

Original Article

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Can we determine burdensome transitions in the last year of life based on time of occurrence and frequency? An explanatory mixed-methods study

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Abstract

Objective. Burdensome transitions are typically defined as having a transition in the last three days or multiple hospitalizations in the last three months of life, which is seldom verified with qualitative accounts from persons concerned. This study analyses types and frequencies of transitions in the last year of life and indicators of burdensome transitions from the perspective of bereaved relatives.

Method. Cross-sectional explanatory mixed-methods study with 351 surveyed and 41 interviewed bereaved relatives in a German urban area. Frequencies, *t*-tests, and Spearman correlations were computed for quantitative data. Qualitative data were analyzed using content analysis with provisional and descriptive coding/subcoding.

Results. Transitions rise sharply during the last year of life. 8.2% of patients experience a transition in the last three days and 7.8% three or more hospitalizations in the last three months of life. An empathetic way of telling patients about the prospect of death is associated with fewer transitions in the last month of life ($r = 0.185$, $p = 0.046$). Professionals being aware of the preferred place of death corresponds to fewer hospitalizations in the last three months of life (1.28 vs. 0.97, $p = 0.021$). Qualitative data do not confirm that burden in transitions is linked to having transitions in the last three days or multiple hospitalizations in the last three months of life. Burden is associated with (1) late and non-empathetic communication about the prospect of death, (2) not coordinating care across settings, and (3) not considering patients' preferences.

Significance of results. Time of occurrence and frequency appear to be imperfect proxies for burdensome transitions. The subjective burden seems to be associated rather with insufficient information, preparation, and management of transitions.

Introduction

The last year of life is characterized by high utilization of health care services and high costs (Davis et al., 2016). Transitions (defined as a change in care setting) occur frequently at the end of life (Hanratty et al., 2014) and contribute to discontinuity and fragmentation of care (Kelfve et al., 2018; Makaroun et al., 2018). While they are sometimes necessary (Reyniers et al., 2014), they can be burdensome (Naylor et al., 2009; Gozalo et al., 2011; Miller et al., 2016; Makaroun et al., 2018) and are often avoidable (Ouslander and Maslow, 2012; Walsh et al., 2012; Gott et al., 2013; Delgado-Guay et al., 2015; Kasdorf et al., 2021).

Palliative Care regulations in Germany include generalist palliative care, as well as allowances for in-patient or day care in hospices, palliative home care by hospice services, and special palliative home care services (Van Beek et al., 2013). Although Germany achieved rank seven in the overall global ranking in the 2015 Quality of Death Index, indicating its good level of palliative care services on a national level (The Economist Intelligence Unit, 2015), access to palliative care varies based on location and demographics (Bertelsmann Stiftung, 2015).

The number of transitions people experience in their last year of life varies in different studies, ranging from 1.5 to 4.2 in different settings in the USA and Canada (Burge et al., 2005; Wilson et al., 2012; Teno et al., 2013). Hospitalizations occur with a high frequency near death, and only some of these transitions can potentially be avoided (Walsh et al., 2012; Xing et al., 2013).

Various factors influence the occurrence of transitions. In quantitative approaches, factors like age, gender, income (Burge et al., 2005; Lawson et al., 2006; Aaltonen et al., 2010; Aaltonen et al., 2014; Abraham and Menec, 2016; Bahler et al., 2016), level of education

(Kelfve et al., 2018), physician, and hospital bed supply (Menec et al., 2010; Abraham and Menec, 2016) have been reported in connection with transitions. Those studies used claims data or national registers with large sample sizes. Retrospective survey-based approaches measured via physicians (Van den Block et al., 2007; Abarshi et al., 2010) or bereaved relatives (Bone et al., 2016) indicate that if end-of-life preferences were discussed and if there had been a health care professional as a single point of contact, end-of-life transitions to the hospital were less likely. So far, to the best of our knowledge, there are no studies that investigate transitions from the views of bereaved relatives independent of the type of transition.

The above approaches do not take into account if transitions are experienced as burdensome. The literature on burdensome transitions primarily uses quantitative measures (Aaltonen et al., 2010; Abarshi et al., 2010; Gozalo et al., 2011; Teno et al., 2013; Bahler et al., 2016; Makaroun et al., 2018; Teno et al., 2018; Chen et al., 2020), based on a definition by Gozalo et al., who define transitions in the population of long-term care residents as burdensome if they occurred in the last three days of life, if there was discontinuity of nursing home care after hospitalization, and if there had been multiple hospitalizations in the last 90 days of life (Gozalo et al., 2011). A recent systematic review synthesized a similar definition based on the existing literature (Hanna et al., 2020).

Qualitative approaches with patients and bereaved relatives show that coordination of care (Harrison and Verhoef, 2002), managing risk (Coombs et al., 2017), support across settings, being heard, and dignity (Hanratty et al., 2012) contribute to how transitions are experienced by patients and relatives. Those and other existing studies are focused either on one specific type of transition, have limited sample sizes, and/or are conducted in one setting (e.g., nursing homes). They also do not specifically investigate factors classifying transitions as burdensome and cannot be linked to the time of the transition before death.

We see the following research gaps in the existing literature:

- 1) There is a lack of studies about the types and frequencies of transitions at the end of life in German urban areas.
- 2) Burdensome transitions are typically investigated based on frequencies and time of occurrence, which is not sufficiently justified with qualitative data.
- 3) Few studies about the subjective experiences of burdensome transitions exist and bereaved relatives are seldom included as a source of knowledge after death.

This study aims to close these gaps by investigating the following research questions:

- 1) What types of transitions in the last year of life occur in German urban areas and at what frequency?
- 2) What are the indicators of burdensome transitions as experienced from the views of bereaved relatives?

Methods

Study design

Patterns of end-of-life transitions were assessed with an explanatory sequential design. A retrospective cross-sectional survey with bereaved relatives ($N=351$) was followed by in-depth interviews with a subset of this sample ($N=41$). The two study phases

were carried out in Cologne, which is exemplary of an urban setting in Germany with well-developed palliative and hospice care structures.

Participants

We included relatives, friends, or voluntary workers (henceforth: "informants") if they were 18 years or older and have recently cared for a person who lived their last year of life in the Cologne area. Deaths of people under the age of 18 years, as well as accidental and suspicious deaths, were excluded. Interviewees were selected from the survey sample, stratifying with pre-defined variables to ensure maximum heterogeneity regarding these characteristics. Stratifying variables were time of communication of foreseeable death, because this significantly influences the course of the last year of life, and overall rating of the quality of care as the main outcome for patients and relatives.

Multiple channels for recruitment were combined to reduce selection bias. Participants were recruited via more than 100 cooperation partners (care homes, hospice networks, bereavement cafés, doctors, hospitals, undertakers, nursing services, local public health department) and through newspaper articles, flyers, and posters.

Data collection and measures

Quantitative

Data were collected in a post-bereavement survey as part of the Last Year of Life Study Cologne (LYOL-C) (Strupp et al., 2018) from November 2017 to August 2018. In the quantitative strand, the VOICES-LYOL-Cologne was used, which is described elsewhere in more detail (Voltz et al., 2020). The questionnaire examines experiences with care by multiple providers in the last year of life from the views of bereaved informants. Participants were further asked to provide information about all care settings during the last year of life, including dates. We defined five settings: home (including assisted living), hospital, care home, hospice, and rehabilitation clinic. A transition was defined as a change in location of where the patient was cared for.

Qualitative

An interview guideline was developed, revised by the research team, and discussed within a research workshop. The interview guideline was structured around three main areas: (1) breaking bad news about incurable disease, (2) transitions between care settings, and (3) the dying phase. All participants were asked the same basic set of questions. Questions were added depending on the individual questionnaire to elaborate on the quantitative results. Interviews were carried out by NS and CvR in the participants' homes or in the research institute. Interviews were audio-taped and transcribed verbatim. All interviewees provided written informed consent.

Data analysis

Quantitative analysis

Types and frequencies of transitions in the last year of life and associations with age, illness, and communication patterns were analyzed exploratively, computing descriptive statistics, *t*-tests, and Spearman correlations with SPSS Statistics 25 (IBM Corp., Armonk, NY, USA) and R version 3.5.1 (The R Foundation).

Exact *p*-values are reported in cases where significance tests were carried out (American Psychological Association (APA), 2020). We performed nonparametric tests for ordinal data and parametric *t*-tests using the Welch-Correction for metric outcomes. Care trajectories were reconstructed in cases where participants gave information about all places of care including durations for the last year of life. In that way, the time between the transition and death could be computed. Variables for the quantitative analysis were selected from the questionnaire depending on their thematic relevance for the interview. We included all cases, where data were provided for the respective calculations.

Qualitative analysis

Interviews were analyzed using content analysis with provisional and descriptive coding/subcoding (Miles et al., 2014). Deductive codes were drawn from the ecological systems theory (Bronfenbrenner, 1994), which was used previously for building a framework for assessing palliative care on different levels (Pask et al., 2018). We conducted across-case summaries for transition-related categories and within-case summaries for cases that experienced a burdensome transition according to the definition of Gozalo et al. (2011): (1) any transition in the last three days of life, and (2) multiple hospitalizations in the last three months of life.

Integration is carried out on three levels: design, methods, and interpretation (Fetters et al., 2013). On the design level, the sequence of the study phases (Quantitative–Qualitative) was picked to examine frequencies and patterns of transitions and secondly explore how the burden is experienced. On the methods level, we used *linking* and *building* by sampling interview participants purposefully from the questionnaire. On the interpretation level, we used *weaving* and analyzed both data sources on a theme-by-theme basis (Fetters et al., 2013).

Results

Our quantitative sample was representative for Cologne decedents regarding gender (47.9% male) and age ($\bar{x} = 76.5$, $SD = 13.0$ years) compared with full data from the City of Cologne (gender: 50% male) (Stadt Köln - Amt für Stadtentwicklung und Statistik, 2019), age: 77.7 years (Stadt Köln - Amt für Stadtentwicklung und Statistik, 2018); see also Voltz et al. (2020). It showed small to moderate deviations regarding education (39.7% lower secondary education, 16.1% high school, 42.5% baccalaureate, 1.8% no degree) compared to the people over 50 in the state North-Rhine-Westphalia (46.7%, 21.4%, 26.2%, 5.8%) (Landesbetrieb Information und Technik Nordrhein-Westfalen (IT.NRW), 2020).

In our survey, we asked all informants ($N = 351$), if they wanted to participate in an interview, to which 266 (75.8%) agreed to. Patient characteristics of the interview sample were similar to the survey population regarding the variables displayed in Table 1, although we oversampled in the underrepresented cells of the stratifying variables to get more insights into trajectories where prospects about approaching death were discussed shortly before death or where overall care was rated badly (Table 1). The average duration of an interview was 54.7 min.

Transitions in the last year of life

We found that 13.7% of the patients experienced no transition in their last year of life. The mean number of total transitions per

person in the last year of life was 3.72 ($SD = 3.1$), while they ranged between 0 and 16 transitions. There was a significant difference in the number of transitions between people aged 85 and older ($\bar{x} = 2.53$) and people under 85 ($\bar{x} = 4.27$, $p < 0.001$). Education, gender, and multimorbidity did not show significant associations with transitions or hospitalizations.

Full reconstruction of the trajectories in the last year of life was possible for 255 deceased persons. The following analyses of specific time periods relate to this subset.

Generally, the number of transitions increased as death approached, especially the most frequent transition from home to hospital (Figure 1). In the last month of life, a person experienced on average 0.86 transitions, while in the 12th month before death, he or she experienced only 0.11 transitions.

Burdensome transitions

The two types of burdensome transitions defined in the literature were investigated in a mixed-methods approach, where survey and interview data are mutually integrated. Transitions in the last three days of life were experienced by 21 (8.2%) of the patients. The four most frequent types of these transitions were represented in our interview sample. Table 2 provides exemplary citations for these cases.

The accounts of the informants reveal a mixed picture. While in example 3 (Table 2), the consequence of the transition is reported as negative, the other three accounts do not refer to any burden experienced during the transition. The positive accounts mention transparent communication about the incurable disease and considering the patient's will, even if it went against the doctor's advice.

Two or more hospitalizations in the last three months were reported for 85 cases (33.3%), and a minimum of three hospitalizations was reported for 20 (7.8%). Examples of statements regarding three or more hospitalizations are presented in Table 3.

The first example reports no burden resulting from the transitions. In this case, the social service as a coordinating unit was involved, which seems to have facilitated the positive transitions. In the second case, the burden was experienced as a result of a lack of cooperation between the different providers.

An analysis of the cases who experienced two or more hospitalizations in the last three months ($N = 13$) shows numerous reports of resulting burden, while occasionally referring positively to these transitions. Reports about the transitions range from "necessary" to "incredibly bad". Informants distinguished between the process of transfer ("She said that it was a terrible ride. This car was bumping and rumbling around. And then he didn't find the right building" [friend of 73-year-old woman who died of cancer]) and the organizational fit of the subsequent setting:

No, it was not necessary. I know, for example, in [Hospital X], the first care unit, there was not happening anything else than in [Hospital Y]. That was not what I would imagine as short-time rehabilitation. (daughter of 80 year old woman who died of cardiovascular disease)

The transitions that were not considered necessary and did not result in a positive change in the health status of the patient were described as more stressful for both patients and relatives. Burden was also reported as being higher when transitions were executed against the patients' will.

The number of hospitalizations in the last three months of life also showed associations with the overall rating of care by all

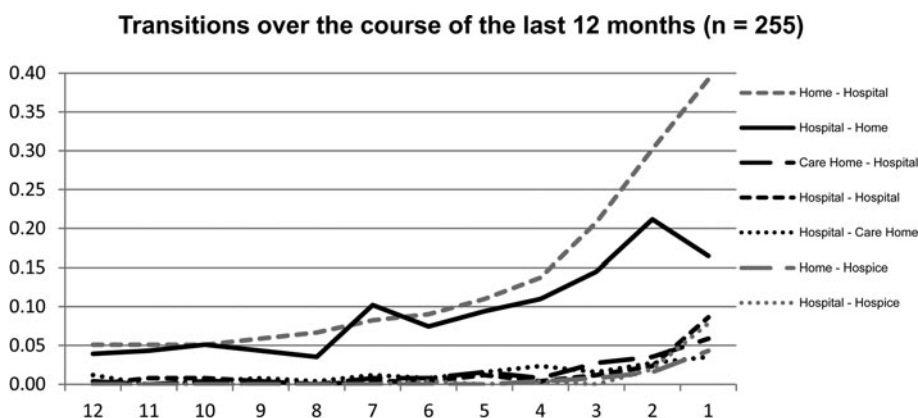
Table 1. Patient characteristics and stratifying variables, see also Voltz et al. (2020)

Characteristic	Number of patients (%) in survey sample (N = 351)	Number of patients (%) in interview sample (N = 41)
Sex		
Female	183 (-52.1)	26 (-63.4)
Male	168 (-47.9)	15 (-36.6)
Age		
18–29 years	1 (-0.3)	-
30–49 years	6 (-1.7)	1 (-2.4)
50–64 years	65 (-18.5)	11 (-26.8)
65–79 years	112 (-31.9)	15 (-36.6)
80+ years	167 (-47.6)	14 (-34.1)
Place of death		
At home	97 (-27.7)	12 (-29.3)
Hospital	148 (-42.3)	17 (-41.5)
Hospice	61 (-17.4)	9 (-22.0)
Care Home	41 (-11.7)	2 (-4.9)
Other	3 (-0.9)	1 (-2.4)
Caregiver relationship		
Spouse	149 (-42.5)	20 (-48.8)
Son/daughter	138 (-39.3)	16 (-39.0)
Sibling	18 (-5.1)	1 (-2.4)
Son/daughter-in-law	9 (-2.6)	-
Other relative	17 (-4.8)	-
Friend	12 (-3.4)	3 (-7.3)
Other	8 (-2.3)	1 (-2.4)
Did he/she have German citizenship?		
Yes	340 (-96.9)	40 (-97.6)
No	11 (-3.1)	1 (-2.4)
What was his/her religion?		
Christian	276 (-78.6)	36 (-87.8)
Muslim	2 (-0.6)	-
Other	4 (-1.1)	-
None	68 (-19.4)	5 (-12.2)
Was he/she told, that they were likely to die?		
Yes	201 (-57.3)	33 (-80.5)
No	115 (-32.8)	8 (-19.5)
Don't know	21 (-6.0)	-
Missing	14 (-4.0)	-
In your opinion, did the person who told him/her he/she was likely to die break the news to him/her in a sensitive and caring way?		
Yes	72 (-20.5)	9 (-22.0)
Rather yes	56 (-16.0)	10 (-24.4)

(Continued)

Table 1. (Continued.)

Characteristic	Number of patients (%) in survey sample (N = 351)	Number of patients (%) in interview sample (N = 41)
Rather no	21 (-6.0)	4 (-9.8)
No	15 (-4.3)	6 (-14.6)
Don't know	30 (-8.5)	3 (-7.3)
Not applicable	149 (-42.5)	9 (-22.0)
Missing	8 (-2.3)	-
Did he/she ever say where he/she would like to die?		
Yes	197 (-56.1)	27 (-65.9)
No	131 (-37.3)	12 (-29.3)
Missing	23	2 (-4.9)
Did the health care staff know about the preferred place of death?		
Yes	146 (-41.6)	21 (-52.2)
No	24 (-6.8)	3 (-7.3)
Don't know	29 (-8.3)	4 (-9.8)
Not applicable	150 (-42.7)	13 (-31.7)
Missing	2 (-0.6)	-
Primary stratifying variables		
Overall rating of care		
Excellent	138 (-41.8)	13 (-31.7)
Good	161 (-48.8)	16 (-39.0)
Fair	24 (-7.3)	8 (-19.5)
Poor	7 (-2.1)	3 (-7.3)
Time of communication of foreseeable death		
< 24 h	5 (-2.6)	2 (-4.9)
24 h–1 week	10 (-5.2)	4 (-9.8)
1 week–1 month	29 (-15.0)	6 (-14.6)
1 month–6 months	49 (-25.4)	6 (-14.6)
6 months–1 year	37 (-19.2)	7 (-17.1)
> 1 year	63 (-32.6)	8 (-19.5)
Burdensome transitions in the LYOL (subset: N = 255 in survey and N = 33 in interview)		
Burdensome transition in the last year of life		
Yes	40 (-15.7)	6 (-18.2)
No	215 (-84.3)	27 (-81.8)
Transition in the last three days of life		
Yes	21 (-8.2)	4 (-12.1)
No	234 (-91.8)	29 (-87.9)
3 or more hospitalizations in the last three months		
Yes	20 (-7.8)	2 (-6.1)
No	235 (-92.2)	31 (-93.9)



Horizontal Axis: Month before death

Vertical Axis: Average number of transitions per person in the respective month. For example 0.2 means every fifth person experienced this transition once on average in this month.

Fig. 1. Number of transitions over the course of the last 12 months before death (n = 255).

providers in the survey data ($r_{(s)} = 0.165, p = 0.01$). This suggests a general dissatisfaction with multiple hospitalizations, which is supported by interview data:

Now that you ask, the ongoing hospital visits and then the transitions, especially in the last four months, were very stressful for me. (daughter of 85 year old woman who died of cardiovascular disease)

For both types of burdensome transitions according to the literature (Gozalo et al., 2011), the reports of experienced burden varied greatly and seem to depend on support, communication, and shared decision making.

Risk factors for burdensome transitions

The analysis of the potentially burdensome transitions revealed no clear indication of the time or frequency of transitions being a precondition of experienced burden. We extended the analysis to the whole sample of informants ($N = 41$) to investigate risk factors of burdensome transitions. We extracted three main topics, which were frequently related to transitions where subjective burden was reported.

1. Transparent communication in the face of an incurable disease

In various cases, interview data indicated how burdensome transitions can be prevented through communication. Participants talked about how doctors could reassure informal caregivers that some transitions are not necessary and how they can provide appropriate care at home.

There is an emergency practice, in [Place X], and my husband sometimes experienced strong pain at night and then I called him. And then it was such a nice ... it was such a nice doctor who ... helped me so much. That was such a positive thing ... who took away my fear a little bit and said, he doesn't need to go to the hospital, you can do this or do that. (wife of 88 year old man who died of organ failure)

This goes along with various reports about how empathetic communication with patients and relatives facilitated a calmer care trajectory. Survey results indicate that the earlier people were told that they were likely to die, the fewer hospitalizations were experienced in the last three months of life ($r_{(s)} = -0.28, p = 0.001$) and in the last month of life ($r_{(s)} = -0.197, p = 0.021$).

One of the participants illustrated the relationship between early communication and transitions in the following way:

That was actually one of the first times I thought, "Finally a clear word". We could have had that earlier (...) actually it would have been most beautiful if they had said that right at the beginning, something like that (...) and she could have somehow spent the last two months sitting under trees instead of this horrible tour back and forth between the houses. (daughter of 80 year old woman who died of cardiovascular disease)

This and various other reports show the importance of early and transparent communication about the prospect of dying.

Survey data also indicated that when patients were told they were likely to die in a sensitive and caring way, they experienced fewer transitions in the last month of life ($r = 0.185, p = 0.046$). One of the informants elaborated on how a non-sensitive way of breaking bad news could lead to further transitions:

It is possible to indicate ways to go. Peaceful ways of saying goodbye. Yes. Clarity, empathy, and courage are needed. The courage to convey something like that. Yes. And to run away and say: "In two days you can go home". And afterwards she is transferred to geriatrics. Well, that is not okay. You can't do that. (daughter of 84 year old woman who died of cancer/stroke)

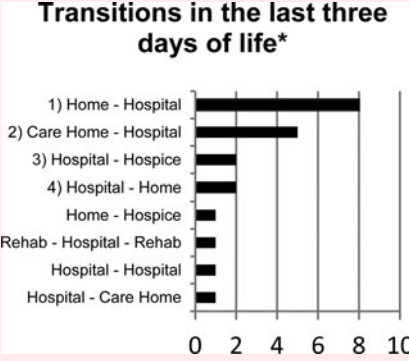
The informant elaborated on how this could have been prevented through clear and transparent communication:

Well, I mean, it was very obvious that mommy was dying. I also believe that this was clear to some of the doctors. But they did not communicate this clearly. (...) This man knew that our mother was dying. And he did not talk about it. I understand that this is not easy. To communicate such sad news. I have great understanding for that. And I think it is important to learn that. How do I convey bad news? (daughter of 84 year old woman who died of cancer/stroke)

2. Coordination of care

Another central topic that emerged with regard to transitions was the structured coordination of care across providers. There were various reports of a lack of guidance given to patients and relatives regarding their subsequent care or different possibilities.


Table 2. Joint display for transitions in the last three days of life

Transitions in the last three days of life*		
1) Home - Hospital		1) It had to be communicated finally, chemotherapy has no more use (...) We realized it wouldn't be long now. (...) finally the situation was such that care at home was no longer responsible (...) Then she was transferred to the palliative care unit in the hospital (...) and then she lived there for three days. And died there under very peaceful conditions, one has to say. (husband of 78 year old woman who died of cancer)
2) Care Home - Hospital		2) So first of all this last phase has been initiated in the nursing home and I think they have reacted great. Quickly. And made the right decision. If, well, I can't blame anyone for not immediately realizing that this was a cardiological problem, it looked like a stroke. And transferred her straight to the [Hospital A]. (daughter of 80 year old woman who died of cardiovascular disease)
3) Hospital - Hospice		3) Yes. So she was well cared for in the hospice, but it has ... this transition was generally a burden for her that she ... I almost claim that it was fatal. (daughter of 90 year old woman who died of cancer)
4) Hospital - Home		4) Where the doctor warned her to go home and still let her go against the doctor's will. And then it was clear that (3) that was more dangerous. But she was still very lively at home, she couldn't walk anymore due to the fall. But she sat on the edge of the bed, her polish nurse put her on the edge of the bed and we still played together, a board game and she participated lively. (daughter of 90 year old woman who died of erysipelas)*
Home - Hospice		
Rehab - Hospital - Rehab		
Hospital - Hospital		
Hospital - Care Home		

8.2% of participants had a transition in the last three days of life (N = 255).

*On the right side, for each of the four most frequent transitions in the last three days, there is a quote from a person whose relative experienced the corresponding transition.

Table 3. Joint display for multiple hospitalizations in the last three months of life

Hospitalisations in the last three months of life		
 <p>N = 255</p>		<ul style="list-style-type: none"> • So, in the hospital, the social worker also gets involved, then talks to the relatives and so on. Well, I think they really put in a lot of effort. They also said what needs to be done now and the transfer (...) so I think it was good. I didn't get any negative feedback from her there. (friend of 73 year old woman who died of cancer) • Yeah, there's no cooperation. I'll say, we were in urology once. Then we were out again. That was it. Then afterwards, as I said, in urology with the vacuum bandage change, there we had the problem with orthopedics, which made a fuss like I already described it. So afterwards we were in neurology. So, and neurology, of course they all work together with the large X-ray department and there you are again with the problem, you have to sign up everywhere anew. (husband of 63 year old woman who died of cancer)

The transport from the hospital, the bottleneck ... so the cogwheel hospital relatives, you have to say, the handover, so we were completely lost. What now? (laughs quietly) Hospice? Private home or care home? So there was nothing at all; they said, "That's up to you. And we don't have anything to do with it anymore". (son of 89 year old woman who died of physical weakness)

This and other statements show how lost patients and relatives may feel when there is a life-limiting diagnosis and no guidance. Oftentimes informants demand a coordinator throughout the care trajectory:

Why don't these people exist? Why isn't there such a pool that can be called up in such emergencies? These are things that I think. Well, you would actually need such a ... yes, like a moderator who steers people a bit or something like that. (daughter of 81 year old woman who died of cancer)

There were indications of clear mistakes when it came to transitions. One informant told us how poor coordination between

professionals in a hospital led to an unwanted transition and death in the ambulance:

The doctor also told me: "We can't possibly move your mother; she is really severely..." (...) and then they said, "No, your mother has now been taken back to the nursing home." This can't be happening. What do they want with a dying woman in a nursing home? And, yes, then she died on the way in the ambulance. And that is for me, that is the confirmation that they really messed up. (daughter of 80 year old woman who died of cardiovascular disease)

Some of the reports also mentioned a lack of further care planning in hospitals. In the following statement, a lack of involvement of the social service in hospitals led to strong insecurity for patients and relatives regarding the care trajectory.

So, in [Hospital X] it was definitely a very big problem, the transition. And ... because there was no agreement at all with us, with the family, how can it go on? What makes sense? Does it make sense that our mother ... For example, it was not discussed with us, does it make sense at this

point that our mother goes to a hospice? Does it make sense at this point for our mother to be placed in a nursing home? If she wants to go home as she wanted, how can she be helped? So that's ... The social service wasn't even involved yet. And that ... I felt very alone. (daughter of 81 year old woman who died of cancer/stroke)

A potential resource for facilitating coordination of care seems to be the relatives themselves, which often is not sufficiently exploited from the views of the bereaved relatives:

So, I say, the A and O are the relatives. It happens on the part of the clinic or on the part of the care home rather still, but more on the part of the clinic the conversation with the relatives is unfortunately not sought and I was also not informed, although they said they would inform me. (daughter of 85 year old woman who died of cardiovascular disease)

Many informants experience themselves as a substantial coordinating unit. Since we collected data only from patients having relatives or friends as informal coordinators, the population of patients without this resource is in even higher danger of suffering from bad coordination.

The worst thing is when a sick person, a terminally ill person, is alone, no longer has any relatives. That he is completely dependent on them [the care personnel]. I was still there, after all, where I put myself out there. When you no longer have anyone, when you are completely dependent on them, that's all I'm saying. That's the worst thing. (wife of 78 old man who died of cancer)

3. Considering patient's preferences

There were frequent reports about experienced burden in transitions or a bad organizational fit of the subsequent setting through a lack of consideration of the patient's preferences. Various informants talked about how previously expressed wishes about treatment or place of care were not considered. This is typically related to the desire to be treated less at the end of life and to spend time at home.

So, the oral arrangements were not kept. And the plans, the daily plans of the rehab were still filled with several therapies every day. (...) So our mother's palliative care physician had his hands clenched over his head because of the report. It even says that our mother should continue to receive ergotherapy, that she should be trained with a lower arm rollator, twice a week and this and that. A dying one. Our mother was dead not even three weeks after that. (daughter of 81 year old woman who died of cancer/stroke)

Not acting in the patient's interest is also partly associated with the ethical self-image of physicians as healers:

With a lot of doctors, it's like ... I'm not allowed to do it for ethical reasons. If I do write, I don't want to be cared for anymore. Then it is my will, right? I do not want to throw myself in front of a train. I can no longer do that in old age. (authorized representative of 87 year old man, unknown cause of death)

The fact that knowing patients' preferred place of death can reduce potentially burdensome transitions is supported by our quantitative findings: If patients spoke about their preferred place of death and professionals knew about this, patients experienced significantly fewer hospitalizations in the last three months of life (1.28 vs. 0.97, $p = 0.021$).

Discussion

To our knowledge, this is the first study investigating burdensome transitions with a mixed-methods approach and the first German study to examine frequencies of transitions by type over the course of the last year of life.

The sharp rise of transitions towards the end of life, especially hospitalizations, was congruent with international data (Aaltonen et al., 2010; Greenle et al., 2019). The amount of transitions reported indicates potential problems concerning continuity and quality of care. The proportion of patients having transitions in the last three days of life (8.2%) was similar to proportions reported in other Western countries, which ranged from 8% in the Netherlands to 13% in Spain (Van den Block et al., 2015), and 9.3% in Switzerland (Bahler et al., 2016), while a similar number of 10.8% was reported in a US study for 2015 (Teno et al., 2018). The rate of multiple hospitalizations (two or more) was 33%, whereas 21% was reported in Canada (Abraham and Menec, 2016). The age differences in numbers of transitions (<85 and >84) were congruent with international data (Lawson et al., 2006; Van den Block et al., 2007; Abarshi et al., 2010; Abraham and Menec, 2016; Bahler et al., 2016). This validates our data and potentially allows for extrapolating our findings to other contexts. Deviating from existing literature, we did not find evidence that gender or having multiple conditions was associated with transitions in the last year of life. This may be due to the fact that effect sizes were not very high for those correlations reported and they may only be visible in large data sets.

We could not confirm that having a transition in the last three days of life was a precondition for burdensome transitions. Having multiple hospitalizations in the last three months of life shows some indications of associations with burden. However, it does not appear to be a sufficient proxy for actual burden. Those or similar definitions are still frequently used in assessing burdensome transitions at the end of life in large quantitative databases (Gidwani, 2018; Chen et al., 2020; Hanna et al., 2020; Lage et al., 2020). Our quantitative and qualitative data suggest that burdensome transitions are predicted by early and transparent communication about life-limiting diseases, coordination of care across settings, and considering patients' and relatives' preferences. Those factors are known to be linked to care quality at the end of life. This study underlines the necessity to consider those factors in approaches to reduce burdensome transitions, which is typically not done in quantitative studies. We, therefore, advice to use time- and frequency-based definitions of burdensome transitions carefully in the future and justify them with qualitative data.

The particular strength of the present study lies in the triangulation of methods, which, despite the high access barriers of the population, enables an expanded understanding of care in the last year of life. The design integrating a sequence of quantitative and qualitative data allows for adding in-depth information to certain patterns of transitions. We could successfully integrate quantitative and qualitative results, both data sources mutually benefiting from each other. A recall bias is to be expected due to the retrospective survey form, as are distortions in the proxy assessments of the quality of care, which typically show moderate deviations from the patient's view (Farber et al., 2003; Jones et al., 2011).

A review of the literature on patient-family concordance concluded that although there are differences between patients and relatives regarding symptom severity, those imperfect proxies

are an important source of information for end-of-life research. Moreover, their views have their own validity, as their memory lives on and further impacts their bereavement and health (Addington-Hall and McPherson, 2001). The VOICES-questionnaire is widely used for assessing experiences including symptoms in the last year of life from the view of bereaved relatives (Burt *et al.*, 2010; Hunt *et al.*, 2014; Office for National Statistics (ONS), 2016; Donnelly *et al.*, 2018). As directly affected persons also after death, relatives offer an appropriate alternative to directly questioning patients at the end of life. Nevertheless, they cannot replace patients' perspectives, which is why future studies on this topic should include their views. In a direct follow-up study to this LYOL-C-study (LYOL-C II), we prospectively follow up patients who are believed to be in their last year of life. By this, we want to expand our understanding of patient trajectories and experiences in the last year of life.

Conclusion

Avoiding a transition in the last year of life is not necessarily a success. When measuring the positive effect of any medical or organizational intervention, a reduction of (certain) transitions in various timeframes at the end of life should not necessarily be the primary outcome. It should at least be accompanied with additional data informing about burden. For assessing possibilities to reduce burdensome transitions, we need approaches where survey or interview data add to the analyses of large routine data sets. Being transferred without sufficient preparation, coordination, and information seems to be the central risk factor for subjective burden. Conclusively, policy and practice should not only focus on preventing transitions but keeping patients and relatives informed, considering their preferences, and exploiting all coordinative resources (including relatives), especially when patients are transferred. In addition, this is supported by the fact that only about a quarter of transitions is regarded by relatives, as well as professionals as potentially avoidable (Hanratty *et al.*, 2014; Delgado-Guay *et al.*, 2015), and only 6.7% as practically avoidable (Gott *et al.*, 2013).

Ethical approval. All procedures for this study were approved by the Ethics Commission of the Faculty of Medicine of the University of Cologne, Germany (#17-188). Participants gave written informed consent before taking part.

Data availability statement. Data are available from the corresponding author upon reasonable request.

Acknowledgments. RV, CR, and JS designed the study. NS, GD, and CvR were responsible for the acquisition of the data. NS performed the analysis and was responsible for the integrity of the data. NS drafted the manuscript. JS provided supervision. All authors revised the manuscript critically for important intellectual content. All authors read and approved the final version to be submitted for publication.

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