Practitioner commentary on: a paradoxical dynamic in a service labyrinth: insights from HIV care

The French city of Chartres, south of Paris, is home to the famous cathedral Notre Dame de Chartres, which was built around 1300. It has beautiful stained-glass windows and exuberant sculpture work, and in crypt the sancta camisa is kept. These are the robes that Maria is said to have worn during the birth of Christ. Because of this relic, the cathedral is a place of pilgrimage for many pilgrims, and also because Jacob’s route to Santiago de Compostella starts there. Pertinent to this commentary, the cathedral has a labyrinth embedded in the floor of the church’s midship. The labyrinth is composed of 11 circular walkarounds that lead to its midpoint. Pilgrims who visit the cathedral walk the labyrinth as part of their pilgrimage, some do it on their knees. The labyrinth’s geometric structure has had spiritual significance for eons and appears in many cultures and religions. The premise is that by walking the route through the labyrinth one contemplates one’s walk of life. Arriving at the midpoint will lead to introspection and being in touch with the divine principle. The fact that this introspection is not easy appears from another characteristic of the labyrinth: one does not go straight to the central point but maximizes one’s route. Time and again one is pulled away from the centre to arrive at the edge. The goal seems further away than ever but it is essential to keep moving and pull through for eventually the destination will be reached, according to the labyrinth’s premise.

In a similar vein, patients try to find their way through the labyrinth of integrated care, where an imagined destination would be better health and quality of life. En route in this service labyrinth, patients encounter doctors, caretakers, social workers and people in various supporting roles. However, in contrast to the Chartres labyrinth, the route does not always automatically lead to the central destination. In the service labyrinth the route is sometimes unclear or filled with obstacles, and wrong choices can be made as a result of which there is a chance of getting lost. The labyrinth can turn into a maze with wrong turns and obstacles. The question is how to navigate the service labyrinth in such a way that better health and quality of life can be reached.

It is very likely that the situation is even more complex than described in the research by Cruz, Snuggs and Tsarenko (this issue). In addition to carers from the regular care circuit, patients often also use complementary and alternative cures (CAC). As a naturopathic practitioner and provider of CAC, I meet these patients on a daily basis. Their decision to opt for complementary treatments is often not based on dissatisfaction with regular care options; they choose to combine regular and alternative care and cure. They want the best from both worlds, as a recent study conducted in The Netherlands reveals (Jong et al., 2012). A study among HIV patients in Trinidad also bears witness to such an outlook; approximately a third use CAC, driven by the motivation to “try everything that could help” and also “take control themselves” (Bahall, 2017).

Patient-centric care only fully emerges when such findings are taken seriously and complementary and alternative care are acknowledged as elements of integrated care.
Unfortunately, this will only make the service labyrinth more complex and it will make the question of how to navigate more pressing. A guide by one’s side, in whatever form and clear signage are essential. Possibly, the Chartres labyrinth with its implied significance of introspection can show us the way. In my work as CAC therapist, I have noticed how important it is for patients that they fit their (chronic) condition with their self-image and life in a positive manner. In order to achieve this, one has to know oneself and one’s own needs and learn how to use one’s health creatively and optimally. This type of introspection increases the capacity to make better use of one’s internal compass. In turn, this will enable patients to navigate through life and through the service labyrinth.

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References