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The Quality of Time and Its Quantifications

Negotiations About the Feeding Tube at the End of Life

Jeannette Pols

Abstract

The measurement and calculations of quality of life have a huge impact on policy and treatment in Western countries and global health policies. The original motivation to develop these measurements was to bring in 'patient values'. However, it is far from clear what 'quality of life' comes to mean when it is quantified, and how it may correspond to things that patient value. In this paper I unravel what quantifications can and cannot make visible by ethnographically studying the different temporalities that are enfolded in different understandings of quality. To this end I analyse interviews and observations that relate how people with ALS who consider or live with a feeding tube encounter concerns with quality and temporality in their daily lives. I will show that the relevant temporalities change as qualities, rather than as quantities. Rather than 'gaining more time' by extending life through treatment, different types of times are added, fade away, or become lost. This can only be made visible through qualitative research.

1 Introduction

The measurement of quality of life has become a large-scale industry. Quality of life functions as an outcome measurement that is increasingly included in medical research. Quality of life outcomes are also used as a policy instrument to determine which treatments should be made available for patients. To this end, the expected extension of life is multiplied with a score that signifies quality of life, divided through the costs of a treatment. These QALY's (quality adjusted life years) are used in national policies and international studies that asses the 'Global Burden of Disease'.[1] These studies inform the funding and accessibility of treatments and shape health care policy nationally and globally. Next to its application in a medical context, various measurements of happiness and well-being are also used to 'take the temperature' of a nation or region outside the context of health concerns. This provides policy makers with instruments to detect and govern the wellbeing of the population.

The measurement and calculations of quality of life have a huge impact on policy and treatment in the Netherlands and other Western countries and global health policies.[2] All these calculations of quality are loosely linked by the aim to bring 'patient values' into the calculation to evaluate treatments. The history of quality of life measurements stems from oncology research.[3] The quality of life measurements were a response to a too narrow focus on isolated medical outcomes, such as the decreased size of a tumor. The tumor could diminish spectacularly, but this may not show effects on patients' wellbeing. Patients may struggle with the effects of the treatment in daily life (e. g. fatigue, nausea, incapacity). Hence, attempts were made to include subjective experience into effect measurements – through objectifying it.

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[1] See Moreira 2013. There is also the DALY, disability adjusted life years. This focuses on functioning rather than quality.

[2] Moreira 2013.

[3] Willems 2010.

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The desire for objectification, however, stands in sharp contrast to the murky understanding of what 'quality of life' could mean. Critics state that quality of life has become merely instrumental for the industry to sell particular treatments.[4] Ways of defining quality in order to make it measurable, they claim, may not show any relation to people's understandings of quality at all.[5] In an earlier study we also found operationalisations of quality that were dubious or debatable. An example is quality understood as the impairment of (normal) functioning.[6] Impairment of functioning may serve as an outcome measurement for the effect of a treatment concerning 'health' (one would not want treatments to lead to impairment of functioning), but it is dubious as a variable to measure quality. It assumes that the lives of people with disabilities and chronic disease are automatically of a lower quality than people who function 'normally', and belies the high scores on self-reported quality of life measurements by people with disabilities. This phenomenon became known as the 'disability paradox'. Moreover, 'functioning' in these questionnaires is interpreted in terms of general physical impairment. They score if one is impaired to walk or not, rather than if one is able to, say, take one's children to school. In this way, 'functioning' is detached from its relevance and value for daily life.[7] In terms used by the World Health Organisation,[8] the disability is ignored by foregrounding the impairment.

In our 2015 paper on quality of life we also argued that there are problems in approaching quality through modes of quantification.[9] Such modes frame quality as general and generalizable outcomes that can be calculated, averaged, added up and subtracted as comparable scores. However, in the same study we saw that the distribution of values in a population could take the shape of nominal scales, establishing qualitative rather than quantitative differences (one person values X, whereas another is indifferent) rather than rational scales (one person values X more than another person). For instance, in the case of anticipating and living with feeding tubes, people with ALS would either see the aesthetic disruption of the body by the feeding tube as essential and ultimately unacceptable, or as a minor nuisance one just has to cope with. To add up and average these aesthetic values as an overall effect on a population would not make sense.

In the paper quoted, we made a start with unpacking the concept of quality of life and unravelling what quantifications can and cannot be made visible. In this paper I will continue with this extensive task by analysing the temporalities that are enfolded in different understandings of quality. This is one of the difficult puzzles for scientists who measure quality of life: people are not stable in their ratings of the quality of their life on questionnaires. Their

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[4] Hunt 1997.

[5] Carr-Hill 1991; Carr/Higginson 2001.

[6] An example is the EuroQol (EuroQol Group 2009) that establishes how well patients are functioning ('I have no problems in walking about').

[7] See also Struhkamp et al. (2009), who compared the difference of quantified scores of 'independence' to the actual meaning of independence in daily life after spinal cord injury.

[8] WHO 1980.

[9] Pols/Limburg 2016.

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responses to the same items tend to shift.[10] It is unclear to the scientists whether these shifts refer to measurement errors, a change in peoples' values, or to something else. By qualitatively exploring the different temporalities at stake, I hope to shed more light on the phenomenon of 'quality', both as an attribute and valuation of daily life practices, as well as on the possibility of measuring it.

1.1 Empirical Ethics

I develop my analysis from the material semiotic approach of empirical ethics.[11] Empirical Ethics empirically studies values, or 'forms of the good',[12] that emerge in practices through the relationships between people, words and technologies. Hence, values are not predefined, but the analysis aims to uncover how forms of the good take shape in care practices and in the research practices that influence them. These goods may be as varied as tastes, norms, technological directives, regulations, research methods and daily activities.

Crucially, empirical ethics studies analyse how orientations toward some form of the good in practice are the result of the interactions between values dispersed over different actors. By closely analysing how the different human and non-human actors engage in care activities, it is possible to reconstruct what they take to be the problem that needs to be addressed, how they distribute the work among each other, and thus enact particular values. Comparing these to intended values may show interesting gaps. For example, in earlier studies we found that telecare technologies aimed at enhancing patients' autonomy through self-management could lead to increased professional control and patient passivity.[13] This was not because the device dictated this, but because it emerged as a result of the relationships that developed between the professionals, patients and the technology. Such analyses lead to contextualised accounts where values can be seen to lead to particular effects. These may be compared to other situations to see what might fit there. Hence, the kind of normative 'recommendations' are not shrouded by principles, but by the actual workings of values in concrete situations.

1.2 New Nursing Studies

This discussion is relevant for nursing studies. With the academisation of nursing studies, as with medicine more generally, Evidence Based Nursing (EBN) has gained pride of place (see for instance the journal with the same title), next to a respectable tradition of qualitative research approaches. For EBN research, the randomized clinical trial and similar designs are adopted to study nursing interventions. Nurses are taught to collect 'evidence', so that they can ground their interventions on a solid knowledge base. However, this line of inquiry

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[10] Response shift is taken to be a shift in values (see the debate about this: Sprangers/Schwarz 2010; Ubel, Peeters/Smith 2010; Eton 2010). In our paper we could see that it can also be a shift in situations and real problems.

[11] Pols 2013a, b; Pols 2015; Sharon 2017; Willems and Pols 2010; Mol 2010; Thygesen and Moser 2010.

[12] Thévenot 2001.

[13] Pols 2012, Ch 4.

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struggles to capture the situatedness, processual nature and variety that is characteristic of nursing practices.[14] Quantitative research aims to make generalizable claims on 'what works' in nursing care. It does not provide the tools to explore the variety of normative orientations in nursing practices. The recently proclaimed 'new nursing studies'[15] links to the qualitative research lines in nursing studies, with the aim to do just that: to analyse (historical) practices of nursing, including their materialities and values. By conducting theoretically informed ethnographic studies in nursing practices and in practices of nursing research, questions may be asked that are pertinent to these practices. This should lead to research that is useful to improve care practices,[16] as well as to a critical exploration of what particular research methods can and cannot make visible.[17]

Studies on quality of life and its temporality fit this agenda because they show how quality and temporality become linked in attempts to both a) measure and quantify what is of value to patients and their families, and b) how ethnographic studies make these values visible. What can both methods, quantitative and qualitative, teach about quality and temporality, in a way that is relevant to nursing practices?

2 The Cases

My main case is the lives of people in the Netherlands suffering from ALS and PSMA (progressive spinal muscular atrophy). We studied these patients' considerations for obtaining a feeding tube, and their experiences with living with a feeding tube over a period of time. ALS (in which we from now on include PSMA) is a severe progressive motor neurone disease. Because of the degeneration of nerve tissue that instructs the voluntary muscles, patients are progressively unable to move and the muscles waste away. The course of the disease is generally devastating: 50% of patients die from ALS within three years of diagnosis; most patients are dead after five years.

A feeding tube (gastrostomy) involves piercing the stomach wall to insert a plastic tube into the stomach. Fluid nutrition can be fed through the tube, either manually with a syringe, or through a motor-propelled drip. There are several methods for tube placement.[18] In the hospital where we did the study, PEG (percutaneous endoscopic gastrostomy) was the most common procedure, as it is elsewhere. With PEG insertion, the patient has to swallow a scope that illuminates the stomach from within and the stomach wall is pierced from the inside out,

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[14] Ceci et al. 2017; Pols 2012.

[15] New nursing studies are a specific type of care studies that are inspired by empirical ethics in care. Empirical ethics studies values and their workings empirically, before suggesting what is good to do, and for what reasons. See for instance: Pols 2015; 2017; Willems/Pols 2010, Mol 2010; 2008; Mol/Moser/Pols 2010. The study of practices aims to bridge the gap between the social sciences that study stories, narratives, culture, and meaning, and the life sciences, that study bodies, nature and materiality. At the time of writing the 'Care Practices Research Network' brings together this work. https//www.ualberta.ca/Nursing/research/research-units/care-practice-research-network (accessed February 2019).

[16] Mol 2006; Moser 2010.

[17] Pols 2012, Ch 8.

[18] See Stavroulakis et al. 2013 for a clear description.

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thereby minimizing potential damage to blood vessels. PEG can only be performed when patients have sufficient lung capacity and do not depend on breathing devices. PEG placement is done by a specialist, the gastroenterologist, who in our study was associated with the ALS team and knew the patients from earlier consultations on ways of dealing with dysphagia (swallowing problems due to the weakness of the tongue and mastication muscles). When a patients do not meet the requirements for PEG but can lie on their back, the radiologist inserts the tube: a procedure known as RIG (radiologically inserted gastrostomy). With RIG insertion, the stomach is inflated with air and the stomach wall is pierced from the outside. The diameter of the tube is smaller than for PEG, the tube is fixed less stably, and the wound needs to be stitched, increasing the risk of infection. The radiologist does not know the patient and this is one reason why PEG is preferred in the hospital where we conducted our study. The reasoning here is that as talking becomes difficult for the patient, and their body has lost much of its strength, a familiar doctor enhances communication and feelings of safety and trust (interview with the gastroenterologist).

We will build on the analysis made in Pols/Limburg quoted above,[19] which identified different ways of understanding the feeding tube in patients' lives. It became a different object over time, for example, it could turn from a scary symbol of deterioration into a life saver. These different identities related to different variables, such as the presence of informal carers or not, the stage and character of the disease, or the particular values the patients either cherished or regarded with disinterest or dismay. The rapid progression and varied courses of the disease made time a prominent feature in the patients' stories. The identity of the feeding tube fluctuated over time. In this paper I am interested in these temporalities. These should be seen within a very particular and challenging temporality: the idea of a life ending.

For our study Sarah Limburg and I interviewed patients whom we met through the ALS Tertiary Care Centre in the academic hospital in the urbanized region of the Netherlands, through the ALS Stichting Nederland (a national funding agency for research into ALS), through social media and through personal connections. The theoretical design of the study aimed to find patients in different stages of relating to the feeding tube, varying from anticipation to experienced use. We interviewed 11 ALS patients anticipating (3) or living with a feeding tube (8) or at both times (2). In total we recorded and/or transcribed 15 new interviews for this study. We collaborated closely with our colleague who worked with the same patient group for her study on advanced care planning.[20] We do not quote the latter material here, but it gave us background to test our findings.

Interviewing ALS patients took particular patience from both the interviewed and the interviewer, as muscle weakening made talking difficult for informants. Partners and children supported the interviewee by explaining things to the interviewer. Some informants used a speech computer. Others could not speak at all, and delivered their story to us in writing or through the spouse. According to Dutch law and research codes we did not need the approval of an ethics committee for this study, but with this particularly vulnerable patient group we

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[19] Pols/Limburg 2016.

[20] Seeber 2016, which gave us extra material on 28 people with ALS.

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took special care to let people know they could always opt out of an interview or cancel an appointment, which they sometimes did. We carefully anonymized the material.

We also interviewed the professionals in the hospital who at different points in time has been concerned with tube feeding the gastroenterologist, the neurologist concerned with diagnosing ALS patients, the nurse specialized in coaching patients with feeding tubes, and the rehabilitation doctor, who was the central carer for ALS patients and our main point of contact. The rehabilitation doctor helped us to approach patients by handing out our information letter to them. If patients wished to volunteer to participate , they could tell the doctor or nurse, who would then give us their contact details. We discussed our results with the rehabilitation doctor to check our findings and interpretations. When possible, we observed patients using the feeding tube and consultations about this, or asked them detailed questions about using it, turning the patients into ethnographers of their own situation.

Next to the ALS study I use some insights gained about temporality from interviews with palliative oncology care patients in a rural hospital in the North of the Netherlands.[21] I was studying a telecare device they were using, to learn if it led to an improvement of their care. The device is used to support patients in the period of life when they are being treated palliatively, and know they will not get better. The telecare device is a white box with a screen and every day patients receive a list of questions that they answer by pressing buttons. There is an extensive check of symptoms, followed by questions on psychosocial wellbeing, spiritual questions on coping with imminent death, information about diet, and so on. The session ends with a 'quote of the day', offering wisdom borrowed from classic and popular philosophers. These patients revealed some interesting temporalities they encountered while facing the end of their lives. I visited 16 patients at their home, and interviewed 14 of them. 6 of the interviews also included their partner, who were sometimes key users of the device. One of the team of 4 oncology nurses was my central informant at the hospital, and I spoke to her several times. I was also present at project group meetings.

2.1 Quality

Much like we did in the first paper on quality and in the discussion on quality of life as a way to bring in patient values, I use quality, and also temporality, as 'loose concepts' to guide the analysis.[22] Quality refers to a characteristic in life (a certain state of the world, or presence of certain features, as with qualitative research that denotes a type of research rather than an appreciation) and the normative understanding of this quality (quality as something good, the way it is often used in everyday language). Temporality refers to both time as it is experienced and narrated by patients and their loved ones, but also to quantified and objectified forms of time, such as linear clock time. As the reader will see, the various understandings of time in specific situations do not 'add up' to a coherent picture or theory on time, but form a colourful

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[21] Pols 2012, Ch 2.

[22] A loose concept is a concept that is to be empirically substantiated in order to get more precise meanings (Pols 2015).

bouquet. It forms a first exploration of what quality related to time might mean when studying it ethnographically, both in patient's practices, as well as in quantitative research.

Our earlier analysis of the feeding tube[23] was motivated by the lack of knowledge about what the feeding tube meant to patients. To the clinicians it was clear that patients did not like the feeding tube at all, were reluctant to think about it, and postponed its placement as long as they possibly could. Biomedical studies attempted to measure the effects of the tube on quality of life, and also on nutritional status and survival, but these studies were indecisive; no effect on quality of life could be established.[24] Through our ethnographic study we showed that the reason for this was the extreme heterogeneity of the patient group, the variation in local treatment regimens, the impact of contextual factors, and the changing identity of the tube over time. State of the art randomized clinical trials could not be performed for ethical reasons. The prominence of time, in the rapidly progressing condition of the patients as well as in their valuating of the feeding tube, lead to the questions of this paper. What temporalities are relevant to quality of life as we can observe it ethnographically, and hear in the stories people tell? How can we think about the relation between quality and temporality, and what does this imply for attempts to quantify quality of life in general terms?

2.2 A Time for Living

The specific temporality of the QALY measure will serve as an entry point. The QALY corrects calendar time according to the quality of this time. If one has, say, 5 years to live, but only with severe treatments that reduce quality, the number of 5 (for the years) can be corrected with a factor between 1 (full health) and zero (death). Hypothetically, there can be a minus score for a situation that is 'worse than being dead', but I have never seen this being reported in medical research. Quality here is related to a temporality that is marked by a clear start (the intervention) and endpoint: the end of biological life. The quality of this time is framed as stable once the intervention takes effect. It is one score that stands for a stable outcome, effect or end result of a particular treatment. Transient inconveniences of the treatment and fluctuations are hence not represented in the outcomes, unless repeated over time. This focus on end results fits with a general orientation of medical research that studies interventions that cure particular conditions.[25] A relatively short period of suffering from the administration of the treatment is bracketed to establish the eventual outcome, which would be 'a return to health', or a loss of quality when this is not achieved. This framing and shaping of quality fits less well with chronic or terminal conditions, for which different temporalities are at stake. The disease cannot be cured and will stay with the patients, who will eventually deteriorate rather than regain 'health'. They will persistently need support and treatment, which increases these interventions' impact on people's lives and substantially changes its quality.[26]

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[23] Pols/Limburg 2016.

[24] Benatar/Katzberg 2011; Langmore et al. 2006.

[25] Weisz (2014) calls this the infection model of disease.

[26] See Pols (2013).

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3 The End of Life

The first ethnographically observed temporality related to the ALS patients' quality of daily life resembles the temporality built into the QALY measurements in some ways. It is the temporality that emerges when people get their diagnosis and realise that their life will end prematurely. As a nurse in palliative care once explained to me: 'We are all immortal, until we get a life-threatening disease.' This means that we generally live without a clear sense of an ending. We all know that life has an ending, and some actively desire for this ending to come. In general, however, it is not a type of knowledge that is relevant to our daily activities, nor is it in the foreground when we plan our lives.

This idea of a final ending and people's neglect or lack of understanding of this is food for thoughts for existentialists and phenomenologists. They write about Death as the Eternal Black Nothingness and negation of life. We can only tolerate this by showing 'bad faith', i.e. through denying this truth.[27] We negate nothingness. However, the patients to whom we talked, who were confronted with a near ending of their lives, had to be much more pragmatic about life's ending. Rather than denying death, they had to, somehow, live with a shortened life expectancy.[28]

As Seeber et al. show,[29] for the ALS patients this meant, first of all, a concern for this new life span or a first consideration of lives' temporality. After recovering from the initial shock, they generally wanted to learn first about the way they would die.[30] They discussed and organised will statements with their general practitioners, in which they formulated their wishes for (non-) resuscitation, palliative sedation, or situations in which they would opt for euthanasia if suffering would become unbearable.[31]

The relevant temporality here is, much like that of the QALY, one's total life span. This life span emerged at the time of diagnosis, and made patients' lives acquire an ending that was closer than anticipated. It demanded new perspectives and planning. Interestingly, an anticipation of living with a feeding tube was not part of this temporality. Living with a feeding tube was so repulsive to patients that they used the proverbial mantra 'If I have reached that stage [to need a feeding tube], I'd rather be dead'. At that point in time they saw the feeding tube as a symbol of a gruesome and unacceptable deterioration. At the time of diagnosis and directly after, the feeding tube represented a life that is not worth living. The quality of a time to live

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[27] See for example Nolan (2011), who discusses the work of existentialist Gabriël Marcel and Sartre (2001).

[28] One of the oncology patients in palliative care said to me: "It is a gradual difference. We all die, I may go a bit earlier than you. That is, if you are not run over by a bus. But for both of us it is unclear *when* we will go. So it is not all that different." Future time is hard to predict.

[29] Seeber et al. 2015.

[30] Seeber et al. 2015.

[31] Seeber et al. 2015. This is a possibility in the Netherlands. Veldink et al. (2002) show that 17% of ALS patients use the possibility for euthanasia in a late state of the disease. It was clear to all participants that these were provisory determinations, and the rehabilitation doctor warned people that they might change their ideas along the way and that this was perfectly fine; Seeber et al. 2016.

with a feeding tube was a time they did not want, and they did not want to consider it. It was bad enough to consider an early death.

Here we already see a difference with the quantifiable QALY-time (calendar time corrected for quality): a perspective that includes a life that is ending in the near future is in itself a change of the quality of that life (as it has gained an ending). When this ‘life with an ending’ can be lived in an acceptable way, this could be thought of as a life of good quality. However, the time in between diagnosis and death differs from the QALY-time. The patients did not see it as a time that is corrected for sadness, and stable thereafter. They also did not anticipate deterioration and ‘reduced functioning’ that will inevitably follow. The ‘in between’ time had yet to emerge. It was not there at the time of diagnosis and in the concerns for the last parts of life. It only emerged by living it.

3.1 The Time of Getting Through the Day

There was another temporality in this anticipation of life’s ending. This was the temporality of life each day. I first learned this from the oncology patients in palliative care. They were brave enough or found it inevitable to consider their approaching death, and some even anticipated and organized their funeral when they were still fit.

> Mrs Veronica: I’d looked at the questions [on the screen of the telecare device] with a friend, and she told me later that she found it puts you in confrontation with reality so terribly. It said so clearly: you won’t get better, asking questions like ‘How do you see this, how do you deal with that, and are you sad about that?’ She thought that was making you face unwanted facts. But I said to her: ‘Yes, but I have this disease. And I live with it.’ So, to me, it’s very different. I know I can’t get better. They’re doing lots to slow down the disease. But they can’t stop it. So you know what the situation is. This is the way it is, I don’t have a choice. I have to take it from there.

Dying became part of living, but the patients insisted they could not and did not want to do this 24 hours a day. They could not be dying persons for the whole day. They could take a certain amount of time to consider the end of their life and what came with that. But they also needed time to live life on a daily basis. Mr Jansen worked in a shop and his customers were very concerned about his condition.

> Mr Jansen: They [the customers] constantly wanted to know what was going on, how you are, really, right down to the bone. But if you tell that story 10, 20, 30 times a day, you get sick of being ill. That’s really heavy, psychologically speaking. So I said: ‘If you want to visit a patient, come when I’m in hospital having chemo.’ With a tube stuck into my hand, me lying flat out on a bed, a nurse in the vicinity. Then I’m sick. Not on other days. Outside the hospital I don’t want to be confronted with this. Then it’d rule your life. I don’t want to be just someone sick. That’s not how I want to live my life. […] [About the telecare device]: It makes you aware of certain things. Have I got fever, did I throw up, have I weighed myself? I always do what the [telecare device] tells me to do. It says: ‘Did you step on the scales today?’

> so I go to the scales and check my weight. I do the questions, and when I am done with the [device] for the day, I concentrate on the rest of my day.

Mr Jansen pointed to the temporal intensity or duration of being confronted with his fatal disease. When using the device he remarked that it took him 5 minutes a day to answer the questions, and that was just enough time for death. 'Living' the patients explained, consisted of the small things of everyday life. They wanted to be involved in how their children were getting on at school, the colour of the new curtains, and to have a cup of coffee and a chat with the neighbour. They valued things more, because they knew they would end.

> Mrs Franken: Well you see, we say: he is not in pain, and that is great. Because you often hear about people who are always in pain, and that is awful. And, well, we are here, and we live here so beautifully. And then he is pottering about outside, fiddling in the garden. That is really wonderful. You can complain 'we cannot go on holidays anymore!' But well, just look at what you still have. It is a lot.

Important relationships and moments of intimacy were cherished by the patients and their families, showing a remarkable appreciation of life. Rather than devising 'bucket lists' of great things still to achieve, they became more aware of the 'small events' and relationships they valued and enjoyed. The time scale here was that of everyday life. Mr. Jansen separated a small part of the day for dying by using clock time, but the rest of the time in the day related to many small pleasures, as well as neutralities and necessities such as brushing one's teeth or getting dressed. It is the more fluid time of getting up in the morning and getting through the day. It is the here-and-now-time. It is lived, but little reflected upon.

3.2 Every Day Time and Swallowing

This every day time also emerged in the life of people with ALS when it concerned their problems with swallowing, and hence, with eating. When swallowing became difficult due to decreasing muscle power, patients became more and more occupied with the activity of making food move from their mouth to their stomach. Even if doable at first, the task could slowly become an obsession, taking several hours in the day. Patients also worried about weight loss and there was the real danger of an inflammation of the lungs when food strayed and got stuck there. This could mean intensive care treatment and a near ending of life.

> Partner: Eating was very difficult, and it took a lot of time.
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> Jenita: I was busy eating the whole day.
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> Partner: And obsessively, eh, because it is also a fight against losing weight. It was really tense. And now, with the feeding tube, she wins lots of time and energy that does not go into eating and worrying about food. She eats soup, custard, whipped cream, all the things she really likes. And it's no longer the main thing, or a necessity.

Obsessive eating had an abstract temporality. There was no discrete point in time in which it could be pinpointed as 'too much'. Limits slid all the time anyway, slowly, as bodies changed. It was hard to establish when 'enough was enough' and the feeding tube could be considered as a solution rather than a threat. The rehabilitation doctor would keep an eye on this relative time of weight loss, as a gate keeper. But until a limit was recognized, time was fluid. It was not clearly evaluated for 'quality', in a positive or a negative sense. Things were as they unfolded, they emerged slowly as events that came with the disease. Not as things to act upon to change life for the better.

This fluid temporality changed when concerned doctors or spouses intervened, or when swallowing problems became acute problems for the patients. This happened when people experienced choking on their food. Difficulties swallowing meant that food could get stuck in the oesophagus. The lack of muscle power and lung capacity made it difficult to cough, which caused people to have near-death experiences or the real risk of dying. This choking caused a lot of immediate fear and extended anxiety. One of our informants even dubbed this 'swallowing anxiety' as if it were a diagnosis in itself ('slikangst'). Time lost its fluidity here and closed in on the patients. There was a problem *now* and they were confronted with the need for acting on it soon. The fluid everyday time was breached by a discrete urgency. At this point the feeding tube could solve a problem the patients did not have before, one which they were anxious to get rid of.[32]

> Interviewer: Can you tell me what happened to make you need a feeding tube?
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> Mr Klaasen: I had problems swallowing, and I choked. And eating took a very long time… One month, two months ago, eating dinner took the whole evening. I couldn't swallow food. So that's why, really. […] And then it takes you more than an hour to eat. It takes so much energy. And you leave lots of food on your plate, because you give up trying. So then I lost weight, I was underfed. And I lost more and more weight. So at a certain moment… We have a very good doctor and she wanted to do it [the placement] before she retired. So we had to think about it a lot, before we accepted the feeding tube.
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> Interviewer: What did you have to think about?
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> Mr Klaasen: Well, of course, the fact that you have such a thing in your stomach wall!
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> Mrs Klaasen: Yes, you considered the down side, eh? But then, this explanation [by the doctor], that was really nice. She told us everything about it. And then we knew it just had to be done. We [the family] decided immediately. But Hans [Klaasen] said: I don't want it. So we took a leaflet home, deliberated, considered. That was Wednesday. And then, the other day, [to husband:] you choked terribly, [to interviewer:] he chokes every day, but this time we thought: "This is the end". And the boys [sons] were there and we said to Hans: "What do you want? Do you want

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[32] This is not a shift in values or responses, but in problems and needs. It is a change of the situation, not a shift in response (Pols & Limburg 2016). For people with a bulbar onset of complaints, their trouble started with swallowing. For them, the trajectory was different, as they took into account that the feeding tube would give them more time to do things they found important.

> to choke?" And then he said: "You've convinced me." And he sent an email on Friday, straight away. [To Hans:] And you even looked forward to it!

At this point Mr Klaasen submitted to a treatment which he had not wanted to consider before. Suddenly, the quality of his life, in the normative sense, breached the fluidity of everyday time and things that are-as-they-are. The feeding tube held promise to improve this.

3.3 A Time for the Tube

The placement procedure for the feeding tube was as bad as patients had feared it to be. It implied hospitalization, which in turn meant being away from the supportive technologies that had started to fill their homes. They felt helpless, with bodies they were unable to move and control. Many had difficulties breathing, and none of the patients considered the placement to be a 'minor intervention', as the literature labels it (from the perspective of the doctors and the technical procedure).[33] Their time in the hospital for the placement was a time to endure, but they also understood it as being of limited duration and serving the larger aim of choke prevention, which enabled them to continue with the intervention.

> Mr Frederiks: I was afraid of the operation. They, well, they move into your body. I had to think about that! And yes, it is another thing on your body. And it was exhausting, also because the nurses didn't know my devices. So I had to explain all the time [while speaking was difficult and cost a lot of energy]. And I noticed my hands had deteriorated. So that was very demanding.

After this bad time there came a bifurcation in temporalities and qualities. Having solved the immediate problem of choking, the feeding tube could lead to an improved life, or it could lead to a change of the type of misery to endure. With respect to improved life, what the patients gained with the feeding tube we could dub 'quality time'. Instead of having to be occupied with feeding oneself through the mouth, one way in which the new quality time could be spent was, paradoxically, by enjoying eating again. There were, however, limits to what the patients could swallow. Too liquid fluids were difficult. When thickened, they could be swallowed, even though this did not work for all fluids. Many patients regretted that they could no longer taste coffee. One of our informants told us he had found a way to experience some taste of coffee, by inserting coffee through the feeding tube with enough air to produce a 'burp with coffee taste'. This would certainly sit uneasily with standards of decency of most patients, but shows creative ways in which people could regain the taste of food and the pleasure of tasting things. Where tasting and calories had become separated with the loss of taste, tasting was regained with the loss of worries about calories.

> Mrs Velds: You really like yoghurt, Greek yoghurt. And we put fruit in it, a mashed banana, that's what we did.

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[33] Hossein et al. (2011); Mazzini et al. (1995).

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> Mr Velds: Or a mergpijpje [a meringue coated in marzipan and chocolate] every now and then.
>
> Mrs Velds: [laughs] Yes, a mergpijpje, something sweet, he likes that. It's soft.
>
> Mr Velds: And yesterday we had chicken tandoori.
>
> Mrs Velds: Yes, just for the taste. We mashed it, really crushed it because the bits of it are really hard. But he likes it anyway, so we put a little on his plate with something.
>
> Mr Velds: With asparagus, yes. [laughs]
>
> Interviewer: Also mashed?
>
> Mrs Velds: Yes, yes! [...] And now and then an alcohol-free lager, or just a beer. Like yesterday.
>
> Mr Velds: Two! [smiles broadly. Mrs Velds and interviewer laugh too]

Clearly the couple had great pleasure in helping Mr Velds re-enjoy the taste of food. The feeding tube made patients gain time to eat what they enjoyed, even if it could not restore all affective relations to food. Eating out for instance, eventually became too much of a burden. It was one more quality to be crossed off the list of possible activities.

The temporality of this quality time here is a relative temporality; it is changing a (bad) time of obsessively absorbing calories with a good time for tasting and eating as an enjoyable activity. This was a gain if eating had always been a pleasure for the person. Some people, in contrast, thought that not having to eat meant 'good riddance'. No need to spend time on what one does not enjoy. And this points to the second way in which the feeding tube could lead to quality time: if one had the possibility to do things one enjoyed, the feeding tube could change time for obsessive eating into time used for activities to enjoy.

> Gastroenterologist: The tube does not give quality of life in the sense that it cures a patient, because they cannot be cured. The only quality it gives is that people say that they did not enjoy the social aspects of eating so much, 'because it takes me hours to eat, my food gets cold'. Well, we give them plate-warmers, we do everything possible to facilitate eating. But at a certain point people say: 'Oh, I'm so tired of it.' I had one patient, he was an artist, a painter, who because of his ALS could only draw dots. He'd go to the zoo, and he would make dots with his pencil, make drawings just out of dots. And he said to me: "Thanks to the tube I have won so many hours in a day. I have only a couple of hours in the day when I am fit enough to draw my dots. Before, I used those hours for eating, and now I don't have to do that anymore!"

The example shows that the feeding tube might allow for positive characteristics that do not in themselves relate to the tube, but are facilitated by it. Then the tube is not a positive characteristic in itself. It delivered 'free time'. Patients had to find out what they could do with the time won by obtaining a tube.

3.4 Changing Bad Times for Bad Times

The example of the artist who gained time for enjoyable expression, is in sharp contrast to the bad time gained by others. Mr Gonders had to administer fluid food constantly, because his stomach could not bear too much fluid at a time.

> Interviewer: Is there anything else you'd like to mention about the tube?
>
> Mrs Gonders: well, if I may say this for him, the worst was that he couldn't move. When he had to go to the loo for instance. First he had to detach the power cord for the motor of the feeding drip. Then the oxygen… he could take the oxygen with him. And then he had to bring the whole circus with him. He couldn't just get up to get something, or go to the door when somebody rung the bell, or to go to the toilet. He couldn't do this, and this put him totally in the doldrums. Not going to the computer, or moving to the table, because it was so much fuss!

Mr Gonders was shackled by his drip machine. Even if he was physically able to walk, he could not do it easily because of the machines attached to him. He could not do the things that he liked. Other informants said this could also involve time spent waiting for the nurse to come to switch bags of fluid food. A lack of possibilities to do other things, or a lack of possibilities to do things one could enjoy, could make the life of ALS patients with a feeding tube miserable again. Rather than working to stuff oneself with calories through the mouth, which was caught in the fluid temporality of everyday life, their life turned into a life fixed to the motor drip with their eyes on the clock ticking, wasting time away. In this bad quality time, the everyday time changed into a time of emptiness. It promised no pleasurable events but turned the everyday into a time devoid of order, activities and meaning.

3.5 The Last Bit of Time

A last temporality I would like to discuss returns to the QALY-time in the sense that it relates a discrete linear calendar time to an ending. This is the retrospectively observed time of patients who had opted for the feeding tube, when it turned out they only survived after the placement for 3 months. Here, a calculation between quality and length of life seems to be in order. The difficulty patients experienced with the placement procedure, as well as their bad condition, could be compensated for by the extra time won (if there was any), that may or may not get filled with meaningful activities. Yet there is again a fluidity, a tragic one: who may predict the time of dying? In the really terminal stages this may be more obvious. In the time span of 3 months, the end is apparently hard to foretell. We have not spoken to these patients, or we do not know if some of the patients we talked to died. It was a group of patients we could only identify through the literature. [34]

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[34] See for instance the study by Stavroulakis and colleagues (2013), quoted in Pols/Limburg (2016): 27 patients volunteered to be interviewed about their tube three months after placement. Five of them died before the interview could be conducted, and the condition of eight patients had deteriorated so severely that they had to withdraw. Nearly half of the patients dropped out within three months after placement.

4 Discussion

In the analysis of temporalities and their relation to quality, it became clear quality may not always be about time, but that time is indeed always about quality. At first it was a temporality that related to an idea of a life span, much like a QALY that connects people with a total span of life left. But, unlike the QALY, for the patients contemplating this time, there was no 'in between' time to consider yet. The in-between temporalities only became palpable later.

Then there was the bad time of the feeding tube placement. This could be a relatively short time to endure, and gained in significance when the end was near. Once this bad time ended, everyday temporalities became important again: the time of getting through the day, filled with some preparations for dying, but which mostly pertained to the everyday trivialities and (small) pleasures that made up daily life. Matters of brushing one's teeth were important next to concerns about 'what life is all about' or what one really values. This everyday life time was characterized by a fluid 'this is how it is', of fiddling with food, of concerns with homecare nurses who might prepare a sandwich for lunch, or who were only allowed to feed the patient ready-made food. It is a fluid temporality of what has to be done on a day. As one's action radius for 'larger' assignments diminished, such as going to school or work, these smaller things became the things that 'living' was all about, and where life could gain its quality. Quality here was not so much about what can be done, but about if and how things could be done.

This fluid every day temporality stopped when a 'big issue' emerged that needed immediate evaluation and action: the fear of choking on food. Then time would solidify and become dense. Action was demanded at short notice. Due to its acuteness, this was not always related to the time one would gain by the placement of a tube. To some, the time gained was quality time for tasting, eating and other enjoyable activities. For others a dense time for troublesome eating and occasional choking was swapped for the endless emptiness of waiting for the next administration of fluid food to take place. Finally, there was a return to the QALY-like time when death approached. In this final phase, however, the time of ending was not of a phenomenological nature, as patients did not experience it. It could only be established retrospectively. Yet it is relevant for clinical care, as a short survival period may not outweigh the cost of the placement procedure.

A last temporality to consider when regarding these different temporalities is their 'addition'. Contrary to the addition of abstract numbers, the addition of temporalities and qualities in daily life is one of fractures, discontinuities and partial connections. There are different times to live, but they do not add up to a 'whole' or a clear linear time with a beginning and an ending. The different temporalities are folded into one another. For example, the lived time of the total life span may encompass every day times, but not automatically. Meanwhile, 'the total life span' also changed shape, depending on the closeness of the ending or the nearness of this ending as the patients experienced it.

The relevant temporalities change as qualities, rather than as quantities. Foregrounding one temporality rather than another re-sets, so to speak, the axes within which time gets its meaning. This may not be measurable at all. Rather than 'gaining more time' by extending life through treatment, different times are added, fade away, or become lost. These complex and discontinuous temporalities that are so strongly related to quality make a general quantification difficult. As temporalities fluctuate, the 'effect' of the tube could vary from the bad times of hospitalization and being tied to the motor drip, to finding time to spend on reading books or making art. Rather than one stable 'average' quality factor or QALY-time, different temporalities are gained and lost. One way of capturing these fluctuations in temporalities would be to repeatedly measure them. Yet these repeated measurements cannot capture the different qualities related to time and the differences for different people. One cannot add up Mrs Jansen's bad time of hospitalization with Mr Franken's good time of being able to potter about in the garden. The temporality of a 'total life span' interferes with the temporality of everyday-ness.

5 Finale: Nursing Nudies

What does this analysis teach for nursing studies? Our ethnographic analysis does not show obvious generalisations, except to say that for every person different temporalities fluctuate in different ways. It is a generalization that insists on particularity. Yet the foregrounding of the situatedness of findings does other, more interesting things.

First, the findings can be made clinically relevant. The analysis shows what kind of concerns might emerge around the complex situation of anticipating a feeding tube. It shows why and when patients are reluctant to think about it. It also shows what are the relevant questions to ask when the question about tube placement becomes pertinent. Is the time won by the feeding tube quality time for the patient? And if not, how may that change the prospect of having a tube placed at all? Patients and clinicians may learn from the situated lessons learned by others, and they may exchange 'tips and tricks' ('How to go to the beach with a feeding tube without getting stared at?'). Where guidelines may suggest a general applicability to any case at hand, such an analysis demands explication of what can be learned from specific situations. How may the specificities of a case differ from the situation I am involved in with this patient? The work to analyse what can be transported from one situation to another and what needs adaptation is explicitly demanded, it asks for a comparison of specificities.[35] In this way, there is much more to say about feeding tubes to patients other than: 'there is no evidence that it influences quality of life'.[36] It invites us to explore what quality and temporality mean in their particular situations.

Second, a commitment to the situatedness of treatment procedures and effects opens up new areas for research, by paying close attention to everyday practices of (nursing) research. It shows how methods, quantifications and conceptualizations make some things visible and others invisible. Scientific methods are not mirrors of nature, but tools that co-shape the object of inquiry. In the case of quality and temporality it showed that common quantifications

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[35] These specificities are often missing in quantitative studies, where 'the intervention' is often briefly described in the methods section. For new technologies, for example, this black boxes the way these technologies transform practices and are used in ways nobody had expected (see Pols 2012).

[36] A friend pointed out that the general 'reassurance' that 'this treatment enhances quality of life!' did not mean much anyway in the situation where she was engaged with thinking about an intrusive cancer treatment for her partner. That still would not answer the question if it might help her partner or not, and how.

of quality, such as the QALY, imply certain assumptions about relevant temporalities and qualities that hide many temporal complexities in daily life. It hence also questioned the relevance of these quantifications for clinical practice, while simultaneously providing insight in the processes pertinent in a life with ALS in relation to feeding tubes. Also, such studies provide building blocks for further studies on 'big concepts' like quality and temporality. This in turn may provide interesting theoretical lenses to the study of practices. A worthy challenge for nursing studies indeed!

Jeannette Pols, Socrates Professor for Social Theory, Humanism & Materialities, Department of Anthropology, Section of Medical Ethics, University of Amsterdam Medical Centre, The Netherlands

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