

Unbridled Care

A close look at Huber's concept of health

Frans Vosman

My purpose in this essay is to examine more closely a number of presuppositions that Huber and Garssen use in their argument for 'positive health'. I will limit myself to their essay *Relaties tussen zingeving, gezondheid en welbevinden* ('Connections between meaningfulness, health and well-being') in *ZonMw signalement Zingeving in zorg* (2016). ((1)). Their article appeared in the *ZonMW* thematic part in *Waardenwerk* nr 68, 2017), ((2)) and I will leave aside their other publications, as well as other contributions to the journal edition in question.

I have no doubt that Huber's and Garssen's article sprang from the best of intentions. Ever since her doctoral dissertation was published ((3)), Huber's concept of positive health has gone from strength to strength, and her ideas have been eagerly embraced in many places in the Netherlands. The sense of relief which the two authors evoke is all too familiar: caregivers are glad that the topic of 'meaningfulness' is finally part of the conversation. And yet I am extremely critical of their concept of positive health. I will outline my reasons here, to the extent that the limited context of this essay permits, in essayistic form (that is, using the same literary form that Huber and Garssen used), and will speak from the perspective of the ethics of care understood as a form of political ethics.

The ethics of care, which has its roots in feminism, regards caring as a practice that makes it possible for people to live together as a society in an ordered fashion. I use a broad definition of caring that includes activities ranging from cooking and changing nappies to specialised work in healthcare and welfare. Ideally, the caring that takes place in a professional and organised context retains the characteristics of the caring of everyday life: assisting vulnerable people and not leaving them to their own devices. But first, I will describe a scene of everyday caring in the Netherlands (taken from my own research, but obviously anonymised).

Candle

The dementia consultant is going to visit today. After many years of ups and downs, Klazien has now told the GP that her husband Marco needs to go to a care home. Klazien is 62 and has worked as a cleaner for years, but she now says, referring to herself, 'the wanderer has become weary'. She has had several operations to treat abdominal adhesions, but her stomach is still giving her trouble. They have no children, and she says that when they were in their forties, they 'reconciled themselves' to this.

Marco is currently 59 and has been suffering from dementia for years. He was officially diagnosed eight years ago, but at the time he had been at home already for several years. His employer was very patient and allowed him to carry on working for a while. Marco was a welder, but when this became too dangerous for him, his boss reassigned him and he became a kind of factotum. That lasted until he began to make too many mistakes. Marco now goes to day care. But over the past two years, he has become increasingly aggressive: bad language, swearing, hitting, and both Klazien and her relatives have been on the receiving end. Her younger brother, who's on a preretirement scheme, and an older sister sometimes come to look after Marco when Klazien is at work and he can't go to day care.

The pressure is mounting slowly but surely, and Klazien can't cope any longer. The consultant's visit is one of the steps in the procedure of admitting Marco to a home. The consultant has a chat with Klazien about how things are going. Then she spots a devotional candle burning on the oak sideboard. 'Are you religious?' Klazien replies hesitantly, yes, she is. 'Is there someone in particular you're burning that candle for?' Klazien says she'd prefer to keep that to herself, it's for a few people. She thinks of her sister, who has stage-4 liver cancer and whose condition is slowly deteriorating, and of an acquaintance waiting for test results who asked her for a prayer. As the consultant leaves, she tells Klazien, 'We always like to know what people regard as meaningful in their lives; it does give a broader picture.' I will return to this scene in a minute.

Positive health

In response to an all too limited notion of health ('the absence of illness'), Huber has proposed that we should speak instead of positive health. She has advanced the terminology of people 'functioning', of 'resilience' and 'self-management'. Someone may live with certain limitations and yet be healthy, because they are able to 'adapt' and self-manage. Huber has summarised her point in a formula that appears in a much-quoted article in BMJ 2011: 'Health as the ability to adapt and self-manage in the face of social, physical and emotional challenges of life' ((4)). The definition is about the ability to react and adapt in a certain way.

Care can help with this, can help to achieve this. A popular diagram, the 'spiderweb', identifies six constituent dimensions of health: bodily functions; mental functions and mental experience; the spiritual-existential dimension; quality of life; social and societal participation, and, lastly, daily functioning. Anyone who is surprised to find these six disparate categories placed together in this list will find Huber's critics on their side. How is quality of life a dimension of health?

As Theo Poiesz has pointed out, it is the other way round, health is a dimension of the quality of life ((5)). I am reluctant to adopt this highest accolade, 'quality of life', from Poiesz, under which health is then supposed to be subsumed, but I agree that it is conceptually unclear what 'dimension of' [health] means in these six items.

The wrong remedy

But my objections are of a more fundamental nature. To explain, let me return to the enthusiasm with which Huber's definition has been greeted in the Netherlands. There is clearly something amiss in relation to health. It is with good reason that people who work in healthcare and welfare, but also patients (through the Netherlands Patients Federation or otherwise – see *ZonMw signalement*) experience a sense of relief when told that 'health' can be about more than, or something other than just being ill, having a condition or having a limitation. It is oppressive to be seen only as a patient. We know the quasi-remedies like 'holistic thinking' (thinking about human beings as a whole, not just about their disease).

But talk of meaningfulness is no less a quasi-remedy. Huber has also given a definition that emphasises activity: 'to give, and be able to give, meaning or sense to one's own life'. Why is this a quasi-remedy? Because the quest for a vocabulary capable of expressing the notion of 'more than sick' or 'more than broken' ignores the reality that it used to be the most ordinary thing in the world for nurses to talk to their patients about what concerned them, what scared them, what they used to be able to do but can't do anymore. In fact, many caregivers still do this today: they try to become attuned to their patients' and clients' concerns with regard to illness or limitation, and they use everyday language about emotions, hope, expectations and disappointments.

It is possible to use the vocabulary of 'meaningfulness' for this (or indeed to impose this vocabulary – the meaningfulness industry can be very insistent). *But the real question is: what is the cause that this aspect of 'more than the disease' is ignored in healthcare?* The self-referentiality of healthcare plays an important role, that is, its intense focus on itself, on its own organisation and coordination, its preoccupation with the problem of the complexity of care, with mergers, lateralisation and the repositioning of healthcare and welfare organisations. Management and control problems are drivers of the ever-growing systemisation of healthcare (resulting in such things as 'palliative care paths' and electronic health records).

On the one hand, care is becoming more complex, and on the other, this complexity must be mastered and reduced to a more or less manageable form and measure. And somewhere in the middle of all this there are sick people, people who suffer, but who are also citizens. I believe it is important when reflecting on health, to speak not just of sick or potentially sick people. These people are also citizens of the state. This means they have a share in sovereignty: they participate in government, and are not just objects of policy. Citizens are able to reflect on the policies applied to them, and they can critically resist policies as citizens. I will come back to this later.

Healthcare is losing sight of patients even as it continues to work very professionally to improve them. There is much to be said, therefore, for ideas that foreground patient-centred care, advocate giving patients (or clients) a say in their own medical team, etc. Yet at the same time these ideas are powerless, they have no leverage over the complexity.

These ideas reveal much about the powerlessness of the care system, and they ride a cultural wave (autonomy, self-reliance) in doing so. To every point, they have a

counterpoint: they seek to remedy the focus on the care system by focusing on the patient. But they fail to adequately analyse the underlying problem. This can also explain why new care formulas emerge every few years, each trying to establish some variant of the principle of ‘putting the patient first’. But despite this rhetoric, which has been in vogue since the 1960s, patients still have very little say.

To put it simply: healthcare should solve its own problem of rampant complexity. It should not impose the vocabulary of meaningfulness on patients who are trying to express the ‘more’, the ‘not-only-sick’. It should not foist on them the language of autonomy and ‘quality of life’. It is remarkable that the ordinary language that patients use every day, and that so many excellent doctors and nurses (to name only these two categories) use, is being suppressed. We already have an intelligible vocabulary, and it is no longer being used: the language of ‘I’m afraid of’, ‘I hope that’. An artificial, contrived language is being put in its place, that of ‘existential meaningfulness’.

Linguistic work

Huber and Garssen devote much of their *ZonMw* essay to ‘linguistic work’: they work hard to make the proposal of ‘positive health’ look acceptable. But I have to say: without presenting a proper definition of the problem. How can it be that healthcare has forgotten that it is all about the patient, and is ignoring the fact that organised healthcare has become selfreferential? Their linguistic work consists in using the words ‘positive’ and ‘dynamic’ a lot.

Huber’s and Garssen’s linguistic work has not been unsuccessful: after all, who does want to think negatively or statically? These are tropes, rhetorical strategies that work. The medicine and ethics professors who formed me taught my class fellows and me: never use vague rhetorical language, always avoid words like ‘dynamic’ (which implies that others, to their discredit, think statically). Such terms are covert devices to create an opponent and then tear him down again.

Don’t do it; instead, look at the real problems, because we have our hands full with them. The real problem in this case – in my view – is that a now-systemic form of healthcare and welfare is offloading the complex problems that professional practitioners and managers face onto sick citizens. But what is happening goes beyond offloading, beyond healthcare’s failure to control its own problems.

The idea of ‘positive health’ also implies a broadening of healthcare work: in addition to technical experts, we now also need experts on meaningfulness. Everything is brought within the remit of care; care becomes unbridled if meaningfulness is included in the definition. No boundaries have so far been formulated, nor has any sound justification been given for allowing care workers to penetrate that deeply into the lives of citizens: on what grounds can more invasive interventions, more numerous interventions, interventions now also in respect of mental functions, mental experience and ‘existential meaningfulness’ be justified?

We are not speaking here of psychiatric patients who choose to see a psychiatrist, but of people like Klazien and Marco. The objection might be raised: surely the misery that

people are going through, their depressions, their feelings of meaninglessness are sufficient reasons to 'provide care'?

Healthy citizens

But this is more complicated than it looks. A while ago, Jaap van der Stel vigorously criticised Huber's notion of care (which, as we have seen, has now been adopted by half the care institutions in the country) ((6)). One of the questions he asked is whether Huber's definition of health – unwittingly – also implies a new definition of citizenship. And it is true: according to Huber, to adapt, to function socially, to participate – all these things fall within the definition of health. But there is an entire chapter missing from Huber's reflection at this point.

On the one hand, citizens are portrayed as self-reliant and resilient, two features that define their health. On the other, there is a theoretical void, there is no explicit, socially and politically oriented reflection on healthcare, on its current state, on the great problem of legitimacy that arises when citizens are made to bear the responsibility for their own health. Nor is there any reflection on the question where the new boundaries of healthcare must be drawn. This problem does not seem insoluble to me, provided the definition of positive health is supplemented by an elaborated political theory.

However, it will not be easy to formulate a more or less *consistent* political theory that corresponds to Huber's partly neoliberal thinking: a theory that defines what the government should do, what citizens should do, vis-à-vis each other and themselves, and what care institutions should do and – this is often more difficult – not do, if the concept of positive health were to be adopted.

Ordinary and extreme

But I think it would be better not to have any such theory at all. I say this because there are a number of fundamental lacunae in Huber's work. There is no reflection anywhere on the self-evident and quotidian nature of health: breathing, moving, organs that function, environmental influences on the body. Health happens without having to think about it.

To put it more poignantly: health 'happens' to people. They may have some influence over their health, but they do not sovereignly control it. Nor is there any reflection on what ill health is, what handicaps are. It is as if the fact that illness *happens* to people, befalls people, often without any involvement on their part, must be kept at arms' length at all costs: the citizen must resist.

And of course this is necessary: there is nothing wrong with taking care of your health and looking after yourself. But as soon as patients and caregivers realise that the primary reality is that *you undergo health and illness*, and even that health and illness to a certain extent exist *despite* all action and intervention, this yields an entirely different perspective.

It does not begin with intervention and self-management. It begins with undergoing life. This is to broach – very briefly – one of the philosophical categories that threatens to derail the notion of positive health. Government policy that regards health as an activity misses the elementary insight that health and illness are *undergone*.

To rephrase this in terms derived from the ethics of care: any talk of self-reliance, resilience and adaptation that elides the fact that all human beings are vulnerable beings has got the wrong end of the stick. A caring society acknowledges the fundamental vulnerability of its citizens and accepts the consequences: it does not individualistically point to citizens' own responsibility for their health, but regards them as vulnerable members of a society that bears its share of the responsibility for its citizens' health.

There are other figures of thought here that strike me as extremely odd: Huber and Garssen contend that it is a fitting way to look at health to argue from the extreme to the ordinary. They use the Shoah as an example to assert that people who have a sense of meaningfulness are better survivors. Arthur Frankl's theory is quoted to argue that the survivors during and after the Shoah were those victims who had a sense of meaningfulness in their lives. Apart from the fact that this is historically grotesque, it is also dubious as a figure of thought. The devout Jew who is said to have called upon the Almighty in the gas chamber, 'Shema Israel', 'Hear, O Israel', stood beside a person beaten and exhausted, and was murdered just like him.

Are we to believe that the people who survived thanks to their sense of meaningfulness are the healthy ones? I will limit myself to these comments, and will refrain from further discussing the use of Frankl's theories and those of Aaron Antonovsky, whom Huber also quotes.

Instead, I would like to turn to ethics. Aristotle already warned against reasoning from the extremes of war to everyday life, as if everyday life is a kind of extrapolation of the extreme. It is a popular question sometimes asked by educators who teach ethics badly: 'what would you do if the Gestapo is at the door and asks you if you are concealing fugitives?' This is one of the worst kinds of ethics there is (and that is saying something). Why? Because a person who must act now is none the wiser for studying the war, because they are not in a situation of war.

If students are to be confronted with the question of how to develop a moral backbone and how to think morally, it suffices to discuss the here and now: what do you do today when you are on a bus and you see a Muslim girl being verbally abused? Every day, daily life presents new trials, in the literal sense. Or on an even smaller scale: what do you do when you see customers in front of you treating the supermarket cashier as if she doesn't exist? You develop a moral backbone in everyday life. The Shoah has been abused enough for it now to be put to use as the underpinning of a particular definition of health.

Concern versus meaningfulness

The things that turn out to be important surface *within* practices of life. There is no stand in the stadium from where you can make life meaningful. The Dutch term for 'furnishing

meaning', *zingeving*, is misleading and is unknowingly tied hook, line and sinker to the presuppositions of Modernity: the subject who thinks she can 'make' herself and her world (autopoiesis, in the analyses of the philosopher of culture Charles Taylor and the sociologist Andreas Reckwitz and others).

The English sociologist Andrew Sayer has proposed a clear vocabulary that can be used to discuss 'the things that turn out to be true'. He speaks of concern: that which you are concerned about, that which perturbs you, that which matters to you. ((7)) This is all much more consistent with everyday life than talk of existential meaningfulness. It is also true in particular to one specific feature of life: life that you enter into, in the mode of passibility (a neologism of Paul Ricoeur's, which can be translated as passive endurance), instead of conceiving of life exclusively in the mode of activity and selfmanagement. A concern is something that you care about *during* your life, as it unfolds. Let me give an example of a concern (for instance 'to care about something'). ((8))

After tests in A&E, the man is admitted once again to the ward for heart problems. He knows the drill, he has been through this three times over the past few years. He isn't particularly concerned about himself, but he is concerned about something else: his wife suffers from dementia and he wonders whether she will still be able to cope at home alone in his absence.

There is no need to take a seat in the stand, as if you were planning to be a spectator to your life together with other spectators instead of being on the field: it is possible to live without 'spectating' life, and without 'making it meaningful'. Life has no meaning, and no talk about meaningfulness can change this. You take part in life. ((9)) Many people are perfectly happy with this. We cannot here entertain the sociological question what specific social groups feel the need to position themselves as spectators or purveyors of meaning. ((10))

There is no tenable argument for the idea that meaningfulness is a universal category; in fact, meaningfulness is a term that belongs to a *regional ontology* and to certain specific groups. This is how a particular group of people in the Western context speaks about itself; they feel the need to think of themselves as persons who furnish meaning. Thanks to the hegemonic position they occupy, they are able to impose their concept of themselves upon others. But why should their categorisation of health be adopted by others? I seriously doubt that 'meaningfulness' must somehow be regarded as the ideal perspective for all citizens.

Politics

Policies that are premised on positive health and, within that concept, on 'existential meaningfulness', are closely linked to a particular concept of government, of policy and of citizenship. The Dutch government is now effectively telling its citizens, in the context of the changes required by the new Social Support Act (*WMO kanteling*): 'The state can no longer deal with the complexity. Sort it out yourselves, take care of yourselves and make sure you have people who will look after you. This main commandment is

followed by the statement: only if all else fails will the government provide certain limited facilities.'

Hence the emphasis on self-reliance and adaptation, hence the emphasis on 'survivors' who are able to furnish their own meaning, including by adopting the perspective of positive health.

I would like to point out that advocates for positive health forget not only the patient, the sufferer, but also the citizen. From the perspective of the ethics of care, the actual practice of caring and of actually living together already carries a certain order within itself. Caring contains the rudiments of politics. Living together in a state, specifically in a late modern Western state, means forming a political community of common destiny, one which does not begin by imposing conditions on the members of the community, to the effect that they must rely on themselves, but that views its citizens as co-bearers of sovereignty.

The political community of common destiny exists only to the extent that its members know that they belong together as vulnerable beings. But this political vision also implies the necessity of being attentive to hegemony and hegemonic tendencies by groups within the community of common destiny, being attentive to the agonal character of society. Friction is part of living together. It need not necessarily lead to civil war, but it should lead to dispute.((11))

This outline (that is all it is) paints a different picture of society and of citizens, one in which both the latter's passivity (the fact that they are 'subject to life') and their citizenship appear in a different light than in Huber's and Garssen's project. Huber and Garssen see citizens as subjects of policy. Citizens are subject to policy, including health policy. But citizens are much more than that. They understand how the hegemony of care systems works, and they talk back to policy.

Individuals

Huber and Garssen have an individualistic and individualising perspective on health. In the beginning is the individual, and social contacts are secondary. But human beings are (1) social beings, (2) they live in a specific society, but (3) they are also vegetative beings and an animal species (that is, beings who have much in common with vegetables and animals): these things are all relevant to what health is. Yet Huber and Garssen ignore them.

Let me look only at the link between health and society. What use is an individual conception of health to citizens of Utrecht, a city notorious for its high levels of particulates, due, among other things, to the ring road? They can adapt as much as they like, but their respiratory system is still compromised. In many respects, people live in environments that make them ill, or in environments that are conducive to their health; and this notwithstanding 'existential meaningfulness' and self-management, and notwithstanding a healthy lifestyle or even highly effective self-management.

To put it differently, health is not just individual health, but also the health of a wider group, in the specific society in which the individual participates. This yields a wholly different outlook than that of positive health.

Suffering

Let me go back to Klazien and Marco. They are one of the many examples of everyday survivors, despite having been spared the Shoah. Self-development has never been among their ambitions, nor do they seek existential meaningfulness, or insist on calling adversity 'a challenge'. They have their own, perfectly intelligible words for fear (Marco's fear is 'to have to leave') and guilt (Klazien: 'what am I putting him through?'). They are aware that they are being used by the care institution representative, despite the latter's best intentions.

Many Dutch citizens, whether adeptly or maladroitly, play along with the game by adopting the language and categories of the caregivers. ((12)) They do this because they are suffering and want help. They realise that care will add to their suffering, but their only chance of survival is to traverse the care system and defy the caregivers and their categories of thought.

Asma Abbas has pointed out to what extent suffering is obscured in late modern societies, or, to be more precise, is translated, converted into a different, more acceptable language: suffering becomes 'dealing with challenges', barely pulling through together becomes 'coping', mourning at length at the loss of body parts, like one's beautiful breasts, becomes 'depression'. ((13)) Care does indeed add to the suffering, as the care ethicist Van Heijst observed back in 2008. ((14)) Almost ten years later, I am still amazed at the thoughtless, shamelessly politically naïve nature of the suffering that care is adding through healthcare lingo.

Thankfully, there is an ever-flowing source of moral insight in Dutch healthcare: sensible caregivers and patients continue to speak of suffering, fear, hope, joy, relief and support, without resorting to talk of meaningfulness. Those who do use this terminology to speak about themselves should do so to their hearts' content. But there are no solid grounds for thinking that this kind of language is better than that of being scared before your operation, being happy that your CT scan results came back negative, or hoping someone will be there to help when a person you know is suffering from dementia.

(Translation: Brian Heffernan)

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Notes

1. ZonMw signalement Zingeving in zorg
2. As of 2013, *Waardenwerk* is the continuation of *Tijdschrift voor Humanistiek* (Journal of Humanistic Studies): waardenwerkdigitaal.nl
3. Huber, M., *Towards a New, Dynamic Concept of Health. Its Operationalisation and Use in Public Health and Healthcare, and in Evaluating Health Effects of Food*. Maastricht University: Maastricht. 2014.
4. 'Health as the ability to adapt and self-manage in the face of social, physical and emotional challenges of life'
5. Th. Poiesz, J. Caris, F. Lapré. Gezondheid, een definitie?, in *Tijdschrift voor gezondheidswetenschappen* 2016, no. 7 (July).
6. Jaap van der Stel, Definitie 'gezondheid' aan herziening toe, in *Medisch Contact* 8 June 2016.
7. A. Sayer, *Why Things Matter to People. Social Science, Values and Ethical Life*. Cambridge, Cambridge University Press 2011.
8. On concern, see also A. Baart and F. Vosman, *De patiënt terug van weggeweest*, Amsterdam: SWP, 2015.
9. R. Kuhn, *Leben*. Freiburg: Albert Verlag, 2015
10. For this, see for example the Nijmegen dissertation (2015) by Peter Abspoel, *Zingeving in het Westen. Traditie, strijdersethos en christendom*, Nijmegen: Vantilt, 2016
11. O. Marchart, *Das onmögliche Objekt. Eine postfundamentalistische Theorie der Gesellschaft*. Berlin: Suhrkamp 2013
12. A. Baart, *De zorgval*. Amsterdam: Thoeris, 2013
13. A. Abbas, *Liberalism and Human Suffering. Materialist Reflections*, London New York: Palgrave MacMillan. 2010
14. A. van Heijst, *Menslievende zorg. Een ethische kijk of professionaliteit*, Kampen: Klement, 2008.