

Residents' and relatives' experiences of acute situations: a qualitative study to inform a care model

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Conflict of Interest

We have no conflict of interest to declare.

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ABSTRACT

Background and Objectives: As new models of care aiming to reduce hospitalizations from nursing homes emerge, their implementers must consider residents' and relatives' needs and experiences with acute changes in the residents' health situations. As part of the larger INTERCARE implementation study, we explored these persons' experiences of acute situations in Swiss nursing homes.

Research Design and Methods: Three focus groups were conducted with residents and their relatives and analyzed via reflexive thematic analysis.

Results: The first theme, *the orchestra plays its standards*, describes experiences of structured everyday care in nursing homes, which functions well despite limited professional and competency resources. The second theme, *the orchestra reaches its limits*, illustrates accounts of acute situations in which resources were insufficient to meet residents' needs. Interestingly, participants' perceptions of acute situations went well beyond our own professional view, i.e., changes in health situations, and included situations best summarized as "changes that might have negative consequences for residents if not handled adequately by care workers." Within the third theme, *the audience compensates for the orchestra's limitations*, participants' strategies to cope with resource limitations in acute situations are summarized.

Discussion and Implications: Our findings suggest differences between care providers' and participants' perspectives regarding acute situations and care priority setting. Alongside efforts to promote staff awareness of and responsiveness to acute situations, care staff must commit to learning and meeting individual residents' and relatives' needs. Implications for the development and implementation of a new nurse-led model of care are discussed.

Keywords: Nursing Homes, Thematic Analysis, Quality

BACKGROUND AND OBJECTIVES

Globally, residential long-term care facilities, or nursing homes (NHs), are challenged by both professional organizations and government regulators to deliver high-quality care to their residents (Larson, Sharma, Bohren, & Tuncalp, 2019; Silvestre, Bowers, & Gaard, 2015). However, maintaining high care standards in NHs is often hampered either by staff shortages or by high ratios of low-qualified care staff; and lack of access to in-house geriatric expertise or general practitioners often leads to avoidable hospitalizations (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011; Trein, 2018).

Avoidable hospitalizations from NHs often result from lack of awareness, late detection, or slow responses to acute situations, defined as slight or rapid deterioration of residents' general condition or decrease of functional performance, either of which may signal injury, infection, or exacerbation of chronic illness (Ouslander et al., 2010). Considering that any hospitalization typically causes major stress and disruption for residents, leaving them in a more vulnerable state with reduced quality of life, avoidable ones also indicate poor quality of care (Kirsebom, Hedstrom, Wadensten, & Poder, 2014; Ouslander et al., 2010). Still, estimates indicate that in Canada, the United States, and Switzerland, between 20% and 60% of hospitalizations from NHs are potentially avoidable, e.g. due to an exacerbation of a change in condition of a chronic heart disease detected late, or the management of pneumonia or end-of-life care that could have been handled in the NH (Muench et al., 2019; Ouslander et al., 2010; Walker, Teare, Hogan, Lewis, & Maxwell, 2009).

Therefore, new models of care have been designed to actively support NHs in their mission to improve care quality by targeting common causes of avoidable hospitalizations, several of which have proved effective (Cacchione, 2020). The most successful of these rely on interprofessional care teams. Shifting from a traditional physician-managed medical care model, they maximize the roles of nurses by having them co-manage care alongside physicians (Cacchione, 2020). Such models are called nurse-led models of care, focusing on nurses exerting their full scope of practice, interprofessional collaboration, person-

centered care, capacity building of care workers, and advance care planning (Cacchione, 2020; Testa, Seah, Ludlow, Braithwaite, & Mitchell, 2020).

Residents' and relatives' involvement

Patients' involvement is necessary to redesign and improve service and care delivery (Denegri, 2015; Selby, Beal, & Frank, 2012). In particular, efforts to include patients' first-hand insights into their experiences of care services and living environments, like, for example, in NHs, and their needs concerning their health conditions are essential in order to develop interventions (O'Cathain et al., 2019). Their input can positively impact the quality and patient-centeredness of interventions and sustainably address high-priority problems (O'Cathain et al., 2019). However, to date, NH residents/relatives' involvement in the redesign or development of interventions or models of care is rarely described (Ahouah & Rothan-Tondeur, 2019; Backhouse et al., 2016). The most common reasons for the limited involvement of residents/relatives are power relations with staff, unsupportive NH culture, and/or lack of research resources or skills (Ahouah & Rothan-Tondeur, 2019; Backhouse et al., 2016). Hence, to overcome such barriers and avoid developing interventions solely based on provider or researcher input, thoughtful use of the methodological approach is needed to integrate residents/relatives in the model development.

Addressing the involvement gap

Both to fine-tune a new nurse-led model of care and to inform its implementation, this study explored NH residents' and relatives' experiences and needs regarding acute situations. It was conducted within the multi-center implementation study "Improving INTERprofessional CARE for better resident outcomes" (INTERCARE) (Zúñiga et al., 2019). The INTERCARE nurse-led model of care supports NHs in improving their quality of care and reducing avoidable hospitalizations. By placing registered nurses in expanded roles— as INTERCARE nurses, it also supports in-house geriatric decision-making. A protocol

for this study, describing that intervention and its implementation in detail, has been published elsewhere (Zúñiga et al., 2019).

The development of the INTERCARE model's initial version began with a literature review and case studies (Figure 1). In the next step we elicited input from national stakeholder groups via a modified Delphi method to define the competencies necessary for the INTERCARE nurses (Basinska et al., 2020). Lastly, to fine-tune the INTERCARE nurses' roles and align in-house decision making with end users' needs, the current study explored residents' and their relatives' experiences and needs in situations involving acute changes in residents' health.

METHODS

Design

We used a qualitative descriptive research design to describe direct experience and perceptions of participants (Sandelowski, 2010). To add to the transparency of the study reporting, we followed the guidelines of O'Brien, Harris, Beckman, Reed, and Cook (2014).

Setting

During the INTERCARE model's development phase, directors of nursing or medical directors from the nine involved NHs were asked whether they would agree to focus groups with samples of their residents and relatives. Of the nine NHs approached, three (two German-, one French-speaking) agreed to recruit residents and relatives (NHs characteristics are described in Table 1). These NHs were highly motivated to offer their residents and relatives an opportunity to talk about their experiences and to learn from the results. Six other NHs declined to participate due to a lack of resources to recruit participants and to organize the set-up for the focus groups.

In Swiss NHs approximately 70% of the overall personnel are care workers including 40% of nursing aids with on-the-job training or 3 months education; 35% of licensed practical nurses with 2-3 years of education, and just 25% of registered nurses with 3 to 6 years of education (Bundesamt für Statistik, 2020). Residents' average length of stay in a NH is 2.3 years, and three out of ten residents are 90 years old or older.

Participants

A local nurse expert recruited residents and relatives (inclusion and exclusion criteria are described in Table 2). Using maximum variation sampling (Marshall, 1996), we ensured the inclusion of 1) residents and relatives with diverse family relations, and 2) relatives of residents with dementia. Before the interviews, the local nurse experts informed participants about the study, supplied them with written study information and obtained informed consents.

Data collection

We conducted focus groups, including both residents and relatives, to explore their individual and shared meanings and perspectives. With this approach, we aimed to allow a) participation for residents limited in their verbal communication, and b) for residents with impaired cognitive function to be represented by relatives (Krueger & Casey, 2000). We conducted one focus group per NH between May and June 2018 with both residents/relatives of the respective NH together, to allow physically frail residents' participation. Overall, seven residents and 11 relatives participated in one of three focus groups lasting 80, 86 and 73 minutes. Among these were four dyads; all others participated independently (for participants' characteristics see Table 1). All focus groups were audio-recorded and transcribed verbatim. Two moderators, using open-ended questions and facilitating discussions about life in the NHs and experiences with and needs in acute situations, conducted the interviews (e.g., "Tell us about a situation where you had a serious problem with your health, here in the NH", for complete

interview guide see supplementary file 1). For extensive description of data collection, see supplementary file 2.

Data analysis

We conducted reflexive thematic analysis to find patterns of meaning that are not mapped directly from the interview questions (Braun & Clarke, 2006, 2019). The analysis, combined with a constructivist orientation, served the analytical goal of constructing knowledge to understand participants' experiences and needs in situations involving acute changes in residents' health (Appleton & King, 2002; Lincoln & Guba, 1994). An eight-member qualitative research team, including nursing PhD students, PhD-prepared nurses, a public health expert, and a NH consultant analyzed data supported by Maxqda Analytics Pro (VERBI Software, 2018). See Table 3 for steps of the analysis, reflexivity and trustworthiness, and supplementary file 3 for an illustration of the coding.

Ethical approval

Ethical approval (EKNZ BASEC Req-2017-00938) for this study was waived by the ethics committee of northwest/central Switzerland because it presents minimal risks to participants and no personal data was to be collected.

RESULTS

Overview

At the beginning of each focus group, residents and relatives were invited to describe what they appreciated about daily nursing care. Given this opportunity they described their experiences of everyday structured care, which functions well despite perceived limited professional resources and competencies. This is presented in the first theme, *the orchestra plays its standards*. This theme provided a useful background against which to contrast acute situations where these limited resources failed to cover their needs. This is described in the second theme, *the orchestra reaches its limits*.

Although this study's focus was on increasing our understanding of acute situations that may have led to hospitalizations, remarkably, the participants' perspectives broadened that focus considerably. Whereas we had defined acute situations as slight or rapid deterioration of residents' general condition or decrease of functional performance; residents' and relatives' understanding of acute situations encompassed virtually any situation that might have negative consequences for residents if not handled appropriately by care workers. From their perspective, acute situations included not only changes in health situations, but also changes in basic care activities and relationship maintenance. The third theme, *the audience compensates for the orchestra's limitations*, summarizes participants' strategies to deal with resource limitations during acute situations. Throughout the interviews, the participants referred to different professional groups, which we referred to as nurses if registered or licensed nurses were meant, and care workers, if nurse aids were included.

The orchestra plays its standards

The metaphor of *an orchestra playing its standards* facilitates an analogy of the NH as an orchestra that plays its standard repertoire well, although it includes only a limited number of musicians with different competencies. Although the participating NHs' specific characteristics, e.g., geographic location, bed capacity, number of staff and residents', mean length of stay, differed, all participants shared similar experiences. In general, while they found everyday care provision sufficient, they also highlighted their perceptions that care workers and general practitioners (GPs) were limited both in their availability and in their competencies.

Residents considered their care well-organized, well-planned and sufficient to cover daily needs and emphasized the kindness of the care workers. Relatives considered residents generally well looked-after, receiving morning assistance for bathing, dressing and having their meals. They also noted that nurses

kept them well-informed regarding their NH's routines. One resident with a major physical impairment described the situation as follows:

“In general, I must say, they look after you well. Maybe they have fewer [registered] nurses, but the staff are friendly, adorable, they are available, they are listening. And the women [nurses], they do their best (...) under such difficult working conditions. Hats off [to the nurses].” (resident 3)

Despite feeling well cared for, participants observed that the care workers had limited resources on several levels. Some described that few “trained” (registered) nurses were available to support care aids. More specifically, one relative explained that because too few nurses with competencies to prepare medications are present, her partner often received his too late. One resident's wife shared that her husband, who had early-onset dementia, had received an inappropriate medication for several months. She added that not only trained nurses but overall more care workers specialized in dementia care would be needed:

“I wish they had more care workers specialized in dementia, because ... 80% of the older people there are already a bit demented or senile somehow, and I miss [care workers with dementia expertise] a bit.” (relative 6)

Other participants more generically commented that, nurses were usually short of time and they could not check regularly on residents. One resident's daughter asserted that two nurses were simply not enough to continuously cover 30 or more residents' needs. In particular, residents perceived all care workers as constantly under time pressure and inflexible about their care plans. A resident with physical impairment described the situation as follows:

“... In the dining room there are about six people at the table ... I am now 100% care dependent, because I can't walk. And when others want something and they [care workers] inform me that I

will have to wait, because they don't have time. They promise to come later but often they just forget because of the many tasks and requests. They just leave me sitting and I don't think that's right." (resident 2)

As with the registered nurses, some participants mentioned having limited opportunities to see a GP: either because GPs have no in-house residency or because participants had no easy access to an in-house GP. One resident explained this as follows:

"You just don't have a direct contact person because the doctor office is downstairs or you have to tell somebody if you want to see a doctor if you have pain, it is difficult for me to see one, you don't have a direct access." (resident 6)

Additionally, some relatives perceived that the GPs responsible for their NH's residents lacked geriatric competencies, particularly regarding geriatric-specific polypharmacy.

Irrespective of the perceived resource limitations, all participants had come to terms with the situation. They explained that "*there is not a lot one can do about [care workers' shortages and competency deficits]*" and had accepted their situation ("*one needs to get used to the new situation*"). They generally perceived conditions as adequate on an everyday basis, and expressed their gratitude towards the care workers, who were doing their best. This attitude was summarized by one relative:

"So, I have to put nurses' kindness at the center. But I mean sometimes, when a nurse comes in and says, 'What do you want now?' I mean, you can't blame her for that. Because she has so many other residents to take care of. And I don't think there's much left to wish for, I believe we must have understanding for the situation, and sometimes just say 'yes, well, it is like it is'." (relative 4)

The orchestra reaches its limits

The metaphor of an *orchestra reaching its limits* illustrates how, if the music repertoire suddenly needs to change, the orchestra reaches its limits, leading to disharmony. In the NH context, disharmony is analogous to inappropriate or non-existent responses or otherwise inadequate attention to residents' care needs in acute situations. The data indicated that from the participants' point of view, acute situations emerged not only from changes in residents' health situations that could lead to hospitalizations due to *physical symptoms*. The acute situations also emerged from a range of situations they believed could lead to negative consequences for residents if not handled appropriately by care workers, resulting in the subthemes *problems performing basic care activities* or *maintaining relationships*. Because of limited resources in NHs, care workers and GPs either did not react or were unable to execute appropriate or timely reactions, this triggered feelings of distress, helplessness, and dissatisfaction.

Close to our definition of acute situations ("slight or rapid deterioration of the resident's general condition or decrease of functional performance"), participants noted acute changes if they saw or felt *physical symptoms*, e.g., pain or itchy skin, that they experienced as worrying. However, when they spoke to care workers, their concerns fell on deaf ears. This was also the case with other acute situations. Several talked about a vague but ominous sense of a deteriorating health situation. For example, one relative working in health care said that, while visiting one resident, she had a "fuzzy yet serious feeling" that her health situation had changed dramatically. Although she acknowledged the home's resource limitations, she still felt abandoned when she did not receive the decision-making support she needed to decide whether a hospitalization was warranted:

"I saw him and then I also felt very uncertain, I couldn't make a diagnosis ... the [registered] nurse came to see him, she did the right thing, but at some point she also had something else to do and then, then I realized a little bit also the

limits and I found myself a little bit confronted with the fact that I had to make the decision (...). They left it up to me to decide, but I couldn't decide.”

(relative 2)

What is more, participants described acute situations linked to *personal care activities* such as eating, drinking, and hygiene. One physically impaired resident and his wife described how problematic it was to have to wait long periods for toileting assistance: if the needed assistance regularly came too late, it could lead to infection, which eventually might trigger a hospitalization. Moreover, the wife of the resident with dementia said that, because care workers had no time to discuss the menu with the residents, her husband was not getting the food he liked and was not eating enough. The husband of another resident with advanced dementia explained that, because his wife could not verbally express her needs, she was not getting enough to drink. He explained that he felt disappointed that her needs were being neglected, with potentially serious consequences for her, including an infection that might lead to a hospitalization:

“My Frida has always been thirsty. She drank two liters of mineral water [each day]. Already before the breakfast, she had a glass. And here [in the NH] she gets a little bit, just a little bit, a little bit too little (water) and if she doesn't get enough she gets a bladder infection afterwards. (...) Here she gets a little bit too little water.” (relative 7)

Lastly, relatives spoke about acute situations related to *maintaining meaningful social interactions* with residents. Bonding with residents gives both the residents and their relatives a feeling of belonging and meaning. For relatives of residents with dementia, this is particularly true. Relatives emphasized how crucial it was for them to have meaningful social interactions with their fully care-dependent family members. Relatives felt that *meaningful social interactions* made the residents feel loved and happy, while the sense of having established relationships gave them a sense of security. The wife of one

resident shared that when she visited her husband, she would expect the care workers to have prepared (i.e., dressed and toileted) him to go for a walk or do some other activity he enjoyed to keep him in physical health. If he was not prepared and it was impossible for them to go out together, she feared the lack of these bonding activities would weaken their emotional connection and eventually divide them. The same relative described once feeling that her husband was receiving unnecessary sedative medication, reducing both his physical strength and the positive impact of their social interactions. She described both situations:

“Often I found him wet. Then I could not go for a walk with him either. My husband is still relatively young. And he has the [dementia] disease already, he got it at a very young age and he was always a very sporty guy and everything. And I simply tried to get a little bit more quality of life for him ...[here]. My husband got a little restless and walked around the department a little too much. And then they gave him this medicine (...). I have a video where he just sits there at the table. Just like a drug addict. He was sedated, and that hurt me to watch, because he was only hanging there. We couldn't do anything together anymore.” (relative 5)

While participants had generally accepted the limited resources regarding everyday care, this was not the case for exceptional acute situations: all feared and several had experienced such situations' negative consequences regarding their or their loved ones' well-being and health. Such failings invoked negative emotions such as frustration and sadness. In particular, relatives wanted to actively do something to overcome the health care workers' lack of reaction.

The audience compensating for the orchestra's limitations

The metaphor of *the audience compensating for the orchestra's limitations* illustrates the importance of the audience for whom the music plays: positioned to detect both harmony and disharmony, they can give valuable feedback, or sometimes even step in to show how to play a new piece. Similarly, relatives/residents may try to counteract unmet care needs by *speaking up*, thereby preventing potentially serious consequences such as hospitalizations due to dehydration, malnutrition or falls; and if that is not enough, they can *take over responsibility* for their loved ones' care.

Once the participants recognized that they would not receive the necessary attention from the care workers, they began intervening to prevent negative consequences. Several explained that the people to whom they would "*speak up*" were care workers on their wards. For the resident with abdominal pain, when her problem was initially ignored, that meant insisting—including pointing out blood in her urine—so that the care staff would respond to her problem before it gets too serious to be managed in the NH. In cases of residents with cognitive impairment, who could not verbally express themselves, relatives acknowledged that they needed to speak up on their behalf in acute situations. Aware of the care workers heavy workload, they were careful to speak up only where it was necessary to prevent negative consequences regarding their family members' well-being and health. Examples of this attempt to balance personal need with collective resources include the husband who told the care workers his wife should receive more to drink to avoid future bladder infections, or the wife who approached the staff because her husband living with dementia disliked the food they were serving him and was under-eating:

“[The resident] often didn't get what he really wanted to eat and drink. So, I had to discuss this with him very slowly and then explain to the nurses [care workers] what he would like to have or not.” (relative 1)

Overall, participants emphasized that it was of vital importance for residents to have relatives to *speaking up* for them:

“You have to have someone to help you out, you just have to have someone to help you out; otherwise you are lost. Like a contact person or representative who says, ‘it doesn’t work like this.’” (resident 5)

The participants described that even when they did *speaking up*, they did not get a care worker’s reaction. They explained that this happened because the care workers had no available resources, and as a result the situation would deteriorate further. The relatives would take responsibility for the care tasks if possible or involve other professionals either in- or outside the NH. The wife whose husband received unnecessary sedatives said that she involved several professionals and although they did not react in the beginning, she insisted until the medication was changed, thus avoiding an exacerbation of the situation and reducing the risk for falls and fractures:

“I talked to a nurse. But she didn’t want to talk about the medication (...). And then I asked for a psychiatrist, I asked for a psychiatrist to come, not the GP. He doesn’t understand this medication stuff, does he? But of course, he prescribed this medication, so they just keep on administering. But then finally they moved him to another ward. There he doesn’t need even half of the medication. It worked! He is human again, not the zombie he was before.” (relative 5)

In other case a resident’s daughter had a “fuzzy yet serious feeling” that her father’s health situation had changed. However, the registered nurse was not able to give the medical advice and she called the GP. However, even that had no effect, as the GP was unable to provide a judgment regarding hospitalization over the phone. In the end, the daughter assumed responsibility and decided upon hospitalization

without medical advice. Based on a previous experience regarding hospitalization and its negative consequences for her father's health, she experienced this lack of support as extremely stressful. Overall, participants and particularly relatives used a range of strategies to prevent negative outcomes. However, this process often required considerable persistence and was accompanied by negative feelings such as frustration, anger, or helplessness.

DISCUSSION

On the one hand, our reflexive thematic analysis shows that NHs lack care workers and access to geriatric expertise. On the other, the results challenge the conventional understanding of acute situations, which are based solely on changes in health situations that could require hospitalization if not dealt with. We learned that our participants also perceived situations related *to basic personal needs* or *to relationship maintenance* as acute. This difference suggests that residents have a broader view of care priorities—one that oversees physical and psychological health and well-being. Notably, our findings show that residents'/relatives' involvement during an intervention's development phase is essential to tailor care models to residents'/relatives' expectations and needs (Denegri, 2015; O'Cathain et al., 2019).

To explain residents' and relatives' perceptions of acute situations, the first theme, *the orchestra plays its standards*, involves structured everyday care functioning with limited personnel and professional resources. Limited resources addressed by participants, such as scarce registered nurses staffing, deficits regarding geriatric competencies and poor access to GPs, are all long-standing quality issues for policymakers, NH leadership and the public (Colombo et al., 2011; Kirsebom et al., 2014). The described perceptions of structured care have also been discussed in a qualitative meta-synthesis of four unrelated research studies, suggesting that, in every NH, regardless of the country, care processes

remain routinized and ritualistic (McCormack, Karlsson, Dewing, & Lerdal, 2010). The common denominator is very likely a shortage of professional competence.

As described in 'the orchestra plays its standards', participants in our study are aware and compose with limited NH resources. Comparably, a Swedish qualitative study (Holmgren, Emami, Eriksson, & Eriksson, 2014) has shown that if relatives are aware that the NH cannot always meet residents' needs due to working overload, relatives very likely accept the sub-optimal care, as they heavily rely on care services. Other studies indicate that if residents perceive NH placement as a necessity, they will lower their expectations to make the best out of the situation (Baxter, Sandman, Bjork, Lood, & Edvardsson, 2020; Bergland & Kirkevold, 2006). Indeed, in our study, some residents emphasized that they were admitted to the NH at a time when care at home was not feasible anymore. Additionally, the suboptimal care received can be compensated by pleasant and kind care workers (Baxter et al., 2020).

The second theme, *the orchestra reaches its limits*, illustrates relatives' and residents' perspectives of acute situations. This key finding expands the traditionally narrow understanding of providers and researcher about acute situations. They are usually related solely to *physical health* to design interventions focusing on reducing hospitalizations and impacting clinical decision making. From our participants' perspectives, acute situations can also include activities focusing on *basic personal care* or *relationship maintenance*. If not addressed by care workers, it may lead to negative consequences regarding residents' health and well-being, and indirectly lead to hospitalizations. Importantly, as described in our study, other qualitative studies also highlight that residents' and relatives' concerns and needs were not followed-up by NH care workers (Baumbusch & Phinney, 2014; Holmgren et al., 2014). The experience of acute situations highlights a wide gap regarding experiences of care rationing in NHs. On one hand stand residents' and relatives' care needs and, on the other hand, care providers' missing out on tasks that are deemed acute for residents/relatives. Missed care has been associated not only with high workload and inadequate teamwork but also with care workers perception of inadequate

staffing (Nelson & Flynn, 2015; Song, Hoben, Norton, & Estabrooks, 2020; Zúñiga et al., 2015a). Indeed, findings of studies in the United States (Nelson & Flynn, 2015) and Canada (Song et al., 2020) indicate that tasks our participants considered acute as taking residents for walks, talking to them, toileting, bathing, feeding, and dressing them are reported by up to 57.4% of registered nurses as missed during their last shift worked, with up to 65.4% reporting rushing at least one such task (Nelson & Flynn, 2015; Song et al., 2020). In contrast to the above-cited studies, Zúñiga et al. (2015a, 2015b) found that up to 76% of Swiss NH care workers rarely or never miss care related to activities of daily living, however, if necessary, sacrifice attention to residents' and their families' social needs (Zúñiga et al., 2015a, 2015b). Even if missed care may be lower in Swiss NHs than internationally, a Swiss qualitative study conducted in a NH highlighted that residents perceived nursing interventions as rushed or delivered poorly. This resulted in residents' feeling uncomfortable, vulnerable and the care not being individualized (Braun, Mauthner, & Zúñiga, 2018). Differences between care providers' and residents'/relatives' perspectives represent a widespread need to acknowledge residents' as individuals with specific needs and preferences shaped by particular life experiences to redesign care delivery towards person-centered care practices (Ahouah & Rothan-Tondeur, 2019). Additionally, on the policy level, it requires revising the financial systems accordingly.

The final theme, *the audience compensates for the orchestra's limitations*, indicates that relatives are censoring themselves in dealing with limited resources and do not feel empowered to advocate and speak-up unless the situation is dire. Studies from Canada (Legault & Ducharme, 2009) and Norway (Helgesen, Larsson, & Athlin, 2013) indicate that relatives only advocated on behalf of the residents if quality of care falls below an acceptable level (e.g., basic care needs like eating, drinking were not covered). Additionally, advocating for residents causes feelings of distress and helplessness (Jakobsen, Sellevold, Egede-Nissen, & Sorlie, 2019).

Studies show that advocating relatives carefully consider the timing of dialog with care workers and strategically use diplomatic communication style to not provoke negative consequences for vulnerable residents (Harnett, 2010; Hewison, 1995; Holmgren et al., 2014; Legault & Ducharme, 2009). Caution in advocating, rooted in social and relational power structures, may explain why relatives in our study advocated for residents only in certain situations. On the one hand, relatives may fear that their complaints would result in retaliation against residents (Bern-Klug & Forbes-Thompson, 2008; Holmgren et al., 2014; Legault & Ducharme, 2009). On the other hand, relatives may feel they could be perceived as demanding and burdensome by care workers and therefore left out from care processes in the future (Harnett, 2010). A study of daughters of residents with dementia found a relationship between relatives' empowerment and advocacy. Relatives who do not feel empowered are less likely to advocate and even feel marginalized if they try to do so (Legault & Ducharme, 2009). Therefore, relatives visit residents regularly to check on them (Davies & Nolan, 2006), as participants in our study noted.

These findings highlight how crucial it is to facilitate residents' and relatives' involvement in care—a participative process that depends on understanding their expectations and needs and overcome power imbalance (O'Cathain et al., 2019). Relatives' involvement can help improve care for residents living with either cognitive decline or dementia, representing up to 80% of NH residents in Europe (Roen et al., 2017). For residents without families to advocate for them, guardians or support persons might be necessary to ensure that their needs are addressed.

Reshaping the orchestra with INTERCARE model

Residents' and relatives' perspectives re-shaped the INTERCARE nurse-led model to incorporate their needs and not solely concentrate on medical care to reduce hospitalizations (Zúñiga et al., 2019). In a specifically developed curriculum the INTERCARE nurse will acquire knowledge and skills about person-centered care and advance care planning to prepare residents/relatives for changes in health situations and allow care teams to better handle acute situations. To address care workers' limited competencies,

the INTERCARE nurse will coach them daily, such as for conducting residents' biography records. The INTERCARE nurse is also present in clinical practice to support relationship building between residents/relatives and care workers, e.g., by evaluating care, emotional needs and tailoring care plans to residents' preferences. to improve the orchestra's routine work. The INTERCARE nurse will implement instruments to support observation and communication between care providers and support care workers in the preparation for GP visits to assure that residents' needs are heard. To prevent relatives' concerns falling on deaf ears, they will be involved in care processes at admission to discuss expectations and needs.

Limitations

This study has certain limitations. Firstly, only three of the nine invited NHs enabled their residents/relatives to participate in this study. Residents of non-participating NHs might have very different experiences and unvoiced needs that should be integrated into our model's development. Secondly, there is a sample bias in our study. Participants with moderate severe to very severe cognitive impairment (scores of ≥ 4 on the CPS) (Morris et al., 1994) were excluded and only represented by relatives' voices. Therefore, we suggest conducting further ethnographic research within residents' live environment to explore this population's experiences and needs (Brink & Edgecombe, 2003). Moreover, nurse experts might have recruited participants compliant with the 'nurse-led' model; however, their narratives reflected broad experiences.

IMPLICATIONS FOR PRACTICE AND RESEARCH

While we found that the care workers in NHs handled routine care needs well, shortages of personnel and competencies, particularly of nurses, commonly left residents and their families feeling abandoned and powerless in acute situations. These included both physical deterioration and personal needs such

as inadequate toileting or water provision, which, left unchecked, could easily lead to avoidable hospitalizations. Nurses need to voice their concerns and act politically to promote the need for staff improvements. A balanced staff-to-patient ratio adapted to the resident needs would provide the basis for person-centred care. Residents and relatives expressed also deep concern over acute emotional situations, i.e., care deficits that limited residents' interaction with visiting family members. Regarding residents with dementia or cognitive decline, relatives worried that such deficits would erode the residents' emotional bonds. Nurse-led models of care, which include measures to strengthen care workers' geriatric expertise and provide highly qualified resource persons (possibly nurse specially trained to provide additional support for NH staff on a daily basis), offer one possible way to improve NH care quality, particularly in acute situations, while fostering person-centered care.

Most importantly, it is essential that residents and relatives influence care practices—not only as service users but as full partners in NH continuous quality evaluation processes, for example, by regular individual interviews or observations on experiences and needs, having expert residents/relatives in advisory boards or providing feedback on projects. In the INTERCARE study, residents and relatives influenced the development and evaluation process with their experiences and perceptions (Backhouse et al., 2016). This led to the necessary fine-tuning of planned intervention. Moreover, an ongoing understanding of these persons' concerns, experiences, and needs should be demanded not only of all levels of NH care staff and leaders, but of policymakers. It should be considered a prerequisite for any research aiming to improve care practices.

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Figure 1. Steps of the Development Phase of the INTERCARE Nurse-led Model of Care.

Note. The figure was self-developed using OmniGraffle Software (The Omni Group 2020).

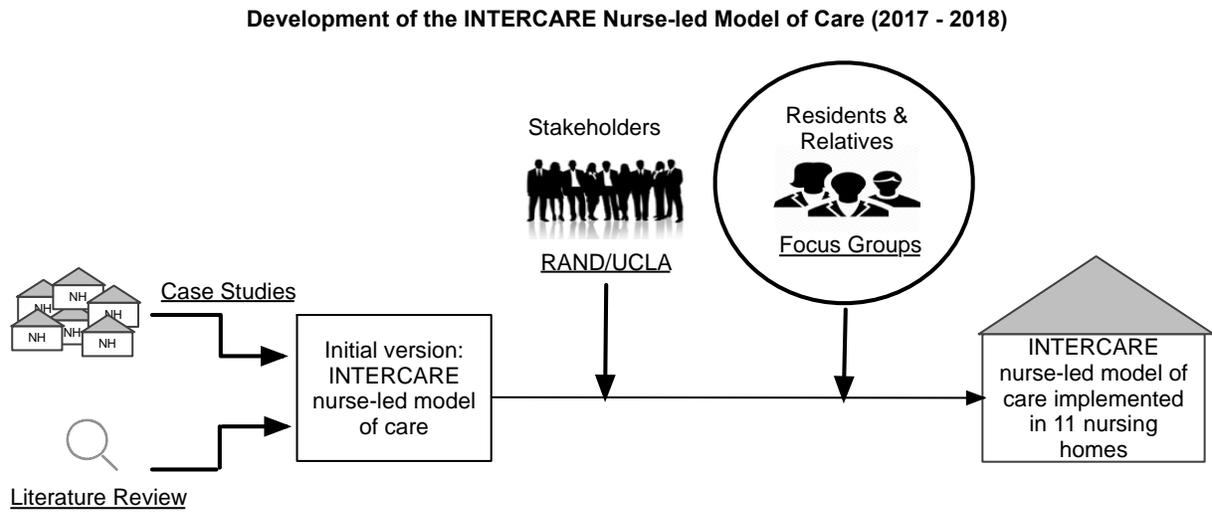


Table 1.*Participating Nursing Homes and Participants' Characteristics*

| Variables | Nursing home 1 | Nursing home 2 | Nursing home 3 |
|------------------------------------------------------|--------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------|-----------------------------|
| Nursing homes characteristics | | | |
| Language region | German | German | French |
| Status | Private-subsidized | Private | Foundation |
| Location | Suburban | Rural | Urban |
| Bed count (range) | 80-100 | 100 -120 | 80-100 |
| Registered nurses per 1000 nursing days ^a | 1.9 | 1.5 | 0.6 |
| Physician model | Primary care | Facility-based | Primary care |
| Participants characteristics | | | |
| Residents | 1 Female 1 Male | 1 Female with dementia 2 Males (one with dementia) | 2 Females |
| Length of stay | Between 1 month and 3 years | Between 1 month and 3 years | Between 1 month and 3 years |
| Relatives | 4 Females: | 2 Females 1 Male | 4 Females |
| Social relationship with the resident | Sister 2 Wives Partner as a proxy for resident with dementia | Wife Wife as a proxy for resident with dementia Husband as a proxy for resident with dementia | 4 daughters |
| Dyads | 1 partner dyad 1 sibling dyad | 2 partner dyads | - |

^a the number of registered nurses per 1000 nursing days in Swiss nursing home is 1.1.

Table 2.*Inclusion and Exclusion Criteria for Residents and Relatives Participating in the Focus Groups and Justification for Exclusion of Residents with Impairment*

| Inclusion criteria | Exclusion criteria | Justification for the exclusion of residents with impairment ^a |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Experience or involvement of (relative) in at least one acute change in his or her health situation, i.e., slight or rapid deterioration of general condition or decrease of functional performance, with or without hospitalization, within the 12 weeks preceding the interviews</p> <p>Willingness of the resident or the relative to participate either independently or as a dyad</p> <p>Ability to understand, read, and speak German or French</p> | <p>Residents with moderate severe, severe or very severe impairment (score of ≥ 4 on the Cognitive Performance Scale (CPS))</p> <p>Residents judged by the local nurse expert to be unfit for a focus group due to their cognitive or health status</p> | <p>Focus group discussions require a high cognitive capacity level to follow the discussion and respond to questions, which makes it difficult for residents with cognitive impairment to participate. Nevertheless, we secured the participation of residents with mild and moderate cognitive impairment and participation of proxy decision-makers (closest relatives) of residents with moderate severe, severe or very severe impairment while keeping in mind during the analytic process that proxies may have different views and provide different data than participants with dementia would do.</p> |

^a moderate severe, severe, or very severe impairment.

Table 3.

Six Steps of Reflexive Thematic Analysis (Braun & Clarke, 2006, 2019) With the Authors Role, the Reflexivity and Trustworthiness

| Steps | Description |
|---------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Familiarizing with the data | To familiarize themselves with the data, authors KB, PK, RG, and DN initially read through the full transcripts and field notes, concurrently taking notes in chunks of critical and reflexive comments. |
| Generating initial codes | Thereafter the lead investigator (KB) started inductive coding for both German transcripts, sequentially coding the French transcript with a native French-speaking research group member (RG). After rounds of coding the codes were reviewed and compared with the coded text by KB, PK, and DN. |
| Generating themes | After five coding rounds, initial summary themes were developed with KB, PK, and DN. |
| Reviewing themes | This was an iterative back-and-forth process between codes and raw data until all investigators collectively agreed on themes and later on meaningful patterns of themes. To schematize the relationships between the themes we developed “thematic maps.” As typical for reflexive thematic analysis, we adapted these maps several times before deciding upon a clear thematic structure. The last author, DN, who had senior expertise in qualitative research, guided and participated in each iteration of the analysis. |
| Defining and naming themes | Several INTERCARE research group members, including co-authors FZ, MS, NW, and CS, were involved in the discussion regarding summary themes and thematic maps, including illustrative quote selection. We presented the results twice to a stakeholder group. |
| Producing the report | This collaboration eventually produced a full report with carefully selected quotes. |
| Reflexivity and trustworthiness | The diversity in co-authors' expertise and reflexivity allowed identifying early in the process patterns of data around acute situations concerning participants' experiences. Reflexivity challenged our thinking about acute health situations as the only situations that may have led to hospitalizations. Personal experiences with NHs offered a check for the emerged themes. Rounds of coding and robust discussions around themes and interpretation added to the rigor. |