoin	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures	Described, see methods

		in response to evolving study findings; rationale	
S11	Data collection instruments	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Not applicable
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Described: Goal papers > goal terminology > goals > goal typologies
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	Described, Nvivo
S14	Data analysis	·Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale b	Described, see methods
S15	Techniques of trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	Described – use of multiprofessional author group
S16	Synthesis and interpretations	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Described - see results.
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	See appendix
S18	Integration with prior work, implictations, transferabiltiy and contributions to the field	·short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field	See discussion
S19	Limitations	Trustworthiness and limitations of findings	See discussion
S20	conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Not applicable
S21	Funding	Sources offunding and other support; role offunders in data collection,	Reported.

		interpretation, and reporting	

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