

ABANDONING QUESTIONNAIRES

Improving quality of life in daily nephrology practice

by Anna Mann

Care-concepts have proliferated over the past couple of years, and have been used to study all kinds of practices, situations and sites. This begs the question: What is gained by studying practices in terms of care? The paper addresses this question by using a specific care-approach, which is the study of daily life dealings (Mol et al., 2010). It mobilises this approach to investigate a particular object, namely a good provision of haemodialysis treatment in nephrology practice. It does so in a given place, a dialysis unit in Austria. Based on ethnographic fieldwork with a focus on how patients' quality of life was improved, the paper reports how, in this dialysis unit, a quality of life questionnaire was introduced but soon abandoned. It first analyses how the prominent ideal that quality of life is to be measured with a questionnaire arrived in the goings-on in the unit. It then teases out how connecting and disconnecting patients to dialysis machines, and seeing them during the daily round enacted knowing, improving and quality of life in other ways than the prominent practice. It argues that questionnaires, forms, protocols, and the prominent practice they are part of may not only be made to fit into daily clinical practices or that daily life dealings are other to prominent practices. Daily clinical practices may also be the basis upon which questionnaires, forms, protocols, and the prominent practice they are part of are evaluated, abandoned, and forgotten. Recommending further investigation into the conditions of possibilities for alternative enactments of a good provision of health care to thrive, the paper concludes that what has been gained by using this specific care-approach to study this particular object are insights into daily life practices that have so far been othered in nephrology practice and STS.

Keywords: Quality of life, dialysis, nephrology, quantification, daily life, care

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Turning to 'care', gaining what?

Fieldnotes, 24 March 2017, City Hospital, dialysis unit, 7:14 o'clock

"Aren't they graceful, my legs?", Herr Fialka asks nurse Angelika, pointing at his upper thighs around which wrinkled skin hangs loosely.

Like every Monday, Wednesday and Friday, Herr Fialka had been brought by the ambulance to the dialysis unit of the City Hospital shortly before 7:00. After arriving, he had stood on the scale, strolled into Room 1, and climbed into one of the beds. As soon as he was lying down, Angelika had started attentively touching two knobs on Herr Fialka's upper left thigh. These were arteries that had been surgically connected with veins, "fistulas." They served as access to Herr Fialka's vascular system. Next, Angelika swiftly guided at a steep angle a needle through the skin, through the fistula's hardened wall, tilted it, and pushed it further into the fistula. She secured the needle with tape. She inserted the second needle into the other fistula and connected both to the tubes, the "lines", that lead to the haemodialysis machine standing next to the bed. All the while, Herr Fialka and Angelika had been exchanging jokes.

"Absolutely!", Angelika answers, "And when will you follow through on your promise to put on your superman boxers for me?" Herr Fialka chuckles and, eyeing the ethnographer with notebook, teasingly asks, "Are you writing down everything or only the juicy details?" He turns back to Angelika and shares his body weight with her, "Fifty nine." "Three and a half kilos?", Angelika suggests as amount of fluids to be extracted throughout the run. Herr Fialka sighs and nods. She types on the touchpad of the machine: 3500 ml, presses "Enter", then "Start". The coils of the machine are set in motion and begin drawing blood through the lines, out of Herr Fialka's body and into the machine. For the next four hours it will carry out what Herr Fialka's kidneys have ceased doing five years ago: extracting fluid, potassium, calcium, phosphate, and other waste products - keeping the body alive.

Care has become a 'hot' topic in science and technology studies (STS) over the past couple of years.¹ Annemarie Mol, Ingunn Moser, and Jeannette Pols have urged us to study "care in practice" (2010), by which they have meant to study daily life practices that tend to the fragility and fleshiness of life. These daily life practices are crucial, Mol, Moser, and Pols (2010, p. 7) have argued, because the Enlightenment tradition and its celebration of the mind, reason, autonomy and choice have made the body, its pains and pleasures and all the daily life practices that attend to it become othered, taken for granted and devalued. Mol, Moser, and Pols have not been the only ones who have turned to care. Marie Puig de la Bellacasa (2011) has done so as well. In the light of a looming ecological crisis, she has called for studying matters of facts and sociotechnical

assemblages not only as matters of concern (Latour, 2004), but to turn them into "matters of care". She has detailed (2011), this implies that, as one investigates technoscientific agencies, one exposes invisible labours, intervenes in the articulation of issues by thinking about how things could be "otherwise", and allows oneself to become affected by the issues one investigates instead of divorcing affects from the research experience. Reacting to these turns towards care in terms of daily life practices and ethico-political concern, Aryn Martin, Natasha Myers and Ana Viseu (2015) have warned against forgetting care's darker side: its lack of innocence and the violence that is committed in its name. They have proposed conceptualising care as a "mode of attention" (Martin et al., 2015, p. 627) that is highly selective: although it "cherishes some things, lives, or phenomena as its object [...], it excludes others" (ibid.). Other STS scholars have, in parallel, mobilised these various concepts of "care" to investigate practices that are rarely described in terms of "care", such as policy practices (Gill et al., 2017), animal husbandry (Law, 2010; Singleton, 2010) and natural science laboratory practices (Pinel et al., 2020; Giraud & Hollin, 2015). Capitalising on the tension between "care" and notions like "implementation" or "objectivity", these studies have nuanced our understanding of these practices.²

A wide range of different conceptualisations of care with partially very contradictory political commitments have been used to investigate all kinds of practices, situations and sites. This proliferation of care-concepts and expansion of their use prompts the questions, as the editors of this special issue put it: What is gained by studying practices in terms of care and what is lost? What is made present and what is made absent? This paper addresses the question of what is gained by investigating practices in terms of care not in general terms or in an abstract way, but using one of the above mentioned care-approaches to investigate one object in a given place.³

In 2016, I happened to be very inspired by the care-approach developed by Annemarie Mol, Ingunn Moser, and Jeannette Pols. They have, as already mentioned, urged us to investigate care through a study of daily life practices that tend to the body, its pains and pleasures, the fragility and fleshiness of life.⁴ They have done so by setting out to sites that advertise themselves as providing "health care" or "nursing care", such as diabetes outpatient clinics, nursing homes, and long-term psychiatric wards. At these sites,

1 I thank all my informants for the new ways in which they have made me think and laugh all names have been anonymised; my colleagues from the VITAL-team Ayo Wahlberg, Jieun Lee, Laura Louise Heinsen, Marie Kofod Svensson, Natasja Kingod, Arseli Dokumaci for many inspiring conversations; the editors of the special issue Doris Lydahl and Lisa Lindén for creating such a warm space to write in; and Jeannette Pols and Annemarie Mol for ongoing support and care. The research was conducted within the project "The Vitality of Disease - Quality of Life in the Making" (ERC-20140-STG-639275) funded by the European Research Council.

2 For a more exhaustive overview over the "turn towards care" in STS, see the introduction of this special issue.

3 For an example of an abstract discussion of care-concepts, see Duclos and Sánchez Criado (2020).

4 This is one approach to "daily life" that has developed in STS in parallel to a second one. The latter uses a focus on "daily life" as a heuristic device to unravel the work, negotiations, and contestation that have gone into that which in the end appears "ordinary" and "mundane" e.g. Latour (1995) and Woolgar and Neyland (2013). For a short summary of the approach, see Mesman (2017).



they joined in as ethnographers as diabetes nurses discussed with diabetes type 1 patients nitty-gritty details of how to best measure their blood sugar levels, when care givers brushed the teeth of elderly suffering from dementia, and as psychiatry health care professionals supported patients with mental disorders to learn to wash themselves. The ethnographers noticed that what was going on in these moments was a silently embedded "practical tinkering" and an "attentive experimentation" (Mol et al., 2010, p. 13). In their analysis, they teased out what, through this practical tinkering and attentive experimentation became performed as good, what as bad, and ambivalences and complexities unfolded in this process. They have pointed out that putting into words these silently embedded processes provides much more than a mere description of practices going on in the provision of health care in 'the world out there.' An ethnography, they have argued, is able to articulate alternatives within the ideals, discourses and practices that currently govern the provision of health care in Europe and North America.

The object that I wanted to investigate was a good provision of haemodialysis treatment to patients in the end stage of renal disease in nephrology practice, focusing in particular on how - as it is often put - a patient's quality of life is improved. A good provision of haemodialysis treatment in nephrology practice has not remained uninvestigated in STS. Andrew MacDougall and his team (2016) have investigated the disputes that nephrologists had with cardiologists about the aim of haemodialysis and the authority of clinical decision making when providing health care to patients in the end stage of renal disease who also had advanced heart failure. In the debates, the researchers learnt, fluid constantly changed

between a "matter of fact" and a "matter of concern" (Latour, 2004), leading them to argue that the object of nephrologist's intraprofessional collaboration is more granular and less stable than the idea of 'the patient' suggests. Wen-yuan Lin (2012) has zoomed in on patients receiving haemodialysis treatment and the tactics that they deploy when, for instance, problems with their vascular access emerge. Some patients, Lin observed, went to see alternative healers and brought alternative treatments to the dialysis unit without telling staff about it. Lin suggested that these tactics enact both a biomechanical body and one in which chi is circulating. Yet again differently, Pascale Lehoux and her team (2008) have concentrated on policies designed "to improve" the provision of haemodialysis treatment. They found that the call to provide "closer-to-patient services" was implemented in projects in diverging ways. While in one project haemodialysis facilities were built into a bus, in another a dialysis unit was constructed in a local hospital. As in both projects, the length of dialysis treatment remained four hours and the daily rounds of nephrologists were replaced with videoconferencing, Lehoux and her team have argued that the practice of nephrology remained the same and at the same time became different. STS studies have thus highlighted how a good provision of haemodialysis treatment is debated by nephrologists and other health care professionals, is enacted in specific ways by patients, and is reconfigured through the implementation of policies that aim at improving it.⁵

In order to investigate with this care-approach how a good provision of haemodialysis is crafted, contested and negotiated in nephrology practices, I set out to carry out fieldwork in Austria. What follows is the outcome of this process.

Haemodialysis treatment and nephrology in Austria

Around 4,000 patients (out of a total population of 8.7 million) were receiving haemodialysis treatment to replace lost renal function in 2016 according to the Austrian Dialysis and Transplantation Registry's annual report (ARGE ÖDTR, 2017). Most of these patients had entered renal failure due to hypertension or type 2 diabetes. Their mean age at initiation of haemodialysis was 64 years. Haemodialysis either served as a "bridge" to a kidney transplant or, if the type of kidney disease foreclosed a transplant or the patient did not want one, as a clinical prolongation of life. The other renal replacement therapies in Austria are kidney transplant and the much less frequently used peritoneal dialysis.

The provision of haemodialysis treatment takes place in around 70 dialysis units all over the country, most attached to internal

medicine departments in hospitals. A unit has, on average, 17 beds to perform this treatment. Together all units employ around 1,000 certified dialysis nurses and more than 200 physicians with an additional qualification in nephrology. Nephrology, as the website of the Austrian Society of Nephrology explained when I was carrying out fieldwork, is "the subarea of internal medicine that deals with kidney disease. (...) Nephrologists are physicians who are specialised in [the kidney's] diseases. Their tasks comprise the early recognition of disease, the diagnostic differentiation of diseases, the evaluation of functional disorders and the provision of non-surgical therapies."⁶ Haemodialysis treatment is, in other words, the core task and expertise of an organ focused subspecialty, nephrology, which is part of the larger speciality, internal medicine. The treatment and the specialists providing it are part of a state-run system.

⁵ These studies fill an important gap created by STS research focusing primarily on the promises and practices of transplant, e.g. Felt, Fochler and Winkler (2010) and Amelang (2014) medical sociological studies zooming in on social interactions, in particular shared decision-making processes around dialysis, most recently e.g. Selman et al. (2019) and Ladin et al. (2018), and medical anthropological work on patients' experiences of living on haemodialysis treatment, e.g. Kierans (2005) and Russ et al. (2005).

⁶ {NOTE_LABEL}. <https://www.nephro.at/oedr2016/oedr2016.html> 15, August 2018.



Physicians specialised in nephrology have organised themselves into the Austrian Society of Nephrology (ÖGN), which holds semi-annual meetings that provide updates and continued medical education. The society also collects information about each individual patient with renal replacement therapy for the Austrian Dialysis and Transplant Registry (ÖDTR), and forwards that data to the European registry run by the European Renal Association (ERA-EDTA) based in Amsterdam.

The provision of haemodialysis treatment in Austria is fairly typical of the situation in Western and Northern Europe, with two exceptions.

First, in some countries, such as the Netherlands, health insurances also cover haemodialysis treatment at home. Second, over the past couple of years, dialysis units in Austria have experienced a hollowing out of material and personnel infrastructures. This kind of tightening of economic resources is different to other countries where financial restrictions have taken place through an explicit "rationing" of treatment that becomes reimbursed, like in Switzerland, or through policy changes that induce a shift towards more "patient involvement" in the form of home treatment, for instance in Denmark.⁷

Collecting data on the provision of haemodialysis treatment in Austrian, analysing "practical tinkering" embedded in "daily life"

In order to study how quality of life of patients in the end stage of renal disease on haemodialysis is improved in nephrology clinical practice through practical tinkering embedded in daily life dealings, in 2016 I identified a medium-sized dialysis unit in a public hospital and I set out to it. At this unit, I recorded data on the provision of haemodialysis treatment for 12 weeks through participant observations of the daily rhythms. To identify idiosyncrasies in the observations, I identified a second medium-sized hospital-based dialysis unit in another part of Austria, where I conducted participant observations in the same manner for four weeks. I complemented the observational data by conducting interviews at the primary research site. These interviews were carried out with the head of the dialysis unit, the head of the internal medicine department that the unit was attached to, the psychologist, and nine patients and/or their significant others. These were in total 19 interviews, lasting between 30 minutes and 3 hours. The observations and interviews focused on what informants were doing, their practices. I further contextualised these materials through participant observations at the annual conferences of the Austrian Society of Nephrology (ÖGN), the Austrian Working Group for Nephrology Nursing and Dialysis Technology (ÖANPT), the European Renal Association (ERA-EDTA) and through interviews with stakeholders in Austrian nephrology. Data collection ended in May 2018.

I began data analysis by identifying processes, which through an emphasis on reason, autonomy and choice in nephrology practice were the focus of attention and those that became taken for granted, devalued and othered. Preparing patients for a kidney transplant received a lot of attention in the two dialysis units, while the provision of haemodialysis treatment was often taken

for granted. I therefore started to focus on the latter. Within the provision of haemodialysis treatment and the tasks it consisted of - the monthly blood analysis and the daily rounds - not all practices were equally valued either. The division of labour in the second unit I had collected data in, which was organised in a particularly hierarchical way, mirrored this. In that unit, the chief physician was present at the monthly blood analysis and communicated results to patients. The daily rounds were carried out in alternating ways by three senior physicians. Thus, I focused on the rounds and what happened during them. The rounds themselves depended on nurses connecting patients to the dialysis machine in order to start treatment and disconnecting them at the end. I took the daily round, the connecting and disconnecting as constituting the "daily life" dealings in the provision of the haemodialysis treatment. Next, I analysed the kind of doings undertaken during the daily round, the connecting and disconnecting, which I determined as constituting the "practical tinkering" and "attentive experimentation".

In what follows, I present my findings by providing fieldnotes of what happened on the very first morning on the first day of fieldwork and of what happened to one patient, whom you have already met in the introduction, during the daily round. He was presented to me by the staff in the dialysis unit as a, for the unit, "typical" haemodialysis patient.⁸ I call him Herr Fialka. He is also representative of haemodialysis patients in Austria in terms of age, co-morbidities, and disease trajectory. In 2016, when I first met him, he was 74 years old. In 1997, he had been diagnosed with chronic kidney disease, and in 2011, he had begun haemodialysis treatment. Herr Fialka never wanted a kidney transplant.⁹ Prior to this, in 1975, he had been diagnosed with chronic inflammable

7 Ethnographies from places other than Europe and the U.S. provide a vivid reminder that dialysis is far from being a standard treatment that is available universally. For an analysis of the political etiology that patients in Egypt develop where not only kidneys, but also the state, fail, see Hamdy (2008); for the ways in which dialysis turns into a "gift" that poor patients in Thailand are waiting for, see Seo (2016); and for the liminality of lives of dialysis patient who are undocumented migrants in the United States, see Kline (2018).

8 The main distinctions made by the staff were between patients who were "running on their own" (and did not need much attention), who represented "a complicated case" (for example a patient who, in addition to being in renal failure, was also unemployed, divorced, and had three children out of whom one had disabilities), or patients who were "doing badly" (and expected to pass away within the next few days or the week). For a critical analysis of the categories of "bad patients" and "good patients" used by medical students in the United States, see Sointu (2017).

9 There are many good reasons why patients on dialysis might refuse offers of living donor kidneys for instance, as Gordon (2001) shows.



bowel syndrome and many operations had followed. In 2018, he was diagnosed with testicular cancer and developed an inoperable

fistula between his abdominal wall and stomach. He passed away from a cerebral haemorrhage in October 2018.

Measuring side-effects? A prominent ideal enters local clinical practices

Fieldnotes, City hospital, 11 July 2016, around 7 o'clock

The corridor is flooded with light, and, although the sun has just started rising, it already promises to become another hot summer day. Doktor Doblinger, my main contact, has told me via email to meet her after her nightshift. A few minutes before the agreed time, I am waiting, slightly nervous, at the nurses' station on the internal medicine unit. Around the corner, a tall woman in her late 40s appears. She walks briskly towards me. Her white coat swishes around her legs. After short introductions, she gestures me to follow her towards the dialysis unit. "You know," she starts recounting, "a couple of years ago, when we began developing the palliative care project, we distributed Quality-of-Life-questionnaires to all our dialysis patients. Susanne, our psychologist, had developed them. But out of the 80 questionnaires that we had distributed, we got back only 10. And some of them weren't filled out honestly even. Frau Prohaska, for example, you'll meet her at the daily round, had answered the question concerning sleep with 'very good'. At the same time, she was seeing Susanne to whom she was complaining about how bad her nights were. So, we knew that she had sleeping problems!" We have entered the dialysis unit, passed the nurses' station, the patients waiting area and arrived in Doktor Doblinger's office. She sits down at her desk. The swivel chair sags down under her weight with a sigh. Moving the mouse to wake up the computer, she prints out the patient list for today's round and clips it onto a purple clipboard.

To situate this observation, the insights on quality of life provided by medical sociologists and STS scholars are helpful. Quality of life emerged as a concept in the 1960s, when three separate debates unfolded in medicine and society (Armstrong & Caldwell, 2004). The first revolved around the question of social progress and social crisis; the second concerned haemodialysis and other newly developed medical technologies that prolonged life, but, as some physicians asked, at what cost? The third debate arose around the question of how to assess the quality of treatment and care for patients with chronic diseases that could not be cured, and elderly people, for whom survival was not a good measure. Armstrong and Caldwell have argued that quality of life served as a "device" (2006, p. 361), as they put it, in these three debates that allowed the debates to settle at a rhetorical level. The concept was formalised in the 1980s, when four instruments, developed between 1950 and 1980, were merged into one (Armstrong et al., 2007). These were a mental health assessment, a symptom list, a measure of so-called "activities of daily living" (i.e. the effects a disease yields on activities like climbing up stairs), and an assessment of "social functioning" (i.e. how limitations of everyday physical functioning affect the pursuit of hobbies and sexual life). Armstrong and his

colleagues have argued that, between 1980 and 1995, this four-dimensional quality of life instrument "consolidated its hold over medical outcomes research and practice" (2007, p. 577).

What is it that quality of life measures do? The introduction of Quality Adjusted Life Years measurements by the Swedish Pharmaceutical Benefits Board, which has been investigated by Ebba Sjögren and Claes-Fredrik Helgesson (2007), provides an example. The board introduced the metric to decide which prescription pharmaceuticals, out of the plethora of pharmaceuticals approved for use, should be included in the public pharmaceutical scheme. However, in order to use this measurement, the STS scholars highlight, the board not only had to delineate which products should be compared, but also which use of drugs to compare, how to compare the products, what kind of effects to count, and which data to use in the first place. The use of quality of life measurements, Sjögren and Helgesson (2007) argue, depends on a lot of work. What quality of life measures do in clinical practice is yet again different, Arseli Dokumaci's auto-ethnography (2019) suggests. Dokumaci reported how she was asked, as a rheumatoid arthritis patient, to fill out the Health Assessment Questionnaire (HAQ), a quality of life questionnaire developed for assessing disabilities caused by rheumatoid diseases. It includes question like "Over the last week, were you able to dress yourself, including tying shoelaces and doing buttons?" Based on her observations, Dokumaci argues that quality of life instruments expand the clinical gaze. In addition to seeing and knowing a disease and/or treatment through clinical markers, laboratory results, mortality rates and survival times, in other words by looking at 'the inner workings of the body', quality of life instruments bring into focus how the body that is afflicted by this disease and/or receiving this treatment functions in daily life. They leave intact, Dokumaci points out, the causal link between pathology -> disease -> disability, extensively criticised in disability studies.¹⁰

These medical sociologists and STS scholars have brought out how a concern for a patient's daily life with a disease and/or a treatment has come to be articulated in terms of "quality of life" that needs to be "improved" and a particular way of going about it, measuring quality of life with a questionnaire, has gained prominence and often dominance. They have shed light on what this prominent practice does and does not do in health care policy and clinical practices.

Let us return to the dialysis unit of the City Hospital. There, in the process of setting up a project on palliative care in 2013, a questionnaire was distributed. Susanne, the psychologist, specified

¹⁰ For an investigations into what quality of life measures do in global health practices, see Wahlberg and Rose (2015) and in daily life practices of patients, see Pols and Limburg (2016).



that it was the German version of the Health Related Quality of Life Questionnaire. She had found it on the internet. It consisted of questions relating to physical health (sleep, fatigue, loss of appetite), emotional health (sadness and enjoyment of life) and social functioning (work and sexual relations). For example, it asked patients to choose, with regard to their previous week between the following statements: "1 - I do not get tired more easily as usual." "2 - I get tired quicker than I did before." "3 - Nearly everything makes me tired." "4 - I am too tired to do anything." The questionnaire was printed out and distributed by one of the unit's nurses. Ten patients answered the questions and returned the filled-out forms.

Let me draw your attention to what, then, did *not* happen. Doktor Doblinger and her colleagues did not follow up on the missing questionnaires. They did not sit down and rephrase the questions in such a way that they might solicit more "truthful" answers. They had not systematically reviewed the literature on health related quality of life in patients on haemodialysis, then assessed the current quality of life of all patients in the unit, then designed the palliative care intervention, tested the intervention in a pilot study, performed a full blown and preferably randomised controlled trial, and, had the intervention proven successful, implemented it in the existing structures in the unit and disseminated it to other units in Vienna, the rest of Austria and the rest of the world. They did not follow what a key player in Austrian health care identified as the gold standard of Evidence Based Medicine (Berg & Timmermans, 2003). Instead, the questionnaire, which I tried to follow up on between 2016 and 2018, could not be retrieved on the many computer backups the psychologist had made. Nor could anyone tell me where the 10 filled-out sheets had ended up.¹¹

This was not the only quality of life questionnaire that I learnt about during my fieldwork. In a second unit, where nephrologists both regularly participated in international research projects and carried out research on their own, the head of the unit decided, in 2005, to carry out in collaboration with a pharmaceutical company a study on patients' quality of life. As he told me in an interview, he tried to involve in the study design a psychologist, "an expert", as he put it. Unsuccessfully, so an item battery was developed without a psychologist. Questionnaires were distributed, filled out and the completed sheets collected. The head had been in the process of hiring a student to enter the answers into Excel and perform the statistical analysis when "luckily", he explained, he had realised that the validity of the results would have been "very poor". The questionnaires were then stored in a cellar. When I was undertaking my research in 2016, no one could locate them or say conclusively whether they still existed.

In a third unit, in around 2000, an email arrived from the European Renal Registry of the European Renal Association.

It was addressed to the head of the unit who happened to be the physician who, from the 1980s onwards, was responsible for sending data from Austria - numbers of patients in the end stage of renal disease, type of kidney replacement therapy, and others - to the European registry. In parallel, he had established an independent Austrian dialysis and transplant registry. The email asked whether quality assessment instruments in Austria included a measurement of patients' quality of life. They did not. In response, he assigned one of the physicians in training on his ward to develop a prototype quality of life questionnaires. This physician, whom I also interviewed, explained that he did so by combining items of the generic Short Form (36) Health Survey (SF-36) with the symptom and dialysis-oriented Kidney Disease and Quality of Life-Short Form (KDQoL). The former included questions on physical, emotional and social functioning, the latter inquired into side-effects of chronic kidney disease through questions like "During the past four weeks, to what extent were you bothered by cramps, itchy skin, nausea", and asked patients to rate the occurrence of each of these side-effects by ticking one of four boxes ranging from "not at all bothered" to "extremely bothered." The combination of the two measures resulted in an instrument of over 50 items. The questionnaire was distributed to the unit's patients receiving haemodialysis, those on peritoneal dialysis and those who had received a kidney transplant. If patients did not return the questionnaire, the physician went looking for them and asked them the questions face-to-face. In the evenings, he entered the results in an Excel file and calculated each patient group's rating, compared the rating between the groups, and presented the results at the biannual conference of the Austrian Society of Nephrology. Both the head of the unit and the physician formerly in training me that the study had required "a lot of effort" and could "not be performed on an Austria wide scale." The reasons for this, they explained, were that dialysis units were often short of staff and that including items regarding quality of life into the existing registry questionnaire would make it longer and jeopardise the current high return rate. The former physician in training ventured that the completed assessment forms had probably been disposed of when the nephrology department and its dialysis unit had merged with another department and moved to a new location.

The quality of life questionnaires in the dialysis unit of the City Hospital and the two other dialysis units that I came across during fieldwork require specifying the arguments developed in medical sociological and STS studies on quality of life. They suggest that the ideal and practice to improve quality of life by measuring it with a questionnaire arrive in clinical practices that are going on in a specific particular place through highly particular dynamics. What creates an impetus in clinical practice to search for a quality of life questionnaire, print it out, and distribute it ranges from the implementation of a project according to the

¹¹ While the quality of life questionnaires were not followed up on, the palliative care project became developed and implemented. For a detailed analysis of how this and other projects enact "quality of life", see Mann forthcoming a.



gold standard of Evidence Based Medicine (in the dialysis unit of the City Hospital), to the aspiration to produce knowledge and do science intertwined with the aim of improving products and increase profits (in the second unit), to the ideal that the provision of health care services should be monitored and steered through quality measurements, and to the tradition of teaching medicine through practical exercises (in the third unit).

More important is the fate of the three questionnaires. Many STS scholars have argued that questionnaires, protocols, and forms are not blindly followed by health care professionals and patients, stressing that there is a "mutuality" (Timmermans & Berg, 1997, p. 288) between questionnaires and their requirements and locally ongoing clinical practices. As Timmermans and Berg put it, the *sine qua non* for the functioning of a questionnaire, form or protocol is an "ongoing (...) (re)articulation of the protocol to meet the primary goals of the actors involved." (ibid., 291) Through case studies ranging from Cardio Pulmonary Resuscitation protocols in emergency wards (ibid.), Do Not Attempt Cardiopulmonary Resuscitation orders in acute wards (Cohn et

al., 2013), person-centred care assessment protocols in internal medicine units (Lydahl, 2019), and health assessment protocols in psychiatric clinical practice (Bister, 2021), they have brought out how such a (re)articulation happens, how questionnaires, protocols and forms are adapted and adjusted to fit into locally ongoing clinical practices. This, however, is not what happened with the questionnaires reported about above. The unreturned quality of life questionnaires were not followed up on in the dialysis unit of the City Hospital, the answers of the questionnaires were not entered into an Excel file in the second unit, and the instrument developed in the third unit was not integrated into the quality assessments forms used across Austria. In fact, the three quality of life questionnaires and the fate they had in nephrology clinical practice provide examples of patients and medical professionals who stop bothering with questionnaires and their requirements and of forms that cease to be adapted and adjusted in local clinical practices. They exemplify questionnaires, forms and protocols that are abandoned, forgotten, and thrown away. The next section unfolds how such a forgetting, abandoning and forgetting can happen.

Making a phone call: A rejection of the prominent ideal through daily life practices

Doktor Doblinger, her medical colleagues, the nurses, and the psychologist, as mentioned above, did not follow up on the missing questionnaires. The ten questionnaires that had been eventually returned were thrown away. Did this imply that Doktor Doblinger and her colleagues stopped attending to the way their patients in the end stage of renal disease on haemodialysis treatment lived their lives and ceased to improve it? In order to answer this question, let me introduce fieldnotes from the daily round and what happened around it.

Fieldnotes, 24 March 2017, City Hospital, dialysis unit, 9:04 o'clock

Doktor Doblinger has seen the last patient on the morning round and heads back to her office. She sits down at the desk. The swivel chair sighs. She reaches into the pocket of her white coat and takes out her phone.

On the daily round, Herr Fialka had answered her question "How are you?" with a finger pointing towards his mouth. In the corners of the mouth and around the lips, an eczema had developed. "Na geh..." "Oh no..." Doktor Doblinger had exclaimed. "Do we have a skin [department] in the house?" Herr Fialka had asked. "Can't they concoct something?" "There is a skin department in the house, but they have very long waiting times. I'd rather call a good friend of mine who is a dermatologist," Doktor Doblinger had answered and added with a twinkle, "We will use her as telephone joker!" Herr Fialka had nodded while Doktor Doblinger had taken out her phone and dialled the number. Nobody had answered. "She isn't there. I'll try again later and bring you the prescription before you leave." She had made a note on her purple clipboard.

When she had finished, Angelika, who had followed the exchange

standing next to the dialysis machine stated, "We have entered three and a half kilo... and are seeing how it goes." Doktor Doblinger had gotten some disinfectant and started touching Herr Fialka's right shin. In the middle, further up and further down. Her fingers had left imprints, a sign for her that too much liquid had accumulated there. "It's already better than the last time," she had observed. "Let's see to it that next time we get down to 55,5 kg dry body weight." Angelika had nodded and Doktor Doblinger had made another note on her clipboard.

After a moment of silence, Herr Fialka had started turning his head back to the TV, and Doktor Doblinger had muttered, "Good bye!" and started walking to the next bed in which the next patient was waiting.

Now, she takes up her phone and presses "redial." After the second ring, a voice crackles through the receiver. "Hallo Verena! ... May I ask you a question? ... I have this patient, born in 1942..."

To replace Herr Fialka's and other patients' kidney function, two temporally distinct routines were going on in the dialysis unit. On a day-to-day basis, nurse Angelika and the other dialysis nurses meticulously attended to fluids. On the morning described above, Herr Fialka's body had retained all the fluids he had taken in during the 48 hours since the previous dialysis run. Based on calculations of what Angelika and Doktor Doblinger called "dry body weight", 3,5 liters was set as the target for removal during this run. Achieving this was not obvious. Extracting too much liquid or extracting it too quickly could strain Herr Fialka's circulation, cause a sudden drop in blood pressure and make him faint, and extracting too little could leave him breathless. Angelika



therefore measured Herr Fialka's blood pressure every 30 minutes and attentively observed how he was keeping himself in his bed. In addition, Angelika and the other nurses watched over the state of Herr Fialka's and other patients' fistulas and measured the potassium level in patients' blood. At the end of every month, "the monthly bloods" were taken. For each patient a set of parameters were assessed: vital parameters - haemoglobin and C-reactive protein -, amount of waste products - calcium and phosphate - and other parameters, such as Kt/V, a dialysis quality parameter that had been introduced in the 1970s and 1980s, but that had never established itself as sole indicator (Cameron, 2002, p. 247). Depending on the values, Doktor Doblinger and her colleagues increased or decreased medication dosage (for example of phosphate binding drugs), replaced one drug with another (three pills of a blood pressure drug a day with another drug that required intake of one pill a day only), and increased or decreased the length of dialysis run or speed.¹²

Still, on the morning described above, Doktor Doblinger did more than attending to the amount of fluid in Herr Fialka's body. She reacted to another bodily ailment that Herr Fialka was afflicted with. This bodily ailment was neither cramps, nor itching skin, nor nausea caused by chronic kidney disease or haemodialysis treatment. It was a bodily ailment which, in common pathophysiology, was completely unrelated to Herr Fialka's kidney failure or dialysis. It was one morning among many during which I observed nurses and physicians attending to issues that Herr Fialka and other patients brought up that were related neither to renal failure nor to its treatment. I will provide just two more examples. On another day during the daily round, a patient mentioned how tired he was. To differentiate between a tiredness that was normal, one that was a sign of depression and one that indicated a slowly progressing dementia, Doktor Doblinger called the psychologist. When the patient came in for his next dialysis run two days later, the psychologist carried out a dementia test, which was positive. Doktor Doblinger then called a colleague from the neurology department, who advised her on the best possible medication to prescribe, wrote a letter of request for reimbursement of the drug which was covered only "under special circumstances", filled out the prescription form and handed it to the patient at the end of the dialysis run. On another day during the daily round, yet another patient had wanted to receive an influenza vaccination. Her general practitioner would have charged €30 for it. The patient had ventured that the solution might simply be "poured into" the dialysis machine. Doktor Doblinger explained that "pouring the vaccine into" the dialysis solution was definitely not feasible. She,

then, called a colleague specialised in general medicine to ask whether the serum was to be injected subcutaneously (under the skin) or intramuscularly (into muscle mass). When the patient came in two days later, she administered the vaccination according to her colleague's advice. In all these cases, Doktor Doblinger, nurse Angelika and their colleagues during the time that a patient spent in the dialysis unit established new diagnosis', provided prescriptions and administered drugs unrelated and in addition to kidney failure and haemodialysis treatment.¹³

Many other STS scholars have argued that the practical tinkering embedded in daily life dealings in the provision of medical and nursing care enacts knowing, improving, and that which is to be improved in other ways than prominent practices do. They have illuminated this divergence through case studies ranging from mundane goings-on in rehabilitation clinics versus rehabilitation outcome measures (Struhkamp, 2004), daily practices of washing in mental health care facilities in contrast to formal care-plans (Pols, 2004), day-to-day provision of nursing care provided for elderly with dementia (Moser, 2010) and health care for patients with arteriosclerosis versus randomised controlled trials. (Mol, 2006)

Such a divergence can also be observed in the provision of haemodialysis treatment in the dialysis unit of the City Hospital. Let me tease out the differences between the ways measuring quality of life with a questionnaire, which Doktor Doblinger originally set out to do, and the establishment of new diagnosis, provision of prescriptions and administration of drugs reported above enact knowing, improving and quality of life.

Measuring quality of life enacted knowing as a way of making explicit, a formalisation that transformed answers that patients had provided by ticking boxes into numbers, and a quantification. Improvement, in this practice, would have happened if a change of values had been observed before and after an intervention, at two clearly delineated and distinct points in time. Quality of life, in this process, would have become located in a fixed set of parameters. They would have been the effects that one and only one disease, chronic kidney disease, and the treatment provided for this one disease, haemodialysis, had on physical and emotional health, activities of daily living and social functioning. A questionnaire that had comprised kidney disease specific items would also have located quality of life in itching skin, cramps and nausea.

In contrast, through connecting and disconnecting patients, and doing the daily round physicians, nurses and other health care

¹² Each of these values deserves to be further unpacked. For an example of an indicator in practice, see Amelang and Bauer (2019).

¹³ These activities were described by Doktor Doblinger, nurse Angelika and their colleagues not in terms of "Verbesserung von Lebensqualität", the German equivalent of "improvement of quality of life". As the fieldnotes illustrate, they focused on issues to be avoided. Instead of articulating how a good was strived towards, what became put into words were the bads to be circumvented (Mol, 2002). Asked by the ethnographer about what they did to "improve patients' quality of life", they pointed out how quality of life differed for each patient and was experienced by some patients as very poor while, as they put it "objectively", being quite good. This reflects how quality of life, besides being a treatment goal, is also a concept about which informants reflect. A detailed analysis of the gaps between doings and the German word for "quality of life", "Lebensqualität", goes beyond this paper. For such an analysis focusing on the case of sensual engagements with foods and the word "tasting", see Mann and Mol (2019).



staff knew how patients were doing in a way that was an implicit, distributed and collective sensing.¹⁴ Nurses gathered information through casual chatting with patients while connecting and disconnecting them while physicians learnt about how a patient was doing when encountering him or her during the daily round every other day over months, sometimes years, and, in rare cases, decades. The psychologist had appointments with them. The information and impressions were partially shared during the daily meeting of the nursing and medical staff, over coffee and in the corridors. Improving, in these practices, was an ongoing process.¹⁵ It sometimes began with an evaluation and re-evaluation of what could and should be attended to. Doktor Doblinger, for example, did not examine a sprained ankle that a patient brought up during the daily round. The dialysis unit did not have an x-ray machine, necessary to either diagnose or rule out a fracture. If an issue was attended to, such as the eczema of Herr Fialka, it was followed up on. Most striking was the quality of life that the establishment of a new diagnosis, handing out of a prescription or administration of a drug improved. Against the backdrop of patients already spending three times every week with being driven to the hospital, often waiting to be connected, having a four hour long run, becoming disconnected, driven home and recovering from the procedure, quality of life was located in the time and money that these patients spent seeking and receiving health care for acute or chronic diseases they happened to become sick from *in addition* and unrelated to chronic kidney disease. Improving quality of life meant freeing patients' time and money so that they could spend these resources in ways other than seeking and receiving health care in the hospital and other health care facilities, which were part of a health care system that was differentiated according to medical specialties and distributed geographically.¹⁶

The connecting and disconnecting of patients and meeting them during the daily round that took place in the dialysis unit in the City Hospital suggest that daily life dealings do more than enact in other ways knowing, improving and that which is striven towards. When quality of life questionnaires were introduced, a patient's answer on the questionnaire (that she was sleeping 'very well') was brought together with the information that the physician and the psychologist had gathered during the daily round and a consultation. In the end, it was the questionnaire's information that became judged as "not truthful." In similar ways, in the second unit, the daily life of administering haemodialysis treatment went on without entering the questionnaire's results into Excel. In the third dialysis unit, the practice of measuring quality of life with questionnaires was brought together with all the other tasks that providing haemodialysis treatment included and the number of staff available to perform them. It was, again, the practice of distributing questionnaires that became ruled out as "being too much work." I, therefore, suggest that in empirically observable encounters that happen between a prominent practice and daily life dealings in the provision of medical and nursing care, daily life dealings can be the backdrop against which the prominent practice becomes evaluated and can constitute the resource through which it becomes questioned, abandoned, and forgotten. From the vantage point of daily life nephrology practices, the quality of life questionnaires that had been distributed had been neither been useful nor necessary. They had not detected the issues that patients brought up and might even have yielded harm, as they might have created a causal link between a patient's tiredness, chronic kidney disease and haemodialysis treatment, and left the patient's onsetting dementia undiagnosed. They became a story of something that "had not worked out" and was "too much effort".

The vital importance of daily life practices

STS scholars have studied how a good provision of haemodialysis treatment is crafted, negotiated and contested in disputes that nephrologists engage in, in tactics that patients pursue, and in policies designed to "improve" the health care service. Mobilising an approach to care as the study of daily life dealings and the practical tinkering embedded in them, this paper has brought out what is at stake in processes that have been othered, taken for granted and devalued in nephrology practice and also STS studies so far: the daily round and connecting and disconnecting patients. Based on ethnographic fieldwork carried out in one dialysis unit and other relevant sites in Austria, it has reported how a quality of life questionnaire was distributed to patients in the unit, but soon abandoned. I have analysed first the highly

specific and diverging dynamics through which the prominent practice and ideals to improve patients' quality of life, it is to be measured with questionnaires arrive in locally ongoing nephrology practices. Second, I have brought out the ways in which the connecting and disconnecting of patients and the daily round enact knowing, improving and quality of life in other ways than questionnaires do. My main argument has been that questionnaires, forms and protocols neither always become adjusted and adapted to fit into locally ongoing clinical practices, nor are daily life dealings simply other to questionnaires, forms, protocols and prominent practices. Rather, daily life dealings in the provision of health care may also be the basis upon which prominent practices become assessed, evaluated, and end up

¹⁴ That sensing is anything but erratic has been argued in a variety of ways in studies on tasting (Mann, 2018; Teil, 2001).

¹⁵ The ongoingness of the tinkering involved in crafting a "good life" while living with a chronic disease has been emphasized in many studies on a variety of chronic diseases (e.g. Mol, 2008; Pols, 2013; Struhkamp, 2004). What has been left unexplored, however, is the question how a tinkering for a "good life" is able to include and eventually turn into a striving for a "good death". For an explorative study on the complex processes leading towards a withdrawal of dialysis and end of life, see Axelsson et al. (2020).

¹⁶ For a more detailed analysis of how patients from the City Hospital enjoy life outside the dialysis unit, see Mann forthcoming b.



becoming judged as being "too much effort" and "not having worked".

If, as I have argued, questionnaires, forms and protocols and the prominent practices they are part of may become abandoned and other ways of knowing, improving and a good provision of health care continue to thrive, this raises the question of under which conditions such an abandoning can occur. In the dialysis unit of the City Hospital, it seems two types of processes contributed to patients' resources becoming freed instead of kidney disease and dialysis treatment side-effects being measured. First, the dialysis unit was managed in a particular way by the head of the internal medicine department that the dialysis unit was attached to. She did not get involved in the provision of haemodialysis, but relied on the senior physician, who was leading the dialysis unit, and everybody else there "doing their thing." This implied that, amongst other things, if a staff member developed a project, rather than expecting that they strictly followed the gold standard of Evidence Based Medicine in its implementation, she appreciated that someone had taken initiative at all. Second, accounting practices were crucial. The values that the quality of life questionnaire would have produced never became part of the annual budget negotiations of the internal medicine department that the head of department had with the hospital's finance department. Also, the accounting system in the City Hospital did not list all the services that the dialysis unit had provided. Instead it lumped them together with those of all other outpatient clinics

of the hospital. Prescription of medication for diseases other than chronic kidney disease, treatments other than haemodialysis and the establishing of novel diagnosis, thus, remained invisible. I, therefore, recommend further investigation into processes, especially management and accounting practices, that enable alternative enactments of a good provision of health care to thrive and prominent practices to become abandoned.

What is it, then, that has been gained by studying practices in terms of care? This paper has addressed this question not in general or abstract terms, so not forgetting that there are vital issues at stake in the worlds that we, STS scholars, and our research are embedded in, such as Herr Fialka's and other chronic kidney disease patients' quality of life. Instead, it has made three moves. First, it has mobilised one specific care-approach, which was the study of daily life dealings and the practical tinkering embedded in them. It has used this approach to, secondly, investigate one specific object, which was a good provision of haemodialysis treatment to patients in the end stage of renal disease in nephrology practices. It has done so, thirdly, in a given place, which was a dialysis unit in Austria. What has been gained has arisen out of a relational effect between the object and its specificities, the way the object had been studied so far in STS, and the strengths of the care-approach taken. This is insights into daily life practices: doing the daily round, connecting patients with and disconnecting them from dialysis machines, and an anything but benign phone call that has happened in between.

Author biography

Anna Mann works as a PostDoc researcher at the University of Copenhagen, Denmark. Anna's research is situated at the intersection of science and technology studies, sociology and anthropology. It investigates goods in practice through ethnographic case studies set in Western Europe. After having studied moments in which something "tastes good" in eating, she is currently tracing the making of "quality of life" in medical practice. With her research, she contributes to ongoing debates about values in practice, and the body and its materialities.

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