“Dementia” and “Good Dementia Care” in Denmark: Implications for Danish-Chinese Dementia Care Collaboration

Lillian Prueher

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Annette L. Fitzpatrick

James Pfeiffer

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University of Washington

Abstract

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Lillian Prueher

Chair of the Supervisory Committee:

Annette L. Fitzpatrick

Family Medicine, Epidemiology, and Global Health

As countries around the world grapple with how to provide effective dementia care to aging citizens, there is tremendous opportunity for both constructive cross-cultural collaboration and ineffective attempts at transplanting care models into cultural contexts where they do not meet local needs. In response to increasing interest and investment in Danish-Chinese elder care and dementia care collaborations, this study draws on qualitative data collected in Denmark and long-term ethnographic research in China to explore the limitations and potentials of these collaborations. Specifically, this study explores (1) Danish understandings of what dementia is and (2) how understandings of "good dementia care" are influenced by those conceptions of dementia. In Denmark, semi-structured interviews (n=13) and direct, naturalistic observations at two care sites (n=3) were carried out in the Fall of 2016. Analysis in this project also draws on 16 months of ethnographic fieldwork carried out in Sichuan, China primarily in 2017-2018. Results of this study revealed that participants tended to understand "dementia" in terms of how it was experienced by individuals, how it fit into individuals' existing relationships to the Danish

state, and as a condition with shifting associations to stigma. “Good dementia care” was described in terms of its complexity, the way it required caregivers to use new forms of communication, its relationship to specialized caregiving spaces and institutional environments, its reliance on a “professional” workforce, and the idea that “good dementia care” is an ideal that is limited by real world constraints in practice. Differences in expectations of family member involvement in dementia care sites, in volunteerism, and in political economic activism among older adults were identified as potentially limiting factors in successful collaborations. Infrastructure and systems support were also found to be potential barriers for partnerships. In contrast, collaborations around caring for violent or difficult residents, addressing the limitations of a person-centered care approach, and finding ways to strengthen non-state-provided dementia care systems and support family caregivers offered more promise. This study raises important issues for consideration when evaluating or developing Danish-Chinese elder care collaborations and suggests developing new care frameworks, engaging and supporting family caregivers, and finding new ways to manage difficult or violent residents offer especially promising areas for such partnerships.

Introduction

Cross-Cultural Collaborations in Elder Care

The world is aging at an increasingly rapid rate, demanding new responses from public health practitioners, elder care providers, and society at large (*WHO | World Report on Ageing and Health 2015*, vii). As a 2014 editorial in The Lancet described, "current elderly care systems worldwide are already unable to address the soaring demand from fast growing numbers of older people, even in higher-income countries" ("Global Elderly Care in Crisis," 2014). Caring for aging populations offers a tremendous challenges as the "elderly support ratio"[1] is projected to drop to as low as 1 (in Japan) and below 20 for all countries by 2050 (Tsai & Kaneda, 2010). This shift will create new challenges for balancing formal and informal caregiving systems, incentivizing young people to become elder care providers, and responding to daily care needs as people age.

As countries around the world work to respond to these challenges, there is tremendous potential for productive, cross-cultural elder care collaborations to develop. Anthropology and Anthropological approaches offer an especially rich set of methodologies for studying and understanding such collaborations. As Closser et al. explain (Closser et al., 2016), Anthropology is a field that implicitly grew out of cross-cultural comparisons when Euro-American researchers analyzed and compared cultures around the world (Boas, 1896; Lévi-Strauss, 1969; Morgan, 1870). Unlike the way these early anthropological studies often relied on second-hand data, however, this project strives for what Closser et al. describe as "comparative ethnographies relying on in-depth research [that] pull together data from several ethnographic studies,

[1] The elderly support ratio is defined as "the number of working-age people ages 15 to 64 divided by the number of people 65 or older" (Tsai & Kaneda, 2010).

conducted using somewhat different methodologies" (Closser et al., 2016). This project thus follows in the footsteps of more recent comparative ethnographies (Hodgson, 2002; Kingfisher & Goldsmith, 2001; Whyte, 2009).

One challenge in assessing different elder care approaches and trying to determine which kinds of collaborations might be most promising is the limited comparative models available in scholarly literature on elder care and dementia care, in particular. In Anthropology, much of the writing on elder care and dementia care has focused explicitly on high-resource, Euro-American care settings investing in cutting edge care practices (Harbers et al., 2002; Hendriks, 2012; Moser, 2010). These studies have contributed to theoretical discussions of what "personhood" actually means and how it can shift and become enacted in new ways for individuals living with dementia (Buch, 2013; Hellström et al., 2005; Lamb, 2014; Leibing & Cohen, 2006; Taylor, 2010). In particular, researchers have explored how the "value" of a life can get communicated in new ways once advanced cognitive impairment makes verbal communication untenable (Kontos, 2006; Mol, 2010; Pols, 2005). Unfortunately, research connecting literature on "care" to serious analyses of how political economy and local contexts can influence care outcomes in less high-resource settings has been more limited (Brijnath, 2014; Buch, 2018; Livingston, 2012). By bringing together analyses of dementia care in the dramatically different resource settings China and Denmark offer, this study aims to bridge these conversations and explore comparisons that engage larger discussions of the inherently fraught nature of defining "good care" in the first place (Brown, 2010; McKearney, 2020; Mol, 2008).

Why study Denmark and China?

Examining elder care dynamics within and between Denmark and China offers a valuable opportunity to contribute to emerging scholarship on evaluations and practices of "good" elder care in general and to facilitate the development of more successful Danish-Chinese elder care partnerships. Though these countries seem very different on the surface, the governments of both are interested in building collaborations that would allow their care providers to "learn from each other and develop their expertise" (Liao, 2015). The openness to investigating and developing new forms of elder care and the state commitments to supporting aging populations in Denmark and in China make elder care collaborations between these countries especially promising. To date, these collaborations have included everything from Danish elder care training programs in China (Marcincowski, 2015), to the opening of a Danish nursing home in China (*First Danish Nursing Home in China Opens Its Doors · Healthcare DENMARK*, 2015), to care providers and concepts moving between Danish and Chinese settings as clinicians and policy makers gather at summits to build and strengthen partnerships (Lund, 2018). Evaluating existing and prospective elder care collaborations between these countries is integral to their success, but it is also complicated. This project provides a small-scale example of how attention to differences in resource availabilities, care practices, and care expectations in these two countries can inform the way care approaches are evaluated and their potential for successfully translating across these contexts.

On both sides, financial incentives are a driving force behind emerging Danish-Chinese elder care collaborations. On the Danish side, as one Danish health services researcher interviewed in this study described it, "there's a lot of investment in new healthcare technologies…we see it as a possibility for…sustain[ing] the welfare state". In other words, the more Denmark can create and *successfully* export "Danish elder care" approaches abroad (to

China and elsewhere) the more resources the Danish state will have available to provide elder care services to its own citizens. On the Chinese side, a burgeoning elder care market (Chu & Chi, 2008; Zhang, 2017) full of private and private-public elder care providers interested in distinguishing themselves from competitors can make any specialization into a selling point. While the Directors of some care sites in China would highlight collaborations with local Chinese gerontologists as a form of unofficial credentialing for their facilities (Prueher, Forthcoming), access to "European" or "Danish" expertise or care models also offers a valuable potential edge when it comes to marketing Chinese facilities. With such strong financial incentives on both sides, it is important to step back and consider the comparative usefulness or appropriateness of different possible elder care collaborations between these two settings. Otherwise, superficial partnerships may be attempted for purely financial gain without actually serving the needs of care recipients, their families, or their caregivers.

Danish and Chinese Elder Care Landscapes

Denmark and China are similar in that both their populations are aging at dramatic rates. In Denmark, the percentage of the population age 65+ is projected to rise from 16% in 2010 (Needham, 2013) to approximately 25% by 2050 (OECD, 2017). According to the National Bureau of Statistics of China and the Chinese Ministry of Civil Affairs Report, the percentage of the Chinese population age 65+ is projected to triple, rising from approximately 8.87% in 2010 to 27% by 2050 (Yeung & Xu, 2012). In both countries, these changes represent significant demographic shifts, drawing both government investment and societal interest in elder care systems and approaches.

Both countries also face elder care challenges related to developing and sustaining adequate populations of people who can work as caregivers for their aging populations. Even while Denmark's long-term care investments are more than double the average percentage of GDP invested by the EU overall (4.5% in Denmark vs. 1.8% in the EU-28), data show that in "up to 30 percent of cases where care is given daily" in Denmark that care is still provided exclusively by friends and family (*Rising Need for Elder Care in Europe Necessitates New Paradigm for Elder Caregiving Training: A Landscape Analysis*, 2017). While Denmark currently provides good care options for older adults overall, "costs and labour demands of an aging population could strain these extensive LTC systems in the near future" (ibid). In China, Feng et al. describe caregiving challenges related to comparatively low levels of public long-term care spending (Feng et al., 2020). Specifically, public long-term care spending in China in 2010 was approximately 0.1% of GDP, as opposed to approximately 0.8% in OECD countries (Maisonneuve & Martins, 2015). In addition to lower public funding levels, there is also a caregiver shortage in China with "an estimated 300,000 registered long-term care workers nationwide and over 40 million older people with disabilities who need care (much of that care is provided by family caregivers at present)" (Feng et al., 2020).

In both Denmark and China, the state's interest in elder care provision is also shaped by particular local histories, social welfare systems, and government provided services. The Danish context, what can be understood as a "Nordic health care system", has undergone significant reforms and financial restructuring since the 1970's, with increasing, though still limited, privatization beginning around the 1990's (Magnussen et al., 2009). The result is a deeply engrained sense that (at least in theory) all Danish citizens are entitled to equal access to support from the Danish state. However, attempts to reserve institutional elder care facilities for those

most in need of support have resulted in nearly 60% of all patients in Danish elder care facilities having a dementia diagnosis (Ministry of Health, 2016). As the state works to strike a balance between community provided and institutionally provided elder care and dementia care, new policies are frequently put forward and negotiated, even as recently as 2016 (Ministry of Health, 2017). With an in-depth Dementia Action Plan (ibid) and attempts to create and expand a "dementia friendly" society in Denmark, the state seems to be encouraging and supporting older Danes to age in place for as long as possible. Not only is this less costly for the state than paying to keep aging citizens in fully staffed elder care facilities, but it is also seen as offering an inherently higher quality of life to all but the most severely cognitively impaired individuals.

In the Chinese context, a "social welfare system rooted in its socialist ideology and planned economic system" was developed in the 1950's (Cai et al., 2018: 816). This system was modified over time as the state moved away from its (at least theoretically) all-encompassing social welfare system providing an "iron rice bowl" for all citizens to a system offering stratified levels of support (Frazier, 2010). After significant cutbacks in the 1990's, the Chinese social welfare system continued to develop as public investments were made in education, healthcare, and pension support up through the present day (ibid: 816-818). The stratified levels of state support for citizens' access to elder care remains today, and the degree of support individuals receive from the state depends on a range of factors, including their degree of familial support, whether they live in urban or rural areas, whether they were previously employed by the state, and in what capacity they were employed. For those whose families or pensions allow them to afford high-end in-home care or institutional elder care, there are many options (Feng et al., 2020). Based on visits to a range of dementia care wards in Sichuan, it seems those without as many financial resources generally tried to stay at home as long as possible – either hiring a live-

in aide (保姆）or relying on adult children to provide elder care – before turning to whatever level of institutional care families could afford once staying at home became unsustainable.

Research Approach

This project analyzed qualitative findings from research conducted in Denmark in the context of longer-term ethnographic research carried out at elder care and dementia care sites in China. Through interviews and observations with Danish and Chinese researchers, elder care providers and policy makers, as well as informal interviews with a range of elder care recipients and family members in China, this project asks: What are the limitations and potentials for elder care collaborations between these two countries? To address this, one must first examine how "dementia" and "good dementia care" are conceived within Denmark and how understandings of these concepts might be different in China. While such a small study cannot produce generalizable findings, it offers insights and potential starting points for anyone considering embarking upon or evaluating such collaborations in the future.

Specific Aims

This project focuses on examining conceptions and provisions of elder care and dementia care operating in the Danish welfare state. It does so in an effort to better understand whether and how aspects of Danish care models might effectively operate in mainland China. This project thus responds to increasing Danish-Chinese collaborations around elder care. Specifically, this project addresses the following questions:

1. What are the goals and ideals related to "good" elder care and dementia care in Danish research settings, care settings, and policy settings, and how do these ideals shape care practices?
2. What resources – financial, personnel, physical, etc. – are most important in shaping Danish elder care ideals and practices?
3. How does the state shape elder care conceptions and practices in Denmark?
    a. In relation to the welfare state, how are elder care and dementia care in Denmark understood and enacted in uniquely *Danish* ways (relative to China)?
    b. What are key similarities and differences between Danish and Chinese elder care and what implications might those have for potential collaborations between these countries?

Through its engagement with these questions, and as a study of Danish care systems aimed at facilitating cross-cultural collaboration, this research stands to enrich elder care partnerships currently emerging between Denmark, China, and, potentially, other nations, as well.

Design and Methods

Overview

This paper incorporates research from two projects that both employed a grounded theory, exploratory, qualitative approach to understand how differing local contexts may complicate collaborative elder care models. The first and primary study undertaken was a six-week project carried out in 2016 exploring how participants perceived and shaped elder care and

dementia care practices in Denmark. The second and supporting study was a long-term ethnographic project on institutional dementia care in mainland China carried out over more than 16 months between 2015 and 2019. For both projects, subjective and open-ended research questions made a more deductive, positivist, hypothesis-driven approach inappropriate (Bernard & Ryan, 2010). Instead, data were collected in a grounded theory spirit to allow for flexible, open-ended, ethnographic work that could help "build theory from data" (Corbin & Strauss, 2008). Data in Denmark were collected mainly through one-time qualitative interviews. To help contextualize interview data collected in Denmark, data were also collected via observations at two Danish dementia care sites and at academic workshops and Center for Healthy Aging meetings at the University of Copenhagen. In China, more extensive data collection was done through repeated semi-structured and unstructured interviews, as well as various forms of observation.

Sampling and Recruitment

Interview sampling strategy involved purposive and snowball sampling in both Denmark and China.

In Denmark, three categories of participants were interviewed: researchers (n=6), elder care providers (n=4), and policy makers (n=2). Participants in all three groups were identified in one of two ways. Purposive sampling was used to connect the researcher with scholars engaged in applied research related to aging and/or the Danish welfare state's service provisions[2]. As

[2] Given the breadth of this category of researchers, it is impossible to define the sampling frame for this group. There are dozens, if not hundreds, of researchers in Denmark who engage in applied research related to aging and/or the Danish welfare state's service provisions. Given the limitations on available time, the researcher focused on connecting with scholars accessible via professional networks to which she had access, prioritizing those with more extensive experience

much as possible, the researcher sought to connect with scholars whose work impacted or was impacted by dementia care policies, particularly the Dementia Action Plan that had recently come out at the time of data collection. Likewise, the policy makers sought out in this study were selected based on either having worked directly on the Dementia Action Plan or having worked regularly to coordinate dementia care services within Denmark. As much as possible, the researcher drew on her connections to researchers at University of Copenhagen, the University of Washington, or her broader professional network to connect with participants. Snowball sampling was also used to extend the number of people interviewed or observed in this project as interviewees were asked to recommend other people in their professional networks whose work related to elder care or dementia care in Denmark and who might be interested in participating in the project at the end of each interview session.

In China, the researcher primarily used snowball sampling in an effort to speak with as many people connected to the primary research site as possible. This included administrators, doctors, nurses, nurse's aides, cleaning staff, nutrition staff, rehabilitation therapists, residents, residents' family members, and researchers and other specialists who worked with the site. Snowball sampling began with the researcher's connection to the main director of the facility and continued as the researcher built relationships with family, staff, and residents in the facility's dementia care ward over the course of three rounds of pilot research and approximately six months of initial observations and informal interviews. Formal interviews began with administrators, doctors, nurses, nurse's aides, and family members and then each person who agreed to be interviewed from this first group of contacts was asked if there were other people in

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in aging and dementia related research, while also attempting maximize the diversity of participants' academic backgrounds.

their role who they could recommend the researcher contact about being interviewed. Between pilot research and the completion of long-term fieldwork, key informants were interviewed up to three times to assess changes in their experiences or perceptions of the care site. Purposive sampling was also used to reach out to elder care policy experts in Sichuan and to select as diverse a range of elder care facilities as possible to visit as part of (1) selecting the primary research site and (2) providing context for data collected there.

All research protocols for data collected in Denmark and in China were separately approved by the University of Washington Human Subjects Division's Institutional Review Board (IRB). Research protocols for data collected in China were also evaluated, approved, and covered under human subjects authorization via the Sichuan University West China Research Center for Rural Health Development.

Data Collection in Denmark

Data in Denmark were collected between September 2016 and December 2016 via semi-structured interviews and direct (Bernard & Ryan, 2010), naturalistic (Angrosino & Rosenberg, 2012) observations at elder care sites, government offices, and academic and research settings. Interviews ranged from thirty minutes and two hours, with an average length of approximately 50 minutes. Interviews focused on participants' professional backgrounds, how they thought about their work, how they saw their work in relation to Danish elder care or dementia care systems in Denmark, and how they saw their work in relation to the Danish state (see Appendix A: Interview Guide). Follow up questions were also asked to prompt participants to describe their views on how dementia impacted people's lives and how effective current systems were at meeting the needs of people with dementia and their families.

Thirteen interviews were carried out with twelve interviewees. One of the two policy makers' experiences were especially rich, and she consented to be interviewed twice. All other participants were interviewed once. Interviews took place primarily in English and primarily with only the researcher present. For two interviews (one with an elder care provider and one with a policy maker), the interviews were carried out in a mix of English and Danish with two scholars from the University of Copenhagen co-interviewing and assisting with real time Danish-English translations. Interview locations were chosen by the interviewees and took place in a range of venues, including interviewees' workplaces (n=7), their homes (n=2), or in public settings like a restaurant (n=1) or café (n=1). Due to logistical constraints, a small number of interviews were carried out remotely via Skype video chat (n=2). Unless interviewees declined (n=2), all interviews were audio recorded and pertinent sections of all interviews were transcribed by the researcher.

Direct (Bernard & Ryan, 2010), naturalistic (Angrosino & Rosenberg, 2012) observations were also carried out at two dementia care sites in Denmark[3]. The first was an urban dementia care site in Copenhagen that was selected because it was considered to be a standard bearer for "good dementia care" in Denmark. The researcher conducted an interview with the facility director and one day of observations with two University of Copenhagen researchers at this site. The second was a rural dementia care site in Southern Denmark. This second site was selected because a policy maker recommended it as an example of a less well funded site that still

[3] As of 2018 there were 30 memory clinics, or specialized dementia care sites, in Denmark and a government plan to "reduce that number by half" as part of the National Action Plan for Dementia 2025 "in order to promote further multi-disciplinary specialization, uniformity of diagnostic procedures, and a faster process of diagnostic procedure and initiation of treatment" and movement toward a more dementia friendly society (*Denmark – a Dementia Friendly Society*, 2018).

provided "good dementia care," and because that policy maker provided an introduction for the researcher to connect with leadership at that site. This made observations there logistically feasible, and the researcher conducted two days of observations and interviews independently at this second site. At both facilities, observations focused on how participants engaged with other people in their line of work, how they engaged with the physical environments within which they worked, how they engaged with people outside their line of work (e.g. other professionals, dementia care recipients, visitors to care sites, etc.), and how other people in the caregiving environment seemed to engage with participants (see Appendix B: Observation Guide). The goal of these observations was to give the researcher context for how closely academic and policy focused participants' descriptions of dementia care mirrored dementia care practices and care providers' experiences of their work. Field notes were recorded manually and then typed by the researcher following all observations.

Data Collection in China

Data in China were collected by the researcher during a long-term ethnographic project in Sichuan province. This project included over 500 hours of direct (Bernard & Ryan, 2010), naturalistic (Angrosino & Rosenberg, 2012) observations, limited degrees of participant observation (Bernard & Ryan, 2010) and over 40 hours of recorded semi-structured interviews with dementia care providers, researchers, policy makers, and families conducted by the researcher in Mandarin over the course of over 16 months between 2015 and 2019 (primarily 2017-2018). Due to the longer-term nature of this project, many unrecorded, unstructured interviews and observations were also carried out as the researcher became acquainted with people connected to the primary research site. Semi-structured interviews focused on

participants' background, their perceptions of their work, and their feelings about dementia and the other people they interacted with in dementia care settings (e.g. professionals, family members, care recipients, etc.), with tailored interview guides based on the role of the participant (e.g. administrator vs. doctor vs. nurse/nurse's aide vs. family member).Unrecorded, unstructured interviews were carried out with elder care recipients throughout the project. While most observations were focused on understanding how different groups of participants interacted with one another and with their physical environment in a dementia care ward, structured observations were also carried out using Dementia Care Mapping techniques (*Dementia Care Mapping*, 2020). Analysis and discussion here engaged with the primary themes synthesized from the observational and interview data collected in China. Data collection was primarily based at an urban, private dementia care ward. Unless participants declined, all semi-structured interviews were audio-recorded and pertinent sections of each interview were transcribed and translated by the researcher.

Data Analysis

In an effort to identify and validate trends as they emerged, preliminary findings from data collected in Denmark were shared with a team of local researchers at the University of Copenhagen throughout the data collection process. Data were then coded and analyzed by the researcher using ATLAS.ti with an inductive coding approach to keep findings grounded in the empirical data (Miles et al., 2014). A code book was developed and modified in an iterative approach throughout the analysis process (see Appendix C: Codebook). This entailed creating new codes and deleting, splitting or merging existing codes over the course of data analysis. The final code book included 78 codes, each associated with an average of 13.6 quotations in the data

(minimum: 2 quotations; maximum: 58 quotations). Using a bottom-up approach, codes were organized into "categories" or "themes" in the data (Corbin & Strauss, 2008). Themes were then grouped and presented according to the research question to which they most closely related.

Results

As shown in Table 1, interviewees in Denmark came from a range of professional backgrounds. Broadly, they included researchers (n=6), elder care providers (n=4), and policy makers (n=2). All researcher participants had received a doctorate in a field related to their research, except for one of the occupational therapists who had worked in her field for over thirty years at the time she was interviewed. The two elder care providers who were directors of elder care facilities each had a master's degree, and the two nurse's aides had completed the 1-2-year training programs required of nurse's aides within Denmark. Both of the policy maker participants had a background in nursing. Participants were predominantly women (n = 11) and all were White.

Table 1: Interviewee Characteristics

Researchers, *n*	6
- Chronic illness researcher	1
- Researcher with occupational therapy background	3
- Health services researcher	2
Elder care Providers, *n*	4
- Director of elder care facility	2
- Nurse's aide	2
Policy Makers, *n*	2
- Dementia Coordinator	1

- Public Health Official	1
Gender, *n*	
- Female	11
- Male	1

How Participants Understood "Dementia"

Several key themes emerged related to how Danish participants understood what "dementia" was and its impact on the people and families living with it. Participants described "dementia" in terms of how it was experienced by individuals (Theme 1), how it fit into individuals' existing relationships to the Danish state (Theme 2 and Theme 3), and as a condition with shifting associations to stigma (Theme 4).

Theme 1: Dementia experienced in variable ways

Participants described dementia as a highly variable medical condition that could create a wide range of experiences for individuals and families confronted with it (see Table 2). Multiple participants described dementia as something that manifested differently in each individual case (Quote 1). As a result, participants also tended to perceive care needs of people living with dementia as highly variable, which they also saw as having implications for caregiving institutions catering to people with different types of dementia (Quote 2). People's prognoses and abilities to "rehabilitate" were also understood to be highly variable for those living with dementia (Quote 3).

Table 2: Descriptions of dementia experienced in variable ways

Quote Number	Example Quotes
1	"[I]n Denmark we say every person with dementia should be met as a unique person and there are 200 reasons for having dementia or 200 different kinds

	of dementia you could have…you have to look at the person, and environment and family, and you cannot make a formula." (researcher)
2	"Some people with dementia must not be stimulated…They just need everything to be calm, and no activities, just nothing…they can't handle it. And some people must be stimulated…if you have those two kind[s] of people together, it's difficult." (policy maker)
3	"[I]f we get in contact with people who are suffering from dementia very early…by doing hard physical training and cognitive [training] you can make them more self-sufficient. For a longer period…we're going to have a new healthcare health center, it's where our rehabilitation is going to take place…we're going to make a special offer for people suffering from early dementia to go three times a week doing half physical activities and cognitive training." (policy maker)

Theme 2: State responsibility to offer dementia support

All participants described dementia as a condition for which the Danish state had a responsibility to help citizens manage (See Table 3). They framed this responsibility in terms of historical precedents for state involvement in care within Denmark (Quote 4), in terms of patient entitlements to healthcare more broadly within Denmark (Quote 5), and in terms of family caregiver entitlements to support from the Danish state (Quote 6).

Table 3: Descriptions of the state responsibility to offer dementia support

Quote Number	Example Quotes
4	"We have this older generation born after the second World War, who built society but also grew up with pretty high expectations in terms of what the state is supposed to give." (researcher)
5	"In the Danish health care law…there has to be…equal access [to care] according to need." (researcher)
6	"[We] talk much about the user involvement and also family involvement…the municipality is trying to…[have] people being at home and for longest as possible. It also spare[s] the municipality [money], but it can also be a good human strategy. Just, we have to ensure that the relatives are not [burning] out…[families] are very important…for supporting their demented relatives, so we should support them….and we're trying to, but it can still be better." (researcher)

Theme 3: Dementia discourse shaped by citizen rights

Related to Theme 2, participants described a political landscape in which older adults wielded significant political and economic power, situating discussions of dementia care in the broader context of citizen rights in Denmark (See Table 4). This occurred both in discussions of the political will and financial resources older Danes had (Quote 7) and discussions of all Danish citizens' entitlement to equal treatment from the state (Quote 8).

Table 4: Descriptions of dementia discourse shaped by citizen rights

Quote Number	Example Quotes
7	"DaneAge for example…the political impact they have is immense. They have 800,000 members in the population of five-and-a-half million….[I]t's like every second retired citizen…that is part of this huge organization…the national budgets for next year is being agreed upon in these days, and…the head of that organization is…in the assembly…they are so important." (researcher)
8	"[The resources available for care] depends on the communities…the Danish system trie[s] to treat people equal." (researcher)

Theme 4: Dementia as stigmatized but perhaps unnecessarily

Dementia was seen as both stigmatized in contemporary Danish society – framed in terms of various forms of "loss" (Quote 9) or "fear" (Quote 10) – and as a condition that people in Danish society were actively working to make less stigmatized (See Table 5). Participants described active efforts to destigmatize dementia through "dementia friends" programs (Quote 11) and theoretical and clinical work related to dementia care that argued high quality of life was still possible for those living with dementia (Quote 12).

Table 5: Descriptions of dementia as stigmatized but perhaps unnecessarily

Quote Number	Example Quotes
9	"[I]n the narratives of the fourth age…that expected loss of self, which is in…being diagnosed with dementia…that's very massive." (researcher)
10	"The residents are…ashamed of this disease and everybody fears to get it. Nobody says 'When I get old, I want to be demented' Nobody say[s] that. Everybody say[s] 'I hope I not going to be demented.'" (elder care provider)
11	"We have the Alzheimer organization…they want 100,000 dementia friends…they [have] reached the half[way point]…all the municipalities are trying to get dementia friends. I think what they're looking for is that everybody should know at least just a little a little bit about dementia…So they know how to help and how to support. Not looking the other way" (researcher)
12	"[T]hey're trying to push an idea of life with dementia as something that can also be good…one of the big models at the moment in Denmark is this flower model…if we can create the good soil then people can blossom again." (researcher)

How Participants Understood "Good Dementia Care"

Key themes also emerged related to how participants described their understandings of what "good dementia care" entailed in Demark. Participants described seeing "good dementia care" in terms of its complexity (Theme 5), its reliance on new forms of communication (Theme 6), its relationship to specialized caregiving spaces and institutional environments (Theme 7), its reliance on a "professional" workforce (Theme 8) and the idea that "good dementia care" is an ideal that is limited by real world constraints in practice (Theme 9).

Theme 5: Good dementia care relies on a complex system

Participants described good dementia care in Denmark as broadly happening within the context of the bureaucratically complex Danish welfare state (See Table 6). This occurred whether they were remarking on the need for having bureaucratic infrastructure in place to help care recipients navigate the welfare system (Quote 13), having large-scale collaborations within

civil society to plan and coordinate care responses (Quote 14), having "systematic" care techniques to address the complexity of each individual case (Quote 15), or having highly educated caregivers with the capacity to respond to a wide range of difficult behaviors (Quote 16).

Table 6: Descriptions of good dementia care relying on a complex system

Quote Number	Example Quotes
13	"I think one of the most important things [is] our welfare system. And therefore the organization of the welfare system and the care system for people with dementia. We have a lot of municipalities, but each of these [has] some kind of organization. Some are better than others, but it's very normal in all municipalities for example to have a…dementia coordinator…arranging and helping, supporting [patients and families], [and] also [working] across different barriers and across different sectors." (researcher)
14	"[The Dementia Action Plan is] a good start because when the government…catche[s] their eyes [on] something, it is good. [But] we should not think that they have the solutions for everything. We have to get the solutions together…they have said that dementia is one agenda, but we don't have one solutions. And we need to create the solutions together." (elder care provider)
15	"[With the flower method] If people are not like a bright flower…then there's a systematic way to try to find out, ok, what, why is this person so depressed or so sad or so aggressive…it's one person educated to use that technique and then you take a number of people working with that person, some of them from the day shift, from the evening shift, from the night shift, a nurse and social healthcare people, and then they systematically discover this person. And I have observed some of those sessions, and it's fantastic to see how…they see this man – he's aggressive, his wife is afraid to be near him and…the people working there are afraid of walking in the door…and then when they have that session and systematically go through this person all the way around, they see something else than [what] they saw before. It's so fantastic…they see another person and they understand what's going on and then they can change [the] way [they] work [with that] person." (policy maker)
16	"[S]taff hasn't got the skills to make a good analysis of what they are able to do. They're sort of listening to [patients'] language, but they are not realizing how [patients'] abstract thinking [has] changed…you must talk [to patients]… but you should be believing your observations…[staff] at all levels…doesn't understand that this abstract thinking is changed." (researcher)

Theme 6: Good dementia care requires new forms of communication

Nearly all participants described communication challenges inherent to working with people living with dementia and the need to find new ways to overcome those challenges in order to provide good dementia care (See Table 7). Some focused on the need to engage people living with dementia directly as opposed to via family proxies (Quote 17). Others pointed to the need for valuing embodied communication (Quote 18) or being creative about using observations or other non-verbal techniques to identify and respond to patients' needs (Quote 19).

Table 7: Descriptions of good dementia care requiring new forms of communication

Quote Number	Example Quotes
17	"[I]n Denmark there is a huge focus on user involvement. On nothing about us without us and all that kind of policies…but when it comes to dementia, the subject…the spoken subject is the relative. So you are kind of, you're erased or something as a person with dementia. You're not expected to have a voice of your own." (researcher)
18	"The Occupational Therapy way [is best]…show them! Because they'll mirror you." (researcher)
19	"[I]t's very difficult to discover if people with dementia have a somatic disease because they can't explain…they systematically took blood samples and all kind of things to make sure that [patients] were not somatically ill because that might be a thing that make[s] them aggressive…They could be in pain." (policy maker)

Theme 7: Good dementia care enhanced by caregiving environments

The physical infrastructure of care sites was identified by several participants as contributing to good dementia care (See Table 8). In particular, the design of care sites was seen as reinforcing caregiving philosophies (Quote 20) and reflecting or reinforcing shifting priorities as new caregiving approaches were developed (Quote 21).

Table 8: Descriptions of good dementia care being enhanced by caregiving environments

Quote Number	Example Quotes
20	"[The care site] LOOKS like a family…They are sitting in the living room and now they are going to the dining room *laughs a little*…sometimes you need some…visual-like explanations to make people understand what you want them to do. So perhaps it…might have been a way for [the site director] to explain what she wanted. 'I want this to be like a family'…that would make everybody…have a kind of understanding, 'oh that's what she wants.'" (policy maker)
21	"[L]ast five years in Denmark there has been a tendency to [say]… the home has been moved away from the nursing home…the kitchens weren't really there…You don't bring a hammer to a nursing home. You bring your photo. A picture of your family, right?...But these utensils and stuff like that, it's part of making a home a home. So they have moved the kitchen back in in a lot of places. And…now there are…locked doors to the kitchens because it was too dangerous…for the people living there…even though there are these moral ideals…there are also all these instances where it's not really possible. That they're seeing it as something that is a bit too dangerous and then they're putting up obstacles for doing it." (researcher)

Theme 8: Good dementia care requires "professional" caregivers

Participants often described "professional" staff as essential to the provision of good dementia care (See Table 9). In describing what made for ideal, "professional" caregivers, participants discussed an ability to provide person-centered care that engaged the care recipient in caregiving processes (Quote 22). Participants also described professionalization as an ongoing process throughout caregivers' careers (Quote 23) and as something that was especially important when dementia caregivers needed to respond to aggressive or difficult patients (Quote 24).

Table 9: Descriptions of good dementia care requiring "professional" caregivers

Quote Number	Example Quotes
22	"The ideal mindset is that you have to discover the person. What kind of person is this? And then you have to change the way you work with that person so that it fits with that specific person." (policy maker)

23	"[T]he training of the professionals, it's a continuing process. It never stops." (researcher)
24	"[P]eople suffering from dementia…a lot of them act…very aggressive. And we had so many problems handling that. Because the staff…working at the nursing homes, traditionally they are not very well educated. Now we are trying to get more people more education, but it's going to take a long time…they didn't have the knowledge, and they didn't have the nerves to handle those people…they were scared, and we have terrible situations where the people with dementia were kicking other people with dementia or their relatives or the people working there. We have had broken arms and things like that. So we had to do something completely different." (policy maker)

Theme 9: Good dementia care as an ideal limited by real world inequalities in practice

Participants described myriad ways in which good dementia care was an ideal that could not be fully attained in practice (See Table 10). Some emphasized the financial realities limiting caregiving capacities within Denmark (Quote 25). Others pointed to various forms of inequality inherent to the Danish welfare state, including unequal levels of support some families received from the state (Quote 26), unequal understandings of and abilities to navigate the bureaucracy of the welfare state in order to obtain care (Quote 27), or unequal care resulting from prejudices against migrants and ethnic minorities within Denmark (Quote 28) or from how well a person's caregiving needs happened to aligned with the services provided in his or her area (Quote 29).

Table 10: Descriptions of good dementia care as an ideal limited by real world inequalities in practice

Quote Number	Example Quotes
25	"I have the money I have, and I have to make things run…I can't just have extra…I have a budget of 800 million Krona…300 million Krona is paying to for people to go to hospital…all people. Little children and people having birth…so that's a large part of my budget." (policy maker)
26	"[First generation immigrants] are still in the situation where they have to care for their older people. It's more expensive for them to have an old person in a nursing home than it is for a Danish family. So there is a [real] inequality…when…you've been accepted to stay in Denmark and to have the

	rights to stay and live here, and then you ask to have your mom or dad brought to Denmark as well. And then you have to sign [a document saying] that you will promise the Danish government that you will take care of the older people economically. So there is much poverty [from] taking care of older people from other countries. They have to care for [those older relatives] and they do not have much money themselves." (researcher)
27	"I have tons of examples of well-functioning older ethnic Danes who get three home visits a day for absolutely no reason. Whereas, the older, more introvert widow, for example, who has much more needs…[is] not able to negotiate that in the visitation meetings with the municipality, so [then] we talk about…reablement and "you should do this yourself and blah blah" but you have fully functioning people who even have people heating up their food for them, and they go and pick up their grandkids in their own car, and I'm sort of like, "what?"...I think the paradigm is that it's obviously need-based and equality for all and all this Scandinavian stuff. But in reality it's much more complicated." (researcher)
28	"[W]hat they do now…is that those who have ethnic minority background get to care for those that have ethnic minority background. So the ethnic Danes…can actually say no I just want a…pure blood Danish health care provider…that request is accommodated. So…we have some issues that we don't want to talk about, but they are all over in the health care encounters…It's completely illegal, but it's part of the matching…not to cause too many frictions…If you take that to a union…you could make so much trouble." (researcher)
29	"[A]ll municipalities we talk to have these problems with recruiting the people that are actually most in need of being engaged with what the municipality [is] doing…that could be older people, older lonely people. It could also be people who are retired but who are not in that age group…or younger people who are not part of the system somehow. So that's really a project about the limits of the welfare state and how the welfare state can somehow do something good for these people without putting them into…the usual initiatives they have." (researcher)

Incorporating Key Themes from Research in China

Analyzing data collected in Denmark alongside key themes from long-term ethnographic work in China helped identify particular ways in which participants' understandings of dementia and good dementia care could have implications for Danish-Chinese elder care collaborations. The four key themes gleaned from interview and observation data collected in China were: (A) "Person-centered care" is not necessarily the ideal for good dementia care in China, (B) Shifting

understandings of who is responsible for providing elder care can shape care decisions, (C) Chinese elder care infrastructure is rapidly changing, and (D) Limited resources provide challenges in meeting residents' care needs (See Table 11).

Table 11: Key Themes from Data in China and Potential Impacts on Danish-Chinese Collaborations

Key Theme in Data from China	Explanation	Potential limiting factor in Danish-Chinese Collaborations	Potential facilitating factor in Danish-Chinese Collaborations
Theme A: "Person-centered care" is not necessarily the ideal for good dementia care	Institutional dementia care designed to provide "family-centered care" or "relational-care" (Zhang, 2020) seemed to offer a stronger ideal form of good dementia care	-Danish care systems designed to center a patient's needs as a "citizen" might not translate into Chinese contexts centering the experiences of patients' families and social networks -Danish understandings of the family's role as a source of social and economic support more than providing daily bodily care may not translate into a Chinese setting where families are expected to engage in bodily care by providing material support (e.g. diapers, snacks, tissues, etc.) and regularly visiting care sites to ensure staff are meeting families' care standards	-In both countries there is an interest in learning about "person-centered care" approaches alongside reservations about its applicability to all types of care needs -In both countries there are serious efforts to engage and support family members as part of care teams, offering rich opportunities for collaboration and experiments with how best to accomplish this
Theme B: Shifting understandings of who is responsible for providing elder care can	-Changes in state provided social welfare systems since the 1950's have left older adults, their families, and professional caregivers with different understandings of their own, and the state's,	-The Danish focus on "equal" access to support within care facilities, as well as "equal" entitlement to state provided social welfare for all citizens could lead to care models that do not translate well into a	-In both countries, state efforts to increase non-state involvement in elder care could provide opportunities for collaborations and experiments on how best to develop and support family, volunteer,

shape care decisions	responsibilities for providing elder care -Caregiving institutions are becoming more "flexible" by offering highly stratified levels of care and support depending on a range of factors including how demanding a resident's family members are, personal connections between each caregiver and resident, and the resources available for each person's care	Chinese context where stratified levels of care may be expected	public-private, or resident-to-resident based care models
Theme C: Chinese elder care infrastructure is rapidly changing	Everything from caregiver education standards and certification programs, to physical caregiving infrastructures, to elder care laws and healthcare financing is actively being negotiated and changing as China's elder care landscape develops	-Danish care systems relying on established networks of healthcare volunteers or complex bureaucratic healthcare systems may not translate into Chinese settings where whole hospitals and elder care sites may only be a few years old, themselves -The pace of change in the Chinese elder care landscape could destabilize longer term collaborations as elder care priorities and approaches within China can shift rapidly	-Potential for rapid development of new collaborations that do take root -Potential for collaborations in many forms given the openness to experimenting with new approaches to elder care and new kinds of elder care systems in China
Theme D: Limited resources provide challenges for meeting residents' care needs	-Staffing levels (often 1 nurse's aide per 6 residents and sometimes as low as 1 nurse's aide per 20+ residents during night shifts in a dementia care ward) can lead to prioritizing residents' physical safety over other concerns	-Staffing levels (sometimes as high as 1 nurse's aide per 1-3 residents) in Denmark might be so dramatically different that it's difficult to adopt Danish care approaches in Chinese settings without jeopardizing residents' physical safety	-In both countries, staff face the challenge of how to handle violent or difficult patients with dementia without causing them undue harm and could build valuable collaborations around how to best address these patients' needs

	-Staff grapple with when and how to use physical and/or chemical restraints to keep residents safe despite staff limitations	-Dramatically different standards around what level of physical and/or chemical restraints are acceptable in each country could make it very difficult for collaborations to develop	

Each of these themes has the potential to be a limiting or facilitating factor in Danish-Chinese elder care collaborations, and that is reflected in the final recommendations made in this project.

Limitations and Potentials for Danish-Chinese Dementia Care Collaboration

Drawing on comparative analyses described in the previous section, data collected in Denmark were organized into factors that might limit the applicability of Danish care models in Chinese settings (Theme 10) and factors that might allow for productive collaboration or model sharing between Danish and Chinese dementia care providers (Theme 11).

Both limitations and potentials for collaboration were identified through a combination of analyzing themes that emerged naturally across interview responses and through direct questions during interviews. Direct questions during interviews focused on (1) what participants perceived to be the defining traits of Danish elder care approaches, (2) what they saw as Danish strengths and weaknesses relative to elder care approaches in other countries, and (3) how they perceived changes over time in the Danish welfare system and its approach to elder care.

Theme 10: Limitations for Danish-Chinese dementia care collaboration

Interviews revealed several potentially limiting factors in Danish-Chinese dementia care collaborations (See Table 12). Some factors were related to different resource landscapes in the two countries, including the fact that Danish care sites relied significantly on volunteer networks and other resources outside the care facilities themselves (Quote 30) and the fact that the Danish welfare state already had more established infrastructure for moving people into and through its dementia care institutions (Quote 31). Another potentially limiting factor included different understandings of family members' roles in institutional dementia care (Quote 32).

Table 12: Descriptions of limitations for Danish-Chinese dementia care collaboration

Quote Number	Example Quotes
30	"The Danish welfare state is really known throughout the world it seems for good reasons, but there's also of course been a lot of cutbacks and it seems…really cut down to the bone, what's going on in a lot of the nursing homes. And then, the volunteers are called upon…it's the volunteers that…bring life in or make a birthday cake or have a song club or whatever. So, a lot of these third-agers are engaged in that…you have people paying to be volunteers." (researcher)
31	"[W]e're a rich country. [We have] a welfare system and we are well organized. Also in terms of doing the diagnosis of dementia, we have memory clinics and so on…It's not perfect, but at least we have a system, and we're trying to specialize it." (researcher)
32	"There are bigger and bigger expectation[s] of the families to take part in caring. Still, in Denmark…bodily care should be done by an authority. But all the social care, the economic help with finances – this will be [done by] the families. And social activities [are] expected, also, more and more [to be] done by the families." (researcher)

Theme 11: Potentials for Danish-Chinese dementia care collaboration

Interviews revealed several areas where there could be potential for constructive Danish-Chinese dementia care collaboration (See Table 13). These included collaborations related to caregiving techniques, such as how to manage particularly aggressive or difficult patients (Quote 33) or how to address limitations in a person-centered care framework (Quote 34). Participants

also identified broader trends within Danish dementia care that seemed to offer potential inroads for fruitful collaborations, including efforts by the Danish state to become less directly responsible for providing care (Quote 35) and acknowledgement of the important roles family members play in dementia care and a desire to provide support to them, as well (Quote 36).

Table 13: Descriptions of potentials for Danish-Chinese dementia care collaboration

Quote Number	Example Quotes
33	"We have a regulation [that says] that you are not allowed to [use] any forces. When the residents say "no," you cannot do it. But in some specific cases, you can do it. If the person with dementia is damaged when you [don't do] it. If…you have a diaper…you can take it with force if a doctor [has] said "if you don't do it, you [will] get [an] infection [that will make] you die." So it dangerous for you not to [do something]…you should have a permission to [use] forces…I can hear it when I go out…[staff talk about residents spitting at them and] it's often when you spit, it's because you cannot use your hands. So where [are] your hands? Maybe somebody is holding your hands when you're spitting. Then you have to be curious about the situation and often the staff have told [me] that they are holding their hands [which counts as using force]. And they have not [thought] to report it." (elder care provider)
34	"[P]erson-centered care by Tom Kitwood has really had a good, big effect. But also [it has] the side-effect…that all the care has been very personalized, individualized. And as an Occupational Therapist, I've always been very aware of…people's need…[to be] in activity together with other people and meeting other people. The social dimension has been forgotten I think. So people with dementia, they are very nicely cared for individually, and people take account of their life history and so [on], but [not] their need for being together with other people." (researcher)
35	"[T]hey're also trying to…make us, as a people, go back to when we felt some sort of responsibility for our neighbors and our…close relationships…I think this has also been sort of like a value discussion about whether we have some sort of responsibility [to provide care to each other] or is it all the state." (researcher)
36	"[S]ociety is also very dependent on the relatives because the informal care, if you relate that to what it costs if it should be a formal care[giver], it's a huge sum of money. When they deliver six eighteen[-hour] work[days] to take care of their relative when they live at home. So society is dependent on keeping the relative healthy. And it's well known that it's stressful [to be a caregiver], and caregivers] get sick as the disease progresses [in their relatives], so there's also that kind of interest from the society." (researcher)

Discussion and Implications

This project's findings support the argument that "social context" is critically important to studies of "good care" (McKearney, 2020). While the data collected in Denmark did not allow for in-depth analysis of caregivers' interpersonal grappling with providing care in morally ambiguous situations (ibid), analyzing those findings alongside data from China offers insights into differing understandings of dementia and good dementia care in each country. Perhaps most importantly, the elder care system in China is rapidly changing, and participants in China described their main care recipient as a relationally defined family member rather than the individual citizen receiving services from an already established care system that participants described in Denmark. From these distinct understandings of who receives dementia care stem additional discontinuities and potential areas for meaningful Danish-Chinese collaboration. Specifically, these two understandings of what it means for a person to have dementia also then lead to very distinct approaches for organizing a dementia care facility. In a Danish dementia care site, attempts to serve individual citizens/persons created a care environment where equality in treatment was paramount. In a Chinese dementia care site, attempts to serve a relationally defined family member created a care environment where staff, families, and residents valued flexibility and the possibility of negotiating stratified care services. While practitioners in both China and Denmark described limited resources impacting their abilities to meet residents' needs, low staffing levels had an especially large impact on caregiving decisions in China relative to Denmark.

Taking these differences into account when evaluating or designing Danish-Chinese elder care collaborations is critical. Ultimately, this study suggests that developing new care frameworks (i.e. thinking beyond "person-centered care" and developing or experimenting with

new care practices and approaches altogether), further incorporating family members of those living with dementia and other non-state actors into formal care systems, and finding new ways to manage difficult or violent residents beyond the use of restraints or purely one-on-one care may be the most promising areas for Danish-Chinese elder care collaborations.

A closer look at Denmark to understand values underpinning Danish care approaches

While "dementia" is understood to encompass widely variable diagnoses and prognoses (Astell, 2015), it is important to note that findings from this study echo other research on the characteristics of Danish conceptions of dementia. For example, this study supports findings that Danish understandings of dementia tend to be highly individualized and focused on supporting residents' personhood (Gjødsbøl et al., 2017; Gjødsbøl & Svendsen, 2018; SVENDSEN et al., 2018) and that dementia in Denmark is seen in relation to patients' rights *as citizens* of a Danish welfare state that has a responsibility to support them (SVENDSEN et al., 2018). Findings related to shifting perceptions of dementia as stigmatized also reflected and captured the Danish government's focus on moving toward a "dementia friendly society" at the time data for this project were collected and in the years following (*Denmark – a Dementia Friendly Society*, 2018).

This understanding of dementia is reflected in participants' descriptions of good dementia care in Denmark. In particular, the focus on dementia's inability to undermine an individual's claims to personhood or being a citizen supported participants' understandings of good dementia care as centered on the Danish state and the infrastructures and "professionals" it produced. It reinforces previous Euro-American studies of dementia care that call for attention to embodied communication (Kontos, 2006; Moser, 2010; Pols, 2005), the relationship between physical

environments and care (Robbins, 2013; Selberg, 2015), and highly educated, professional caregivers skilled in communicating with and responding to those living with dementia (Hendriks, 2012; Kitwood, 1997). The focus on inequalities of various kinds as primary drivers of the gaps between idealized "good dementia care" and the way such care is provided in practice resonates with previous studies that have found a particularly strong tendency in Denmark to match "equality" with "the good," especially when it comes to care (SVENDSEN et al., 2018).

A closer look at China to identify connections across themes and countries

While each of the key themes identified in the data from China is important in its own right, there are also meaningful points of interconnection across them that should be considered in Danish-Chinese collaborations. For example, the Chinese focus on patients as parts of larger families or webs of relationships as opposed to as individual citizens (Theme A) also inherently supports Chinese care systems explicitly providing stratified forms of care to patients (Theme B) because more highly engaged networks of loved ones can advocate for more specialized or intensive forms of care. As opposed to understandings of "good dementia care" providing equal care to all, the primary research site in China was explicitly designed to have wards that charged different monthly rates in exchange for (1) different staff to resident ratios, (2) different degrees of formal training or dementia expertise among staff, and (3) different levels of material support for care (e.g. families needed to provide diapers and daily care items unless they paid for their relative to live in the facility's more expensive "VIP ward"). This stratification of care services (Theme B) was in turn exacerbated by the degree to which elder care institutions, training standards, legal frameworks and state polices were changing far more rapidly in China than in

Denmark at the time of this study (Theme C). Without the same degree of established and "systematic" bureaucratic and professional frameworks to structure caregiving expectations and practices, oversight within the researcher's primary field site in China often required family members to monitor and contribute to their loved ones' care until it reached a level that they personally deemed "good" (or at least good enough) (Theme A). In other words, support from outside the facility – whether in the form of political economic pressure from organizations, daily support from volunteer groups, or oversight from the state – was extremely limited relative to Danish care settings. Limited resources – including and beyond oversight systems – created unmet resident needs in both China and Denmark that were responded to very differently in each setting (Theme D). While Danish care models seemed to rely on volunteer support, funding or oversight gained through political economic pressure, or complex or bureaucratic systems, their reliance on such supports outside healthcare facilities could make it difficult to successfully translate them into Chinese care settings. Likewise, programs or care models that do not find ways to work with patients' family members and their concerns could be difficult to implement.

Key themes from the data collected in China also intersect with one another in ways that point to possible avenues for productive Danish-Chinese dementia care collaborations. In particular, interviews and observations at the researcher's primary site in China revealed a strong desire among staff to manage aggressive residents and residents who might try to leave the care site without needing to rely on physical or chemical restraints. Given Danish care workers' descriptions of the difficulties with using "force" in Denmark (see Quote 33) and the challenges aggressive residents posed to staff and other patients at care sites, this may be a potentially rich area for collaboration. Similarly, given that several Danish participants identified a person-centered care approach as potentially insufficient for meeting care needs within Denmark (See

Quote 34), it is possible there could be fruitful collaborations with Chinese dementia care practitioners operating in a "family-centered" or "relationship-centered" framework.

Implications for Danish-Chinese elder care collaborations

Continued research is needed to determine how "family-centered" or "relational-care" (Zhang, 2020) models might be translated into Danish caregiving settings or become successfully incorporated into Danish-Chinese collaborations aimed at serving Chinese patients and families. These kinds of collaborations should involve explicit conversations around: (a) the roles family members of patients are expected to play in caregiving, (b) to whom staff will look (patients or families) to determine whether a specific caregiving intervention has been successful, and (c) what practices might be adapted within collaborative care settings in China to restructure person-centered care models in ways that support and engage "family-centered" or "relational-care" (ibid) conceptions of dementia care recipients.

With the Danish state attempting to engage and support family caregivers to decrease the caregiving burden on the state, there are also new opportunities for Danish-Chinese collaborations related to family involvement in dementia care. Given that family involvement in daily care is already far more common in China, collaborations around engaging and supporting family caregivers could be especially fruitful. Not only would these potentially allow Danes to learn from and import Chinese approaches to interacting with residents' families into Danish systems, but they could also allow caregivers on both sides to work together to develop new models for supporting family caregivers, as this is a shared issue for both. Future research would be needed to determine specific ways in which, and to what extent, families' needs and desires for engagement were comparable between Danish and Chinese care sites.

It is also important that collaborations take into account the very different economic considerations participants identified as shaping elder care in Denmark and in China. Danish care facilities were generally financed by the state and able to provide high staff-to-resident ratios with highly educated staff, well-funded volunteer programs to offer additional support, and Danish political groups like DaneAge (*About the DaneAge Association*, 2019) lobbying for additional funding. As a result, particularly difficult patients generally received access to highly resource intensive care, even to the point of long-term one-on-one care from their own designated nurse's aides. The care sites visited in China, by contrast, operated in a highly competitive, semi-privatized elder care landscape where providers worked to be as flexible as possible, accommodating patients' families' expectations in order to keep those families from moving their loved ones to competitors' care sites. At the researcher's primary site in China, unless extremely dedicated family members organized themselves to effectively provide their own 24/7 one-on-one support for their loved one, difficult or aggressive residents were often physically or chemically restrained. Additional research around ways to effectively meet the needs of difficult or violent residents without having to assume the financial costs of one-on-one care, or the physical or psychological costs of physical or chemical restraint, could also be very fruitful in collaborations. Participants in both countries described wanting more options for responding to patients with especially difficult cases.

Future research partnering with local organizations in each country to gain access to financial records regarding sites' per capita earnings and expenditures would be extremely useful for informing Danish-Chinese elder care collaborations, as well. Because the resource landscapes in these two care systems are so different, it is currently difficult to determine the costs and profits associated with particular staffing or care provision decisions. This makes it difficult to

ascertain which kinds of care models or practices are most in-line with the resource levels each setting currently has available. On the one hand, care models relying on highly complex and rigid bureaucratic systems in Denmark might be less likely to successfully take root in a Chinese setting that relies on negotiated and stratified care for different residents. On the other hand, care models that allow for individualization or differentiated access to caregiving staff which depend on staff assessment of patient needs may be more likely to succeed. Additional research is needed to test whether or not this is the case.

Limitations

This research had two primary limitations involving parallel design across research sites and time restrictions. Due to the researcher's different levels of familiarity with Danish and Chinese language and cultural contexts, as well as the different lengths of time during which the researcher was collecting data in each country, this project cannot offer a direct comparison of Danish and Chinese dementia care. Instead, it focuses on data collected in Denmark and provides analysis grounded in the researcher's long-term study of dementia care sites in China to consider how Danish care models might or might not translate well into Chinese settings.

Data related to Denmark alone are of limited generalizability due to the small sample sizes and the fact that these data were collected during a relatively short, 6-week period. Data collection in Denmark were also limited by the researcher's inability to speak Danish. In particular, this limited data generated through observations within care sites, as many of the caregiving interactions observed were between people speaking Danish, which the researcher could not understand without asking others to translate after the fact. This means important exchanges at care sites may have gone unnoticed.

All individuals invited to participate in this project agreed to be interviewed, which likely resulted at least in part from the researcher's positionality as a white American PhD student working with an established researcher at the University of Copenhagen. More broadly, the researcher's positionality has offered her privileged access to educational resources, funding support, and mentorship throughout her career in the United States, as well as additional social capital when conducting fieldwork abroad.

Conclusion

This study identifies several rich areas for potential Danish-Chinese elder care collaborations, especially those focused on developing new care frameworks. These could involve thinking beyond "person-centered care" and developing or experimenting with new care practices and approaches or collaborating around how to further incorporate family members of those living with dementia into existing formal care systems. Fruitful collaborations could also involve exploring new ways to manage difficult or violent residents beyond the use of restraints or purely one-on-one care.

Although this study has limitations, it raises important issues for consideration when evaluating or developing Danish-Chinese elder care collaborations. By identifying factors that are incompatible, as well as areas where shared contexts could potentially allow partnerships to flourish, this work aims to contribute to advancing collaborative efforts between Denmark and China to improve elder care in both countries.

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Conflicts of Interest

The author is not aware of any conflicts of interest related to this project.

Appendix A: Interview Guide

All interviews will be semi-structured and focused on the ordinary and usual aspects of participants' jobs. Interviews will cover topics like:

- A general overview of the interviewee's background as it relates to his/her current position
    - i.e. Can you tell me a bit about your background? What brought you to this line of work?
    - How long have you been working here?

- What training has the interviewee has received in preparation for his/her current position
    - i.e. What kind of training did you need to be able to become a [insert current job title]?
- How the interviewee describes his/her current position
    - i.e. How would you describe your current job? What does a typical day look like for you at this job?
    - What would you say are the most important parts of what you do at your job?
    - What are some challenging things about your job? How do you handle these challenges?
    - How is [insert current employer] structured administratively?
- How the interviewee sees his/her work in relation to other aspects of elder care or dementia care in Denmark
    - i.e. How does the work you do here relate to how elder care is provided in Denmark overall? Does [insert current employer] partner with any other organizations or institutions in Denmark that you know of?
    - What people or things outside of [insert current employer] affect the work you do here? [prompt with "government organizations," "health insurance systems," "family members/' "elders, themselves," etc. if necessary)
- How the interviewee sees his/her work in relation to the Danish government
    - i.e. Would you say that your work here is supported by the Danish government? If so, can you tell me a bit about how this operates?
    - How, if at all, is your work overseen or regulated by the Danish government?
- Whether or not the interviewee is interested in continuing engagement with my project
    - i.e. [DEPENDING ON THE TYPE OF PARTICIPANT] Would you potentially be interested in letting me observe you and how you go about your work for this project?
    - [IF THE INTERVIEWEE SEEMS ENGAGED/THE INTERVIEW SEEMS TO HAVE GONE WELL] Do you think you might be able to refer me to three other people in your line of work who might be interested in being interviewed by me for this project?

Appendix B: Observation Guide

Though there will be no formal, standardized checklists or other metrics used during observation sessions, they will generally focus on topics like:

- How the participant engages with other people in his/her line of work
    - i.e. Topics they discuss, if/how they describe other groups [i.e. elders, their families, other kinds of professionals, etc.], when/how they work together and when/how they work independently to accomplish different tasks, etc.
    - Who, if anyone, seems to oversee the participants' work? Who, if anyone, does the participant seem to oversee?
- How the participant engages with his/her environment in his/her work
    - i.e. What is the work environment like? How does it sound/smell/look/feel?

    - Does the participant use any special tools or equipment to do his/her job? If so, what/when/how?
    - Relatively speaking, about how much time does the participant seem to spend on different activities [i.e. paperwork vs. communicating with colleagues vs. meetings vs. providing care directly vs. transportation, etc.]?
- How the participant engages with people who are not in his/her line of work
    - i.e. Does the participant engage differently with different kinds of professionals in his/her work environment?
    - Does the participant engage with elders and their loved ones differently (if at all)?
- How others seem to engage the participant
    - i.e. What kinds of people, if any, engage the participant throughout his/her work? How do any such people engage [i.e. in person, via phone, via email, etc.]?

Appendix C: Codebook

ATLAS.ti Report

MPH

Codes

Report created by Lillian Prueher on Dec 3, 2020

○ "Dementia Action Plan"

Created: 5/13/20 by Lillian Prueher, **Modified:** 5/13/20 by Lillian Prueher

Comment:

> Any specific references to this plan

○ "Good" Care: Equality

Created: 10/28/20 by Lillian Prueher, **Modified:** 10/28/20 by Lillian Prueher

Comment:

> Descriptions of "good" care being care that treats everyone equally/promotes and/or reflects equality OR addressing inequalities

○ "Good" Care: Flexible/Responsive

Created: 10/28/20 by Lillian Prueher, **Modified:** 10/28/20 by Lillian Prueher

Comment:

> Descriptions of "good" care as care that is felxible or responsive to patient needs

○ "Good" Care: Physical

Created: 10/28/20 by Lillian Prueher, **Modified:** 10/28/20 by Lillian Prueher

Comment:

> Descriptions of “good” care related to providing physical/bodily care

○ "Good" Life/Care: "Good" Death

Created: 10/28/20 by Lillian Prueher, **Modified:** 10/28/20 by Lillian Prueher

Comment:

> Desscriptions of a “good” life or “good” care that center on the idea of someone having a “good” death

○ "Good" Life: Quality of Life

Created: 6/26/19 by Lillian Prueher, **Modified:** 10/28/20 by Lillian Prueher

Comment:

> Descriptions of a “good” life where quality of life is a key metric

○ "Money"

Created: 6/26/19 by Lillian Prueher, **Modified:** 10/21/20 by Lillian Prueher

Comment:

> Discussions of “money” in relation to eldercare

○ "Real World" vs. ideal

Created: 6/26/19 by Lillian Prueher, **Modified:** 10/20/20 by Lillian Prueher

Comment:

> Descriptions of/responses to differences between what one would ideally do for care and what is possible given “Real world” constraints - the exceptions to the ideal?

○ "Systematic"

Created: 6/29/19 by Lillian Prueher, **Modified:** 6/29/19 by Lillian Prueher

Comment:

> Anytime eldercare or dementia care institutions/practices are described as “systematic” or “systems”
>
> Is this key idea of dementia care being “systematic” at tension at all with the idea of flexible institutions? / Is this related to the idea of making the system in Denmark increasingly specialized?

○ Active Aging

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

Any reference to active againg or third age

○ Busy / Lazy Ethic

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/28/19 by Lillian Prueher

Comment:

Any reference to a busy or lazy ethic

○ Care Tool

Created: 10/2/19 by Lillian Prueher, **Modified:** 10/2/19 by Lillian Prueher

Comment:

Descriptions of specific tools/methods/frameworks/technologies/etc. used in care work

○ Career Path/Interviewee Info

Created: 6/26/19 by Lillian Prueher, **Modified:** 5/11/20 by Lillian Prueher

Comment:

Descriptions of interviewees' personal career paths or the impact(s) they feel their career paths have on their own expereinces/responses to interview questions

○ Caring for Difficult Patients

Created: 10/21/20 by Lillian Prueher, **Modified:** 10/21/20 by Lillian Prueher

Comment:

Descriptions of particular approaches taken in attempts to care for "difficult patients"

○ Co-Creation/Participation

Created: 6/26/19 by Lillian Prueher, **Modified:** 5/11/20 by Lillian Prueher

Comment:

Descriptions of working with people who have dementia to define and/or produce care outcomes/environments OR to engage them as participants in care

○ Communication

Created: 6/29/19 by Lillian Prueher, **Modified:** 6/29/19 by Lillian Prueher

Comment:

> Anything related to how communication happens with / does not happen with / is perceived in regard to older adults living with dementia; NOT about communication between staff and families when it does not involve the older adult
>
> Consider splitting into physical vs verbal communication?
>
> Inability to communicate/challenges with communication seen as a sign of dementia (For non-caregivers) whereas being able to communicate/helping patients gain/regain the ability to communicate seems to be a skill caregivers associate with their work - when it comes to force, the fundamental valuing of what patients communicate as their preferences is seen; In the Danish context, “communication” is predicated in part on abillity to successfully navigate the welfare state (and to be recognized by it)

○ DaneAge

Created: 6/28/19 by Lillian Prueher, **Modified:** 6/28/19 by Lillian Prueher

Comment:

> Any reference to DaneAge or ÆldreSagen

○ Danes

Created: 2/12/20 by Lillian Prueher, **Modified:** 2/12/20 by Lillian Prueher

Comment:

> Commentaries on Danish people (societal level)

○ Danish System: Financial Resources

Created: 5/12/20 by Lillian Prueher, **Modified:** 5/12/20 by Lillian Prueher

Comment:

> Descriptions of the financial resources available in Denmark for eldercare — structural level forces

○ Danish System: History

Created: 5/11/20 by Lillian Prueher, **Modified:** 5/12/20 by Lillian Prueher

Comment:

> Related to how the Danish healthcare/elder care system has changed over time

○ DCM

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

> Any reference to "Dementia Care Mapping" or “DCM"

○ Death/Dying

Created: 5/11/20 by Lillian Prueher, **Modified:** 5/11/20 by Lillian Prueher

Comment:

> Related to discussions of death and dying in elder care/Danish healthcare systems

○ Dementia as Loss

Created: 5/11/20 by Lillian Prueher, **Modified:** 10/20/20 by Lillian Prueher

Comment:

> Descriptions of losses of any kind for people living with dementia/their families/etc.

○ Dementia Friendly

Created: 9/30/19 by Lillian Prueher, **Modified:** 9/30/19 by Lillian Prueher

Comment:

> Any reference to Dementia Friends and/or Dementia Freindly communities/movements/etc.

○ Diagnosis

Created: 5/11/20 by Lillian Prueher, **Modified:** 5/11/20 by Lillian Prueher

Comment:

> Related to diagnosing, being diagnosed, and having particular diagnoses

○ Difficult Patients

Created: 6/29/19 by Lillian Prueher, **Modified:** 5/12/20 by Lillian Prueher

Comment:

> Any reference to people living with dementia as being difficult, includes those that are difficult due to violence/aggression as well as high care needs/requiring more than usual staff interactions
>
> Add separate code(s) for aggressive? Sex? Family Response? Infrastructure/Coping with?

○ Education / Training

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/28/19 by Lillian Prueher

Comment:

> Talking about how staff/volunteers are trained/the types of training that are useful for staff/how to bring training into everyday care
>
> Consider creating a sub category for education required (to do different jobs) vs. approaches to educating (different kinds of staff)

Consider subcodes fro educating staff vs. educating patients vs. educating families?

○ Expertise Scaffolding

Created: 5/11/20 by Lillian Prueher, **Modified:** 5/11/20 by Lillian Prueher

Comment:

Related to how people with different levels of need are triaged/matched with care providers with different levels of expertise

Merged comment from Viso on 11/13/20, 3:39 PM

Any use of the term “Viso” or “Visos"

Merged comment from Pedagog on 11/13/20, 3:41 PM

Any use of the term “Pedagog” or “Pedagogs"

○ Export/Import

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

Related to descriptions of care exports/imports between Denmark and the rest of the world

○ Family Role

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

Descriptions of what role participants see the fmailiy members of people with dementia (ideally or actually) playing in their care

Create a code for State vs. Family Role?

○ Force

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

Use of “force” or coersion in care — includes stories of instances of this and descriptions of percetions of it

○ Funding Sources

Created: 6/28/19 by Lillian Prueher, **Modified:** 10/21/20 by Lillian Prueher

Comment:

Any descriptions of how care activities/institutions/programs are funded beyond just directly receiving funds from the State

- Gaps: Care Capacity

Created: 10/27/20 by Lillian Prueher, **Modified:** 10/27/20 by Lillian Prueher

Comment:

Describing times when care institutions/social care systems/etc. fall short because of an inability to fully meet patient needs with the resources available

Merged comment from Discontinuing Care on 11/13/20, 3:40 PM

Related to examples of people ending or losing access to care

- Gaps: Dementia Expertise

Created: 10/22/20 by Lillian Prueher, **Modified:** 10/22/20 by Lillian Prueher

Comment:

Descriptions of gaps in care related to/caused by lack of expertise in the healthcare sector

- Gaps: Interpersonal Connection

Created: 10/27/20 by Lillian Prueher, **Modified:** 10/27/20 by Lillian Prueher

Comment:

Descriptions of times when there is a need for more attention paid to interpersonal connection

- Gaps: Involvement of Patients

Created: 10/27/20 by Lillian Prueher, **Modified:** 10/27/20 by Lillian Prueher

Comment:

Descriptions of a caregiving gap being produced/reinforced due to a gap in involvement of people living with dementia in care processes

Merged comment from Youth on 11/13/20, 3:42 PM

Discussions of youth/youthfullness intersecting with dementia, including references to young caregivers/families, as well as young people living with dementia

- Gaps: Lack of Oversight

Created: 10/21/20 by Lillian Prueher, **Modified:** 10/21/20 by Lillian Prueher

Comment:

Descriptions of the care system producing/maintaining a gap due to lack of oversight

○ Gaps: Money bridging gaps

Created: 5/13/20 by Lillian Prueher, **Modified:** 5/13/20 by Lillian Prueher

Comment:

Examples of money/financial resources solving a specific care need

○ Gaps: Patient Knowledge Gaps

Created: 10/21/20 by Lillian Prueher, **Modified:** 10/21/20 by Lillian Prueher

Comment:

Describing gaps in care created or intensified by knowledge gaps on the part of patients/families trying to access it

○ Gaps: Prejudice

Created: 10/21/20 by Lillian Prueher, **Modified:** 10/21/20 by Lillian Prueher

Comment:

Discussions of gaps in care being produced/maintained due to prejudice

○ Gaps: Related to Family Involvement

Created: 10/21/20 by Lillian Prueher, **Modified:** 10/21/20 by Lillian Prueher

Comment:

Descriptions of gaps in care resulting from insufficient or too much family support/engagement

Merged comment from Family: Lack on 10/27/20, 2:21 PM

Examples of families not being available/involved in care

○ Gaps: State Understanding

Created: 10/23/20 by Lillian Prueher, **Modified:** 10/23/20 by Lillian Prueher

Comment:

Descriptions of times where gaps in care are produced/reinforced by gaps in the State's understanding of care needs as people age

○ Gaps: Urban vs. Rural Resources

Created: 5/11/20 by Lillian Prueher, **Modified:** 5/11/20 by Lillian Prueher

Comment:

> Examples of elder care being more difficult or happening less well as a result of differences in urban vs. rural resource availabilities.

○ Gender

Created: 5/11/20 by Lillian Prueher, **Modified:** 5/11/20 by Lillian Prueher

Comment:

> Specific comments about gender as a defiining characteristic for care giver or care recipient experiences

○ Inst. "Family"

Created: 6/26/19 by Lillian Prueher, **Modified:** 5/12/20 by Lillian Prueher

Comment:

> Anytime “Family” or a familial construct (e.g. “sister” “mother” etc) is invoked to between staff and residents

○ Inst. "Home"

Created: 6/28/19 by Lillian Prueher, **Modified:** 6/28/19 by Lillian Prueher

Comment:

> Discussions of caregiving institutions related to “home” or being “like home” or “not like home"

○ Inst. Change

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

> For descriptions of how institutions change in Denmark - can include culture/how participants see the field/health care systems/etc moving forward overall OR things that add new challenges/change caregiving environments by necessity
>
> Add a subcode just about Societal change?

○ Inst. Residents

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

> Descriptions of the kind of older adults who end up being residents in dementia care institutions in Denmark

Merged comment from Inst. Residents - Limit on 10/28/20, 2:33 PM

Describing when/why/for whom institutional care reaches its limit and a resident cannot be cared for within a dementia care site

○ Inst. Residents - Helped

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

Stories of residents benefiting from institutional care

Merged comment from Improving Patients on 10/20/20, 12:09 PM

Descriptions of formal eldercare helping a patient or resident “improve” in their physicial, cognitive or soical abilities or experiences of daily life

○ Inst. Role

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

Descriptions of what the institution is there to do

○ Inst. Social vs. Medical Health

Created: 5/11/20 by Lillian Prueher, **Modified:** 5/11/20 by Lillian Prueher

Comment:

Discusions of a tension or differentiation between elder care institutions as providing/facilitating social health and care vs. medical health and care for patients

○ Inst. Space

Created: 9/30/19 by Lillian Prueher, **Modified:** 9/30/19 by Lillian Prueher

Comment:

For describing institutional care settings/physical spaces/environments

Merged comment from Inst. Resources on 10/20/20, 4:17 PM

Descriptions of the resources available/discussions connected to resources as they relate to care

Narrow down to Institutional Infrastructure/combine with Institutional Space code?

Merged comment from Villages on 11/13/20, 3:38 PM

Any comments related to dementia villages

○ Inst. Staff

Created: 6/29/19 by Lillian Prueher, **Modified:** 6/29/19 by Lillian Prueher

Comment:

Descriptions related to staff working in caregiving institutions

Consider dispersing these quotes among more granular codes? E.g. One for Staff Safety?

Merged comment from Policy: Staff Workarounds on 11/13/20, 3:37 PM

Related to healthcare staff finding ways to provide care outside the bounds of official policies

Merged comment from Turnover: Staff on 11/13/20, 3:38 PM

Any references to turnover/changes in caregivers in institutional eldercare settings

○ Intra-Dane Exchange

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

Use for descriptions of supports and/or exchanges within the broader healthcare/legal/policy/volunteer/etc. landscapes in Denmark supporting individual care sites/programs there

Add collaboration here, too?

○ Leadership

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

Describing what leadership looks like in relation to dementia care/how it operates / what it takes to be a good leader in a caregiving institution

○ Magical Moments

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

> Descriptions of "magical mments" or extreme benefits to/moment of connection for care recipients as a result of receiving care
>
> Nest under "Inst. Residents - Helped"?

○ Medication

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

> Any references to medication use/perceptions of medications related to elder care adn dementia care

○ No Model Model / (anti-)Normativity

Created: 6/28/19 by Lillian Prueher, **Modified:** 6/28/19 by Lillian Prueher

Comment:

> Instances where "best practices" is described as individuation/flexibility/the lack of a standardized model

○ Older Adults - Power

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

> Descriptions of political/economic/social power/status [or lack there of] that older adults have in Denmark

○ Older Adults as Resources

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

> Is this always connected to "potentials" of older adults?

○ Org. Details (quant)

Created: 6/26/19 by Lillian Prueher, **Modified:** 2/12/20 by Lillian Prueher

Comment:

> Quantitative descriptions that paint a picture of the scale/nature of organizations participants work at/for

○ Oversight

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

Descriptions of how eldercare is overseen/regulated on a systemic level from the outside

Merged comment from Inst. Oversight on 10/22/20, 11:05 AM

Descriptions of institutional oversight for eldercare and demenita care sites

○ Patient's Rights: Decision-Making

Created: 5/11/20 by Lillian Prueher, **Modified:** 5/11/20 by Lillian Prueher

Comment:

Related to protecting or restricting patients' decision making rights in relation to their care

○ PCC / Flower Method

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/29/19 by Lillian Prueher

Comment:

For quotes related to Tom Kitwood or person-centered care

○ Percep. of Asia

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

For descriptions of Danish perceptions of the care landscape in Asia and/or China specifically

○ Percep. of Dementia

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

Any descriptiosn of dementia/what someone's experience is expected to be while living with it

Add a separate code for descriptions/understandings of "memory"?

○ Percep. of Dementia: Negative

Created: 5/13/20 by Lillian Prueher, **Modified:** 5/13/20 by Lillian Prueher

Comment:

Descriptions of fear/disgust/negative perceptions of dementia

○ Perception of Aging

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

> Maybe merge with Perception of Dementia at the end?

○ Policy / Politics

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/28/19 by Lillian Prueher

Comment:

> Descriptions of the Danish policy landscape as it relates to dementia care - Includes Dementia Action Plan, Dementia Friendly Communities [eventually add oversight?]
>
> Merged comment from Politics on 11/13/20, 3:41 PM
>
> Related to politicians/politics shaping care for political gain

○ Policy: Legal Frameworks

Created: 5/11/20 by Lillian Prueher, **Modified:** 5/11/20 by Lillian Prueher

Comment:

> Laws or policies shaping healthcare/elder care

○ Professional*

Created: 9/30/19 by Lillian Prueher, **Modified:** 9/30/19 by Lillian Prueher

Comment:

> Descriptions or discussion of Professional/qualified/professionalized care work and care workers

○ Public/Private

Created: 10/2/19 by Lillian Prueher, **Modified:** 10/2/19 by Lillian Prueher

Comment:

> Any discussions or comparisons of private and public sector activity

○ Rehabilitation

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:

> Any time rehabilitation is mentioned in connection to dementia [and independence?]

○ Research Limitation

Created: 2/4/20 by Lillian Prueher, **Modified:** 10/20/20 by Lillian Prueher

Comment:
For anything related to limitations of my research/method

○ Scandal

Created: 5/11/20 by Lillian Prueher, **Modified:** 5/11/20 by Lillian Prueher

Comment:
Mentions or descriptions of public scandals related to eldercare

○ State Role: Miss

Created: 5/11/20 by Lillian Prueher, **Modified:** 10/22/20 by Lillian Prueher

Comment:
Descriptions of the State missing an opportunity to meet a need/coming up short

Consider adding a subcode for the State doing too much/being over involved?

○ Turnover: Moving Patients

Created: 5/11/20 by Lillian Prueher, **Modified:** 5/11/20 by Lillian Prueher

Comment:
Any references to turnover/changes in location for care recipients

○ Volunteer

Created: 6/26/19 by Lillian Prueher, **Modified:** 6/26/19 by Lillian Prueher

Comment:
Anything related to volunteer work - both older adults volunteering AND volunteers in facilities