Good representation

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Executive summary

Health Council of the Netherlands

When it comes to their (health) care and treatment, every individual has the right to make their own decisions. However, people are sometimes unable to effectively represent their own interests in certain situations or with regard to specific decisions. In cases such as these, a surrogate assists the patient or acts on their behalf. This can be either a family member (default surrogate) or someone else designated by the patient (patient-designated). Alternatively, the representative could be appointed by a judge: a guardian. In practice, the reach of a surrogate's powers is not always clear. The same applies to the (quality) standards that should be met by good representatives. Furthermore, good representation can sometimes clash with the best practice in health care provision. This can give rise to tensions in the care relationship which, in turn, can adversely impact the care and treatment of the patient in question. The number of complaints (including those involving disciplinary proceedings) concerning the relationship between surrogates, healthcare providers, and the patients involved appears to be growing. For this reason, the Health Council of the Netherlands' Committee on Ethics and Law independently took the initiative to investigate which aspects of patient representation are subject to statutory (or other) regulation. The committee also investigated the problems with representation encountered in practice, and the views of those involved on what constitutes good patient representation. The Committee's goal was to provide assistance for policymakers, healthcare providers, representatives and patients.

Inconsistency in legislation

The Committee has found differences between various parts of legislation, in terms of the way these describe representatives' duties and powers. Moreover, while the powers of guardians (and the associated quality requirements/standards) are extensively regulated by law, the same is not true of patient-designated and default surrogate. The Committee recommends to ensure that the terminology used in the various part of legislation (as well as the descriptions of representatives' powers and duties) should be as consistent as possible, or even actively coordinated.

In practice, the scope of a guardian 's powers and responsibilities is unclear in cases where patients are able to make a given care-related decision themselves. The Committee takes the view that legally competent adult patients can make their own decisions, but that their guardian should be informed about this. It feels that legislators should ideally take a clear and consistent position in such matters.

Timely discussion about the choice of representative

Doctors, representatives and patients consider the scope of the surrogates' duties to exceed what is currently laid down in law. In practice, the surrogate role is not limited to treatment decisions alone. Other important duties include flagging up issues as they arise and providing information. Problems associated with

representation vary, to some extent, from one healthcare sector to another. However, some issues are common to healthcare sectors. For example, in practice it is not always clear who is acting as the patient's surrogate. At the start of any treatment relationship, the Committee recommends that healthcare providers discuss the matter of who should represent the patient (or who will do so in the event of their future legal incompetence) and record these details in the medical file.

Providing information about types of representation

Furthermore, in practice, doctors often prefer family representatives (default surrogates). This is because these are people who are close to the patient, with whom they share a common life history. However, family members are not always available to take on this role, so there is a growing demand for guardians. In practice, there is a need for more information about the various types of surrogates and guardians (statutory or otherwise) and about their duties and powers. The Committee recommends that professional groups and patient associations give more consideration to this matter. A key issue here is that the statutory duties and responsibilities of guardians do not appear to be consistent with what is expected of these individuals in practice.

Expand the permitted types of representatives and establish quality requirements

A problem that doctors occasionally encounter in practice is that the surrogate is not performing their duties properly, or that there is no representative at all. They have a range of strategies for dealing with such eventualities. Doctors are generally reluctant to apply for a guardian through the sub-district court. However, this will become compulsory under two new pieces of legislation – the Care and Coercion Act (WZD) and the Mandatory Mental Healthcare Act (WVGGZ) – which are expected to come into force in 2020. It is often the case that no surrogate is available for a legally incompetent patient. The Committee, therefore, recommends that the default surrogate hierarchy listed in the Medical Treatment Contracts Act be expanded to include grandparents and grandchildren. This would be in accordance with the Healthcare Quality, Complaints and Disputes Act, the Care and Coercion Act, and the Mandatory Mental Healthcare Act. The Committee also recommends that minimal quality standards and principles of effective representation are drawn up. In case of doubt, healthcare providers could use these as criteria for assessing a representative's performance.

Effective communication, even when views differ

Finally, doctors and surrogates may disagree about what is best for the patient. In principle, the surrogate's consent is paramount, unless the surrogate seems not to act in the patient's interests. The healthcare provider can countermand the surrogate 's wishes if these are incompatible with the principles of best practice in care provision and might harm the

patient. In practice, it appears that good representation largely depends on relational aspects, effective communication, involvement, due consideration, and the bond between the surrogate and the patient. That is why the identified problems cannot be resolved through adjustments of the legal framework (or not by this means alone). This also requires the active involvement of individual healthcare providers, their professional organisations, and patient associations.

The Committee advises healthcare providers to take certain steps both at the start of the treatment relationship and ongoing. This involves discussing and regularly evaluating the care provider’s and the surrogate ’s individual expectations, rights and obligations, in terms of their respective responsibilities towards the patient. The Committee also advises professional organations and patient associations to draw up guidelines that healthcare providers, representatives and patients can use when discussing their respective expectations. In the event of a difference of opinion between the healthcare provider and the surrogate, the Committee feels that it is best to postpone any decision until the patient is once again legally competent. In cases where such decisions cannot be delayed or where legal competence (or the restoration thereof) is out of the question, the Committee recommends that an independent expert (such as a mediator or a complaints officer) be appointed and/or that a moral case deliberation be held. It also advises care institutions to appoint a confidential counsellor to guide and support surrogates .

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