

# **CHAPTER 1**

## GENERAL INTRODUCTION

*"Say here's a little story that must be told..."*

Double Trouble,

by The Roots featuring Mos Def

On 31 March 2005 Terri Schiavo died in the American state of Florida. At that point she had been in a vegetative state, a permanent and irreversible condition of unconsciousness due to brain damage, for 15 years. The legal struggle over the decision to stop artificial feeding and hydration lasted 5 years and involved her feeding tube to be re-inserted 2 times, the second time after interference of Jeb Bush, at that time governor of the state of Florida <sup>1</sup>.

Although an anomaly, the case of Terri Schiavo is an example of the complexity of medical care and accompanying decision-making at the end of life nowadays. Terri Schiavo could be kept alive in the state she was in, whereas in the past she would have died. The progress of medicine gives more possibilities, but also offers more choices. The choice whether or not to withdraw life-sustaining treatment divided her close-ones and led to the lengthy legal procedure, where different courts tried to establish what Terri Schiavo would have wanted herself. There had been similar cases, like the ones of Karen Quinlan and Nancy Cruzan in the U.S. <sup>2</sup> and the one of Ineke Stinissen in the Netherlands <sup>3</sup>.

An advance directive (AD) is a way to try to prevent such situations like the one that occurred surrounding the death of Terri Schiavo. An AD is a document in which a person puts down his or her preferences concerning care at the end of life in advance. It can be consulted if the person in question is not able to express his or her preferences anymore.

The aim of ADs seems to be clear: to ensure that someone receives the care at the end of life he or she wants. However, questions arise about the status of ADs in practice. For instance, do these documents reflect the actual preferences of their owners? Did their owners understand the impact of the often-complex medical procedures at the end of life when they put their preferences down in a document? And do these preferences stay stable over time?

To help answer these questions, the focus of this thesis is on ADs and the people who own them. In this first chapter ADs and their background are introduced further. The situation surrounding ADs in the Netherlands, the place where our study took place, will also be discussed briefly. The chapter concludes with the aim and design of this thesis.

## **A BRIEF HISTORY OF ADVANCE DIRECTIVES**

ADs stem from the increasing importance attached to the principle of respect for autonomy. This principle implies that individuals have the right to determine their way of living and dying, in other words the right of self-determination. One of the implications of this principle for medicine is that every patient has the right to accept or refuse certain treatments. It led to the concept of informed consent: patients have to agree with medical treatments administered to them and base their choice to do so on adequate information <sup>4,5</sup>. ADs are a way to ensure informed consent in situations where patients are not able to express their wishes themselves anymore. One of the first to describe the concept of a written document containing a person's wishes about possible future medical care, referring to it as a 'living will' was the U.S. lawyer Luis Kutner in the year 1969 <sup>6</sup>.

Over the years different versions of ADs were introduced. There are types where treatments are declined, like a do-not-resuscitate order. Another type is a durable power of attorney for health care, where someone appoints a representative to uphold his or her wishes, also called a healthcare proxy.

Countries showed differences when it came to the pace and extent in which ADs were embedded in legislation and policy. The U.S. was at the forefront in making ADs legally binding and obligatory for physicians to follow. The verdict in 1976 by the New Jersey Supreme Court in the case of Karen Quinlan, who had been in a persistent vegetative state for years, meant the first legal basis for ADs. The court ruled that a person had the right to refuse life-sustaining treatment. Evidence of prior made preferences on this subject should influence decisions about treatment if the person in question had become incapacitated <sup>2,7</sup>. In the wake of the case of Nancy Cruzan, another example of someone in a persistent vegetative state with difficulties surrounding the decision to withdraw treatment, which led to court rulings in order to create clarity <sup>8</sup>, in 1990 the U.S. adopted a law to promote the use of ADs, the Patient Self-Determination Act (PSDA) <sup>6</sup>.

Also in Europe increasing importance was attached to informed consent and ADs, but differences between countries were big, ranging from ADs being legally binding to no specific legislation on the subject at all <sup>9</sup>. In other parts of the world, countries like Canada, Australia, New Zealand and Singapore belonged to the vanguard when it came to this subject <sup>10</sup>, while more recently the topic received attention in countries like China and South Africa <sup>11,12</sup>.

## CONCERNS

Over the years ADs and their usability became scrutinized and criticized, especially in the U.S. after the adoption of the PSDA <sup>7,8,13,14</sup>. A number of concerns reappeared throughout these criticisms, which will be outlined now. The first was about the dissemination and rate of completion of ADs, which remained low, 4% to 25% among different patient groups <sup>14</sup>, in the U.S. despite the attempt to promote them by the PSDA. A follow-up question was if people have the desire to draw up ADs. Do they want to think about preferences about care at the end of their life beforehand? Maybe they do they not wish to be confronted with these kinds of matters or rather leave it to their family members or physicians to decide <sup>7,13,14</sup>.

Completed ADs raised concerns as well, about their content. Some of these concerns involved the holders of ADs. Did they know what they wanted when it came to care at the end of their life? Did they grasp the complexities of present-day medical care? <sup>7,13,14</sup> In addition it was doubted if preferences could be accurately translated in written form. According to the critics a problem with ADs was that they were mostly drafted in general terms and lacked the specifics needed to be useful in practice.<sup>7,13,14</sup> In short: are ADs an accurate display of someone's wishes and are they applicable to practice?

Besides the rate of completion of ADs and the doubts about their content, a third concern

was if preferences recorded in ADs stayed stable over time <sup>7,13</sup>. If preferences indeed would prove to be instable, an AD could be a misrepresentation of someone's actual preferences at the time it was used. Several studies were done on stability of preferences, reviewed by Auriemma et al. in 2014 <sup>15</sup>. They found that generally preferences seem to stay stable over time. However, they also concluded more research was needed, for instance on the influence of changes in health on stability of preferences.

The last concern is communication about ADs. ADs by themselves did not automatically seem to result in communication about preferences between patients, their close-ones and physicians <sup>8,16</sup>. This while the notion grew that meaningful communication was needed to make the use of ADs successful <sup>8</sup>. As a consequence, in recent years not only the completion of ADs, but also the process of communication surrounding it, got more attention. This resulted in advance care planning (ACP), which is defined as "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness." <sup>17</sup> Brinkman-Stoppelenburg et al. and Houben et al. performed reviews on the effects of ACP. The results showed that ACP could improve the quality of care at the end of life <sup>18,19</sup>.

## **ADVANCE DIRECTIVES IN THE NETHERLANDS**

The case of Ineke Stinissen, a woman who was in a persistent vegetative state for 16 years before she died after the removal of her feeding tube in 1990, played an important role in the public debate about medical decisions at the end of life <sup>3</sup>. Just as in the similar cases in the U.S., the court was asked to help decide about whether to stop artificial feeding. In the years afterwards two laws were passed that would regulate medical decision-making and treatment at the end of life in the Netherlands.

In the year of 1995 Dutch parliament passed a law, the Dutch Medical Treatment Act (*Wet op de Geneeskundige Behandelingsovereenkomst (WGBO)* in Dutch), which, among other things, made informed consent obligatory in medical care. Also included in this law was the provision that if a person had recorded preferences in an AD, these had to be followed in case of incompetence <sup>20,21</sup>.

Also relevant to end-of-life decision-making in the Netherlands was the law on euthanasia, which was adopted in 2002. This law permitted euthanasia if certain requirements were met, like a voluntary and well-considered request and unbearable and hopeless suffering by the patient. The law explicitly mentioned ADs as a way to replace current requests for euthanasia. With an advance euthanasia directive (AED) a person was able to request euthanasia in a possible future situation, in which he or she was incapacitated and not able to express such a request anymore <sup>22</sup>. The passage in the Euthanasia Act about AEDs gave rise to a debate about whether it is possible to perform euthanasia based only on a written request <sup>23,24</sup>. Although

sparse, the cases actually reported through the years, where incapacitated patients with dementia received euthanasia on basis of their AD<sup>25-30</sup>, did from time to time fuel the public debate<sup>31-33</sup>.

As a result of these laws, several standard ADs were developed. The most common were the ones provided by two associations, the Right to Die-NL (NVVE in Dutch) and the Dutch Patient Organization (NPV in Dutch)<sup>34</sup>. The NVVE, an association that prior to the Euthanasia Act of 2002 had as one of its main objectives to legalize euthanasia, was committed to the possibilities of individuals to determine the end of their life. It provided refusal-of-treatment documents (ROTDs), healthcare proxies and AEDs. The NPV was a Christian orientated association and provided the Wish-to-live-statement ('Levenswensverklaring' in Dutch). This AD refused actions directed at actively ending the owner's life, but also refused medical futile treatment at the end of life.

In recent years ACP got attention in the Netherlands as well. In the ACTION study an ACP program will be implemented in several European hospitals, under which Dutch ones, and its effects on care at the end of life will be studied<sup>35</sup>.

## AIM AND DESIGN OF THIS THESIS

This thesis tries to clear up some of the issues surrounding ADs and takes the perspective of the people who have an AD.

Three important themes are central to the thesis:

- *The meaning of advance directives*

The meaning of ADs in society: how widespread are ADs and does the general public have the desire to draft an AD?

The meaning of ADs for the people who have one: what are the reasons to have an AD? What do people hope to reach or prevent with ADs?

The meaning of the content in ADs: do the preferences recorded in ADs reflect what people actually want? How do the views of people owning ADs on the end of life relate to actual practice?

- *Stability of preferences about care at the end of life.*

Do preferences about care at the end of life stay stable over time? What is the influence of a change in health or other life-events on this? Do people make adjustments in their ADs?

- *Communication surrounding advance directives*

How often are ADs discussed over time and with whom? What are reasons to discuss ADs?

## METHOD

The data for this thesis was derived from two sources: the Consumers' panel for Health services (CoPa) and the Advance Directive Cohort (ADC).

The CoPa (n=1621), established in 2005, was a sample of the Dutch public established

by the Netherlands Institute for Health Services Research (NIVEL in Dutch), representative of the population of the Netherlands aged 20 years and older. A questionnaire was sent to the members of the CoPa containing questions about background characteristics, end-of-life issues and ADs. 1402 respondents returned this questionnaire.

The ADC was a cohort of people who had an AD. We used the two associations that provide the most common standard ADs to reach people who had one: the NVVE, from which 5661 members participated in the ADC and the NPV, from which 1261 members participated in the ADC. The cohort provided us with quantitative as well as qualitative data, so we could use both methods to investigate the subject of ADs. The quantitative data was obtained longitudinally by means of written questionnaires, which were sent each 1,5 year in 5 waves from 2005 until 2011. In the next chapter the design and origin of the ADC is described more thoroughly.

## OUTLINE

This thesis consists of four parts. Apart from the first part, the introduction, and the last part, the general discussion, the two middle parts will focus on the research findings. Two of the main themes of this thesis, the meaning of ADs and stability of preferences, will each be addressed in one part, part two and three respectively. The third theme, communication, will get attention in all parts.

This chapter, 'General Introduction', and the next, 'Design of the Advance Directives Cohort: a study of end-of-life decision-making focusing on advance directives', in which the design of the ADC is described, together form part one, 'Introduction'.

Part two, 'The Meaning of Advance Directives', consists of three chapters. Chapter 3 'Advance directives in the Netherlands: an empirical contribution to the exploration of a cross-cultural perspective on advance directives', looks at the dissemination of ADs among the Dutch general public and the inclination to draft one in the future and puts the results in an international perspective. It uses data derived from the CoPa.

Chapter 4 'Motivations, aims and communication around advance directives: a mixed-methods study into the perspective of their owners and the influence of a current illness' describes the reasons to draft an AD and what people hope to aim or prevent with them. It also treats communication about ADs. It used quantitative data, but also qualitative data derived from interviews with a purposive sample of members of the ADC, who had indicated they suffered from an illness.

Chapter 5 'Continuing or forgoing treatment at the end of life? Preferences of the general public and people with an advance directive', focuses on what people would want at the end of life, focusing on continuing or forgoing treatment. It treats the preferences of members of the general public as well as people who have an AD. It uses both the CoPa and the ADC to provide data.

Part three, 'Over time', also consists of three chapters and mainly focuses on the longitudinal data the ADC produced. Chapter 6, 'Stability of end-of-life preferences in relation to health

status and life-events: a cohort study with a 6-year follow-up among holders of an advance directive' focuses on the stability of general preferences concerning care at the end of life of the holders of ADs. It addresses the influence of life-events on stability of preferences, adjustments in ADs and how often ADs are discussed over time.

Chapter 7, 'Preferences on forgoing treatment are stable over time with people owning an advance directive; a cohort study' describes the stability of specific preferences about continuing or forgoing treatment at the end of life of the holders of ADs.

Chapter 8, 'Preferences about euthanasia and their stability over time: a longitudinal cohort study' focuses specifically on preferences about euthanasia, cross-sectional as well as longitudinal.

Part four, the last part, consists of chapter 9, 'General Discussion'. This chapter will give an oversight of the main findings and will put them in perspective. It will end with the main conclusions and recommendations from this thesis.

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