A fair balance: health data protection and the promotion of health data use for clinical and research purposes

Kist, I.R.

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The sustainability of consent by elderly persons developing dementia

2. The sustainability of consent by elderly persons developing dementia[177]

This chapter answers sub-question 1 that reads as follows:

In what way does the focus on the lawful basis of consent influence the provision of care when the individual is unable to express his will?

Abstract

Patient-centered self-management and shared decision-making are popular concepts in health care. A diverse array of rules and legislation center around the patient's position and his[178] rights as a patient. Self-determination and autonomy are key concepts. Patients can give their consent for their health data to be used, have the right to make decisions about their treatment and, in principle, control the care provided to them. The boundary between the self-management that an elderly person, developing dementia, can exercise over the processing of his personal data and the care he receives differs for each individual case. Whether his (formal or informal) representative co-decides differs in each situation as well. Although Dutch health legislation offers a framework for this issue, the implementation of that framework may prove intractable in practice.

In this chapter, I discuss the principle of consent: consent for the processing of health data and for the provision of care to elderly persons developing dementia. I conclude that focusing only on the consent given by the patient to legitimize the use of his health data and the provision of care to the patient, may restrict the exchange of health data among various health institutions. It may also create the risk of depriving the patient of optimum health care, for example because he has refused to give consent for the sharing of his file or for receiving domestic or other care.

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[177] Kist, I.R. (2021). De houdbaarheid van toestemming door de dementerende oudere, *Privacy & Informatie* (4), 165-170. Key reference words: autonomy, consent, dignity, self-determination.

[178] References to he, him and his may be read as references to she and her.

2.1. Introduction

In principle, processing health data is prohibited. An exemption to this prohibition consists in the explicit consent of the person involved. Consent as a legitimization for sharing data or providing care is set out in several sections of health care legislation. In this introduction, I discuss consent as included in the Dutch Medical Treatment Contracts Act (*Wet inzake de Geneeskundige Behandelingsovereenkomst*, chapter 7, title 7, section 5 Dutch Civil Code, hereinafter WGBO), the General Data Protection Act (hereinafter GDPR), the *Uitvoeringswet Algemene Verordening Gegevensbescherming* (Dutch GDPR Implementation Act, hereinafter UAVG), and the Dutch Care and Compulsion (Psychogeriatric and Intellectually Disabled Patients) Act (*Wet zorg en dwang psychogeriatrische en verstandelijk gehandicapte cliënten*, hereinafter Wzd).

The consent requirement in article 7:450 WGBO pertains to consent to enter into a treatment contract on the one hand, and consent for the actual medical treatment on the other.[179] To this end, articles 7:454 and 7:455 WGBO include the record-keeping requirement for care professionals. Patients are entitled to inspect their files. [180] In addition, articles 7:457 and 7:458 WGBO state how personal data may be supplied to other recipients than the care professional, for example, for further scientific research. The point of departure is the patient's consent (article 7:457 WGBO), with an exemption in some situations (article 7:458 WGBO). In principle, it is assumed in the WGBO that a patient is able to understand and take stock of his choices.[181]

If explicit consent has been obtained, health data[182] can be processed despite the prohibition in article 9 (1) GDPR.[183] Article 9 GDPR provides several exemptions to the prohibition on processing special personal data, in this case health data, to protect vital interests,[184] for the provision of health care,[185] for reasons of public interest in the area of public health,[186] and with a view to scientific research.[187] Article 22 UAVG lists the general exemptions from the regulation regarding the processing of special categories of personal data, including health data. Consent constitutes one of the exemptions to the prohibition on processing. In article 30 UAVG together with article

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[179] Art. 7:450 WGBO: "*Voor verrichtingen ter uitvoering van een behandelingsovereenkomst is de toestemming van de patiënt vereist*" ("The consent of the patient is required for any treatment in the performance of a treatment contract"). Also H.J.J. Leenen et al (2020). *Handboek gezondheidsrecht*, 137 et seq.

[180] Art. 7:456 WGBO.

[181] J. Legemaate, *Staat van de gezondheidszorg 2006: patiëntenrechten in wetgeving en rechtspraak*. Report commissioned by the Dutch Healthcare Inspectorate, May 2006, 12.

[182] See section 1.5 sub a for an explanation about health data as a special category of data in the GDPR.

[183] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC, art. 6 (1) (a) in conjunction with art. 9 (2) (a).

[184] Art. 9 (2) (c) GDPR.

[185] Art. 9 (2) (h) GDPR.

[186] Art. 9 (2) (i) GDPR.

[187] Art. 9(2) (j) GDPR.

9 (2) (h) GDPR, the prohibition on processing health data is lifted for care professionals.[188] Article 24 UAVG sets out exemptions to the prohibition on processing data for the benefit of scientific or historical research or statistical purposes, in view of article 9 (2) (j) GDPR.

The Wzd provides that, in principle, clients decide on the care provided to them.[189] I discuss consent by an elderly person developing dementia, for data processing and medical treatment. The principle of consent is based on a person's autonomy, dignity, and self-determination as enshrined in international and European treaties. Self-determination is a right of all human beings and is closely related to freedom, in particular the freedom to organize one's life.[190] Autonomy is defined as a person's ability to further his own life and to give it authenticity. In addition, autonomy comprises a moral right: each person's right to give shape and meaning to his own life and to reach his own decisions.[191] Autonomy has several dimensions, focusing on the individual and on the individual's relationships with his loved ones and his immediate circle.[192] A person's dignity is not just a fundamental right but also the foundation of all fundamental rights.[193] Human dignity is inalienable.

In this chapter, I discuss how the right to self-determination, autonomy, and dignity of persons developing dementia may be retained in the provision of care and the processing of personal data. I support the view[194] that the current approach to the individual, the explicit consent of and the self-management exercised by clients, do not do justice in all stages of life and at all decision moments, to the everyday lives of people with dementia, their loved ones, and their care professionals. In this context, I discuss the triangle of care that connects the care professional, the client, and the formal or informal representative. I will call the person developing dementia "client" pursuant to article 1(1)(c) Wzd and "patient" pursuant to article 7:446 (1) WGBO. Although the designation *client* is not identical to that of *patient* or *resident*, this distinction is beyond the scope of this chapter.

I start with the legal framework of the principle of consent, and the way in which the position of the client is enshrined in the Wzd (section 2.2). Subsequently, I will explain

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[188] Art. 30 (3) (a) in conjunction with art. 30(4) UAVG.

[189] Art. 3 (1) Wzd.

[190] H.J.J. Leenen et al., *Handboek gezondheidsrecht* (Den Haag: Boom Juridisch, 2020), 55-63.

[191] J.J.M. van Delden, Over de autonomie van de oudere patiënt, in C. Hendriks et. al., *Grondrechten in de gezondheidszorg. Liber Amicorum voor prof. Mr. J.K.M. Gevers* (Houten: Bohn Stafleu van Loghum, 2010), 104-111.

[192] In a broader sense, also the general interest or '*Gemeinwohl*'. See Bundesverfassungsgericht 15-12-1983, ECLI:DE:BVerfG:1983:rs19831215.1bvr020983.

[193] Preamble to the Universal Declaration of Human Rights 1948, GA Res, 217 A (III) (hereinafter UDHR); art. 1 Charter of Fundamental Rights of the European Union 2012/C 326/02.

[194] Anne-Mei The, *Dementie en wat er uiteindelijk echt toe doet. Naar een socialere benadering van dementie*, Dutch National Health care Institute, 2016 lecture.

that in European and national legislation, a system has been established based on the client's autonomy and self-determination as expressed by the client's consent (section 2.3). I describe a case to illustrate the legal fiction that a person developing dementia gives his consent independently (section 2.4). I test the real-life situation described in the case against the standards, and conclude that the embeddedness of autonomy and self-determination in the explicit consent of the client may have undesirable effects on nursing home care. I end this chapter with a conclusion (section 2.5).

2.2. Legal framework

Articles 10 and 11 of the Dutch Constitution (*Grondwet*, hereinafter Gw) include the right to respect for one's privacy and physical integrity.[195] The GDPR provides a prohibition on the processing of health data, which may be lifted with the client's explicit consent.[196] In principle, consent is also the legal basis provided in the WGBO for any treatment carried out in the performance of a treatment contract.[197] The Wzd centers on the client's self-management, expressed in the *ultimum remedium* principle of 'no, unless'. This means that involuntary care may be used only as a last resort, when other suitable solutions are no longer available.[198] In other words, any alternatives based on voluntariness must be exhausted before involuntary care may be provided without the client's consent. Clients must consent to the care provided to the greatest possible extent, even if involuntary care is given. The clients decide on this care and on the exercise of rights and obligations as based on the law. A representative can only act in his behalf once a client can no longer be deemed capable of making a reasonable evaluation of his interests as regards a decision about him.[199] If court authorization is sought, the client will be heard by the court beforehand, assisted by a legal counsel. The client plays a central role in this process.

The comprehensive section-by-section explanation of the Dutch Constitution (*Integrale Artikelgewijze toelichting*)[200] shows that the client's representative has specific powers only and exclusively if and insofar as the client is incapable of making a specific decision. It is doubtful whether the client can reach adequate decisions and if he grasps the consequences of his choices. Again, involuntary care may only be given once no options for voluntary care are available.[201] Admittance to or continuation of

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[195] M. Overkleeft-Verburg, Artikel 10, in A.K. Koekkoek et al., *De Grondwet – een systematisch en artikelsgewijs commentaar* (Deventer: W.E.J. Tjeenk Willink 2000), 177. See also B.J. Koops, Digitale grondrechten en de Staatscommissie: op zoek naar de kern, *Tijdschrift voor Constitutioneel recht*, March 2011.

[196] Art. 6 (1) (a) in conjunction with art. 9 (2) (a) GDPR.

[197] Art. 7:450 (1) WGBO. An exception to this is art. 7:450 (3) in conjunction with art. 7:465 WGBO.

[198] Art. 10 Wzd.

[199] Art. 3 (2) Wzd.

[200] See https://www.dwangindezorg.nl/documenten/publicaties/implementatie/wetgeving/1/wzd-artikelgewijze-toelichting. This informal section-by-section explanation of the Dutch Constitution was mainly intended as field support for the implementation of the Wzd.

[201] Art. 10 Wzd.

a stay in a registered accommodation takes place pursuant to an in-patient treatment decision of the Dutch Care Needs Assessment Center (*Centrum Indicatiestelling Zorg*, hereinafter CIZ). In this situation, the client neither exhibits the requisite willingness for this admission or continuation, nor resists it.[202] The CIZ must decide whether serious harm resulting from the client's behavior, because of his condition or impairment or a mental disorder related thereto, or a combination of these factors, can only be averted by his admission.[203] If the client resists this, court authorization is required for involuntary admission.[204]

2.3. Dignity, self-determination, autonomy, and respect for one's privacy

Consent as a legal basis for processing personal data stems from the respect for human dignity, self-determination, autonomy, and privacy. Human dignity and the right to self-determination are formulated in the Universal Declaration of Human Rights (hereinafter UDHR).[205] The right to self-determination is also included in article 17 of the International Covenant on Civil and Political Rights (hereinafter ICCPR).[206] The UN Convention on the Rights of Persons with Disabilities (UN, 2006) was ratified by the Netherlands in 2014 and centers on autonomy and self-determination, as expressed in a client's self-management and supported decision-making, inter alia.[207]

In article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms (hereinafter ECHR), the right to one's private and family life is honored.[208] Article 8 of the Charter of Fundamental Rights of the European Union (hereinafter CFREU) includes privacy, and article 9 provides the right to protection of one's personal data.[209] The European Court of Human Rights (ECtHR) connects the right to self-determination to the right to personal autonomy and privacy,[210] recognizing that the right to privacy also comprises the right to personal development, including the individual's vital interest in receiving information about himself, thus obtaining personal freedom regarding himself and his identity.[211] In addition, the

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[202] Art. 21 Wzd.

[203] Art. 21(2) Wzd.

[204] Art. 24 Wzd.

[205] Preamble and art. 12 UDHR.

[206] 16 December 1966, New York.

[207] Kingdom Act approving the Convention on the Rights of Persons with Disabilities adopted on 13 December 2006 in New York (Treaty Series 2007, 169 and Treaty Series 2014, 113). Parliamentary Papers II 2014-2015, 33992-(R2034) no 5.

[208] 1950, ETS 5.

[209] 2012/C 326/02 ELI: http://data.europa.eu/eli/treaty/char_2012/oj. O. Lynskey, Deconstructing data protection: the 'added-value' of a right to data protection in the EU legal order, *International and Comparative Law Quarterly* 63 (2014) (3), 569-597.

[210] ECtHR 29 April 2002, *Pretty v. United Kingdom*, no 2346/02; ECtHR 11 July 2002, *Christine Goodwin v. United Kingdom*, no 28957/95, ECtHR 16 October 2008, *Renolde v. France*, no 5608/06, para 83, ECtHR 20 March 2007, *Tysiaç v. Poland*, no 5410/03, para 15. Council of Europe 'Guide on Article 8 of the European Convention on Human Rights', 31 August 2019.

[211] ECtHR, 7 July 1989, *Gaskin v. United Kingdom*, no 10454/83, ECtHR 13. See also ECtHR, 13 February 2003, *Odièvre v. France*, no 42326/98, ECtHR 86.

ECtHR recognizes autonomy pursuant to article 8 ECHR.[212] In 1997, the ECtHR explicitly acknowledged for the first time that medical personal data also fall under the scope of application of article 8 ECHR.[213] Autonomy has several dimensions, centering on the individual and on the relationships of the individual to his loved ones and his immediate circle, respectively.[214] The ECtHR has repeatedly held that necessary treatment (compulsory or otherwise) does not constitute a violation of article 3 ECHR. Accordingly, providing necessary care may justify involuntary admission to a nursing home pursuant to article 5 (1) ECHR.[215]

In Dutch law, article 10 of the Constitution pertains to privacy and article 11 to physical integrity.[216] These two classic constitutional rights safeguard the freedom and equality of the individual and restrict public powers. Those rights may be limited by or pursuant to the law, as in article 7:450 in conjunction with 7:465 WGBO and in article 3 (2) Wzd. If a client cannot be deemed capable of a reasonable evaluation of his interests in relation to a decision about him, a representative may act on the client's behalf. In this situation, the representative has been tasked with the client's representation by the law or a physician, who has the requisite expertise and is not involved in the client's care, has decided that the client cannot be deemed capable. If a person is legally capable, he has the right to reach his own decisions about his own life.[217]

Self-determination does not merely comprise a right in the relationship between the state and the citizen.[218] The right also affects horizontal relationships, such as those between health care professionals and patients.[219] In case law, the connection between the provision of information by a practitioner and the patient's consent as an expression of his self-determination has also been recognized.[220] In sum, the principles of

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[212] ECtHR 20 March 2007, *Tysiaç v. Poland*, no 5410/03, NJCM Bulletin 2007, p. 497 (annotated by A.C. Hendriks). NL Supr. Ct. judgment in re. Baby Kelly, Netherlands Supreme Court 18 March 2005, NL 2006, 606. ECLI:NL:HR:2005:AR5213.

[213] ECtHR, 25 February 1997, *Z. v. Finland,* ECLI:NL:XX:1997:AD4448, *NJ* 1999, 516, with commentary from Knigge, *NJB* 1997, pp. 1722-1724. *NJCM-Bulletin* 1997, 712 et seq. annotated by A.C. Hendriks.

[214] In a broader sense, also the general interest or '*Gemeinwohl*'. Bundesverfassungsgericht 15-12-1983, ECLI:DE:BVerfG:1983:rs19831215.1bvr020983.

[215] ECtHR 24 September 1992, *Herczegfalvy v. Austria*, no 10533/83, NJ1993, 523; ECtHR 10 February 2004, *Gennadi Naoumenko v. Ukraine*, no 42023/98 and ECtHR 11 July 2006, *Jalloh v. Germany*, no 54810/00; ECtHR 26 February 2002, *H.M. v. Switzerland*, no 39187/98, BJ 2002, 20.

[216] Parliamentary Papers II 1978/79, 15463 nos. 1 and 4. See also B.C. van Beers, Commentaar op artikel 11 van de Grondwet, in E.M.H. Hirsch Ballin & G. Leenknegt (eds.), *Artikelsgewijs commentaar op de Grondwet*, webeditie 2020. https://www.nederlandrechtstaat.nl. Accessed 1 March 2021.

[217] J.J.M. van Delden, Over de autonomie van de oudere patiënt, in A.C. Hendriks (ed.), *Grondrechten in de gezondheidszorg. Liber Amicorum voor prof. Mr. J.K.M. Gevers* (Houten, Bohn Stafleu van Loghum, 2010), 104-111.

[218] NL Supr. Ct. 9 January 1987, *Bespiede bijstandsmoeder*. ECLI:NL:HR:1987:AG5500, NJ 1987/928, annotated by E.A. Alkema, and AB 1987/231, annotated by F.H. van der Burg.

[219] NL Supr. Ct. 23 November 2001, NJ 2002, 386 and 387, annotated by J.B.M. Vranken. ECLI:NL:PHR:2001:AD3963. See also A.J. Akkermans, *De 'omkeringsregel' bij het bewijs van causaal verband* (Den Haag: Boom Juridische Uitgevers, 2002) and R.P. Wijne, *De omkeringsregel in medische zaken opnieuw toegepast*. Annotated by the District Court of Amsterdam, 13 November 2013, ECLI:NL:RBAMS:2013:7837. ECtHR 13 August 1981, *Young, James & Webster v. United Kingdom*, Series A, No. 44, Ch. 49.

[220] NL Supr. Ct. 12 March 2013, LJN BY4876/ BY4858, ECLI:NL:HR:2013:BY4876.

self-determination and autonomy comprise the client's freedom from infringement on his life and integrity by others, and the freedom to choose and to develop himself. In practice, these principles may cause tension with persons developing dementia as is shown in the case set out in section 2.4. It concerns a fictitious case based on a realistic scenario.

2.4. Case study: Mr. X

Mr. X (69) goes to his general practitioner (GP) with memory complaints. The GP carries out checks with X and refers him to the geriatrics department of the regional hospital. X takes more tests and an overview is made of his living conditions. He receives the diagnosis of dementia and he is referred to mental health care for the elderly. X is asked to sign a consent form for the exchange of his personal data, including the test results, between the hospital and the mental health care organization. He is also asked to give his consent that his data be sent from the regional hospital to the academic hospital. He voluntarily participates in a study on memory complaints at the academic hospital. Over the years, X's mental and physical condition deteriorates. However, X is convinced that he does not need any help. He refuses to consent to a modular or comprehensive package of home care, in spite of the decision regarding necessary care from the CIZ, in which it has been established that he needs this care. Subsequently, he refuses his consent for voluntary admission to nursing home care. Eleven years after his initial visit to the GP, X is placed in a nursing home following a court authorization. The first assessment there takes place after six months. X is asked whether he consents to an extension of his stay. He looks at the CIZ and nursing home staff questioningly. The CIZ concludes that X neither consents to nor resists the extension of his stay. X's stay is continued.

With his consent, X expresses his self-determination and autonomy. He is deemed legally capable of making decisions up to the moment he cannot be deemed capable of reasonably evaluating his own interests in the matter. In this context, the view on his legal capacity is dynamic, based on his capacity to make a decision.[221] The criteria of Appelbaum and Grisso can serve as a guideline upon which to base an assessment of legal capacity. An assessment of a person's legal capacity can be made using a step-by-step plan.[222] In the case at hand, the question of legal capacity is relevant in every expression of consent. I will elaborate on the various decision moments. The first moment is when the mental geriatric health care facility requests the test results from the regional hospital. The second moment is when the academic hospital sends the

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[221] C.H. Vinkers et. al., *Is mijn patiënt wilsbekwaam? Volg de leidraad, Nederlands Tijdschrift voor Geneeskunde* 2014;158: A7229, 1-8. See also *Stappenplan wilsbekwaamheid. Van wet naar praktijk.* https://www.goedvertegenwoordigd.nl/wp-content/uploads/sites/14/2013/12/Stappenplan-wilsonbekwaamheid.pdf. Accessed 23 April 2021.

[222] See H. Vinkers et al. footnote 221 and T. Grisso & P.S. Appelbaum, Comparison of standards for assessing patients' capacities to make treatment decisions, *American Journal of Psychiatry* 152 (1995), 1003-1037.

results of a medical research to the regional hospital. At this time, the diagnosis of dementia has just been made. X may have been able to express his will based on the information provided to him. However, it remains unknown whether he was able to give his explicit consent and whether he had a full or partial grasp of the consequences of the expression of his will. Upon giving his consent, X can receive care based on the complete file. If he refuses to give his consent, the file will remain incomplete.

Nonetheless, medical treatment can be continued, pursuant to article 7:450 (2) WGBO, "*if this is clearly necessary to avoid serious harm to the patient.*" Pursuant to article 7:465 (2)-(6), a representative can give consent on X's behalf, while involving X to the greatest possible extent in carrying out his representative task. If X had not given his consent, it would have been better to involve X's (formal or informal) representative already in the decision-making process. This would have allowed the legitimization of consent to continue – in the triangle of care that connects the patient, the care professional, and the representative. Because Mr. X was not capable or only partly incapable of expressing his will in the initial stage of dementia, his consent or co-consent served a purpose. The representative could have supported X in the decision-making process, whereas X's consent lies at the heart as well.

The third moment concerns the necessity of – perhaps comprehensive – home care for X, for which X does not give consent. Article 7:465 (5) WGBO contains an indirect reference to the wishes of the legally incapable patient to be honored to the greatest possible extent, since the representative is held to involve the patient as much as possible in the exercise of his duties. Article 8.1.2 (4) of the Dutch Long-Term Care Act (*Wet langdurige zorg*, hereinafter Wlz) starts with the perspective that the care professional follows the client's views unless this is inconsistent with the care to be provided in good clinical practice, and provided that the care professional has consulted another care professional about this.[223] The Wzd follows the WGBO in establishing legal incapacity. In practice, the situation may be more intractable. Even if, as evidenced from his illness process, a client can no longer grasp the consequences of expressing his will when he refuses the home care offered. Although the case at hand may be considered one of legal incapacity, the care professionals accepted X's refusal. In practice, the (formal or informal) representative is not always involved in the decision-making.

I would argue that self-determination and autonomy, as expressed in X's self-management and his choice to refuse his consent to receive care, clash with the objective to provide appropriate care. Moreover, the representative could also have played a part in serving X's interests. X's dignity would have been better served in the triangle of

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[223] Art. 8.1.2(2) Wlz.

care connecting the care professional, the representative and the client. He would have received care, both in line with his wishes as a client and in line with the necessity for care as observed by the care professional and the representative. His self-determination and autonomy are expressed in his refusal to give consent, and this backfires: he fails to receive the care he deserves.[224] If more attention were paid to the situation of X in relation to his immediate circle and the context in which he lives, X can be offered the suitable care he deserves, with respect for his dignity throughout.

The fourth moment concerns the stay in a nursing home and the extension of that stay. Following the court authorization, X is placed in a nursing home. After a period of six months, the CIZ reviews the situation to decide whether to extend his stay.[225] X is the first to answer the questions. His opinion is asked, and based on his response it is concluded that X does not resist the extension of his stay. This could be observed as another clash between the respect for his self-determination and autonomy, as expressed in the conversation in which his consent is requested, and the necessity of suitable support and the involvement of the representative, by which X's interests are served to the greatest extent possible. However, in the situation at hand, X's legal incapacity has been established. Unfortunately, his condition, dementia, is progressive, as a result of which his legal incapacity is not temporary or incomplete. Considering the triangle of care, this third situation warrants giving a stronger voice to the care professional and the representative, in the interest of the client.

2.5. Conclusion

This chapter answered sub-question 1 that reads as follows:

> *In what way does the focus on the lawful basis of consent influence the provision of care when the individual is unable to express his will?*

I conclude that, by giving or withholding his consent to the use of his personal data and for medical treatment, a person exercises his right to self-determination as an autonomous individual. He is considered an independent, rational person, who is free to make choices. However, exercising this consent requires specific capacities of the individual, such as the capacity to understand the information received and to make a well-considered choice, and the capacity to view his autonomy also in the context of his relationships with his loved ones and his immediate circle.

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[224] A.C. Hendriks, B.J.M. Frederiks & M.A. Verkerk, Het recht op autonomie in samenhang met goede zorg bezien. *Tijdschrift voor Gezondheidsrecht* 32, 1 (2008), 2-18.

[225] Art. 21 Wzd.

The freedom of choice and his self-management, expressed in his consent, may diminish the dignity of a person developing dementia, and the value of expressing his preferences. Hence, the focus on the lawful basis of consent may influence the provision of care to the individual who is unable to express his will, since the consent is not based on a well-considered choice. His human dignity may better be served with the recognition of his partial or comprehensive legal capacity or incapacity, and the attention this warrants for the client together with those around him. It is beyond dispute that the care professional involves the client in the decision-making. The representative must serve the client's interests to the best of his ability.

Unfortunately, it is a fact that the value of expressing his preferences by a person developing dementia decreases as the process of his illness progresses. Accordingly, I conclude that the strength lies in the triangle of care in which the person developing dementia is involved as much as possible, with suitable care given by the care professional, and in which the representative serves or helps to serve the client's interests in the best possible way. In this triangle of care, the client's dignity is respected, as served by the representative, and with appropriate care provided by the care professional.

And Mr. X? After his legal incapacity had been established, his consent for the use of his personal data and his consent to receiving care were repeatedly asked. His dignity as a human being was not served. The representative was not always involved. More careful implementation of the triangle of care connecting the client, the care professional, and the representative may have offered a solution to these issues.