

CARE FOR CARE

20.10.2022 - HUIS PERREKES

Geerdts Magiels

This is a personal report on the VUB Crosstalks workshop held as part of the long-running 'Shake the Disease' project, which maintains an open dialogue on the future of health, healthcare and well-being for everyone. The workshop took place on 20 October 2022 in Huis Perrekes in Oosterlo. **Benedicte De Koker**, coordinator of the 360° Care and Welfare research centre, guided everything in the right direction. **Mieke Van Gramberen**, a researcher into new forms of organizing and director of the Tabor group, which brings together some sixty socially committed organizations, is looking for levers to increase the well-being of carers and patients in organizations. **Christophe Aussems**, artistic director of Het Nieuwstedelijk (city theatre of Genk, Hasselt and Leuven), talked about making and dealing with mistakes in healthcare, based on his personal story and his performance Hybris. **Lara Vesentini**, a researcher into intimate feelings in psycho-therapeutic relationships and affiliated to the VUB research group MENT (Mental Health & Wellbeing), explored the limits of intimacy in the healthcare context. These stories were supplemented by comments from **Roel van Giel**, a general practitioner in Kalmthout and chairman of Domus Medica, and **Anneleen de Bonte**, who after ten years as a GP in now working with Blender (innovation by all for all), after which a group-wide discussion focused on the subject of caring care for all.

Care is in the genes

Man is a social animal, and an unmistakable aspect of man's social life is that people care for each other. The evolutionary evidence for this can be found in paleo-anthropological finds. Australian Lorna Tilley specializes in the 'bio-archaeology of care', collecting archaeological evidence that demonstrates that people in the past spent a great deal of time and scarce resources caring for those in need. Caring for the weak and sick is a behaviour that dates back at least to Neanderthal

man. From the very beginning of mankind, there is evidence that people who were unable to function were helped and cared for. There is now ample evidence that prehistoric injured or disabled people were cared for by members of their social groups, like the man who died more than 45,000 years ago, who was missing his forearm and hand, walked with a limp and was partially blind and deaf but alive well into his 40s, for which the daily help of others must have been indispensable.¹

¹ In this connection, a statement by Margaret Mead is often quoted that the archaeological find indicating the beginning of human civilization would be a broken and healed femur. However, this statement is apocryphal and has no scientific evidence or source.

So caring is in our genes, we can't help it, so to speak, it's part of our culture. Caregivers and those cared for, as Mieke Van Gramberen puts it, are members of the same tribe. It is humanity that binds us. She approvingly quotes *Zorg* by Lynn Berger: "The home nurse said that she sometimes keeps her coat on when she enters someone's house, knowing she can only stay for a while. Efficient but not so nice: 'do take off your coat', say the people she cares for, 'it's so unfriendly [to keep it on]'. That may be where the shoe rubs. Care has now become a profession, institutionalized in training courses, organizations and structures. What do the findings of the bio-archaeologists of contemporary care tell us about the quality of that care, both the quality of the work of the carers and the quality of the care provided for dependent people?"

Van Grambergen knows from experience at De Goestingarchitecten that organizations can be set up in such a way that people enjoy coming to work. In the TUBBE houses, facility residents are given a voice to enable the care to be tailored to their needs. Because residents and employees have the same voice, the former can live with pleasure and the latter can work with pleasure. Her hypothesis is that the better the quality of care providers' environments, the better the care provision.

Research has shown that meaningful, effective work rests on three pillars: autonomy, involvement and competence. A survey by the Stichting Innovatie en Arbeid (Foundation Innovation and Work) shows that the quality of work in healthcare is generally good. But that the workload and the emotional burden are experienced as (too) high. A discrepancy lurks here, as emotional involvement is essential in care. In the aftermath of the covid epidemic, however, a negative trend is emerging, reinforced by the large drop-out, as a result of which even minimum staffing requirements are not met and the pressure on those still at the bedside is further increasing. There is a chronic lack of hands, heads and hearts on the beds. Among other things, competence came under pressure (everything was new at the start of the pandemic, there was a lot of uncertainty, on top of a lack of resources). And it was difficult to maintain a balance between distance and involvement. The art of getting (not too) close was put to the test.

With the covid crisis, organizations were also confronted with the urgent duty to take care of their employees. The quality of work is not a question of individual resilience, but is embedded in the structure and culture of an organization. The core of that corporate culture lies in the vision. For this reason, Huis Perrekes, where the workshop took place, has opted to be an ordinary house in the street, without sign or

banners. Residents do not live in their own rooms (which serve for sleeping) but in the communal living room as they do at home. In addition, leadership (empathetic, caring, coaching...) and team building (with the strength and/or the ability to direct and protect oneself) are part of an organization's culture. In many hospitals these teams fell apart in the first covid waves, which placed additional pressure on people ripped out of their familiar working relationships.

A vision has very practical consequences for how people work (together). In covid days, however, the process, as the bearer of the structure, gained the upper hand in many facilities: medical procedures became a priority and often directed the vision. The organization's macro-structure, such as the small-scale architecture, determines the quality of care and work. Systems also make their mark: how important is the computer? Does it serve to support the work or to be able to control more?

In this way, healthcare is a dynamic playing field in which the human image and ambitions, vision and mission, regulatory requirements and regulatory capacity, technology and humanity, values and processes must be adapted to each other. That balance will never be fixed once and for all, but is constantly shifting according to the expectations of the outside world, the labour market, the carers, those cared for and their families.

Culture and care, culture in care, culture as care

Theatre-maker Christophe Aussems made the culture of care into the starting point of a cultural product about care. In the play *Hybris* he analyses how errors are dealt with in the hospital, in this case the operating theatre.

The germ of his story lies at his birth. As a baby he had a little scapular pinned to him to protect him during the months in which his mother hovered between life and death shortly after his birth. Fortunately, all turned out well, but years later she was told that during the caesarean section there may have been a medical error that had been covered up all those years.

Another starting point was the Jérôme Lemaire documentary *Burning Out*, filmed in a Paris hospital operating theatre. It is a drama about life and death in which the teams of the understaffed operating room can barely keep their heads above water. It raised the question of how it is possible that, in a place where people care for each other, the work itself makes people sick. Aussems was inspired by many conversations

with stakeholders, patients and professionals. The latter go to extremes in hospitals day and night to save lives. But in order to survive that cauldron themselves, they gradually change into line workers in care factories. Surgeons and their crews succumb to the pressure of work and their own failures. This is how a system comes up against its limits.

'Hubris' is ancient Greek for pride. Typically, hubris dazzles and suffocates and is impossible to stop. And you don't see it in yourself. It's a blind spot for both doctors and patients and for society as a whole. With fragments of the performance, Aussems sheds light on this hubris from different perspectives: the hubris the surgeon needs in order to be able to decide, act and cut into a living person. In addition, the negative hubris of the surgeon who thinks he is infallible, as well as the hubris that a victim of a medical error needs in order to go to court to litigate against a surgeon or hospital and their insurance for years. As a sauce on top of this comes the hubris of society that flirts with the limits of its health care. Aussems also notes in passing that a theatre maker who makes a performance out of all this may also be displaying a form of hubris.

His conclusion, as a person and as a director, is that we must learn to say *sorry* when we have hurt someone, even if it was not done intentionally. Errors are inevitable, but the context in which they occur can help a lot. Truck drivers have regulated driving and rest times, while surgeons pride themselves on being able to work day and night without much rest. And when the inevitable 'patient safety incident' or 'accidental healthcare-related harm' occurs, openness and honesty are the very best, if not the only, answers. Experience shows that talking (and listening) prevents long and painful (and unproductive) legal proceedings. *Hybris* is a plea for more talking, from person to person, between doctors and patients.

Intimate boundaries

Care without contact is impossible, and that contact is not only verbal, but also non-verbal and physical. The healthcare professional must be able to handle this intimacy competently, authentically within the care framework, with room for emotional and intimate moments, neither avoiding physical contact nor taking it too far.

Lara Vesentini referred to Hemelaar's definitions (2000) for differentiating between intimacy, eroticism and sexuality. Intimacy is all about mutual trust and warmth. Sexuality is based on gender and lust, while eroticism has more to do with the art of seduction and sexualizing intimate situations.

No sharp line can be drawn between these overlapping aspects of human experience. In addition, everyone can experience touch of any kind differently depending on the situation, context and culture. Misunderstandings arise because these different perceptions are not recognized or are interpreted differently.

People in healthcare are particularly confronted with this ambiguous lack of clarity: having to be human and keeping one's distance at the same time. It is walking a tightrope between keeping a professional distance and therefore being perceived as aloof, and showing humanity, which threatens to undermine professionalism (or the perception of it). That this limit is difficult is shown by the (scarce) figures: 71% of therapists say they are attracted to a client, a quarter fantasize about a romantic or sexual relationship, and 3% start a sexual relationship after therapy. At the same time, therapists say that three-quarters of clients say they are sexually attracted to the therapist or make sexual jokes or comments, and nearly half become sexually aroused.

This is accompanied by shame and confusion, feelings of guilt and, above all, fear of condemnation. The latter leads to taboo and undiscussability. For more than half of those surveyed, this is very difficult, for a minority (4%) impossible to discuss. Nevertheless, a large number do not shy away from the subject: 35% discusses it in inter- or supervision, 23% discusses it with colleagues.

This should not be surprising. Sexuality has always been a difficult subject to discuss. Nowhere do we learn the difference between sexual feelings and sexual behaviour. The less people are able to make this distinction, the more difficult they find it to talk about. Moreover, the more people automatically associate sexual feelings with sexual behaviour, the less it becomes possible to talk about them. This creates a vicious cycle and a self-perpetuating taboo. This taboo is also reinforced because of the prohibition on sexual relations in many countries, of the existence of reporting obligations and other protocols and rules in institutions, and the large amount of (negative) media attention to cases of sexual abuse. The ability to discuss these matters is not facilitated by the fact that study programmes mainly or exclusively look at technical-ethical aspects.

Nevertheless, talking about sexual feelings and associated emotions is essential in order to deal with this whole issue. Talking promotes self-reflection, helps people make better choices and is emotionally supportive: doubts are shared, the lack of discussion and the accompanying isolation can be broken. Talking also helps prevent abuse.

To be able to talk about it, it is essential that this can happen in a safe environment. Managers need to be better trained in order to work proactively and to create that safe atmosphere. (Group) conversations can offer the opportunity to talk about feelings without being judged. In this way, people also know better what to do when sexual feelings arise and where to turn in such a case.

Sustainable care?

Health care is in trouble, everyone agrees on that. To state that things have to change is to walk through an open door. Everyone knows that things have to be different and want them to be, but how to shape these new care models remains a hot topic. Many smaller projects are already under way, such as 'caring neighbourhoods', but implementing them on a large scale is not yet possible. There is also a great need to link formal and informal care. The latter is under great pressure. People take care of a partner or family member until there is no room left in the house or in the agenda. People often give up their work to take care of a loved one but are not recognized for it.

In the formal sector too, the worst is yet to come. As was already reported in previous Crosstalks workshops: the outflow of GPs and dentists is greater than the inflow, at the same time as the need for care is increasing. The urgency for change is increasing and the transition will have to happen faster than a longer time-scale of ten or fifteen years. There isn't much time left. There is good will, but the sector itself offers resistance, because interests and positions of power are being defended. This is also related to the current financing system, which causes doctors and hospitals to fear that they will come off worse. This does not, however, necessarily have to be the case. This is proven by a major transition programme that was set up in Colombia in 2015 by Alex Jadad. Every year, \$500 per person was allocated for health care. The money was managed in one big pot while all stakeholders were involved in how it was used, with the guarantee that no one would lose out financially and any profit would be shared fairly. The project builds a revenue model based on being healthy, not curing. (On our countries, the hospitals would go bankrupt without sick persons to fill the beds.) According to the OECD, this 'Trusted Networks' generates better health parameters than, for example, the Dutch health system, which costs ten times more.

For the umpteenth time it was repeated that in Belgium only two percent of the health care budget goes on prevention,

while that is precisely where the most gain can be made. For the time being, prevention is equivalent to screenings, tests or stop smoking programmes, while healthy living environments and lifestyles remain outside its purview. Prevention must become everyone's business for the sake of good health for all of us. Just as in Huis Perrekes, everyone from the street and surrounding area is involved in the shared concern as to 'what can a good life be at the end of life'. It is essentially a simple story, but it shows, just like the play *Hybris*, that a story can connect and involve everyone where vision texts or policy documents fail.

Between possible and desirable

There are limits to care, especially at the end of life. Based on the hubris that we must continue to treat health problems medically, how long should we keep people in care, even if the therapy no longer offers a cure or improvement? Why do we continue to treat people in situations where we know the outcome will be negative? Choices are already being made in a number of countries, on the basis that medical interventions that no longer serve any useful purpose will no longer be reimbursed. In Norway, as a healthcare provider you have to refund the cost of cancer chemotherapy if the patient dies within three months. Due to our insistence on therapy, we continue to take people to hospital even when it makes no sense. In this way, patients are snatched from home environments in which peace and dignity can be guaranteed, and where relatives and caregivers can still ensure a dignified end.

For that to be possible, death must become an integral part of life. But death is far away these days. In the past, dead people remained in the home in a coffin for a while, so that as a child you became familiar with death. Now death is something that you are often only confronted with at a later age and from a distance, at a funeral or in a funeral home. In this way we have also learned not to talk or think about death. Death is something to be avoided at all costs, while it is in fact part of life. We need to tell the from-birth-to-death story more often. In this way we can as a society dare to make choices and in some cases also dare to say that an intervention or treatment (a prosthesis, a pacemaker above a certain age) is pointless, and opt instead for good care. This care must recognize that as helpers and caretakers we are often powerless. Yet you can do something with that impotence, as a strength in weakness. Or as Bauke Koekoek says in his recent *Helpen is moeilijk* (Helping is difficult): "You can give space to powerlessness be, dare to feel it, just like sadness

and mourning in ordinary life. If you are able to do this, you can, as a carer, carefully move alongside, around or through this powerlessness and still ask or say the things that matter.”

This means that in certain situations and in good consultation with all parties involved, it is better for people to hold each other’s hands than to call in the mobile resuscitation unit. The conversations ahead of such decisions should not be about living as long as possible, but about living as well as possible. As doctors, nurses, informal carers and in residential care centres we must learn to have those conversations in good time. In crisis situations, emotions can run high. Feelings of fear, but also guilt or shame, can gain the upper hand

so that the idea of ‘having to do something’ takes over. In such a case, professional care is the voice that can restore the perspective on quality. This why talking is so important, talking on all levels. In order to feel secure. But also to find the (emotional) support, to give each other confirmation, and appreciation and recognition for the decision we make at such a moment. If you feel yourself alone and isolated in making that difficult decision, it won’t work. When you feel like-mindedness, you are stronger. Then you are not alone, even if you look death in the eye.

Or as someone remarked: if you take out a moment to pay attention to what you need to pay attention to, you can also continue together.