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A survey of self-directed dying attended by proxies in the Dutch population☆

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ABSTRACT

Physicians may hasten death by medical decisions to end life (MDEL) that have been extensively researched. However, outside the medical domain, some individuals hasten their death by Voluntary Refusal of Food and Fluid while receiving some palliative care (VRFF) or by Independently taking Lethal Medication attended by a Confidant (ILMC). Both dying trajectories are more or less under the control of the individuals themselves. No survey data are available on how often these self-directed deaths occur in the Dutch population. We have isolated VRFF and ILMC from other dying trajectories in a population-based study employing after-death interviews with relatives, friends or nurses. Members of a research database that is representative of the Dutch population ($n = 31{,}516$) were asked whether they had been a confidant in someone's decision to hasten death by VRFF or ILMC. In this sample, 144 deaths that conformed to our definitions were reported by proxies. We have computed an annual frequency of 2.1% VRFF deaths and of 1.1% ILMC deaths. The annual frequencies of VRFF and ILMC appear to be roughly the same as the yearly frequency of physician-assisted dying (1.8%). In seventy percent of those who had died by VRFF or ILMC, a diagnosis of cancer or a serious illness was reported by the informant. The proxies retrospectively described the self-directed hastening of death by both methods as a dignified death in about 75% of deaths. Both VRFF and ILMC require strenuous efforts and reflect a strong desire to control the process of dying. End-of-life research has shown that some control over the time of death is an important aspect of a 'good death' in western countries. We therefore presume that these self-directed methods for hastening death in consultation with proxies occur in other countries as well.

Introduction

In a special issue of Social Science and Medicine on 'Good and Bad Death', Seale and van der Geest conclude that the similarity of some death perceptions is nearly universal across cultures and times: 'a death occurring after a long and successful life, at home, without violence or pain, with the dying individual being at peace with his environment and having at least some control over events' (Seale & van der Geest, 2004, p. 885). They observe that in the high-income societies of Japan, the USA and Australia, 'control over the timing and manner of death is an increasingly important concern in wealthy societies' conceptions of what it is to die well' (Seale & van der Geest, 2004, p. 884). Other studies have documented the importance of control over dying for the general public and for AIDS patients in Western countries (Pierson, Curtis, & Patrick, 2002; Rietjens et al., 2006; Vig & Pearlman, 2004). Another aspect of a good death concerns dying at home while attended by relatives and contrasts with a bad death surrounded by strangers 'without anyone giving you some water to drink for your final journey or receiving your last breath' (van der Geest, 2004, p. 909). Dying at home alone is constructed in the media as a form of bad death (Seale, 2004). In the research reported here we have focused on individuals who have persistently strived for control over their death attended by proxies, while restricting dependence on the health care system to standard palliative care.

In high-income societies, palliative care provides dying patients with some control over the time, place and manner of their death (McNamara, 2004; Seale, Addington-Hall, & McCarthy, 1997; Walter, 1994). Quill and Battin (2004) have introduced the concept of physician-assisted dying (PAD) to refer to both physician-assisted suicide and euthanasia at the explicit request of the individual. PAD provides individuals with somewhat more control over their death in those countries where it is legally permitted (Switzerland, Oregon, the Netherlands and Belgium). Other studies have paid attention to attitudes towards and prevalence of PAD in countries where it is illegal (Emanuel, 2002; van der Heide et al., 2003; Kuhse et al., 1997; Mitchell & Owens, 2003; Seale, 2006).

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PAD is a legal option in the Netherlands, where it occurs in 1.8% of all yearly deaths (euthanasia in 1.7% and physician-assisted suicide in 0.1%; van der Heide et al., 2007). A decision for PAD is reached after many discussions between a competent patient, the attending physician and relatives (Norwood, 2005).

All survey studies of which we are aware, both in the Netherlands and elsewhere, have ignored the possibility that the decision to end life can be taken and death can be brought about by a competent person himself at home or in a hospice while attended by relatives. This is a surprising gap in research on how some individuals end their life in close contact with others in whom they confide. Surprising, for if control over the time and manner of dying has become important in Western countries, as has emerged from the literature, then it is to be expected that some individuals whose repeated and explicit request for PAD has been turned down will look for methods to control their death that will make them less dependent on the medical system. We have explored this hypothesis in the Dutch population by focusing on two dying trajectories by which individuals may try to hasten their death.

The first author conducted a literature search on end-of-life decisions in the medical and right-to-die literature to explore which methods people reportedly chose to hasten their death in close contact with one or more confidants and without illegal involvement from a physician. In the medical literature, case histories have been published about people who have brought about their own death in consultation with others. Our attention was drawn to what has become known as 'Voluntary Refusal of Food and Fluid' (VRFF), by which competent persons deliberately hasten a death that is not yet imminent while being cared for and often receiving palliative care either at home or in a hospice (Bernat, Gert, & Mogielnicki, 1993; Ganzini et al., 2003; Quill, Lo, & Brock, 1997). In Oregon, hospice nurses have reported this to be a good or 'natural' death in patients with a fatal disease whose death is not yet imminent (Harvath et al., 2006). From interviews with Dutch doctors it appeared that in the case of an elderly person who is not terminally ill, some physicians regard a death hastened by VRFF as a suicide and refuse to provide palliative care. However, this does not prevent determined, aged people without a serious illness from dying at home in the care of their children or of an experienced nurse by stopping all food and fluid intake (Chabot, 2007). Some of these cases were reported as a good death by the informants.

Another method by which competent individuals have directed their own death in consultation with one or more confidants has been documented in the right-to-die literature (Humphry, 1991; Magnusson, 2002; Ogden, 1994). There exists an 'underground' practice in which the deceased may secretly collect lethal medication, takes it at a time which is known to one or more confidants and dies at home. Sometimes a physician secretly prescribes the lethal medication (Back et al., 1996; Quill et al., 1997; Slome et al., 1997; Meier et al., 1998). Relatives, friends and/or right-to-die activists may give information on the combination of medicines needed, provide some assistance in collecting the medication and sometimes be present at the death scene even if they are fully aware they are breaking the law. We will refer to this method as 'Independently taking Lethal Medication attended by a Confidant' (ILMC).

We did not find data on the prevalence of either VRFF or ILMC deaths in any country. In view of this gap in end-of-life research we set out to estimate the yearly frequency in the Dutch population of a hastened death by VRFF and by ILMC that was planned and executed by a competent person after discussions with a proxy.

Definitions

Before embarking on the survey study that is reported below, the first author conducted preliminary interviews with 54 people who had been involved with someone who had died by VRFF or by taking lethal medication without assistance by a physician. The interviews centered on how the decision to die had been reached, the role of the attending physician and of relatives and friends, the reasons for and the manner of the self-directed death. It turned out to be more difficult to collect cases of VRFF (14) than of ILMC (40 cases). From the interviews it transpired that the deceased had shown a considerable effort of will to control his/her death in consultation with others. This is not the place to report and analyse the qualitative data we have collected on how the informant and others had questioned the motives of the deceased and had persistently but unsuccessfully opposed the decision to die by VRFF or ILMC. Suffice it to say that once they had been convinced they could not reverse this decision, some relatives and friends had complied with it for various reasons. One recurring reason mentioned was that they did not want the person to die in solitude. This interview study was published in Dutch (Chabot, 2001). It has provided the basis for the definitions, the method and design of this study.

We have defined a proxy as any person (relative, friend, nurse, right-to-die activist or others) who had been informed by the deceased about the why and how of the hastened death. Proxies have been used in other studies and their validity as a surrogate for patient self-reports has been explored regarding different types of information (Addington-Hall & McPherson, 2001; Klinkenberg et al., 2003; McPherson & Addington-Hall, 2003).

The preliminary interviews in this qualitative study were analysed with the purpose of refining our definitions of VRFF and ILMC to the extent that they could be used in a nationwide survey. We had to be able to distinguish a self-directed death by VRFF from a 'natural death', from PAD and from a death by terminal sedation. We also had to specify criteria by which to demarcate a death by ILMC from a physician-assisted death as practiced in the Netherlands on the one hand and from a suicide in isolation on the other. All these criteria should be straightforward enough to be observed and reported by someone who had become involved in VRFF or ILMC as a confidant of the deceased and who has no medical training.

In many terminal diseases it is quite normal that someone drinks less and less without taking a deliberate decision to stop drinking in order to hasten death. For the purpose of our research we have defined VRFF as a major contributing cause of death if a competent person had deliberately refused to drink for at least seven consecutive days before death occurred. We questioned the informants about the number of days before death in which the deceased had not taken fluids. If death had occurred after less than seven days of refusal of all fluids, we considered it more likely that an underlying disease had been the major cause of death and the deceased was excluded from the VRFF cases. With these conditions, i.e. a deliberate and persistent refusal to drink over at least seven days, we demarcated VRFF from a 'natural death' after a few days of not drinking.

We demarcated a death by VRFF from a death by continuous sedation without hydration by the condition that in a VRFF death communication had been possible intermittently in the first four days after stopping all drink during which the decision to hasten death had been confirmed. If a proxy reported that communication had become impossible in the first four days after someone had deliberately stopped drinking, we excluded the case from the study because a delirium may have occurred or because palliative care may have involved continuous sedation rather soon after the person had stopped drinking. In both cases, a voluntary decision to continue hastening death by VRFF would have become impossible. Sedation in an early phase of not drinking transfers control over dying from the individual to the physician before he/she can show the determination required to carry on with VRFF. Proxies did not

know our criteria for inclusion in the study: at least seven days of not drinking before death occurred, of which at least the first four days had to have been spent with intermittent periods of clear consciousness that enabled communication to take place.

For the purpose of our survey, we defined a death as self-directed if the decision to die *and* the immediate cause of death had both been under the control of the deceased. In VRFF as just defined, the dehydration had probably been the immediate cause of death. The decision not to drink is under the control of the person himself and therefore a death by VRFF with adequate palliative care was included in our study as long as no continuous sedation had been applied within the first four days.

Because PAD is a legal option in the Netherlands, relatives are well aware of the role of a physician and speak openly about it before and after death. If the proxy reported that a physician had provided assistance by prescribing lethal medication or had supervised the ingestion thereof, we excluded the case from our study because we would consider this a physician-assisted death, which in the Netherlands is a legal option. However, if the attending physician had neither provided the lethal medication nor supervised its ingestion but, according to the proxy, had only discussed with and informed the patient about hastening death by using some kind of lethal medication, we included the case as a self-directed death by ILMC.

For the purpose of our study, a death by ILMC was distinguished from other suicides by two criteria that can be observed by any lay informant. Firstly, a death by ILMC takes place after discussions with a confidant. Suicides that are prepared and executed in solitude cannot be identified by using proxies as informants. Secondly, if the deceased had not used lethal medication but a method that had mutilated the body, such as hanging, jumping, shooting or cutting, the case was excluded from our study as well. Proxies were very much aware of whether the body was discovered in a mutilated state. However, they did not know that if such a method had been used, their report would not count as an ILMC death.

Sample and screening procedure

In December 2003, a sample ($n = 31{,}516$) of Dutch adults over the age of 18 was randomly drawn from a database of 102,000 adults who had indicated that they were willing to participate in research. The research institute that manages this database takes great care to compose a database that is representative of the Dutch adult population in terms of sex, age, education and geographical location. However, individuals over the age of 60 and non-Western Dutch citizens (most of whom are Muslims) are underrepresented. Members of the database are assured that their anonymity is protected by the research institute at all times. In order to stress this point we made the anonymity explicit in the introduction to the questionnaire, which was sent online and returned to the research institute under a coded number. The answers of each respondent were sent to the researchers with this coded number only. Ethical approval was granted by the medical ethical commission for the Dutch mental health institutions.

To check whether the experiences of the respondents conformed to our definition of a death by VRFF or ILMC, a two-stage screening procedure was used. The first stage of broad screening is summarised in Textbox 1 and the second, more stringent screening in Table 1. We define an informant as a proxy who has passed all the pre-defined screening steps in Textbox 1 and in Table 1 and can therefore be considered to have been a confidant of someone who died by VRFF or ILMC. Once they had passed part of the screening steps in Table 1, proxies gained access to 100 pre-structured questions and five open-ended questions on the demographic and clinical characteristics of the deceased, on the planning and course of the dying process and on the involvement of relatives, friends and/or carers. From the answers to these last questions, we were able to estimate how many other individuals might have been confided in by the deceased, a statistic that we needed to estimate the prevalence in the population. Some of the screening steps in Table 1 were 'hidden' in the questionnaire (Table 1 step 5–8).

Textbox 1. Screening questions used in online sample ($n = 31{,}516$).

1. Over the past ten years did you ever become closely involved with someone who — after intense conversations with you — ended his/her life by sleeping pills while no doctor was present? [response options: yes/no]
2. Over the past ten years did you ever become closely involved with someone who — after intense discussions with you — hastened death by a deliberate choice to stop eating and/or drinking? [yes/no]
3. Had the deceased had conversations with you preceding death about the wish to end life or to hasten death *and* about the way in which he/she was going to do that? [yes/no]
   Question 3 was presented to those who had answered 'yes' to question 1 and/or 2.
   If 'yes' to question 3, then question 4 was presented.
4. Are you willing to answer an online questionnaire about that experience? [yes/no]

Statistical analysis

The frequency of both types of end-of-life decisions in the population can be estimated with the standard weighting method that is used by Statistics Netherlands (CBS) in estimating the annual frequency of events such as traffic incidents. We used an adapted standard weighting method in order to reduce the high percentage of health care workers among our respondents (23%) to the average number of Dutch adults who work in health care (12%). Each informant is weighted by the inverse of one (the informant) plus the number of other individuals who had been confided in by the deceased about the intention to hasten death by VRFF or ILMC. The proportion of reported cases was computed for the estimated responding part of the sample, i.e. 0.685(response rate) × 31,516 (members approached) = 21,560 members.

For the frequency estimation, we made use of the number of informants on a death by VRFF or ILMC in the five years from January 1st 1999 to December 1st 2003. The annual frequency of VRFF and ILMC can then be computed as the estimated proportion of reported cases in the sample (i.e. weighted sum of informants on VRFF deaths and ILMC deaths respectively divided by sample size corrected for non-response), multiplied by the total number of Dutch adults minus non-western adults (underrepresented in the sample) and divided by the five years covered by the informants. The Poisson distribution was used in calculating the 95% Confidence Interval (CI).

The alpha level was set at 0.01.

Results

Out of 31,516 members of the database, 839 persons indicated they may have been a confidant in VRFF and 557 in ILMC ("yes" to question 1–3 in box 1; a total of 1396 responses). Some of them refused to answer the online questionnaire ("no" to question 4 in Textbox 1) and others had agreed to answer it but did not return the questionnaire. With regard to VRFF, 570 persons answered "yes" to question 4 *and* answered the questionnaire; 386 did the same for

Table 1
Screening process of potential informants on VRFF and ILMC.[a]

Screening steps [b]	VRFF screening process		ILMC screening process	
	Number of potential informants	Number (%) not passing	Number of potential informants	Number (%) not passing
1. VRFF & ILMC Did the attempt at a self-chosen death succeed[c]	570	137 (24%)	386	93 (24%)
2. VRFF & ILMC Did you discuss with the deceased options other than death?	433	73 (17%)	293	91 (31%)
3. VRFF: Had the deceased stated clearly and in full consciousness the wish to die by VRFF?	360	31 (9%)		
ILMC: Had a lethal overdose of pills been taken?			202	60 (30%)
4. VRFF: Were fluids given by a tube or infusion? (if 'yes', the case was excluded from the study)	329	93 (28%)		
ILMC: "Had a physician been present when the deceased took the pills?" (If 'yes', the case was excluded from the study)			142	30 (21%)
5. VRFF & ILMC Did death occur less than 10 years ago?	236	30 (13%)	112	29 (26%)
6. VRFF & ILMC Did the respondent answer 7 core questions?[d]	206	30 (15%)	83	8 (10%)
7. VRFF & ILMC Was the deceased completely competent?	176	13 (7%)	75	20 (27%)
8. VRFF & ILMC Did the description of the dying process by the respondent fit with the operationalisation? [e]	163	66 (40%)	55	8 (15%)
Informants in study:[f] VRFF	97 (17% of 570)			
ILMC:			47 (13% of 386)	

[a] VRFF = Voluntary Refusal of Food and Fluid. ILMC = Independently taking Lethal Medication attended by a Confidant.
[b] The phrasing of the screening questions had to be slightly different for VRFF and ILMC. A complete list of the questions can be requested from the first author.
[c] Question 1–4 preceded the presentation of the questionnaire. Each screening step corresponded to one question. In case of a 'wrong' answer the respondent was excluded and the message appeared on the screen: "Your experience is not included in our study." A subsequent attempt at correction of the answer was blocked by the research institute. The screening steps 5–8 were hidden in the questionnaire and in case of a 'wrong' answer the respondent was not informed that (s)he would be excluded.
[d] Screening step 6 consisted of seven questions. If one or more of these questions had been skipped by the informant, s(h)e was excluded from the study.
[e] Screening step 8 involved 5 open and 4 closed questions.
[f] Respondents could report on (at most) one case of VRFF and one case of ILMC. At the end of the screening process only 1 respondent was included as a proxy in a case of VRFF and of ILMC. We could check that proxies had not reported the same case of VRFF or ILMC.

ILMC, which makes a total of 956 responses. The response rate for the second screening was therefore 68.5% (956/1396). Only 17% of the 570 respondents for VRFF and 13% of the 386 for ILMC passed all the subsequent screening steps (Table 1). By the end of this second screening, there remained 97 proxies whom we were sure had been a confidant of someone who had died by VRFF and 47 proxies of someone who had died by ILMC.

The mean number of persons in whom the deceased had confided was 3.4 in VRFF deaths (median: 3.5; range 1–32) and 2.9 in ILMC deaths (median: 3.0; range 1–8). In VRFF deaths the majority of informants consisted of close family members and nurses. In ILMC deaths, friends had been confided in more often than close relatives, while health care workers had rarely been taken into confidence. In Table 2, the estimated annual frequencies are given in absolute numbers and as a percentage of the total annual number of deaths.

Non-respondents were approached in a separate study with questions about the demographic characteristics of the deceased and about their reasons for not responding. We found no significant differences ($p < 0.001$) between respondents and non-respondents on demographic characteristics. Fifty percent of the non-respondents said they had refused to answer the questionnaire: 30% because they feared this would evoke strong emotions and 20% because they had promised absolute secrecy to the deceased. About half of the non-respondents had apparently been involved with a death that had been an emotional or secret event they did not want to report on. We do not expect, therefore, that differences between respondents and non-respondents had caused an overestimation of the prevalence of emotional or secret deaths. Because of these non-response results and because the screening procedure had been strict, we believe that these estimations do not overestimate the frequency with which VRFF and ILMC occur in the population. The estimation of VRFF is probably too low because persons over the age of 60 were almost absent in our sample, while 80% of VRFF deaths occur over the age of 60 (Table 3). Siblings and friends of the same generation as the deceased therefore rarely got a chance to report on VRFF in widowed, high-aged individuals without children.

We found no significant age and gender differences between informants on VRFF and ILMC (Table 3). Those who died by VRFF were significantly older than those who died by ILMC and had a significantly lower level of education. A death by VRFF occurred as frequently at home as in an institution, while a death by ILMC always occurred at home.

There is no significant difference between VRFF and ILMC in the number of patients with a diagnosis of cancer, a physical and/or psychiatric diagnosis, or those for whom no diagnosis had been reported (Table 4).

We had expected most of the deceased to have asked their physician for PAD, but it turned out that only half of them had asked for it while 40% had not. We had also expected patients who reportedly suffered from cancer or another serious disease to have

Table 2
Estimated number of deaths by Voluntary Refusal of Food and Fluid (VRFF) and death by Independently taking Lethal Medication attended by a Confidant (ILMC) per year in the Netherlands over 1999–2003.

	Death by Voluntary Refusal of Food and Fluid (95% CI)	Death by Independently taking Lethal Medication attended by a Confidant (95% CI)
Number of deaths per year	2800 (1700–3900)	1600 (800–2400)
Percentages of total number of deaths per year	2.1% (1.4–2.9%)	1.1% (0.5–1.7%)

Note: Numbers are rounded off to the nearest hundred.
Statistics used in computations: average number of Dutch adults over 1999–2003: 12,500,000, average number of non-western Dutch adult citizens: 1,000,000. As non-Westerners were strongly underrepresented in the online sample, the total adult Dutch population was set at 11,500,000 (12,500,000–1,000,000). Also used in computation: sample size corrected for non-response: 21,650.
Average number of deaths in 1999–2003: 138,500.

Table 3
Demographic characteristics of the Informants and of the deceased.

	Voluntary Refusal of Food and Fluid (VRFF) ($n = 97$)	Independently taking Lethal Medication attended by a Confidant (ILMC) ($n = 47$)	p-value of difference between VRFF and ILMC[a]
Informants			
Age (years)			0.26
20–39	23%	34%	
40–59	67%	55%	
60–79	10%	11%	
80–99	0%	0%	
Sex			0.56
Male (49%)[b]	41%	36%	
Female (51%)	59%	64%	
Education			0.004
(Extended) basic education (70%)[b]	62%	36%	
Secondary school or higher education (30%)	38%	64%	
Deceased			
Age			<0.0001
20–39 (2%)[b]	2%	28%	
40–59 (11%)	17%	34%	
60–79 (40%)	32%	25%	
80–99 (47%)	48%	13%	
Sex			0.79
Male	38%	40%	
Female	62%	60%	
Education			0.002
(Extended) basic education (70%)[b]	69%	60%	
Secondary school or higher education (30%)	11%	38%	
Unknown	20%	2%	
Partner			0.45
Yes	30%	36%	
No	70%	64%	
Place of death			<0.0001
Home	45%	89%	
Institution[c]	41%	2%	
Other	13%	9%	

[a] Calculated by the Mann Whitney U test and the chi-square test; significance level $p < 0.01$.
[b] Percentages of Dutch population.
[c] A home for the elderly, a home for invalid elderly patients or a clinic.

Table 4
Diagnosis and process characteristics.

	Voluntary Refusal of Food and Fluid ($n = 97$)	Independently taking Lethal Medication attended by a Confidant ($n = 47$)	p-value of difference between VRFF and ILMC[a]
Disease diagnosis			0.65
Cancer	40%	47%	
Psychiatric[b] and or somatic[c] diagnosis	32%	32%	
No diagnosis	28%	21%	
Request for PAD reported[d]			0.88
Yes	49%	49%	
No	43%	40%	
Unknown	8%	11%	
A dignified death[e]			0.49
Yes	75%	82%	
No	17%	10%	
Unknown	8%	8%	
Death certificate by			<0.0001
GP or attending physician	90%	66%	
Medical examiner	4%	23%	
Unknown	6%	11%	

[a] Calculated by the chi-square test and by Fisher's exact test.
[b] A psychiatric diagnosis, e.g. 'depressive', was reported in 5 VRFF and in 10 ILMC cases; more than half of them also had a diagnosis of cancer or a somatic illness.
[c] Diagnoses reported were e.g. cerebral palsy, MS, Parkinson, ALS.
[d] Answers to question: 'Had the deceased put forward a request for euthanasia or physician-assisted suicide to a physician?'.
[e] Answers to question: 'Would the deceased have considered his/her death a dignified one?'.

asked their physician more often for PAD than those without a serious diagnosis. This relationship turned out to be significant (chi-square (1 df): $p < 0.005$).

The physician who performed a post-mortem examination in VRFF cases might sometimes have been aware that the death had been caused deliberately. In 93 out of 97 people who had died by VRFF, the informant reported that the attending physician had written a certificate recording a 'natural death'. In only four cases of VRFF had a medical examiner been asked to inspect the body. When a person had died by ILMC, a medical examiner had examined the body in 11 out of 47 cases (23%).

Discussion

We started our survey with the idea that if control over the time and manner of dying has become important in high-income countries, then some Dutch individuals whose request for a physician-assisted death had been refused would look for other possibilities to accomplish a self-directed death in consultation with confidants. To explore this hypothesis, we have estimated the frequency in the Dutch population of two end-of-life decisions by which competent individuals might take control over hastening their death. We found an annual frequency of dying by voluntary cessation of eating and drinking of 2.1%. Dying after collecting and independently taking lethal medication that had been discussed with at least one confidant occurred in 1.1% of annual deaths. Our non-response study did not give any indications of an overestimation.

No other survey estimating the prevalence of VRFF or ILMC in the community is available with which to compare our findings. However, we can compare our results with the prevalence of suicide as registered by Statistics Netherlands: 1.1% of all deaths, or 1500 yearly cases (www.statline.nl). In less than 200 of these 1500 suicides, a lethal combination of medicines had been used (oral information from Statistics Netherlands). An overlap of at most 200 cases thus exists between the officially registered suicides and the self-directed deaths attended by proxies. Flawed classifications in post-mortem examinations by Dutch doctors have been uncovered in research by the coroner (Das, 2004) and, for England, in field research on the classification of sudden death (Maxwell Atkinson, 1978). Most of the self-directed deaths attended by proxies in our study are apparently not registered as a suicide. Many sudden deaths of elderly people who die at home in bed without any obvious signs of pill boxes or farewell letters pass unnoticed into the death statistics as a 'natural death'. Some informants reported that a death by ILMC had been registered as a 'heart attack' or just 'frailty in old age'.

We can also contrast our estimated prevalence with the prevalence of legally permitted PAD in the Netherlands (1.8%), which, after 25 years of public discussion, became a legal option in 2002 (Weyers, 2004). Both methods of self-directed, confidant-attended dying that we investigated have received hardly any attention in the public debate on end-of-life decisions over the past 20 years (Griffiths, Weyers, & Adams, 2008). It came as a surprise to us, therefore, that self-directed deaths occurred as frequently as physician-assisted deaths.

We were aware that an underground, erratically available practice of assisted suicide exists in countries where physician-assisted suicide is illegal (Brock, 2004; Coombs Lee, 2004;

Magnusson, 2002; Ogden, 1994). In these cases some assistance is sometimes given by a physician who secretly prescribes lethal medication, while others occur with assistance and in the presence of relatives, friends, nurses or right-to-die activists. But we had certainly not expected ILMC to occur in about 1% of yearly deaths in the Netherlands, where PAD has become a legal practice.

Fifty percent of both ILMC and VRFF deaths were preceded by a request for PAD that had been turned down (Table 4). These refusals by doctors are less surprising than they may seem at first, in view of the fact that in the Netherlands about two out of every three explicit and repeated requests for PAD are turned down because one or more of the requirements of due care laid down in the law have not been met (van der Heide et al., 2007; Onwuteaka-Philipsen et al., 2003). We were more puzzled that about 40% of ILMC and VRFF deaths were apparently not preceded by a request for PAD. Two recurrent reasons given by our informants were: 'She didn't have cancer and realised that her wish to hasten her death would not be negotiable with her doctor' and 'if the GP had known that he intended to take lethal medication, the GP would have tried to prevent this. All those involved kept his plan a secret from his GP'.

Even in classic Greek and Roman societies, abstinence from eating and drinking was recorded as a method for elderly people to hasten death (van Hooff, 1990). We had not expected, however, that death by VRFF after seven or more days of not drinking would amount to about two in every hundred deaths.

We regard the results of this survey as a confirmation of the hypothesis that the wish to control the time of one's death has grown in importance in the Netherlands. Apparently the wish of some people for control is strong enough to make some of them plan their own death and to carry out those plans outside the formal medical and health care system. After many years of public discussion on physician-assisted dying and palliative care, many citizens nowadays are not only aware of a diagnosis of a terminal disease but also start planning their preferred dying trajectory in consultation with their dear ones. This is not restricted to Dutch citizens. Based on a random sample of deaths in England in 1990, Seale et al. (1997) concluded that a significant group of individuals who are aware of the terminal nature of their cancer 'have a generalised desire to exercise some control over the timing and manner of their deaths. This leads them to be both more accepting of hospice care, and prone to discussing the possibility of euthanasia with their relatives'. It remains to be seen to what extent this desire incites some individuals in other high-income societies to choose one of the dying trajectories that we have studied.

Both methods for a self-directed hastened death require considerable planning and an effort of will. This is most evident in persons who have decided to cease eating and drinking.

We could not, of course, find out how the deceased would have rated the quality of dying by VRFF. Research in Oregon has shown that hospice nurses generally rate the quality of dying by VRFF as 'good' (Harvath et al., 2006). Informants in our study judged the dying process by VRFF in about 75% of cases as 'a dignified death' (Table 4). However, qualitative research should provide insight into what respondents mean by attributing 'dignity' to dying. *Social* dignity, as distinguished from *human* dignity, is an ambiguous and multivalent concept (Jacobson, 2007). Were proxies expressing respect for the decision of the deceased by saying that he/she had died a dignified death? Were they perhaps using the label 'dignified' to cover up a sense of failure in providing caring love? We simply don't know.

We do not think that our results should have immediate implications for Dutch law on PAD. There is a surprising lack of qualitative and quantitative research data on both VRFF and ILMC which makes any policy recommendations premature. However, we consider it important in terms of public awareness and policy making to study the prevalence and quality of dying by VRFF and ILMC that occurs more or less outside medical control in Western countries.

Our results may have implications for the training of Dutch physicians who regularly attend dying patients. Many of them lack professional knowledge about these dying trajectories. A death by VRFF or ILMC does not require any illegal acts from the attending doctor. In a death by VRFF, adequate palliative care is all that is required (Chabot, 2008). In ILMC, a physician can restrict his involvement to confirming that the decision to hasten death is an autonomous decision of a competent person and to addressing the emotional burden for those proxies who care for the person who has communicated this choice.

In other Western countries, the wish of some patients for control over dying by intensive pain treatment, by physician-assisted dying or by terminal sedation has fuelled a public debate and acquired political importance. Some physicians do not want to become involved with end-of-life decisions, either within or outside the medical domain. They consider this involvement to be a violation of their central ethical task to protect life under all circumstances. Other physicians regard the attempts of seriously ill patients to strive for a good death as part of their end-of-life care, even though the doctor may disagree with a particular decision to end life by VRFF or ILMC at a time the patient feels appropriate. We wonder whether Dutch physicians have the professional knowledge to explore the autonomous decision making of competent and well-informed individuals about a self-directed death in consultation with a confidant that seems to occur outside the medical and health care system. Since the results of this survey indicate that in the Netherlands these self-directed deaths attended by proxies occur about as frequently as physician-assisted deaths, the importance of this professional knowledge cannot be underrated.

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