

Relational approach to ethics and quality improvement in institutional care for people with dementia

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Background: Autonomy has become a key organizing principle in the official and expert discourses of the social services focused on strengthening of clients' independence and self-sufficiency. While "caring" has been seen as a threat to the autonomy of an individual, the care dependency and need for palliative care for people with dementia living in residential institutions are growing.

Methods: Participatory action research was realized in 9 homes providing services for people with dementia with the aim to improve the quality of care. Research teams from the homes were involved in assisted self-assessment which included observation, documentation analysis, workshops, interviews and interventions targeting the issues arising from practice. Ethnographic research was performed by the consultant/researcher to reflect on the experience.

Results: Over the last 15 years, the needs of clients in the residential care institutions in the Czech Republic have changed significantly and the pressure on people involved in direct care is growing. I suggest that relational approach to care, enhancing personal commitment of care workers and their appreciation of sociomateriality of caring relations, is well suited for enacting autonomy and dignity of people living and dying with dementia. The relational approach to care improvement is embedded in everyday practices and thus brings a wider scope of possibilities for providing good care than the controlling mode of improvement, measuring evidence against the national standards.

Conclusions: If we are, as a collective, to build up appropriate structures and resources in dementia care, more attention must be paid to the needs of residents and care workers alike, as well as to realities of the daily practices.

Keywords: Ethics of care; dementia; improvement; relational autonomy

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Introduction

Care is central to our lives (1-3) and, as ethnographical research has shown, it is relational in its practice (4-6). But what good care is and how it is practiced is not easy to say and impossible to prescribe by either quality standards or codes of ethics. While in the discourse of social services caring has been seen as a potential threat to the autonomy of an individual, the data from my field work in long term care facilities for people with dementia have led me to the opposite conclusion. Care is a value which needs to be nurtured. Its practice deserves to be carefully attended to, so it is not enacted only as a set of rules,

procedures and manuals (4). In the following text, I use the excerpts from my field notes to demonstrate that both caring relationships between humans and the materialities of daily care have decisive impact on the quality of care for people with dementia. In our complex world, where boundaries between life and death are fragile, the need for an ethical perspective promoting caring relations seems critical.

Methods

During my field work in 9 homes, my task was to support

care teams in improvement of the care practices for people with dementia. The teams of co-researchers from homes consisted of care assistants, nurses, social workers and technical staff members. During the 2–3 years action research project, they were supported in their efforts by a consultant/researcher, the author of this article. Data were gathered through observations, documentation analysis, group discussions and interviews. The areas of interest and research questions were negotiated within each team, as the institutions progressed in their improvement efforts. Collaborative approach to data gathering and analysis emphasizing practical aspects of our work were applied. Events providing opportunities for reflection and sharing on topics of common interest were organized for all the 9 teams. Ongoing training events, consultations and specific interventions were implemented to address the issues arising from the dialogue. Topics such as person-centered care, communication, dining and nutrition, family involvement, case management, health care issues (e.g., pain, depression), palliative nursing care, multidisciplinary team work and quality improvement were included. As a consultant and researcher, I was involved in the participatory observation of daily practices of care, conducted interviews with the residents, or took part in their daily activities. My main task was to follow work organization and to reflect on the research through group discussions with the co-researchers. In this article, I use excerpts from my field notes to point out some of the ethical issues our team has encountered during the project implementation.

Results

The neoliberal transformation undertaken by the Czech Republic at the end of the 20th century was led by a vision of citizens liberating themselves from dependencies. The post-socialistic emancipatory movements in social and health services have been based on ideals of individualism and independence, and the inclusion of social services' users into "normal life" (7). For good reason, there was a strong movement away from medicalization of the services in institutions, and many nurses who traditionally worked there had left. However, ten years of national strategy for transformation of social services has not brought significant development of services in communities (8). The older people living in large institutions called homes for seniors were not eager nor expected to become new style citizens liberating themselves from dependencies, or to make free choices in the market. This was not the world as they used

to know it. They aged, hidden in the institutional homes, while their needs for care have been changing significantly.

According to recent research, the proportion of persons with dementia living in social institutions is about 66% in homes for seniors and 97% in homes for people with cognitive impairment, introduced into the law in 2006 to provide long-term care for people with dementia (9). Nowadays, care workers in these institutions are every day confronted with unexpected level of dependence and lack of resources to provide good care (10). According to Holmerová *et al.* (11), the number of clients with high need for support, and people who die in institutional settings, has rapidly increased, while care provided by health care professionals in homes is seriously limited, and many of the residents are left without proper palliative care (e.g., symptom management, advance care planning, access to specialist palliative care).

Since the early 1990s, with the emergence of new trends in the Czech social sector promoting the ideal of autonomy, 'care, caring and carer' have been problematized. In an effort to support the deinstitutionalization of the services, some experts in gerontology and geriatrics consider "care" as a synonym for oppression and for all which social services should not be (12). For example, Kalvach *et al.* warn us of the dangers posed by care, especially when it is provided in the residential institutions: "*In the Czech Republic, traditionally we talk about care – health, social, holistic, long-term, community based. Thus, the perception of clients as 'disabled' and care dependent is strengthened and that is how care easily becomes restricting, subjugating and undermining the client's autonomy and social roles. Care also makes the impression that the more of it we have, the better it is, that by caring we can literally overwhelm the client for his own good (...)*" (13).

Abuse and poor treatment of people in institutional settings has been a sad reality. Therefore, it is correct to criticize the asymmetries between care providers and clients/patients, and the paternalistic approach embedded in the system and enacted by some professionals. Kalvach *et al.* suggest abolishing "care" from the vocabulary and practices, and instead designing a well-structured integrated support system strengthening autonomy, while promoting self-sufficiency, self-esteem and meaning of life (13). But each discourse carries its own dangers, as Foucault explained when talking about genealogy of problems: "*My point is not that everything is bad, but that everything is dangerous, which is not the same as bad. If everything is dangerous, then we always have something to do (...)* I think that the ethical-political choice we have to make every day is to determine which is the main

danger (...)” (14).

In the present situation, care as such might not be the most pressing danger in the residential services for older people in the Czech Republic. Care dependency certainly poses some threats, but criticizing care in general terms is unsettling, because we may lose the potential of caring relationships, while the structural inequalities remain in force in the transformed services. Moreover, describing care provision in institutions as inherently abusive, might be taken as an offence by many care workers, for whom caring remains to be a fundamental moral value.

Not surprisingly, hand in hand with care, “relationships” became problematic in the official and expert discourses of the social services sector. On many occasions, carers are puzzled when trying to figure out how they should “be in relationship with clients”, not to endanger respect for their autonomy and independence, as well as proper user-provider interactions. During my fieldwork in the homes, I often realized that when talking to strangers, staff members try hard to make clear divisions between what is personal and what is professional in their interactions with “users”. They correct themselves immediately when the word “relationship” slips off their tongues, or if their account of care practices signals emotions rather than task delivery as prescribed by manuals. From the managers point of view, there are good reasons for maintaining a certain distance during “service delivery”, of which one of the most important is to protect care workers from burn out. But as the care workers told me, to maintain interactions with clients purely in the mode of service delivery, without getting personally involved, is impossible: “*It is simply impossible not to create a close relationship with someone in these circumstances. Well, it should not be said, but I sincerely admit it, that we (care workers) have clients who are close to our heart, we know it about each other, so we know that when the client dies, some of us will take it badly (...)*”. (interview with the care worker).

“*What Anna (the care worker) meant is that from the professional point of view, it should not be like that, but it is (...). We know we are here at work, that it is our job, but we like our clients. We all like them. It's human. We are human beings, it is part of what we do, it is normal, well... the legislation says 'blab, blab, blab' ... but we are only humans (...). Sometimes it is so sudden... Like this lady recently, she came and after three months she was dead... We just want their end of life to be pleasant, every day of it.*” (interview with the social worker).

First of all, we are reminded by these statements that giving and receiving care is a basic human activity (1).

Secondly, from the carers' perspective, what is dangerous in the homes is not the strengthening of the dependence of clients by too much of caring, but the inability to accommodate the needs of people who come to live and die there. The need for palliative care for people with dementia has not yet become part of the official discourse of social services in the Czech Republic. Nevertheless, for care workers in residential institutions, caring for people approaching the end of life has been inescapable reality. Despite the absence of clear policy and strategy, continuity and coordination of care, appropriate staffing and sufficient rewarding, which all are part of the recommendations for optimal palliative care (15), the care workers have to act even when other professionals may feel that not much or nothing can be done. As they “prioritise the relationship as much as care” (15), not acting is irreconcilable with the ethical ideal of many professional caregivers.

Residents of the homes cannot attend to their own needs, so the dependency care/work, when it could not be done by the family, is delegated to care workers (16). Meanwhile, the numbers of qualified nurses in the homes are decreasing (17), so most of the dependency work and related administrative tasks are being done by the care assistants. And while they struggle with information technology systems and with documentation required by quality standards, the possibility of addressing the basic needs and to facilitate the access to health care is severely limited. Sometimes, they feel helpless and on the edge, as in this case, which they wanted to share during our meeting: “*The carers were furious. One of their clients, Ms Klara, had been screaming for what felt like ages. They had tried 'everything possible – being with her, leaving her alone, activities with others, relaxation, food, different places and positions' – nothing worked. It's been heartbreaking, such a distress, listening to this calling: 'I am so sick. I can't take it anymore. Kill me!' For weeks, they've been trying to get some support from the physician and psychiatrist. With no success. They blame the head nurse for it.*”

“*Later when we talked, the head nurse confirmed the despair: Well, the doctors work on a long-distance basis; they quite often do not even see their patients. They leave it up to us, or on what we tell them on the phone. In this case, it was around Easter, I called the psychiatrist, and he said that 'we should see after the holiday' (...). I also called the family; the family wanted us to solve the problem here. It was another five days of suffering ahead of us. The physician would not help either. She used to come twice a week, but now it is once a week for an hour around lunch time (...). I am not God to make the decisions. I am so scared that something will go wrong.*” (interview with the nurse).

We do not know what would have happened if the doctor and psychiatrist had responded positively to the call from the head nurse. It is not clear whether they would have been able to help. The carers are aware that there is not always a medical solution or a happy ending to each situation. But they felt that neither the patient nor they were heard; and they felt neglected.

After a few more days, on the day the head nurse was not at work, the care assistants asked their supervisor “to do something about it”. She called the ambulance, informed the family and Ms Klara was admitted to a psychiatric clinic. Nobody was happy with this solution, but as the carers were also worried about the other clients, who were effected by Ms Klara’s behavior, they felt relieved. What to think of this? Should Ms Klara have stayed in the home as her family wanted? Is this what she would wish? Should the carers have tried to do more, or to do something else? Could the doctors have attended to the calls for help?

While possible solutions to one and each situation in care are many, one thing is certain. Caring relations and people enacting them in the *homes* are in danger. In recent years, the needs of clients of social long-term care services changed significantly and the pressure on people involved in direct care in *homes* is growing. The attentiveness, kindness, and experimenting when striving for *good* in daily practice are embedded in the system of social and health care services in which the necessary competences and required resources of palliative care approach are not available.

How to attend to care and carers?

In a contrast to the concept of an autonomous subject striving for independence, the ethics of care, developing in the last few decades, see persons as relational and mutually interdependent (18). Feminist ethics of care foregrounded relationships between people and brought our attention to feelings (19), to the joys and challenges of caring and to the collective responsibilities for care. There is no doubt that there are some *bads* in care, as the above quoted excerpt from my notes has shown. But let us not forget that care has many *goods* as well. There are many virtues associated with care: compassion, attentiveness, and patience, honesty, trust, humility, hope and courage (20). And in the many practices associated with care, we could see those virtues being enacted.

In her book, *Moral Boundaries: A Political Argument for the Ethics of Care*, Tronto defines care in four phases (2). “Caring about” implies recognition of care

needing subjects, together with attentiveness to their unmet needs. In the second phase, “caring for”, there is always someone or a group of people who takes responsibility to address identified needs. In the third phase, “care giving”, certain competences and resources must be available to provide good care, to search for the best solutions. And finally, in “care receiving”, the cared-for responds to the work done, and thus feedback is provided and opportunities for further improvement are opened.

If we apply this analysis to the story of Ms Klara, we can see many gaps which might not be easy to overcome. Some of them could be solved face to face among the actors involved on site, others require changes in the care organization and policies. With the population ageing, the need for long-term care facilities is expected to grow, while many problems, such as access to health care, remain unresolved (7). In such circumstances, it is difficult for the carers to meet the clients as one-caring, while maintaining good spirits and not despairing.

Stories like that of Ms Klara usually remain hidden from the public. It is not something to be shared with quality inspectors or auditors. Carers would not go public with them because they feel responsible and guilty for not being able to help. The manager would not use such story for claiming more money for salaries, because she would not like to be perceived as the one who cannot solve the problems. And for similar reasons, most public images representing *homes* are of comfort, excellent ‘homelike’ care, friendship and peace.

During our session concerning Ms Klara, the carers talked about how tired they were of all the quality certificates, public presentations of homes’ achievements, and always yet one more “participation in another program for quality improvement”. At the end of our meeting, they asked one question which remained unanswered: “And what if we did not respond and just left her alone?” At that moment, I felt they had enough of us, consultants and researchers of quality improvement. What do we have to offer besides listening and attempts at understanding and consolation?

The main task of consultants and researchers involved in care improvement is to show the diversity of daily practices of care, without omitting its practicalities, limits, challenges and uncertainty. The aim should not be adding more colors to the horrors of care, but to draw attention to the needs of people in dementia care, calling for collective responsibility and initializing action. The “hands on” care workers in the homes, mostly women, are themselves vulnerable

concerning their physical, emotional and economic status. Therefore, they need others who are ready to get involved with them in a caring relationship based on the respect for their integrity and needs. Researchers and quality improvement consultants might take on greater role in this task.

Opportunities and limits of improvement in ordinary life

In many stories which came to life through this research, we could see that not only relationships between humans, but also the realities of daily care have immense role in our lives. Thus, at one point in our research, the co-researchers suggested food as one of the main media for care improvement. Getting ready for a meal and eating constitutes quite a portion of daily activities for people in the homes, and, as Harbers *et al.* put it, "(f)ood is a wonderful entrance into practices, central as it is to both physical survival and social relations" (21).

Through the following excerpts from my communication with Kate, a care coordinator in one of the homes, I want to show how people, together with things, strive for the improvement of dining experience: *"During a workshop with care workers from other homes, Kate shared her story. She was presenting photographs depicting how they are getting ready for and eating breakfast with Ms Lena. The pictures were so powerful. The beauty of two women sitting together, the way they deal with bread, butter, cup... attention, patience, and smile of contentment when things worked. Before she went into detail, Kate gave a short introduction: 'When Ms Lena came to our home from the long-term care hospital, she was in a state of advanced dementia, practically immobile, did not speak, just occasionally responded in one word, but not always and not to everybody. We were feeding her pureed food in her room. As we started to look for improvements, we reevaluated the situation and invited Ms Lena to dine with others. For two or three weeks, I was there in the morning to cut the buttered bread into small pieces and to keep her a company. Sometimes she needed more help, sometime less... she enjoyed eating her bread for breakfast (...)'"* (field notes from the workshop).

Accepting the responsibility of carer feeling with the other, Kate did not take things for granted. She thought Ms Lena spent too much time alone, and noticed that she did not enjoy pureed food. Ms Lena could enjoy better life than she had been enjoying, since she came into the *home* from the hospital. She spent some time with her, consulted with the nurse and with other colleagues. Using new opportunities opened by our quality improvement program,

she reorganized her working schedule so she could be in the dining room during the morning meals and accompany Ms Lena. Dedicating their time to the tinkering of care (4), they tried together different alternatives. They looked for things that worked well and put aside those that did not. But not everybody and everything in the home was conducive to the experimentations. During one of my subsequent visits, Kate wanted to talk: *"Last week one of the nurses came in with crushed pills for Ms Lena. She forgot the spoon. So, she looked around and as she could not find any extra spoon nearby, she was ready to take one of the bread cubes and serve it with pills as a mouthful.*

'You won't do it!' I said quietly but forcefully.

The nurse looked at me, surprised and annoyed, and then she left...

You know, I really feel bad about it. The nurse is a colleague of mine, she is much older than me and more experienced, so I feel ashamed of my reaction. But I could not help it... It is a great effort for Ms Lena to eat her breakfast and I think she enjoys it; I do not want the taste of the bread she enjoys spoiled by bitter pills." (an interview with Kate, the care coordinator).

For weeks, Kate, her client and the bread cubes were holding together the joy of dining. Then, all realities which they have brought into being—dignity of Ms Lena eating food, her sense of belonging, socializing with others in the dining room, her autonomy enacted in taking the mouthful in her own hand, as well as hope for more pleasant days—could have been compromised by the act of one of the nurses. Kate, surprised by the insensitivity towards Ms Lena and by the disrespect for all they have achieved, reacted promptly. But she also cared about her colleague, whom she did not want to offend.

The insensitivity of the particular person in these particular circumstances does not mean that the care workers don't put effort in activities related to dining. They take them seriously, as meaningful activities, sometimes as a matter of life and death. But when Kate as a coordinator started to work with the rest of the team on the overall improvement of dining, the limits of the relational mode of improvement soon became apparent. Nurses and care assistants shared Kate's enthusiasm and could see the potential benefits for the clients. But they knew that they must compromise. As we talked about the incident with pills, they pointed out that the reality of dining is different in the evenings, and during the weekends, when there is less people on the shift and only one nurse to attend to 70 clients. It was obvious that the practices which work for Kate and Ms Lena might not work for others in other places and in other times. They would have to be adapted,

made to work in new realities, through different routines and relations (22). And when the improvement of the daily practice of care is at stake, the tensions and problems are as important as successes and failures. As Mol, Moser and Pols write in their foreword to the anthology *Care in Practice: On Tinkering in Clinics, Homes and Farms*, good care “is attentive to (...) suffering and pain, but it does not dream up a world without lack. Not that it calls for cynicism either; care seeks to lighten what is heavy, and even if it fails it keeps on trying” (4).

Few days after we discussed the problem with the team, I received an e-mail from Kate: “*I’d like to come back to the difficulties we discussed. Often, I have in my head several scenarios or ways to resolve the situation. I always try to choose ‘the best’ of them, but it does not always work well for everybody... (...) I realized, I do not have to be just observing things I do not like in silence, as I did when I started this job. I am glad that I did not ‘become blind’ to discomfort or bad things that might be done during care in our home just because ‘this is the way we’ve been doing it for years’. I am not saying that now I know perfectly well how to intervene, and what to say to more experienced colleagues, but I am trying, I am looking for ways to say what needs to be said, to make sure that clients will be safe, will be fine here (...).*” (e-mail from Kate, the care coordinator).

Kate insists that it is important to maintain the ethical ideal of care in the tiny details of everyday life and thus to care for oneself as a human and as a professional (23). But she also takes it as her task to deal with the tensions and limits, trying to answer the question of what shall be done to hold all the people living in the *homes* – the cared-for and the carers as well—in caring relationships. Hers is the approach which strives to minimize the compromising in the improvement of care through patiently and carefully built alliances.

The strategies for improvement

Kate and others sitting around the dining table are striving for the goods and trying to avoid the bads, and in this way they are setting up the standards in the day to day practice of caring. In fact, what care is, differs from place to place, practice to practice, relationship to relationship. It could be creative endeavor, ‘persistent tinkering in a world full of complex ambivalence and shifting tensions’ (4).

When working in the homes, I found that people in dementia care are frustrated by the lack of attention and insufficiency of efforts to address their concerns. This includes political and strategic decisions being (or rather not) being made, regarding home caring, accessibility of

health services, as well as decent employment conditions and wages in caring professions. On the other hand, the care workers felt to be at “the top of the list and in the firing line” when the effectiveness, satisfaction and results are being measured, to show “objectively” how good or bad care is. Quality inspections, as described by the staff members, constitute a process of evidence gathering and delivering unequivocal judgments, which are then translated into numbers and funding. To prove the quality of services, manuals and procedures are developed by institutions, memorized by the staff members and checked upon by the inspectors. Before such events called “exams” or “interrogations” by the staff, care workers talk about their fears and “do not sleep at night”. In case the date of the inspection is known ahead, shifts are assigned to “the best workers” who are able to present what’s been written in toolkits and manuals and to prove that it is exactly what they do in daily practice.

With the few exceptions, the controlling mode of care improvement makes care workers feel neglected rather than respected, or supported, which is what the code of ethics of quality inspections promises. The demands for quality and financial control are understandable, but from the carers’ point of view, “they do not go to the heart of the problem”, as they do not influence the structural conditions in which care is provided—physical environment, personnel allocation and access to health care needed by people with dementia. Many of the care workers and managers feel paperwork, and hastily gathered evidence, are the most important things for the inspectors: “*We are here to do everything on paper, that is the evidence. But I like to work with people, I like to help them. When I am with them, I can see who needs what, but I cannot always do it. For example, one of the clients needed a bedside commode chair, she wanted it there, but I could not put it there because it would not look good. Where is the individualized care here?*” (an interview with a care assistant).

For one of the care coordinators, the commode chair represented a potential problem in the eyes of the strangers, as she knew it could signal disrespect for the dignity and self-sufficiency of the client. Action described above would be kind of a protective camouflage to persuade others that the situation is much better than it really is. Due to this approach, it takes time to build relationships in which we as visitors are allowed to learn more about the daily practices of care. In the case of inspections, it could not be otherwise. Their task is to measure to what extend the care work is meeting the principles of autonomy and to what extend it is efficient. The shortcomings of social services quality

control have been recognized. According to one research, standards are vague, time the inspectors spent on site is short, the inputs are anecdotal and mostly derived only from paperwork. Because of that, there is a lot of space for ‘subjective’ interpretation and as there are asymmetries in power between inspectors and the staff, the opinion of the inspectors is indisputable, which makes those providing care feel powerless (24).

My presence in the homes was by no means immune to the existing power asymmetries. Despite that, in our time spent together with the carers, there were many opportunities to care for each other and care for what we were trying to do. While working as a researcher and consultant in the homes, I was learning few lessons: Do not get drowned in papers and formal talks, attend to the practices of care. Look at what people are doing and what they are using. Listen to what they say. After two or three years, depending on the dynamics of the team and other circumstances, the caring improvement effort served some of its purpose. Here are few which were appreciated by my research partners: changes to the environment (setting up living rooms and dining rooms, lowering the number of people sharing the bedrooms, increasing the number of single rooms); training and an on-site consultancy support in palliative care; sharing experiences; and after negotiations with regional authorities, increasing the number of care workers in some of the homes.

Conclusions

In this article, I shared few examples about care practices in homes where people with dementia live and die. The way we speak and write about care matters. Through my stories, I am trying to make sure that the needs of older people living and dying with dementia will not be seen as an individual problem, as a collective burden of an ageing society (25), or as a business opportunity in a growing market, where everybody shall freely choose and some can make a lot of money (26). Reciprocity in private or professional relations—receiving others with their needs—means personal involvement. It could be joyful as well as painful. The recognition of interdependence, vulnerability and the importance of relationships should be perceived as ‘normal’ in care practices and politics (27). This way, the voice of cared-for people living with dementia and the ones-caring, as well as the diverse realities of daily care practices, could gain more attention. To provide good care in democratic societies means not only attentiveness

and responsiveness when people meet face to face in daily activities, and when care workers see to the needs of their clients. If we are, as a collective, to provide appropriate structures and resources to people living and dying with dementia, care needs to gain an important place in morality and politics.

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