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Presence at the time of death and factors associated with dying alone: A nationwide registry study

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ABSTRACT

This study used data from the Swedish Register of Palliative Care, supplemented with questions, to investigate presence at the time of death and explore factors associated with dying alone. The sample consisted of 10,574 patients who had died an expected death, of whom 77% had someone present at the time of death. Only 19% had expressed a wish regarding the presence of others; among those who had not, the odds of dying alone were higher. In 93%, family members had been informed that death was imminent; when they had not been informed, the odds of the patient dying alone was higher. When patients died alone, the time since someone was last present ranged from between one minute to more than 60 minutes. Furthermore, the absence of a documented medical decision regarding transition to end-of-life palliative care and higher age were associated with higher odds of dying alone.

Introduction

The concept of a "good death" was first defined by Weisman as "a situation in which everyone knows and accepts the approach of death and addresses the social, emotional, and material concerns of the dying person" (Weisman, 1988). Since then, the concept has been widely explored, and several factors have been identified as important, including symptom control, clear decision-making, a sense of closure, being seen and recognized as a person, preparation for death, and the ability to continue giving to others (Krikorian et al., 2020). One recurrent component in descriptions of a good death is not dying alone. Cicely Saunders, the founder of the modern hospice movement, initiated her work to develop end-of-life care based partly on her earlier experience of caring for a patient who had died alone in an acute care setting. Subsequently, the importance of preparation for death, for example through clear decision-making, information, and end-of life conversations, has been recognized as a means of reducing the risk of persons dying alone (Clark, 2008).

The importance of having someone present at the time of death was particularly highlighted during the COVID-19 pandemic. Several studies during this period showed that many people died alone, resulting in frustration, grief, and stress among both healthcare professionals and family members (Bloomer et al., 2023; Hanna et al., 2021; Selman et al., 2021; Strang et al., 2020). Few situations underscore the importance of relationships as strongly as dying and death. However, even outside the context of a pandemic, family members and friends may not have the possibility to be present, and not all patients have family or friends. In such cases, healthcare professionals can offer a comforting presence. Ways of being present include listening, focusing attention on the person, being still, and accepting silence. Presence may also

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involve practical actions, for example holding a phone or a tablet for the patient, thus enabling family members to be virtually present (Falk-Rafael, 2020).

In theory, a "good death" is understood as a death that is not faced alone, is anticipated and planned, and is consistent with the individual's preferences being determined through a process of informed decision-making (Clark, 2002; Gott et al., 2019). However, there is a need for more knowledge about presence at the time of death in practice and across different care settings.

Aim and research questions

The aim of this study was to investigate presence at the time of death and to explore factors associated with dying alone. The following research questions were addressed:

1. How many patients had someone present at the time of death?
2. Had the patient expressed a wish regarding the presence of another person at the time of death (i.e., to have someone present or to be alone)?
3. Had family members been informed that death was imminent?
4. When a patient died alone, when was someone last present with the patient?
5. Which care-related and demographic factors were associated with dying alone?

Methods

Design and data source

This nationwide registry study utilized data reported to the Swedish Register of Palliative Care, v 2024, (SRPC) (supplementary file 1). The SRPC has been systematically used in Sweden since 2005 and is an end-of-life registry including data on the quality of care, primarily during the last week of life. After a patient has died, healthcare professionals complete the web-based SRPC questionnaire comprising approximately 30 questions regarding care during the last week of life, along with add-on questions. Of all deaths in Sweden, 60% are registered in SRPC, with rates varying by place of death. In specialized palliative care settings more than 95% of deaths are registered, in nursing homes 74%, in hospitals 52%, and for deaths occurring in patients' own homes the registration rate is 42%. Further information about the development and the validity of the SRPC can be found elsewhere (Lundström et al., 2012; Martinsson et al., 2017). Researchers have the opportunity to propose up to three specific add-on questions in areas where further knowledge is needed. Once the questions have been approved by the register board, researchers may apply for data by submitting a research plan and a copy of the ethical approval decision. The add-on questions are included in the register for a period of three months. The present study used data reported in the SRPC for patients who had died an expected death between 1 July and 30 September 2025, including three add-on questions regarding presence at the time of death. The study was approved by the Swedish Ethical Authority (No. 2024-08460-01). No informed consent was obtained as all patients were deceased.

Study variables

The add-on questions regarding presence at the time of death (supplementary file 2) came at the end of the original questionnaire and corresponded to research questions 2–4: 2) whether the patient had expressed a wish regarding the presence of others at the time of death, 3) whether family members were informed about the imminent death, and 4) in cases of dying alone, when someone was last present with the patient. In addition, an option to provide free-text comments was available at the end of the questionnaire. In addition to the add-on questions, the following variables were extracted from the SRPC: place of death, (home, specialized in-patient palliative care, nursing home, or hospital), documented medical decision regarding transition to end-of-life palliative care, documented individual end-of-life care plan, time since the latest examination by a physician, main diagnosis, age, and sex.

Statistical analyses

Descriptive statistics were used to present the distribution of the study variables; means and standard deviations were used for continuous variables, whereas numbers and percentages were used for categorical variables. The Pearson chi-square test was used to compare study variables by place of death.

To explore factors associated with dying alone, univariable and multivariable binary logistic regression analyses were conducted. The aim of these analyses was explanatory (etiological), that is to examine adjusted associations between potential risk factors and the outcome rather than to develop a prediction model. Dying alone was used as the outcome variable

(0 = not dying alone, 1 = dying alone). Missing data in the outcome variable (n = 574) were excluded from the analyses. The predictor variables included were selected based on their theoretical and clinical relevance and comprised place of death, patients' wishes regarding the presence of someone at the time of death, information to family members that death was imminent, a documented medical decision about transition to end-of-life palliative care, individual end-of-life care plan, time since last examination by a physician, cancer diagnosis, age, and sex. Age was included as a continuous variable (10-year increase), whereas all other variables were treated as categorical. The predictor variable "wishes" was recorded, with the categories "Family members" and "Healthcare professionals" combined into "Wishes regarding presence". All categorical variables, except sex, comprised more than two categories and were therefore dummy-coded, with one category designated as the reference. Most categorical variables included a category for unknown values. To preserve statistical power and avoid listwise deletion, this category was retained in the analyses but was not interpreted. In the first step, each predictor variable was examined separately using univariable models to describe crude associations. In the second step, all predictor variables were included simultaneously in a multivariable model to estimate associations adjusted for the other included variables. The results from the multivariable model are interpreted as adjusted associations rather than causal effects. The results are presented as odds ratios (ORs) with corresponding 95% confidence interval (CI).

The level of statistical significance was set at $p < 0.05$. All analyses were conducted in R version 4.6.1 (R Foundation for Statistical Computing, Vienna, Austria), including the following packages: gmodels (version 2.19.1), janitor (version 2.2.1), summarytools (version 1.1.5), and tidyverse (version 2.0.0).

Free-text comments

Although the free-text comments were concise and provided clinical examples, they were too limited to allow for meaningful qualitative analysis. They are therefore presented as illustrative examples.

Results

Sample characteristics

Altogether, the sample consisted of 10,574 patients who had died an expected death. The mean age was 82 years (SD = 11), 54% were women, and 40% had a cancer diagnosis. The place of death was nursing home (47%), hospital (19%), specialized in-patient palliative care (17%), or at home (17%). For 92%, there was a documented medical decision regarding transition to end-of-life palliative care. More information is presented in Table 1.

Presence, wishes, and information about imminent death

Presence at the time of death

In 77% of all expected deaths, family members or healthcare staff were present with the patient in the same room at the time of death. There was a significant difference between presence by place of death, ranging from 85% at home, to 78% in nursing home, 75% in specialized in-patient care, and 69% in hospitals ($p < 0.001$) (Table 2).

Wishes about presence

In the total sample, 19% (n = 1,980) of the deceased were reported to have expressed a wish regarding presence at the time of death (Table 2). Of these, 81% had wished to have a family member present: "*Had a wish to die close to his wife. A decision regarding a place at his wife's residential care facility was made promptly, so that his wish was met*" and "*The patient had expressed a wish for her daughter to be present during the final period of life, which she was during the last days before the patient died*". Some of the deceased (16%) had wished healthcare staff to be present and a few (3%) had expressed a wish to be alone: "*Wished to manage independently and not burden family members or healthcare professionals*".

According to the reports, a majority of the patients had not expressed a wish about presence at the time of death (42%); however, the comments indicated that healthcare professionals or family members sometimes interpreted a potential wish: "*The presence of a family member or healthcare professionals had a significant impact on the patient, he became much calmer*" and "*Advanced dementia, we assumed from the body language that she wanted company. She became calm with touch and the presence of someone*".

For 40% it was not known whether wishes had been expressed: "*The patient was unresponsive throughout the entire care period following a stroke*" and "*A patient with multimorbidity and a dementia diagnosis, had difficulty speaking for themselves*". There was a significant difference between reported wishes by place of death, ranging from 38% at home, 19% in specialized palliative in-patient care, 14% in nursing homes, and 10% in hospital ($p < 0.001$).

Table 1. Sample characteristics by place of death.

		Place of death			
	All, n = 10,574	Home, n = 1,770	Hospital, n = 2,030	Nursing home, n = 4,982	Specialized inpatient palliative care, n = 1,792
Age (years), Mean (SD)	82.4 (11.1)	79.6 (12.3)	80.7 (10.7)	86.5 (8.4)	76.0 (12.1)
Sex, n (%)					
Women	5,682 (53.7)	842 (47.6)	934 (46.0)	2,962 (59.5)	944 (52.7)
Men	4,892 (46.3)	928 (52.4)	1,096 (54.0)	2,020 (40.5)	848 (47.3)
General home care, n (%)[a]					
Yes		1,121 (63.3)			
No		649 (36.7)			
Missing		0			
Specialized palliative care, (%)[a]					
Yes		868 (49.0)			
No		902 (51.0)			
Missing		0			
Cancer diagnosis, n (%)					
Yes	4,245 (40.1)	1,152 (65.1)	613 (30.2)	1,071 (21.5)	1,409 (78.6)
No	6,329 (59.9)	618 (34.9)	1,417 (69.8)	3,911 (78.5)	383 (21.4)
Documented medical decision about end-of-life palliative care, n (%)					
Yes	9,762 (92.3)	1,683 (95.1)	1,721 (84.8)	4,597 (92.3)	1,761 (98.3)
No	657 (6.2)	68 (3.8)	266 (13.1)	296 (5.9)	27 (1.5)
Unknown	155 (1.5)	19 (1.1)	43 (2.1)	89 (1.8)	4 (0.2)
Individual care plan, n (%)					
Yes	7,876 (74.5)	1,393 (78.7)	891 (43.9)	4,085 (82.0)	1,507 (84.1)
No	2,171 (20.5)	290 (16.4)	903 (44.5)	713 (14.3)	265 (14.8)
Unknow	527 (5.0)	87 (4.9)	236 (11.6)	184 (3.7)	20 (1.1)
Latest examination by a physician, n (%)					
Days	6,604 (62.5)	868 (49.0)	2,005 (98.8)	1,957 (39.3)	1,774 (99.0)
Weeks	2,559 (24.2)	624 (35.3)	6 (0.3)	1,920 (38.5)	9 (0.5)
Months	1,213 (11.5)	246 (13.9)	2 (0.1)	963 (19.3)	2 (0.1)
Unknown	198 (1.9)	32 (1.8)	17 (0.8)	142 (2.9)	7 (0.4)

[a]Only reported for deaths at home.

Table 2. Presence, wishes, and information about imminent death by place of death.

		Place of death				
	All, n = 10,574	Home, n = 1,770	Hospital, n = 2,030	Nursing home, n = 4,982	Specialized inpatient palliative care, n = 1,792	p-value[a]
Someone present at the time of death, n (%)						<0.001
Yes	8,140 (77.0)	1,500 (84.7)	1,406 (69.3)	3,885 (78.0)	1,349 (75.3)	
No	1,860 (17.6)	215 (12.1)	399 (19.7)	882 (17.7)	364 (20.3)	
Unknown	574 (5.4)	55 (3.1)	225 (11.1)	215 (4.3)	79 (4.4)	
Wishes regarding presence at the time of death, n (%)						<0.001
Family members	1,603 (15.2)	573 (32.4)	184 (9.1)	527 (10.6)	319 (17.8)	
Healthcare professionals	314 (3.0)	77 (4.4)	13 (0.6)	213 (4.3)	11 (0.6)	
Self	63 (0.6)	20 (1.1)	6 (0.3)	28 (0.6)	9 (0.5)	
No wish	4,406 (41.7)	529 (29.9)	631 (31.1)	2,435 (48.9)	811 (45.3)	
Unknown	4,188 (39.6)	571 (32.3)	1,196 (58.9)	1,779 (35.7)	642 (35.8)	
Information about imminent death to family members, n (%)						<0.001
Yes	9,785 (92.5)	1,673 (94.5)	1,759 (86.7)	4,608 (92.5)	1,745 (97.4)	
No	333 (3.1)	47 (2.7)	70 (3.4)	196 (3.9)	20 (1.1)	
No family members	121 (1.1)	12 (0.7)	20 (1.0)	80 (1.6)	9 (0.5)	
Unknown	335 (3.2)	38 (2.1)	181 (8.9)	98 (2.0)	18 (1.0)	
Time since someone was last present with the patient, n (%) [b]						<0.001
1–5 minutes	322 (17.3)	34 (15.8)	77 (19.3)	151 (17.1)	60 (16.5)	
6–10 minutes	326 (17.5)	14 (6.5)	78 (19.5)	149 (16.9)	85 (23.4)	
11–30 minutes	445 (23.9)	25 (11.6)	110 (27.6)	198 (22.4)	112 (30.8)	
31–60 minutes	334 (18.0)	37 (17.2)	74 (18.5)	159 (18.0)	64 (17.6)	
> 60 minutes	433 (23.3)	105 (48.8)	60 (15.0)	225 (25.5)	43 (11.8)	

[a]Pearson chi-square test.
[b]Only for those dying alone (n = 1,860).

Table 3. Factors associated with dying alone based on binary logistic regression analyses (n = 10,000).

	Univariable logistic regression models			Multivariable logistic regression model		
Exploratory variables	OR	95% CI	p-value	OR	95% CI	p-value
Place of death: Home	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.
Place of death: Hospital	1.98	1.65, 2.38	< 0.001	1.68	1.36, 2.07	< 0.001
Place of death: Nursing home	1.58	1.35, 1.86	< 0.001	1.27	1.07, 1.51	0.008
Place of death: Specialized inpatient palliative care	1.88	1.57, 2.27	< 0.001	1.88	1.53, 2.31	< 0.001
Wishes regarding presence	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.
Wishes to die alone	16.00	9.44, 27.53	< 0.001	14.82	8.65, 25.77	< 0.001
No wishes regarding presence	3.10	2.60, 3.71	< 0.001	2.69	2.25, 3.24	< 0.001
Unknown	2.52	2.11, 3.03	< 0.001	2.15	1.79, 2.59	< 0.001
Information to family members	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.
No information to family members	4.33	3.43, 5.46	< 0.001	3.22	2.48, 4.18	< 0.001
No family members	3.24	2.19, 4.75	< 0.001	3.24	2.16, 4.82	< 0.001
Unknown	1.46	1.05, 1.99	0.020	1.19	0.85, 1.65	0.293
Documented medical decision about end-of-life palliative care	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.
No documented medical decision about end-of-life palliative care	2.35	1.96, 2.80	< 0.001	1.52	1.21, 1.90	< 0.001
Unknown	1.28	0.84, 1.89	0.240	1.06	0.68, 1.60	0.787
Individual care plan	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.
No individual care plan	1.45	1.29, 1.64	< 0.001	1.06	0.92, 1.23	0.413
Unknown	1.10	0.86, 1.38	0.442	1.08	0.84, 1.39	0.521
Examination by physician in days	Ref.	Ref.	Ref.	Ref.	Ref.	Ref.
Examination by physician in weeks	0.91	0.81, 1.03	0.148	1.07	0.92, 1.24	0.385
Examination by physician in months	1.00	0.85, 1.17	0.982	0.97	0.81, 1.17	0.785
Unknown	1.07	0.72, 1.56	0.724	1.05	0.69, 1.56	0.826
No cancer diagnosis	1.11	1.00, 1.23	0.053	0.92	0.81, 1.04	0.182
Age (10-year increase)	1.09	1.04, 1.15	< 0.001	1.13	1.07, 1.19	< 0.001
Male sex	1.04	0.94, 1.15	0.462	1.02	0.92, 1.14	0.678

Information to family members

In the majority of all deaths (93%), family members had been informed that death was imminent (Table 3). There was, however, a significant difference regarding whether information had been provided in relation to place of death, ranging from 97% in specialized palliative in-patient care, 95% at home, 93% in nursing homes and 87% in hospital ($p < 0.001$). Free-text comments reflected different care situations. For example, a comment made about a patient who died alone was: "*Family members were informed only one hour before the patient died*". Another comment illustrated situations when death was expected but occurred rapidly: "*Family members could not be informed as the death was not expected to occur so rapidly*".

When dying alone

Among the patients who had died alone (18%), someone had last been present with the patient: 1–5 minutes earlier (17%), 6–10 minutes earlier (18%), 11–30 minutes earlier (24%), 31–60 minutes earlier (18%), or more than 60 minutes earlier (23%). There was a statistically significant difference between place of death and the time since someone was last present with the patient ($p < 0.001$). Time intervals shorter than ≤ 30 minutes were most common in specialist inpatient palliative care at home (71%) and in hospital (66%), while longer intervals > 60 minutes were most common at home (49%) and in nursing homes (26%) (Table 2). Free-text comments described situations in which deaths occurred without anyone present. For example, some comments referred to deaths that were sudden despite being expected: "*The patient died suddenly without signs of distress, pain or nausea and died peacefully in the armchair in his room*" and "*The day before, the patient was able to drink independently and had not required injections during the previous 24 hours, and therefore no bedside vigil was arranged despite ongoing palliative care*". Other comments reflected deaths occurring during shifts of staff or at night: "*The time of death occurred between two close visits*" and "*Passed away when the night vigil ended and the day staff took over, therefore no one was present at the actual time of death*". In addition, comments illustrated deaths occurring during very brief absences: "*The daughter had stepped outside the room for a minute and when she returned, the patient had passed away*"; "*Family members left the room to get coffee and were absent for approximately two minutes. The patient died during that time*" and "*The wife was in the bathroom at the time of death*".

Care-related and demographic factors associated with dying alone

Care related and demographic factors were overall significantly associated with dying alone. In the univariable logistic regression models, the odds of dying alone were higher when death occurred in hospital

(OR = 1.98, 95% CI = 1.65, 2.38), in a nursing home (OR = 1.58, 95% CI = 1.35, 1.86), and in specialized palliative in-patient care (OR = 1.88, 95% CI = 1.57, 2.27) compared to dying at home. The odds of dying alone were higher among patients who had wished to do so (OR = 16.00, 95% CI = 9.44, 27.53) and among patients who had not expressed any wish regarding presence at the time of death (OR = 3.10, 95% CI = 2.60, 3.71). The odds of dying alone were also higher among patients whose family members had not been informed that death was imminent (OR = 4.33, 95% CI = 3.43, 5.46) and among those without family members (OR = 3.24, 95% CI = 2.19, 4.75) compared to patients whose family members had received such information.

When there was no documented medical decision regarding transition to end-of-life palliative care, the odds of dying alone were significantly higher (OR = 2.35, 95% CI = 1.96, 2.80) compared to when such a decision was documented.

Patients without an individual end-of-life care plan had higher odds of dying alone (OR = 1.45, 95% CI = 1.29, 1.64) compared to patients with such a care plan. Finally, the odds of dying alone increased with age (OR = 1.09, 95% CI = 1.04, 1.15) (Table 3).

The multivariable logistic regression model showed largely similar patterns to the univariable analyses, with one exception. Not having an individual care plan was no longer significantly associated with dying alone after adjustment for other variables in the model (Table 3).

Discussion

This nationwide register-based study including 10,574 patients registered in the SRPC, found that a majority (77%) of those who had died an expected death had someone present at the time of death, whilst this information was unknown for 18%. Consequently, almost one in five patients died alone, and the place of death was of significance. Only 19% of the patients had expressed a wish about having someone present, and among those who had not, the odds of dying alone were higher. For 93% of patients, family members had been informed that death was imminent, and when such information had not been provided, the odds of dying alone were higher. When patients died alone, the time since someone was last present ranged from one minute to more than 60 minutes. Furthermore, the absence of a documented medical decision regarding transition to end-of-life palliative care and older age were associated with the odds of dying alone.

We found that most of the patients (77%) in our study had someone present at the time of death, although there were variations in percentage between hospitals, home care, specialized palliative inpatient care, and nursing homes. Although dying alone is often regarded as undesirable from the perspectives of policymakers, healthcare professionals, and the general public, people do still die alone. However, among older people living alone, dying alone does not necessarily need to be understood as problematic. Their concerns have instead been shown to focus more on how their death might affect family members and others than on the experience itself (Caswell & O'Connor, 2019). This aligns with another study suggesting that concerns about dying alone may be more pronounced among family members and healthcare professionals than among patients (Meier et al., 2016). Taken together, this indicates that perceptions of what constitutes a good death may vary, and the presence of family may be of greater importance to others than to the person who is dying.

According to SRPC reports, only a minority (19%) of the patients in our study had expressed a wish about presence at the time of death. Many had not expressed a wish and, importantly, a large proportion of the reports showed that it was unknown whether a wish had been expressed. This highlights the importance of creating opportunities for patients to discuss such preferences before death, ensuring that both patients and their family members have sufficient time to prepare for death. One way to facilitate patients in expressing their values, goals, and care preferences, as well as their wishes regarding family involvement, is through Serious Illness Conversations with healthcare professionals. These conversations provide a structure that may enable meaningful communications, not only about how patients want to live their remaining time but also how they wish to die (Baxter et al., 2024). However, research shows that healthcare professionals may find it challenging to identify who needs Serious Illness Conversations and that these conversations can be difficult, often requiring an established relationship (Morberg Jämterud & Sandgren, 2022). Furthermore, many hesitate to raise the topic of death and dying, fearing that doing so may diminish or take away the patient's hope. This may partly explain why there were so few registrations about wishes of presence at the time of death. An earlier study based on a review of the medical records of patients identified from the SRPC revealed that just over 60% of 249 patients with life-threatening illness, most in specialized palliative care settings, had communicated with healthcare professionals about

dying. On average, patients had two such conversations, with the first occurring approximately 53 days before death and the second approximately nine days before death (Tranberg et al., 2022). Healthcare professionals' own attitudes and discomfort regarding death are often barriers to Serious Illness Conversations (Pusa et al., 2024), suggesting that training in addressing sensitive topics could be beneficial.

In our study, a small minority (0.6%) were reported to have expressed a wish to be alone at the time of death. The Integrated Process Model of loss and grief (Guldin & Leget, 2024) describes a central existential tension between feeling alone and feeling connected to others. This tension becomes especially important during dying. This may mean that, for some persons, navigating this tension does not necessarily require physical presence with others at the time of death, but rather the ability to maintain meaningful bonds, seek support, and find ways to both hold on and let go during the illness. Opportunities to say goodbye, express love, or feeling that important things have been said may therefore meet the person's social and existential needs to the same extent as having someone present at the time of death.

A large majority of the patients' family members in our study had been informed that death was imminent. This is in line with a study assessing the care of patients dying from cancer across several countries which found that 87% of family members reported having been informed that death was likely to occur soon (Haugen et al., 2021). Our results indicate a strong association between information given to family members and dying alone. Another study in Sweden found that approximately half of family members had been contacted in time to enable them to be present at the time of death (O'Sullivan et al., 2021). However, around 8% had not been informed and described missing the opportunity to be present as upsetting. Further, 15% of the family members did not fully understand how imminently death would occur, which affected their ability to be present and contributed to feelings of being unprepared, as death occurred sooner than expected.

In media discourse, dying alone is often portrayed as a non-normative and stigmatized form of death (Nelson-Becker & Victor, 2020). This may lead to fear and shame among family members who are unable to, or choose not to, be present at the time of death. It is therefore important that healthcare professionals are aware of the normative idealization of death and dying, and remain open to the possibility that individuals may hold different views of what constitutes a good death, including differing preferences regarding presence at the time of death (Pollock et al., 2024). This also highlights that there might be a need to place less focus on the exact moment of death and instead talk about presence during dying. Meaningful conversations, opportunities for closure, and farewells may be equally or even more important. A study has shown that the opportunity to achieve such closure, rather than presence or absence, was associated with better outcomes in terms of depression and complicated grief among bereaved family members (Otani et al., 2017).

Our results point to the fact that both care-related and demographic factors are associated with the odds of dying alone. A documented end-of-life palliative care decision, the patient's wishes regarding presence, and information to family members are important. It can be challenging for healthcare professionals to shift care from a curative to a palliative focus, sometimes leading to delayed or undocumented end-of-life decisions (Lind et al., 2022), and thereby reducing opportunities for timely conversations about patients' wishes regarding care and dying. For nurses, when transitions are unclear or insufficiently discussed within the care team, it may become more challenging to interact and advocate for the patients and their family members (Lind et al., 2022).

Furthermore, the present study found that the odds of dying alone increased with age. Previous research among older persons suggests that, for some, dying alone may be perceived as less problematic than becoming dependent on others for care and support (Caswell & O'Connor, 2019). However, this stands in contrast to results from a survey among Danish older adults in which 69% reported concerns about dying alone and almost all (94%) wished to be involved in decisions about treatment and preferred place of death, indicating that dying is equally important as death. Despite this, nearly half had not documented their end-of-life preferences (Krarup et al., 2025).

Methodological considerations

This study is strengthened by its nationwide, register-based design and large sample size, which enabled the investigation of presence at the time of death and associated factors across several care contexts. However, it should be acknowledged that the SRPC is based on reports from healthcare professionals rather than direct clinical observations or interviews. It is possible that reporting whether a patient died alone may be perceived as sensitive. It also needs to be recognized that coverage differed considerably across settings and that there might be possible selection bias, with specialist palliative care being more represented than other contexts. It could therefore be

that the overall result does not give a true picture of the reality. In addition, the restriction to expected deaths registered over three months might also affect the generalizability of the findings.

Most categorical variables included a response option labeled "unknown", reflecting a lack of available information or documentation rather than true missing data. Although these categories were retained to preserve the full sample size in the logistic regression analyses, they are likely to be heterogeneous and not substantively meaningful. Their inclusion may therefore have influenced the estimated associations, and the results should be interpreted with some caution. In the multivariable binary logistic regression, all explanatory variables of interest were included simultaneously to estimate associations adjusted for other factors. However, this approach assumes that all included variables are relevant confounders for each association, which may not be the case. As a result, some estimates may be affected by overadjustment or adjustment for variables that lie on the causal pathway or are not true confounders. Thus, the results should be interpreted as adjusted associations rather than causal effects.

Conclusion

This Swedish nationwide registry study contributes knowledge about presence at the time of death. Although the majority of patients, regardless of place of death, have someone present at the time of death, almost one in five still die alone. Our results show that several aspects are of significance and that healthcare-related factors matter. The results highlight the importance of addressing end-of-life concerns proactively. It is crucial to take medical end-of-life palliative care decisions and document these, provide information to family members about imminent death, and to offer possibilities that enable patients to express their thoughts about dying and death, as well as their wishes regarding the presence of others.

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