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Understanding home ventilation patients' chosen place for their final moments – A study of association and experience.

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BACKGROUND

Advance Care Planning (ACP) documents an individual's healthcare preferences, including preferred place of death (POD) (HealthHub, 2021). Hospital deaths often require more medical resources than home or hospice death (Hyun et al., 2013). Identifying the preferred POD can point to gaps in the care journey to reduce hospital deaths. One group of patients that undertake ACP are patients on Home Mechanical Ventilation (HMV). HMV can improve symptoms in patients with motor neurone disease and prolong their survival, but it does not prevent disease progression (Wilson et al., 2024). One study examined the complexity and evolution of HMV patients' end-of-life decision-making, highlighting the importance of support from healthcare professionals in the ACP process (Wilson et al., 2024). Despite HMV posing a significant care and financial burden on patients and the health system (Tan et al., 2019), to our knowledge, there is little information on the patient factors that may influence the preferred POD for patients on HMV. Studies which have identified sociodemographic factors, patient experiences with illness and care, and access to resources as factors associated with POD preferences pertained mostly to patients with terminal cancer (Gomes et al., 2012; Thomas et al., 2004; Wales et al., 2018). Our study aims to identify patient factors that are associated with different POD preferences among patients on Tan Tock Seng Hospital's Home Ventilation and Respiratory Support Service (HVRSS).

METHODS

A retrospective cohort study was conducted. Data from decedents of HVRSS enrolled between 2009-2018 were extracted from an existing database. Decedents enrolled in HVRSS but did not complete their ACP were excluded. Preferred POD information available from ACPs of included subjects was categorised into preferring home death or healthcare institution death. Subject characteristics examined were selected from previous literature (Gomes et al., 2012; Thomas et al., 2004; Wales et al., 2018), and included (Table 1): Sociodemographic factors (e.g. gender, race, marital status, age of enrolment and age of death) ; experiences with illness and care (e.g. type of diagnosis, number of comorbidities and hospitalisation within 3 months prior to death); access to palliative care, medical social worker involvement, having paid caregiver, the number of paid caregiver available and the number of family living in the same house as the subject). STATA was used for the statistical analysis. Univariate statistical analysis was conducted to examine the relationships among the subject characteristics (Figure 1). Separate univariate tests were conducted based on the type of variable. Normality was assessed using the Shapiro-Wilk test. Independent T-test was conducted for subject characteristics that can be assumed as normal, while Mann-Whitney U test was conducted for subject characteristics that cannot be assumed as normal. Statistically significant characteristics were defined as having $p<0.1$ and are retained for multivariate analysis. Multivariate logistic regression was conducted for the retained characteristics (Table 2) to examine potential associations between these characteristics and preferred POD. Statistically significant characteristics were defined as having $p<0.05$. Patients' considerations and concerns relating to their POD preferences were also documented in the ACP and informed the interpretation of the quantitative results.

Table 1. Subject characteristics selected for univariate statistical test

Sociodemographic factors	Experiences with illness and care	Access to resources
Gender	Type of diagnosis	Access to palliative care
Race	Number of hospitalisations within 3 months prior to death	Medical social worker involvement
Marital status	Total number of comorbidities	Having paid caregiver
Age of enrolment		Number of paid caregiver available
Age at death		Number of family living in the same house as the subject

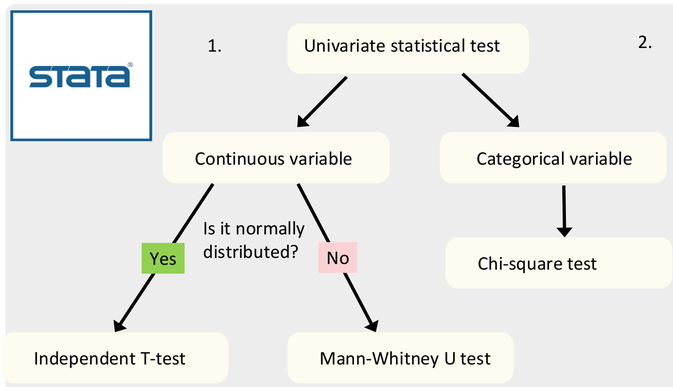

Figure 1. Univariate statistical tests conducted based on the type of variable, and whether normality can be assumed.

Table 2. Subject characteristics retained for multivariate logistic regression

Sociodemographic factors	Experiences with illness and care
Gender	Type of diagnosis
Race	Number of hospitalisations within 3 months prior to death
Marital status	
Age at death	

Multivariate logistic regression

RESULTS

A total of 52 HVRSS subjects were included in this study, with 38 subjects preferring home death and 14 subjects who indicated healthcare institution/s as their preferred POD (Figure 2). Overall, most subjects were male (n = 33, 63.5%) (Figure 2), aged 59.5 years (SD: 2.5 years) on average at enrolment (Figure 3). The enrolment age was slightly higher in those who preferred home death (60.7 years, SD: 17.2 years) as compared to those who preferred healthcare institution death 56.0 years (SD: 19.8 years) (Figure 3). Other subject characteristics examined are shown in table 3. From the univariate analysis, only the number of hospitalisation within 3 months prior to death and access to palliative care had significant differences between subjects preferring home death and preferring healthcare institution death (Table 3).

Multivariate logistic regression conducted for selected characteristics suggested that only the number of hospitalisation within 3 months prior to death was significantly associated with preferred POD (Table 1). An increase in hospitalisations was associated with 70% lower odds of preferring home death (OR: 0.30, p = 0.048, 95% CI: 0.09 – 0.99).

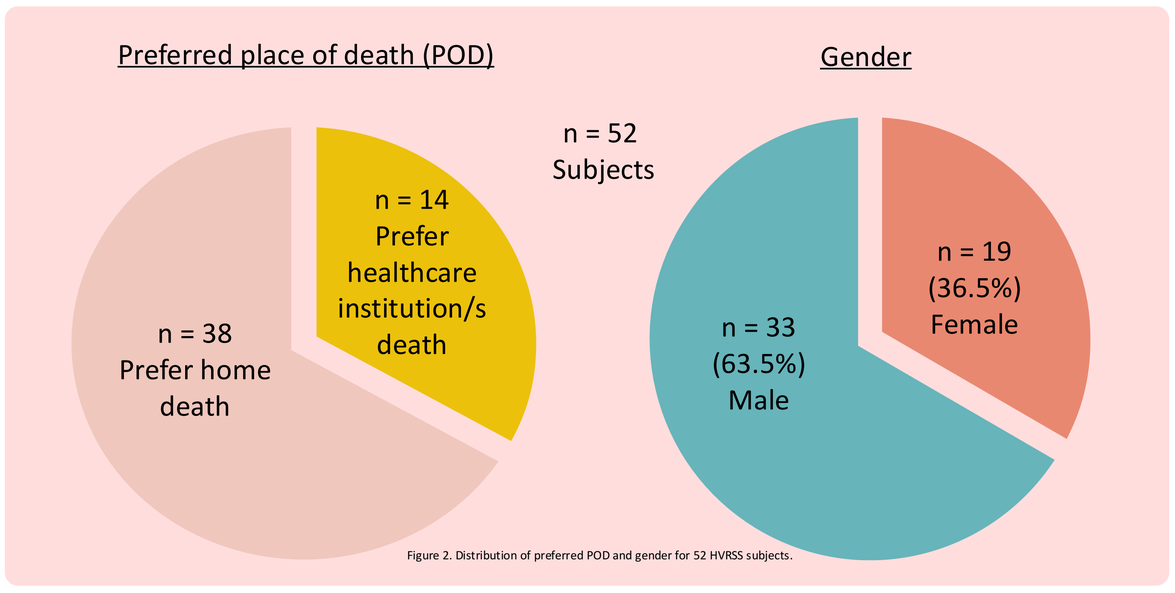

Figure 2. Distribution of preferred POD and gender for 52 HVRSS subjects.

RESULTS (CONTINUED)

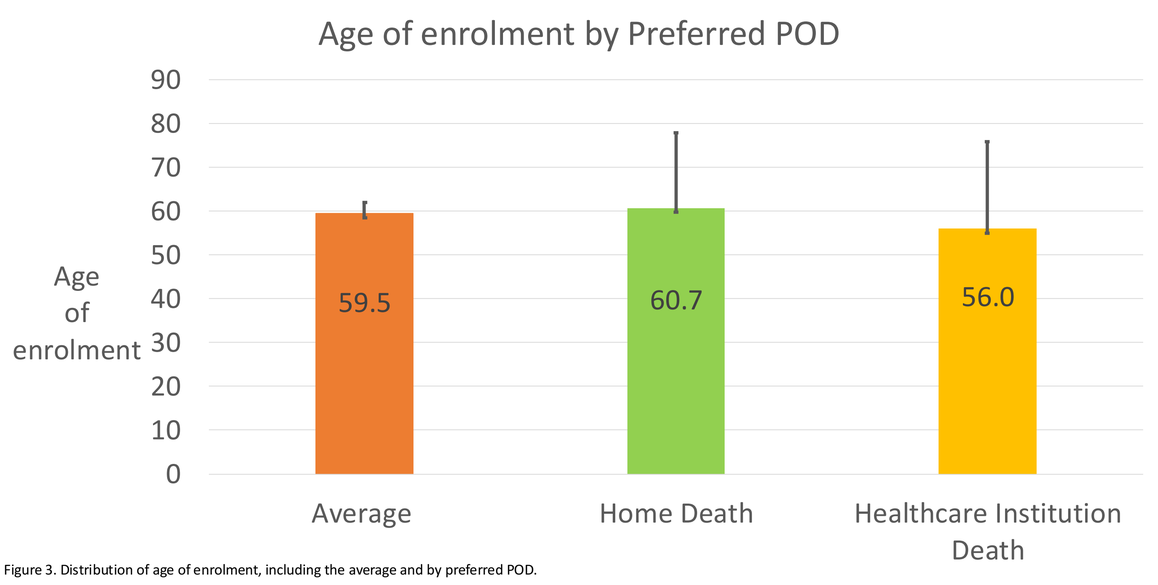

Figure 3. Distribution of age of enrolment, including the average and by preferred POD.

Table 3: Adjusted subject characteristics associated with preferred POD and odds ratio.

Subject characteristics	Overall (n = 52)	Home death (n = 38)	Healthcare institution death (n = 14)	P-value (Univariate test)	Odds ratio (95% Confidence Interval)	P-value (Logistic Regression)
Gender, n (%)				0.566[a]		
Female	19 (36.5)	13 (34.2)	6 (42.9)		0.861 (0.123 – 6.02)	0.880
Male	33 (63.5)	25 (65.8)	8 (57.1)		Reference	
Race, n (%)				0.139[a]		
Chinese	43 (82.7)	31 (81.6)	12 (85.7)		Reference	
Others	9 (17.3)	7 (18.4)	2 (14.3)		0.884 (0.117 – 6.70)	0.905
Marital status, n (%)				0.202[a]		
Married	32 (61.5)	26 (68.4)	6 (42.9)		Reference	
Single	11 (21.2)	6 (15.8)	5 (35.7)		0.319 (0.036 - 2.85)	0.306
Widowed	9 (17.3)	6 (15.8)	3 (21.4)		0.060 (0.002 - 1.46)	0.084
Age at death, mean (SD)	61.8 (17.9)	63.1 (17.2)	58.2 (19.9)	0.483[b]	1.08 (0.998 – 1.17)	0.055
Type of diagnosis, n (%)				0.828[a]		
Motor neurone disease	27 (51.9)	18 (47.4)	9 (64.3)		Reference	
Neuromuscular disease	7 (13.5)	5 (13.2)	2 (14.3)		36.8 (0.751 - 1810)	0.069
Spinal cord injury	5 (9.6)	4 (10.5)	1 (7.1)		1.41 (0.089 - 22.3)	0.808
Others	13 (25.0)	11 (29.0)	2 (14.3)		21.6 (1.09 – 428)	0.043*
Number of hospitalisation within 3 months prior to death, mean (SD)	0.6 (0.8)	0.4 (0.6)	0.9 (1.1)	**0.098**[b]	0.301 (0.092 – 0.988)	**0.048***
Total number of comorbidities, mean (SD)	4.4 (2.9)	4.5 (3.1)	4.1 (2.6)	0.827[b]	0.859 (0.584 – 1.26)	0.438

a = independent T-test, b = Mann-Whitney U test

DISCUSSION & CONCLUSION

Our findings can help healthcare professionals and policymakers better understand how people's experiences of illness and care, both at home and in hospital, influence end-of-life choices We found that increased hospitalisation is associated with a lower likelihood of preferring home death. This finding could reflect greater disease burden, suggesting current HMV treatment might be insufficient for a comfortable death at home. Family members may not then be confident enough with supporting their loved ones in their final days at home. Our study addresses an evidence gap for patients on HMV, which is a group of patients with very limited existing evidence on their end-of-life choices. The long study time frame improves reliability as it is less affected by short-term fluctuations, indicating that the ACP choices made truly reflect patients' choices. The limitations of our study includes a small sample size, which can limit the number of factors adjusted for in the multivariate logistic regression. Our analysis is also limited by characteristic selection and may not be all encompassing. The findings are also not generalizable to other types of patients given the focus on patients on HMV. Future work can examine the barriers families and caregivers face in caring for patients on HMV, with implications for the latter's POD; and how healthcare providers could ameliorate or overcome the barriers.

References:

1. Gomes, B., Calanzani, N., Gysels, M., Hall, S., & Higginson, I. J. (2013). Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliative Care, 12(1). https://doi.org/10.1186/1472-684x-12-7
2. Gomes, B., Higginson, I. J., Calanzani, N., Cohen, J., Deliens, L., Daveson, B. A., Bechinger-English, D., Bausewein, C., Ferreira, P. L., Toscani, F., Menaca, A., Gysels, M., Ceulemans, L., Simon, S. T., Pasman, H. R. W., Albers, G., Hall, S., Murtagh, F. E. M., Haugen, D. F., & Downing, J. (2012). Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. Annals of Oncology, 23(8), 2006–2015. https://doi.org/10.1093/annonc/mdr602
3. HealthHub. (2021). advance-care-planning. https://www.healthhub.sg/a-z/medical-and-care-facilities/advance-care-planning
4. Masefield, S., Vitacca, M., Dreher, M., Kampelmacher, M., Escarrabill, J., Paneroni, M., Powell, P., & Ambrosino, N. (2017). Attitudes and preferences of home mechanical ventilation users from four European countries: an ERS/ELF survey. ERJ Open Research, 3(2), 00015-2017. https://doi.org/10.1183/23120541.00015-2017
5. Min Woo Hyun, Kyung Hae Jung, Young Ho Yun, Young Eun Kim, Woo Jung Lee, Young Rok Do, Lee, K., Dae Seog Heo, Choi, J.-S., Kim, S., Heung Soo Kim, & Hyo Geun Choi. (2013). Factors Associated with Place of Death in Korean Patients with Terminal Cancer. 14(12), 7309–7314. koreascience.or.kr/article/JAKO201305981342402.pdf
6. Tan, G., Hse, L., Ni, B., Cheng, H., Wai, A., Ai Ching Kor, & Chan, Y. (2019). The pattern of use and survival outcomes of a dedicated adult Home Ventilation and Respiratory Support Service in Singapore: a 7-year retrospective observational cohort study. Journal of Thoracic Disease, 11(3), 795–804. https://doi.org/10.21037/jtd.2019.02.18
7. Thomas, C., Morris, S. M., & Clark, D. (2004). Place of death: preferences among cancer patients and their carers. Social Science & Medicine, 58(12), 2431–2444. https://doi.org/10.1016/j.socscimed.2003.09.005
8. Wales, J., Kurahashi, A. M., & Husain, A. (2018). The interaction of socioeconomic status with place of death: a qualitative analysis of physician experiences. BMC Palliative Care, 17(1). https://doi.org/10.1186/s12904-018-0341-1
9. Wilson, E., Palmer, J., Armstrong, A., Messer, B., Presswood, E., & Faull, C. (2024). End of life decision making when home mechanical ventilation is used to sustain breathing in Motor Neurone Disease: patient and family perspectives. BMC Palliative Care, 23(1). https://doi.org/10.1186/s12904-024-01443-1

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