HOSPITALLER ORDER OF ST. JOHN OF GOD

ETHICS PROGRAM

DEMENTIA GOVERNANCE

HOW ORGANIZATIONAL ETHICS HELPS SHAPING AN ACUTE-CARE HOSPITAL TO BECOME MORE DEMENTIA-FRIENDLY

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J. WALLNER

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CONTENT

Today, I will tell you how we have started a program for getting our acute-care hospitals more dementia-friendly. It is a talk that combines two messages: First, patients with dementia are a complex challenge for acute-care hospitals. Second, organizational ethics can help shaping hospitals to become more dementia-friendly organizations.

THE COMMON GROUND FOR ETHICS AND DEMENTIA IN A HOSPITAL

Have you ever wondered what common ground ethics and dementia share when it comes to a hospital organization? – Well, they can both be frustrating.

As with dementia, ethics and ethicists often struggle to be understood by the outside, so-called "real" world. People without dementia as well as without ethics experience are talking about other things and in other ways; they seem not to understand what you are trying to tell them; they have other priorities, and often you are in their way.

As with dementia, ethics and ethicists are often confronted with the problem that things do not stick to the memory. In the case of dementia, it's the person with dementia herself who often cannot remember what has happened yesterday. In the case of ethicists, this may be the case with clinicians and hospital managers who are dealing today with so many tasks that let them easily forget what yesterday was important, especially, when that point was important but not urgent.

And as with dementia, ethics problems get worse when they occur in an organization that is not suited to deal with them. Acute-care hospitals primarily are designed for "healing" – some would say "repair" – a patient with an acute disease. Internationally, they are under the pressure to do so in more and more efficient ways. Which, for a number of reasons, is good also from an ethical point of view. However, for patients with dementia who do not fit into this system, things get worse. Capacities they have had at home are now under threat in a new surrounding. What seemed clear in a familiar setting now is strange and frightening. Analogously, ethics can be so easy and clear when you think things through in your office. When the rubber hits the road, when ethics becomes practical, things get complicated. You have to deal with real people. And even worse: in a hospital, you have to deal with the organization.

So, to sum up:

Dementia and ethics can be frustrating. That's their common ground.

Let me illustrate this with a case:

One day, a 79-year old patient was admitted to the oncological day-care facility in one of our hospitals. He was accompanied by his wife. They were told that a former tumor had reoccurred. In this case, the oncologist recommended a combined radio-chemotherapy for a mainly palliative goal of care. After briefly consulting with his wife, the patient consented to this plan and was admitted to the hospital's oncology ward. His wife went home and the therapy started with placing a peripherally inserted central catheter (PICC) in the patient's body and preparing him for chemotherapy. Then the first night came. In this night, the nurse on duty suddenly couldn't find the patient in his room. He was sitting in the toilette; the PICC removed and placed in the trash can. The patient was disoriented.

It turned out that he had Alzheimer's. His cognitive impairment was recorded in his medical history but when having the conversation in the oncological day-care facility, the patient seemed oriented enough to start the therapy. Probably, it was his wife who was the stabilizing factor. As soon as she was gone and the patient in a new surrounding, his cognitive impairment intensified. Nevertheless, it was decided to continue with the radiation therapy. As this had to be done in another clinic, the patient was daily transferred from one location to the other. As those of you who have some experience with people with dementia could tell, this constant change in the environment was not especially good for this patient. In fact, I am afraid, after two weeks in the hospital, he was discharged in a worse condition than he was admitted. This would clearly be in conflict with the do-no-harm principle of ethics.

This case is frustrating in the sense I mentioned in the beginning. Not only is it frustrating because an individual patient has suffered a less-than-optimal therapy but because this is due to the fact that his underlying condition – his dementia – has not adequately been acknowledged by the hospital as an organization.

OUR STORY

However, there's something to be done. I will tell you the story of how one hospital in the Hospitallers' group has committed itself to become more dementia-friendly. It is a story that entails two parts:

First, I will explore what it means for a hospital to become more "dementia-friendly".

Second, I will show you how you can work on getting an organization to become whatever it should be, in our case more dementia-friendly.

It is a story about a journey that has just started last year. And although the story's main characters are determined to fight the frustration dementia and ethics are confronted with in a hospital, there will certainly be many episodes along the way when you think that you will never reach the goal.

PART 1: EXPLORING THE TERRAIN, OR: WHAT DOES IT MEAN TO BECOME A "DEMENTIA-FRIENDLY HOSPITAL"?

Think about a person you consider to be a "friendly" person. – When I ask you why you would consider him or her a friendly person, you would probably tell me that he or she is helpful, shows empathy, has manners and so on. I am pretty sure that you would think of a person that you already have known for a longer time or have encountered in several situations. That's because for being a friendly person, it doesn't suffice that I am friendly only once in a while. What we are searching for when thinking about a friendly *person* is his or her *friendliness*. That's a trait that this person usually shows, often even in situations which are a real challenge for keeping friendly.

When we talk about a "dementia-friendly hospital" it is the same: We are striving for friendliness, but this time *organizational* friendliness – not merely personal friendliness, let's say, of the hospital's healthcare staff. Organizational friendliness is a specific trait that has to be developed, tested, and proven over time in different, especially challenging, situations. Now that's about as hard as being received as a friendly person. And I will show you how to work on an organization in this regard in part 2 of my talk.

UNDERSTANDING THE SCOPE OF DEMENTIA-FRIENDLINESS

But first, let me explain to you how we in our project of becoming a more dementia-friendly hospital came to understand what "dementia-friendly" means. Of course, we did research. And we found lots of material in academic journals, books, and projects worldwide. We explored several concepts for assessing the dementia-friendliness of hospitals. What soon was clear to us was the following:

First, becoming more dementia-friendly would not mean treating dementia as a disease but caring for patients with their dementia when they become so sick that they would be admitted to our acute-care hospital. Having the same acute disease, patients with dementia have other needs than patients without dementia. Becoming more dementia-friendly therefore would mean respecting this difference.

Second, becoming more dementia-friendly would not be a single project but a long-term program. As with friendliness: You must consider many different aspects of life. When it comes to a dementia-friendly hospital, you must ask yourself what dementia-friendliness means in medical treatment and nursing as well as in administrative processes or the facility's architecture.

In other words, when we are talking about a dementia-friendly hospital, we are talking about a certain, dementia-friendly *culture* of this organization.

REACHING OUT TO THE WHOLE SPACE: CRITERIA FOR DEMENTIA-FRIENDLINESS

What are the characteristics of such a dementia-friendly hospital culture? – After evaluating several international concepts for assessing it in a project, we decided to rely on a concept originally developed in the UK and adopt it for our Austrian requirements. This concept is known as "SPACE"-criteriology, and I will briefly explain our reception of it.

"SPACE" is an acronym for:

Staff – Partners – Assessment – Care – Environment.

- **STAFF**: Good care for patients with dementia requires competent staff that is effectively allocated where it is needed. By "staff" you would of course first think of the hospital's healthcare professionals. But as patients with dementia have contact to all sorts of employees, it is important that each employee has a basic understanding of what living with dementia means.

- **PARTNERS**: Good care for patients with dementia requires cooperation between different partners within and outside of the hospital. Within the hospital, it should be a cooperation between the different professions and specialties, as well as between healthcare professionals, families, support groups, and volunteers. Outside of the hospitals, "partners" refers to family doctors, nursing homes, support groups, and other societal stakeholders in dementia care.
- **ASSESSMENT**: Good care for patients with dementia requires a thorough assessment of their cognitive condition. "Dementia" is an umbrella term that is – often incorrectly – used for all kinds of cognitive impairments. On the other hand, "real" dementia is often not acknowledged when it is detected for the first time during an acute-care hospitalization. Without good assessment, patients with dementia risk being stigmatized in the one or the other direction.
- **CARE**: Good care for patients with dementia requires professional standards for medicine, nursing, therapy, and psychosocial support: The core question in developing and reevaluating these standards is: Does it make a difference if the patient has dementia for how we should proceed with her? If the answer is yes, you should take a specific clinical pathway for patients with dementia.
- **ENVIRONMENT**: Good care for patients with dementia finally requires an environment that supports these patients as well as those caring for them. The hospital's architecture, ward and room designs, orientation system, light and sound system and so on can ease the symptoms of dementia but they can also worsen them. Therefore, it is essential to think about the hospital environment that patients with dementia are brought into.

So, in order to become more dementia-friendly, a hospital must reach out to the whole SPACE. There must be organizational interventions in Staff, Partners, Assessment, Care, and Environment. One or two domains aren't enough. Dementia-friendliness requires the whole SPACE. To this time, we have about 80 criteria for dementia-friendliness which break down the 5 SPACE-domains.

WHY SHOULD WE DO THIS?

As you can imagine, this is no easy task. And, frankly speaking, patients with dementia are not the topic you will get famous for in medicine or healthcare. So, why should we nevertheless engage in this program? It is a question that routinely comes when change

is in the air, also in our organization. – There are at least two answers to that: a normative one and a pragmatic one.

The normative answer to the question, why *our* hospital should engage in becoming more dementia-friendly lies in the Hospitallers' organizational mission. The Hospitallers of St. John of God were founded in 1537 by a man that was considered psychologically ill by his fellow citizens because he envisioned a healthcare system that treats people with intellectual disabilities and cognitive impairments with respect and dignity. The Hospitallers' mission therefore is especially directed towards those who are marginalized by society and healthcare systems. Patients with dementia in an acute-care hospital are certainly among those people. Hence, it is an expression of the organization's mission to engage in this program. – But maybe, you don't even have to appeal to this high notion of your organizational mission.

Because the pragmatic answer to the question, why *a* hospital should engage in becoming more dementia-friendly and do so in a system-based way, is the following: In our hospitals, as well as in most acute-care hospitals in the Austria, at least 1 out of 10 patients has some form of chronic cognitive impairment, most often a version of dementia. So, if you imagine *this* room as being a hospital ward, there would be 10 among us having dementia. This could cause serious challenges: First and foremost, for the person with dementia; second, for some others of you; and third, for the ward's healthcare staff or, in our case, for me as the presenter. – Therefore it is a matter of prudence that we should adapt our organizations, hospitals in this case, for meeting the needs of people with dementia. They are there; and, at least for the next years, they will become more. Not dealing with this reality not only harms the people with dementia but also those around them, including their caregivers.

PART 2: PLANNING THE JOURNEY, OR: HOW TO GET AN ORGANIZATION TO BECOME WHATEVER IT SHOULD BE, FOR EXAMPLE, MORE DEMENTIA FRIENDLY

Now that we have a basic understanding of the scope and the content of the program of developing a dementia-friendly hospital, it is time to explain to you the methodological approach and architecture that we use to get there. This is the part where I will show you our understanding of doing organizational ethics.

OUR APPROACH: SYSTEM THINKING

Organizational ethics works with the concepts and tools of organizational development; in our case, it is embedded in system thinking. If you want to develop a hospital to become more dementia-friendly, you should address three aspects that shape an organization: strategy, people, and structure.

STRATEGY: A strategy tells you what is important in an organization. It tells you the goals of the organization, or, ethically speaking, the good an organization is striving for. To become more dementia-friendly, an organization has to adopt this goal in its strategy. Without that, all efforts of becoming more dementia-friendly (or whatever) will be regarded as philanthropy, nice-to-have, or add-on to the "real" organizational goals. With strategic agenda-setting comes resource allocation. Therefore, getting "dementia-friendliness" into the hospital's strategy is not easy; but once you have accomplished it, an important step is set. It is, however, not enough to mention "dementia-friendliness" in some strategy paper or slideshow. As with all strategies, you have to break them down and control them. I will get to this point in a minute.

PEOPLE: You cannot reduce an organization to its people (also not to the sum of all people acting within the organization) but you must acknowledge that an organization acts through its people. Therefore, developing an organization also means developing its people. In the case of a dementia-friendly hospital this involves strengthening the competencies of individuals and teams for caring for patients with dementia. You have to empower the staff but also family and volunteers. It's good that there are training programs which have specialized on this topic. What an organization has to do in this respect is developing a track for its staff: Who must have which knowledge and competencies? How do you organize them within the hospital? – Many organizations focus on this aspect of organizational development; they send staff to good qualification programs and trainings where they learn state-of-the-art approaches to caring for patients with dementia. And then they come back to their hospital. And it is still the same organization: If strategy and structure do not fit the personal engagement, these highly motivated and qualified people will not bring their competencies to the ground.

STRUCTURE: Therefore, it is essential for organizational development and ethics to work on the hospital's structures and processes. It is, at the same time, maybe the hardest task. A hospital is one of the most complex organizations. Different professions and specialties work in historically evolved structures that often do not reflect the need of today's patients. Furthermore, there are literally thousands of processes that govern the caregiving, from admission to intervention to discharge. We work in these routines.

Structural and procedural routines have strengths, but they also encompass risks. It is an ethical question how structures and processes guide us in our decisions and interactions. If these structures and processes do not acknowledge the special needs patients with dementia have, they cause ethically problematic situations. Therefore, organizational ethics has to work on them.

If you work on these three aspects – strategy, people, structure – you will, over time, shape the organizational **CULTURE**. A dementia-friendly strategy, dementia-friendly people, and dementia-friendly structures will lead to a dementia-friendly hospital culture. There is no shortcut to this goal. You have to reach out to the whole SPACE.

OUR ARCHITECTURE: SYSTEM LOOP

When we talk about developing a hospital to become more dementia-friendly, we are speaking of a long-term program. Changing an organizational culture demands 10+ years – if all factors are in favor of this change and you manage to keep your energy level for this cause. How can you imagine an architecture for this task?

Think of clinical routine: It dominates the organization. With good reason: Organizations are created to establish routines. However, it is hard to get into a state of reflection when you are absorbed by routines. So, we need a methodology that allows us – from time to time – to break up our routines. This break-up is "the system loop." It is a not dramatic but constant sequence of following steps:

1. **ANAMNESIS**: As with a patient's case history, you observe and collect information in your daily business related to a criterion of the SPACE-catalogue.
2. **ANALYSIS**: Together with your colleagues or team you analyze you perceptions. You develop a "diagnosis." Regarding the SPACE-criteria, you ask yourself: what is wrong with our daily business?
3. **GOAL OF CARE**: Based on your diagnosis you develop a "therapeutic plan" with goals of care. They specify which intervention(s) may be appropriate to change your routine in order to become more dementia-friendly.
4. **INTERVENTION**: You try out your "therapeutic plan," which means you change your routine.

After performing the intervention, the loop starts again: You observe and collect information on how your intervention has affected the patients, families, and staff.

The system loop is a constant mode of thinking and practicing. It gets its benchmarks for dementia-friendliness from the SPACE-criteriology. Its strength is that it does not require some sort of master plan where you would try to think all interventions through before you start with them.

However, it is still hard to stick to this tool. So, how could you ensure that the program does not get lost in the hospital's multiple tasks and challenges? What you need is some sort of *institutionalization* of the loop's idea.

OUR INSTITUTIONALIZATION: DEMENTIA GOVERNANCE

We came up with the term "Dementia Governance." Governance is a system by which an organization keeps its responsibilities, ensures compliance, controls goals, and communicates with its stakeholders. Dementia Governance is a mechanism for clinical and management decision-making in the hospital:

- **CLINICAL DECISIONS** like individual therapeutic plans and
- **MANAGEMENT DECISIONS** like budgeting, recruiting, or facility development

...must incorporate the benchmarks of dementia-friendliness and the methodology of becoming a more dementia-friendly hospital. For example, when a hospital ward has to be renovated, this should be an occasion for asking what you can do to make its design more dementia-friendly.

Elements of Dementia Governance are:

SUBSTANTIAL INDICATORS: They are derived from the SPACE-criteriology.

KEY PERFORMANCE INDICATORS: For each criterion you want to monitor and improve, you need quantifiable indicators that are discussed in budget meetings and other management decision-making.

STRUCTURES: An "expert team dementia" assists clinical staff and management in their decision-making. Like other expert teams, they have to be consulted when certain decision have to be made.

MONITORING: The development of dementia-friendliness must be assessed from time to time. This could also be done in internal performance reviews or through an external audit.

REPORTING: Efforts in order to become more dementia-friendly are reported to all stakeholders, including the general public.

We have not established this system of Dementia Governance yet. At the moment, we are still exploring the "system loop", which means healthcare teams are trying to alter some of their routines to adapt them for patients with dementia. The next step will be the formation of the "expert team dementia," because it takes resources to keep the program running.

OUTLOOK

Now, that you may have a picture of what the Hospitallers understand under "dementia-friendly hospital" and how we try to get there by organizational ethics and development, let me conclude with an outlook.

One important lesson leaned is:

Organizational development is a fragile undertaking. Efforts to become more dementia-friendly are under the constant threat of being "absorbed" by the mass of other problems. Therefore, it takes a reliable system of governance with the same professional standards as in other areas of the hospital to keep the course.

My conclusion for today is:

Ethical questions relating to patients with dementia have a strong organizational context. You have to engage in organizational ethics to overcome the problems. Reach out to the whole SPACE: Staff, Partners, Assessment, Care, and Environment.

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