

*This is a post-print version (i.e. last manuscript after the peer review process) of the published article; for detailed citations please refer to the original publication, which is available at doi: 10.1080/13576275.2018.1483906.*

## ‘Doing death’ the Mediterranean way: End-of-life in a segregated nursing home

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### ABSTRACT

This paper presents ethnographic data on a migrant-specific nursing home ward in Switzerland. It shows that the structurally pre-defined segregation of residents sharing a common characteristic affects care practices along three dimensions: performances of sameness/otherness, informalisation of relationships and language/understanding. Yet, ‘death work’ showed little difference to non-segregated wards. However, relatives’ practices in dying trajectories were less congruent with nursing home ‘doing death’, and collisions may evolve. The need for negotiations associated with running a segregated ward seems to elicit enhanced institutional reflexivity with potential to increase the ability of institutions to provide diversity-sensitive services to all residents.

### KEYWORDS

Nursing home; end-of-life care; doing death; migration; diversity; ethnography

This paper describes a nursing home ward offering specific care services to former ‘guestworkers’ of Mediterranean migrant origin within a mainstream nursing home in Switzerland. Based on ethnographic data from a research project on nursing home end-of-life care in a pluralised society<sup>1</sup>, it focuses on the issue of how ‘Mediterranean’ end-of-life care is ‘done’ compared to general end-of-life care in Swiss nursing homes. In Switzerland, migrant-specific nursing home wards are a new and rare form of long-term care that is debated in policy and practice with reference to integration/segregation issues. If considered as a field of experimental social practice regarding new forms of diversity-sensitive end-of-life care, the study of this practice can provide insight into care issues, institutional dying and the provision of palliative care in old age. Thus, the aim of this paper is to describe the everyday care practices observed on a ‘Mediterranean’ ward, to compare them to the practices on other wards in the same institution and to explore if ‘Mediterranean’ care practices bring about different modes of dealing with dying trajectories at the very end of a resident’s life. It concludes with reflections on how the practices on segregated wards may inform end-of-life care in nursing homes more broadly.

### ‘DOING MIGRANT DIVERSITY’ WHILE ‘DOING DEATH’: A CONCEPTUAL FRAMEWORK

Institutional long-term elder care is constantly confronted with death. Consequently, nursing homes have brought about specific practices of co-constructing dying and death, which have been described as ‘doing

death' (e.g. Salis Gross, 2001, p. 70).<sup>2</sup> While the concept of 'doing death' includes the interactions of all actors involved in dying trajectories, nurses and nursing aides as 'death workers' are in a powerful position to 'do death' (Sudnow, 1967; see also Soom Ammann, Salis Gross, & Rauber, 2016). Nursing home 'doing death' tends to 'tame' death (Kellehear, 2007) by institutional procedures and practices. Still, present-day ideals of a 'good death' (Green, 2008; Hart, Sainsbury, & Short, 1998) stress person-centeredness, individuality and diversity, including diversities related to migration. Nursing homes are thus confronted with challenging demands to provide high-quality and efficient end-of-life care for an increasingly diverse population. Against this background, a new mode of service provision is currently evolving in Switzerland, segregating residents supposed to share common characteristics and care needs due to migrant background.

The research on which this paper is based investigates how two nursing homes in Switzerland 'do diversity' while 'doing death' and manage the challenging task of caring for nursing home residents with an increasingly diversified background (see also Soom Ammann et al., 2016). We chose an ethnographic research strategy to study selected wards of the Brunnhof and the Centre Burgallee.<sup>3</sup> The former runs a ward with specific services for migrants from Mediterranean regions, mostly Italian 'guest workers'.

Inspired by classic social interactionist (Glaser & Strauss, 1968; Sudnow, 1967) and more recent ethnographic studies of dying in institutions (e. g. Dresske, 2005; Kayser-Jones, 2002; Salis Gross, 2001), our understanding of 'doing death' refers to the entire process from residents' entrance into the nursing home to the exit of their dead body. We focus not only on acute dying, but include the processes of institutional end-of-life care and their social closure after death. To understand how diversity structures 'doing death' within the migrant-specific ward, we contrast its practice with those on non-segregated wards in the two nursing homes. We are particularly interested in the conditions under which the mere existence of diversities emerges as differences that matter for the actors involved. We focus on where 'doing diversity' is becoming explicitly 'doing difference' (West & Fenstermaker, 1995) and discuss the consequences of the nursing home's structurally pre-determined focus on segregation from this angle.

## FRAMING MIGRANT-SPECIFIC CARE IN SWITZERLAND

Swiss nursing homes are generally organised to host and care for residents by stressing equality and individuality<sup>4</sup> and to focus on the integration of diverse residents into a standard framework of nursing home care. At the same time, there are trends towards segregating nursing home residents along specific diversity dimensions, such as in the Mediterranean ward of the Brunnhof nursing home. Segregated homes for wealthy residents, or for specific professional or religious groups have a certain tradition. Other forms of segregation are now developing, promising better frameworks to deal with residents assumed to have specific needs and requirements. One of the most prominent trends is the separation of residents with dementia. Less common but publicly more debated is the segregation of migrant residents. In Switzerland, a few pioneering organisations already provide such services to former 'guest workers' from Italy on so-called 'Mediterranean' wards. 'Mediterranean' on the one hand refers to the idea of a broad 'Mediterranean' culture. On the other hand, it suggests to the public that these wards do not serve a single national group of migrants, but potentially all migrants of Mediterranean origin.

The emergence of Mediterranean wards in Switzerland is situated in the context of the 'guest-worker' regime<sup>5</sup> of Swiss migration and integration politics of the twentieth century, which focused on drawing migrants from the Mediterranean region, mainly Italy (Piguet, 2006). It is in this context that issues regarding migrant ageing<sup>6</sup> have entered public discourse over the last few years. As the first cohort of these migrants grows old, long-term effects of the 'guest worker' regime on health-care and social security come to the fore (e.g. Soom Ammann, 2011; Soom Ammann & van Holten, 2013). A vast landscape of migrant organisations, initially offering social support to young 'guest workers' (Soom Ammann, 2006), is now claiming a stake in the field of ageing migrants and their supposed needs. Some organisations advocate strongly for ageing migrants while others offer themselves as voluntary partners for services designed by the host society. The Mediterranean ward of Brunnhof nursing home, for example, was initiated after intensive lobbying by local migrant associations, the latter also providing substantial volunteer work for its residents.

All Swiss Mediterranean wards are organised within mainstream not-for-profit nursing homes. They offer standard nursing as well as targeted care and support services. The latter are intended to address an imagined 'Mediterranean culture', for example with reference to room decoration, food, social activities and festivities. The core element of 'Mediterranean' care is to provide bilingual care workers, expected to be acquainted with the language and 'culture' of the residents and the language of Swiss-German long-term care. This aim is challenging due to general shortage of care workers and the difficulty of around-the-clock provision of Italian speaking staff trained to shoulder greater responsibility in care homes.<sup>7</sup>

## STATE OF RESEARCH

Research on migrant-specific services in old-age long-term care is scarce. Existing academic literature focuses on the general relevance of ethnicity for long-term elder care (Badger et al., 2009) or the professional conception of 'ethnic others' and their needs (Kahn-Zvornicanin, 2016). An exception is the Australian case, where research focuses on language needs (Runci, O'Connor, & Redman, 2005a) and on the benefits of ethno-specific services in dementia care (Runci, Redman, & O'Connor, 2005b). Another study addresses the underuse of formal dementia care by non-English speaking persons and the need for culturally and linguistically adapted services for those groups (Shanley et al., 2012). Runci, Eppingstall, van der Ploeg, & O'Connor (2014) document that relatives of nursing home residents with migrant backgrounds appreciate ethno-specific care services that address language needs, adapt social and cultural activities and attend to food preferences. Thus, the Australian research points to some advantages of ethno-specific care services. Dying and death, however, have received no attention yet when migrant-specific long-term elder care facilities are discussed. Worldwide, migrant dying and death have only partially been treated in the wider context of specialised palliative care (Gunaratnam, 2008, 2013; Soom Ammann & Salis Gross, 2014; Turner, 2002; Walter, 2012).

## METHODS

Our research project involved extensive ethnographic fieldwork in two Swiss nursing homes. Both are situated in an urban environment characterised by heterogeneous populations, including migrants of various origins. They care for approximately 120 to 130 residents each. The Brunnhof nursing home offers single rooms and is organised in households of 10 to 12 residents, one of them a Mediterranean ward. The Centre Burgallee nursing home offers single and double<sup>8</sup> rooms and is organised in wards without segregated care options. Fieldwork consisted of nine months of participant observation and interviewing done by Soom Ammann in Brunnhof and Rauber in Centre Burgallee in 2012/2013. To complement the data on the specific mode of Mediterranean long-term care, Soom Ammann also conducted short fieldwork visits in three other institutions offering Mediterranean services. Research methodology was inspired by a constructivist understanding of Grounded Theory suitable for ethnographic data (e.g. Charmaz & Mitchell, 2001). The research field was entered with an open research focus, data were collected and analysed iteratively, observations and informal talks were recorded in field notes, and interviews were selectively audio-recorded (if circumstances allowed) and transcribed. Data analysis was done by first and second author, and interpretations were regularly validated by the research team. The responsible Cantonal Ethics Committee declared in August 2012 that no ethics approval was required. Following the ethical standards formulated by the Swiss Ethnological Society, consent was obtained from the management of the two nursing homes, research participants were initially informed of the aim of the research project, and their willingness to participate was constantly re-evaluated by the researchers in concrete interactions. Data were systematically pseudonymised.

## DOING MEDITERRANEAN-NESS: EVERYDAY PRACTICES

Focusing on everyday practices of 'doing Mediterranean-ness', three central dimensions of 'doing difference' have been elaborated: First, observations and interviews demonstrated the necessity to explicitly perform the postulated sameness of the residents living on the Mediterranean ward and thus stress their otherness from residents of the other wards in order to legitimise segregation. Second,

everyday practices in Mediterranean wards appear to tend towards overt informalisation of social relationships by staging family, especially between residents and staff. Third, achieving understanding by using the appropriate language is one of the main foci of 'doing Mediterranean-ness'.

### *PERFORMING SAMENESS AND OTHERNESS*

The tendency of 'othering' is inherent in attempts to consider migrant diversities in health care (e.g. Canales, 2000; Torres, 2006; Torres, Agard, & Milberg, 2016). On the Mediterranean wards, the 'otherness' of residents is defined as a structural prerequisite, which leads to a need to perform<sup>9</sup> this otherness in order to legitimise this structural segregation. Performances of sameness and otherness serve to situationally clarify the borders between ingroup and outgroups (Barth, 1998 (1969); see also Douglas, 1970).

The following field note, focused on three staff members, exemplifies this:

Back in the kitchen, Marina and Sabrina discuss what the latter is supposed to prepare for lunch. There is Pasta all'Amatriciana on the menu today, as well as braised beef with runner beans, they say loudly to involve the residents, while reading the menu plan hanging on the wall. After looking into the basket of fresh groceries each ward kitchen gets every day from the central facilities, a lively discussion arises between the two, and Carmela enthusiastically joins in: How does Amatriciana have to be prepared properly? They obviously disagree on details, e.g. if anchovies should be part of the tomato sauce and how it is prepared in different regions of Italy, but they all agree that, according to the contents of the grocery basket, the central facilities do not have the slightest idea on what 'a real Amatriciana' is. There are no anchovies in the basket and not the right kind of bacon either, not to speak of the proper grated cheese to accompany the daily pasta dish. (field note by first author working as a nursing aide on the Mediterranean ward)

Staff is 'doing difference' by drawing a clear border between 'us', the Mediterranean ward and 'them,' the central facilities. However, other dimensions of diversity are at stake in this scene. It obviously is tricky to cook Mediterranean food 'properly', or 'doing it right' in the eyes of critically attentive audiences: residents present in the kitchen, the ethnographer, or 'outsiders', such as relatives of residents or representatives of the migrant community, as we have shown elsewhere (see van Holten & Soom Ammann, 2016). Amatriciana is a regional Italian dish, and while this knowledge once helped Mariella to 'bring a spark to the eyes' of a severely demented new resident born and raised in that region, it may also be something that other Mediterranean ward residents are not acquainted with. Thus, the Mediterranean ward, which is in practice a mostly Italian ward, constructs sameness by stressing 'Italian-ness'. However, it is at the same time confronted with diversities within this supposed 'Italian-ness'. Other borders are simultaneously at stake: between the ward and the nursing home, the ward and the migrant community, the care workers and the residents.

Mrs Vuillemier was a picky eater who loved to complain about meals to her friend Mrs Moretti, who then told her daughters. The daughters, known among the staff as 'difficult relatives', in turn, repeatedly used this information to complain that the nursing home was not offering adequate quality of care because the postulated Mediterranean-ness was not achieved by the staff. The pressure on the staff to 'do Mediterranean-ness right' was thus clearly observable in the case of food. The staff's questioning of the central facility's knowledge of what ingredients should be delivered to the ward may be seen as a re-affirmation of 'doing Mediterranean care well' by demonstrating competences that are truly different from mainstream nursing home wards.

The most obvious ways of 'doing diversity' on the Mediterranean wards thus affirm internal sameness against external otherness. This is also seen in room decoration, for example paintings of famous Italian tourist destinations, or Catholic<sup>10</sup> iconography, e.g. the Madonna placed centre-stage in the living room. Diversity is also 'done' when leaving the Mediterranean ward, e.g. for festivities or excursions: The residents of the Mediterranean ward use to wait for each other and leave as a group, and they are clearly perceived as 'the Mediterraneans' by other residents. The construction of borders by performing sameness and otherness can be understood as an attempt to present the ward as a 'community', and so legitimise the segregation and the need for special arrangements within the organisational structures of the nursing home.

While 'community' is 'done' very explicitly when constructing the borders of the Mediterranean ward and when moving beyond these borders, there seems to be no need to perform 'community' within everyday life on the ward in a more explicit manner than other wards of the Brunnhof nursing home do. Everyday social life and interactions among residents do not differ significantly, residents are individuals grouped together by chance just the way residents are on other wards, and they use a variety of strategies to relate to each other. Some of the practices observed in the context of everyday social life on the Mediterranean ward may also be understood as mimetic performative acts of ethnic identity in Judith Butler's sense (see e.g. Clammer, 2015; Mueller & Hofmann, 2017). However, what we have described above are institutionally orchestrated performances of 'Mediterranean-ness' or 'Italian-ness' aimed at legitimising the specialization of care on this ward towards audiences that could potentially question the necessity of Mediterranean caregiving. Being a minority within the organisation seems to encourage residents and staff to explicitly perform borders when interacting with the outside by positioning the ward as a community that is different from the 'outside world'.

Constructing borders by doing sameness and otherness is also relevant with reference to the wider societal and political context: The segregation of a minority in a political framework based on the principle of equality needs to be legitimised not only through everyday performance, but also on a discursive level. All the Mediterranean wards in Switzerland are specialties of standard care services and are intended to be experiments whose future is unclear. Political debates on the integration of migrants into the Swiss society thus frame the ways of reasoning about the Mediterranean wards. The views of management and staff reflect a shared acknowledgement of the obligation to make amends for previous neglect.

Well, the migrant experience involves this aspect of having come off badly, we hear this repeatedly. [. . .] And it happens that we have residents who feel that they never got what they deserved, they never fully belonged here, they were always assigned a secondary role. (Ms Ricci, head of Isola Mediterranean ward)

This sense of not being a full member of society due to one's migrant status is a central argument in favour of migrant-specific wards for those who still feel unfamiliar with Swiss contexts. As Mr Meier, the managing director of Brunnhof nursing home, puts it, "the migrants on the Mediterranean ward tend to construct themselves as a community based on the issue of being a minority". This is also observable in the practice of leaving the ward as a group while not necessarily sticking together on the ward. Thus, segregation fulfils the purpose of having minority status and associated needs acknowledged.

However, there are also explicitly sceptical voices who question whether differences between migrants and non-migrants are large enough to legitimise segregated nursing home wards and even interpret this supposed need as a failure of previous societal integration.

For this generation, of course, they did not have the opportunities to learn the language, to integrate, I don't know, maybe they stayed a bit among themselves. But I, as a migrant, today I have the possibility to learn German, to achieve a professional degree, I do not expect to be cared for on a Moroccan ward in the future. I am against it. The Swiss state is investing millions in integration programs, but where is integration if we offer such services? So in the future I think it would be counterproductive, it would be like a ghetto. (Yasmin, nurse in Brunnhof nursing home, originally from Morocco)

As these interview quotes show, the legitimacy of migrant-specific nursing home wards is contested among the nursing home staff, and debated with reference to the wider political and societal context of migration and integration policies.<sup>11</sup> The future of existing wards is unclear. Is it a service meant to bridge a specific gap for the first cohorts of labour migrants, or is it a permanent requirement of increasingly diversified societies? If migrants need specific services, which migrant groups will get them, and which will not? Ms di Biagio, quality manager at Hirschtal nursing home, is convinced that such wards will also be necessary in the future: "[M]igration will not disappear as an issue! For this reason, we will clearly stick to this ward. Maybe we will have Turkish speaking residents, or languages from the Balkans. [. . .] I think that other groups will need it in the future." However, if migrant-specific diversities are used as a segregating criterion, the issue of other diversity dimensions, e.g. class, are underestimated in this discourse.

Well, the nuances between the Mediterranean ward and our other wards are small. It is simply another cultural background, another social habitus, but with respect to the needs associated with ageing it is almost the same. Food is a bit different, and the rituals, but I have the feeling that it is a small

difference. This has also brought me to think about creating other household wards, e.g. a little bourgeois, or blue-collar worker style, . . . that we would steer this a bit when residents enter, so that they share some kind of similar atmosphere. (Mr Meier, managing director of Brunnhof nursing home)

As we have already pointed out, Swiss policies favour integration and are sceptical of services restricted to specific groups. What is it then that drives the need for nursing home facilities offering Mediterranean services? The main reasons for this mentioned by the actors involved—residents, their relatives, staff, management, external professionals and volunteers—may be grouped around two main topics, which will now be treated in detail: providing a feeling of familiarity and belonging, and meeting the language needs of the residents.

### *STAGING FAMILY*

One of the main topics raised regarding Mediterranean wards are differences around family and familial solidarity that have vital consequences for organising professional long-term care in a residential setting. Practices related to this issue came to the first author's attention in the interactional styles on the ward, which were different from those on other wards in the same nursing home, but were present also in other Mediterranean wards. Interactions between caregivers and residents were characterized by overt performances of informality. These were evident in the use of first names to address someone instead of using the polite form, as well as in the sense of being more tactile and exchanging physical signs of affection: hugging, kissing, caressing.<sup>12</sup> This may be interpreted as a strategy for creating a 'Mediterranean' sense of belonging through fostering informal, family-like relationships in professional care work:

Yes, we are more the family type of people. Community is very important to us. Here in Switzerland, it is – a bit more individualism, everyone for himself. Well, I for example give a lot of my free time to the residents, shopping, getting special things they want, dark chocolate for example. For me it's normal, I already did this in Morocco, with my neighbours. A Swiss wouldn't do this. Their free time is important to them, it's sacred. For me instead it's not a big deal, I simply do it. Yes, that's true, we don't stick too close to the schedule, don't drop everything when it's four o'clock and go home. When they need something, I do it for them. (Yasmin, nurse in Brunnhof nursing home, originally from Morocco)

Staff on the Mediterranean ward was at ease with less informal relationships to residents, but also seemed to be better acquainted with the familial histories and relationships of their residents than on other wards. The presence of relatives in the nursing home was widely accepted by staff. Phone calls by sons and daughters were frequent, and carers took considerable time in talking to relatives, showed appreciation of extensive visits and the participation of extended families (including children) in activities on the ward. Moreover, when leaving the ward, 'staging family' was one of the characteristic features of 'doing otherness' with reference to the other residents. This was observed by the first author when attending a festivity organised for the entire nursing home on the occasion of St. Nicholas Day (6th December) in the main hall of the nursing home. Although relatives were explicitly welcome at the event, most residents attended alone, but the Mediterranean residents showed up accompanied by a considerable group of relatives. On their arrival the hall was already rather crowded and staff started to re-seat residents and to move chairs and tables in order to group the Mediterranean residents and their relatives together, positioning the children centre-stage. This re-arrangement of residents and relatives by the Mediterranean staff took considerable time, it caught the attention of everyone present and was accompanied by occasional expressions of disapproval by other staff and residents.

The importance of informal, family-oriented relationships also became obvious with reference to the children of Mrs Moretti. To the observer (first author), they seemed to have a very good, informal relationship with the staff, using first names, greeting them like old friends and talking about private matters—as they did with other residents on the ward. They seemed to be warm and caring especially towards residents with no relatives, such as Mrs Vuillemier. The Moretti relatives were the embodiment of 'family kind of people'. However, they were also creative in exerting power by repeatedly questioning the appropriateness of care delivered by staff. They complained that their mother had to wait too long after ringing the bell, that food amounts were insufficient, and that their mother's medication was incorrectly administered. Complaints were addressed not only to the ward staff, but also gossiped about with other residents and members of the Italian migrant community, some of whom worked as volunteers on the ward. The strong emphasis of the ward on doing informality thus allowed the Morettis to act as

caring sons and daughters with good relationships to the ward community, but also allowed them to use this informality to criticise and exert pressure. Due to the informal relationship they established with staff, the latter found it very challenging to handle such behaviour.

The nursing home is, in Ahrendt's (2012 (1960)) terms, a semi-public space offering an institutional service that is used when the organisation of informal care and support in the private sphere is not possible. In such cases, residents leave their private home to establish a new home within the institutional setting. Consequently, the nursing home seems private for them, but for the staff it is a public working space: they care for residents as their job executed in an institution which is part of the public welfare system. Nursing home life lies on the border between private and public, and relationships oscillate between informal and formal (see also Rauber et al., in preparation). The professional standard of avoiding informality in caregiver-resident-relationships, exemplified by institutional rules on addressing residents (i.e. by using the polite form), is a formalised strategy to handle this critical borderline.

The Mediterranean team's strategy of promoting familiarity by transgressing this border and fostering informal, family-like interactions may be regarded as a more resident-centred way of dealing with the problematic borderline between private, informal care by the family and public, professional care by staff (see also Ramos & Karl, 2016). Migrant-specific care seems to assume that migrants are strongly family oriented and unacquainted with Swiss individualism, therefore requiring institutional care that creates family-like environments.<sup>13</sup> This strategy, extensively observed in the Brunnhof, was also referred to by staff members of the other Mediterranean wards included in this study. Staff members were convinced that one main difference between Mediterranean and integrative wards was the way relatives are involved in care. Relatives of Mediterranean residents have different expectations, they say, and therefore have to be handled differently.

Interestingly, the staff on the Mediterranean ward did not talk about the 'difficult' Morettis in terms of group characteristics but as individual family characteristics. The Moretti family was an important topic during our fieldwork stay, exemplifying demanding relatives throughout the institution, but without any reference to their being of Italian origin or being customers of the Mediterranean ward. They were never described as typically Italian or migrant or in a similarly stereotyping way. This suggests that Mediterranean nursing home wards, although repeatedly obliged to perform their uniqueness and to negotiate their right to exist, are very able to step back from 'doing sameness/otherness' and to focus on individualities. We might even go further and say that it is precisely because difference is structurally inscribed into the institution that conflicts do not have to be ethnicised and reduced to differences between 'us' and 'the others' (see also Soom Ammann et al., 2016). Staging family and being sensitive to its importance for residents and relatives in the context of debated migrant diversities is helpful in handling challenges and conflicts in a more individualised way.

#### *ACHIEVING UNDERSTANDING*

Another reason commonly evoked when justifying the existence of the Mediterranean ward is achieving mutual understanding by using the same language. During the Swiss 'guest worker' regime, there was little emphasis on migrants learning the local languages. As a result, ageing Italian migrants are not well acquainted with the dominant language. Key reason for organising a migrant-specific service is thus to provide staff speaking the residents' native language.

One of the main challenges associated with Mediterranean wards is to recruit appropriate caregivers with sufficient Italian language skills to communicate with the residents and to understand their needs and worries. Staff on Mediterranean wards are very diverse. On the qualified nurses' level, it ranges from younger second-generation Italians with nursing training in Switzerland, or Swiss nurses fluent in Italian, to recently 'imported' nurses from Italy or other Mediterranean countries. Among nursing aides are first-generation Italian (or Spanish) migrant women who entered care work later in life after being a low-qualified worker or a housewife/mother. But there are also persons of various origins who have recently migrated to Switzerland and speak a language related to Italian (such as Spanish) or people assumed to have a 'similar sense of caring culture' to Italians.<sup>14</sup> With respect to staff being able to care in a 'Mediterranean' way, borders are constructed and shifted according to available workforce resources.

Staff language proficiency is the aspect most valued by relatives when asked why they prefer a Mediterranean ward for their spouses or parents. They almost always first point out that residents do not speak German well enough to be cared for adequately on an integrated ward. Being unable to speak German, however, is less often mentioned as a handicap by the residents themselves than being unable to understand what is being said, as Mrs Leccese notes:

Mrs Leccese: Well, I do not understand much German. [. . .] And even though some [of the staff] here speak Italian, there are also quite a few who don't, or don't want to. I always talk to Mariella, but she is only a 'sous-chef', isn't she? And she's not always here. But I accustomed myself, and even though I am not able to speak, I understand a little. I adapt myself. [. . .]

First author: And there is also staff with another mother tongue which is neither German nor Italian.

Mrs Leccese: Well yes, that's a real problem! Because I don't understand anything at all what they're saying. And this makes me feel bad, since I don't know what they've said, if it was something good or bad. [. . .] I like it best if someone speaks Italian; then I clearly understand. Otherwise one feels uneasy. (Mrs Leccese, resident of the Brunnhof Mediterranean ward)

Not being able to fully understand what others say, especially those one has to rely on when being in need of care, leaves residents unable to control situations and therefore feeling insecure and excluded. What Mrs Leccese touches on here opens up a number of complexities around the issue of language. Being able to speak the same language does not automatically lead to good communication. Another dimension of good communication is trust. Being confronted with diverse staff, of whom some speak Italian, some German, and some neither, leads Mrs Leccese to focus on individual staff members she selects to talk to. Her choice of preferred caregivers, as observed and discussed in the course of the fieldwork, not only rests on Italian language proficiency, but, first, points to the importance of being understood in a broader sense (being taken seriously, being acknowledged, sharing affection) and, second, to issues of power and patronage.

The first is exemplified in her preference for Irene, a Swiss protestant nurse with minimal Italian language skills, with whom she felt an exceptional closeness. Irene and Mrs Leccese understood each other very well, despite the lack of language skills. The second becomes obvious in her preference for Mariella, who is the team leader on the Mediterranean ward and thus in a good position to change things on behalf of Mrs Leccese. An important prerequisite for access to the benevolence of powerful caregivers is investment in relationships (see also Rauber et al., in preparation), and speaking a common language may function as a shortcut in this context.

Dementia care is another example where Italian language use on the Mediterranean ward is both of major benefit and at the same time reaches its limits. Mrs Ilario was a woman with advanced dementia who had lost her competences in languages other than her native tongue. Having Italian-speaking caregivers allowed the staff to communicate with her. However, with increasing dementia, Mrs Ilario regressed to only speaking a local dialect, which was very hard for staff to understand, as they came from other Italian regions or had learned Italian as a foreign language. Mrs Ilario's capacity to express herself was in this sense just as restricted as it would have been in the German-speaking wards. Still, as staff pointed out, having some knowledge of where Mrs Ilario came from and what life had been like in her place of origin helped to understand her, to read her nonverbal communication and to give her a feeling of familiarity. In this sense, staff members who share biographical experiences with residents may in some cases be in a better position to provide migrant-sensitive care than staff speaking the same language. As Ms Ricci, head of the Isola Mediterranean ward, a Swiss married to an Italian and perfectly fluent in Italian, points out:

Well, I sometimes just do not feel very secure on the ground here. When I was working on an integrated ward, I knew better, for example, what song I could sing or what prayer I could read if I had the feeling that someone needed it. Here I have to rely on my staff. For example, Chiara, whom you have just met, she is technically the cleaning woman, but she is also our expert for prayers. Of course, I can go and fetch a little book with nice prayers, but if I don't pick the right ones, it doesn't help much. Especially residents with dementia. Songs, words, prayers – they recognise them, they experience it, if they know it. (Ms Ricci, head of Isola Mediterranean ward)

Again, reference is made to dementia care, and, very explicitly, to the fact that such 'cultural expertise' is not primarily a matter of professional competence, but of biographical experience. Although the highly-qualified team leader Ms Ricci may have excellent language proficiency and be in a good position

to judge the needs of the residents, it is Chiara, the cleaner, who is the expert for choosing the right intervention to convey a sense of familiarity.

### **'DOING DEATH' WHILE 'DOING MEDITERRANEAN-NESS': DYING TRAJECTORIES**

As has been shown, 'doing Mediterranean-ness' in Swiss nursing homes is characterised by 'performing sameness/otherness' and by negotiating the legitimacy of this kind of service. Moreover, 'staging family' and 'achieving understanding' have been discussed as the most prominent features of 'doing Mediterranean-ness'. However, while stressing sameness, practices on the Mediterranean wards are at the same time as much to guarantee person centredness as non-segregative wards are. Thus, 'doing Mediterranean-ness' does not lead to a stereotyped and inflexible Mediterranean service. When looking at dying trajectories on Mediterranean wards, this becomes even clearer.

The dying trajectories on Mediterranean wards that have been observed and/or discussed in interviews show considerable similarities to those on the non-segregative wards of Brunnhof and Centre Burgallee (see also Soom Ammann et al., 2016; Rauber et al., in preparation). They are characterised by residents retreating to their private rooms, accompanied by a very discreet solicitude by fellow residents. Thus, the community of the ward is only minimally involved in dying trajectories, both on integrative and segregative wards. The involvement of the professional caregivers, on the other hand, tends to focus on professional routines in incidents of acute dying. Therefore, as on the non-segregative wards of Brunnhof and Centre Burgallee, the 'Mediterranean' caregivers also tend to refer to usual procedures of 'death work' in nursing homes (Soom Ammann et al., 2016), which they regard as their main duty in dying trajectories, as the following quote illustrates:

Since I have been working on the Mediterranean ward, I have experienced two death events. And I have to say ehm – I had the impression that it's not different. Maybe with regard to dying rituals, in this respect it's a bit different to us. Italians are Catholics, you know, they receive last sacraments, the priest comes by and so on. But we leave this to the relatives, they organize this. And we focus on the care, the nursing, the humane. (Irene, nurse on Brunnhof Mediterranean ward, Swiss, protestant)

Conceptualising dying as something humane, universal and at the same time highly individual, is a central aspect of the nursing home staff's understanding, which is, as we have shown elsewhere (Soom Ammann et al., 2016), a variation of contemporary ideals of palliative care broken down to pragmatic, ready-to-use measures such as giving morphine and stopping previous treatments. Sticking to their routinised professional practices of 'death work', caregivers on the Mediterranean wards strongly focus on the dying resident's individual wishes and interests. Interpreting how the terminal and thus mostly unresponsive resident feels and what he/she needs becomes one of the main tasks of the caregivers while 'doing death' in the terminal phase. Language proficiency is in this context of minimal importance; what is crucial is knowledge of the individual, a relationship with the dying person giving the caregiver grounds to interpret what should be done. 'Death work' is highly individual, for both the dying resident and the caregiver. At the same time, it is also considerably structured by institutional rules and professional practices. Furthermore, Ms Ricci's expression that "in the terminal phase it is essentially about empathy, and language is indeed not so important any more" stresses that communication in acute dying seems to refer to very universal, human forms of bodily signs, such as tone of voice and bodily reactions to touches.

What is helpful in doing 'death work' on behalf of dying residents is to have some indication as to what the person felt about his/her death. Talking to residents about death is generally regarded as a taboo, but also as a duty of professional caregivers to facilitate their 'doing good death work'. Having indications as to what the dying resident would wish for is especially important in situations where decisions are contested (see e.g. Soom Ammann et al., 2016, p. 128, case of Mrs Ilario). In this respect, some caregivers state that there is a difference between integrative and Mediterranean wards, in that there is less willingness on the latter to communicate about death and plan in advance.

Well, the way I can talk with our residents about dying and death is to talk about a concrete death of a fellow resident. If I ask them about their own deaths, fears immediately come up, this – kind of – fears from below, which probably refer to: you attract it, if you talk about it. But if I tell them I have been to the funeral of Mrs So-and-so and it was like this, then I can ask: How is this for you? Is this the way you

would also like it to be? Or is this completely strange to you? Then I get a much better impression of what they think than if I confront them with: We need to fill in a patient's directive!<sup>15</sup> [laughs] (Ms Ricci, head of Isola Mediterranean ward)

Thus, caregivers tend to use spontaneously arising occasions to talk about death with residents. Mrs Motta was a widow with no children or other clearly definable proxies living on the Mediterranean ward. When her health deteriorated, nurse Mariella had to decide if a transfer to hospital was appropriate or not. The nurse referred to Mrs Motta's earlier expressed wish to die. Knowing this, Mariella was at ease with her decision not to call an ambulance and allow things to develop without drastic intervention. Due to the fact that Mrs Motta had talked freely and repeatedly about her weariness of age-related frailty with staff members, fellow residents and the field researcher, Mariella's decision was accepted by the whole team.

Other incidents were observed or talked about in the course of fieldwork, indicating that it is not uncommon for Mediterranean residents to talk about death, nor for caregivers—at least the experienced ones—to be attentive to such utterances and sometimes to note them in the resident's record. There were no major differences on integrated wards in the observed reluctance to talk about death and death-related wishes with residents if they themselves did not do so on their own initiative. However, what is perceived as clearly different by the staff working on Mediterranean wards is how relatives deal with dying and death. In Mrs di Lorenzo's case, nurse Laura and her colleague were very much at ease with the resident's acute dying trajectory, since due to conversations they had with her about an especially elegant dress and set of underwear in her cupboard reserved for her deathbed, they 'knew' that Mrs di Lorenzo was 'prepared to go', and they 'knew' what their role was. However, what was challenging was the behaviour of Mrs di Lorenzo's relatives.

Relatives generally become more important in nursing home dying trajectories than they are during earlier phases of the nursing home stay. When residents retreat from the community of the ward and caregivers interpret this as potentially terminal, relatives are contacted by the staff and usually increase their presence. On Mediterranean wards, this presence may be intensified considerably.

I don't think there are differences regarding dying itself. It is the social context that is different, relatives coming by, and especially many more people coming to say goodbye. (Laura, nurse on Hirschtal Mediterranean ward, second generation Italian)

Mrs di Lorenzo's case illustrates this as, according to nurse Laura's account, her extended family increased their presence at the deathbed, including people the staff had never seen before. They stayed day and night, asked for medical interventions and—this was the point where Laura's tolerance came to an end, as she explained—they requested at a certain point that Mrs di Lorenzo's death should be medically postponed until a nephew from Italy had arranged for his travel to come and see her before she died. Laura had a talk with the son registered as first proxy and, as she reported in the interview, argued from the perspective of Mrs di Lorenzo that such interventions would only cause harm and distress to her and that this certainly was not in the best interest of her relatives. Laura drew on professional arguments compatible with palliative care ideals and put them into words acceptable to the relatives, who certainly made their claims with good intentions. Laura understood her role in this conflict both as a 'cultural expert' understanding the efforts of the relatives to 'do death well' and as a professional expert advocating primarily for the dying resident, but also for the safety and peace of the other residents on the ward.

Staff experience relatives with a migrant background as potentially different, because they may articulate demands as to how one should react to a resident's dying that collide with 'death work'. The wish to do everything to postpone death seems to be more prevalent among relatives with a migrant background than among the majority of relatives present in the nursing home. This tendency has also been reported in research on palliative care services for migrants in clinical settings (Soom Ammann & Salis Gross, 2014). The relatives of Mr. Romanoli, a resident of Italian migrant background at Centre Burgallee, probably tried to do the best for their father when they started to feed him, while the staff interpreted the fact that he was not eating autonomously as an expression of his will to die and would have refrained from forcing him to eat (see Soom Ammann et al., 2016, p. 127). Our data show that relatives often do become central actors in acute dying trajectories, and there are incidences where relatives with a migrant background have implicit notions of how to deal with dying and death that potentially collide with the dominant norms of 'doing death' in nursing homes (see also Soom Ammann et al., 2016). However, the

strong focus on sameness/otherness characterising the Mediterranean ward and the negotiations on its appropriateness seem to lead to a broad tolerance towards the unexpected behaviour of relatives and a high competency to negotiate with them. As Mrs Moretti's case illustrates, excessively interfering relatives are regarded as individual cases. Their being of migrant background is an acknowledged, but at the same time not overvalued aspect of their personalities and family dynamics. They are not difficult because they're Italian, they are difficult because they are the Morettis. In this sense, the segregation of residents with a common migrant background, and the negotiation of what this means for caring for them, not only leads to performances of sameness/ otherness, but also to a flexible way of dealing with diversity in a nuanced way. Focusing on one specific dimension of diversity, and having to legitimise this focus, seems to enhance diversity-sensitive end-of-life care and 'doing death' and not to foster stereotyping culturalised forms of 'doing death'. As Ms Ricci puts it below, having to negotiate diversity seems to enhance professional self-reflexivity:

Well, one has to be sensitive towards one's own values, and to appreciate that others may have other values. Especially in the context of dying and death, this is a recurrent topic. Where do I have my limits, when is something reaching beyond my own personal limits, and why? And in what respect are these expectations not compatible with those ruling here, you know, in professional elder care. For example, we often prioritize values such as autonomy or independence. Their [i.e. the residents' and relatives'] values often focus on being cared for well, delegating, not having to decide anymore. And also: enjoying and letting go, not having to pull oneself together. And one has to be aware of this, and reflect on it if one feels that something is disturbing one's own values. Being aware of one's own values and being tolerant towards differing values. (Ms Ricci, head of Isola Mediterranean ward)

Ms Ricci points to an important aspect of nursing home 'doing death' when mentioning the ruling expectations in the nursing home. As we have noted elsewhere (Soom Ammann et al., 2016), these expectations are informed by a very pragmatic and often not well-reflected version of Western European palliative care ideals, which may collide with other expectations regarding what 'doing a good death' may involve (see also Walter, 2012). Reflexivity thus seems to be a valuable solution for dealing with difference in everyday practices of nursing home 'doing death'.

## **CONCLUSION: 'DOING DIFFERENCE' AND INSTITUTIONALISED REFLEXIVITY**

This paper aimed at exploring the field of migrant-specific nursing home care in Switzerland, describing its evolving practices of end-of-life care, and considering its potential for increasing diversity-sensitivity in institutions of old-age long-term care. It has been shown that practices on segregative wards are organisational modes of 'doing difference' which are characterised by a) performing sameness/otherness, b) staging family and c) achieving understanding. 'Doing death', however, is dominated by nursing home 'death work' practices, not by practices of 'doing Mediterranean-ness'.

What is remarkable in our findings is that in cases of collisions arising from diverging conceptions of a 'good death' in the course of acute dying trajectories, the Brunnhof staff do not refer to migrant specific or 'cultural' stereotyping, in the sense of explaining collisions with divergent characteristics associated to migrant origins. The Centre Burgallee, however, seemed to be more prone to explain conflicts in terms of the supposed 'otherness' of the counterpart. We would therefore argue that the Mediterranean ward, although it uses collective 'othering' to construct its 'Mediterranean-ness', has less recourse to using individual 'othering' strategies to explain the unexpected behaviour of specific residents and relatives than integrated long-term care. Thus, while there is 'othering' in everyday practices of 'doing Mediterranean-ness', the practices in critical phases of 'doing death' (i.e. dying trajectories, conflicting interpretations of 'doing a good death') are characterised by diversity-sensitivity. This is to our view in large parts a consequence of the questionable legitimacy of segregating within an integrated type of organisation and the associated practices of negotiation we have discussed here.

'Doing death the Mediterranean way' seems to lead to an increased diversity-fitness of not only the ward, but also the whole organisation. The structural pre-determination of migrant specific diversity, as practised in the Brunnhof nursing home by running a Mediterranean ward leads a) to an early-onset negotiation of diversity issues in individual 'doing death', and due to this, b) to a general sensitivity of the institution towards diversity issues, since the structural segregation remains questionable. The confrontation with structural segregation within the institution may lead to an increased consciousness of diversities and situations in which they may be of importance. In addition, the enhanced awareness

may result in rehearsed strategies to deal with diversity issues. In this sense, dealing with diversities is to a certain extent integrated into the professional routines of 'death work' in nursing homes running segregated wards. Consequently, the advantages of segregated forms of nursing home end-of-life care may lie in the fact that diversity issues are subject to early and repeated negotiations and that the institution thus accumulates experience in negotiating unexpected behaviour and tolerating difference. Individual (self-) reflexivity of staff is thus fostered, as our data indicate, and this also involves the possibility of a more differentiated handling of diversity issues in nursing home end-of-life care. The reflexive practices observed in Brunnhof, however, have not been explicitly institutionalized yet within the framework of mission statements, peer consulting, or case conferences. In this sense, there is potential to acknowledge and formalise this emergent institutional practice of dealing with diversity in end-of-life care for the benefit of the whole institution. More generally, our results point to the conclusion that institutional sensitivity to diversities is not about abstract knowledge of 'the other' (e.g. 'how-to' guidelines), but about the repeated practices of negotiating sameness and otherness in concrete interactions, as well as about abilities to reflect on and adjust actions. Institutional investment in encouraging staff to become 'diversity-fit', in the sense of having opportunities to negotiate and to reflect, may be extended to other diversity dimensions, for example gender, disabilities or sexual orientations. More ethnographic research on 'doing diversity' in other health care settings may further contribute to move beyond classical concepts of 'cultural competence' towards a broader sensitivity to multiple diversities and how they matter in concrete interactions.

## NOTES

1. The data presented in this paper were collected within the framework of a larger research programme financed by the Swiss National Science Foundation (NRP 67 'End of Life', grant number 406740\_139365/1) aiming at a better understanding of end-of-life experiences, practices and service needs in Switzerland to inform future research and policies.
2. The notion of 'doing death' refers to Ethnomethodology and the idea that social realities are constructed in concrete practices and interactions, as for example elaborated in the work of West and Zimmerman (1991) on 'doing gender'.
3. All institutions and persons have been assigned pseudonyms.
4. The vast majority of Swiss nursing homes are not-for-profit. All nursing homes (also the profit-oriented ones) offer standard nursing services reimbursed by health insurances and a set of residential and social services paid by the individual resident. Not-for-profit nursing homes get public financial support and are obliged to conceptualise their services so as not to exceed a defined amount secured by social welfare if individual residents are not in a position to pay for it by themselves. Nursing home care is guaranteed to everyone, including migrants holding a residence permit.
5. The term 'guest-worker' regime refers to a policy-driven migration pattern prevalent in Switzerland in the decades after World War II, focusing on short-term migration from Southern Europe for work purposes, usually aimed at flexible, low-paid workforce and based on short- to middle-term residence permits, conditional on being employed. Migrants were expected to return to their home countries, resulting in very low emphasis on integrative measures. Policy measures to foster return did, however, not succeed; along with circular migration patterns, a considerable part of the 'guest-worker' migrants stayed for decades, worked and had children, and is now retired or facing retirement. As a study by Bolzman, Fibbi, and Vial (2001) showed, a third each of Italian 'guest-worker' migrants facing retirement either plans to return upon retirement, to regularly commute or to stay with their children and grand-children. Swiss 'guest-workers' immigrated to a large extent from Italy, starting directly after World War II and going on until the 1970s, followed by other (smaller) groups from the Mediterraneans, for example from Portugal, Spain, former Yugoslavia and Turkey (see also Piguet, 2006; Soom Ammann, 2011).
6. Switzerland has a rapidly ageing population, with a current old age dependency ratio of 29 persons aged over 65 in relation to 100 persons of working age (20–64 years) (see population statistics for the year 2016 on [www.bfs.admin.ch](http://www.bfs.admin.ch)). Migration ratio is high: The permanent population with non-

Swiss nationality amounts to 24.6 % (2015) of approx. 8.5 million inhabitants. If naturalised and second-generation migrants are included, the migrant population of Switzerland is estimated to a little more than one third (e.g. 36% in 2014, estimated on the basis of the working population with foreign born parents, SAKE database, see [www.bfs.admin.ch](http://www.bfs.admin.ch) for details). The migrant population's age structure is considerably younger: the old age dependency ratio of the non-Swiss population parts is 16, compared to the population parts with Swiss nationality displaying a ratio of 38 (BFS 2017: 23). Higher ages in the migrant population are, however, increasing among the larger national groups with long-term residencies from neighbouring countries, among which Italians are the largest group (and the only group characterised by mainly low-skilled work migration patterns). In 2014, there were a total of 164,137 Italian migrants aged 50+ permanently living in Switzerland, of which 66,588 persons were aged 70+ (population statistics, [www.bfs.admin.ch](http://www.bfs.admin.ch)).

7. Thus, staff requirements are situationally interpreted and expanded to include not only Italian, but also 'Mediterranean' or 'Mediterranean-like' characteristics, as will be illustrated later on.
8. Issues regarding double rooms and 'doing death' will be addressed elsewhere (Rauber et al., in preparation).
9. In this paper, we refer to an understanding of performance as elaborated in the frame of Ethnomethodology, especially by Goffman's idea of everyday performances of self towards an audience (Goffman (1990 (1956)) constrained by principles of social order governing interactions and respective interpretations (Goffman, 1974).
10. The Brunnhof nursing home is a secularist institution in a predominantly protestant region.
11. These legitimacy discourses also inform the ways in which residents and relatives discursively refer to the Mediterranean wards. Those opting for such a ward mostly argue in favour of recognition of specific needs and previous neglect. On the other hand, some residents (and/or relatives) with Italian migrant background have explicitly chosen to be cared for on an integrated ward, to avoid the supposed 'ghettoisation' or the expected ways of 'doing community' on those wards.
12. This explicit physical exchange of signs of affection was mainly observed between female caregivers and residents.
13. The issue of family orientation of migrants is debated, specifically with respect to care. While there is a tendency in research and practice to assign family orientation to 'culture' and 'primary socialisation', that is to pre-migration contexts, migrant experiences and experiences with welfare systems are additional dimensions to be considered in this context (see e.g. Soom Ammann, 2011). Informalisation is not necessarily a primordial cultural trait, but also seems to be a promising strategy to deal with precarities and insecurities related to migration (see e.g. Môret & Dahinden, 2009 for the Swiss context). For this reason, it may be an organisational pattern very commonly observed in migrant communities, irrespective of origin and host country. Family and other forms of informal communities based on long-term reciprocity (such as associations, peer groups, patron/client groups) may be more helpful in times of dependency and insecurity than formal welfare state-based modes of relationship (see also Rauber et al., in preparation).
14. Care work is one of the domains of the labour market in Switzerland most easily accessible to migrants whose professional qualification is not valued by Swiss employers, and due to this, the workforce in nursing homes is—not only, but especially at the level of low-skilled work (nursing aides)—extremely heterogeneous. Language fluency is one of the main problems associated with this situation.
15. Although Swiss legislation as well as Palliative Care policies strongly advocate advance care directives, the resident populations of Brunnhof and Centre Burgallee mostly had not filled out written patient directives, or only in a very minimal form, e.g. stating that they did not wish 'to be put on tubes', as several residents and staff members called it, and designating a proxy.

## DISCLOSURE STATEMENT

No potential conflict of interest was reported by the authors.

## FUNDING

This work was supported by the Swiss National Science Foundation [406740\_139365/1]

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