SPEECH

Dignity in care – The Launch in the lounge conference

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Introduction

Ladies and gentlemen,

Let me start with a remark referring to the title of this conference.

I'm not the 90 year old silent man in the wheel chair sitting with his back to the window, I'm not the nurse worried about her sick baby, I'm not even a son or a grandson of a resident. I'm just a daily witness because I'm married to an occupational therapist. This reminds me Brussels is not the centre of the world when it comes to care.

Whatever I am, I wonder if a lounge of a nursing home reflects the core of the care. How cosy the welcome seats may be, a lounge is only the entrance, a place often revealing the first stone.

As we all know ethics of care goes far beyond the first impression of a one time visitor.

Three topics I would like to deal with today: firstly the main drivers in the policy discourse about care, secondly care ethics as an object of policy and legislation and thirdly the introduction of care ethics in policy strategies.

When I mention 'policy' or 'policy-makers', I'm not pointing at particular persons. I'm rather referring to the general tendencies I observe.

I. Current discourse about care in policy

First some of the main drivers in the current discourse about care in policy:

1. Waiting lists, a tight subsidy level, depreciated buildings, non-transparent quality management, time pressure and lack of collective work, formal care systems always seem to struggle with a mixture of **shortages**. A shrinking labour market stands perhaps for the biggest shortage. The supply of labour force is a major concern for policy-makers. Unemployed housewives therefore could be dovetailed into care jobs, quoting an important public servant. This proposal is not that profound, but if we reject it, do we deny then the idea of care being something quite natural ?

   Whether we live in a Bismarckian or a Beveridgian system: **care is rare**.

   Care ethics corresponds with a shortage of another kind, the human kind. Even when all the structural conditions are fulfilled a nursing home without budgetary restrictions still can be an utmost empty experience. We cannot put money on language.

When we give flowers to our volunteers, we realise their work is more than just compensating for staffing shortages.

2. **Quality** is also a key word in the dominant discourse. Processes are being described and monitored. Inspired by methods like Six Sigma (6σ) quality managers identify the causes of errors on the floor, like fall incidents, and they are keen to minimize variability by standardized care plans.

   Quality however derives from the latin word *qualitas*, which covers **the quality of persons** too. Care-givers **being empathic and involved even under the threat of daily routine** stand for real and good quality.

   If we reshape public expenditure towards P4P (pay-for-performance) will we be able to see empathy and involvement as the basics of performance, and not as a mere appendix of it ?

3. Like Oscar Wilde's Dorian Gray we only want our picture to grow old. Being dependent is a disturbing state[i]. Care is **all about scare**, so we have to restore the balance, shouldn't we ?

   Apparently this bothers policy-makers too. As a consumer a care-needing citizen shall buy and maintain his dignity with an individual care budget and rights of a client. Informed consent, be it by representation, is the holy grail. The curse of institutions can be broken when we **change the flow of taxpayers' money**: this is how we want to stay at the steering wheel of our life.

How **superficial** this **client-centred approach** can be compared with the **face-to-face encounter** of Levinas !

4. **Technology** will save us. Physical and mental deficits can be overcome in a nearly scientific positivism. A former CEO of one of the biggest hospitals in Flanders declared we need a kind of 'carwash' for the elderly. This would improve efficiency. I guess he was serious.

   There's no need for hostility between discourses on care and discourses on technology of course. Technology can be integrated in such a way that the lives of our residents and our carers become *"more meaningful and more explicitly organized in practices of care"*[ii]. However if technology affects the core of the care, care may become degrading.

5. More than a decade ago Pine and Gilmore published 'The Experience Economy', in which they described this economy as the next economy following the most recent service economy[iii]. They argue that companies must offer unique and memorable events for their customers, and that memory itself becomes the product, the experience.

   This **business concept** has already reached our care systems for example when we talk about 'care hotels' instead of nursing homes. In the Experience Economy value is charged for the value of the transformation that an experience offers.

   There's nothing wrong with swimming pools, high definition screens and fitness equipment, but when sTimul talks about 'experience' it's all about being

recognized as a human being or not, being touched physically and morally as a care-giver and a care-receiver, having a body through which our personality is accepted or not[iv]. Experience here is about reciprocity or worse, the lack of it[v].

As you notice the main drivers in the current discourse about care in policy are producing moral assumptions over and over again. STimul is operating in this context.

II. Care ethics as the object of policy and legislation

This leads me to my second theme: the ethics of care can be an indirect or direct object of policy and legislation.

1. Most of the time social welfare policy is about structures, financing structures. The main task of policy is **to shape the prior conditions** for good care. Good caring requires a variety of resources: education, people, skills, money and infrastructure. The distribution of it is a political mission through which values are expressed[vi]. Ageism for example might be hidden behind subsidy regulations which are only neutral at first sight.

   Those who determine how needs will be met are far away from care-giving and care-receiving. Brussels, remember. Moreover, like Tronto wrote, we quickly equate the provision of resources (*taking care of*) with the satisfaction of needs (*care-giving*)[vii]. For that reason policy-makers shouldn't focus that much on a

necessary set of qualifications. These qualifications correspond with a Tayloristic labour division which makes human needs inferior to the logic of the organization.

In the same sense a policy plea for more home care and day care against residential care won't help us any further when it comes to good care. It's a false debate knowing that only for less than a quarter of the people older than 80 residential capacity is available in Flanders.

Eventually by shifting structures towards community care the question remains what makes care with dignity. Up to now sTimul focuses on residential care for the elderly. This could lead to the misconception that dignity is less at stake when care is offered at home.

2. To what extent could policy-makers and legislators **intervene more directly** in this noble matter ? They already do.

Here in Flanders a Decree of 2009 states nursing homes have to develop a policy on ethical responsible care[viii]. STimul took off earlier but to me it's clear this model of practical ethical reflection matches with this legislation.
How important and valuable the art of dying might be, we sincerely hope this will not be reduced to a set of guidelines for end of life-decisions. In the most narrow sense working on ethical responsible care will be nothing more than using ethics decision trees[ix]. Policy-makers became more and more obsessed

with the paradigm of evidence-based working. Working with ethics decision trees or moral planning schemes could be tempting for the administration who monitors rules of certification, but this approach is not what care ethics is all about.

It's the first time a Flemish coalition agreement refers to care ethics: in this agreement the government engages in subsidizing initiatives contributing to higher quality and more wellbeing from a care ethics' point of view[x].
Let me say that the inspiring words of our Flemish Minister in this house some months ago were very promising and put high expectations.

Care ethics can be an elaborated part in secondary and higher education. An interesting report of the Dutch Centre for Ethics and Health about ethics of care in school and training programs concluded that theory is not connected sufficiently with practice. Ethics doesn't stick the way it is presented. The idea that ethics concerns daily care isn't vivid enough[xi].
Policy must work on that. In Flanders the Care Department and the Department of Education don't have much in common, it seems. Nothing could be further from the truth.
This could be better, as is proved by sTimul where schools and care providers come together in order to realize experience-based learning. One of the side-effects of this European project could be an evaluation of our systems of internship. Therefore it might be useful to compare the current systems in our four neighbouring countries.

III. Introducing care ethics in policy strategies

To conclude I would like to say something about care ethics in policy strategies. Care ethics is about the core of the care. How can we urge for care ethics in policy strategies ? In my opinion care ethics must not be presented as an isolated layer of a care system. It must be integrated into the new recipes of policy-makers and question them.

1. Dignity doesn't appear out of thin air at the end of our lives or when it comes to fixing or force-feeding persons. I think indignity is raised when nothing physically happens between persons. Of course I say this provocatively, but after the waiting list comes a new time to be killed: waiting for the toilet, sometimes being forgotten on the toilet, waiting for a grandchild, waiting for the past to be remembered, waiting once more and at last being forgotten as a person inside and outside the walls[xii].

   Dignity requires us to consider the dignity of both the care-receiver and care-giver[xiii]. **Indignity starts with the absence of presence.** The most important sentence in the chapter with recommendations on ethical issues in the French Alzheimer Plan is: *"Etre toujours en relation lorsque la maladie progresse"* ('always being related to the other when the disease deteriorates'). Unfortunately the most important sentence is not much more than a title.

Care ethics shouldn't focus on the extremes, like legislation does. It's not about euthanasia in the first place, it's all about incontinence, being nude, spilling a meal and the stress we put on hygiene[xiv]. Indignity is articulated through our body[xv].

From the so-called banalities we learn the most.

That's a big recommendation for this project. Make sure policy-makers become familiar with the basics of care ethics. Keep it tangible.

2. Administrations recall their models of inspecting the use of public resources by care providers. In a most conservative approach input variables like the user-staff ratio are being checked. Documents are being produced to meet the quality rules. In some care systems the satisfaction of the residents must be measured. To what extent **can dignity be measured** on a scale from 0 to 10 ?

3. In the coming years accountability will prove to become a major value for nursing homes. Policy-makers believe care becomes a part of public life by introducing 'social governance' in our boards of directors. This will not be sufficient if care really has to occupy a different location in our lives.

   Public disclosure implies a clarification of the values we demonstrate day by day in our roles of care-giver and care-receiver.

   This will bring us closer to **socially responsible care** which includes quality. According to a recent report of the Flemish Strategic Advisory Board for Social Welfare respect for human dignity is a component of the quality

concept[xvi]. Next year nursing homes will have to carry out a self-evaluation about the quality being offered. By considering systematically the wellbeing and the involvement of care-receivers and care-givers, quality will become a more profound concept[xvii].

sTimul can contribute to a **continuous self-evaluation**[xviii].

What happens for example when our nurse no longer understands the few words our man in the wheel chair says, when her persistence to communicate shifts to resignation, indifference and neglect, when a kind of professional 'omerta' arises.

Documenting and reflecting on these long-term processes is public disclosure too.

4. Skills updating is a substantial part of government plans on HR in care[xix].

   Care pathways are created for people with long-term care needs in order to guarantee continuity of care.

   If **workability and retention** is our concern, I think we should present the sTimul-formula as a tool in a **care path for care-givers**. In this formula care-givers and students undergo a kind of 'rite of passage'. This goes along with feelings of confusion, anxiety and fading self-esteem.

   When the salary level is no longer decisive to stay or go as a nurse, the sTimul-experience can help to reinforce the choice she or he once made as a young adolescent. By this sTimul, especially with this Interreg-project, will contribute to social innovation.

Ladies and gentlemen, you are facing the start of a European project which moves our values into the spotlight. Almost a century ago miss Nellie Spindler was killed not so far from here at the age of 26.

She was a qualified English nurse. She is buried nearby Poperinge as the only female amongst almost 11.000 male soldiers. When we remember her, we remember her dedication. Her grave reminds us that those who believed to be powerful, were dependent all the time.

Good luck with the project and thank you for your attention.

Gianni Loosveldt

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[i] Cf. M. Timmermann, *Relationele afstemming. Presentieverrijkte verpleeghuiszorg voor mensen met dementie (proefschrift)*, Tilburg, Universiteit van Tilburg, 2010, 49-50.

[ii] G. Widdershoven, "Technology and care: from opposition to integration", in C. Gastmans (ed.), *Between Technology and Humanity. The impact of technology on ethics*, Leuven, Leuven University Press, 2002, (35) 46-47.
[iii] J. Pine & J. Gilmore, *The Experience Economy: work is theatre and every business a stage*, Boston, Harvard Business School Press, 1999, 236p.
[iv] Cf. M. Timmermann, *o.c.*, 304-306.
[v] L. Vanlaere en C. Gastmans, "To be is to care. Een literatuurstudie van het concept 'zorg' en de implicaties voor verpleegkundige zorg", *Ethische Perspectieven* 2008, 211-212; L. Vanlaere & C. Gastmans, *Zorg aan zet. Ethisch omgaan met ouderen*, Leuven, Davidsfonds, 2010, 139.
[vi] J.C. Tronto, *Moral Bounderies: A Political Argument for an Ethic of Care*, Londen/New York, 1993, 110.
[vii] J.C. Tronto, *o.c.*, 109.
[viii] Art. 4, 14° Woonzorgdecreet van 13 maart 2009, *Belgisch Staatsblad* 14 mei 2009.
[ix] Cf. L. Vanlaere & C. Gastmans, *o.c.*, 132.
[x] Vlaamse Regering, *Vlaams regeerakkoord 2009-2014 'Een daadkrachtig Vlaanderen in beslissende tijden – Voor een vernieuwende, duurzame en warme samenleving'*, Brussel, 2009, 61.
[xi] M.S. Munk, *Ethiek in zorgopleidingen en zorginstellingen – achtergrondstudie*, Centrum voor Ethiek en Gezondheid, Zoetermeer, 2005, 34-37.
[xii] Cf. L. Stevens, *De invloed van ervaringsgericht leren tijdens een inleefsessie in sTimul op de (zorg)ethische deskundigheid van medewerkers in de ouderenzorg – Onderzoeksrapport in opdracht van het Ministerie van Welzijn*, Brussel, 2009, 26-27, 37 en 45.
[xiii] W. Tadd, "Dignity and older Europeans", Cardiff Centre for Ethics, Law & Society, 16.
[xiv] G. Widdershoven, "Regie over eigen leven: een zorgethisch perspectief", *Ethiek en maatschappij* 2003, afl. 2, (24) 24; L. Vanlaere & C. Gastmans, *o.c.*, 134; M. Timmermann, *o.c.*, 304-305.
[xv] L. Vanlaere & C. Gastmans, *o.c.*, 147.
[xvi] Strategische Adviesraad Welzijn, Gezondheid en Gezin, *Visienota Maatschappelijk Verantwoorde Zorg*, Brussel, 2011, 8 (www.serv.be/sites/default/files/documenten/SARWGG_20110224_Visienota_MVZ_DEF.pdf).
[xvii] Cf. E. Herbots, C. Van Cleynenbreugel, J. Moons en F. Laevers, *Welbevinden en betrokkenheid als richtsnoeren voor een kwaliteitsvolle aanpak in rust- en verzorgingstehuizen. Ontwikkeling van een instrument voor zelfevaluatie*, Leuven, KULeuven – Expertisecentrum Ervaringsgericht Onderwijs, 2011, 28.
[xviii] Art. 80 jo. 6, § 2 B. Vl. Reg. 24 juli 2009 betreffende de programmatie, de erkenningsvoorwaarden en de subsidieregeling voor woonzorgvoorzieningen en verenigingen van gebruikers en mantelzorgers, *BS* 17 december 2009.
[xix] Vlaams minister van welzijn, volksgezondheid en gezin, *Werk maken van werk in de zorgsector – Actieplan ter bevordering van de werkgelegenheid in de zorgsector*, Brussel, 2010, 40-41.