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Decision-making in complex health care situations: Shared understanding, experimenting, reflecting and learning

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Abstract

People who have complex problems affecting multiple areas of their lives need a different approach than people who have singular health conditions. They benefit more from an effectively cooperating support network that explores appropriate ways of providing assistance, rather than a strong focus on outcome-based care.

Keywords

Complex health problems, shared decision-making, patient empowerment, outcome-based care

Introduction

A person who is ill needs care and support. However, a person who is not only ill, but also unemployed and in psychological distress, requires more extensive assistance. Complex health care problems are often precisely where adequate service provision falls short. The Dutch Council for Public Health and Society,[1] an independent advisory body for the national government and the Dutch parliament, advocates a fundamentally different approach that aims to give a voice to patients with complex problems (see Figure 1). The Council's proposal was described in its recent advisory report on a shared approach to complex care situations,[2] and is summarised here.

The Netherlands, like many other countries, is seeing a growing demand for care – and increasing complexity in the care that is needed. Approximately 10% of patients face complex problems in multiple areas of their lives, e.g. physical, social and psychological.[3]

Such cases often incorporate multiple care providers and organisations, with varying frequency and duration of involvement. These care providers operate on the basis of diverse and wide-ranging objectives, tools, rules and budgets. The care and support they provide are difficult to organise, and may not be compatible. For example, tools such as the ICT systems used by medical specialists may not be able to link to the systems used in primary care, while rules may be in effect that assign responsibility for care to medical specialists, making it difficult for other health care professionals to contribute. As a result, people with complex problems often do not receive adequate assistance.[4]

The Dutch Ministry of Health, Welfare and Sport (VWS) asked the Council for advice on the following question: What is needed to arrive at an 'outcome-oriented decision-making process, based on what is really important for the patient in question'? The focus is on people with complex care needs who end up in hospital via their General Practitioner (GP), on patient empowerment and on shared decision-making.

The standard roadmap

Most medical specialists in hospitals currently use the same approach for people with complex problems as for people with singular problems, such as hip operations or bypass surgery. In hospitals where a shared decision-making process has been embraced, medical

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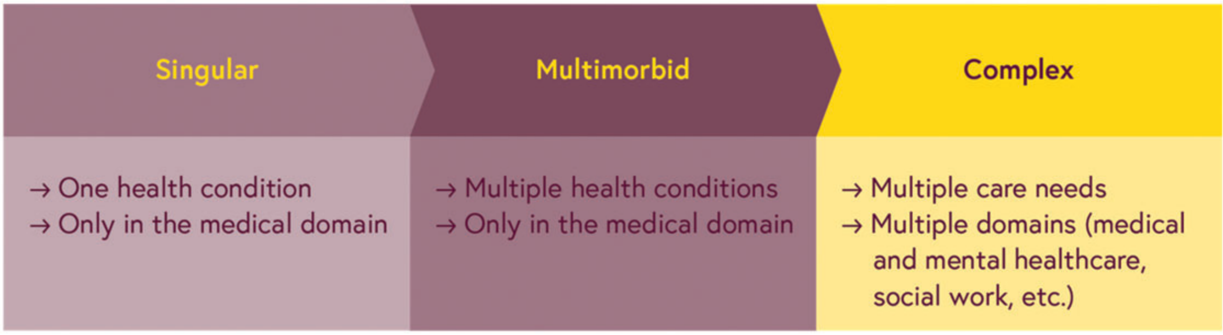

Figure 1. Comparison of singular, multimorbid and complex situations.

specialists involve patients in deciding how to treat their condition. They present patients with a limited number of treatment options from their narrow field of expertise, outline the pros and cons, and share the available evidence about the options, chances, risks of side effects and expected results. The emphasis is on information transfer with the aim of enabling patients to form their own judgement (patient empowerment). After that, patients can express their preferences.

The next step is to integrate the doctor's knowledge and competences, and the patients' preferences, values and prior experiences. Only then do health care providers and patients reach a shared decision about treatment, with the aim of curing or containing the disease (shared decision-making). Treatment starts after this step (see Figure 2).

In treating most singular disorders, physicians can rely on models, guidelines and protocols. That makes their work manageable and efficient. The models generate their own objectives; a specific intervention is chosen with the aim of achieving a specific outcome. Effectiveness of care can be measured by the extend to which these objectives are achieved.

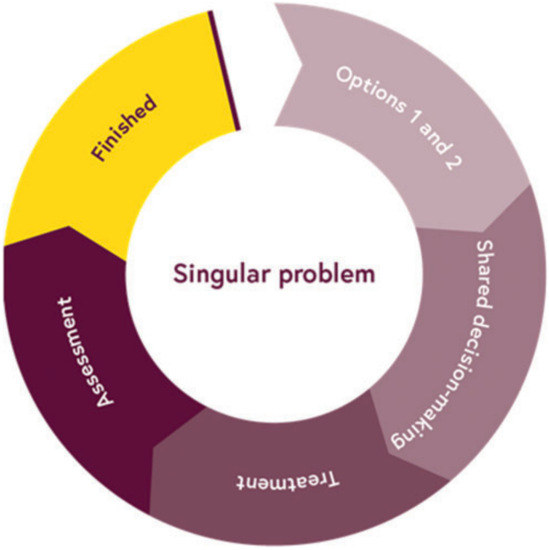

Figure 2. The process of addressing a singular problem.

Cumulative obstacles

For people with complex problems, this state of affairs leads to cumulative obstacles. Most importantly, hospitals will first and foremost consider the patients' problems from a medical perspective. Specialised, in-depth medical knowledge can also lead to a fragmented, disease-specific approach that does not sufficiently account for how the various aspects of the patients' lives are interrelated.

In cases involving complex care needs, a shared decision-making process with equal input from patients and health care providers must go beyond information about the pros and cons of treatment options. Extensive dialogue is needed about what matters to patients. This takes place in the context of primary care, but the resulting input remains relevant in secondary care, although it is currently almost entirely disregarded in that context.

Health care providers easily dominate the dialogue with patients. An equal relationship is established when their respective areas of expertise are acknowledged: the health care providers possess knowledge and experience about health care, while the patients can contribute essential knowledge and experience about their own lives. Close contacts can play a key role in getting to know the patients and in providing support, but are currently not acknowledged as partners in shared decision-making processes.[5]

In complex care needs, the decision-making process cannot be simplified to consideration of a few unambiguous alternatives. In presenting options to patients, care providers often provide generic outcome information based on large-scale studies involving similar interventions. However, this has limited relevance in complex care situations. A random controlled trial is mainly suitable for researching singular interventions. The variable and often rapidly changing life circumstances of patients with complex problems, which escape any attempt of research controllability, make RCTs less suitable and generalizable in these cases.[6]

Care and support for people with complex problems almost always requires a multi-track strategy and a long-term approach. It is often unclear how problems can be resolved, so the best possible outcome that satisfies patients may be learning to deal with some of the limitations.[7] This is difficult to reconcile with the Ministry's commitment to outcome-based care and Porter's model[8] of value-based health care.[9] Both involve pitfalls for people with complex problems. If information is limited to a specific subset of quantitative data, there is a risk that patient experiences will be reduced to quantifiable fragments, disregarding aspects that are not quantified or identified in codified questionnaires, but may still be very relevant.[10,11]

The needs of patients with complex problems do not fit into a streamlined course of treatment focused on serial production, efficiency and effectiveness. Their care needs may fluctuate over time, and the results may be affected by location, care provider and context. Consequently, there is no unambiguous treatment result that can be defined as the intended outcome.

Outcome-based care can be counterproductive for people with complex problems. Where they mainly need more coordination of care services, including cooperation between care providers value-based health care according to Porter's competitive model can lead to further fragmentation of care, with negative results.[12,13] The same applies to efforts to pursue outcome-based care for the purpose of comparability and control of health care providers.

As long as medical specialists in hospitals adopt identical approaches for people with complex problems and people with singular problems, these vulnerable patients will not be sufficiently heard. For that reason, the Council proposes an alternative approach that involves an enriched decision-making process.

Separate roadmap for complex problems

In cases involving hospital patients with complex care needs, the Council advises replacing 'shared decision-making' with 'shared understanding, experimenting, reflecting and learning'. The aim is an iterative decision-making process that focuses on the different problems, addresses multiple areas and considers the patients' context (see Figure 3).

This is often standard practice in primary care, but has not yet been sufficiently extended to secondary care. This step-by-step approach involves an ongoing, iterative search for customised solutions that includes formal care providers and informal carers. People involved in primary and secondary health care therefore take a shared approach to triage, guiding towards a classic or alternative decision-making process. Possible solutions for treating patients with and without complex needs on the same day could include timeslots or, more radically, outsourcing clients with singular problems altogether by sending them to highly efficient clinics dedicated to that specific problem.

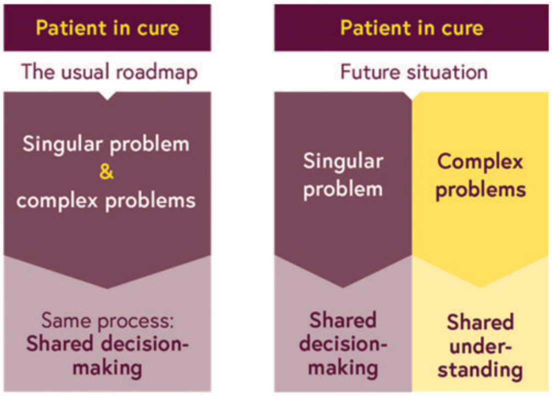

Figure 3. A comparison between current standard practice and the envisioned future situation.

Shared understanding

The dialogue between care providers and patients should not be limited to discussing medical treatments, instead including non-medical difficulties and possibilities – outside the health care system, in primary care, and potentially also in secondary care. The narrative constructed in dialogue based on subjective experiences gives care providers essential tools for incrementally presenting their own expertise to patients.

In this sense, there is a reciprocal dialogue between patient and care provider. Patients contribute stories, ideals, motivations and priorities. Care providers contribute medical and/or societal knowledge, structure and experience involving complex care issues. Based on these multifaceted sources and data, a shared decision-making process becomes a mutual understanding of the patients' situation.

In situations involving complex care needs, patient empowerment does not focus on alternatives and outcomes, but on encouraging patients to present their own narrative and express their own personal values, desires and uncertainties. This requires trust and time, in informal care contexts as well as in primary and secondary care, allowing for contact with patients as well as cooperating partners.

Cooperation in close proximity

As soon as it becomes apparent that complex problems are involved, there should be a strong focus on interdisciplinary cooperation. The network of formal care providers and informal carers should ideally be located close to the patients. Close proximity is easier for patients, and facilitates contact between key figures in various domains. Consultation within the network should take place regularly, online if not face to face. Similar ideas may have been developed in the past, but are far from common practice. However, in view of the growing number of people with complex problems, as well as a plethora of new technologies for connecting with others (including apps like Zoom, Facetime, etc.), the Council considers the current situation highly conducive to new forms of interdisciplinary cooperation within the network for formal and informal care providers.

Care-seekers should be explicitly encouraged to involve a trusted person from their own social circles. These close contacts could be friends or family members, or some other trusted person, such as a volunteer or a neighbour, who is willing to be involved in the long term.[5] For a broad overview, mutual understanding and continuity of support, it is important to acknowledge close contacts as equal partners in the care network and in the shared decision-making process. The Council advocates legal recognition of their position.

People seeking care should have the opportunity to designate a coordinator in their care network; that could be the General Practitioner, a social worker, or a clinical geriatrician in the hospital. The coordinator should have a broad overview and should ideally remain involved for as long as the problems persist. Coordinators keep the process moving, although patients play an active role wherever possible.

Shared experimenting, reflecting and learning

After building trust, exploring the situation, and getting an impression of the patients' problems and perspectives, it is time to start experimenting. This means exploring various interventions to improve the situation, in a care network that is resilient enough to accommodate trial and error. The aim is for the care-seeker to gain confidence that step-by-step improvement is possible, by repeatedly making small-scale shared decisions to break the spiral and find the way back up, or find the best possible solution to the problems.

The process is incomplete without regular reflection within the care network (see Figure 4). Setbacks, unexpected developments and interpersonal friction are likely, so the process should include ongoing learning and adjustment. Has it been possible to achieve what the patients intended? Have we understood the patients correctly? What more can we try? How can we avoid handing off difficulties to others? And who might offer different alternatives?

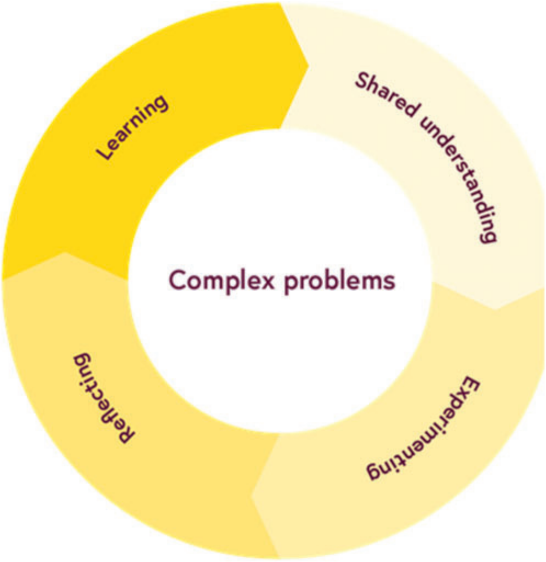

Figure 4. The process of addressing complex problems.

This process is also important at the level of policy and care funding. The Council believes that care for this group of people should be funded primarily on the basis of interaction within the care network, not on outcomes.

Progress can be monitored at a local level, based on how the patients and their care network jointly define relative quality. During assessment visits to the care network, the process adopted by care providers should clearly prioritise getting to know the patients. Have the care providers worked with the patients and their close contacts in an iterative process of shared understanding, experimenting, reflecting and learning? Are care providers learning from best practices within the network and regularly coordinating with the patients, their close contacts and each other? Is the focus on what is important to the patients? And what progress is being made in those areas?

The added value of care and support cannot be quantified in terms of the degree of cure, or whether all the problems have been resolved, but rather by the extent to which a concrete and stable care network has been established that provides optimal and visible support to the patients. That care network is proactive and responsive, relying on narrative input as well as quantitative data. It reflects, evaluates and learns. The person seeking care feels heard and acknowledged, not crushed by bureaucracy or disregarded by a fragmented care system.

Conclusion

When people with complex care needs come to the hospital, care providers do not pay sufficient attention to their non-medical problems. After triage with this group, it is advisable to enter into an enriched, iterative decision-making process that focuses on various problems, addresses multiple areas and considers the patients' context. This is only possible in a multidisciplinary care network. Close contacts must have a solid position in this network, and care and support must be coordinated effectively. In view of the increase in people with complex problems, as well as new technologies for connecting with others, the current situation is highly conducive to new forms of interdisciplinary cooperation within the network for formal and informal care providers. Hospitals would do well to experiment with different approaches to people with complex problems. The Council advises an approach based on encouraging and appreciating the quality of interactions between different elements in the multidisciplinary network of care and support surrounding the patients, rather than focusing on the end result (outcomes).

In treating most singular disorders, physicians can rely on models, guidelines and protocols. That makes their work manageable and efficient. The models generate their own objectives; a specific intervention is chosen with the aim of achieving a specific outcome. Effectiveness of care can be measured by the extent to which these objectives are achieved.

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References

1. Raad voor Volksgezondheid & Samenleving. https://www.raadrvs.nl/about-the-rvs (accessed 13 January 2021).
2. Raad voor Volksgezondheid & Samenleving. *Hoor mij nou! Samen begrijpen, proberen, reflecteren en leren bij complexe zorgvragen [Hear me! Shared understanding, experimenting, reflecting and learning in complex care situations]*. The Hague: Raad voor Volksgezondheid & Samenleving, https://www.raadrvs.nl/documenten/publicaties/2020/10/15/hoor-mij-nou (2020. accessed 13 January 2021).
3. Van der Feltz CM. *Complexe mensen, hoe behandel je die? Valedictory lecture*. Tilburg University, Netherlands, https://www.researchgate.net/publication/332866446_Complexe_mensen_hoe_behandel_je_die/link/5cceb78a92851c4eab83be88/download (2019, accessed 14 January 2021).
4. Kruiter AJ, De Jong J, Van Niel J, et al. *De rotonde van Hamed. Maatwerk voor mensen met meerdere problemen*. The Hague: Nicis Institute, 2008.
5. Van Nistelrooij I. Wat moeten we met naasten en familie? Gezamenlijke besluitvorming en het relationele netwerk van de patiënt. *Tijdschrift voor Gezondheidszorg en Ethiek* 2015; 25: 14–18.
6. May A and Mathijssen J. *Alternatieven voor RCT bij de evaluatie van effectiviteit van interventies!*: final report, Utrecht, 2015.
7. Vrijhoef HJM. Care coordination: complicated or complex? *Int J Care Coordination* 2019; 22: 3–1.
8. Porter ME. What is value in health care? *N Engl J Med*. 2010; 363: 2477–2481.
9. Steinmann G, Van de Bovenkamp H, De Bond A, et al. Redefining value: a discourse analysis on value-based health care. *BMC Health Serv Res* 2020; 20: 862. doi: 10.1186/s12913-020-05614-7
10. Delnooij DS, Beslissen, et al. *Via uitkomstinformatie naar patiëntgerichte zorg?* Valedictory lecture.. Erasmus University Rotterdam, the Netherlands, 2019.
11. Ordónez LD, Schweitzer ME and Galinksky AD. *Goals gone wild: the systematic side effects of over-prescribing goal setting*. Working paper, Harvard Business School, USA, 2009.
12. Elf M, Flink M, Nilsson M, et al. The case of value-based healthcare for people living with complex long-term conditions. *BMC Health Serv Res* 2017; 17: 24. doi: 10.1186/s12913-016-1957-6
13. Groenewoud AS, Westert GP and Kremer JAM. Value based competition in health care's ethical drawbacks and the need for a values-driven approach. *BMC Health Serv Res* 2019; 19: 256. doi: 10.1186/s12913-019-4081-6