Medicine of the Person
74th International Meeting
07th - 10th August 2024
UK - NORTHAMPTON

Conference ***1***

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08/08/2024

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Continuity of care needed to build a relationship of mutual trust

In order to illustrate the importance of continuity of care I have chosen some accounts taken from my clinical practice, and also from the volunteering I do with people who are gravely ill.

I would like to propose that we address the topic straight away with this **clinical illustration:**

A 55-year-old lady was referred to me by her doctor with incapacitating palpitations. A 24-hour ECG tape demonstrated a supraventricular tachycardia at more than 200 beats per minute which explained her symptoms. When I asked her, the patient said she didn't have any particular concerns. After failure of medical therapy (treatment with medication), I arrange for her to come to hospital for thermal ablation (a percutaneous procedure to interrupt the circuit causing the tachycardia, at that time still a new procedure). After a brief period of improvement, the arrhythmia recurred and the professor of electrophysiology who had done the ablation said to me (meaning it but also with humour) that he didn't want to hear any more about that patient as he didn't know what else to suggest. Some weeks later, she spontaneously confided in me that she is hostage to her oldest son, now adult, who suffers from schizophrenia and that her younger son committed suicide at the age of 18, exhausted by his older brother harassing him. She admitted her shame and her feeling of being to blame for not having known how to protect her younger son. At the following consultation, her rhythm disturbances have all but disappeared, an improvement which will turn out to persist long term. It needed many months for this person to feel enough confidence to be able to confess how much she was suffering. It is testimony to the importance of continuity of care.

1. What continuity of care?

On the one hand there is continuity of care in the organisation, in terms of access to care and transmission of information, and on the other a continuity of care in the human relationship with the patient. The two are indispensable, particularly in psychiatry, paediatrics, oncology, end of life care, linking two different episodes of care (hospitalisation, transfers, return home) and in all chronic disease.

- **A. Practical continuity of care in the organisation of therapy.**

Continuity of care is both longitudinal (in time) and horizontal (in space), without interruption and in a coordinated fashion: there needs to be a solution that works 24 hours a day, 7 days a week for the patient and their relatives. And when it comes to coordinating transmission of information: the medical situation with the results of tests, the results of clinical examinations, the treatments being undertaken, in a way that avoids things being forgotten, duplication of tests, medical interactions and approaches which are inadequate in relation to the patient's way of thinking. Although the

principle is simple, the emergency department often consists of 'Save those who you can', where it would have been enough to plan ahead in a more realistic fashion for 'who should do what'.

- **B. Relational continuity of care**

Human relationship is central to the therapeutic relationship, it is an encounter in which the doctor and the patient interact united by a need for trust in each other. The patient not only has a need to be heard, but also needs to be understood; (Paul Tournier (1) tells us 'Feeling oneself understood, that is what helps us to live,' and he adds: 'not just understood with the mind, but also with the heart.' Trusting enough to dare to be authentic. As for the doctor, they must have confidence in their patient, in their resources and in their capacity to engage with the care process.

That trust needs time to build up, therefore it needs continuity of care.

2. Good use of time: continuity of care.

The doctor needs to know not only the patient's medical situation, but also their family, professional, socio-economic situation, the story of their life. What does the patient know about their illness, what is their opinion about it? What is really important for them, how is their illness affecting the way they live? Do they have any cognitive impairment, have they drafted an Advance care planning document, have they given power of attorney for health to anyone?

Relatives form an integral part of the life of the patient. It is the duty of doctors to make sure that the patient's relatives are able to assume the role of carer and to accompany them as well and put them in touch with any help available to them. There again, continuity of care is essential.

3. The advantages of continuity of care

The advantages of continuity of care are considerable for the patient: numerous studies (2) have shown better results of treatment, better adherence to therapy, better quality of life, less anxiety, reduction in risks of errors, emergency admission to hospital, length of stay in hospital and costs, reduction in all-cause mortality, better preventive medicine and rehabilitation, better consideration of mental health.

For the carers, the benefits of continuity of care are no less: a commitment in terms of responsibility but also a humanitarian commitment, all of which contribute to motivation and satisfaction, with the result that there is less professional burn-out caused by loss of purpose. In short, it is a win-win situation. It is all the more important in that the younger generations of carers (doctors and nurses) are complaining about the loss of humanity in their work, in spite of it being the most important reason for them becoming carers in the first place. They leave their profession without a backward glance, as soon as they have finished their training. **It is one of the factors contributing to the severe shortage of personnel in the caring professions world-wide.**

Continuity of care leads to a broader knowledge about the patient and to a quality of dialogue between doctor and patient, which allows the doctor to personalise their approach to treatment in complex situations, sometimes even to have the courage to abstain from treatment or conversely to take risks agreed with the patient. It underpins the problem of informed patient consent. Even if we admit that the information has been well communicated, how can we know if the patient has really understood in order to give their consent to a treatment or to an invasive investigation. We would have to get the patient to explain it back to us to make sure.

There again, continuity in relationship is an essential element in building trust and having a good quality of dialogue if we don't just want to function in an authoritarian or paternalistic manner.

The desire for continuity isn't only found in the medical profession, relationship in care is a mutually agreed cooperation, the patient could also decide to change their doctor. Studies have even shown that the quality of welcome by the receptionist (on the telephone or in the consulting room) played a not negligible role in the effects of continuity of care

Continuity of care is a public health factor, as much humanly as medically or economically. The absence of continuity of care leads to a waste of time, staff energy and money.

4. **Continuity of care is not a guarantee of quality.**

Continuity of care is built on the foundation of duration and quality of the therapeutic relationship.

The carer's investment needs to go beyond their expertise to allow their soft skills to emerge. Doing no more than one's duty is not enough. That remark applies also to teaching professions, social workers, to the relationship between parents and children etc. These soft skills don't take any time chronologically but involve an investment of self and require one to create the inner space for a real encounter.

In order for continuity of care to bear fruit, it must be inhabited by love.

5. **Quality of the therapeutic relationship: the spiritual dimension**

Erich Fromm (3) (1900-1980), sociologist and psychoanalyst, tells us that love is the only sane and satisfying response to the problems of human existence such as solitude and our finite existence, and that the only way to face them is to take care of each other. Love gives purpose to life, from the moment where the child discovers that he can give love, right until the last breath when love remains the last possible exchange, to give, to receive, given for free, witness to the fact that one is still alive.

And here is an illustration: **a clinical case history**

A 54-year-old man had been operated on for a very aggressive brain tumour a few months earlier. He is divorced, has an adult daughter with whom he is no longer in contact, but he has a sister with whom he is very close who has put her life on hold to be by his side while there is still time. She asks a charity to provide her brother with a companion. He doesn't see much point in this companion, he is passionate about weapons (there are many attached to his walls) and by ice hockey. I wonder what we are going to talk about during these encounters lasting a half day per week. At the end of our first meeting, he tells me that he feels we are going to get on well, which turns out to be the case. We will end up seeing each other about ten times at his home, he makes a lot of effort to stay independent. But he deteriorates rapidly, he is hospitalized in a hospice 40km from his home. He can't walk any more, can't see any more. During one visit, I enter his room, greet him and tell him my name since he can't see any more. He is very surprised, thinks a bit and asks me: 'but you came for me?' He is very touched that someone would make the journey just for him. Shortly afterwards, he can't talk any more, but he understands what people are saying to him. His sister and I help him to eat. We ask him if it tastes good. He replies by opening wide his mouth for the next spoonful. It is an overwhelming spiritual experience because of the simplicity of the communication and its authenticity. He dies a few days later.

For Emmanuel Levinas (4) (1905-1995), a philosopher who was Paul Tournier's contemporary, real encounter takes on the dimension of an overwhelming event which makes us pass from 'being for oneself' to 'being for the other'. It is the other who gives birth in us to a movement to go beyond ourselves, a concern for the other, a responsibility, to accede to a more radical transcendence, a

doorway to that with is infinitely beyond us. We spontaneously feel the existence of the inner being of the other, and also their uniqueness. Emmanuel Levinas talks of the enigma of otherness with its unpredictability, its vulnerability. The unconditional welcome of the other will allow him to accept himself. His face imposes on us a renunciation of all forms of power.

Last year you had the privilege of hearing Professor Jan Bonhoeffer, paediatrician at Bâle, who underlines the potential for healing which is generated by a good quality interaction between the carer and the patients, which he calls Heart Based Medicine, in parallel with Evidence Based Medicine. It is in fact a question of love in this relationship, an instinctive love, like that of a mother for her sick child, a love which we are all agents of. He says, we don't need to do anything, it is our natural state if we are inhabited by humility and an open spirit. And that love links us together.

Our friend Anne-Lyse Chabert insisted last year on the importance of the long-term in the relationship between carer and cared-for, particularly in chronic disease, she even talks of fellow team members, of working together, of two people sharing their vulnerabilities together.

François Rosselet, chaplain in a hospice, opened the meeting of Médicine de la Personne in 2017. He re-affirmed 'it is the relationship which heals', borrowed from the contemporary psychiatrist Irvin Yalom (4). François Rosselet talks to us of our vision being opened to see the person in all their dimensions – bio-psycho-socio-spiritual, of the unique character of that encounter. But also, of allowing ourselves to be indwelt by someone greater than us, keeping the heart's enthusiasm, that momentum which comes from afar and carries us further.

That humanitarian vision of the therapeutic relationship is nonetheless not usual in our modern medicine which keeps doctors' legacy on a pedestal, in its scientific prison (in Paul Tournier's words), one could call it arrogant and above all always in a hurry.

We need to go back to Eugen Bleuler (6) (1857-1939), a Swiss psychiatrist, to see humanitarian behaviour appear. He was responsible for Burghölzli Hospital at Zurich which was ahead of its time and where Jung worked early in his career. The patients were treated with a great humanity, considered as separate whole beings whatever their state, who deserved the respect and the devotion of all the medical personnel who, by the way, had to sleep at the hospital to be available 24/7. Eugen Bleuler thought that if the doctor managed to build a 'human' relationship with the patient, they would do better, and even be healed.

Carl Rogers (7) (1902-1987), a contemporary of Paul Tournier would deepen that quality of being, that state of therapeutic presence, the necessary precondition for the three other pillars of the therapeutic relationship, which are empathy, congruence and the unconditional positive regard for the other person. The therapeutic presence sees itself in the present moment and asks that the person empties themselves of knowledge, of expectations, to allow intuition and above all the appreciation of the uniqueness of their client. The therapeutic presence is an experience both physical, emotional and cognitive. In order to arrive there, one must prepare for these encounters in everyday life, by making oneself available to self, and to the other. It's about seeing each person as a being worthy of respect and consideration, to recognise the other person's full worth as a human being, looking on them with warmth. Carl Rogers thinks that we all have within ourselves the capacity to realise our potential and that the trust between two people can only become established through authenticity.

Paul Tournier (1898-1986) draws our attention to the fact that the degree to which the patient confides in us depends on our availability. He describes the sacred aspect of the encounter using the term 'flash', borrowed from Balint to describe the authentic encounter between doctor and patient, lived through reciprocity. It is a communion, an unforgettable spiritual experience. From

there, the doctor can help his patient to realise his reaction to events in his life, a reaction which can be productive or destructive. The patient is responsible for his self-fulfilment through a harmonious relationship with himself, with others, with nature, with God. Everything which contributes to giving him an ongoing sense of being alive. Paul Tournier says that even more than cure, patients need to learn to live with their illness.

But the practice of medicine of the person does not require continuity of care. Each medical intervention should be able to take inspiration from it, even in one sole encounter.

Maurice Bellet (8) (1923-2018), priest and French writer, tells us that listening is benevolent hospitality, friendship, situated in respect and non-judgement, but also acceptance of one's impotence and reconciliation with oneself. It is listening to the patient as a whole (with one's third ear), to their voice, their face, the way they look, listening with one's mind, but also with one's heart and one's body. One forgets all knowledge and one renounces any power. And if the patient is seeking to be heard, it is in order to finally be able to hear themselves. Maurice Bellet calls on 'divine gentleness', which is like a gentle and maternal hand, a gaze similar to that of a mother on her child, an attentive ear which doesn't judge, a smile. The divine gentleness is as vital as breathing, eating and sleeping, it is that which communes with the necessary essential health, that which the illness hasn't affected. It isn't given because of duty, but by choice. It allows mankind to find inner resources to sustain himself in the sometimes-terrible journey of his life.

For Cynthia Fleury (9) (1974), philosopher and psychoanalyst, the first duty of the doctor is to make the patient capable of looking after themselves. That which is shared by all human beings is vulnerability. But that vulnerability is not only a negative, if one takes care, it can become a strength by allowing he patient to develop a quality of being present in the world, whatever their state, rather than holding on to an illusory hope that they will return to their previous state. In other words, to get better from the very idea of getting better, an argument also developed by the contemporary Swiss philosopher Alexandre Jollien, who suffers from cerebral palsy.

Marie de Hennezel (10) (1946), a French psychologist and writer, dares to achieve that intimacy by letting fall the defensive barriers to allow the fertile potential of the intimate encounter, a grace. To open oneself to one's own vulnerability in order to have an authentic encounter with the whole person, not just their sick body, changes the way one sees them, to see the beauty of the person, over and above their decline.

Clinical case: I would like to share this story with you; a 75-year-old Algerian lady recently arrived in Switzerland to get treatment for breast cancer. She is living with her daughter who has settled in Switzerland with her family who has asked for her to have a volunteer companion. She is a cultivated woman, a practising Moslem who had to leave behind in Algeria an adult son who suffers from a serious psychiatric illness, and who she looked after until her illness. We go for a walk, we have a coffee together, she recalls happy memories of the community of women in Algeria who share household chores. We talk of religion, sometimes we pray together each in her tradition. We are rapidly linked by strong ties, but one day she is unable to cut her pastry. She is admitted to hospital, she is told the diagnosis, cerebral metastases. She undergoes a period of confusion and agitation where she relives the Algerian war, tells me to get on the floor because people are firing guns everywhere. Thankfully she is transferred to a psychiatric hospital which is able to control that agitation while allowing her to continue to maintain a good level of communication with her relatives. One day, she confides in me that she is afraid of dying, and shortly afterwards, while

holding my hand, she says to me, pleasantly surprised, 'They are all there, my mother, my sister, my father', deceased a long time ago, and she returns to herself, at peace. She dies a few days later. Overwhelming moments of closeness.

The therapeutic relationship engages the doctor in a quality of presence which goes far beyond their white coat. It is a difficult and demanding art which starts with the hard work (tr. literally 'uphill') during the consultation of the personal work required to accept oneself and others, to accept that one is finite, one's vulnerability, one's limits. Making available that inner space and listening with care.

But as we go on, it can also weigh on us, overtake us to point of **altering our therapeutic relationship,** and it is there that we need to watch out for the dangers of continuity of care.

6. The risks of continuity of care

The risks of continuity of care are multiple and insidious. Firstly, the risk of **doing the same thing out of habit, of taking the person for granted,** faced with a patient who we think we know too well and who may not be able to make themselves heard when talking about a symptom which hasn't previously caused concern. It is down to the doctor to inform the patient, to make them realise their responsibility when it comes to asking for care.

Danger also lies in the exhaustion **of powerlessness,** and let us not forget that the patient is vulnerable, perhaps because of anger or guilt, or in distress spiritually, sometimes incapable of receiving the love that we are able to give them. That can engender suffering for the doctor, a narcissistic injury, born of the frustration resulting from failure of their omnipotence and also of confrontation of their own limits with several possible reactions: withdrawal and failure to make themselves available, fleeing from further encounter, abandonment or on the contrary a hyperactivity in the form of a frenzied treatment, aggression, even malpractice. These behaviours add to the suffering of the patient: a feeling of solitude, abandon, humiliation and above all lack of understanding. Recognised, accepted, revisited, the suffering of powerlessness can have a meaning, a sharing of our communal vulnerability.

Clinical case: a 68-year-old man consults me because of extreme exhaustion. He doesn't have a cardiomyopathy, but he is morbidly obese. I suspect he is suffering from sleep apnoea. Polysomnography (monitoring while asleep) confirms severe sleep apnoea, but in spite of detailed information about the advantages of treatment for his fatigue and the risks of doing nothing, the patient refuses categorically to use CPAP at night (a device which delivers air under pressure to avoid the airways closing down during the apnoea's). The patient continues to complain of symptoms, distressed and confrontational, in spite of relatively good consultations. This patient is one of those rare patients who annoy me when I see their name on my clinic list, as I feel powerless, and I know that the consultation will be hard-work and frustrating. Around that time, I was taking part in training to stop centring on self and to let go by practising Eutony (a practice based on being aware of one's body) and I was having sessions with psychiatrists, to learn to allow intuition to emerge. On that day, I decided to apply this method, having no idea of what would happen during the consultation and without any expectations. I was very surprised by how much I enjoyed the consultation, a pleasure shared by the patient, and by the ideas that emerged spontaneously during our session. The situation hasn't significantly changed, but that experience will allow us to mutually accept each other better and to have a better relationship in the long term.

Another risk of continuity of care is **empathic suffering:** by projection, having forgotten that what the patient feels is not the same as what is felt by the person treating them. If the therapist remains connected to their own spiritual life, they will be less prone to emotional exhaustion.

With continuity of care, there is also the danger of the doctor **influencing** the patient, of the patient becoming **dependant** on the doctor, whether this is conscious or not.

Another danger of continuity of care, is staying in a **diagnostic rut,** staying attached to a single approach, where it would be better to bring a new approach to the situation; questioning the diagnosis, the therapeutic options.

That is why, it's a matter of returning to the patient's requests, helping them to express their needs in order to be able to bring an answer tailored to what they are asking. To know also how to give up on cure, but to search with the patient for the path which suits them, finding a way of accessing their inner and external resources.

It can also make you ask yourself why you chose this profession.

7. Conclusions

- **Continuity of care is of fundamental value in caring for someone, as much in the practical aspects of delivering care as in the relationship with the patient.**
- **The benefits of continuity of care are considerable for the patient and for the doctor, it is a really important issue for public health, humanly speaking, medically and economically.**
- **Continuity of care is not enough on its own. It is the quality of the therapeutic relationship which determines the quality of care.**
- **Continuity of care is built on the quality of the therapeutic relationship.**
- **Continuity of care includes risks which can result in suffering on both sides.**

8. Proposals:

- **Establish training** for students and doctors on **the importance of the quality of human relationships, as well as preparing them personally** to confront their personal limits, what they are capable of and an awareness of their own needs.
- **Make space for the patient to express themselves** allowing more time than a single consultation, when we know that the mean length of free expression before being interrupted is less than a minute. Béatrice Beauverd will tell you about her remarkable experience on this theme in her talk on Saturday.
- Make health authorities and politicians aware of the benefits of continuity of care so it can be promoted.
- **Nominate a doctor-patient or relative partnership** responsible for guaranteeing that continuity of care right until the end. It is a team effort, a **relay event,** we must be able to pass on our testimony without it falling by the wayside, which is what will give purpose and continuity. Building continuity of care is a collaborative affair.

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