GOAL-ORIENTED CARE

A SHARED LANGUAGE AND CO-CREATIVE PRACTICE FOR HEALTH AND SOCIAL CARE

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Where primary care matters
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FOREWORD

Goal-oriented care is a relatively new concept. The idea has caught on and it is becoming more and more significant in the development of primary care. Recently an International Learning Collaborative has been set up to clarify the concept and promote steps to ensure that it is put into practice. This is being done by providing training courses and tools, and identifying promising practices. A Summer Academy, organised in September 2019 jointly by the Dr. Daniël De Coninck Fund and the International Collaborative, explored the undoubted potential of this new and wide-ranging concept of goal-oriented care. The De Coninck Fund aims to disseminate innovative concepts as part of its vision of supporting future-oriented, integrated, strong primary care which is accessible, caring and of high quality.

The starting-point is that strategies based on patient goals are more likely to be effective and efficient than those derived from problem-solving. When these goals are targeted, the outcomes are meaningful to patients. That puts the person with a need for care and support at the centre. Staff are encouraged to work in partnership with users, their families, carers, citizens and other service providers to deliver care in a way that is responsive to their individual needs and priorities. We are looking at ways of adapting our conversations to make them more proactive, and personalised. The question is: what matters to the person? This includes their clinical needs, but it also means wider aspects of their health and well-being. It is important to point out that people value their autonomy and sometimes prioritise life-goals other than health. This needs to be respected.

Goal-oriented or person-centred care can be viewed in a way that focuses solely on individual health. This would probably be ineffective in addressing social determinants of health and could also create inequality in access to health and social care. There is a direct link between goal-oriented care and community development. The two concepts are interlinked and both deserve our attention.

There is still a lot to learn about goal-oriented care and how to make it a reality. We want to learn how to empower people to understand their care options where these involve risks, benefits and consequences. How inclusive is the way these questions are framed? How is it possible to deal with the ethical dilemmas that arise

- Where there are conflicts between the patient's aims and the therapeutic perspective?;
- Between the patient's views and the values and standards of the professionals involved in their health and well-being;
- Between the patient's perspectives and the values and reference frameworks acquired by professionals during their training or prevalent in the organisations where they work.

There seems to be some momentum behind goal-oriented care in Belgium, especially within the ongoing primary care reforms in the regions. It is on the agenda for policymakers, practitioners and researchers. The Primary Care Academy[1] and Be.Hive[2], two interdisciplinary chairs of primary care supported by the Fund, are also focusing on further ways of putting goal-oriented care into practice. Person-oriented and community care, support for self-management and interdisciplinary collaboration are all key areas for research.

This publication was nearly finalised before the COVID19 pandemic. This sanitary crisis revealed fragilities of our healthcare system and creates opportunities for a more richly textured and locally sensitive health care that connects to individual and community strengths and addresses social and environmental determinants of health.

We hope this publication will contribute towards a better understanding of goal-oriented care. The first two chapters of the report set the scene in the area of goal-oriented care. Specific tools that help to change the conversation between patients and providers are discussed in the third chapter. Three examples of collaboration anchored in a goal-oriented approach are then described. Finally, the ethos of goal-oriented care and some strategic considerations related to the transition towards goal-oriented care are discussed.

We are grateful to the authors and the International Collaborative for their pioneering work, their willingness to share their expertise, their critical approach and their infectious enthusiasm.

Patricia Adriaens, President of the Management Committee
of the Fund Dr. Daniël De Coninck

1 https://academie-eerstelijn.be
2 http://www.be-hive.be

GOAL-ORIENTED CARE: POLICY SUMMARY

Medical and social care professionals are used to entering a relationship with care seekers with a diagnostic pair of glasses. They are looking for problems to be solved. In caring for patients with complex medical and social needs this is likely to lead to suboptimal results. Goal-Oriented Care is a response to the limitations of problem-oriented care, particularly in confrontation with increasingly complex needs of patients with multiple chronic conditions and challenging socio-economic conditions.

Goal-Oriented Care takes a pragmatic approach to deal with this kind of complexity. It puts the priorities and life goals of the patients at the centre. This helps practitioners to prioritise, and to co-create, with peers and patients, an efficacious and humane path towards living with multiple conditions. Patient, practitioner and the wider health care system are poised to benefit from this.

- Care strategies derived from patients goals are likely to be more effective and efficient than those derived from problem-solving because the outcomes of interest are meaningful to the patients. This positively impacts treatment adherence and health outcomes;
- In patients with multiple problems, clinicians benefit from a rational framework for prioritization. Decision-making is often simplified by focusing on outcomes that span conditions and by aligning treatments toward overarching person-centered instead of disease-oriented goals;
- Goal-oriented care can reduce the costs of care by context-sensitively eschewing the use of tests and treatments that are unrelated to the patient's goals. Unnecessary therapies that do not contribute to the patients goals can be avoided.

Goal-Oriented Care is pragmatic but foundational. It pivots on a positive conception of health that seeks to strengthen people's abilities to prevent premature death and disability, achieve and maintain a high quality of life, grow and develop as an individual, and experience a good death.

Goal-Oriented Care requires practitioners to question the way they understand their professionalism, in light of what they see as 'the good', in a moral, instrumental and aesthetic sense. Patients are invited to reciprocate and take up a more active role in their health care. It is key that both patients and professionals are adequately supported in this practice. Adequate tools and training and opportunities for peer learning will help in lowering the threshold in making the move away from merely curing to healing.

Goal-Oriented Care has implications beyond the patient-provider relationship. It provides a shared language for multidisciplinary teams of providers, an incentive for cross-sectoral learning and a pragmatic framework to develop care plans for people with complex needs. However, more stakeholders need to be invited into the debate about the definition and underpinning values of goal-oriented care. At the same time, research is needed to assess and measure the effects of goal-oriented processes of care at the patient level. This will increase buy-in and pave the way for a wider acceptance of the approach.

Structural changes in the health and social care systems, such as the move towards integrated community care, create opportunities and barriers for adoption of goal-oriented care. A strategic agenda needs to be developed, backed up with real-world evidence, to proactively steer key policy debates about financing, integration, centralisation and decentralisation in a direction that facilitates the adoption of goal-oriented care.

01

FROM PROBLEM-ORIENTED TO GOAL-ORIENTED CARE

Good care: persistent tinkering in a world
full of complex ambivalence and shifting tensions.
[...] What changes along the way?
One answer is: what it is to be human.
Care practices move us away from rationalist
versions of the human being.
For rather than insisting on cognitive operations,
they involve embodied practices.
Rather than requiring impartial decisions,
they demand attuned attentiveness
and adaptive tinkering.
Crucially, in care practices what it means
to be human has more to do with being fragile
than with mastering the world.
This does not imply a docile acceptance
of fate: care is active, it seeks to improve life.

ANNEMARIE MOL

THE LIMITS OF THE PROBLEM-ORIENTED APPROACH IN HEALTH CARE

The current health care system is facing a demographic and epidemiological transition due to aging, the increasing number of chronic diseases and expanding social and environmental problems.

As a result, health care providers are increasingly confronted with patients who display complex patterns of needs. However, the current problem-oriented or disease-oriented approach works best when health issues are mostly acute and correctable. There are many indications that this indirect approach, which focuses on remediation strategies rather than patient goals, has reached its limits. Piling therapy upon intervention, often initiated by different providers, often results in suboptimal outcomes and unintended consequences.

We will illustrate this by means of four patient cases.

CASE 1

DORA

Dora celebrated her 101st birthday this year.
However, a few months after her 100th birthday she began to have trouble getting out of bed. She was unable to make her legs work properly. At that time, Dora was living in her own home, completely independent; something she valued a great deal. She was able to call her daughter, who took her to the local hospital emergency room.

For several years, Dora had been treated for lumbar spinal stenosis, a condition in which overgrowth of bone in the lower spine cause pressure on the spinal cord, which can eventually result in paralysis. Since no other cause was found on initial testing at the hospital, the spinal stenosis was believed to be the most likely cause of her leg trouble. However, since she needed additional X-rays and a neurosurgical evaluation and because she was not unable to care for herself, she was admitted to the hospital.

On admission to the hospital Dora's blood pressure was 180/90, with no other signs that would indicate a risk of bleeding. Nevertheless she was given medication to lower her blood-pressure which is standard practice. Unfortunately, the medicine caused a significant drop in blood pressure that reduced the amount of blood reaching a vulnerable area of her brain. The result was a stroke, which left Dora paralyzed on one side of her body and unable to speak. After months of physical, occupational and speech therapy, Dora now lives in an assisted living center.

Using the logic of problem-oriented care, a person with blood pressure measurements above 140/90 is said to have hypertension. In Dora's case, her blood pressure was high, so she was given medicine to lower it.

From a goal-oriented perspective, Mrs. Menninger's doctor would have recognized that Mrs. Menninger's primary goal was to maintain her independence.

At the age of 100 with no signs of serious heart or kidney disease or risk of bleeding, there was no short-term risk of harm from an elevated blood pressure, and her life expectancy was too short to benefit from long-term blood pressure reduction. He would have concluded that her blood pressure elevation was irrelevant, thus not prescribing the medication that resulted in a potentially avoidable stroke.

J. MOLD from '*Achieving your personal health goals. A patient's guide*'

Dora's case illustrates that identifying every diagnosis and applying every available preventive measure recommended for a patient can actually cause more harm than good.

The same applies to carrying out all the tests and treatments that are indicated by evidence-based guidelines. Problem oriented thinking can result in over-diagnosis and over-treatment simply because it fails to take the context into account and is disconnected from patient-relevant goals.

CASE 2

MARIETTE

Mariette is a 68-year-old lady who had been a patient of a general practice surgery for several years. Recently she has been facing several health issues and has undergone medical interventions: a hip replacement due to advanced osteoarthritis, high blood pressure, type 2 diabetes and chronic obstructive pulmonary disease (COPD). Since her husband's death she lives by herself and takes care of her three grandchildren. Her daughter is divorced and is sole caregiver for both her children. Her son has been hospitalized several times due to alcohol misuse and lives with a psychologically vulnerable partner, which means that Mariette's grandson regularly stays with her for long periods of time.

Before the practitioner collects Mariette out of the waiting room he has a list of topics he will want to discuss with her. He must ask about the symptoms of her COPD, give lifestyle advice about food, smoking and exercise, and schedule the next laboratory controls for her diabetes and high blood pressure. He may have to adapt her medications, check the entire medication list and even discuss and be beware of a possible next check-up at the ophthalmologist because of her diabetes.

When Mariette sees the practitioner in the consultation room, she has a different list that she wants discuss.
The doctor listens to her concerns: sometimes they are about uncertainty about her heart, then her lungs, then the hip,... At each visit, in accordance with existing guidelines, standards and recommendations, the doctor suggests all kinds of examinations that do not improve her situation. He often gets the feeling he is not doing enough, though. Planned checks remain outstanding but at the same time there's a feeling of missing the point.
Particularly when Mariette is upset or concerned about the situation with her grandson, it feels inappropriate to focus on what ought to be done on paper according to the guidelines. Moreover, family doctors have to deal with guidelines and recommendations that are contradictory: for her COPD she sometimes needs corticosteroids that have a negative impact on her diabetes.
She has little interest in adjustments in her medicines (sometimes too high, sometimes too low) nor in the doctor's interest in her HbA1C and lung function tests.

Based on the current guidelines and recommendations Mariette does have a lot of things to do: aerobic and muscle-strengthening exercises, monitoring blood sugar levels, avoiding exposure to air pollution, wearing adequate footwear, reducing her alcohol consumption, maintaining her weight and responding appropriately to exacerbation of COPD.
She needs to follow diabetes education and she must be trained to take her COPD medications correctly.
She needs to take eleven different medicines every day, which add up to twenty doses a day (Boyd, 2005).

P. BOECKXSTAENS, J. DE MAESENEER
CLEVER doelen bepalen in de eerste lijn

The example of Mariette illustrates that problem-oriented approaches can lead to overwhelming and contradictory lists of interventions when diseases coexist.

The whole list of recommendations taken from the disease-oriented guidelines overlooks the needs of the individual patient and leaves little room for life besides disease management. Moreover, multimorbidity is not only associated with poor quality of life, physical disability and mortality, it also entails risks of high health care use, multiple medications, and increased risk for adverse drug events (Boyd, 2005).

A goal-oriented approach would involve a discussion of Mariette's functional needs and aspirations, starting with questions about difficulties encountered during a typical day and things she would like to be able to do that she is unable to do now. A variety of strategies might be considered. It would then move on to an assessment of modifiable factors that could result in premature death or disability and a discussion of trade-offs she is willing and able to make between quality and quantity of life. Eventually, there would be a discussion of advance directives for end-of-life care. Throughout those discussions, the clinician would support her needs for connection (personal relationships), autonomy, and competence as she learns to adapt to her disabilities.

Next in line is Frank.

CASE 3

FRANK

Frank is a 57-year-old man who lives in isolation in his own house in a peri-urban area. He inherited the house from his parents who died a few years ago.
He is single and has no friends. The house is not maintained and is barely inhabitable: it is dirty, and there are a lot of vermin (mice) and cigarette butts. Frank has a good relationship with his family doctor and has a consultation once a month. Frank has various conditions including type 2 diabetes (poorly controlled), an ulcer on his foot that is not healing, and chronic renal failure.
When he was 41 years old he had a work accident that caused a fractured vertebra. An operation went wrong, and he was placed on disability. He is not rich but has no major financial problems.

Frank has recently been diagnosed with advanced throat cancer. There are metastases, and he is clearly deteriorating. At the doctor's insistence, home nursing for medication and wound care have been started. Frank still buys his own groceries using his rollator. This is difficult, but that doesn't seem to bother him. He only eats chocolate pudding, since solid food is difficult to swallow.

For a medical practitioner it is a difficult environment to work in, because of the vermin. It smells bad, and it is difficult to work properly when providing wound care. Home care has been approached to help with the situation, but they want the house to be cleaned first. A social worker has been asked to visit Frank so that the house can be cleaned and better meals can be arranged for Frank.

M. VAN LYSEBETTEN, K. DUBOIS, W. DOBBELEER
Trainingen doelgerichte zorg

The story of Frank illustrates that the values and needs of the patient don't always match the priorities and wishes of health-care providers.

It also foregrounds that patients with advanced cancer are faced with decisions involving trade-offs between often invasive tests and treatments, with a low probability of life extension, and interventions to improve quality of life (i.e. palliative care). Because of the threat of imminent death, they are also motivated to focus on end-of-life values and preferences. Many patients also benefit from counselling as they struggle to accept the finality of their lives. Focusing on those goals and trade-offs can provide a more effective and humane guide for clinical decision-making than a technical, problem-oriented approach.

Finally, goal-oriented care could also improve collaboration and communication between medical and para-medical workers as all providers are committed to achieving the same goals.

Here is a fourth and final story, about Jeremy

CASE 4

JEREMY

Jeremy was a 33-year-old engineer who, at the insistence of his wife, made an appointment with her primary care doctor to discuss a shoulder problem he'd had for more than a decade. The problem began with a high school sports injury. Jeremy had been a very good baseball pitcher, but his sports career had been short because of the injury to his shoulder. Since high school, he had continued to endure intermittent pain, which had prompted him to see various health professionals over the years, including several primary care doctors, an orthopedic surgeon, and a physical therapist.

Jeremy had tried periods of rest, heat, and ice, a variety of exercises, an injection, and anti-inflammatory medications, each of which only helped temporarily. The orthopedist had offered him an operation but had also said that he couldn't guarantee the shoulder would be significantly better afterward. Jeremy's new primary care doctor took a different approach. He began by asking Jeremy, "How does the pain affect your life? What does it keep you from doing?" After considering these questions, Jeremy reported that the most important thing he was unable to do was to hunt deer with a bow and arrow, a hobby he had acquired as a teenager and had shared with his father and brother prior the shoulder problem.

At that moment, an imaginary light bulb appeared to switch on in Jeremy's mind. "You know, I've seen some deer hunters using crossbows," he said. "I could probably do that, but to get a crossbow license I think I would need a doctor's note saying that I am unable to use a traditional bow."

The clinician's initial thought was, "What can I possibly do for this patient who has already tried everything I usually suggest?" Once the goal was clarified and the obvious path was clarified, both physician and patient were relieved.

Jeremy's case illustrates that simple and cheap interventions may be able to contribute more to a patient's functioning and overall wellbeing than risky and expensive medical treatment. A goal-oriented mindset will alert professionals to possibilities connected to non-clinical pathways, even in patients without complex needs.

It is clear that the classical disease-oriented model is not the best fit for these patients. It was ideally suited to understand and manage acute and curable diseases, but is at risk of bypassing the needs of the new generation of patients with chronic diseases and health-related problems, thereby compromising quality of life, therapeutic effectiveness and appropriate use of care services

THE PROMISE OF A (PATIENT) GOAL-ORIENTED APPROACH

A goal-oriented approach takes a patient's self-expressed life goals as a guide for strategies and treatment decisions. In other words, goal-oriented care is about aligning care decisions with goals that matter to individual patients.

These are foundational elements of Goal-Oriented Care:

- GOC takes its cue from patient-relevant needs and priorities.
- GOC entails the co-creation of personalized care plans between patients and practitioners.
- GOC pivots on a positive conception of health that seeks to strengthen people's abilities to prevent premature death and disability, achieve and maintain a high quality of life, grow and develop as an individual, and experience a good death.

It is about a positive approach of health, starting from patients' own capabilities and strengthening these capabilities. It requires a different attitude and other skills from the caregiver, other ways of collaboration between the care and welfare workers and the development of a common language.

Advantages of goal-oriented care can be expected at the level of the individual patient, the patient-provider interaction, the provider, the team, the health system and society at large.

Advantages for the patient

The stories help to understand how a goal-oriented approach may engender important advantages for patients:

- It protects them from risks and inconveniences associated with technically defensible, but contextually senseless or risky medical interventions;
- It helps to reduce the sometimes overwhelming burden of disease management;
- Care strategies derived from patients' goals are likely to be more effective and efficient than those derived from problem-solving because the outcomes of interest are meaningful to the patients;
- Patients feel more heard when providers focus on their personal goals which is likely to improve their experience of care.

The interactions in which patients and providers identify and discuss patient goals require a language that is understandable for both the patient and the provider, leading patients to feel more capable of participating in the decision-making processes.

Advantages for care providers

- Practitioners who adopt a patient goal-oriented approach are likely to experience increased professional satisfaction because they can tie their interventions more directly to meaningful outcomes for their patients.
- As a result, goal-oriented care improves the relationship between providers and patients and their families due to a better alignment between the doctor's and the patient's agendas.
- Goal-oriented care places the person with a need for care and support at the center. This encourages clinicians and staff to work in partnership to deliver care in a way that is responsive to their patients' individual needs and priorities.
- Focusing on the patient's individual health goals has the potential to enhance their involvement in their treatment and positively impact treatment adherence and health outcomes.
- In patients with multiple problems, clinicians benefit from a rational framework for prioritization. Decision-making is often simplified by focusing on outcomes that span conditions and by aligning treatments toward overarching person-centered rather than disease-oriented goals.

Advantages for the care-system as a whole

- At the level of the health system, goal-oriented care may be the lynchpin for integrated care. Integration is to a large extent shaped by and based on professional behavior and attitudes. Coherence between the level of the patient, the professional, organization and the system is defined as one of the main premises for integrated care at various levels in the health care context as a whole (Valentijn, 2013). Goal-oriented care may therefore serve as a common philosophy of care and a clear mission and vision that reflects the needs of the local population.
- Goal-oriented care can reduce the costs of care by context-sensitively eschewing the use of tests and treatments that are unrelated to the patient's goals. Unnecessary therapies that do not contribute to the patients goals can be avoided.

The next section takes a closer look at the foundational notions of goal-oriented care and patient goals. Section 3 zooms in on a number of tools that can aid in changing the nature of the conversation between providers and patients. Section 4 discusses how goal-oriented care can help interprofessional collaboration by providing a shared language and framework for the collaborative development of care plans. Section 5 focuses on the ethos of the goal-oriented professional and the process of normative professionalization that can help to nourish that ethos. The paper closes with strategic considerations for a wider adoption of goal-oriented care.

02

UNDER-STANDING GOAL-ORIENTED CARE

TOWARDS A DEFINITION OF GOAL-ORIENTED CARE

What exactly is goal-oriented care? The concept was summarily introduced in the previous section, but it warrants a more in-depth discussion. We start with the observation that 'Goal-Oriented Care' is not well defined in the literature.

Box 1 illustrates the diversity of descriptions of goal-oriented care derived from the literature.

BOX 1

DESCRIPTIONS OF GOAL-ORIENTED CARE IN THE LITERATURE

Mold (1991), the first author of the seminal paper on goal-oriented care who is considered to be the founding father of the concept, originally defined goal-oriented care as the clinical process of encouraging each individual to achieve the highest possible level of health, which is defined by the individual. More recently Dr. Mold has proposed that goal-oriented care is a conceptual framework in which the focus is on helping each person to be able to do the things they enjoy and find meaningful for as long as possible, while facing, overcoming, and learning from the inevitable challenges that occur during life, and then dying in a manner compatible one's values and preferences, having had an opportunity to reach one's full human potential.

Rueben and Tinetti (2012) describe goal-oriented care as a process of care that focuses on a patient's individual health goals and how these goals are being met. Individual health goals can range across a variety of dimensions (e.g. symptoms, physical functional status,..).

Nagykaldi et al (2018) describe the goal-directed health care model as an approach that uses patients' life and health goals to guide health care professionals in co-creating personalized care plans that are responsive to the shared priorities, needs, preferences and values of patients.

Muth et al (2014) refer to sharing of realistic treatment goals between the physician and patient which requires a thorough interaction assessment of conditions and treatments and a prioritization of health problems in a way that takes patient preferences into account.

De Maeseneer et al (2017) see Goal-oriented care as an alternative to a supply-driven approach of care. It is a practice that is co-created with the person with a care need and what (s)he wants to achieve.

Incidentally, all these authors are physicians which indicates that researchers or practitioners in other sectors, for example social care, do not have a voice in this process. They may define, understand and operationalize goal-oriented care in quite different ways (Bernsten, 2015; Grudniewicz, 2016). The lack of a shared and unequivocal definition of goal-oriented care and the underpinning values is hindering the adoption of goal-oriented care.

TYPOLOGIES OF PATIENT GOALS

A goal can be pragmatically defined as 'a desired outcome about which it makes little or no sense to ask why a specific individual would want it to happen'.

Researchers have tried to classify patients' goals in different categories: Vermunt developed a three-goal model for patients with multimorbidity which better illustrates the challenges related to the understanding of a 'goal' within the concept of goal-oriented care.

Berntsen (2015) added a fourth goal to Vermunt's model, namely social adaptive goals which view health as a social construct. Social goals reduce the impact of a health condition and prevent or create opportunities for health through social action.

BOX 2

THREE-GOAL MODEL

1 **Fundamental goals**
Described as goals specifying a patient's priorities in life, such as their values and core relationships or themes that serve as reference points for decision making.
These are goals considering the patient's personal views what constitutes quality of life. Fundamental goals reflect a patient's view on their own future in the broader sense.
Fundamental goals concern questions like:
What makes your life worth living?
How do you lead your life?
What are you views on the end of life?
How do you feel about quality of life vs lengthening of life?

2 **Functional goals**
Goals related to reducing limitations in functioning. Examples: 'Being able to wash or dress oneself', 'driving a car', 'staying mobile'.

3 **Disease-specific or symptom-specific goals**
Goals relating to the diagnosis or treatment of a specific disease or symptom. Patients may ask for example for the reduction in distress caused by symptoms like shortness of breath, itching or pain. In a goal-setting process, clinician and patient can set a patient symptom-specific goal together, which incorporates personal choices in diagnostic trajectories and treatments.
Some patients, for example, do not want to engage in all kinds of diagnostic trajectories as long as a certain symptom can be reduced by a certain symptomatic treatment. Other patients want to know what is causing the symptom. This type of goal can also originate from a certain disease. An example of this is a patient asking for disease-specific medication.

VERMUNT, Harmsen et al. 2018

BOX 3

JIM MOLD'S FOUR MAJOR GOALS

In his work on goal-oriented care, Mold defines four major goals of health and healthcare:
- Prevention of premature death and disability;
- Maintenance or improvement of quality of life;
- Preparation for a good death;
- Maximization of personal growth and development.

He includes Vermunt's functional and social goals as wellas some fundamental goals within the 'quality of life' goal set. In most cases, he believes, symptom relief and evaluation and treatment preferences are more appropriately considered as either strategies or objectives rather than goals.

Prevention of premature death and disability
Most people want to avoid premature death. They also prefer not to become disabled. With some exceptions, the strategies – primary, secondary, and tertiary prevention – used to prevent premature death also prevent or delay disability.
But most doctors are not accustomed to thinking about their patients' individual health goals. Their assumption is that successful treatment of a person's disease will result in a longer and pleasant life. They approach health and health care indirectly: focusing on the disease rather than on the goal. This is despite the fact that premature death is the most important health-related goal for most people.

Length and quality of life do, of course, often come into conflict. Interventions to achieve one may reduce the ability to achieve the other. For people with no significant disabilities, it is difficult to imagine being able to enjoy life with a serious disability, however people with disabilities are more likely to want to stay alive. When disabilities inevitably occur, people generally discover that they can tolerate much more than they would ever have thought they could.
This reminds us that life is precious and almost always better than the alternative. Helping patients to make informed choices is an important responsibility of goal-oriented clinicians.

Quality of life

Quality of life is a broad concept that includes more components than health, but good health certainly plays a major role in one's ability to enjoy life. Within a goal-oriented health care framework, the focus is primarily on the ability to participate in essential and meaningful life activities. Meaningful life activities are activities and relationships that give life value, meaning and purpose. Quality of life goals tend to be very powerful and can therefore be leveraged to help patients to accomplish more difficult preventive strategies, particularly those involving long-term behavior changes.

A good death

A good death is a death that is free from avoidable distress and suffering, for patients, family and caregivers, generally in accordance with the patients' and families' wishes and reasonably consistent with clinical, cultural and ethical standards. From a problem-oriented perspective, a dying person represents a failure of medical care; death represents defeat. This makes it difficult for physicians, patients and families to have an open conversation about how and where the person would like to die. It also leads to unwarranted and unwanted aggressive measures to keep people alive, often until the bitter end.

E.J. and L.L. Emanuel have proposed six categories of modifiable factors that may contribute to the quality of the dying process: physical symptoms, psychological and mental factors, economic and caregiving needs, social relationships and support, spiritual beliefs and hopes and expectations. The relative importance of these factors varies a great deal from person to person and situation to situation.

A goal-oriented approach to health and health care would encourage each person to think about their values and preferences regarding death and dying and document these as a guide for caregivers and health care providers.

Optimize personal growth and development

Personal growth and development are lifelong processes consisting of at least two major components: achievement of major developmental tasks and the ongoing process of becoming more resilient, adaptable and capable of handling challenges. A goal-oriented health care system takes both of these components into consideration for every patient, at every age.

For humans, good health always involves the experience of personal growth and development. This is the ability to grow and develop physically, psychologically and spiritually in response to the interactions we have with others and our environment. Drs. Edward Deci and Richard Ryan have proposed that optimal growth and development are most likely to occur when three basic psychological needs are met: the need to feel connected to others (relationship), the need to believe we can accomplish and achieve goals we set for ourselves (competence) and the need to feel that we can make personal decisions that matter (autonomy). A goal-directed approach to health care would support all three psychological needs and take these components into consideration for every patient at every age. The assumption is that you are working collaboratively with your health care providers, that you are able to set and achieve goals, building your sense of competence, and that you are clearly in charge of any decisions that are made, supporting the need to feel autonomous. This should be a goal throughout life and may actually be enhanced by the experience of losses.

A goal-oriented approach would support optimal growth and development, both directly by acknowledging specific developmental goals and objectives, and indirectly by reshaping interactions between patients and health care professionals. Health challenges would always be considered within the context of each patient's life trajectory and including optimal growth and development as a goal would make it possible to view aging in a more positive light.

03

CHANGING THE CONVER-SATION: TOOLS FOR GOAL-ORIENTED CARE

THE CHALLENGE OF GOAL ELICITATION

Helping patients to express pertinent goals can be experienced as simultaneously straightforward and challenging, by both patients and providers.

Jim Mold's experience in his clinical practice and in research conducted by his team suggests that the goal-setting process can be comfortably embedded within processes of care without even using the specific word 'goal'. The challenges that do exist are different for each type of goal. For the prevention goals, the challenges involve analyzing risk profiles, prioritizing risk reduction strategies, and determining when an individual is no longer concerned about life prolongation. Growth, development and good death goals can also be assumed with no end point and few problems with prioritization. Identification of quality of life goals can be difficult or relatively simple depending upon how important it is to get them right from the beginning. Dr. Mold and his colleagues have found that nearly all patients are able to identify both necessary and desired activities in response to the kinds of questions mentioned earlier: "Describe a typical day for you and tell me what activities are giving you trouble. What would you like to be able to do that you can't do now?" Their answers seem to be sufficient to guide an initial plan of care.

Clearly, the 'simplicity' of goal elicitation is embedded in deep clinical experience. In absence of that experience, dedicated tools may come in handy. Some researchers succumb to the temptation to adopt the SMART (specific, measurable, acceptable, realistic, time) principle when identifying goals, but these processes have been criticized as too reductionist and not incorporating patients' underlying values and norms.

Further, from the discussion in section 4 ('Stories of collaboration') it transpires that, more generally, professionals seek guidance and instruments to help them make the shift away from a problem-centered approach.

Not only professionals, but also patients may need support in the process of goal elicitation. In a qualitative study that aimed to identify patient goals in patients with COPD and comorbidity, encountered the challenges of goal-oriented care conversations with patients (Boeckxstaens et al). Even in the most structured interviews, where the Canadian Occupational Performance measure was used patients struggled to identify with the concept of goal-setting.

To identify a patient's goal more accurately and comprehensively, or when patients are having difficulty identifying quality of life goals, there may be a need for validated instruments that help to change the conversation between patients and providers.

Below we discuss three such tools, all of which have been developed and implemented in Belgium.

CLEVER

The purpose of the tool is to elicit goals through a narrative approach in primary health care. The method relies on a principle of shared decision-making between the person with a chronic care need and the professional. The aim of the tool is to describe CLEVER goals that are based on meaningful everyday activities in a real-life situation.

GOAL FINDER

The purpose of Goal Finder is to generate insights into the person's own experience of quality of life, as well as to enhance meaningful communication between the person with a chronic illness and those providing them with care or assistance.

PERSONALIZED GUIDANCE PLANS

The Personalized Guidance Plan is a tool developed within the context of the BOOST project in Brussels (on integrated care for people with chronic conditions).

CLEVER

WHAT IS THE PURPOSE OF THE TOOL?

The CLEVER tool has been developed at Artevelde University College by Patricia De Vriendt, Vanessa Gauwe and Dominique Van de Velde. The purpose of the tool is to elicit goals through a narrative approach to initiate a goal-oriented approach in primary health care. The method relies on a **principle of shared decision-making between the person with a chronic care need and the professional**. The aim of the tool is to describe CLEVER goals that are based on **meaningful everyday activities in a real-life situation**.

In this method, GOALS are defined on the basis of:

- The **Context** in which the individual lives;
- The individual's **Life-narrative**;
- The individual's level of **Engagement**;
- The personal **Values** associated with the activity;
- The personal **Emotions** associated with the activity;
- The **Relevance** for the individual.

In summary, goals should be defined according to the individual's Context, Life narrative, Engagement, Values, Emotions and Relevance: **CLEVER**.

WHAT IS THE TOOL'S TARGET AUDIENCE?

People with **chronic conditions, social problems and multimorbidity**. Research has shown that there are different categories of people for whom CLEVER can be useful. The three most important are:

- People who have a clear idea of their goals, have good heath literacy and self-management skills, but haven't been able to discuss the goals with their primary health care professional. These people feel acknowledged and recognized by using CLEVER.
- People who don't yet have a clear idea of their goals but have good to fair health literacy and self-management skills. These people can find their goals and identify a solution using CLEVER.
- People who don't have the skills to define their goals by themselves and have poor health literacy and self-management skills. People in this group feel supported and guided when CLEVER is used to define their goals.

WHO ARE THE STAKEHOLDERS INVOLVED IN THE TOOL?

The tool has been developed on an interdisciplinary basis involving occupational therapists, nurses, general practitioners, social workers and patients. The tool can be applied by all health care professionals in primary care. Training in interviewing technique is recommended.

HOW DOES THE TOOL WORK?

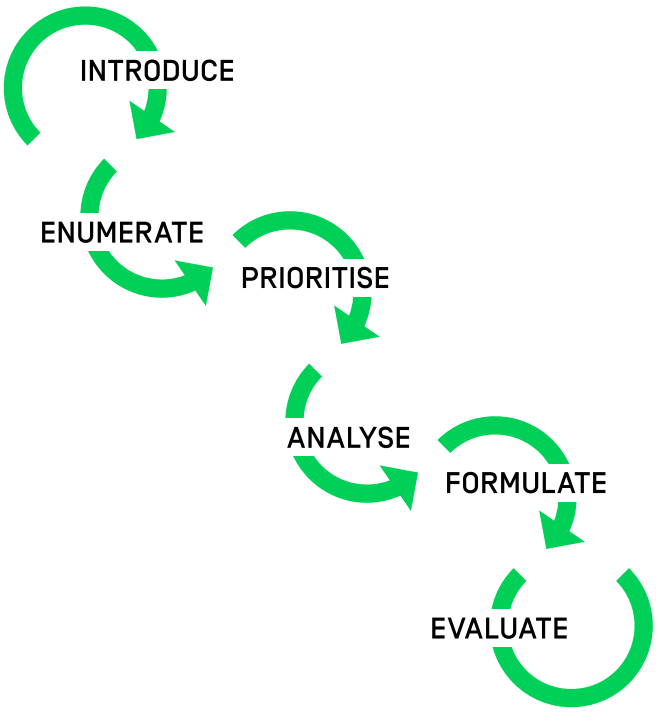
The CLEVER protocol relies on an open interview and communication technique and starts with an open question: «tell me something about your daily life, the things you do.»

During this conversation six steps are followed:

- **Introduce** yourself and get to know the person;
- Make an **Inventory** of all relevant activities;
- **Prioritize** the most meaningful activities;
- **Analyze** which the most important activity on the basis of its form and meaning;
- **Formulate** the CLEVER goal and include the context, life narrative, engagement, values, emotions and relevance in defining the GOAL;
- **Evaluate** the goal together with the person.

MORE INFORMATION

https://www.arteveldehogeschool.be/opleidingen/bijscholingen-en-studiedagen/doelgerichte-zorg



CLEVER
DOELEN BEPALEN IN DE EERSTE LIJN
artevelde hogeschool

GOAL FINDER: FINDING THE WAY TO PERSONAL CARE TOGETHER

WHAT IS THE PURPOSE OF THE TOOL?

The purpose of Goal Finder is to help people with a chronic illness to organise their care and support in a targeted and meaningful way.

To achieve this the Goal Finder has several underlying aims:

- Goal Finder aims to help people with a chronic illness think about the aspects of life that matter to them, and about what gives them energy. Looking at the past, the present and the future allows people to think about things that improve their quality of life and allow them to enjoy life more.
- Thinking about this with the help of carefully chosen questions (based on self-determination theory) can help a person to gain more insight. This insight can lead to empowerment.
- The insights that are gained, combined with summary questions, are an invitation for people to start communicating with those who provide their care (both formally and informally). They can then say what is important to them and this can help to guide their care (e.g. possible rehabilitation goals for physiotherapy, occupational therapy or speech therapy, the most appropriate medications or treatments, the kind of support that is the best match for the person's wishes etc.).

The aim is to include the output of the sense-making process facilitated by the Goal Finder into the Electronic Patient File so that it can more easily become part of the care plan.

To sum up, the purpose of Goal Finder is:

- To bring about well-targeted care;
- To generate insights into the person's own experience of quality of life;
- To initiate a process of empowerment;
- To enhance meaningful communication between the person with a chronic illness and those providing them with care or assistance (both formally and informally).

WHAT IS THE TOOL'S TARGET AUDIENCE?

Goal Finder has been developed by and for people who need care and support. Goal Finder is designed to be completed independently, but depending on the level of care required, an informal or formal care provider can help (e.g. during a therapy session).

WHO ARE THE STAKEHOLDERS INVOLVED IN THE TOOL?

The tool has been developed by the Vlaams Patiëntenplatform (Flemish Patient Platform) with support from the Flemish Government. People with chronic conditions from several patient associations in Flanders were involved throughout the development process. The steering group was diverse and consisted of academics with a medical/paramedical background, care providers and representatives from the Flemish Government.

HOW DOES THE TOOL WORK?

Goal Finder helps you to think about what is important to you, what you enjoy and what makes your life better. You can use it to set helpful goals and think about the future.

Once you have completed the Goal Finder you can show it to doctors and people providing care or advice. They can see what you want to achieve and provide care that helps with those areas. Inside the Goal Finder there is a lifeline. This has sections about the past, present and future, with questions in each part about your independence, your talents and your relationships.

Read the questions carefully and complete all the parts. You can start with the past, present or future. Completing the Goal Finder could help you to identify things that you miss, or things you hope to change in future. There are circles in each section where you can put things that are important to you. You can write, draw or use the stickers provided. Look carefully at the stickers. They show photographs, symbols or words. How you understand each sticker is up to you. For example: a "rabbit" could mean "my pet", or "a walk in the woods". If one of the stickers means something to you, put it in the circle. If you want to link the sticker to another a question, draw arrows, write something or find a sticker with a similar meaning. It is all about expressing your story.

After completing all the lifeline questions, look at the questions on the back. These are about the life goals you have found. You can write a summary, say what you are happy with, mention things you want to work on, choose which goals to talk about (for example to your GP, a specialist or your partner), and decide on some small steps to achieve or hold on to your goals. Goal Finder helps you to enjoy life more, guiding the care you receive so that it helps you towards your goals.

You can complete Goal Finder alone or with help from friends, family members or a trusted carer.

MORE INFORMATION

http://vlaamspatientenplatform.be/themas/doelzoeker

PERSONALIZED GUIDANCE PLANS

WHAT IS THE PURPOSE OF THE TOOL?

The Personalised Guidance Plan is a tool, materialised as a card deck, developed to initiate a dialogue between a patient and his/her trusted front line professional. The trusted front line professional is a health care professional working on the front line who is involved in supporting the patient and those close to them.

The tool is intended to:

- Facilitate assessment at key moments of vulnerability (a deterioration in the person's health and/or loss of social contacts) and avoid further deterioration in their health and loss of independence;
- Anticipate medical and psychosocial needs and put in place solutions that are in accordance with the individual's life plan to stabilise the situation;

Specifically for the patient, the tool allows them:

- To express themselves and be understood: to express their needs and difficulties and also to identify their aspirations and strengths;
- To say things as they perceive them, independently of the context and what is currently available (they do not need to adapt to the way the care system is organised to know who to contact / where to look);
- To clarify and prioritise what is important to achieve a breakthrough in situations: based on the idea that creating movement with a limited number of actions can potentially lead to change in other dimensions or the context of the person's life, the tool voluntarily limits the number of priorities.

Specifically for the professional, the tool allows them:

- To make changes in his practice and approach: to shift away from his usual processes and break away from automatic responses, in order to detect needs that have not yet been expressed or taken into account in specific care plans (in the gaps);
- To provide guidance in resolving difficulties and reassure the patient if they have worries so that they can turn their attention to therapeutic priorities, making it easier for him to provide professional guidance.

WHAT IS THE TOOL'S TARGET AUDIENCE?

The tool is intended for use in the relationship between the trusted front line professional and the patient.

The project will target patients suffering from a **chronic health condition** (cardiovascular disorders, diabetes, COPD and chronic renal impairment) combined with **frailty** (multiple comorbidity, polypharmacy, frequent hospital admissions, mental health problems, isolation, low income etc.).

The project is taking place in the centre of the Brussels region (Saint-Gilles and Saint-Josse municipalities and the "Pentagon" central district of Brussels).

WHO ARE THE STAKEHOLDERS INVOLVED IN THE TOOL?

The Personalised Guidance Plan (French: PPA) is a tool developed within the context of the BOOST project in Brussels (on integrated care for people with chronic conditions).

A **working group** has been set up on a voluntary basis within the consortium of partners involved in the BOOST project: representatives of patients and carers, front-line care professionals (care providers, medical practices, home care services, assistance services), hospitals, the health promotion sector, the academic and research sector (universities), support organisations for health care professionals etc. A trial version is **currently being tested** by trusted front-line professionals.

HOW DOES THE TOOL WORK?

The tool consists of:

- A pack of cards: the drawings illustrate or suggest various dimensions that may have an impact on quality of life and management of a chronic condition. The images offer plenty of scope for interpretation and may evoke completely different things across a wide range of individuals. As a result, each individual can find something that they can use to express themselves, making it possible to address any aspect that may be affecting their health in the broad sense. Finally, since there is no text, they are suitable for everyone, whether or not they speak the local language and whether they are able to write or not;
- A short leaflet: this is a brief written summary given to the patient (or those close to them).

Based on the study that is being carried out:

- The tool is always used with the aim of building a relationship of trust.
- The tool supports the individual relationship between a professional and a patient / recipient / user.
- The tool can be used in different contexts: during a first contact with the patient to get acquainted, at a key moment in their journey such as communicating a diagnosis, a quieter moment to strengthen the relationship, exploring new dimensions of their pathway or raising difficulties that have not yet been expressed.
- The tool is used outside emergency situations because it makes it possible to take time to identify what is important and start a dialogue between the professional and the patient.
- Using open questions, the tool makes it possible to identify a maximum of three key elements (priority goals)
- The tool is like a snapshot: it focuses on specific things at one moment in time.
- The tool does not commit the professional using it to find solutions to all the patient's problems. The aim is to listen to what is troubling the patients or what they would like to put in place and to start processes to get there, but they maynot be successful or may take time.
- The local professional can make use of other resources developed in the context of the BOOST project: a telephone help desk, a resource directory, a Community of Practice, training.
- The tool may also lead to a dialogue with an informal caregiver to find solutions together with the patient, for example when the carer does not agree with the patient's goals / wishes.

SUMMARY

TOOLS TO SUPPORT GOC

Tools can aid in initiating and structuring a different type of conversation between patient and care provider. This is a conversation that has a wider scope and a deeper emotional resonance than is usually the case. Its aim is to reveal elements from the patients' daily lifestyle and life narrative that usually remain undiscussed. The purpose is to give the care provider a better understanding of the patient's context, values and priorities, and to incentivise the patient to take a more active role in the process of shared decision-making and in the development of a care plan. Tools fit suggestive elements (open questions, visuals) into a structured protocol, grounded in insights from social psychology, chronic care and occupational therapy. Providers need to use these tools in a context-sensitive way and within an appropriate setting (sufficient time, access to other professionals if needed, adequate patient support if needed).

04

THE SHARED LANGUAGE OF GOAL-ORIENTED CARE: STORIES OF COLLABO-RATION

Much of the discussion up to now has centered on the question how goal-oriented care can help the shift towards a genuinely co-creative relationship between a patient with complex needs and a medical professional.
Additionally, GOC has profound implications for the way in which care providers collaborate with one another. GOC can provide a common framework for interdisciplinary collaboration based on patients' priorities. Here we recount three examples of collaboration, two in Belgium and one in the US, that have been anchored in a goal-oriented approach.

NIEUW GENT COMMUNITY HEALTH CENTRE

BACKGROUND

The Nieuw Gent Community Health Centre (CHC) was set up in 2000. It grew and evolved from a small care team and a small care population to become a mature CHC with 4500 patients and a team covering six different health care disciplines and consisting of more than 30 health care providers. The patient population at Nieuw Gent is characterised by diversity and social vulnerability. The CHC aims to provide accessible, high-quality patient care, taking both health and welfare into account. The CHC also maintains a focus on the local neighbourhood, with activities aimed at health promotion and prevention.

The team from the CHC learned from practical experience and a neighbourhood analysis that patients are not only becoming chronically sick earlier and more frequently, but also that their social situations often make health care more complex.

GOAL-ORIENTED CARE AS A CONCEPT TO SHAPE INTERDISCIPLINARY CARE

As the Community Health Centre continued to explore the health care context and look for concepts to support the provided care, they encountered "goal-oriented care". At that time they were carrying out an exercise in the team to make the content of the care provided by different disciplines more visible to each other, promote care substitution and efficiency and improve interdisciplinary collaboration and overall care.

They developed a "chronic care plan". This label is used to describe a process involving the patient, which consists of a conversation and the creation of a care plan, as well as a consultation within the health care team.

The patients for whom care plans were created were initially those in a chronic and/or complex (medical or social) situation, with a limited or absent social network, involving multiple care providers and/or in which the care providers involved have a sense of being "stuck". Patients with these characteristics generally view structuring the care provided by the team and sharing of information as a very meaningful exercise.

CREATING A CARE PLAN

An in-depth conversation takes place with the patient with the aim of creating an ICF "photo" and finding out the patient's (and the informal carer's) health care goals.

The health care provider can be from any discipline, and a trusting relationship is more important than a medical or paramedical background. This is because goal-oriented care uses a universal language that is spoken by all health disciplines and used with patients and their informal carers. The care providers sequentially weigh up their own care goals and test these against each other during care team consultations. The care team consultation is used to finalise the care plan and set out a number of specific "things to do" for the members of the health care team. The care plan is included in the electronic medical record (Dutch: EMD) and used as a reference resource. The care team itself determines when it is time to evaluate the plan.

LESSONS LEARNED

1 A care team with a diverse membership and a reasonable size takes time and needs tools for the structuring of care. The GOC concept is the ideal catalyst for this within the care vision of a CHC.

2 Creating a care plan is an intensive process that is carried out alongside the patient. Time must be made available for it. The time investment is quickly repaid because one of the results is that the patient feels better about the care that is provided and the actual provision of care becomes more efficient.

3 The care team must structure the process by incorporating meetings and deadlines so that care plans can take shape. It is a feature of day-to-day care provision that acute situations always take priority over "taking a step back and getting an overview of the patient's care as a whole". A "care coordinator" function can mean that the agenda set out in a care plan is detailed and monitored.

THE VERMONT STORY

BACKGROUND

The Vermont Blueprint for Health is a nationally-recognized initiative, leading the transformation of funding and delivery of primary and comprehensive health services are paid for and delivered across the state. The model represents a state-wide approach to a population health which emphasizes health, wellness and disease prevention in the delivery of primary care services. The Blueprint for Health started in 2009, and supports a variety of different community-led programs to meet the aims of the model. One of these programs adopted a goal-oriented care approach to help bring different health and social care organizations together as a means to coordinate health and social care services for individuals with complex care needs during a lifetime.

THE STRUCTURE OF THE PROGRAM

The implementation of Blueprint supported programs is enabled through the use of Practice Facilitators with experience in quality improvement. In the Goal-Oriented Care case, one practice facilitator established a Community Health Team which included primary care physicians, care coordinators, behavioral health specialists, home care providers, mental health support providers, and a case manager situated in the local hospital. Team members met bi-weekly to discuss complex patients who required support from the different team members.

GOAL-ORIENTED CARE AS A FOUNDATION

The providers involved in this program came from different organizations with wide variety of training and backgrounds. In order to bring together these different providers with different perspectives on patient-care, the Practice Facilitator introduced the Goal-Oriented Care approach. Providers who joined the Community Health Team were given intensive and ongoing training in the model of care and were provided tools to support the adoption of the approach. After 18 months working together, all providers defined person-centered goal-setting in the same way as "meeting people where they're at", suggesting a coalescing of beliefs regarding how to approach patient care. Providers were largely guided by patient-identified goals set out in bi-weekly meetings at which they discussed how to develop care plans for their patients. Interviews and observations with this team suggest that using a goal-oriented approach helped providers get on the same page with regard to patient care, despite having different professional backgrounds and perspectives. Each one was able to set their different clinical priorities aside and focus their efforts on meeting patient-identified goals.

LESSONS LEARNED

1 Intensive training in the approach, philosophy and tools of goal-oriented care served to get providers on the same page with regard to patient care despite different clinical priorities. However, pre-conceived ideas about what is "best for patients" from a clinical perspective remained a challenge for some providers, and requires a consistent reflective approach to overcome.

2 Using a goal-oriented care approach helped to overcome pre-conceived ideas about what is "best for patients", however some providers struggled with this and required a consistent self-reflexivity to overcome this challenge.

3 Regular in-person meetings helped reinforce the goal-oriented care approach, but also helped to build understanding, relationships and trust between team members.

4 Having a set of tools was identified as very helpful to guide the goal-oriented care process, particularly for those who were new to the process.

5 Providers required organizational support to engage in this new models, including time for training and meetings.

STORY OF A LOCAL MULTIDISCIPLINARY NETWORK

BACKGROUND

Since 2013, LMN Regio Gent[1] implemented interprofessional community meetings for healthcare providers in the Ghent region in Belgium. Alongside the possibility to meet local colleagues from different disciplines, a disease-specific topic such as diabetes or COPD was explored and often followed by a case study. Although these meetings were positively evaluated, staff members and some providers closely involved with the process felt that there was a lack of a sustainable approach.

TOWARDS A SUSTAINABLE VISION ON INTERPROFESSIONAL COMMUNITY MEETINGS

In 2015 LMN Regio Gent was repositioning itself as an organisation and decided **no longer to work in a disease-oriented way**. Based on several position papers[2] and local trends[3], a consensus emerged during the community meetings on growing towards **the idea of primary care networks**. In a primary care network, there is a strong collaboration between primary care providers in a community/district and they feel responsible for the well-being of all the citizens in their neighbourhood (this idea is based on the concept of community oriented primary care – COPC). Since healthcare in Flanders is characterized by many self-employed professionals, this represents a major challenge.

GOAL-ORIENTED CARE AS A FOUNDATION

In their search for new methodologies and approaches to strengthen these collaborations, staff at LMN Regio Gent came into contact with Ghent University, which proposed the concept of goal-oriented care. Although this input was valuable, there was a lack of a concrete approach and after additional searches, a two-day training course and coaching, developed by Maastricht University, University College Zuyd and consultancy agency 'Dubois & Van Rij' was selected as a possible successful strategy for implementation of the idea of goal-oriented care within primary care networks.

FIRST SUCCESSFUL STEPS TOWARDS MORE COLLABORATION

After a positively evaluated pilot training in October 2018 involving 14 providers from different backgrounds (four GPs, three dieticians, three social workers, one pharmacist, one occupational therapist, one nurse and one podiatrist), a new community meeting was held in their communities to scale up the idea of goal-oriented care within a primary care network. More and more professionals asked for this training and one year later 133 professionals had been trained (called 'champions') from seven communities in the Ghent region. Approximately 150 more professionals were also inspired by the champions through several community meetings.

LESSONS LEARNED

1 Making a change from problem-oriented to goal-oriented care and from patient-based thinking to community-based thinking takes time and requires not only training but also coaching.

2 Due to the close collaboration between all stakeholders, the training courses matched the current needs of providers in the field.

3 It seems that bringing together local providers from different disciplines, makes more and faster referrals possible. There was more trust between colleagues, probably because goal-oriented care provided a common language and vision for professionals. Shared training transcended the differences between disciplines.

4 Successful implementation at the practice level was only possible because there was willingness at the local policy level to organize the training courses and community meetings (for example by providing funding). It took considerable effort for LMN Regio Gent to inform, inspire and in some cases persuade local policymakers and healthcare managers.

SUMMARY

STORIES OF COLLABORATION

These stories testify to the power of goal-oriented care to provide a common language and vision to multidisciplinary teams of care providers that are faced with complex patterns of needs in their patients and communities. A shared language increases mutual trust. It lays down a framework for the collaborative, evolving development of care plans. The stories confirm, however, that professionals need support in taking the new ethos and practice on board.

Training, tools and peer support is essential in making the switch away from problem-oriented care. This is discussed further on section 5. Also, it is clear that the deployment of a practice of goal-oriented care does not happen in an institutional vacuum. Ongoing attempts at transitioning health care systems in response to contemporary challenges create opportunities and challenges for those wanting to increase the adoption of goal-oriented care. This theme is taken up again in section 6 of this paper.

1 LMN is a small network organization with two staff members, funded by the Flemish government but managed by local healthcare professionals.
2 SARWWG en Together we change // 3 Chronic Care project Ghent

05

THE ETHOS OF GOAL-ORIENTED CARE

A key challenge for Goal-Oriented Care lies in reframing and revitalising the relationship between patients and care providers.

Patients need to embrace change. They have to relinquish their semi-comfortable position as a passive subject and recipient of good advice and become an active partner in a process of sense-making, prioritization and deliberation facilitated by the care provider.

However, professionals need to take the lead, create a safe and welcoming space to make this happen, and change their way of thinking about 'doing good for the patient'. This requires a considerable change of perspective, since they may feel strong allegiance to a disease-oriented and problem-oriented perspective, rooted in a traditional model of professionalism, and reinforced by a increasingly regimented healthcare system that is guided by disease-specific quality indicators.

The spirit of Goal-Oriented Care is Whole-Person Care, a concept including both curing and healing: "curing is an activity carried out by a healthcare practitioner to eradicate disease or fix a problem; healing is a process leading to a greater process of integrity and wholeness in response to an injury or a disease that occurs within the patient, which can be facilitated by the healthcare practitioner." (Hutchinson, 2017) In the healing mode, the practitioner must be able to put herself in the patient's shoes, and be willing to relinquish authority and accept the risk of 'not knowing'. The dynamics of the patient-provider relationship will vary from situation to situation, requiring agility from the care provider, as well as a willingness to engage in non-routine work, sometimes at the margin of what is considered to be good practice.

This places the spotlight on the dimension of normativity in professionalism. Normativity is connected to values, but also to craftsmanship and artistry. Goal-Oriented Care has to be rooted in a professionalism that focuses on 'the good', in a moral, instrumental and aesthetic sense. The professional must be able to triangulate between the goals of the patient, the requirements of professional standards and their individual penchant for beauty, sympathy and sense (Van Ewijk, 2018).

Care-Esperanto is an example of a process and instrument that have been developed to support normative professionalization. It has been developed by Bart Deltour and his collaborators at Familiezorg West-Vlaanderen (Home care organization in Belgium) and is finding its way into the wider care community. Care-Esperanto is, as the name suggests, a 'language', a heuristic framework that supports care providers, informal carers and patients in the collaborative process of finding out what 'good care' means (Deltour, 2018).

Key questions are: Which care fits the life and care goals of this particular person? How do we achieve quality care? Which competencies are needed? Which use of care is most appropriate? Which means are necessary or appropriate?

Care-Esperanto distinguishes four major components (see Figure below): the care relationship, clear common goal setting, the approach to achieve the goals, and a reality and values test. The encounter between provider and patient is animated by a basic desire for reciprocity, unhindered by a priori assumptions and categorizations. Care providers are invited to go beyond facts, problems or diagnoses (the outside), and be attentive to feelings, motives and values (the inside) of the person in the relationship. The language used to work through the relationship is explicitly needs-oriented rather than problem-oriented (not: 'this person is stubborn', but: 'this person expresses a need for autonomy'; not: 'this person is a danger to herself', but: 'she needs protection'). While listening reflectively, the care provider gains insight into different areas of life that may or may not require attention.

Loved ones or other key people appear, who may or may not be present (context). Patient goals emerge from the conversations. They are always framed within the meta-goals of maintaining or enhancing quality of life, and they take into account the care seeker's expectations about the extent to which the care process entails relative dependence on the provider. These insights provide the basis for a care or support plan. The framework explicitly provides prompts that go beyond a strictly clinical perspective. Support may be sought in a variety of more or less formal care environments and encompass all areas of life. This quite naturally opens the way to a multi-disciplinary approach that engages professional caregivers, paramedical workers and informal caregivers. A values check concludes and adds a normative layer to the reflective cycle. Values are not ranked or weighted as they are assumed to be play out in a quite specific manner in a given situation. The point is to be attentive to what manifests itself, to possible gaps and to potential conflicts between values.

Care-Esperanto embodies normative professionalism in action. It is an instrument that centres on the articulation of patients goals, invites an ethos of reciprocity and co-creation, provides a foil for a wide range of therapeutic approaches, and subjects plans and strategies to a values-based assessment. It is an accessible approach that can pave the way for a wider adoption of Goal-Oriented Care by medical professionals across sectors and disciplines.

CARE-ESPERANTO

MEETING

OUTSIDE
Problems
Diagnoses
Facts
Objective
Observations

INSIDE
Feelings
Needs
Personal incentives
Values

CONNECTING COMMUNICATION IN EQUAL RELATION
Strength
Vulnerability

GOALS IN LIFE/CARE

AREAS OF LIFE WHAT?
PERSON-CENTRED – HOLISTIC – NEEDS-BASED

- ○ Living environment
- ○ Physical health*
  - ○ Food
  - ○ Exercise/mobility
  - ○ Personal hygiene (washing, toilet, clothing...)
  - ○ Medication(adherence)
  - ○ Sleep/rest
- ○ Psychical health*
- ○ Relational health*
- ○ Administration and finances
- ○ Integrity
- ○ Integration
- ○ Sexuality
- ○ Upbringing/education
- ○ Meaning of life (general/leisure/work...)

WHOSE INVOLVEMENT?
CONTEXT-DIRECTED

- ○ Care seeker
- ○ Partner
- ○ Child(ren)
- ○ Baby
- ○ Whole family
- ○ Informal care
- ○ Care provider(s)
- ○ Others

DESIRED RESULT
GOAL-DIRECTED

- ○ To prevent
- ○ To maintain
- ○ To recover from
- ○ To develop

* 'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.' (WHO)

MEANS/APPROACH

WHAT?

LINK WITH AREAS OF LIFE

Examples of actions:

- ○ To structure
- ○ To observe
- ○ To mediat
- ○ To adapt
- ○ To coordinate
- ○ To guide
- ○ To advis
- ○ To inform
- ○ To cook
- ○ To clean
- ○ To iron

Examples of means:

- ○ Rollator
- ○ Wheelchair
- ○ Handgrip
- ○ Transferring hois
- ○ Pictograms

HOW?

FROM ACTIVE TO PASSIVE FROM THE CARE SEEKER'S PERSPECTIVE

- ○ Complete independence (no care needed)
- ○ Accepting help, aiming at the biggest possible independence (preparation/supervision/teaching)
- ○ Accepting help, aiming at partial dependence (supplementary/supportive care)
- ○ Complete dependence (complete care/take-over needed)

By WHOM/WHERE?

LINK WITH COMPETENCES

- ○ Care seeker
- ○ Environment of the care seeker
  family, friends/relatives, socio-cultural organisations, neighbours/ neighbourhood, working environment...
- ○ Volunteer
- ○ School and student guidance centre
- ○ Legal/financial adviser
  notary, budget controller, administrator, debt mediator...
- ○ First line care provider
  general practitioner, nurse, midwife, (maternity) professional care taker, cleaner, handyman, occupational therapist, physiotherapy practitioner, elocutionist, social worker, first line psychologist, dietician, Child and Family, pharmacist, day support/day care...
- ○ Crisis care support
- ○ Specialised (home care)service
  home care, mobile team, foster care...
- ○ Sheltered and accompanied housing
- ○ Residential care: short/long-term/permanent
- ○ Hospital (general, psychiatric...)
- ○ Other

WEIGHING UP

SMART?

Specific?
Measurable?
Acceptable?
Realistic?
Timely?

VALUES?

Care
Protectability
Autonomy
Privacy
Participation
Quality of life
Justice
Sustainability
Trust
Solidarity

06

A TRANSITION TO GOAL-ORIENTED CARE: STRATEGIC CONSIDERATIONS

LEVERAGING HEALTH CARE 'MEGATRENDS' TO TRANSITION TO GOAL-ORIENTED CARE

The stories in Section 4 underline that goal-oriented care has implications beyond the patient-provider relationship. It provides a shared language for multidisciplinary teams of providers, an incentive for cross-sectoral learning and a pragmatic framework to develop care plans for people with complex needs. Here we want to expand the scope of the reflection beyond operational concerns, to a strategic level.

Indeed, the transition to goal-oriented care does not happen in a vacuum. It is embedded in the wider health care system, which is dynamic reality. For a while now it has been facing a number of pressures – shrinking public resources, more complex and personalized patient conditions, a wave of technological innovations.

Here are seven *'megatrends'* that are are shaping contemporary health care systems. They can be leveraged strategically to further the agenda of goal-oriented care.

- A dominant pattern in responses to current challenges for health care systems is the pursuit of various forms of rationing, of economies of scale, and the increasing reliance on free market approaches.
  There seems to be a significant gap between a system that is increasingly guided by measurable outputs and strictly medical goals, and a practice that orients itself to patient-goals and pivots on social capital and tacit knowledge. Nevertheless, it is important to adopt a win-win mindset and remain alert to the potential of mainstream policy interventions for goal-oriented care.

- The practice of goal-oriented care is fully aligned with the dominant frame of the Quadruple Aim that has been embraced by the health care community.
  The Quadruple Aim assesses healthcare system performance in light of four objectives: improving the health of populations, improving the patient experience, reducing per capita costs of health care and maintain provider satisfaction.

- Notionally, the central position of the patient in the health care system is undisputed. The foundational principle of patient-centric care is to involve patients in decision-making, and to recognize them as individuals with their own unique values and preferences. This is an invitation to providers to treat patients with dignity, respect and sensitivity to his/her cultural values and autonomy. This presents an obvious bridge to a goal-oriented care practice.

- Policy makers are increasingly sensitive to the need for more integrated ways of delivering care.
  This provides opportunities as patient goals may provide the ethical and conceptual focus to weave multidisciplinary contributions into a coherent care plan.
  However, integration entails also challenges.
  With the establishment of multidisciplinary networks, a bond of trust and familiarity between patient and provider may be become harder to achieve, or it may become more episodic. Careful thought needs to be given to how patient-intimacy can be assured as an appropriate setting for the articulation of patient goals.

- More and more the role of the local community is recognized in delivering and valorizing health care.
  Integrated Community Care goes beyond integrated care by recognising that communities are invaluable reservoirs of resources: relationships, expertise, entrepreneurial skills, public space and services, locally supportive ecosystems.
  [The value of these resources has never been more clear than in the recent Corona-crisis.] Integrated Community Care wants to create the conditions for people to take care of their own lives and of their fellow community members.
  Health care systems move away from 'delivery' to genuine 'co-development' with the individuals and communities that are traditionally seen as recipients.
  The pivoting place of 'co-development' is a genuine opportunity for a goal-oriented practice of care that creates meaning for those in need.

- Connected to an enabling community-oriented approach is the increasing recognition of the value of investing in health literacy. Everyone needs knowledge, motivation and skills to get the right information about health, to understand, assess and apply this information. With these health skills, people in everyday life can judge and make decisions for better health and better quality of life. This encompasses health care choices, disease prevention and health promotion. At the heart of a goal-oriented care approach lies a process of exchange of meaningful, context-sensitive information, and the alignment of services therewith.

- It is impossible to bypass the recent COVID-19 pandemic. It remains to be seen now what the knock-on effects will be of this disruption on health care systems. It seems that this discontinuity is revealing the fragilities and fracture lines in key infrastructures and institutions. A renewed emphasis on resilience may create opportunities for a more richly textured and locally sensitive health care that connects to individual and community strengths and addresses social and environmental determinants of health.

The nature of goal-oriented care is such that one size does not fit all. The way it is delivered depends on type of care and organizational setting. The message is to keep tabs on these megatrends and to strategically piggyback on their momentum. In parallel an assertive goal-oriented agenda, backed up with real-world evidence, has to be developed to proactively steer key policy decisions (about financing, integration, centralisation and decentralisation) in a direction that facilitates the adoption of goal-oriented care.

A renewed emphasis on resilience may create opportunities for a more richly textured and locally sensitive health care that connects to individual and community strengths and addresses social and environmental determinants of health.

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GOAL-ORIENTED CARE

A SHARED LANGUAGE AND CO-CREATIVE PRACTICE FOR HEALTH AND SOCIAL CARE

Medical and social care professionals are used to entering a relationship with care seekers with a diagnostic pair of glasses. They are looking for problems to be solved. In caring for patients with complex medical and social needs this is likely to lead to suboptimal results.
Goal-Oriented Care is a response to the limitations of problem-oriented care, particularly in confrontation with increasingly complex needs of patients with multiple chronic conditions and challenging socio-economic conditions.

Goal-Oriented Care takes a pragmatic approach to deal with this kind of complexity. It puts the priorities and life goals of the patients at the centre. This helps practitioners to prioritise, and to co-create, with peers and patients, an efficacious and humane path towards living with multiple conditions. Patient, practitioner and the wider health care system are poised to benefit from this.

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