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Research Article

'What's the most important to them?' Swiss health care proxies, nurses and physicians discuss planning practices for aged care residents who no longer have medical decision-making capacity

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Short Title: Care planning practices for RACF residents lacking medical decision-making capacity

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Abstract

Introduction: Multiple morbidities, including neurodegenerative diseases such as dementia, which result in diminished decision-making capacity, make care and care planning complicated for Residential Aged Care Facility (RACF) residents. While Advance Care Planning (ACP) has been highlighted as essential for ensuring that this population receive care that is coherent with their wishes, there are few models specifically designed for this population. This study aimed to explore the current practices for care planning and decision-making for Swiss RACF residents who no longer have medical decision-making capacity.

Methods: Semi-structured focus groups were conducted with 23 nurses in three RACFs and with 13 physicians working in 9 RACFs. Semi-structured interviews were conducted with 18 health care proxies of 16 residents without decision-making capacity. Thematic analysis was conducted to identify the most salient themes across the data set.

Results: Analyses identified many collaborative processes between nurses, physicians and health care proxies including family meetings, reconstructing residents' presumed will, making anticipatory decisions and documenting these decisions. These processes were, however, highly variable, and differed between institutions and between residents within each facility, with a lack of standardization. This variability was highlighted to be problematic for information transmission within facilities and in case of hospital or facility transfer.

Conclusions: These results highlight the importance of standardized yet flexible processes of care planning for people who no longer have decision-making capacity and provide insights for the development of such models specifically designed to address this problem.

Introduction

Demographic shifts in Switzerland are reflective of those worldwide, with the number of people aged over 80 years predicted to double from 2015 to 2040 [1]. In addition, admission to residential aged care facilities (RACFs) occurs later and later in life, with the average age of admission of 82 years [2] exceeding the life expectancy of their own generation (73.9 years for men, and 80.5 years for women born in 1940) [3] for almost 79% of residents [4]. Residents often have multiple morbidities, including advanced states of neurodegenerative diseases, such as dementia, which result in impaired decision-making capacity (DMC). Improvement of end-of-life care for people with dementia is a moral imperative [5], and person-centred care has been identified as a major priority for this population [6].

Advanced age and multiple morbidities necessitate many decisions about medical treatments over the 2.3 year average stay [7] of a Swiss RACF resident. In Switzerland, over half of all deaths (predominantly in people aged over 65 years of age) are preceded by medical end of life decision making [8]. For RACF residents with end-stage dementia, such decisions often relate to whether to engage in interventions such as the administration of antibiotics and whether to transfer residents to hospitals [9].

However, a lack of medical DMC, combined with low rates of advanced directive completion (14% of people over the age of 65 years) and health care proxy designation [10], complicate medical decision making in this setting, especially when two thirds of residents have dementia [11] and many residents are admitted after having already lost DMC for medical decisions. In these cases, the legal frameworks in each country dictate processes for decision making on the residents' behalf. In Switzerland, the adult protection law was changed in 2013 to stipulate that health care proxies (also known as surrogate decision makers) have legal responsibility for decision making in these cases. Health care proxies can be nominated by a person who has DMC, or, when a person loses DMC, there is a legal hierarchy which stipulates who the proxy is.

Advance care planning is a longitudinal process in which people who maintain DMC reflect on their values and life, nominate a health care proxy, make anticipatory decisions and document these decisions [12]. Various models of advance care planning (ACP), have been shown to improve the end-of-life experience for both patients [13] and their carers [14], promote patient autonomy, reduce uncertainty and stress and improve quality of life for their family and close friends [15]. In addition, ACP reduces unwanted hospitalizations and aggressive care [13], and, is, under certain conditions, such as for RACF residents with dementia, economically viable for health systems [16]. However, maintaining DMC is a necessary condition of participation in these ACP models [12]. Thus, they are not applicable to this population.

In the absence of an advance directive, or in the case that the directive is not applicable to the current situation, health care proxies are charged with making decisions and planning for future care. This decisional process may be complicated by multiple factors including communication barriers, cognitive deficits that necessitate the reconstruction of personal values and narratives of the patient, tensions between the interests of different parties and difficulties interpreting the non-verbal communication of patients who have impaired verbal capacities. In emergency situations, these uncertainties may result in an overuse of futile and costly treatments which cause unnecessary discomfort for the patient [5]. In addition, there is evidence to suggest that there are significant differences in decision-making depending on whether the surrogate decision maker is a relative or not [17]. Importantly, a systematic review has demonstrated that having to make surrogate decisions without any indication about the patient's preferences is a source of significant distress, suffering and guilt for proxies [18]. Furthermore, proxies have also been noted to underestimate RACF resident's desire to live [19] along with the importance of values such as maintaining autonomy in their lives [20] which further diminished over time [21]. These estimations may thus contribute to erroneous perceptions of a residents' presumed will on which they base care planning decisions

about life sustaining treatments, and this evidence further supports the need to develop ACP models for this population in order to accompany health care proxies through reflective and decision making processes and to open lines of communication about perceived values and quality of life.

Although the situation whereby RACF residents lose medical DMC before having formally stipulated their wishes is relatively common, there is little scientific evidence about the decision-making and advanced decision-making or planning processes. While models of ACP exist and recommendations for conducting ACP with people who have dementia exist [22], these models focus on people who maintain DMC. Models of planning and anticipating care and decision-making for people who no longer have DMC are desperately needed [23] in order to provide care that is consistent with residents' wishes when they are no longer able to participate in planning discussions. Information about the current planning and decision-making processes is essential for the development of such models.

This study aims to investigate the current decision making and planning practices employed by RACF nursing staff, physicians and the health care proxies of RACF residents who no longer have medical DMC. This is an essential first step in developing models of ACP that can be used in this context.

Materials and Methods

Study design and Data collection

This is a qualitative exploratory study. Three semi-structured focus groups were conducted by two physicians, with nurses and nurse assistants from three RACFs (n= 23), none of whom were known to the researchers. Three semi-structured focus groups were conducted by one physician and one researching psychologist, with a total of thirteen physicians working in nine different RACFs, two of these physicians were known to the researching physician. Sixteen semi-structured interviews were conducted by one researching psychologist with a total of 18 health care proxies (some participated in pairs) of RACF residents who no longer have DMC in a place of the participant's choosing (their home, the RACF, a cafe and hospital office). Data collection took place in the canton of Vaud (population 800,000, French speaking region with a major city and large rural areas), Switzerland, between June 2018 and December 2019. Interview participants were recruited with the aim of gaining a maximum diversity of experiences (relationships with residents, RACF location) and interviews were conducted until responses to the questions gleaned no new insights. Figure 1 shows examples of interview and focus group questions. Interview and focus group questions were discussed amongst a palliative care research group beforehand. Written informed consent and socio demographic data were collected by self-report questionnaire from each participant directly before the interview or focus group.

Participants

This research concerns RACF residents who no longer have DMC for medical decisions. The criteria for DMC are stipulated by the Swiss Civil Code (art. 16) as a person having the ability to 1) understand the relevant information, 2) Understand their circumstances, 3) reason and 4) express their choice [24]. In clinical practice this capacity is evaluated using several different scales, however there is no standardized approach and no formal guidelines or recommendation for RACF practice.

RACF nurses were recruited through an invitation letter sent to RACF directors. Interested directors then asked health professionals to participate in the focus groups. In all three instances, the head nurse was also present in the focus group. Inclusion Criteria were:

- Qualification as a nurse, nurse assistant, or other health professional recognized in Switzerland
- Has worked in the RACF setting for 12 months or more

Physicians consulting in RACFs were recruited through an invitation letter sent via the association which connects family physicians and geriatricians working in RACFs in the canton of Vaud, Switzerland. Inclusion criteria were:

- Treats at least one resident in one RACF in the canton of Vaud, Switzerland.

Health care proxies were identified by nurses as people who the RACF physicians have judged as no longer having the capacity of make medical decisions and were recruited through an invitation letter sent to them by the head nurse at the three RACFs that participated in the focus groups, along with three other RACFs. Inclusion criteria were:

- Sufficiently fluent in French or English to give informed consent and participate in an interview
- Maintains decision making capacity
- Is listed health care proxy for a RACF resident who
 - o Is over 65 years of age
 - o No longer has DMC for medical decisions, as judged by their treating physician

Analysis

Audio-recordings of the interviews and focus groups were transcribed verbatim by professional transcribers, and checked by Author 1 and Author 2 for accuracy. Transcriptions were then analyzed thematically according to Braun and Clarke's (2006) method to create a rich description of the current decision-making and planning practices. While semantic-level themes were generated inductively, the topic of interest, decision making and planning practices, was pre-defined and informed the interview questions asked and probing during interviewing [25].

During an initial reading of the data, authors 1 (researching psychologist), 2 (student physician) and 4 (advanced practice nurse) noted important aspects of the data and developed a coding framework. Two focus groups were then coded in parallel, and meaning of the codes along with differences and similarities in coding were discussed. The coding framework was adjusted accordingly, and a codebook was developed, and two subsequent focus groups were coded in parallel. The remainder of the data was coded by Author 1. Authors 1, 2 and 4 then identified and discussed themes, and labeled them. These themes were then discussed and checked with authors 5 and 6 (senior physicians in geriatrics and palliative care). MaxQDA software was used to manage the data and analysis.

All discussions were conducted in French, local language of the region. Extracts presented here have been translated from French to English by Author 1 who is a native English speaker and checked for accuracy by authors Authors 2 and 3 who are native French speakers fluent in English. Extracts are identified by the participant type (N- nurse or nurse assistant, P- physician, HCP- health care proxy), the interview or focus group number (FG- focus group, I- interview) and participant number eg: HCPI4 HCP 4.

Results

Socio-demographic characteristics of participants

Characteristics of RACF nurses are presented in Table 1, below.

Insert Table 1 here

Characteristics of physicians are presented in Table 2, below.

Insert Table 2 here

Characteristics of health care proxies are presented in Table 3, below.

Insert Table 3 here

Analysis

Planning processes

Information gathering

When asked about how planning and decision making was conducted for people without DMC living in RACFs, health professionals and physicians working in RACFs commonly began their explanations with a description of information gathering processes.

Evaluating resident's state and capacity

These processes involved ascertaining which types of information about the resident could be obtained from the residents themselves. Both professional groups indicated that they firstly try to establish the level of DMC impairment:

I think it's important to, to, to in fact, ask the question [...] him, how he sees things (PFG1 P2)

in order to establish whether this person could give some information about their past experiences and future wishes. Almost all participants indicated that the information that could be obtained from the resident was highly variable, but that this is an essential first step. Health professionals indicated that the residents are sometimes able to give coherent information about their life history, drawing on long-term memory, however understanding their current situations, the treatment options available to them and articulating wishes for the future posed difficulties. Almost all proxies also expressed the difficulty in communicating with the resident and typically discussed their cognitive decline:

she recognises fewer and fewer [members of] of her entourage, she, she doesn't remember [...] her grandchildren, that she has great grandchildren. Sometimes she forgets who, who I am (HCPI 17, HCP 15)

Examining previous documents

Health professionals sought information upon which to base anticipated medical decisions from documentation produced when the resident maintained DMC. However, consistent with the statistics about documentation rates, all health professional participants (nurses and physicians) indicated that it was rare that prior documentation existed:

Me, I've had one single... only one time that I've had [...] a resident who has told me that they'll bring me a photocopy because they had their directives. It was one and only time but if not they come without (NFG3 N1)

Furthermore, as many forms of documentation, including hand written documents are legally valid, when documentation did exist, health professionals reported that the statements they contained were often difficult to put into clinical practice, were sometimes self-contradictory or stipulated interventions which would not be medically indicated. One health care proxy (resident's wife) who did document an advanced directive with the resident (husband) stated that:

that's where we wrote, one and other, how we don't wish for 'relentless treatment', and that, even still, they give us something to drink, when we are really at the end of our lives, that they don't let us dehydrate (HCPI5 HCP5)

thus illustrating the difficulties in interpreting the concept of 'relentless treatment' from patient, family and clinician perspectives. The example of artificial nutrition and hydration in the final stage of life highlights the complex personal and societal representations of each actor and potential

inconsistencies between the wish for specific intervention (hydration in this case) and the personal goals-of-care/treatment wishes (no relentless treatment).

Discussions with health care proxies

When the resident is unable to participate in the discussion, health professionals sought information about treatment wishes from families and health care proxies. It is important to note that they rarely had systematic ways of identifying legal health care proxies and often conducted planning and decision-making discussions with the people who were most present, with the intention of including all relevant people. Both nurses and physicians reported difficulty starting these conversations that are reported to be 'delicate', and needing to adapt their communication and information-seeking strategies to the proxies' readiness to discuss the resident's presumed will. Strategies included forecasting the need to discuss care planning, in order to give the families time to come to terms with this:

we take the temperature to see a little bit which direction, they are going, we already tell them that we'll meet again to discuss directives, that we are going to try to determine their will, what they want, what they don't want (PFG3 P2)

Conversely, the proxies interviewed did not mention difficulty with such discussions, but did highlight the desire for more communication and implication in decision-making:

It's always me who has to ask [...] and when I ask it's 'why?', I say maybe just to have a meeting and see about a plan for her life (HCPI3 HCP3)

It is common practice to conduct discussions with the families about the resident's' past to obtain clues about their future wishes and more information about 'who' the person is:

...we always talk about what will happen to them later, but what have they lived until now? [...] at this time was there a certain attitude that was apparent... (PFG1 P6)

These discussions also involved asking about the resident's attitudes to health care and treatments:

or whether it's someone, as I said, who took.... Who often went to the doctor, yeah, who took care of their health (PFG3 P1)

However while some proxies reported that they had a clear understanding of what the resident would have wanted in a certain situation, others expressed uncertainty about their wishes and values, notably due to a lack of discussion of the topic:

Proxy 6: [...] there is the Alzheimer's, well, my father visibly didn't want to talk about that [Proxy 5: yeah] it was difficult, hey, because he didn't want to talk about it (HCPI5 HCP5&HCP6)

This was echoed by nurses and physicians, noting that many health care proxies seemed to lack the information necessary to reconstruct the resident's values, notably due to a lack of discussions about personal topics and wishes for the future, and societal reluctance to discuss death and end of life.

Anticipatory decision making

RACF nurses and physicians reported trying to make anticipatory decisions and plans for emergency situations.

Translating values into directives

Health professionals emphasized the importance of ensuring that the proxy has translated the values of the resident accurately:

It's true that it's a concern for us to know if, in fact, the health care proxy, if they have accurately translated what the patient wishes, uh, it's clear that if the patient doesn't have DMC, well, asking the patient is a bit complicated (PFG3 P1)

They also reported that they accompany the residents' family members through a reflection about what that family member would have wanted in the situation, aiming to help families to put themselves in another's shoes:

what I always say, is, 'you need to tell us what your father's wishes were, it's not for you to decide. But we would like to know what your father would have decided' and to make this difference, it seems like nothing, but that, that's very important (PFG1 P1)

while, at the same time, trying to remove some of the pressure that is associated with making anticipatory decisions on behalf of a loved one. They also noted that they try to take the family's values into account, and, if possible, include the resident as much as possible:

I'd like to discuss it with (resident), with their family, about their values. What is the most important for them? Is it... is it to do the maximum to keep him alive as long as possible? Is it to live comfortably? (PFG1 P5)

Most health care proxies reported that this 'life story' at admission was well appreciated, however none reported discussions in which they were accompanied in translating the resident's values into anticipatory decisions.

Health professionals reported some difficulty in transforming 'life history' and values into documented orders in case of emergency, and emphasized the role of the physicians in providing information about treatments and specific pathologies. Physicians also reiterated this role:

We explain, also that.. hospitalization, it's not necessarily quality of life. [...] there are also side effects, finally, undesirable side effects linked with hospitalization (PFG3 P2)

However, with one notable exception, most proxies either did not report contact, or reported having limited contact with the resident's physician. Several expressed the wish for more information about the resident's medical conditions and greater involvement in decision-making, with several reporting that they were not at all involved, and that they were informed after-the-fact about treatments:

I signed a paper, I asked them, I said 'but if he's not well, you call me' 'of course of course'. But I saw that we have, I received the hospital bill, I said 'but why did they send her to hospital' (HCPI6 HCP7)

and that the only reason they knew about the health event is because they received the bill- there was no other communication. Others also reported that they had to specifically ask and insist for such information.

Completing Documentation

Many of the difficulties with current planning practices concerned the use of advanced directives and included, but were not limited to, difficulties completing them with health care proxies, the limited scope of directives, limited utility, and utilization in case of hospital transfer and general public reluctance to complete advanced directives. These documents are therefore rarely used as they are intended:

We have advanced directives, but we hardly ever apply them as they are (PFG1 P4)

Having said this, most physicians, and health professionals from all three RACFs stated that they had developed their own forms of documentation for their residents. However, as, specifically the physicians, noted this development of documentation is both necessary for the RACF records, and is

potentially useful while a resident is within the RACF, but, it presents problems if a residents is transferred for medical treatment as the forms are not standardized and there is therefore no assurance that they will be interpreted correctly.

In addition to the documented wishes, some proxies reported giving orders for emergency cases (resuscitation, etc) orally, without these being documented at the RACF:

'we didn't want relentless treatment if something happens [...] but it was verbal, we didn't, we didn't do anything written (HCPI4 HCP4)

RACF nurses also reported such informal processes.

Timing

Given the health conditions of most RACF residents, and the fact that the large majority will die in the RACF or in hospital, timing of these decision-making and planning processes was a key discussion point in all focus groups. Actual timing varied from the week that a resident is admitted, to within the first three months. While, on the one hand, all health professionals expressed the need to have orders for emergency care upon admission, they also emphasized the need to find a compromise between this need for information and the sensitivity and time that the families of these residents need to adapt to the situation.

It's often difficult to respond to these questions at the start of the stay and then at the same time, if it's already a little unstable we need responses quite quickly (PFG1 P5)

All parties highlighted the importance of a continual process to ensure relevance of decisions and plans. However, health professional time and availability limit the ongoing checking-in process.

Proxy readiness

All health professionals discussed the variable readiness of residents' family and friends to engage in planning processes, and need to adapt their practice as a function of this readiness:

sense whether the entourage is ready to speak about it because they are more or less ready and depending on where they are at, we are going to accompany them in this process but sometimes we have to wait for an event to really speak with them (NFG1 N5)

Proxy readiness was attributed to multiple factors, such as acceptance of the resident's state, and seeking to involve other family members:

they say well, we will speak about it with our brothers and sisters and after we don't have any news, and each time that we bring it up well 'ah, no, we haven't discussed it yet' (NFG1 N2)

In an effort to promote this readiness, two physicians send the documents before meeting with the health care proxy, so that they know what to expect from the discussion. Importantly, and probably due to a self-selection bias in the healthcare proxy participants, proxies in this study did not report needing more time or feeling unprepared to embark on such planning discussions.

Limits to current practices/difficulties

Family conflict

Health professionals commonly discussed difficulties conducting planning which arise from conflict within families, leading to communication difficulties, and uncertainty about the best courses of action:

It's true that sometimes when one or the other want different things it's not simple (NFG1 N8)

Roles and interdisciplinary

Both nurses and physicians highlighted the importance of collaboration with each other; the nurses as they have a privileged position of having continual contact with the resident, and the physician as they have the medical knowledge and are required to prescribe the treatments, and for ensuring that treatment is aligned with medical indication.

Depending on the organizational structure of the RACF, the reference nurse was reported as being highly important through their role as an interlocutor and transmitter of information between the resident, the family, and the other RACF health professionals and physicians:

each resident has a reference nurse [one nurse who is the main point of contact for each resident] and this reference nurse will do the work of... the contact with the family... to... broach also the life history, but also a link a little different (NFG1 N1)

However, RACF nurses reported being in a conflictual position, as they spend large amounts of time with the residents and feel that they have developed a sound understanding of the resident and their interests and values but reported that this knowledge and understanding is not always taken into account in decision-making.

Limits of current systems

Billing systems

All health professionals reported that in-depth planning and anticipatory decision-making is time consuming and needs to be conducted regularly. They reported that all parties are often short on time, resulting in planning being postponed and sometimes forgotten about. In addition, there is currently no billing system for physicians engaging in such planning decisions, which typically exceed the billing time blocks.

Identification of health care proxies

Although a law was changed in 2013 to define the health care proxy, this hierarchy was not mentioned when health professionals discussed who they contact as the legal representative of the residents lacking DMC. Both nurses and physicians described ways of determining the health care proxy and difficulties they have with determining who should take on this role.

I ask them in which capacity, why it's them and I ask a bit about the organization around the person and who does what, they say, I don't know 'my sister looks after the washing, I look after the affairs' there you go, each defines... (NFG1 N1)

However, a lack of discussion about the legal hierarchy probably indicates that it is likely rarely drawn upon in identifying the health care proxy.

Discussion/Conclusion

The results of this study highlight many collaborative processes between nurses, physicians and health care proxies including family meetings, reconstructing presumed will of residents who longer have DMC, making anticipatory decisions and documenting these. However, all parties reported these processes to be highly variable, with a lack of standardization in terms of the content of discussions with health care proxies, the timing of these discussions, the types of decisions which are made, the types of information that are documented and the forms on which these decisions are documented. These variable practices are consistent with findings in other countries, such as Australia [26] and Germany, where document analyses have shown variation in types of decisions, presence of proxy and physician signatures and ethical justifications [27]. This variability reflects the willingness of health professionals to engage in developing their processes within each institution,

but this also poses problems for the transmissibility of information and coordination, especially in case of hospital transfer. Health care proxies themselves expressed this doubt that the wishes they had expressed for their relatives would be accurately interpreted in an emergency situation, and health professionals gave examples of when the documented wishes weren't adhered to.

This study presented the perspectives of health care proxies and nurses and physicians. All parties discussed the difficulties that making decisions on behalf of someone who no longer has DMC poses for health care proxies. This emotional toll is well documented in the literature and has been reported to lead health professionals to rush or avoid discussing death and dying with residents and relatives, and a sparsity of support systems and lack of training and knowledge have been proposed to inhibit engagement in such discussions [28]. Spacey et al.,'s (2021) findings could go some way to explaining the phenomena in our present results that while health professionals report actively engaging in planning discussions with proxies, the proxies, consistent with Norwegian findings [29], report limited involvement and contact from health professionals and physicians.

Health care proxies reported being uncertain about treatments and some reported that they lack knowledge about available treatments, and physicians and RACF health professionals reported that health care proxies change their minds or seem unable to give clear indications about the care desired. These findings may go some way to explaining Malhotra et al. 's (2021) findings that while many family carers of patients with advanced dementia indicate that they prefer 'no life prolonging treatments', a high proportion of these patients do actually receive such treatments (tube feeding and IV antibiotics). Malhotra and colleagues identify several additional reasons for this, notably that withholding treatments is perceived as unethical, feeling that they have no choice but to defer the decision to health professionals, believing that the life sustaining treatments will alleviate suffering, fear of making 'wrong' decisions and subsequent regret for these decisions, and disagreement with other family members about overall goals of care [30]. These reasons may also explain some of our findings, particularly related the health care proxy readiness to engage in decision-making. The importance of timing of planning discussions, and insights into information provision to proxies supports previous research indicating that a lack of knowledge about the progression of dementia, difficulty finding the 'right' time to undertake planning discussions and, preferences for informal plans because written plans seem too rigid and final complicate ACP with people with dementia [31].

All participants discussed the role of the resident, reporting that they try to involve the resident to the extent to which this is possible, consistent with recommendations that RACF residents should be involved in conversations about their care as much as possible [32]. Most participants discussed the ways in which the resident can or cannot be involved in such discussions, highlighting a level of 'negotiation' or 'managing' these roles as facilitators of decision-making processes and as proxy decision makers. A lack of local guidelines about how to plan care with and for RACF residents lacking DMC necessitates this complexity. This is consistent with research highlighting the difficulties establishing the role of the person who has dementia in making placement decisions [33].

These results highlight the clear need for more systematic approaches to planning and decision making on behalf of RACF residents who no longer have DMC. This research supports previous calls for the development and robust testing of models of ACP for the RACF context [34], and goes beyond this by supporting the need for ACP models that can be used with proxies of residents without DMC, such as ACP by proxy [35]. While few systematic models of ACP by proxy have been published, other research reports such practices anecdotally [26] and the ethical legal justifications for such models have been developed [36]. These models will become increasingly necessary as people live longer with impaired DMC. Even if completion of advanced directives increase at a population level (before losing DMC), there are many reasons for the need for ACP by proxy models for the RACF context, for example when the documented wishes are not applicable to the patient's situation, which is likely to have evolved [37].

Limitations

This study was conducted in one state of the French-speaking region of Switzerland, and thus the results need to be interpreted in light of the cultural and linguistic context and the health systems in place. The RACFs were recruited through email advertisement of the study via the association which connects them. RACFs who responded to this advertisement are likely to be more interested and invested in the problem and also better resourced, with better planning practices than average. This may be slightly counteracted through the participation of physicians who worked in nine different RACFs, therefore reflecting a greater breadth of current practices. In addition, the health care proxies were recruited by four RACFs. Emails were sent to the proxies that the staff thought would be receptive to research participation, who are likely to be the health care proxies who have a better experience and a better relationship with the health professionals.

Future research could focus on a systematic quantitative survey of RACF staff and physician practices, or employ ethnographic observational methods to complement these findings, however these methods present difficulties in a care context in which resources are already scarce and participation in research can be seen as burdensome.

Both decision-making and planning practices vary greatly between the different facilities and for different residents. This poses many challenges for initiating planning discussions and difficulties for the documentation of wishes and the subsequent translation of this documentation into care that is coherent with the wishes of residents who no longer have DMC. These difficulties are exacerbated when there is a transfer to another facility. The RACF context is an area in which specific models of advance care planning, designed to be conducted with health care proxies, are needed to ensure care that is consistent with what incapacitated residents themselves would have wanted were they able to express their wishes themselves. Health professionals have expressed the need for systematic models which are integrated into their practice, and such models would be reassuring for health care proxies in knowing that residents' presumed wishes are respected.

Statements

Acknowledgement

The authors wish to acknowledge the generous participation of health professionals and health care proxies in giving their time and energy to participating in this study.

Statement of Ethics

In accordance with the local guidelines, ethical approval from the Canton of Vaud Ethics Committee (CER-VD) (Switzerland) was not required for this study as it did not involve collecting any medical data (LRH art. 2). This research was carried out in accordance with the ICH-GCP guidelines.

Consent to participate statement: Written informed consent was collected from all participants in this study in accordance with the ICH-GCP guidelines.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

Laura Jones: developed study protocol, conducted data collection, analysed data, prepared manuscript

Florent Rhyner : assisted in data collection, analysed data, reviewed manuscript

Rachel Rutz Voumard : developed study protocol, reviewed data analysis, participated in writing manuscript

Fiorella Figari Aguilar: analyzed data, participated in writing manuscript

Eve Rubli Truchard: developed study protocol, conducted data collection, participated in writing manuscript

Ralf J Jox: developed study protocol, conducted data collection, participated in writing manuscript

Data Availability Statement

The data that support the findings of this study are not publicly available due to ethical reasons. Given the small number of participants, and the specific context of the discussions, rendering the data publicly available could compromise the participants' privacy. For the purposes of data verification, further information can be obtained by contacting the corresponding author (Laura Jones laura.jones@chuv.ch).

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Figure 1: Examples of questions asked in interviews with health care proxies and in focus groups with RACF health professionals and physicians.

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RACF nurse focus groups:

Could you talk to us about how medical decisions are made for people who no longer have DMC?

Who is involved? How is the resident involved? And the health care proxy?

Do you have any tools? How are decisions documented?

Physician focus groups:

Vignette of RACF resident with common diagnoses and lack of DMC was presented

When faced with a patient like this, how do you proceed?

Who is involved? What is the process? Do you have tools or documents?

Health care proxy semi-structured interviews:

Can you talk to me about your experience of being the health care proxy on behalf of your (relative)?

Have you been involved in decision-making on behalf of (relative)? How were you involved? Can you talk to me about this experience

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Table 1: Demographic characteristics of RACF nurses and nurse assistants (n=23) (no other health professionals participated)

| | |
|-------------------------------------|---|
| Age | Range= 25-62 years (m= 44.7, SD= 13.0) |
| Years of experience working in RACF | Range= 1-38 years (m=12, SD= 10.7) |
| Gender | Female: 20 (86.9%) Male: 3 |
| Palliative Care Training | 9 (39.1%) |

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Table 2: Demographic characteristics of physicians (n=13)

| | |
|----------------------------------|--|
| Age | Range: 35-66 years (m=48.5, SD=8.9) |
| Years of experience as physician | Range: 7-37 years (m=15.1, SD=9.1) |
| Gender | Female: 5, Male: 8 (61%) |
| Training | Palliative Care: 7 (53%) Geriatrics: 5 (38%) |

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Table 3: Demographic characteristics of health care proxies and RACF residents

| <i>Health care proxies (n=18)</i> | | |
|-----------------------------------|---|---|
| Age | Range : 48-84 years (m=67.5, SD=10.2) | |
| Gender | Female : 9 (50%) Male : 9 | |
| Relationship to resident (n) | Brother | 2 |
| | Son | 5 |
| | Daughter | 5 |
| | Wife | 1 |
| | God child | 2 |
| | In-laws (sister, brother) | 2 |
| | State-nominated power of attorney (known to the resident) | 1 |
| <i>Residents (n=16)</i> | | |
| Age | Range : 65-97 years (m=87.6, SD=9.9) | |
| Gender | Female: 11 (78%), Male: 3 | |
| Time in RACF | Range: 0.2-9 years (m=3.6, SD=2.0) | |