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Complete List of Authors:	Voltz, Raymond; University of Cologne, Faculty of Medicine and University Hospital, Department of Palliative Medicine Dust, Gloria; University of Cologne, Faculty of Medicine and University Hospital, Department of Palliative Medicine Schippel, Nicolas; University of Cologne, Faculty of Human Sciences and Faculty of Medicine, Institute for Medical Sociology, Health Services Research, and Rehabilitation Science Hamacher, Stefanie; University of Cologne, Faculty of Medicine and University Hospital, Institute of Medical Statistics and Computational Biology Payne, Sheila; University of Lancaster, Lancaster University, Faculty of Health and Medicine, Division of Health Research Scholten, Nadine; University of Cologne, Faculty of Human Sciences and Faculty of Medicine, Institute for Medical Sociology, Health Services Research, and Rehabilitation Science Pfaff, Holger; University of Cologne, Faculty of Human Sciences and Faculty of Medicine, Institute for Medical Sociology, Health Services Research, and Rehabilitation Science Rietz, Christian; Heidelberg University of Education, , Faculty of Educational and Social Sciences, Department of Educational Science Strupp, Julia; University of Cologne, Faculty of Medicine and University Hospital, Department of Palliative Medicine
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Improving regional care in the last year of life by setting up a pragmatic evidence-based double loop Plan-Do-Study-Act cycle: Results from a cross-sectional survey

Raymond Voltz*[1,2,3,4], Gloria Dust*[1], Nicolas Schippel[5], Stefanie Hamacher[6], Sheila Payne[7], Nadine Scholten[5], Holger Pfaff[4,5], Christian Rietz[8], Julia Strupp[1], for CoRe-Net

[1]University of Cologne, Faculty of Medicine and University Hospital, Department of Palliative Medicine, Germany

[2]University of Cologne, Faculty of Medicine and University Hospital, Center for Integrated Oncology Aachen Bonn Cologne Dusseldorf (CIO ABCD), Germany

[3]University of Cologne, Faculty of Medicine and University Hospital, Clinical Trials Center (ZKS), Germany

[4]University of Cologne, Faculty of Medicine and University Hospital, Center for Health Services Research, Germany

[5]University of Cologne, Faculty of Human Sciences and Faculty of Medicine, Institute for Medical Sociology, Health Services Research, and Rehabilitation Science (IMVR), Germany

[6]University of Cologne, Faculty of Medicine and University Hospital, Institute of Medical Statistics and Computational Biology, Germany

[7]Lancaster University, Faculty of Health and Medicine, Division of Health Research, United Kingdom

[8]University of Education Heidelberg, Faculty of Educational and Social Sciences, Department of Educational Science, Germany

* RV and GD contributed equally to this paper.

Corresponding author:

Gloria Dust, University of Cologne, Faculty of Medicine and University Hospital, Department of Palliative Medicine, 50924 Cologne, Germany, gloria.dust@uk-koeln.de, +4922147887820

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Abstract (Words: 293)

Objectives To set up a pragmatic double loop Plan-Do-Study-Act cycle by analysing patient experiences and determinants of satisfaction with care in the last year of life.

Design Cross-sectional post-bereavement survey.

Setting Regional health services research and development structure representing all health and social care providers involved in the last year of life in Cologne, a city with one million inhabitants in Germany.

Participants 351 bereaved relatives of adult decedents, representative for age and gender, accidental and suspicious deaths excluded.

Results For the majority (89%) of patients, home was the main place of care during their last year of life. Nevertheless, 91% of patients had at least one hospital admission and 42% died in hospital. Only 60% of informants reported that the decedent had been told that the disease was leading to death. Hospital physicians broke the news most often (58%), with their communication style often (30%) being rated as "not sensitive". Informants indicated highly positive experiences with care provided by hospices (89% "good") and specialist palliative home care teams (87% "good"). This proportion dropped to 41% for acute care hospitals, this rating being determined by the feeling of not being treated with respect and dignity ($p<0.001$) and the impression that hospitals did not work well together with other services ($p=0.002$).

Conclusions Following this first step of a Plan-Do-Study-Act cycle a regional priority for action is improvement of care in acute hospitals, with two interventions starting currently, both how to recognise and communicate a limited life span, as well as improving care during the dying phase. All tools are now in place for a complete and functioning regional learning system. With the next steps of the continuous cycle the impact of system improvements will become measurable.

Trial registration German Clinical Trials Register: DRKS00011925.

Keywords: PDSA cycle, last year of life, satisfaction, hospital care, VOICES questionnaire

Strengths and limitations of this study

- This study presents a multidimensional and comprehensive assessment of care provided in multiple settings in the entire last year of life.
- It describes a pragmatic template for determining regional improvement priorities based on patient experiences using a city-wide health services research and development structure (Plan-Do-Study-Act cycle).
- The reports of relatives cannot be seen as a direct substitute for a self-assessment of patients, although a good agreement has been shown on service evaluations and observable symptoms.
- The retrospective approach bypasses the difficult task of identifying the terminally ill, avoids putting an additional burden on very sick participants, and minimises missing data due to poor functional status.

INTRODUCTION

Patients in their last year of life may be regarded as vulnerable because most of them need complex care provided by multiple health and social care practitioners.[1] Their needs are often not sufficiently met, especially in settings outside specialist palliative and hospice care.[2, 3] Care transitions as well as non-beneficial treatments are common, which may compromise human dignity and quality end-of-life care.[4, 5] Evidence shows that most people prefer their home as place of death.[6] However, the majority of patients still die in acute care hospitals.[7] Fragmentation of multidisciplinary service provision is one major barrier to adequately addressing patients' needs and preferences.[8] Data on patients' and their families' perceptions are essential in order to understand these issues and to inform quality improvements. The last year of life can obviously only be objectively determined in retrospect, but it has to be managed prospectively. Adding palliative care in the last 12 to 24 months of life has proven to be greatly beneficial.[9, 10] Therefore, consideration also needs to be given to the introduction of these services.[11] However, the majority of surveys focuses on the dying phase or the last weeks to months of life and only a few studies have compared end-of-life care across different settings.[11-14] Care in the last year of life encompasses a wide range of services necessitating a multidimensional and comprehensive assessment approach.[12] This comprises the measurement of patients' experiences of the communication of a life-limiting disease ("transition into the last year of life"), transitions between health care settings ("transitions within the last year of life"), and the dying phase ("transition into death and a new phase of life for bereaved relatives"). For Germany, data on patients' perceptions of their experience of care in the last year of life that go beyond diagnoses and care settings are still rare.

Germany possesses a well-defined, government-led strategy for the development and promotion of national palliative care and performed well in the 2015 Quality of Death Index (position seven in the global rank of overall scores).[15] Based on the patients' needs, they may receive generalist palliative care (e.g. provided in a general hospital ward, a nursing home, by a general practitioner (GP) or a nursing service at home) or specialist palliative care provided by specialist personnel with expert knowledge, skills and attitudes (e.g. delivered in a hospital palliative care unit, a hospice or by a specialist palliative home care team).[16] Hospice care in Germany refers to care provided in an in-patient facility. In addition, hospice services delivered by volunteers may support the patients and their families during illness and after a patient's death. All services and accommodations in these facilities are provided at no extra cost to the patient and are part of the service of the statutory as well as private health insurance. As in many other countries, the national level indicates the general direction in which the health care system is developing. However, for the patients and relatives, the regional health care situation matters most, and this shows a lot of heterogeneity in Germany.[17] Due to this regional heterogeneity, this local level should be the driving force for innovation.[18, 19]

Delivering improvements in the quality of healthcare remains an international challenge. Methods such as the Plan-Do-Study-Act (PDSA) cycle have been widely used in healthcare as an attempt to drive such improvements. The PDSA method is an iterative four-step cycle, which includes (1) identifying a change aimed at improvement, (2) testing this change, (3) examining the success of the change, and (4) identifying adaptations and next steps to inform a new cycle.[20] The fundamental principle is iteration.[21] By repeating the cycle (single-loop), it should be complemented by a second loop (double-loop) that facilitates assessment and – if necessary – replacement of the original paradigm of change and improvement (figure 1).[22, 23] Furthermore, in order to assess the effectiveness of changes, health services research is increasingly relying on pragmatic yet evidence-based methods.[24] This includes lower levels of evidence than explanatory trials as randomised controlled trials (RCT) tend to be very time- and resource-intensive. If we want to install a learning regional healthcare system, we need a compromise between RCTs and non-scientific practice. Thus, one practical solution is to establish a PDSA cycle and to use it as a Before-and-after-design without a control group (evidence level IIb).[25] Additionally, we can use observational methods to gain further knowledge on the evidence level III. To inform practice we need practical, but still evidence-based solutions which lead to satisficing decisions.[26-29] Therefore, as a paradigm case for a one million inhabitant urban health care situation, this paper describes the set-up of a pragmatic quality improvement structure to improve regional care. In particular, as the first step of the PDSA cycle we analyse patient experiences across settings and providers and determinants of satisfaction with care in the last year of life as reported by bereaved relatives.

(Please insert here: Figure 1: Strategic learning process framed on the double-loop PDSA cycle)

METHODS

Setting up the regional structure

Initiated by three cooperating faculties (Human Sciences; Medicine; Management, Economics, and Social Sciences) of the University of Cologne, Germany, a regional health services research and development structure has been established involving as many relevant partners as possible from medical and social care as well as from health services research. The "Cologne Research and Development Network" (CoRe-Net)[30] focuses on the further development of health and social care according to the concept of learning organisations based on a bottom-up approach. Its main aim is to analyse and continuously improve healthcare delivery for vulnerable patient groups by going through PDSA cycles. We invited national and international scientific experts, regional health and social care institutions, patient organisations, and statutory health insurance providers to act as CoRe-Net collaboration partners. Within the network three research projects have been initiated, one focusing on patients in their last year of life. For this project entitled "Last Year of Life Study Cologne (LYOL-C)"[31] all relevant health and social care practitioners involved in the care of patients in their last year of life in Cologne were contacted for collaboration.

Patient involvement

Patient representatives were involved in the design and conduct of this research. They worked with us to refine the research question, choice of outcome measures, and methods of recruitment. In collaboration with patient representatives we will design a leaflet for dissemination to distributing to patient groups.

Sample and data collection

Data were collected in a post-bereavement survey as part of the project LYOL-C. Participants were a purposive sample of relatives, friends and voluntary workers (all will be referred to as "informants" hereafter). Inclusion criteria required informants to be aged 18 years and older and to 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 as well as accidental and suspicious deaths were excluded. To ensure maximum variation, informants in this study were recruited in cooperation with health and social care practitioners from Cologne (partners from care homes, nursing services, hospices, bereavement cafés, doctors, hospitals, undertakers, local public health department). We applied two strategies between November 2017 and August 2018 to identify potential informants: i) Questionnaire distribution through cooperating care practitioners through client records by mail or personally. ii) Self-selection through public media (newspaper articles, flyers and posters): Informants who were interested in taking part in the survey could request a postal questionnaire from one of the researchers (GD); one reminder was sent. An information sheet describing the study's goals and a response form for opting out of the study were sent with the questionnaire. Informants gave written informed consent before taking part in the survey. All pseudonymously completed questionnaires were returned directly to the research team.

Questionnaire

The self-complete questionnaire is based on the Views Of Informal Carers – Evaluation of Services-Short Form (VOICES-SF).[32] It is a validated questionnaire to assess the bereaved relatives' perceptions of the patient's care experiences with providers and services across care settings in the last three months of life. VOICES-SF was developed for a nationally representative cross-sectional survey to examine the quality of end-of-life care in England, conducted annually for five years (2011-2015),[33] and has already been used internationally.[3, 34-40]

We developed an adapted German version ("VOICES-LYOL-Cologne") that covers the last twelve months of life and additionally includes the communication of the diagnosis of a life-limiting disease as well as places of care with periods of stay. The questionnaire comprises 106 items and contains skip logic so that informants only respond to questions relevant to the care the patient received. For each specified setting/health care provider (home: nursing service, specialist palliative home care team, hospice service, GP, outpatient specialist physicians; care home; hospital (last admission), in-patient hospice), informants could rate their experiences with care on a 4-point scale with respect to the manner of communication, relief of pain, relief of other symptoms, coordination of care, care quality in the last two days of life (1=yes, 2=rather yes, 3=rather no, 4=no), respect and dignity (1=always, 2=most of the time, 3=some of the time, 4=never), and overall satisfaction (1=good, 2=rather good, 3=rather bad, 4=bad). The questionnaire further assesses places of care with periods of stay; communication of a life-limiting disease; carer support, unmet needs, financial needs, preferences and decision-making, place of death, bereavement support; disease-specific and socio-demographic data. Objectivity, reliability and validity (content validity as well as divergent and convergent construct validity) were taken into consideration. The VOICES-

LYOL-Cologne survey has been shown to be useful to assess the quality of care in the last year of life. [Dust et al. in preparation]

Statistical analyses

Data were analysed descriptively and results are presented as mean ± standard deviation (SD) and count (percentage), respectively. Differences in informants' ratings of care were tested using Mann-Whitney-U test and Wilcoxon signed-rank test.

Secondly, we performed a logistic regression analysis to explore factors associated with overall satisfaction with care provided in general hospital wards and intensive care units (ICU). All variables were dichotomised as applied in previous VOICES studies.[37, 41-43] The dependent variable ("Overall, do you feel that the care he/she got from the doctors in the hospital on that admission was: good, rather good, rather bad, bad?") was merged into the most positive response to the question vs. all other responses. The independent variables comprised socio-demographic variables of the informants and the deceased patients and variables concerning service provision. First, univariable effect was tested. In a second step, all variables with p-value≤0.05 were entered into a multivariable logistic regression model using a stepwise, forward selection procedure. Results are presented as odds ratios (OR), corresponding 95% confidence intervals (CI), and p-values.

Data were analysed using SPSS Statistics version 25 (IBM Corp., Armonk, NY, USA) and RStudio version 3.5.1 (RStudio Inc., Boston, MA, USA). Analyses were restricted to individuals with complete data on all variables required for a particular analysis. All presented p-values are two-sided and considered significant if $p<0.05$.

RESULTS

Regional structure: The "Cologne Research and Development Network"

CoRe-Net has been established as a long-term and sustainable network, making Cologne a model region for the improvement of health and social care in Germany. Its members consist of three research projects which meet once a month and their collaboration partners which meet at least once a year. The interdisciplinary cooperation enables the integration of different perspectives and methods. The management structure is balanced with regard to participation and integration of different stakeholders. The network is run by an executive board, monitored by a steering board, operationally led by a coordinating unit, and supported by an international advisory board.

Around 100 partners from health and social care services in Cologne collaborated in the subproject LYOL-C. They represented care homes, nursing services, hospices, bereavement cafés, doctors, hospitals, undertakers and the local public health department. An initial meeting took place to consent the primary outcome and to discuss practical issues (e.g. recruitment).

Survey sample

The questionnaire was returned by 365 informants. Response rate was 21.1% for postal distribution, 10.3% for personal distribution, and 74.9% for the self-selection group. A total of 14 questionnaires did not meet the inclusion criteria and had to be excluded. Characteristics of the patients and their informants are presented in table 1. For the 351 deceased patients, the majority of informants were a spouse or a child (81.8%), female (71.5%), and aged between 50 and 79 years (77.5%). Point in time of participation in the survey was 7.6 ± 4.9 months after the patient's death. The sample of decedents comprises patients who died between December 2015 and July 2018. It was representative with respect to gender (47.9% male) and age (76.5 ± 13.0 years) compared with full data from the City of Cologne (gender: 50% male[44], age: 77.7 years[45]). The main underlying diseases were cancer (59.5%) and cardiovascular (40.5%), neuro-psychological (32.8%) and pulmonary (29.3%) diseases. One-third lived alone.

Table 1: Demographics and characteristics of deceased patients and informants (N=351)

	n	*(%)*
Deceased age at death (years)		
18-29	1	(0.3)
30-49	6	(1.7)
50-64	65	(18.5)
65-79	112	(31.9)
80+	167	(47.6)
Deceased sex		
Male	168	(47.9)
Female	183	(52.1)
Deceased ethnic group		
German	340	(96.9)
Other	11	(3.1)
Deceased family situation[a]		
Had a partner	163	(46.4)
Lived together with partner	126	(35.9)
Had children	168	(47.9)
Lived together with children	32	(9.1)
Lived together with someone else	21	(6)
Lived alone	114	(32.5)
Someone else had a power of attorney		
Yes	311	(88.6)
No	33	(9.4)
Do not know	7	(2)
Illnesses in the last year of life[a]		
Cancer	209	(59.5)

Cardiovascular disease	142	(40.5)
Neuro-psychological disease	115	(32.8)
Disease of the respiratory system	103	(29.3)
Liver or kidney disease	67	(19.1)
Diabetes mellitus	45	(12.8)
Decubitus ulcer	24	(6.8)
Informant relation to deceased		
Spouse	149	(42.5)
Son/daughter	138	(39.3)
Sibling	18	(5.1)
Son/daughter-in-law	9	(2.6)
Other relative	17	(4.8)
Friend	12	(3.4)
Other	8	(2.3)
Informant age (years)		
18-29	2	(0.6)
30-49	46	(13.1)
50-64	154	(43.9)
65-79	118	(33.6)
80+	31	(8.8)
Informant Sex		
Male	100	(28.5)
Female	251	(71.5)

[a] Multiple responses were possible.

Transition into the last year of life

Two hundred and two (59.9%) of the informants reported that the patient had been told that the disease was leading to death. One-third (n=114, 33.8%) indicated that they had not been told and 21 (6.2%) did not know. Of those who were told, 44 (22.8%) received this information less than a month before death, but one-third (n=63, 32.6%) more than a year before death. Hospital doctors were mentioned as breaking the news most often (n=112, 58%), followed by outpatient specialist physicians (n=29, 15%), close relatives (n=22, 11.4%), GPs (n=15, 7.8%), staff of the specialist palliative home care team (n=6, 3.1%), staff in the care home (n=1, 0.5%) and staff in a hospice (n=1, 0.5%). Seven (3.6%) informants could not name the person who communicated the information.

Transitions within the last year of life

Regarding the last year of life, most informants (n=310, 88.3%) reported that the deceased person spent some time at home and 75 (21.4%) some time in a care home. GPs (n=305, 86.9%) and outpatient specialist physicians (n=270, 76.9%) mainly provided outpatient care. Furthermore, 157 (44.7%) received care from a home nursing service, 135 (38.5%) from a specialist palliative home care team, and 23 (6.6%) were visited by a hospice service. For

224 (63.8%) patients the informant reported that urgent care provided out-of-hours was needed. Furthermore, a total of 320 (91.2%) patients stayed in hospital at least once and almost one-fifth (n=64, 18.2%) in a hospice.

On average, patients had 3.72 ± 3.1 transitions between care settings in the last year of life. Each of the five most frequent transitions included hospital care: home to hospital (47.2%), hospital to home (27.3%), care home to hospital (6.4%), hospital to hospital (6.4%), and hospital to care home (4.1%) (n=255). There was an increasing shift from home to the hospital as the main place of care near death. While 12 months prior to death patients spent 85.1% of their time at home and only 3.1% in hospital, in the final month of life they spent 46.3% of time at home and 30.2% in hospital (figure 2).

(Please insert here: Figure 2: Care settings in the last year of life in Cologne (N=255))

Transition into death

42.2% (n=148) died in hospital, as opposed to only 4.2% (n=8) who wished to die there. 161 relatives reported that the decedent did not express a preference for place of death or that they did not know the preference. The most preferred place of death was home (n=129, 67.9%), and this wish was only fulfilled for 27.6% (n=97) of patients. Nevertheless, the majority of informants stated that the decedent died in the right place (n=294, 87.2%), although one-third reported that the patient did not have enough choice about where they died (n=94, 32.1%).

Perceived quality of and satisfaction with care in the last year of life

Regarding informants' views of professionals' way of communicating a life-limiting disease, they were least satisfied with hospital doctors (table 2). Almost one-third stated that the hospital doctor did not communicate in a sensitive and caring way. Differences between ratings of the hospital doctor and non-hospital health care providers were statistically significant (p=0.003, n=156).

As examples of important quality indicators for care in the last year of life, table 2 further presents informants' ratings of perceived relief of pain and relief of other symptoms, as well as perceived coordination of care differentiated between care settings. It is notable that for symptom control both the home as well as acute hospital setting is rated the most poorly. Only 45.5% of informants stated that pain relief was good at home and 43.6% during the last stay in a general hospital ward or ICU. Proportions were even lower for other symptoms with good relief at home reported by 31.8% and 32.2% in a general hospital ward or ICU. For perceived coordination of care the general hospital wards and ICUs rank worst by far with only one-quarter of informants (25.6%) who said that the hospital worked well together with other services outside of the hospital. Hospice care was best rated for all three aspects. 80% of informants reported good pain relief, 67.2% good relief of other symptoms, and 90% good coordination of care.

Table 2: Informants' views of professionals' communication style, relief of pain, relief of other symptoms, and coordination of care between care settings in the last year of life

		Overall rating							
		Yes		Rather Yes		Rather No		No	
Care setting	*N*	*n*	*(%)*	*n*	*(%)*	*n*	*(%)*	*n*	*(%)*
Communication of life-limiting disease in a sensitive and caring way									
Hospice staff	1	0	(0)	1	(100)	0	(0)	0	(0)
Specialist palliative home care team	5	2	(40)	2	(40)	1	(20)	0	(0)
Care home staff	1	1	(100)	0	(0)	0	(0)	0	(0)
General practitioner	14	8	(57.1)	6	(42.9)	0	(0)	0	(0)
Outpatient specialist	25	9	(36)	11	(44)	4	(16)	1	(4)
Relative	19	16	(84.2)	3	(15.8)	0	(0)	0	(0)
Hospital doctor	91	34	(37.4)	30	(33)	13	(14.3)	14	(15.4)
Relief of pain									
Hospice	60	48	(80)	10	(16.7)	2	(3.3)	0	(0)
Hospital: Palliative care unit	84	51	(60.7)	23	(27.4)	7	(8.3)	3	(3.6)
Care home	66	33	(50)	26	(39.4)	7	(10.6)	0	(0)
Homecare	246	112	(45.5)	91	(37)	33	(13.4)	10	(4.1)
Hospital: General ward/ICU	188	82	(43.6)	78	(41.5)	21	(11.2)	7	(3.7)
Relief of other symptoms									
Hospice	58	39	(67.2)	15	(25.9)	3	(5.2)	1	(1.7)
Hospital: Palliative care unit	84	39	(46.4)	31	(36.9)	9	(10.7)	5	(6)
Care home	60	28	(46.7)	24	(40)	8	(13.3)	0	(0)
Homecare	255	81	(31.8)	113	(44.3)	41	(16.1)	20	(7.8)
Hospital: General ward/ICU	180	58	(32.2)	82	(45.6)	31	(17.2)	9	(5)
Worked well together with other services									
Hospice	50	45	(90)	3	(6)	0	(0)	2	(4)
Hospital: Palliative care unit	54	35	(64.8)	12	(22.2)	4	(7.4)	3	(5.6)
Care home	68	43	(63.2)	18	(26.5)	4	(5.9)	3	(4.4)
Homecare	244	125	(51.2)	72	(29.5)	34	(13.9)	13	(5.3)
Hospital: General ward/ICU	133	34	(25.6)	24	(18)	32	(24.1)	43	(32.3)

ICU: Intensive care unit.

Accordingly, informants' perceived overall satisfaction with patient care over the whole last year of life varied significantly depending on the care setting (table 3). Informants were more likely to rate care provided by hospices (89.1%) and the specialist palliative home care team (86.8%) as "good". Lower proportions of good ratings were given for the hospital palliative care units (68.5%), hospice services (68.4%), GPs (56.7%), care homes (50%), outpatient specialist physicians (47.6%), and nursing services (47.3%). They were least satisfied with the care provided in hospital general wards and ICUs, which was rated “good” by 41.3% and received the most “bad” (9.6%) ratings. Differences in informants’ reports of satisfaction with care in hospital general wards and ICUs were statistically significant in comparison to care provided by hospice (p=0.003, n=41), specialist palliative home care team (p<0.001, n=76), palliative care unit (p<0.001, n=297), home hospice service (p=0.033, n=12), and the GP (p=0.009, n=179).

Table 3: Informants’ overall satisfaction with care provided by health and social care practitioners in the last year of life and comparison with the last hospital stay in a general ward or ICU

		Overall satisfaction with care								**Hospital general ward/ ICU vs. other setting[a]**	
		Good		**Rather good**		**Rather bad**		**Bad**			
Care setting	***N***	***n***	***(%)***	***n***	***(%)***	***n***	***(%)***	***n***	***(%)***	***N***	***p-value***
Hospice	64	57	(89.1)	5	(7.8)	0	(0)	2	(3.1)	41	0.003[b]
Specialist palliative home care team	129	112	(86.8)	13	(10.1)	2	(1.6)	2	(1.6)	76	< 0.001[b]
Hospital (doctor): Palliative care unit	89	61	(68.5)	22	(24.7)	3	(3.4)	3	(3.4)	297	< 0.001[c]
Hospice service	19	13	(68.4)	6	(31.6)	0	(0)	0	(0)	12	0.033[b]
General practitioner	282	160	(56.7)	75	(26.6)	36	(12.8)	11	(3.9)	179	0.009[b]
Care home	72	36	(50)	26	(36.1)	10	(13.9)	0	(0)	52	0.068[b]
Outpatient specialists	229	109	(47.6)	76	(33.2)	30	(13.1)	14	(6.1)	135	0.985[b]
Nursing service	146	69	(47.3)	59	(40.4)	15	(10.3)	3	(2.1)	101	0.085[b]
Hospital (doctor): General ward/ICU	208	86	(41.3)	76	(36.5)	26	(12.5)	20	(9.6)	-	-

[a] Compares informant’s overall rating of the last hospital stay (doctor) in a general ward or ICU with the overall rating of every other care setting for patients who experienced both forms of care (e.g. hospital general ward/ICU vs. hospice).
[b] Wilcoxon signed-rank test for paired samples.
[c] Mann-Whitney-U-Test.
ICU: Intensive care unit.

Determinants of satisfaction with care in an acute hospital setting

Since care provided by general hospital wards and ICUs were rated worst compared to all other health and social care practitioners in the last year of life, we explored the determinants of satisfaction with care delivered in these hospital wards and units. Table 4 shows the variables entered into the model and their frequencies of response to each of the questions by satisfaction of hospital care (satisfied/dissatisfied). It also presents the p-value relating to the univariate chi-squared test.

Table 4: Univariate analyses of satisfaction with general hospital care during the last year of life

	Satisfied with hospital care	Dissatisfied with hospital care		
	n (%)	*n (%)*	*N*	*p-value*[a]
Age				
< 85 years old	62 (72.1)	70 (57.4)	208	0.043
≥ 85 years old	24 (27.9)	52 (42.6)		
Gender				
Male	50 (58.1)	53 (43.4)	208	0.052
Female	36 (41.9)	69 (56.6)		
Family situation				
Patient had a partner	47 (54.7)	41 (33.6)	208	0.037
Other	39 (45.3)	81 (66.4)		
Did someone else have a power of attorney?				
Yes	72 (85.7)	113 (94.2)	204	0.072
No	12 (14.3)	7 (5.8)		
Did he/she receive care by a specialist palliative home care team?				
Yes	39 (46.4)	38 (31.4)	205	0.042
No	45 (53.6)	83 (68.6)		
During his/her last hospital admission, how much of the time was he/she treated with respect and dignity by the hospital doctors?				
Always	73 (90.1)	25 (22.5)	192	< 0.001
Most of the time/some of the time/never	8 (9.9)	86 (77.5)		
During his/her last hospital admission, was his/her pain relieved?				
Yes	53 (67.1)	25 (25.3)	178	< 0.001
Rather yes/rather no/no	26 (32.9)	74 (74.7)		
During his/her last hospital admission, were other symptoms relieved?				
Yes	39 (51.3)	16 (16.8)	171	< 0.001
Rather yes/rather no/no	37 (48.7)	79 (83.2)		
During his/her last hospital admission, did the hospital services work well together with other services outside of the hospital?				
Yes	30 (58.8)	4 (5)	131	< 0.001
Rather yes/rather no/no	21 (41.2)	76 (95)		

[a] Chi-square test.

As a result of the multivariable logistic regression analysis, two variables were found to predict satisfaction with hospital care while all other variables did not reach significance any more. First, the model (n=124) indicated that the feeling that the patient was treated with respect and dignity by the doctor was associated with an almost 24-fold increase in the likelihood of being satisfied (OR=23.80, CI=7.503 to 75.498, $p<0.001$). Second, the impression that the hospital worked well together with other services outside the hospital was associated with an 8-fold increase of being satisfied (OR=8.37, CI=2.141 to 32.71, p=0.002). The adjusted R^2 was 0.478 (Cox & Snell), and 0.647 (Nagelkerkes).

DISCUSSION

Principal findings

This study is the first to our knowledge to set up a pragmatic double loop PDSA cycle to improve regional care in the last year of life. Embedded in a regional health services research and development structure, we comprehensively analysed patient experiences with care in the last year of life from the bereaved relatives' perspectives. Hospitals were reported as the main player for diagnosing a progressive condition, for being involved in most transitions during the last year of life, and being the most frequent place of death despite all home palliative and hospice services available in Cologne. Yet, satisfaction was lowest with care provided in an acute hospital setting, which was determined by the feeling of not being treated with respect and dignity and the impression that hospitals did not work well together with other services. Based on this first step of the PDSA cycle, two interventions were developed to continue the cycle.

Strengths and weaknesses

Most end-of-life care studies focus on a single care setting or are restricted to the dying phase, the last weeks of life or an underlying diagnosis. VOICES surveys include multiple settings to disaggregate findings according to specific setting type. Nevertheless, the instrument only evaluates the last three months of life.[32] Within this study, we utilised an adapted German version of the VOICES-SF, which was expanded to the last twelve months of life and included the communication of a life-limiting diagnosis. This instrument enables the reconstruction of the entire last year of life of patients, irrespective of the underlying diagnosis, to assess the provision and quality of care of all health and social care practitioners involved in patients' care. Our findings demonstrate the feasibility of collecting patient experiences reported by proxy-respondents across multiple care settings.

In Germany there is no national register available that could be used to identify participants. Therefore, a population-based survey was not feasible and the sample of decedents represented in this study was a purposive sample. Due to the recruitment strategy, patients from palliative care services are overrepresented. Nevertheless, it appropriately reflected the age and gender distribution of people dying in the City of Cologne.[44, 45]

We used a retrospective research design and asked bereaved relatives to act as proxies for the deceased patients. Relatives' reports of care experiences after the death of a loved one are an important outcome measure to determine the quality of end-of-life care.[12] This method is, of course, not without its limitations, especially in relation to memory, the impact of bereaved relatives' feelings, and the concordance between patient and proxy reports.[46, 47] A few studies examined these concerns and found that respondents were more accurate in recalling salient events and that satisfaction was mainly determined by service characteristics.[48, 49] A review on the validity of proxies' responses found that the level of agreement was good on service evaluations and observable symptoms, but lower for subjective symptoms such as pain.[50] The retrospective approach has a long history in the conducting of end-of-life-care research. It bypasses the difficult task of identifying the terminally ill, avoids putting an additional burden on very sick participants, and minimises missing data due to poor functional status. It furthermore creates a clear time frame for the purpose of comparing settings of care.[51]

Comparison with existing literature

We found substantial differences in the reported satisfaction with care depending on the care setting. Informants were significantly more satisfied with quality of care provided in hospices compared to other care settings. Unfortunately, only a small number of patients will ever be admitted to hospice. In Germany, approximately 5% of patients, most of them cancer patients, die in hospice.[52] Hospitals remain the most frequent place of death, with the highest levels of dissatisfaction. These results are similar to those from other VOICES studies carried out in Western countries.[1, 3, 35, 37] Previous studies also identified psychosocial rather than physical factors leading to dissatisfaction with care. A lack of personal care and dignity has been reported to cause patients to feel "devalued" or "dehumanised".[53] Being involved in decisions and discussing any worries were also described as predictors of satisfaction with hospital care.[41]

International studies have shown that there is still a discrepancy between current best practice recommendations and observed clinical reality; for example with regard to the recognition of a patient's transition into the last year of life, identifying a patient's palliative care needs, and aspects of shared decision making.[54] Reasons for this may lie in the obvious life-saving culture of hospitals where the norm is to prevent death by whatever means are necessary. Furthermore, it may also be due to the increasing time and cost pressure put on hospitals without these institutions having established standards for patients who will die within the foreseeable future.[55] Since almost 30% of all hospital patients are expected to be in their last year of life,[56] our findings stress the importance of a further integration of palliative care into acute care hospitals. Strategies for integrating palliative care into a country's health care system have been developed. In 2007 the World Health Organization (WHO) published a public health strategy that includes advice and guidelines for governments on priorities and how to implement national palliative care programmes.[57] Furthermore, international experts in palliative care and cancer care formulated written statements regarding how integrated palliative care can be operationalised.[58]

Implications and future research

These data have already led to the next PDSA cycle step with direct consequences for regional action. We concluded by planning interventions in acute care hospitals in Cologne targeting both the beginning and the end of the last year of life. It was therefore decided (1) to target the identification of patients in their last year of life and the initiation of conversations about patient wishes by tailoring and testing the “Acute Hospital Programme” by the Gold Standards Framework and (2) to begin a process within hospital unit teams to discuss how to better reach quality indicators for care in the dying phase as described in the national guideline.[16, 59] With the next steps of this continuous cycle, we will “do” and “study” the effectiveness of the interventions described above. This study could serve as an example for determining regional improvement priorities based on patient experiences.

DECLARATIONS

Contributors: RV and GD are joint first authors and act as guarantors. RV, JS and CR are principal investigators and responsible for the study design, project management, data analysis and dissemination. GD and NiS designed the survey instrument and collected data. GD cleaned and analysed data. SH, SP, NaS and HP contributed to study design, data analysis and dissemination. HP is principal investigator of CoRe-Net. NaS coordinates CoRe-Net. All authors read and approved the final manuscript.

Ethics 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.

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Competing interests: None declared.

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Collaborators: The CoRe-Net Co-applicants: Professor Dr Christian Albus, Department of Psychosomatics and Psychotherapy, Faculty of Medicine (FM), University Hospital Cologne (UHC); Professor Dr Lena Ansmann, Department of Health Services Research, School of Medicine and Health Sciences, Carl von Ossietzky University Oldenburg; Professor Dr Frank Jessen, Department of Psychiatry and Psychotherapy, FM, UHC; Professor Dr Ute Karbach, Sociology in Rehabilitation, Faculty of Rehabilitation, Technical University Dortmund; Professor Dr Ludwig Kuntz, Department of Business Administration and Health Care Management, Faculty of Management, Economics and Social Sciences (FMESS), University of Cologne (UoC); Dr Ingrid Schubert, PMV Health Care Research Group, FM, UoC; Professor Dr Frank Schulz-Nieswandt, Institute for Sociology and Social Psychology, FMESS, UoC; Professor Dr Stephanie Stock, Institute for Health Economics and Clinical Epidemiology, FM, UHC.

Data sharing: Data are available upon reasonable request from the corresponding author.

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FIGURES

Figure 1: Strategic learning process framed on the double-loop PDSA cycle

(based on Pfaff and Zeike (2019))

Figure 2: Care settings in the last year of life in Cologne (N=255)

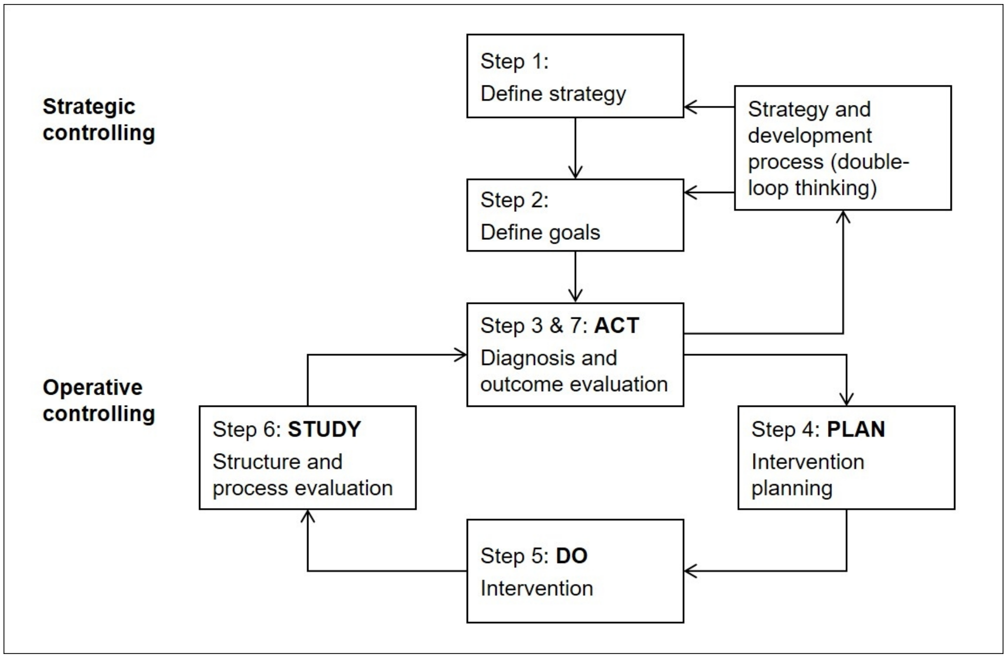

Figure 1: Strategic learning process framed on the double-loop PDSA cycle (based on Pfaff and Zeike (2019))

194x126mm (150 x 150 DPI)

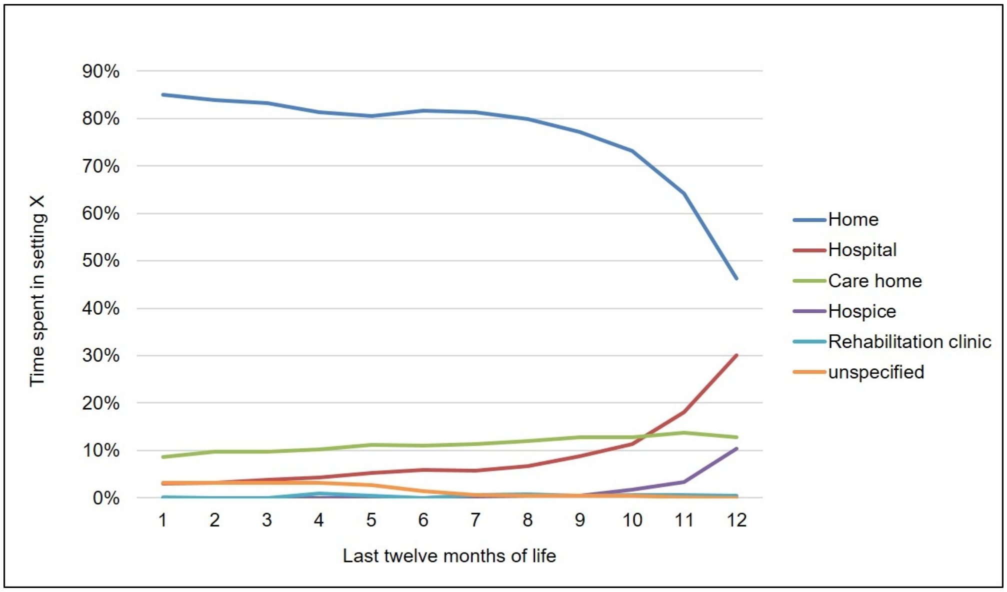

Figure 2: Care settings in the last year of life in Cologne (N=255)

222x130mm (150 x 150 DPI)

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1, 2
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3, 4
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5,6
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6
Bias	9	Describe any efforts to address potential sources of bias	6
Study size	10	Explain how the study size was arrived at	5,6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	7
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	7
		(*b*) Describe any methods used to examine subgroups and interactions	7
		(*c*) Explain how missing data were addressed	7
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	/
		(*e*) Describe any sensitivity analyses	/
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7,8
		(b) Give reasons for non-participation at each stage	7,8
		(c) Consider use of a flow diagram	/
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	8,9
		(b) Indicate number of participants with missing data for each variable of interest	9-14
Outcome data	15*	Report numbers of outcome events or summary measures	9-14
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	12-14

		(*b*) Report category boundaries when continuous variables were categorized	/
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	/
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	/
Discussion			
Key results	18	Summarise key results with reference to study objectives	14
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	14,15
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14,15
Generalisability	21	Discuss the generalisability (external validity) of the study results	14,15
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	16

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Improving regional care in the last year of life by setting up a pragmatic evidence-based Plan-Do-Study-Act cycle: Results from a cross-sectional survey

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Keywords:	Adult palliative care < PALLIATIVE CARE, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Change management < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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Improving regional care in the last year of life by setting up a pragmatic evidence-based Plan-Do-Study-Act cycle: Results from a cross-sectional survey

Raymond Voltz*[1,2,3,4], Gloria Dust*[1], Nicolas Schippel[5], Stefanie Hamacher[6], Sheila Payne[7], Nadine Scholten[5], Holger Pfaff[4,5], Christian Rietz[8], Julia Strupp[1], on behalf of CoRe-Net

[1]University of Cologne, Faculty of Medicine and University Hospital, Department of Palliative Medicine, Germany

[2]University of Cologne, Faculty of Medicine and University Hospital, Center for Integrated Oncology Aachen Bonn Cologne Dusseldorf (CIO ABCD), Germany

[3]University of Cologne, Faculty of Medicine and University Hospital, Clinical Trials Center (ZKS), Germany

[4]University of Cologne, Faculty of Medicine and University Hospital, Center for Health Services Research, Germany

[5]University of Cologne, Faculty of Human Sciences and Faculty of Medicine, Institute for Medical Sociology, Health Services Research, and Rehabilitation Science (IMVR), Germany

[6]University of Cologne, Faculty of Medicine and University Hospital, Institute of Medical Statistics and Computational Biology, Germany

[7]Lancaster University, Faculty of Health and Medicine, Division of Health Research, United Kingdom

[8]University of Education Heidelberg, Faculty of Educational and Social Sciences, Department of Educational Science, Germany

* RV and GD contributed equally to this paper.

Corresponding author:

Gloria Dust, University of Cologne, Faculty of Medicine and University Hospital, Department of Palliative Medicine, 50924 Cologne, Germany, gloria.dust@uk-koeln.de, +4922147887820

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Abstract (Words: 287)

Objectives To set up a pragmatic Plan-Do-Study-Act cycle by analysing patient experiences and determinants of satisfaction with care in the last year of life.

Design Cross-sectional post-bereavement survey.

Setting Regional health services research and development structure representing all health and social care providers involved in the last year of life in Cologne, a city with one million inhabitants in Germany.

Participants 351 bereaved relatives of adult decedents, representative for age and gender, accidental and suspicious deaths excluded.

Results For the majority (89%) of patients, home was the main place of care during their last year of life. Nevertheless, 91% of patients had at least one hospital admission and 42% died in hospital. Only 60% of informants reported that the decedent had been told that the disease was leading to death. Hospital physicians broke the news most often (58%), with their communication style often (30%) being rated as “not sensitive”. Informants indicated highly positive experiences with care provided by hospices (89% “good”) and specialist palliative home care teams (87% “good”). This proportion dropped to 41% for acute care hospitals, this rating being determined by the feeling of not being treated with respect and dignity (OR=23.80, CI=7.503 to 75.498) and the impression that hospitals did not work well together with other services (OR=8.37, CI=2.141 to 32.71).

Conclusions Following those data, our regional priority for action now is improvement of care in acute hospitals, with two new projects starting, first how to recognise and communicate a limited life span, and second how to improve care during the dying phase. Results and further improvement projects will be discussed in a working group with the City of Cologne, and repeating this survey in two years will be able to measure regional achievements.

Trial registration German Clinical Trials Register: DRKS00011925.

Keywords: PDSA cycle, last year of life, satisfaction, hospital care, VOICES questionnaire

Strengths and limitations of this study

- This study presents a multidimensional and comprehensive assessment of care provided in multiple settings in the entire last year of life.
- It describes a pragmatic template for determining regional improvement priorities based on patient experiences using a city-wide health services research and development structure (Plan-Do-Study-Act cycle).
- The reports of relatives cannot be seen as a direct substitute for a self-assessment of patients, although a good agreement has been shown on service evaluations and observable symptoms.
- The retrospective approach bypasses the difficult task of identifying the terminally ill, avoids putting an additional burden on very sick participants, and minimises missing data due to poor functional status.

INTRODUCTION

Patients in their last year of life may be regarded as vulnerable because most of them need complex care provided by multiple health and social care practitioners.[1] Their needs are often not sufficiently met, especially in settings outside specialist palliative and hospice care.[2, 3] Due to the fact that they are often dependent on others to meet their physical care needs, they can deteriorate unpredictably and rapidly and their ability to make informed choices may be reduced due to cognitive impairment.[4] Care transitions as well as non-beneficial treatments are common, which may compromise human dignity and quality end-of-life care.[5, 6] In Germany, the evidence-based guideline "*Palliative care*" was published in 2015 to promote quality end-of-life care by all healthcare professionals. This aim may be achieved by "providing palliative care services in both a timely manner and in accordance with the affected persons' needs, treating the common symptoms according to current scientific evidence and clinical expertise, enabling conversations with patients and their families to be held and treatment goals to be set together, ensuring that support in the dying phase can be appropriately and optimally given."[7]

Evidence shows that most people prefer their home as place of death.[8] This also applies to Germany. However, almost one person in two dies in hospital and one third in care home.[9] Fragmentation of multidisciplinary service provision is one major barrier to adequately addressing patients' needs and preferences.[10] Data on patients' and their families' perceptions are essential in order to understand these issues and to inform quality improvements. The last year of life can obviously only be objectively determined in retrospect, but it has to be managed prospectively. Adding palliative care in the last 12 to 24 months of life has proven to be greatly beneficial.[11, 12] Therefore, consideration also needs to be given to the introduction of these services. However, the majority of surveys focuses on the dying phase or the last weeks to months of life and only a few studies have compared end-of-life care across different settings.[13-16] Care in the last year of life encompasses a wide range of services necessitating a multidimensional and comprehensive assessment approach.[14] This comprises the measurement of patients' experiences of the communication of a life-limiting disease ("transition into the last year of life"), transitions between health care settings ("transitions within the last year of life"), and the dying phase ("transition into death and a new phase of life for bereaved relatives"). For Germany, data on patients' perceptions of their experience of care in the last year of life that go beyond diagnoses and care settings are still rare.

Germany possesses a well-defined, government-led strategy for the development and promotion of national palliative care and performed well in the 2015 Quality of Death Index (position seven in the global rank of overall scores).[17] Based on the patients' needs, they may receive generalist palliative care (e.g. provided in a general hospital ward, a nursing home, by a general practitioner (GP) or a nursing service at home) or specialist palliative care provided by specialist personnel with expert knowledge, skills and attitudes (e.g. delivered in a hospital palliative care unit, a hospice or by a specialist palliative home care team). Hospice care in Germany refers to care provided in an in-patient facility. In addition, hospice services delivered by volunteers may support the patients and their families during illness and after a patient's death. All services and accommodations in these facilities are provided at no extra cost to the patient and are part of the service of the statutory as well as private health insurance. As in many other countries, the national level indicates the general direction in which the health care system is developing. However, for the patients and caregivers, the regional health care situation matters most, and this shows a lot of heterogeneity in Germany.[9] Due to this regional heterogeneity, this local level should be the driving force for innovation.[18, 19]

Delivering improvements in the quality of healthcare remains an international challenge. Methods such as the Plan-Do-Study-Act (PDSA) cycle have been widely used in healthcare as an attempt to drive such improvements. The PDSA method is an iterative four-step cycle, which includes (1) identifying a change aimed at improvement, (2) testing this change, (3) examining the success of the change, and (4) identifying adaptations and next steps to inform a new cycle.[20] The fundamental principle is iteration (figure 1).[21, 22] To inform practice we need practical, but still evidence-based solutions which lead to "satisficing" decisions.[23-26] Therefore, as a paradigm case for a one million inhabitant urban health care situation, this paper describes the set-up of a pragmatic quality improvement structure to improve regional end-of-life care. In particular, as the first step of the PDSA cycle we analyse patient experiences across settings and providers and determinants of satisfaction with care in the last year of life as reported by bereaved relatives.

(Please insert here: Figure 1: Strategic learning process framed on the PDSA cycle)

METHODS

Setting up the regional structure

Initiated by three cooperating faculties (Human Sciences; Medicine; Management, Economics, and Social Sciences) of the University of Cologne, Germany, a regional health services research and development structure has been established involving as many relevant partners as possible from medical and social care as well as from health services research. The "Cologne Research and Development Network" (CoRe-Net)[27] focuses on the further development of health and social care according to the concept of learning organisations based on a bottom-up approach. Its main aim is to analyse and continuously improve healthcare delivery for vulnerable patient groups by going through PDSA cycles. We invited national and international scientific experts, regional health and social care institutions, patient organisations, and statutory health insurance providers to act as CoRe-Net collaboration partners. Within the network three research projects have been initiated, one focusing on patients in their last year of life. For this project entitled "Last Year of Life Study Cologne (LYOL-C)"[28] all health and social care practitioners involved in the care of patients in their last year of life (i.e., care homes, nursing services, hospices, bereavement cafés, doctors, hospitals, undertakers and the local public health department) as well as providers of grief work in Cologne were contacted for collaboration.

Patient involvement

Patient representatives were involved in the design and conduct of this research. They worked with us to refine the research question, choice of outcome measures, and methods of recruitment. In collaboration with patient representatives we will design a leaflet for dissemination to distributing to patient groups.

Sample and data collection

Data were collected in a post-bereavement survey as part of the project LYOL-C. Participants were a purposive sample of relatives, friends and voluntary workers (all will be referred to as "informants" hereafter). Inclusion criteria required informants to be aged 18 years and older and to 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 as well as accidental and suspicious deaths were excluded. To ensure maximum variation, informants in this study were recruited in cooperation with health and social care practitioners from Cologne (partners from care homes, nursing services, hospices, bereavement cafés, doctors, hospitals, undertakers, local public health department). We applied two strategies between November 2017 and August 2018 to identify potential informants: i) Questionnaire distribution through cooperating care practitioners through client records by mail or personally. ii) Self-selection through public media (newspaper articles, flyers and posters): Informants who were interested in taking part in the survey could request a postal questionnaire from one of the researchers (GD); one reminder was sent. An information sheet describing the study's goals and a response form for opting out of the study were sent with the questionnaire. Informants gave written informed consent before taking part in the survey. All pseudonymously completed questionnaires were returned directly to the research team.

Questionnaire

The self-complete questionnaire is based on the Views Of Informal Carers – Evaluation of Services-Short Form (VOICES-SF).[29] It is a validated questionnaire to assess the bereaved relatives' perceptions of the patient's care experiences with providers and services across care settings in the last three months of life. VOICES-SF was developed for a nationally representative cross-sectional survey to examine the quality of end-of-life care in England, conducted annually for five years (2011-2015),[30] and has already been used internationally.[3, 31-37]

We developed an adapted German version ("VOICES-LYOL-Cologne") that covers the last twelve months of life and additionally includes the communication of the diagnosis of a life-limiting disease as well as places of care with periods of stay. The questionnaire comprises 106 items and contains skip logic so that informants only respond to questions relevant to the care the patient received. For each specified setting/health care provider (home: nursing service, specialist palliative home care team, hospice service, GP, outpatient specialist physicians; care home; hospital (last admission), in-patient hospice), informants could rate their experiences with care on a 4-point scale with respect to the manner of communication, relief of pain, relief of other symptoms, coordination of care, care quality in the last two days of life (1=yes, 2=rather yes, 3=rather no, 4=no), respect and dignity (1=always, 2=most of the time, 3=some of the time, 4=never), and overall satisfaction (1=good, 2=rather good, 3=rather bad, 4=bad). The questionnaire further assesses communication of a life-limiting disease; carer support, unmet needs, financial needs, preferences and decision-making, place of death, bereavement support; disease-specific and socio-demographic data. Next the informants were asked to provide the settings in which the patients had received care during the last year of life (e.g. home, hospital, nursing home, hospice, rehabilitation clinic), and the period of time spent per stay. Data was inserted in a table with chronological order. Objectivity, reliability and validity (content validity as well as divergent and convergent construct validity) were taken into consideration. The VOICES-LYOL-Cologne survey has been shown to be useful to assess the quality of care in the last year of life. [Dust et al. in preparation]

Statistical analyses

Data were analysed descriptively and results are presented as mean ± standard deviation (SD) and count (percentage), respectively. Differences in informants' ratings of care were tested using Mann-Whitney-U test for independent samples and Wilcoxon signed-rank test for paired samples.

Secondly, we performed a logistic regression analysis to explore factors associated with overall satisfaction with care provided in general hospital wards and intensive care units (ICU). All variables were dichotomised as applied in previous VOICES studies.[34, 38-40] The dependent variable ("Overall, do you feel that the care he/she got from the doctors in the hospital on that admission was: good, rather good, rather bad, bad?") was merged into the most positive response to the question vs. all other responses. The independent variables comprised socio-demographic variables of the deceased patients (age, gender, family situation, power of attorney) and variables concerning service provision (care by a specialist palliative home care team, treated with respect and dignity by the hospital doctors, relief of pain on last hospital admission, relief of other symptoms on last hospital admission, coordination of care on last hospital admission). First, univariable effect was tested. In a second step, all variables with p-value≤0.1 were entered into a multivariable logistic regression model using a stepwise, forward selection procedure. Results are presented as odds ratios (OR), corresponding 95% confidence intervals (CI), and p-values.

Data were analysed using SPSS Statistics version 25 (IBM Corp., Armonk, NY, USA) and RStudio version 3.5.1 (RStudio Inc., Boston, MA, USA). Analyses were restricted to individuals with complete data on all variables required for a particular analysis. All presented p-values are two-sided and considered significant if $p<0.05$.

RESULTS

Regional structure: The "Cologne Research and Development Network"

CoRe-Net has been established as a long-term and sustainable network, making Cologne a model region for the improvement of health and social care in Germany. Its members consist of three research projects and their collaboration partners. The interdisciplinary cooperation enables the integration of different perspectives and methods. Around 100 partners from health and social care services in Cologne collaborated in the subproject LYOL-C. They represented care homes, nursing services, hospices, bereavement cafés, doctors, hospitals, undertakers and the local public health department. An initial meeting took place to consent the primary outcome and to discuss practical issues (e.g. recruitment).

Survey sample

The questionnaire was returned by 365 informants. Response rate was 21.1% for postal distribution, 10.3% for personal distribution, and 74.9% for the self-selection group. A total of 14 questionnaires did not meet the inclusion criteria and had to be excluded. Characteristics of the patients and their informants are presented in table 1. For the 351 deceased patients, the majority of informants were a spouse or a child (81.8%), female (71.5%), and aged between 50 and 79 years (77.5%). Point in time of participation in the survey was 7.6 ± 4.9 months after the patient's death. The sample of decedents comprises patients who died between December 2015 and July 2018. It was representative with respect to gender (47.9% male) and age (76.5 ± 13.0 years) compared with full data from the City of Cologne (gender: 50% male[41], age: 77.7 years[42]). The main underlying diseases were cancer (59.5%) and cardiovascular (40.5%), neuro-psychological (32.8%) and pulmonary (29.3%) diseases. One-third lived alone.

Table 1: Demographics and characteristics of deceased patients and informants (N=351)

	n	*(%)*
Deceased age at death (years)		
18-29	1	(0.3)
30-49	6	(1.7)
50-64	65	(18.5)
65-79	112	(31.9)
80+	167	(47.6)
Deceased sex		
Male	168	(47.9)
Female	183	(52.1)
Deceased ethnic group		
German	340	(96.9)
Other	11	(3.1)
Deceased family situation[a]		
Had a partner	163	(46.4)
Lived together with partner	126	(35.9)
Had children	168	(47.9)
Lived together with children	32	(9.1)
Lived together with someone else	21	(6)
Lived alone	114	(32.5)
Someone else had a power of attorney		
Yes	311	(88.6)
No	33	(9.4)
Do not know	7	(2)
Illnesses in the last year of life[a]		

Cancer	209	(59.5)
Cardiovascular disease	142	(40.5)
Neuro-psychological disease	115	(32.8)
Disease of the respiratory system	103	(29.3)
Liver or kidney disease	67	(19.1)
Diabetes mellitus	45	(12.8)
Decubitus ulcer	24	(6.8)
Informant relation to deceased		
Spouse	149	(42.5)
Son/daughter	138	(39.3)
Sibling	18	(5.1)
Son/daughter-in-law	9	(2.6)
Other relative	17	(4.8)
Friend	12	(3.4)
Other	8	(2.3)
Informant age (years)		
18-29	2	(0.6)
30-49	46	(13.1)
50-64	154	(43.9)
65-79	118	(33.6)
80+	31	(8.8)
Informant Sex		
Male	100	(28.5)
Female	251	(71.5)

[a] Multiple responses were possible.

Transition into the last year of life

Two hundred and two (63.9%) of the informants reported that the patient had been told that the disease was leading to death, one-third (n=114, 36.1%) indicated that they had not been told. Of those who were told, 44 (22.8%) received this information less than a month before death, but one-third (n=63, 32.6%) more than a year before death. Hospital doctors were mentioned as breaking the news most often (n=112, 60.2%), followed by outpatient specialist physicians (n=29, 15.6%), close relatives (n=22, 11.8%), GPs (n=15, 8.1%), staff of the specialist palliative home care team (n=6, 3.2%), staff in the care home (n=1, 0.5%) and staff in a hospice (n=1, 0.5%).

Transitions within the last year of life

Regarding the last year of life, most informants (n=310, 88.6%) reported that the deceased person spent some time at home and 75 (22.4%) some time in a care home. GPs (n=305, 87.4%) and outpatient specialist physicians (n=270, 77.1%) mainly provided outpatient care. Furthermore, 157 (45.1%) received care from a home nursing service, 135 (38.8%) from a specialist palliative home care team, and 23 (6.6%) were visited by a hospice service. For 224 (73%) patients the informant reported that urgent care provided out-of-hours was needed.

Furthermore, a total of 320 (91.4%) patients stayed in hospital at least once and almost one-fifth (n=64, 18.8%) in a hospice.

On average, patients had 3.72 ± 3.1 transitions between care settings in the last year of life. Each of the five most frequent transitions included hospital care: home to hospital (47.2%), hospital to home (27.3%), care home to hospital (6.4%), hospital to hospital (6.4%), and hospital to care home (4.1%) (n=255). There was an increasing shift from home to the hospital as the main place of care near death. While 12 months prior to death patients spent 85.1% of their time at home and only 3.1% in hospital, in the final month of life they spent 46.3% of time at home and 30.2% in hospital (figure 2).

(Please insert here: Figure 2: Care settings in the last year of life in Cologne (N=255))

Transition into death

42.2% (n=148) died in hospital, as opposed to only 4.2% (n=8) who wished to die there. 161 (45.9%) relatives reported that the decedent did not express a preference for place of death or that they did not know the preference. The most preferred place of death was home (n=129, 67.9%), and this wish was only fulfilled for 27.6% (n=97) of patients. Nevertheless, the majority of informants stated that the decedent died in the right place (n=294, 87.2%), although one-third reported that the patient did not have enough choice about where they died (n=94, 32.1%).

Perceived quality of and satisfaction with care in the last year of life

Regarding informants' views of professionals' way of communicating a life-limiting disease, they were least satisfied with hospital doctors (table 2). Almost one-third stated that the hospital doctor did not communicate in a sensitive and caring way. Differences between ratings of the hospital doctor and non-hospital health care providers were statistically significant (p=0.003, n=156).

As examples of important quality indicators for care in the last year of life, table 2 further presents informants' ratings of perceived relief of pain and relief of other symptoms, as well as perceived coordination of care differentiated between care settings. It is notable that for symptom control both the home as well as acute hospital setting is rated the most poorly. Only 45.5% of informants stated that pain relief was good at home and 43.6% during the last stay in a general hospital ward or ICU. Proportions were even lower for other symptoms with good relief at home reported by 31.8% and 32.2% in a general hospital ward or ICU. For perceived coordination of care the general hospital wards and ICUs rank worst by far with only one-quarter of informants (25.6%) who said that the hospital worked well together with other services outside of the hospital. Hospice care was best rated for all three aspects. 80% of informants reported good pain relief, 67.2% good relief of other symptoms, and 90% good coordination of care.

Table 2: Informants' views of professionals' communication style, relief of pain, relief of other symptoms, and coordination of care between care settings in the last year of life

		Overall rating			
		Yes	**Rather Yes**	**Rather No**	**No**
Care setting	***N***[a]	***n (%)***	***n (%)***	***n (%)***	***n (%)***
Communication of life-limiting disease in a sensitive and caring way					
Hospice staff	1	0 (0)	1 (100)	0 (0)	0 (0)
Specialist palliative home care team	5	2 (40)	2 (40)	1 (20)	0 (0)
Care home staff	1	1 (100)	0 (0)	0 (0)	0 (0)
General practitioner	14	8 (57.1)	6 (42.9)	0 (0)	0 (0)
Outpatient specialist	25	9 (36)	11 (44)	4 (16)	1 (4)
Relative	19	16 (84.2)	3 (15.8)	0 (0)	0 (0)
Hospital doctor	91	34 (37.4)	30 (33)	13 (14.3)	14 (15.4)
Relief of pain					
Hospice	60	48 (80)	10 (16.7)	2 (3.3)	0 (0)
Hospital: Palliative care unit	84	51 (60.7)	23 (27.4)	7 (8.3)	3 (3.6)
Care home	66	33 (50)	26 (39.4)	7 (10.6)	0 (0)
Homecare	246	112 (45.5)	91 (37)	33 (13.4)	10 (4.1)
Hospital: General ward/ICU	188	82 (43.6)	78 (41.5)	21 (11.2)	7 (3.7)
Relief of other symptoms					
Hospice	58	39 (67.2)	15 (25.9)	3 (5.2)	1 (1.7)
Hospital: Palliative care unit	84	39 (46.4)	31 (36.9)	9 (10.7)	5 (6)
Care home	60	28 (46.7)	24 (40)	8 (13.3)	0 (0)
Homecare	255	81 (31.8)	113 (44.3)	41 (16.1)	20 (7.8)
Hospital: General ward/ICU	180	58 (32.2)	82 (45.6)	31 (17.2)	9 (5)
Worked well together with other services					
Hospice	50	45 (90)	3 (6)	0 (0)	2 (4)
Hospital: Palliative care unit	54	35 (64.8)	12 (22.2)	4 (7.4)	3 (5.6)
Care home	68	43 (63.2)	18 (26.5)	4 (5.9)	3 (4.4)
Homecare	244	125 (51.2)	72 (29.5)	34 (13.9)	13 (5.3)
Hospital: General ward/ICU	133	34 (25.6)	24 (18)	32 (24.1)	43 (32.3)

[a] Number of patients for whom the corresponding question was responded

ICU: Intensive care unit.

Accordingly, informants' perceived overall satisfaction with patient care over the whole last year of life varied significantly depending on the care setting (table 3a). Informants were more likely to rate care provided by hospices (89.1%) and the specialist palliative home care team

(86.8%) as “good”. Lower proportions of good ratings were given for the hospital palliative care units (68.5%), hospice services (68.4%), GPs (56.7%), care homes (50%), outpatient specialist physicians (47.6%), and nursing services (47.3%). They were least satisfied with the care provided in acute hospitals (general wards and ICUs), which was rated “good” by 41.3% and received the most “bad” (9.6%) ratings. We tested the differences in informants’ reports of satisfaction with acute hospital care versus all other health and social care practitioners (e.g. hospital general ward/ICU vs. hospice; table 3b). Differences were statistically significant in comparison to care provided by hospice (p=0.003, n=41), specialist palliative home care team (p<0.001, n=76), palliative care unit (p<0.001, n=297), home hospice service (p=0.033, n=12), and the GP (p=0.009, n=179).

Table 3a: Informants’ overall satisfaction with care provided by health and social care practitioners in the last year of life

		“Overall, how would you rate the care he/she got in the last year of life?”			
		Good	**Rather good**	**Rather bad**	**Bad**
Care setting	***N*[a]**	***n (%)***	***n (%)***	***n (%)***	***n (%)***
Hospice	64	57 (89.1)	5 (7.8)	0 (0)	2 (3.1)
Specialist palliative home care team	129	112 (86.8)	13 (10.1)	2 (1.6)	2 (1.6)
Hospital (doctor): Palliative care unit	89	61 (68.5)	22 (24.7)	3 (3.4)	3 (3.4)
Hospice service	19	13 (68.4)	6 (31.6)	0 (0)	0 (0)
General practitioner	282	160 (56.7)	75 (26.6)	36 (12.8)	11 (3.9)
Care home	72	36 (50)	26 (36.1)	10 (13.9)	0 (0)
Outpatient specialists	229	109 (47.6)	76 (33.2)	30 (13.1)	14 (6.1)
Nursing service	146	69 (47.3)	59 (40.4)	15 (10.3)	3 (2.1)
Hospital (doctor): General ward/ICU	208	86 (41.3)	76 (36.5)	26 (12.5)	20 (9.6)

[a] Number of patients for whom the corresponding question was responded

ICU: Intensive care unit.

Table 3b: Comparison of informants’ overall satisfaction with acute hospital care versus other health and social care practitioners

	Acute hospital care (general ward/ICU) vs. other care setting[a]	
Care setting	***n***	***p-value*[b]**

Hospice	41	0.021[b]
Specialist palliative home care team	76	< 0.001[b]
Hospital (doctor): Palliative care unit	297	< 0.001[c]
Hospice service	12	0.268[b]
General practitioner	179	0.069[b]
Care home	52	0.543[b]
Outpatient specialists	135	1.0[b]
Nursing service	101	0.679[b]

[a] Compares informant's overall rating of the last hospital stay (doctor) in acute hospital setting (general ward or ICU) with the overall rating of every other care setting (e.g. hospital general ward/ICU vs. hospice).
[b] p-values are adjusted using Bonferroni correction for multiple comparisons.
[c] Wilcoxon signed-rank test for paired samples; comprises patients who experienced both forms of care.
[d] Mann-Whitney-U-Test; comprises patients who either received care in a hospital general ward/ICU or in a palliative care unit.
ICU: Intensive care unit

Determinants of satisfaction with care in an acute hospital setting

Since care provided by general hospital wards and ICUs were rated worst compared to all other health and social care practitioners in the last year of life, we explored the determinants of satisfaction with care delivered in these hospital wards and units. Table 4 shows the results of the multivariable logistic regression analysis. Two variables were found to associate satisfaction with hospital care while all other variables did not reach significance any more. First, the model indicated that the feeling that the patient was treated with respect and dignity by the doctor was associated with an almost 24-fold increase in the likelihood of being satisfied. Second, the impression that the hospital worked well together with other services outside the hospital was associated with an 8-fold increase of being satisfied.

Table 4: Logistic regression analysis of satisfaction with hospital care

Variable	*OR*	*(95% CI)*	*p-value*
Respect and dignity by the hospital doctor	23.80	(7.503 - 75.498)	<0.001
Hospital worked well together with other services outside the hospital	8.37	(2.141 - 32.71)	0.002

Number of cases = 124; cases correctly classified = 85.5%; AUC = 0.904

DISCUSSION

Principal findings

This study is the first to our knowledge to set up a pragmatic PDSA cycle to improve regional care in the last year of life. Embedded in a regional health services research and development structure, we comprehensively analysed patient experiences with care in the last year of life from the bereaved relatives' perspectives. For symptom control both home as well as acute hospital setting was rated the most poorly. Hospitals were reported as the main player for diagnosing a progressive condition, for being involved in most transitions during the last year of life, and being the most frequent place of death despite all home palliative and hospice services available in Cologne. Yet, satisfaction was lowest with care provided in an acute hospital setting, which was determined by the feeling of not being treated with respect and dignity and the impression that hospitals did not work well together with other services. Based on this first step of the PDSA cycle, two interventions were developed to continue the cycle.

Strengths and weaknesses

Most end-of-life care studies focus on a single care setting or are restricted to the dying phase, the last weeks of life or an underlying diagnosis. VOICES surveys include multiple settings to disaggregate findings according to specific setting type. Nevertheless, the instrument only evaluates the last three months of life.[29] Within this study, we utilised an adapted German version of the VOICES-SF, which was expanded to the last twelve months of life and included the communication of a life-limiting diagnosis. This instrument enables the reconstruction of the entire last year of life of patients, irrespective of the underlying diagnosis, to assess the provision and quality of care of all health and social care practitioners involved in patients' care. Our findings demonstrate the feasibility of collecting patient experiences reported by proxy-respondents across multiple care settings.

In Germany there is no national register available that could be used to identify participants. Therefore, a population-based survey was not feasible and the sample of decedents represented in this study was a purposive sample. Due to the recruitment strategy, patients from palliative care services are overrepresented. Nevertheless, it appropriately reflected the age and gender distribution of people dying in the City of Cologne.[41, 42]

We used a retrospective research design and asked bereaved relatives to act as proxies for the deceased patients. Relatives' reports of care experiences after the death of a loved one are an important outcome measure to determine the quality of end-of-life care.[14] This method is, of course, not without its limitations, especially in relation to memory, the impact of bereaved relatives' feelings, and the concordance between patient and proxy reports.[43, 44] A few studies examined these concerns and found that respondents were more accurate in recalling salient events and that satisfaction was mainly determined by service characteristics.[45, 46] A review on the validity of proxies' responses found that the level of agreement was good on service evaluations and observable symptoms, but lower for subjective symptoms such as pain.[47] The retrospective approach has a long history in the conducting of end-of-life-care research. It bypasses the difficult task of identifying the terminally ill, avoids putting an additional burden on very sick participants, and minimises missing data due to poor functional status. It furthermore creates a clear time frame for the purpose of comparing settings of care.[48]

The present study was conducted in Cologne, a city with one million inhabitants in Germany. It is not clear whether these results are transferable to other regions, rural as well as urban areas. Nevertheless, this study describes a pragmatic template based on patient experiences (PDSA cycle) which can be used to determine improvement priorities by other regions.

Comparison with existing literature

We found substantial differences in the reported satisfaction with care depending on the care setting. Informants were significantly more satisfied with quality of care provided in hospices compared to other care settings. Unfortunately, only a small number of patients will ever be admitted to hospice. In Germany, approximately 5% of patients, most of them cancer patients, die in hospice.[49] In the present study, home was the place where people spent most of their time during their last year of life. Informants reported of insufficient symptom control when being cared for at home. Reasons may include a lack of home care provider expertise, limits on service allocation, fragmentation of multidisciplinary services, and a considerable workload for many family practitioners with regards to home visit frequency and duration.[3, 10, 50-52] Hospitals were the most frequent place of death, with the highest levels of dissatisfaction. These results are similar to those from other VOICES studies carried out in Western countries.[1, 3, 32, 34] Previous studies also identified psychosocial rather than physical factors leading to dissatisfaction with care. A lack of personal care and dignity has been reported to cause patients to feel “devalued” or “dehumanised”.[53] Being involved in decisions and discussing any worries were also described as predictors of satisfaction with hospital care.[38] International studies have shown that there is still a discrepancy between current best practice recommendations and observed clinical reality; for example with regard to the recognition of a patient’s transition into the last year of life, identifying a patient’s palliative care needs, and aspects of shared decision making.[54] Reasons for this may lie in the obvious life-saving culture of hospitals where the norm is to prevent death by whatever means are necessary. Furthermore, it may also be due to the increasing time and cost pressure put on hospitals without these institutions having established standards for patients who will die within the foreseeable future.[55] Since almost 30% of all hospital patients are expected to be in their last year of life,[56] our findings stress the importance of a further integration of palliative care into acute care hospitals. Strategies for integrating palliative care into a country's health care system have been developed. In 2007 the World Health Organization (WHO) published a public health strategy that includes advice and guidelines for governments on priorities and how to implement national palliative care programmes.[57] Furthermore, international experts in palliative care and cancer care formulated written statements regarding how integrated palliative care can be operationalised.[58] In Germany, the evidence-based guideline “*Palliative care”* was published in 2015 to promote quality end-of-life care by all healthcare professionals. This palliative care guideline presents the fundamental principles of palliative care which, in organ specific guidelines, would be repetitive and/or not able to be dealt with in a comprehensive manner.[7]

Implications and future research

In a regional working group on improvement of care in the last year of life, following those data, as regional priority for action improvement of care in acute hospitals was targeted. Two new projects have started, first how to recognise and communicate a limited life span (“Acute Hospital Program” by the Gold Standards Framework), and second how to improve care during the dying phase according to quality indicators of our national guideline [7, 59]. Results and further improvement projects will be discussed in this regional working group, and repeating this survey in two years will be able to – hopefully - measure regional achievements. This study starting a PDSA cycle can therefore serve as an example for determining regional improvement priorities based on patient experiences.

DECLARATIONS

Contributors: RV and GD are joint first authors and act as guarantors. RV, JS and CR are principal investigators and responsible for the study design, project management, data analysis and dissemination. GD and NiS designed the survey instrument and collected data. GD cleaned and analysed data. SH, SP, NaS and HP contributed to study design, data analysis and dissemination. HP is principal investigator of CoRe-Net. NaS coordinates CoRe-Net. All authors read and approved the final manuscript.

Ethics 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.

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Collaborators: The CoRe-Net Co-applicants: Professor Dr Christian Albus, Department of Psychosomatics and Psychotherapy, Faculty of Medicine (FM), University Hospital Cologne (UHC); Professor Dr Lena Ansmann, Department of Health Services Research, School of Medicine and Health Sciences, Carl von Ossietzky University Oldenburg; Professor Dr Frank Jessen, Department of Psychiatry and Psychotherapy, FM, UHC; Professor Dr Ute Karbach, Sociology in Rehabilitation, Faculty of Rehabilitation, Technical University Dortmund; Professor Dr Ludwig Kuntz, Department of Business Administration and Health Care Management, Faculty of Management, Economics and Social Sciences (FMESS), University of Cologne (UoC); Dr Ingrid Schubert, PMV Health Care Research Group, FM, UoC; Professor Dr Frank Schulz-Nieswandt, Institute for Sociology and Social Psychology, FMESS, UoC; Professor Dr Stephanie Stock, Institute for Health Economics and Clinical Epidemiology, FM, UHC.

Data sharing: Data are available upon reasonable request from the corresponding author.

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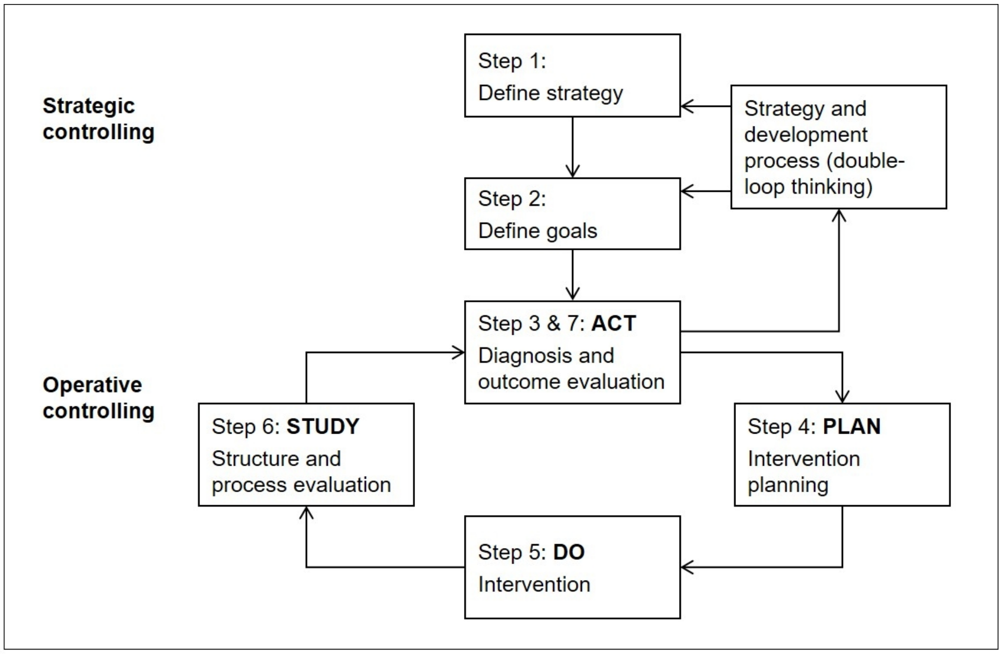
FIGURES

Figure 1: Strategic learning process framed on the PDSA cycle

(based on Pfaff and Zeike (2019))

Figure 2: Care settings in the last year of life in Cologne (N=255)



Based on Pfaff and Zeike (2019).[22]

Figure 1: Strategic learning process framed on the PDSA cycle (based on Pfaff and Zeike (2019))

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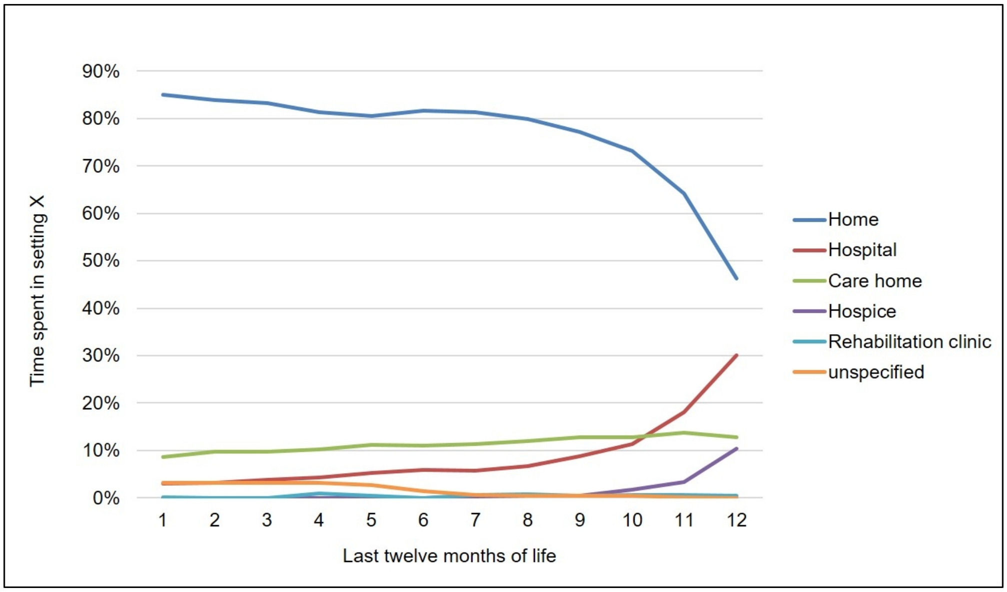

Figure 2: Care settings in the last year of life in Cologne (N=255)

111x65mm (300 x 300 DPI)

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1, 2
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3, 4
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5,6
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6
Bias	9	Describe any efforts to address potential sources of bias	6
Study size	10	Explain how the study size was arrived at	5,6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	7
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	7
		(*b*) Describe any methods used to examine subgroups and interactions	7
		(*c*) Explain how missing data were addressed	7
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	/
		(*e*) Describe any sensitivity analyses	/
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7,8
		(b) Give reasons for non-participation at each stage	7,8
		(c) Consider use of a flow diagram	/
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	8,9
		(b) Indicate number of participants with missing data for each variable of interest	9-14
Outcome data	15*	Report numbers of outcome events or summary measures	9-14
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	12-14

		(*b*) Report category boundaries when continuous variables were categorized	/
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	/
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	/
Discussion			
Key results	18	Summarise key results with reference to study objectives	14
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	14,15
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14,15
Generalisability	21	Discuss the generalisability (external validity) of the study results	14,15
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	16

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.