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DOI
10.1108/QRJ-D-17-00030

Publication date
2018

Document Version
Final published version

Published in
Qualitative Research Journal

Citation (APA)
Teunissen, G., Lindhout, P., & Abma, T. A. (2018). Balancing loving and caring in times of chronic illness. *Qualitative Research Journal*, *18*(3), 210-222. https://doi.org/10.1108/QRJ-D-17-00030

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www.emeraldinsight.com/1443-9883.htm

Balancing loving and caring in times of chronic illness

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Received 10 August 2017
Revised 5 December 2017
Accepted 7 January 2018

Abstract

Purpose – The purpose of this paper is to explore the impact of chronic illness on a couple's life experiences over a period of 40 years. It critically examines the assumptions of the public health discourse in the light of this couple's attempts to balance love and health care within their relationship.

Design/methodology/approach – The couple, the first two authors, put themselves under the magnifying glass. They arranged for a dialogic encounter and built a co-constructed auto-ethnography. This study consists of a "raw" narrative and a reflection. This reflexive part was added by the third author, interpreting the couple's experiences applying in a sociocultural way theories of ethical care. This sheds light on ethical care aspects encountered in the couple's balancing of love and health care.

Findings – This study shows that the couple copes with adversity rather than being in control of it. Nonetheless their love relationship appears to be flourishing, thanks to their acknowledgement of the importance of mutual caring.

Research limitations/implications – The current public health discourse puts the couple's private love relationship under pressure. It turns a blind eye towards the difficulties they experience with the contemporary "self-management" paradigm. The couple feels that the government is an interloper intruding into their private relationship. This creates tension, friction, anxiety, as well as increasing the burden of the illness and makes them feel insecure and unsafe.

Originality/value – The novel method used in this study offers a rare and deep insight.

Keywords Care ethics, Love, Chronic illness, Meaningful life, Mutual caring

Paper type Research paper

> Love bears all things, believes all things, hopes all things, endures all things (*The Bible,* 1 Corinthians 13:7).

Introduction

The issues of the public domain are reflected in the private domain. This is true more profoundly than researchers can assess via polls and statistics. Methodologically, auto-ethnography is better suited to research private issues.

Inspired by Ellis (2004) and Denzin (2014), who focus on the challenges of research into the connection between private and public realms, the first and second authors decided to research their lives using this method.

The first author (Truus), a social scientist in health care, has a history of chronic illness that has grown increasingly complex over three decades. Her struggles with deteriorating health are described in Teunissen *et al.* (2015).

The second author (Paul), her husband since 1975, is an environment, health and safety scientist in industry. Paul has experienced the gradual process of Truus's incapacitation intimately through their marriage. Both have a scientific background, and remain academically active in universities.

The third author, Tineke, is a Professor in the field of patient participation. Tineke's role has been to reflect on the narrative from an ethical care perspective in order to form sociocultural insights into the phenomenon of personal illness.

Qualitative Research Journal
© Emerald Publishing Limited
1443-9883
DOI 10.1108/QRJ-D-17-00030

The couple (Truus and Paul), now in their early 60s, are living their lives under the heavy impact of Truus's multi-morbid illnesses. They also face the adverse effects of the current health system and political discourse. This creates a regime in which patients and their partners rely on self-management, irrespective of the type and complexity of the patient's health problems.

The couple wished to reflect on the damage that chronic illness inflicts on their relationship. Their concern has many aspects: being ill; that one needs to be the caregiver; that one might become more dependent and feel less equal; the many worries; the friction; and the fear of losing one another. They wanted to gain a clearer understanding about the combination of loving and nursing at the same time. They also wanted to consider the roles of the current public health system discourse and current policy discourse in the Netherlands. As well as understanding better the influence of these discourses on their relationship as a married couple, their experiences are a source of broader sociocultural insights into the connection between public policy and personal lives.

They have recognised a conflict between their love relationship and the obligation stated in current policies to act as a caregiver. In their perception, this was caused by the disturbing effects of the illnesses by Truus and Pauls' role as a caregiver. Although relationships are often affected by a variety of physical and, increasingly, mental illnesses (Swaffer, 2014), they could only find one scientific study specifically addressing the impact of chronic illness on a love relationship (Ellis, 1995). The couple decided to inquire deeply into their own situation, which they describe as a balancing act of caring and love. They felt that the exceptional combination of their experiences with health care, their scientific research skills and their strong bond formed a good basis to write reflexively about their experiences with the health problems disrupting their private lives and their love relationship. This is especially relevant against the background of the advancement of medical technology which results in longer life where new treatment options have turned once lethal diseases into chronic illnesses. Chronic illness and multi-morbidity affects an increasingly large group in society (Ursum *et al.*, 2011; Oostrom *et al.*, 2016) and impacts not only on their health but also their well-being. This area gets little, if any, attention in the current discourse. Sharing such experiential knowledge (Williamson, 2010) with others would add to the body of knowledge about the effects of public health discourse on private daily life.

Co-constructed auto-ethnography and care ethics as framework

The couple took on this difficult and challenging research adventure and chose a methodology of reflexive inquiry and mutual dialogue to understand what happened in their relation, and to identify the insights they have gained (Ives and Dunn, 2010). They created light, airy and relaxed conditions in which to conduct their inquiries. Later, they involved Tineke Abma – a friend and colleague – to connect their experiences with a theoretical framework beyond the personal narrative account. The authors hope that this study will encourage further inquiry into balancing between loving and caring, and will contribute to the auto-ethnographic method, specifically as to what happens if researchers put themselves under a magnifying glass (Ellis, 2004, 2007; Denzin, 2014; Ellis *et al.*, 2011).

This study centres on the following question:

> How does a couple balance love and caring in a long term love relationship, affected by chronic illnesses and the public health discourse?

Although the authors consider an insider's perspective (Visse and Niemeijer, 2016) to be essential, they felt that an "ego-document" would not be enough. Although the focus of what matters here resides in the relations within the couple, also significant are the relationships with everyone around the couple and the broader sociocultural context (Mead *et al.*, 2011;

Heijst, 2008). Another option considered was "Investigative journalism" but this was dismissed because it is based on the perspective of an outsider, although depth to a fundamental human level can most certainly be achieved in this way (Kool, 2010). The first two authors felt that their needed a dialogue between themselves rather than answering questions posed by others. Andrews *et al.* (2013) offer a wide range of methods to do this.

Hence, the first two authors chose a co-constructed auto-ethnographic method (Ellis, 2004, 2007; Denzin, 2014; Ellis *et al.*, 2011) followed by a reflection on the findings of their dialogue, originating from their two perspectives in the form of an in-depth narrative, reconstructing episodes and identifying past events that changed their perspective: turning points (Stake, 2000; Heisel *et al.*, 2016; McAdams, 2001; Taylor, 1983). This draws broader sociocultural insights from personal experiences (Chang, 2016).

Writing the story

The first part was a "creative process" to get the narrative story written down on paper. Recording insiders' knowledge and experience required the first and second authors to be simultaneously the researchers and the objects of research (Richards, 2008).

This process started with open discussions on relevant topics. It progressed by making individual lists of problems encountered between love and illnesses, and by individual writing about ones' own problems and about those experienced by the other. This material was shared: first, reading and comparing each other's notes, then though conversation during a long walk, and finally, each in turn writing down their own recollected version of this dialogue afterwards, merging both versions and agreeing as to the clarity and completeness of this joint text. In the event that a relevant topic was not addressed this was taken up in a new dialogue the next day and added to the text. Hence, both were taking notes during and after the conversations either written, in turn, directly into the notebook or, in some cases, on a separate piece of paper which was then pasted into the notebook later on (Plate 1).

The conversations were held between 12 January 2017 and 10 February 2017. After this, the first and second authors worked on translating their Dutch notes into English episode texts. By the spring of 2017, this resulted in an auto-ethnographic "raw" narrative by two persons (Schrag, 1986). The episodes were then numbered and given a heading. In the notebook "P:" (Paul) and "T:" (Truus) indicated who said what. Finally, the episode text was clarified and condensed in interaction with the third author, using peer debriefing techniques (Guba and Lincoln, 1989). The third author then engaged with the first and second authors in the joint theoretical analysis from a care ethics perspective of the turning points in the episodes to assign meaning to the narrative (Etherington, 2004). Care ethics is well suited here, because of its focus on the importance of care for human well-being (Sevenhuijsen, 1998; MacKenzie and Stoljar, 2000; Tronto, 1993; Held, 2006).

Care ethics originates from a feminist critique on dominant values in western culture. These include values, such as autonomy as self-determination, and system values like productivity and efficiency that tend to dominate professional care, leaving out its moral and "human" dimensions. It criticises the traditional boundary between the public and private domain, because this hinders the full participation of women in the public domain (Tronto, 1993). Instead care ethics stresses the importance of other values like trust, solidarity and responsiveness, and reveals that autonomy is relational as well (Verkerk, 2001). We are not autonomous despite of other people (negative freedom), but because of the relations we have with other people (positive freedom) (Schipper and Abma *et al.*, 2014). Care ethics acknowledges mutual interdependencies, is relational in its orientation, centralises vulnerabilities and strives for greater levels of social justice and human flourishing. In care ethics, "caring" is not restricted to intimate relations of care, but is broadly defined as follows: "On the most general level, we suggest caring be viewed as a species activity that

Plate 1.
Taking notes…

includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web" (Fisher and Tronto, 1990, pp. 40-41). We find this definition and approach attractive, because it includes both more intimate, personal and political dimensions of care, including self-care, care for the body and the relationship as well as the democratic allocation of caring responsibilities. The definition takes account of care as an attitude (caring of) as well as laborious work (caring for).

Narrative

12 and 14 January 2017 (in Morro Jable) Zumo de naranja

We (Truus and Paul) are on the Spanish island of Fuerteventura for a three week vacation. We bought a paper notebook with sunny beach pictures on its cover in the supermarket in Morro Jable and use that to keep track of what we talk about. We walk down the beach to the old village centre each day and sip a fresh zumo de naranja natural. We talk about escaping from the illnesses and about how that touches our relationship.

P: As your "informal caregiver" in times of illness I worry about you. I wonder if you are safe "on my watch" since I have no medical training whatsoever.

T: For me this is hard to accept. Not that one spouse looks after the other, because that is what love is all about. That is at the core of being human, to want to care for others, especially your lover. I do have a problem with only receiving care because that creates an imbalance. The romance, intimacy and passion get less.

I feel we need to find little things to keep that going. I remember being in hospital on our 6th wedding anniversary. From the hospital bed and without the ease of present day smart-phones, I went to great length to organise flowers to be delivered to you at home. Your reaction "Oh, that is nice, how did you do that […]?" showed you did recognise the effort. What you did not get is that it meant more to me: me being mindful of our joint love at the wedding day and being not only the ill person in the hospital bed absorbed by pain and grief.

P: Ok, I am not much of a romantic person. Not if it is about flowers anyway. I do feel the importance of holding on to the mutual need to care for one another. That shows from my side when I cook for you even when you have no appetite and from your side when you cook for me as soon as you are a bit recovered. Moreover, I think it is important to see the illnesses as a common enemy. We live, eat and always sleep together. We walk the path of life together. Where you can't proceed because you are ill, I take up the informal care activities. We both have a bad nights sleep when you are coughing all the time, suffer pain from pleurisy or have high fever. We share the suffering. Intimacy and togetherness carry us through […].

T: For me it is about my role as spouse versus yours as care provider, hence about equality, caring for spouse and children versus self-care, and sharing the suffering, pity and expectations.

P: For me it is about fear of losing you as my mate in life.

T: Eh […]?

P: It is the government causing extra obstacles between us and our MD (Medical doctor). You cant get a Dutch MD to do a house call. So, several times I had to shortcut the unresponsive MD "gate keeper" system and simply drop you at the Emergency Department of the hospital in the next town. Every single time you were first checked for pulmonary embolism, a dangerous condition. Although this justified my actions I felt more responsibility resting on my shoulders than I think is safe.

T: As a consequence of all this I wait longer before I see a doctor with any complaints, I suffer more pain and I am ill longer because of this.

P: I do not feel confident to deal with medical things in your multi-morbid illness condition because I know I am not qualified. Experience has shown I need to do it anyhow though. When you are ill, high fever, breathing problems, in pain and all, self-management stops and I step up and act because I want to protect you.

T: When I get more ill, you get more worried. I understand that and like it: someone that cares and shares the suffering with me. My hesitation to take action, like seeing the MD, is often because I don't like to get into the medical circuit yet again, not be confronted again with all that is wrong in my body.

20, 22 and 23 January 2017 (in Morro Jable) good friends

We are spending the second week in the sunshine with good friends. They rented an apartment close to ours in Palm Garden and we spend part of the time together on the things tourists do. We visit the remote and unspoiled village Pozo Negro. Here is one cafÕ serving meals with fresh locally caught fish. Later, back on our own balcony, we explore what was hard to get in our relationship and careers because of the many health issues.

P: When we started with our marriage, a long time ago, we wanted to achieve things in life on basis of equality.

T: What do you mean, equality? You are more taking care of me and I cannot reciprocate, I owe you!

I want to take care of you and our family too, and matter to all of you. I found it hard to let self-care and acceptance of informal care prevail over caring for others. I love to care for others very much. Being cared for doesn't feel equal at all, like the couple of times we had to cancel your birthday party because I had to be in bed or even in the hospital.

P: As I see it, that does not affect our passion, intimacy, connection or determination at all. My ideal right from the start was to find ways to grow and develop ourselves together. I guess we kept finding new ways to overcome the health obstacles and kept going. I admire your strength and perseverance. I do feel equal in the sense that we each fight a different battle in the same war.

T: You are more equal than I am […].

P: You lost a major part of your possibilities but I lost part of my possibilities too.

T: How do you mean, possibilities?

P: One of the effects of the illnesses has been our career bending. You lost your job completely. I rejected several very interesting job offers abroad. Had I accepted we would most likely have become rich, but would perhaps no longer be happily married. There were a couple of reasons not to go that way, the most important one was that I care for you. I accepted jobs allowing me to be closer to home more often and I even worked less than full time for years.

T: Aren't a love relationship and having kids always a constraint to a such a career?

P: Well, not really. You easily talk about a million or more when comparing both your "lost" income due to illness and mine due to career bending together over the last 20 years. During our retirement years there is probably another million or so "lost" income as well. Looking back, your bad health also limited the number of children we could have to just two!

24 January 2017 (At the airport in Puerto del Rosario) couch surfing

Our friends leave again and we follow them to the airport to pick up our daughter, arriving with the same plane they will take to go home. Our daughter will be couch-surfing at our apartment for a week. Waiting for her at the airport, we discuss the extent to which we feel in control.

P: Your getting ill often appears to coincide with low temperatures and high humidity, typical for Dutch winter time. Then, exacerbations of the asthma occur more frequently. In February 2011 we booked a five star holiday in the south of Spain, in Nerja, in an attempt to get away from this threat. The first two days all seemed fine but then a pulmonary inflammation struck and you were taken to the nearest hospital, a small medical outpost in Nerja, Spain.

T: My cherished secret dream of hope fell apart. I can not, never ever, escape the burden of the illnesses. I can not hide from the danger of being ill. Moreover, I had hoped to regain some courage. It slowly deteriorates as time goes by.

P: I felt an overwhelming loss of control. The medical treatment was excellent but of course our holiday was over.

T: Well, we do cope with it. We take a few short holidays each year. A luxury we are fortunate to be able to afford. Sometimes we need to cancel at the very last moment. We told others about going about 3 out of 5 times. We also convinced our selves by repeating that "mantra" […] for me it worked that way.

P: Some of this affects our relation too. We cope with the strange mood swings caused by prednisolon and the negative side effects of strong antibiotics on your appetite. Both of these make it attractive to stop taking the medication and therefore hold a risk of non-compliance with treatment of the illnesses.

T: I know, it changes my behaviour and I hate that, yet another thing I have to fight against. This medicine has a big impact on us as a couple. It makes me irritable and short-fused. I cannot stand your presence very well, I am grumpy and get too little sleep. Touching each other, a kiss, a caring gesture, everything feels unpleasant and you are starting to hold back, even in our conversations. The crazy thing is that I notice this but at the sametime cannot control it. Something uncontrolled, rushed, unrestrained comes over me […]. This makes me stop taking the medication too soon in spite of all the consequences such as prolonged relapses of the lung disease.

25 and 26 January 2017 (In Morro Jable) two coffees

`The sun is shining brighter every day. These weeks are making us zen says our daughter. She goes walkabout (=shopping) while we walk the beach, heading downtown. We are having coffee: a cortado and an americano. We talk about expectations.`

P: You remember that holiday in France in 2009?

T: Yes, that was when that new anti-leukotriene medicine for preventing lung inflammations became available. A very promising drug for treatment of asthma exacerbations. Together with our MD, I decided to do an experiment by starting to use this medicine, trying to stop the continuous relapses of pneumonia with it.

P: Yes I remember it went very well the first week or so. You felt better so we took the car and went on holidays near Sètes in the South of France.

T: I enjoyed that very much. We were the same lovers couple as we used to be, walking hand in hand on the beach and having a drink in the sun! Romance all around us, I felt very happy. This was good, we needed it, don't you think?

P: Yes, sure. But a few days later a strange haemorrhage area appeared on your abdomen for no reason whatsoever.

T: Yes, that scared the hell out of me, I was bleeding inside!

P: So we went to see a French MD, he found out that it was a side effect of the new medicine and advised you to stop immediately. I guess this experiment was life threatening! What if that bleeding would have started somewhere else, like in your brain?

T: I remember the ideas we had just before we got married: about our future, our expectations and ideals. Now I see our love relationship as the addition of many things such as intimacy, wanting to be together, physical attraction, passion and our bond, also wanting to stay together in the future.

P: Although I do not complain often about my own small physical discomforts I like it very much that you notice those. That I can lie down on the couch with a less impressive health problem and you give me a cup of tea. Or think of something for me to do when I get bored. You look after me very well.

10 February 2017 (at home) back and ill on the couch

`A few days after our return from Fuerteventura, Truus could attend only part of the European Congress of Qualitative Inquiry ECQI 2017, held at the Catholic`

University Leuven, Belgium. Truus presented two narrative studies but then became ill and had to leave. Back home, ill on the couch, but safe and comfortable, we remember other sudden twists of our path.

> T: The illnesses began tearing down the idea that we are in control of our own lives.
>
> P: I never forget that "Russian roulette" in a hospital where you were admitted in a hospital room of four. The MD went round and you were last. You were the only one that would probably not die soon.
>
> T: I remember we had just moved to our next house and with two young children and part of the boxes not yet unpacked. I was ill all the time and you were working long days, life was pretty miserable.
>
> P: As a young man I had no clue what to do. What my role should be. I only knew how to work hard, help you and earn enough money to pay the rent and buy food. How could I ever manage two young children and a wife being ill most of the time? Panic, that is what I felt.
>
> T: I went through three major surgeries within only 5 years. In hindsight it was like a roller coaster. I hardly recovered before the next one came. I was all fear and was just in survival mode, not feeling anything but just kept going!
>
> P: I have never been more scared than around the birth of our second child. It came close to losing both you and our new-born daughter. Your health has been a mess since then.
>
> T: I think about the day I was having difficulties with one eye and went out to get new spectacles.
>
> P: Yes, then after checking your eyes, the optometrist immediately arranged for consultation at an ophthalmologist who in turn immediately called the hospital to arrange a scanning test. We went there together. About mid-day we heard the diagnosis: cancer in your right eye! Stunned as we were, a doctor told us there was a 50% survival rate within the coming year and you were sent to yet another hospital for radioactive implant treatment the day after!
>
> T: Yes, that felt like if it was not about me at all! It was some sort of bubble. I felt my health was getting completely out of hand.

Reflection

The second part of the study is an analysis and reflection on the narrative. The first step was to identify turning points, as these are changes and new insights which the couple felt were important in their lives. The illnesses themselves are not particularly relevant, but their effects are. All of these relate to one or more of three aspects: equality and mutual caring, human flourishing and love, and the troublesome self-management of the illnesses. We therefore interpret these three aspects to assign meaning to the narrative.

Equality and mutual caring

The couple experienced a switch of roles from equal partners to informal caregiver and chronically ill patient. This created a feeling of inequality in one of them because of the inability to reciprocate the care informally provided by the spouse (flowers story). This created an imbalance in their relationship. The couple, and especially the ill female partner, felt this was a threat to the value of equality in their relationship. She also felt the fundamental human need to care for others, that is, spouse, children, family, and friends, could not fully be realised. Furthermore, equality was seen somewhat differently by each of the partners. For Truus, losing her job widened inequalities (Hankivsky, 2012), she lost her financial autonomy and became dependent on her husband. In the end, however, her husband also suffered from income loss because of his informal caring activities.

Another complexity reflected in the story is that the couple had to deal with not being able to live up to societal norms on autonomy as self-determination and gender norms on the wife as the one doing the caring work. This created feelings of discomfort, distress, shame, and guilt (Brown, 2012). In the context of experienced inequality and not being able to live up to societal gender norms, it is remarkable that the couple developed a notion of mutual caring over time. Initially, Truus considered herself as a care receiver. Patients are framed as passive: dependent on others, and receiving not giving care. As a result, it was not easy to establish a new balance in the relationship. Both partners needed to learn to appreciate small gestures and attentions as symbols of care. Care ethicists have pointed out that all human beings are both care givers and receivers, stressing the interdependence and mutuality of our relations. This notion of mutuality seems much more adequate to understand the relationship of the couple, and caring work more in general (cup of tea story). Care ethics also emphasises that vulnerability is not something we should get rid of, but something we share as human beings (Heijst, 2005). Yet, there is also the immediate urgent biophysical need that puts someone like Truus in a position of dependence. So, from an ethics of care perspective, there is both equality and symmetry in the caring relation, considering that we are all vulnerable on a fundamental existential level, as well as inequality and asymmetry. This duality creates a tension visible in the story of the couple.

The couple has found a way to deal with duality and to balance the asymmetry in their relationship. What characterises the couple's narrative is the mutual unconditional acceptance of each other (Eisler, 1996) in their relationship, and their mutual caring. This not only included "caring for" in terms of laborious work and effort, but also "caring about" which refers to an attitude that is being attentive to the others' needs (Tronto, 1993). Paul's concerns were a response to the vulnerability of Truus. His attentiveness became an important virtue in the relationship. We notice that Paul is not only openly expressing feelings of unrest and insecurity, but also anger (lost income story). Considering these feelings and emotions is very important from the perspective of care ethics (Zembylas *et al.*, 2014; Ellis, 1995).

Human flourishing and love

Love and a love relationship combine different elements such as passion, intimacy, connection (Sternberg, 1986) and the wish to care (Bauman, 2003). Like many others, the couple made a promise in their wedding vows "[…] for better, for worse, for richer, for poorer, in sickness and in health, […]" before their relationship was struck by illness (Rolland, 1994). They started off with expectations, dreams, and plans for their future but found themselves constrained by the effects of illnesses (lost income story). Both worried about the other partner not reaching their full potential in life. While this implies a loss, financially and socially, and despite the adverse circumstances, the couple talks about growth (Montgomery *et al.*, 2007). The notion of human flourishing comes to mind, the ultimate goal of care ethics, which the couple also value highly. While they may have lost income and career possibilities, they have found other meaningful activities and values in life. Their story reveals that balancing love and caring in times of illness is about giving time, attention, admiration, trust, privileges, kindness, pleasure and security in life, and about accepting vulnerability and imperfection in all of those (Botton, 2016). From a care ethics perspective, we can see how the couple has learned to live with a tragic dimension in their lives: the pain, loss, and suffering that cannot be fixed or controlled. Their story is a story of love and compassion; that is about enduring and being with the pain of the other, rather than attempting to actively manage or get rid of it (Baart, 2004).

We can see that a so-called "healthy lifestyle" does not actually guarantee good health. The couple seems to be merely coping with the adversities on their path and not being in control (Russian roulette story). The erratic behaviour of the illnesses necessitates various ways to work around its effects. The couple learned slowly how to manage all the manoeuvres required to start and stop everything that they are doing at any time.

They decided to continue having fun in life and accept that things may go wrong every once in a while (the three out of five holidays story; bleeding story). A solid finding from this interaction between love, illness and self-management is that the couple has learned to balance and to navigate as they go, and have acquired coping skills. The couple feel that their bond has become even stronger as they endure, fight and suffer together (Neerja story; eye cancer story).

Self-management

The patient in control symbolises the current mainstream vision on health care adopted in western countries. In the Netherlands, the government stimulates everyone to be full citizens and take control of their own lives. Consequently, the Dutch health care system also expects people with a chronic illness or disability to be autonomous, self-managing and to be individuals "in control". In the current Dutch neoliberal context, this means maximising taking care of oneself, and cost control by reducing professional care and, in general, dismantling the welfare state.

Daily life experiences of the couple underline that self-management is not realistic for everyone. The slowly progressing multi-morbid health condition of Truus and the problematic response to it by the health care system make it hard to self-manage the disease. It is believed that patients should be self-managers, should participate, and thus live up to the norms of autonomy and self-determination. The couple tries to adapt to these norms, but is faced with several structural obstacles. The access to health care is affected by thresholds at the MD. The quality of care is affected by the lack of case management coordination and a non-shared, complex medical file. An MD who is unfamiliar with the case cannot fully absorb the information when accessing it for the first time and, therefore often deals with, e.g. an Asthma exacerbation as a single event (Hynes *et al.*, 2012). The illnesses are worsened by being too complex for self-management, by adverse side effects of medication and by its associated non-compliance with treatment (medical circuit story). Self-management in a situation of multi-morbidity with several chronic illnesses is virtually impossible, since it is simply too complicated and too risky (embolism check story). This leads to chronic sorrow (Ahlstrom, 2007). The couple has experienced this frightening reality every day for a long time.

The difficulties with the norm of self-management cause irritation and friction in the relationship. Non-compliance with the medical treatment is being traded off against an expected negative impact of medication on the love relationship (behaviour change story). The consequence of these causes of non-optimum health care is a higher burden of illness. The couple therefore challenges the current Dutch health discourse as characterised by its self-management paradigm. Self-management – as laid down in the Chronic Care Model (Huijben, 2011) – requires that a chronic illness patient knows how to handle symptoms, treatment, physical and social consequences and inherent lifestyle adjustments. Not every illness and not every person fit within the concept of self-management, certainly not Truus.

There is reason for concern about the patient safety of people with multiple chronic illnesses. For several patient groups, self-management is not even regarded as possible (Heijmans *et al.*, 2010; Rijken *et al.*, 2008). This is where the current health system discourse is flawed in general (Machielse, 2015; Ursum *et al.*, 2011) as well as specifically for COPD (Adams *et al.*, 2007; Hynes *et al.*, 2012) and for multi-morbid chronic diseases (Ursum *et al.*, 2011).

Caring practices may be merely superficial and sentimental, if they do not challenge inequalities (Zembylas *et al.*, 2014). This is precisely the point Truus makes again and again, that there is an inequality and unfairness in her situation. Not in being ill, and being cared for, this is something that she has accepted as bad luck, and part of life. Her criticism is targeted at the normalisation of the able bodied, which leads to a situation where she is marginalised. Not only the illnesses constitute an "unwelcome interloper"

(Weingarten, 2013), but the couple also feels that the government is interloping in their love relationship, because its rulings generate friction, anxiety and insecure and unsafe feelings and so increase the burden of the illnesses (behaviour change story).

Care ethics challenges the dominant value of autonomy and self-determination as reflected in self-management (Abma *et al.*, 2012). We can see that Truus is flourishing due to the care and support of her husband. His support enables her to develop herself and have a meaningful life, but the couple is critical of the conditions needed to support each other. Nowadays, caring responsibilities are allocated to the individual, and risks are individualised. The story shows that this distribution of caring responsibilities does not take into account conditions of multiple chronic diseases, and has uneven and unfair consequences. Current caring arrangements establish structural inequalities because taken-for-granted societal and gender norms, such as individualism and ableism.

Conclusion

We conclude from this co-constructed auto-ethnography that the couple of whom one partner is chronically ill has learned to cope, and learned to balance. They found flexibility in the face of adversity and developed a new balance through mutual caring thereby redefining societal gender and patient norms. Their bond strengthened over time. They have kept their compassion and love alive over 42 years, enduring the tragic dimension in their lives and accepting vulnerability, which can be considered inspiring in times where human bonds are more frail than ever. The story witnesses that the current health discourse depicts patients as autonomous, in control and self-managing but ignores the impossibility of this task in multi-morbid chronic illness cases: a troubling phenomenon. In times of illness, the health system's poor response to multi-morbidity is a major concern for both the patient and the caregiver. The couple can only cope with but not accept this unjust distribution of caring responsibilities. The main insight from this study would be that of the fundamental vulnerability of every human as identified in care ethics: the need to care for each other and being able to care for oneself are two inseparable basic human needs.

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