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Pastoral care and dementia: Reflections on the role of empirical practical theology in counterbalancing constructions of dementia as crisis

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This chapter deals with conceptions of dementia-as-crisis or critical event and corresponding professional discourse and practices in contexts of pastoral and spiritual care. It contrasts these conceptions with insights from an ethnographic research project with people living with dementia that explores worship practices in care-homes. Analyzing 'dementia-as-crisis' and dementia-related discourse and practice in contexts of pastoral care as simultaneous or co-constructing events, it reflects upon dichotomously organized role schemata and enactments which form the foundations of the dementia-as-crisis dispositive. To illustrate its workings the researcher's own entanglement into its 'doings' and 'sayings' is critically engaged with. On this basis, options for alternative conceptions and narratives of people living with dementia in pastoral discourse and practice are considered.

Introduction

Everyday conceptions of dementia picture it as an experience of fundamental crisis, both for individuals and their families, as well as for aging societies at large. Images of frailty and despair, and, above all, a profound loss of self and autonomy abound. Powerful metaphors such as the erased hard drive, the empty shell, or the living dead (Grebe 2015), convey how dementia is perceived in western contexts. Constructions of dementia-as-crisis which must be managed by specialists run deep. They appear in discourse; however, they also get inscribed into artefacts, make themselves felt in body-routines and become manifest through everyday practices; particularly in therapeutic contexts.

Discourse within the realms of pastoral or spiritual care has also taken on these tacitly assumed understandings of dementia as a crisis to be managed. (Kevern 2009, 205; Kunz 2014, 441). Concomitantly, this has been joined by increasing efforts of professionalization in the field. Starting from small beginnings in the late 1990s (see for example VandeCreek 1999 for the Anglo-American context; Depping 1993 for German speaking contexts), new concepts of pastoral or spiritual care for people living with dementia have been developed. Models of best practice have been suggested and have grown in numbers since, which, in turn, have been taken up by Practical Theologians to illustrate what dementia-friendly practice in church and society might look like (Fröchtling 2008; Roy 2013; Schlarb 2015; Linthicum and Hicks 2018; Stuck 2020). Dementia friendliness in church, again, has become an ongoing commitment for communities of practice whose initiatives, in the meanwhile, have become subject to (often concomitant) scientific research (Plunkett and Chen 2016; Epps et al. 2021 and Friedrich et al 2021).

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Yet, what seems to be excluded from the picture is the possibility that underlying constructions of dementia-as-crisis are, in part, also the result of professional discourse and practice which understand themselves as pastoral crisis management. In this chapter I would like to reflect on this by taking up one of the questions raised in the *International Academy of Practical Theology*'s call for papers for the 2021 conference hosted in Leuven: "How can practices of care be considered as answers"—and I would like to specify: as reactions—"to a 'rhetoric of crisis'?"

Putting the question this way allows for a reversal of the common view on things, as it suggests focusing on the fabrication and workings of crisis discourse in contexts of pastoral care. That is: rather than contributing to the routinization of crisis by offering additional models of pastoral intervention which might work well for people living with dementia, framing the question in this way invites thinking which puts the cart before the horse and critically analyses images of dementia-as-crisis that are taken for granted in pastoral discourse and practice. Further, it encourages a closer empirical look at the interplay between people, things, and discourse in the constructions of dementia-as-crisis.

Accordingly, this chapter aims to draw attention to 'crisis' and 'dementia' in contexts of pastoral care. To explore some of their complex relations, I suggest conceptualizing both as events rather than as stable entities. Or, to put it differently: one can be looked upon as being 'done' or brought about by the other. 'Dementia-as-crisis' might be an effect of pastoral care's discourse and practice; and in turn, dementia-related 'pastoral care' might be brought about by doings and sayings which make dementia appear as crisis. That is, the crisis-discourse—or, perhaps, more accurately: dispositive (Foucault 1980 [1977])—can be looked upon as emerging from a series of micro-practices and discursive acts in contexts of pastoral care, while at the same time dementia-related interventions of pastoral care could be understood as resulting from specific manifestations of the 'dementia-as-crisis'-dispositive. Yet, this picture of concomitant construction would not be complete without reflecting on the researcher's own role within these processes, or, more specifically, her entanglement in the processes of co-construction of 'dementia-as-crisis' and dementia-related pastoral or spiritual care. I therefore opt for reflexive ethnographic approaches (Bonz 2016 and Dean 2017) putting the researching me in embodied fieldwork (Ellingson 2017) to get to the bottom of the constructive processes of 'dementia-as-crisis' in contexts of pastoral or spiritual care.

Illustrations of this approach are offered in more detail in section 4 and 5 where I draw on field-experiences and methodological insights from my current ethnographic habilitation project based in Ruhr Universität Bochum, Germany. Over the past three years I have been engaged in a qualitative study of worship practices with people living with dementia in care homes. In this research context I explore the interplay between 'dementia' and 'worship' by asking how they relationally produce each other. The most important data of my study are fieldnotes based on participant observation of worship in two different institutions next to adjoining settings of nursing, social work, and administration. In addition, data includes interviews and more informal field conversations next to documents, artefacts, and images. A particular focus on professional discourse is due to Adele Clarke's Situational Analysis (Clarke et al 2018, 217–268). My approach—which draws heavily on what might be called classic ethnographic fieldwork strategies (Emerson et al. 1995) and (Breidenstein et al. 2013)—is recursive, flexibly adapting to research findings and opportunities as well as the development and refinement of my research questions upon closer acquaintance with the practices of 'the' field (Hammersley 2018).

Through framing my research interest in this way, I hope to gain deeper insights into the assumptions which motivate and guide pastoral care in settings where dementia is thought a factor which makes a difference between people and puts some in the position of caring professionals while others get constituted as those to be cared for. While this approach might translate into acts of increased self-reflexivity on the part of chaplains, critical objections might be raised by those who must live with the implications and consequences of what has been diagnosed as dementia. Does a perspective which focuses on the constructive character of dementia not overlook the fact that it cannot be undone simply by an interpretative act of (re-)framing? Indeed, this would be a charge justly laid at my door if my critique of the tragedy-discourse of dementia was blind to the very substantial transformations of brain and body that people living with progressive dementia must cope with day after day. Dementia, therefore, seems to be approached best as a complex, multidimensional syndrome. It is misunderstood if it is reduced either to mere biomedical explanations or to

cultural construction. Thus, instead of giving preference to reductionistic perspectives on either side, it seems helpful to look upon dementia as a complex socio-material figuration which gets even harder to grasp in sight of other intersecting categories of human differentiation, such as age, gender, or race. Drawing from Disability Studies (e. g., Schillmeier 2010) which try to overcome both naïve biologistic as well as culturalist assumptions, I prefer to look upon these differentiating categories as time-specific socio-material expressions of framing, making, and coping with difference. In short, my thoughts on the constructive dimensions of 'dementia-as-crisis' are not meant to downplay the manifold challenges people deal with in sight of the numerous and multi-layered changes dementia brings upon them and their families. But I would like to make a case for a little more reflexivity. For pausing and opening spaces wherein we might consider the role of pastoral care in the negotiation of dementia.

I first introduce examples of the 'dementia-as-crisis' narrative in the public spheres of politics and pop-culture. (1) This is continued by a consideration of what is achieved by labelling a situation as crisis. One effect is the emergence of expertise—people, organizations, or institutions who take care and work to generate knowledge to cope with the crisis. (2) Following this, I critically reflect upon practice literature circulating practical advice in the orbits of Practical Theology and pastoral/spiritual care. How does it contribute to the fabrication of dementia as a critical event? (3) I contrast the optic it reinforces with insights from my recent ethnographic research project with people living with dementia. (4) I conclude with some considerations on how Empirical Practical Theology might contribute to a culture of de-dramatization. (5)

Conceptions of Dementia as Crisis

Alzheimer's disease and other dementias have become some of the most feared conditions of late life. In 2012, the World Health Organisation (WHO) declared dementia a public health priority. In the same year, British Prime Minister David Cameron declared dementia a national crisis demanding "an all-out-fight-back," for it not only "steals lives and tears at the hearts of families", but it also increasingly troubles the country's health care system and upsets its economy (Cameron 2012). Rationales are similar on the other side of the Atlantic: NGOs like UsAgainstAlzheimer's raise large amounts of money to fight "The Alzheimer's Crisis", declaring that "Alzheimer's is not a normal part of aging – it is a devastating disease" which "can be emotionally and financially ruinous for families, caregivers, and society at large." (UsAgainstAlzheimer's 2021)

In western societies, dementia is perceived and publicly addressed as crisis—an assumption which might be spelled out on very different levels: a crisis for the individual, a care crisis (especially behind closed doors), a financial crisis, and, in sight of growing numbers, a global crisis. This view—which is not necessarily shared in other cultural contexts (Ikels 2002; Henderson and Henderson 2002) — goes largely unchallenged. On the contrary, it is supported instead by the media, art, and pop-culture. Amy Macdonald's song *Left that Body Long Ago* or Lisa Genova's novel *Still Alice,* which became a cinema success in 2014, are but a few examples of a growing body of pop-cultural thematizations which tend to stage dementia as a critical event and, furthermore, give flesh to the bone of what seems to make it so critical: stories of alienation and dependency, loss of autonomy, and, what is more, dignity and self. A rather alarming rationale seems to be at work on the backstage of the public 'dementia-as-crisis' discourse which correlates or even identifies autonomy, dignity, and self. Practical Theology, of course, has critically questioned this kind of anthropology (for the British context e. g., Swinton 2012; for the German context e. g., Fröchtling 2008). However, pastoral discourse and practice have not always proved resistant to the lures of the 'dementia-as-crisis' narrative. For, as I would like to argue in the next section, crisis creates expertise. And it creates necessities, which make it easier to hold one's ground in a situation of competitive worldviews and lifestyles.

Narratives of Crisis and Crisis Management

Practical Theology within the German context, and, especially discourse in context of pastoral care, has come to echo this perspective on dementia-as-critical event (Krause 2022; Pilgram-Frühauf 2021). Not in full agreement, of course; the economic rationale can be sharply criticized. However, the strong political urge to keep at bay what seems to be a rising dread in an aging society is rather instantaneously translated into arguments for pastoral action. A new

genre of training literature has emerged showing what can be done to spiritually support people and families coping with dementia. Having started as a side-topic in the 1990s, this literature has expanded rapidly over the last decade and filled meters of bookshelves. This is perhaps because it offers accessible and, what is more, applicable knowledge: knowledge of medical causes, resulting impairments and needs, and, most importantly, very practical ideas for pastoral intervention—ready-made solutions for those who rush into care homes a few hours in the week to offer pastoral care.

What is happening here? Obviously, what is feared as crisis is kept at bay through acts of professionalization which are meant to contain the uncertain and curb the unknown. Talk of 'crisis', as historian Rudolf Schlögl and sociologist Martin Endreß suggest, is a communicative act which gives shape to what is currently still an experience of the indefinite and obscure (Schlögl 2016; Endreß 2014). Crisis becomes a label taken up for lack of a consensual term to name a situation most participants do not yet have sufficient experience of. Talking of crisis or, a bit less pretentious, of critical events, therefore, is an act of constructing reality when routines fail. And it is an act which positions the speaker in relation to what is perceived as crisis to be someone who competently responds to irrefutable necessities. Crisis, in that sense, creates spheres of attention, generates decision makers, and produces positions of power. Those who decide and act in, what is thought to be and addressed as, crisis claim responsibilities while, at the same time, draw boundaries between what is taken to be ordinary routine and its 'other' which seems to be so very different. Framing a situation as crisis, therefore, is giving the world a particular shape and positioning oneself in a specific relationship to it. Narratives of crisis, therefore, do not necessarily say much about the situation itself. Rather, they reveal how it is looked upon and semantically configurated. This, in turn, leads us to look upon 'crisis' as an assessment or evaluation of a situation by observers, which themselves have to be critically observed in respect to the differences they draw and the power-positions they claim.

Discourse in Contexts of Pastoral Care as Perpetuation of Narratives of Crisis?

Against this background, professional discourse on dementia-related pastoral or spiritual care might also be analyzed as bringing about realities with specific effects. And in fact, a discourse-analytical reading sensitive to discursive constructions of binaries, binary-linkages, and the power they convey might well conclude that professional discourse—most particularly in the shape of practical advice on websites, journals, and in guidebooks—has a tendency to produce and reinforce an optic which corresponds in many ways to the cliché of 'dementia-as-crisis'. Paradoxically, this is also the case for authors who work hard to ensure recognition for people living and coping with dementia: "even caring communities can too easily become part of the problem, rather than the solution" (Kevern 2009, 208). Poimenical discourse works from the assumption that "[c]are is a gift from the church to those in need" (Kevern 2009, 206).[1]

The image that the genre of practitioners' literature tends to convey is that dementia makes people 'especially special': especially vulnerable, particularly emotional, in need of affectionate care, and best addressed with the help of multisensory practices speaking to body and senses. Correspondingly, a group of professionals gets configured, able to respond to the needs of the clientele. While this group

1 Kevern deals with this paradox by suggesting a change of perspective: Instead of focusing on what pastoral practice might offer, he reflects upon the gifts people with dementia bring to church. This line of argument is innovative, although it has not been taken up much during the last decade. Research on dementia and dementia-friendly communities in contexts of pastoral / spiritual care rather works from the assumption that to be a person living with dementia is to be in need of the communities' attention and assistance. At the same time Kevern's suggestion does not seem to go far enough. For the gifts, people living with dementia have to offer, mainly consist in being a continual memento of our human condition—an icon of the "uncomfortable truth, that all of us may at some time become disabled, impaired or different in our abilities, because this is simply human finitude" (Kevern 2009, 216). More recently, cultural anthropologist Harm-Peer Zimmermann has offered a cultural studies perspective on 'care' (Zimmermann 2019) which suggests to include self-care into the picture which makes for a more symmetrical conception of agency in light of dementia. People living with dementia in this light are seen as "capable of acting creatively and responsibly" (Zimmermann 2019, 24). This optic has been adopted by Franziska Pilgram-Frühauf (2021) who has been analyzing literature and training material in contexts of pastoral care with conclusions similar to my own (Krause 2022).

takes on an active role, offering stimulation and support, people living with dementia are pushed into the role of the receiving party. Agency, ability, and initiative are placed on one side, disability, vulnerability, and dependency on the other.

Complementing the binary roles are constructions of dementia as something which seems to dominate the whole personality. Practical advice on how to manage a situation so completely different from what one might expect in the parish does not leave much room for individuality. On the contrary, it appears to absorb everything which makes people special (apart from dementia) and pushes it into the background. Curiosity for other people turns into a therapeutic project. Telling one's story is primarily aimed at helping to stay connected to what might have been the former self and, so to speak, as a prophylaxis for a time, when communication is possible 'only' the long way round—by addressing body, senses, and emotions. People living with dementia thereby get positioned as primarily recieving (*patiens*); as particularly emotional (some)bodies in need of stimulation and activation, meant to work against the tailing off of their physical and intellectual abilities and to ensure as much of their autonomy for as long as possible. Professionals, conversely, are positioned as active and competent experts (*agens*) who take the initiative, rationally working upon the grounds of scientific knowledge to find innovative ways of managing the critical fact that these people are about to make a transition into what seems to be a state of getting lost into themselves.

Perfect materializations of this dichotomous construction (and essentialization) of the *agens* and *patiens* binary are giveaways. Made for the purpose of giving people something to hold on to, these objects are handed out as something to hold and touch which addresses people emotionally rather than intellectually as it is laden with memories and sensory experiences (Plieth 2012). Widely made use of in contexts of worship this object conveys a whole range of images of dementia and, what is more, turns them into graspable realities furnished with the evidence of what has become factual.

Irritating Field Experiences

But do these binary conceptions, working within the 'dementia-as-crisis' dispositive, match with field experience? Insights from my current ethnographic research project with people living with dementia in residential homes suggest a much more nuanced story. The backbone of the 'dementia-as-crisis' dispositive with its clear distribution of agency and vulnerability, rationality and emotionality, autonomy and dependency seems to take on a life of its own in the worlds of pastoral discourse. For what to make of Peter (names in the following are pseudonyms) who declared after having been offered anointing that he did not want to get a sticky mark on his forehead? Or Ludwig, urging the chatterbox next to him to shut up and collect herself for church service? And how to reconcile taken for granted assumptions of dementia with Elisabeth who angrily declared after a sermon on Ps 23 during which she was asked to hold tight to a rag of sheepskin that she did not come to be treated like an imbecile but expected to take something home from church worth thinking about? And how does the pastor who got into a muddle and forgot the words of the creed, fit into this picture? What to make of Martha, who took over and began to lead the congregation in a very clear and reassuring manner?

Completely immersed in professional discourse it took me a long time to realize that what I had to focus on were not what professionals assumed to be crucial needs of people living with dementia, but to do fieldwork on the socio-material processes, whereby dementia is 'done', staged, and maintained—in line with associated binaries and binary-linkages. Or, to put it differently: other than focusing on dis/abilities of people which seem to make all the difference, I would attend to practices of difference-making which give rise to asymmetrical positions such as the giving and the receiving, the disabled and its 'normal' other, the vulnerable and its counterpart construction of active, planning individuals. I had to realize that what distinguishes people and puts them into what seems to be a critical situation, is not only an assessment carried out by competent professionals, but a rather messy complex of socio-material activities and micro-practices which include a variety of participants such as skilled bodies, artefacts (like wheelchairs, altar-pieces or food), discourse, but also species like viruses and germs next to fluids, sounds, light and smells which contribute to positionings of the giving or receiving, the active or responding, of agency, and vulnerability.

To illustrate how these positionings get constructed and maintained let us, in an exemplary way, look at the micro-practices of smiling. In a dementia-ward one meets with a variety of smiles,

some of them enacting delight, surprise, or the pleasant feeling of taking part in something good. Also there are polite smiles, exchanged conventionally between professionals and so-called 'residents' in contexts of (rather frequent) greeting. However, there are also smiles which form alliances among those who know better, i. e., the social worker and her chaplain colleague. Beyond that, smiling can be a genuine effort to save face (Goffman 1967) and to preserve the dignity of a so-called 'resident' faced with lapses of self-control. Smiling, then, is a strategy to tactfully repair the awkwardness a wet seat of trousers has caused for the chaplain, who accidentally sat on an incontinent 'resident's' chair. And finally, there are those unsettling, strenuous looking professional smiles which, reminding us of Arlie Hochschild's concept of emotion work (Hochschild 2012), aim to create an atmosphere of assurance and acceptability in a situation which seems to be on the brink of turning into its opposite—smiles to manage not only what seems to be precarious, fragile, and constantly at risk but maybe also one's own fear of getting unsettled by the un-manageable.

Instead of a Conclusion: Analytical Optics Contributing to a More Balanced Perspective

In the previous sections I reflected upon constructions of dementia-as-crisis in both popular discourse and pastoral practice, asking how it is that pastoral care attends to them and what this might imply for power relations in professional practice. I have argued that picturing dementia as crisis brings about positionings of expertise—professional cultures of knowledge and practice who care and take care. I then moved to consider the often contradictory asymmetrical implications of the 'dementia-as-crisis' dispositive which positions some as caring and 'others' as cared for. My observations were initiated by irritating field experiences which forced me to change my point of view. From the outset I imagined my study as offering overdue empirical evidence to what seemed to be proven, if not best practice. But this is where I ran into difficulties. The work proved more challenging than I had expected. Research partners acted contrary to what seemed to be authoritative textbook knowledge. They were also critical towards pastoral intervention which seemed to enact the kind of dominance of those who know better. This forced me to think again of what I was about. I was pushed to attend to the rather messy and intricate processes which result in the positions of the professional and the so-called 'resident'. Due to an ethnographic research design which emphasizes self-reflectivity, I began to see the need to take a different route. Data pointed towards exploring the possibilities that accrue in moving dementia away from being a critical event to be managed. In the sequel I instead followed the complex ramifications of discourse and practice which seem to build into constructions of 'dementia-as-crisis'.

But how to conclude? There is no conclusive outcome here. At best, critical questions have been raised. In closing, therefore, I turn to my ongoing research activity, which, I hope, might contribute to telling a more nuanced story. For I do not intend to come up with another theory of 'dementia' or, concomitantly, dementia-friendly-practice in church. Rather, I would like to offer analytical ideas which aim at liquefying the asymmetric assumptions implied in the dementia-as-crisis-dispositive taken for granted in contexts of professional pastoral practice. My suggestion, in short, is to empirically dis-assemble and re-assemble the assemblages and networks of discourse and practice which seem to be at work and, more especially, to look for the obvious in rather unobvious and miniscule practices that give occasion to positions of dis/ability, agency, and vulnerability.

Instead of summarizing results, therefore, I go on raising (self-critical) questions. At this juncture, it seems to be the only way to address the fixations of the 'dementia-as-crisis' dispositive. The first to address is the question of one's own site or position. If it is true that constructions of 'dementia-as-crisis' make themselves felt and real, even through inconspicuous acts such as smiling—over which, it seems, we don't have much control—what hope is there to foster a culture of de-dramatization, if not de-essentialization? One cannot change one's cultural matrix nor can one escape its hold easily—neither as researcher nor as chaplain.

However, and this is my first suggestion, practical theology might develop a sense for divergent cases and stories where dementia does not seem to make much of a difference; or at least not such an overwhelming one (Ikels 2002). Stories, like I found in my data, where dementia is not hidden and managed as stigma, but offensively brought into play and even gambled with. Practical theology also might listen more attentively to the narratives of people living with dementia who take the view that it comes

along not only with losses but also with gains (Josuttis 2016, 121–132). This interest in counter-narratives, of course, is not meant to talk down the actual and very substantial challenges people living with dementia, together with those who stand by their sides trying to smooth the transition, confront. On the contrary—it is driven by a deep conviction that occasional changes of perspective might help to ease the way. Which is—this my second analytical suggestion—why I currently put much work into reflecting and decentering my own position and point of view as a researcher by asking self-critical questions: what implicit conceptions of 'dementia' and of 'worship' seem to have inscribed themselves into my data? Which institutional perspectives and discourse seem to determine my perception of things? How is this way of looking transferred and counter-transferred during research encounters? In what ways does my optic change during field-socialization? And, above all, how does my research impact me as a person? In what ways have I changed through my involvement into those various processes of concomitant becoming, reflection and counter-reflection?

This leads me to a third analytical strategy, which is trying to look over my own shoulder as if this ethnographer was a stranger to me to find out about her entanglements into the doings and un-doings of 'dementia-as-crisis'. Why, for example, does she feel the urge to save the situation when the pastor drew a blank and so-called 'residents' begin to moan, murmur, and shout against each other? Is she afraid that something (what exactly?) might atmospherically 'spill over'? If that is the case, where does her fear stem from? Has she finally also incorporated this rather peculiar professional gaze, which scans people's feet and facial expression at first to assess whether trouble might be expected which, in turn, must be managed? And why is she so obsessed with different kinds of rolling walkers and wheelchairs in her data? Obviously, people get depicted and categorized according to the technical support devices they are using. But why then does she call those sitting in enormous mobile recliner chairs 'the silent ones'? Does she look upon them as humans with technical devices or have they become machines to her with human proportions? And what do these binaries which seem to form her optic on different stages of 'cyborgisation' tell us about attributions of dis/ability, agency, and human dignity?

Cumbersome as this kind of data analysis might seem, it is my hope that by focusing (auto-)ethnographically on what seems to be taken for granted by the ethnographer herself and maintained in personal interaction, new leeway might be opened for alternative conceptions and narratives of people living with dementia in pastoral discourse and practice. This approach sets seemingly immovable essentializations of dementia into motion by telling a story of distributed agency. It shifts the focus from individuals to events brought to pass by humans and non-humans which relate within complex and ramified assemblages. Telling this story, of course, might turn out to be uncomfortable because narratives of distributed agency cannot easily be translated into applicable models of best practice. Rather than reducing complexity, this kind of empirical work tends to increase it. But I believe pastoral discourse and practice within the adaptive model is ready to cope with a bit more complexity, which, of course, might shake established professional routines of crisis at first and maybe even cause a crisis of expertise here and there. Much however, might be gained for this kind of self-reflexivity and could foster liberating experiences in practice not only for people living with dementia, but for all who care.

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