Essentials for Caring For Frail Seniors Near the End of Life –
Some Lessons from the Violet Programme

Dr Angel Lee
Dr Karen Liaw

Acknowledgement

SACH Violet Programme Staff

SACH Home Nursing / Med Team

SACH Home Care Admin

Dr Ivan Ngeow

SingHealth SORH

Temasek Foundation – SMF Fund

Caring for (Frail) Seniors near the EOL

- What we know
- What we hoped to achieve – the Violet Programme
- What we have learnt … so far
- Concluding remarks

What we know …

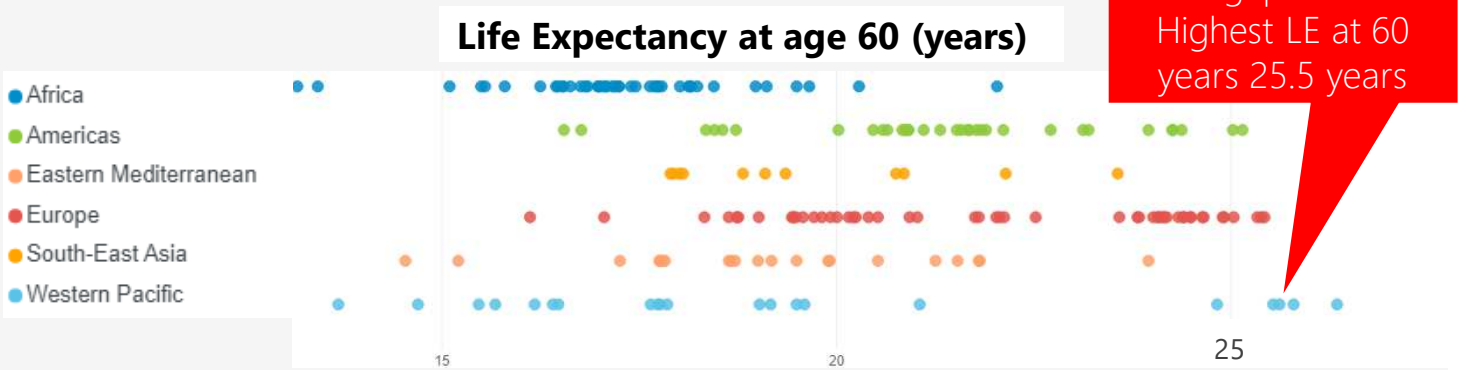
Caring for frail seniors near the EOL in Singapore

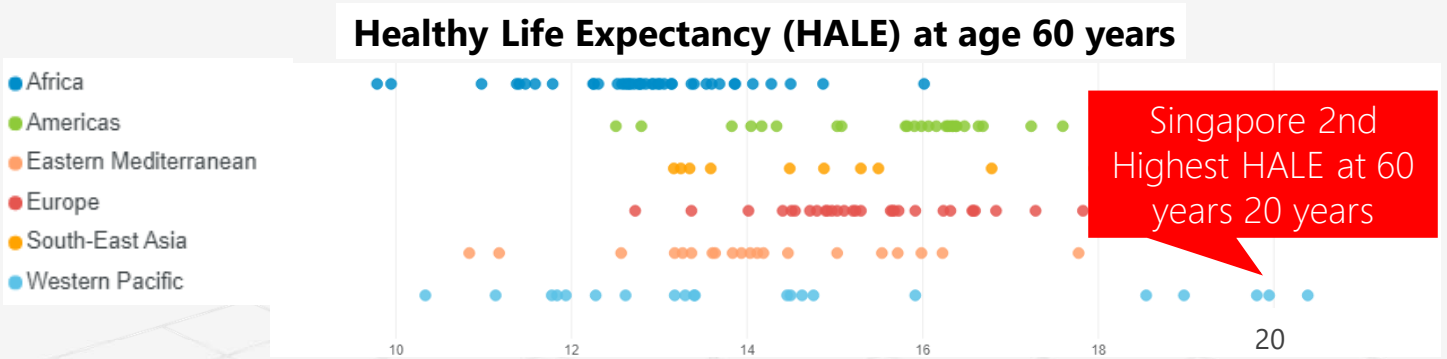
(1) Many people will be disabled for longer periods before they pass away.

Globally: From 2000 to 2019
Increase in LE of 6.6 years but HALE lags behind at 5.4 years.

Prevalence of frailty
- Community Dwelling seniors 6.2-7.6%
- Community Hosp population 45.6% for in-patients

Note: Frailty and Disability are distinct entities but they are often used indistinctly to identify vulnerable older adults





https://www.who.int/data/gho/data/indicators/indicator-details/GHO/gho-ghe-hale-healthy-life-expectancy-at-age-60
https://www.who.int/data/gho/data/indicators/indicator-details/GHO/life-expectancy-at-age-60-(years)
Ge, L., Yap, C.W., Heng, B.H. *et al. BMC Geriatr* **20**, 389 (2020). https://doi.org/10.1186/s12877-020-01800-8
Merchant RA, Chen MZ, Tan LWL et al J Am Med Dir Assoc. 2017 Aug 1;18(8):734.e9-734.e14.
Jeffrey Jiang et al. Aging Medicine and Healthcare 2020;11(2):39-46. doi:10.33879/AMH.2020.062-1907.015

Caring for frail seniors near the EOL in Singapore

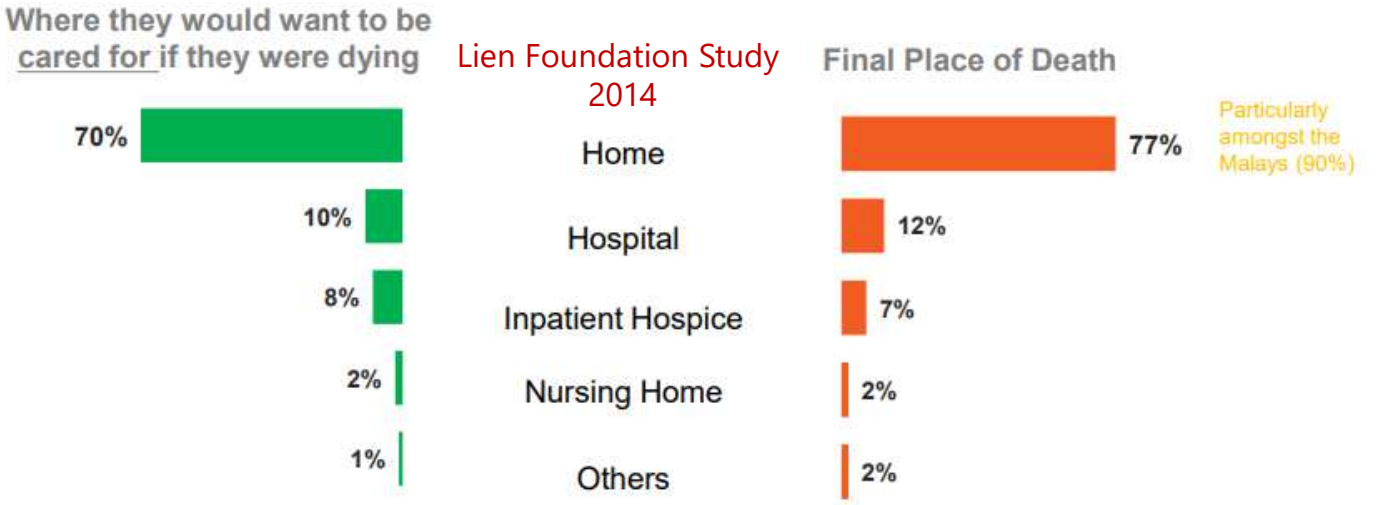
Many pass away in hospitals even though the preference is to be at home.

In 2021, of those who passed away in Singapore,

61% were in acute hospitals

vs

27% were at home



Where would participants like to be cared for at the end of life?

SMU-SHC Study 2019

77% prefer to be cared for at HOME at the end of life.

Largest age group — Majority group is ≥ 61 years (94%)

Largest edu group — Majority group is No formal schooling (100%)

Largest ethnic group — Majority group is Malays (77%)

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http://lienfoundation.org/sites/default/files/Gen%20Pop%20Findings%20Report%20-%20Full%20REPORT%20%28Website%29_0.pdf

Caring for frail seniors near the EOL in Singapore

Many will end up in NHs.

Old Age Support Ratio dropping

1990 **10.5**

2010

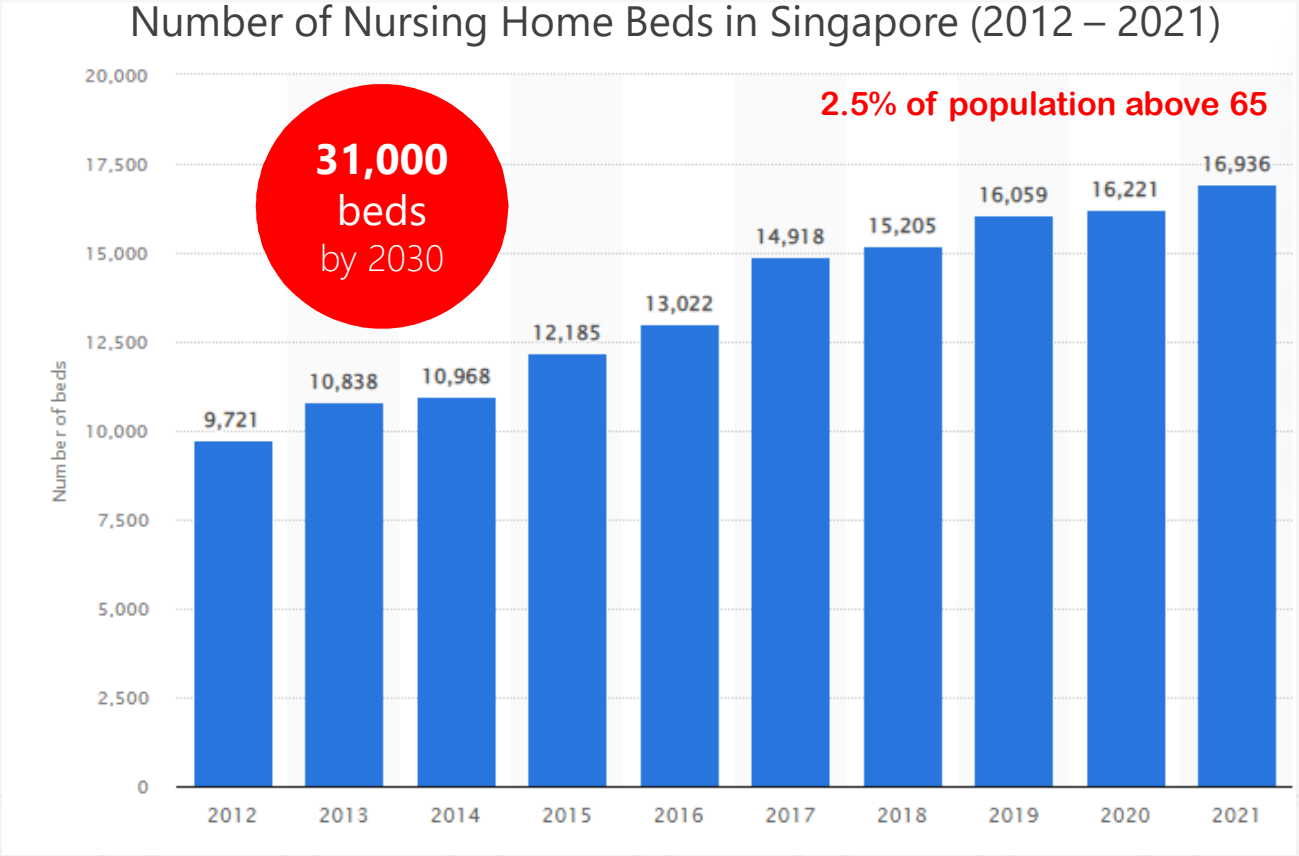
2020

2022 **3.8**

From 2010 to 2020:

One person households have increased from 12.2% to 16.0%

3G households have decreased from 11.3% to 9.8%



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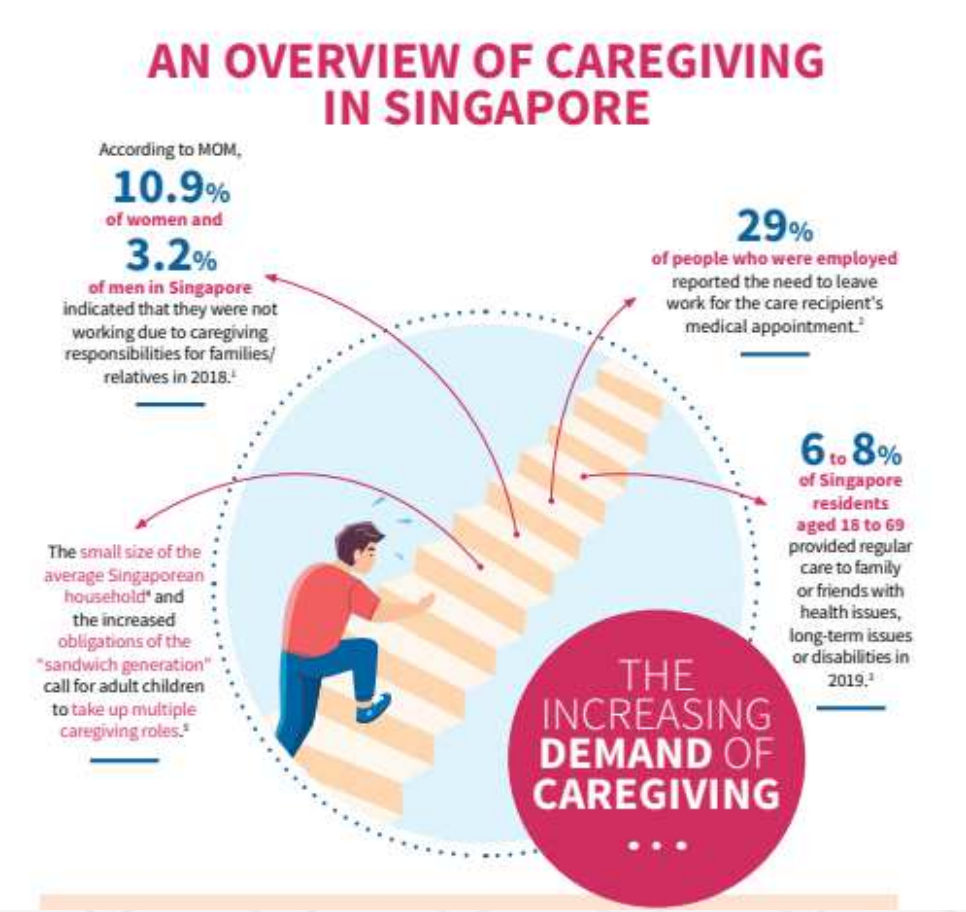
Caring for frail seniors near the EOL in Singapore

The caregiving burden is likely to increase with ageing population.

Risk factors for increased stress amongst informal caregivers (MCYS Survey on Informal Caregiving 2012):

- Low income
- Disruption to daily schedule
- Suffers from chronic illnesses
- Care recipient suffers from depressive disorders



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https://www.msf.gov.sg/publications/Documents/Informal%20Caregiver%20Survey%20Summary%20Report%20(upload).pdf
https://www.ncss.gov.sg/docs/default-source/ncss-publications-doc/pdfdocument/qol-caregiver-report_fa_5aug.pdf

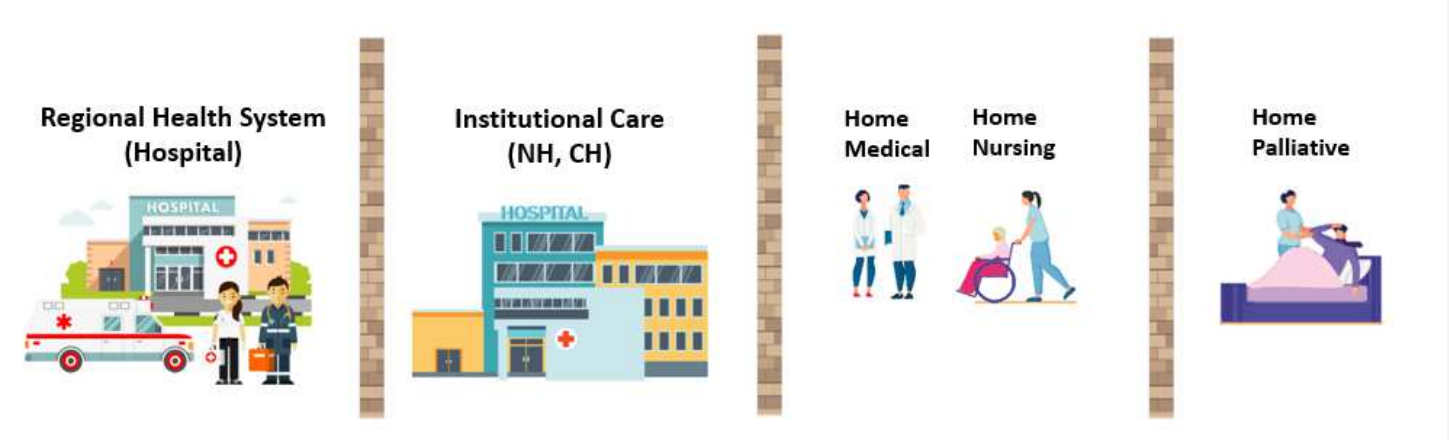
Caring for frail seniors near the EOL in Singapore

We tend to work in silos of care.

Characterised by hand-offs and transfer of care between service providers across the illness trajectory.

Constrained by lines of:

- Communication
- Funding
- Governance



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Current scenario in terms of care of home bound seniors

Home Medical Services

- Provided by **in-house or locum doctors**
- Generally part of a MDT, working with home nursing, home therapy and home personal teams
- Have access to funding for consumables and **equipment**
- Funding is piece-meal for each service type
- Office-hour support

70+ Home Care Providers

Number benefited from subsidised care:

2016 – 5,200

2017 – 6,000

2018 – 6,700

24 Home Medical Teams providing subsidised care

Home Medical

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MOH Parliamentary QA, 7 May 2019

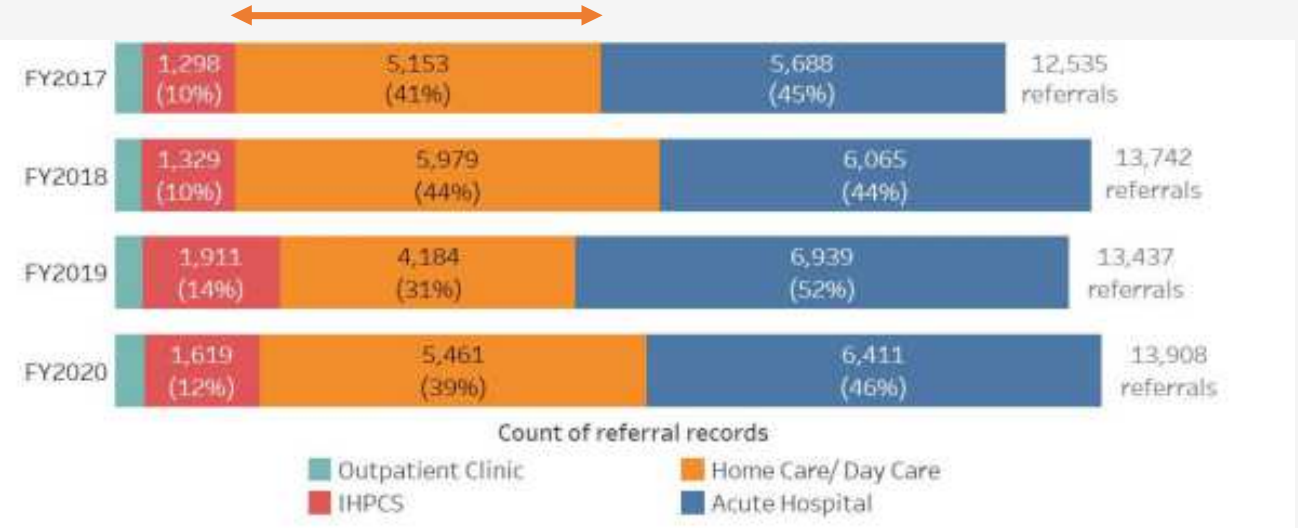
Current scenario in terms of home hospice care

Singapore
22,054
Deaths
(2020)

Home Hospice Services

- Core multidisciplinary team of doctor, nurse, social worker and may also be supported by volunteers and other staff
- Usually have access to own supply of equipment which is loaned out
  - May also have access to highly subsidised equipment
- Have access to funding for respite care
- Most services do not charge service fee. Supported by charity.

9 Home Hospice Providers (2020).



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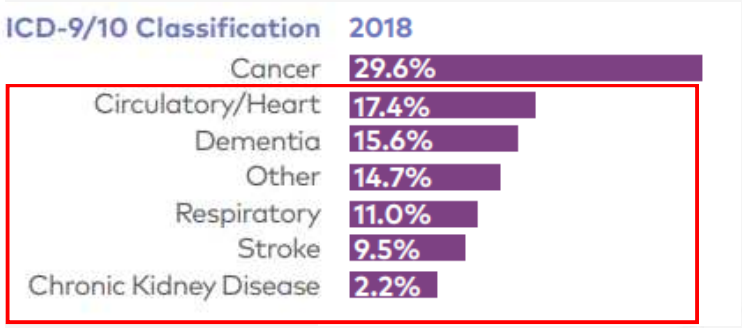
SHC MDS (Minimum Data Set) FY 2019 / 2020 Report
https://www.moh.gov.sg/resources-statistics/singapore-health-facts/principal-causes-of-death

Caring for frail seniors near the EOL in Singapore

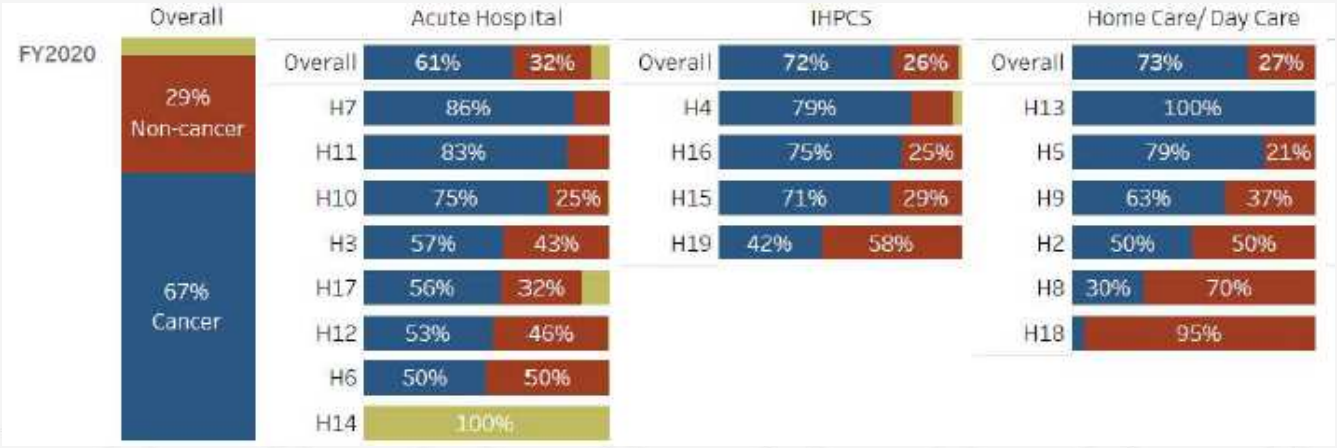
Palliative Care Services locally are still very cancer-centric.

In USA, NHPCO data indicates that **70.4%** of hospice decedents have a non-cancer diagnosis in 2018



In FY2020, **29%** of patients cared for by palliative and hospice services are non-cancer patients.

Of the 3,966 referrals for home hospice care, **27.4%** were non-cancer patients.



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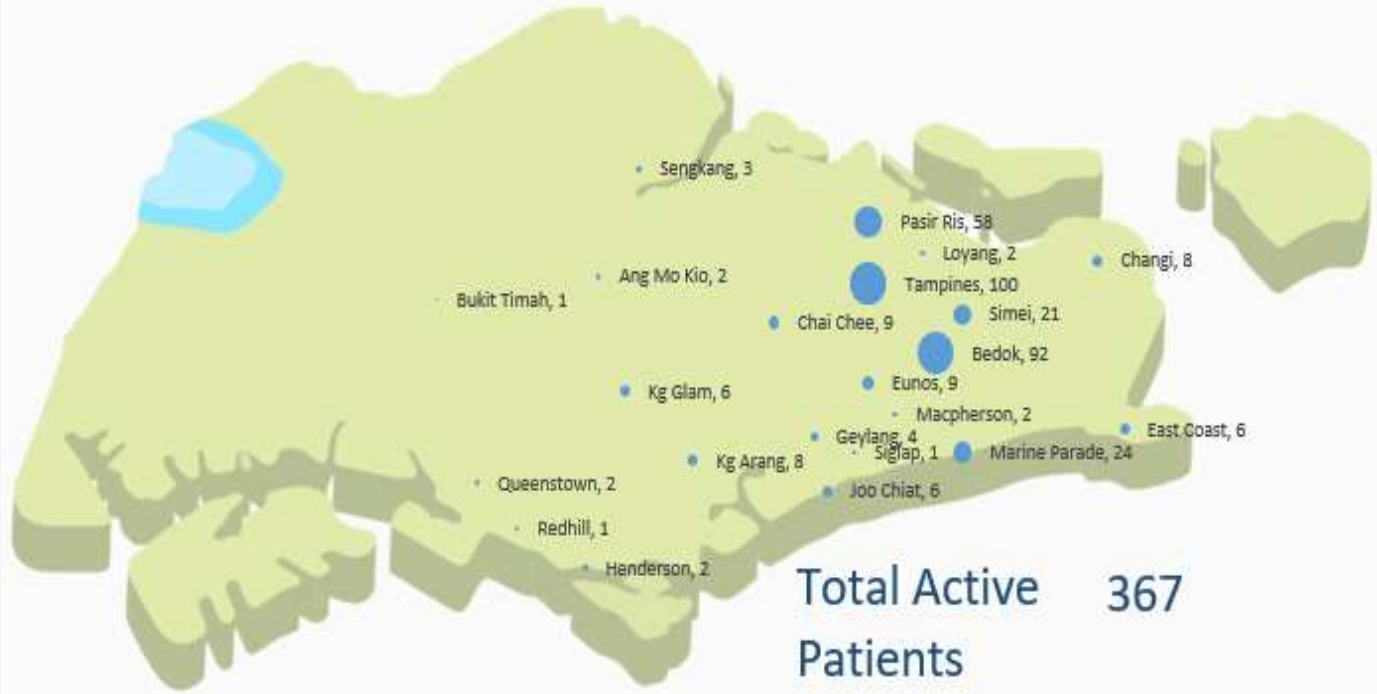
NHPCO facts and Figures 2020 Edition
SHC MDS (Minimum Data Set) FY 2019 / 2020 Report

What we hoped to achieve …

SACH Home Care (Home Medical / Home Nursing / Home Therapy)

Started in 2012. Serving residents mainly in the East of Singapore

- some obligation in Queenstown and Henderson



As of End Sept 2022

83% of patients are ≥ CFS 7

7	LIVING WITH SEVERE FRAILTY	**Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~6 months).
8	LIVING WITH VERY SEVERE FRAILTY	Completely dependent for personal care and approaching end of life. Typically, they could not recover even from a minor illness.
9	TERMINALLY ILL	Approaching the end of life. This category applies to people with a **life expectancy <6 months**, who are **not otherwise living with severe frailty.** (Many terminally ill people can still exercise until very close to death.)

Age

Median Age

81.3 years

21 – 31% each year

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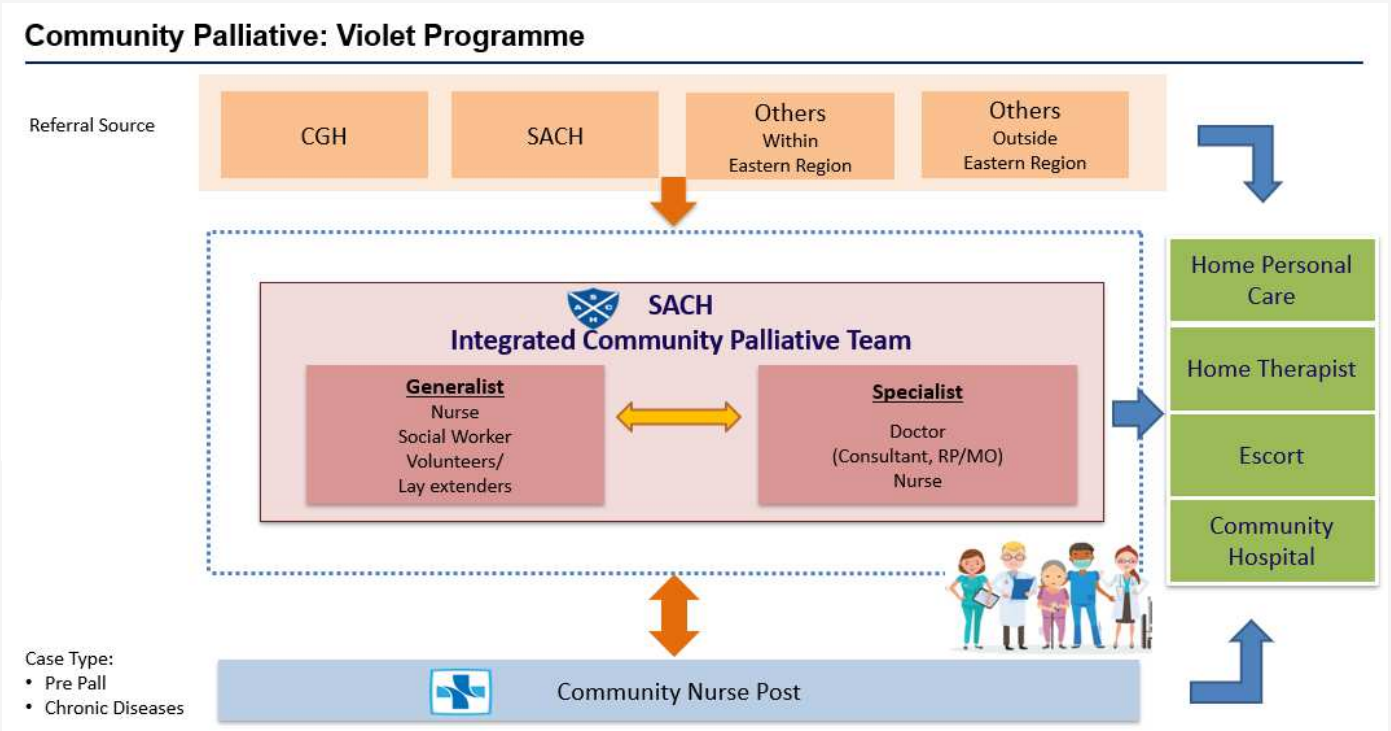
What did we hope to achieve in the Violet Programme

Meet the gap in the **non-cancer** group.

As part of the **integrated care hub** in the East in collaboration with CGH.

Serve as a **support for Home Medical teams** and the community nurses - work towards shared care rather than working in silos

Address the needs of the **frail seniors in NHs** (EagleCare and SANHs)



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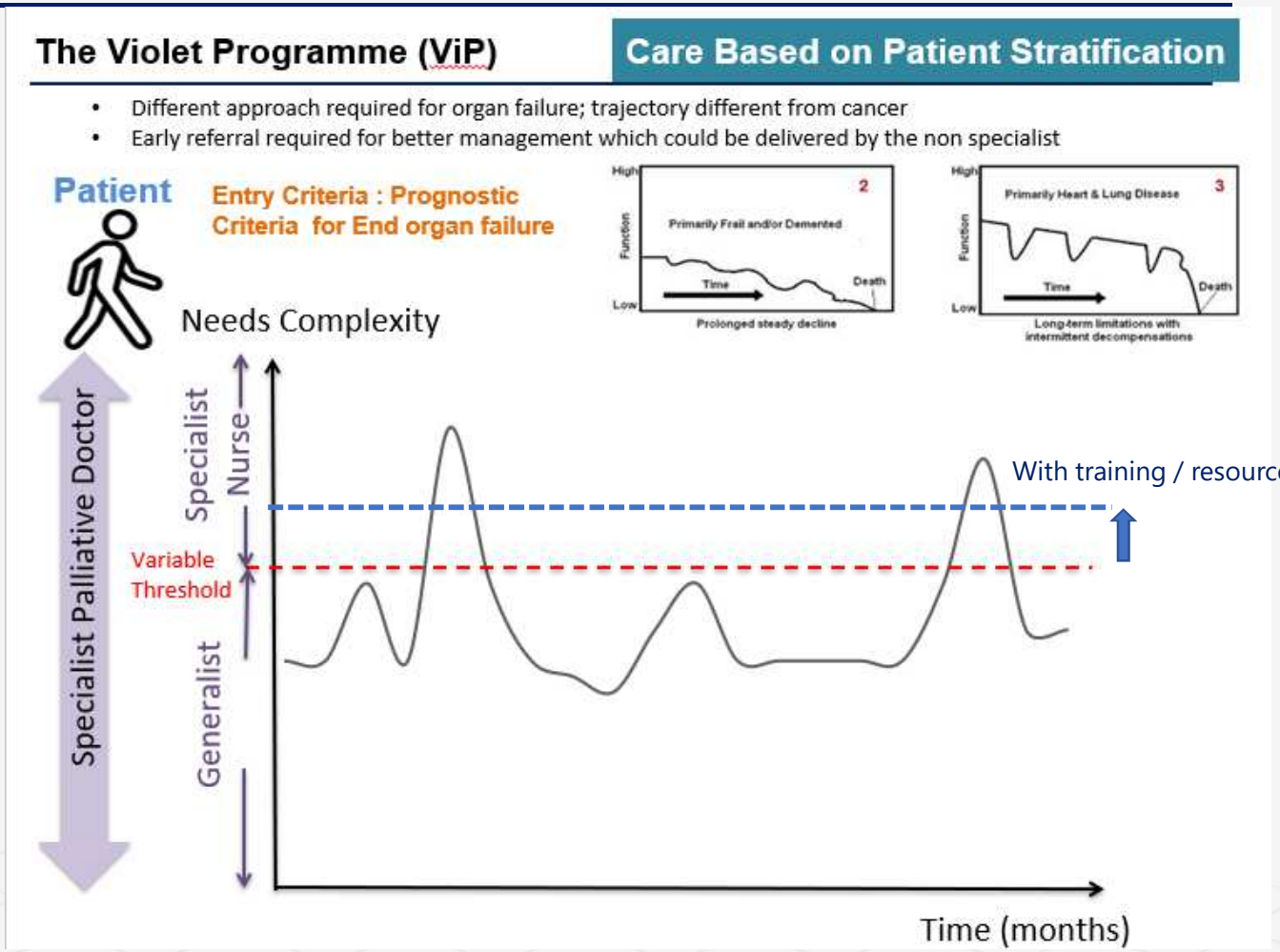
What did we hope to achieve in the Violet Programme

Complexity and Rapid Response Care - for those reaching their end of life

- Multidisciplinary support
- Seamless financial support



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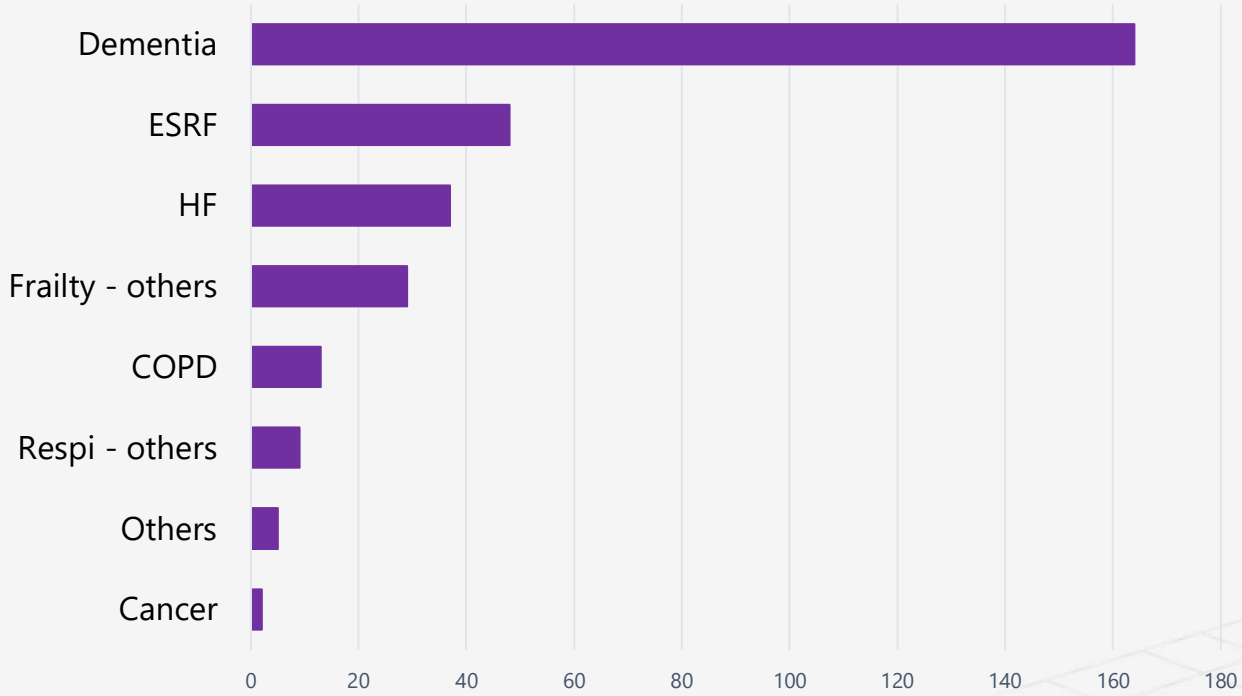
Results (Dec 2020 – Oct 2022)

Patient Demographics



Diagnoses of Patients on Enrolment

n = 307

Mean age 84.5

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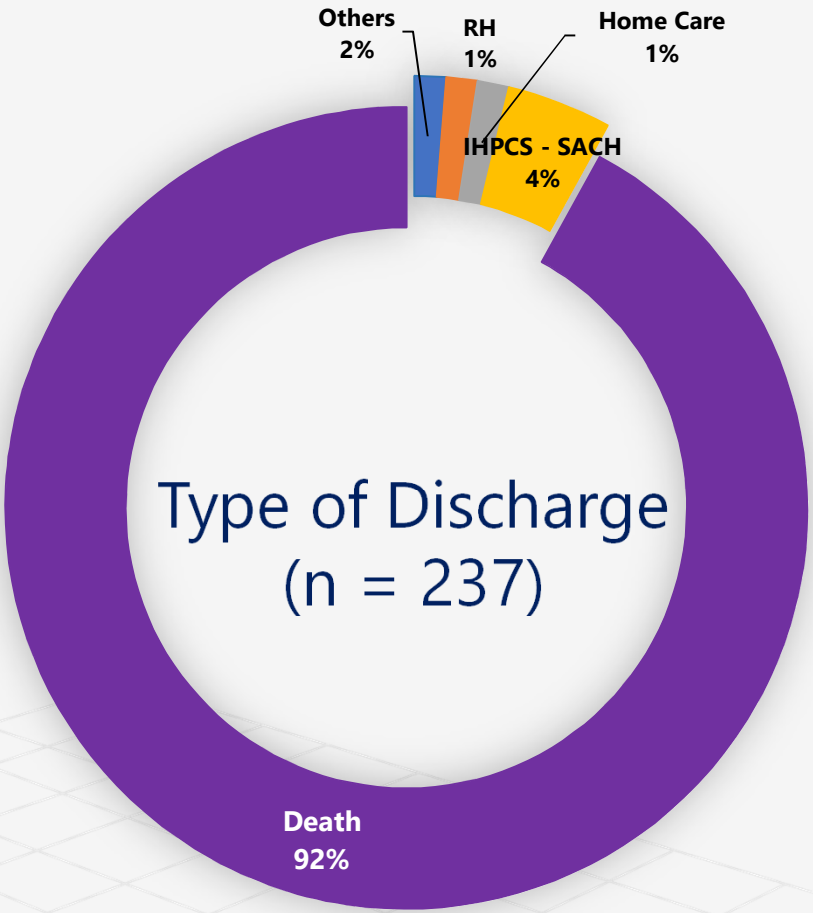
ViP Statistics (as at 31 October 2022)

Place of Death (Type of d/c = death)	Count	Percentage (%)
Home	191	**87.6**
Restructured hospital	20	9.2
Nursing home	2	0.9
Inpatient hospice	4	1.8
Community hospital	1	0.5



Average LOS = 71.1 days

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ViP Statistics (as at 31 October 2022)

88%

Died at home

91%

Completed ACP

60%

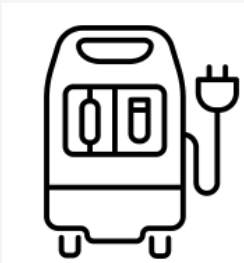
Average Means Test

96%

Had adequate symptom control

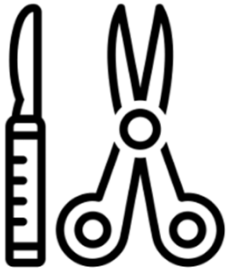
93%

Concordance with preferred place of death



25%

required a palliative procedure/loan of oxygen concentrator before death



29%

required nursing procedures

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What are some lessons …

Where is the data from?

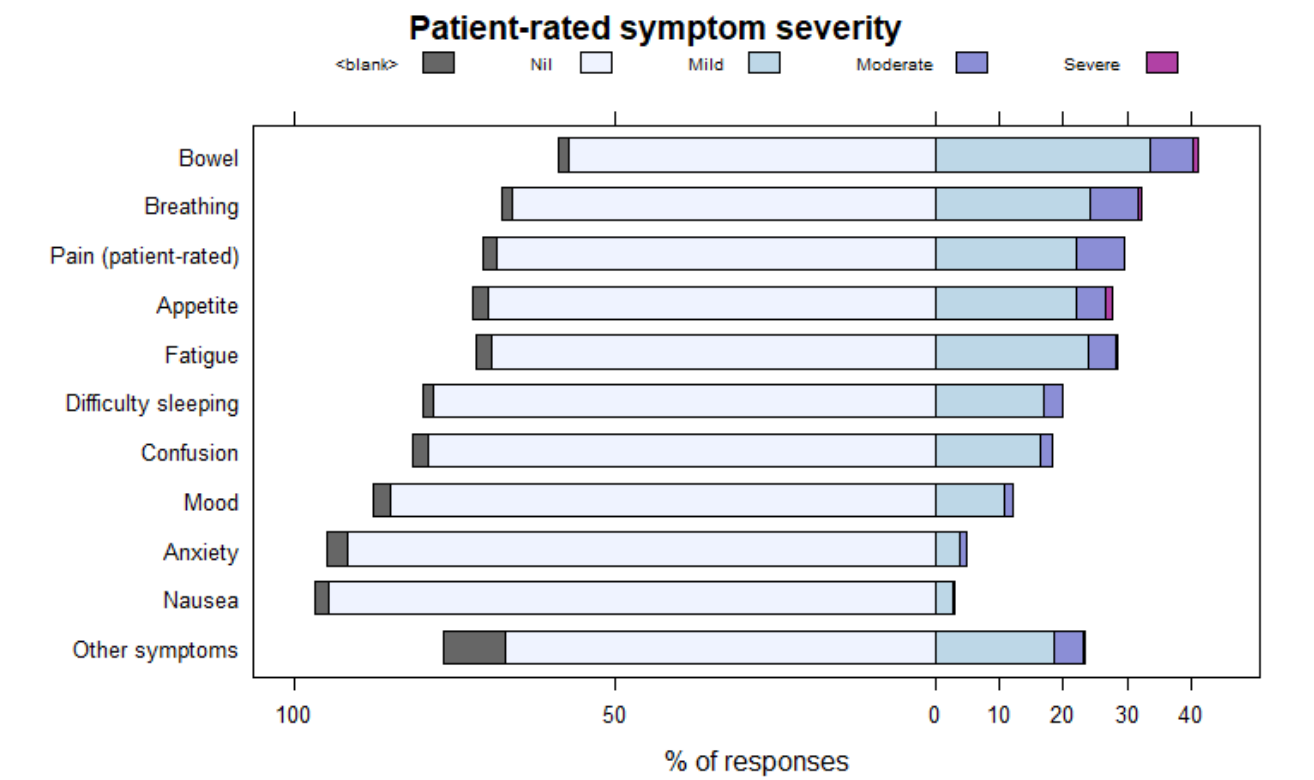
Sources:

1. ViP database and patient registry
2. Staff survey
3. Research : Programme evaluation using the realist approach

Patient Symptom Distress on Enrolment

At referral, the **top 3 symptoms** experienced by patients were:
(1) Constipation
(2) Breathlessness
(3) Pain

There is a need for:
- supply of opioids
- medical equipment



Based on the initial rating of the first 360 PCOC documentation

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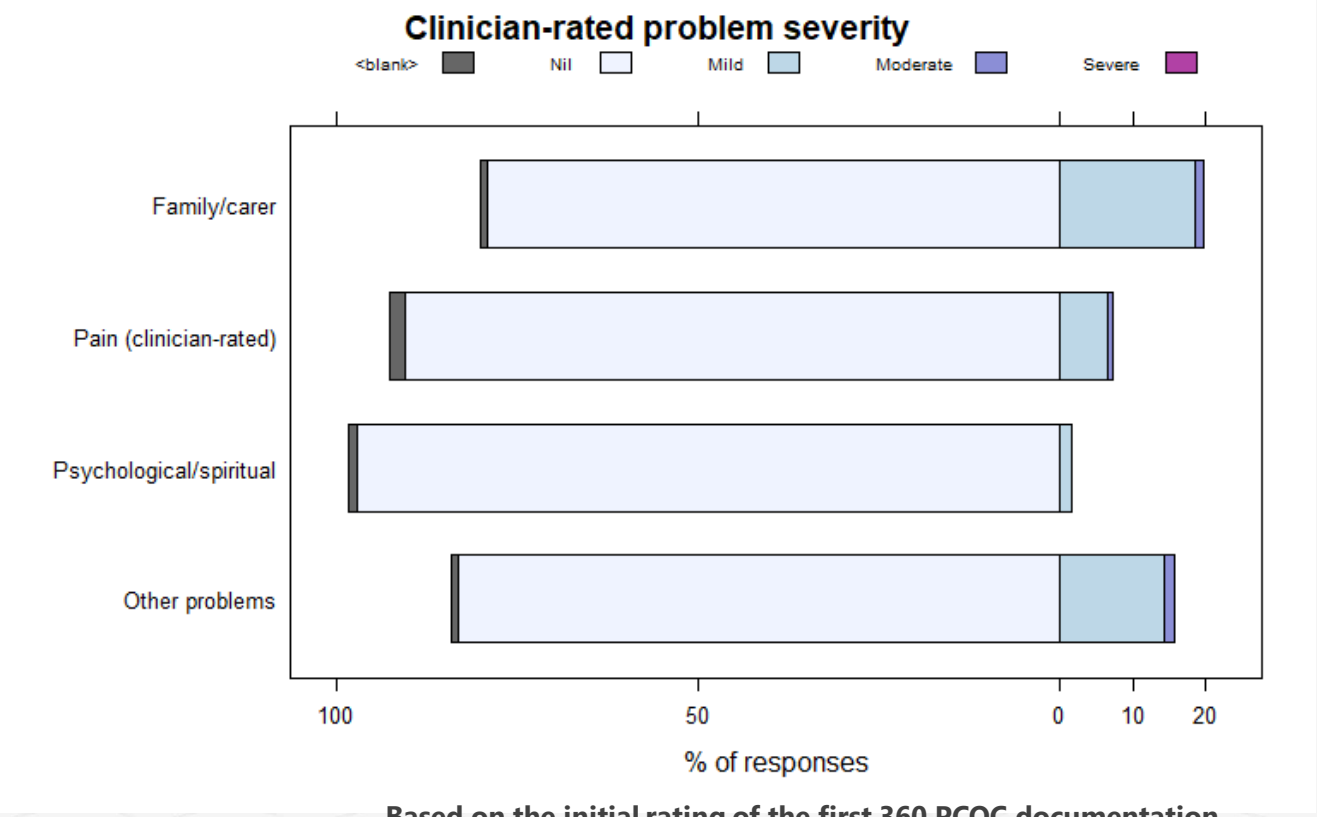
Clinician-assessed Issues on Enrolment

At referral, **family and care/giver related issues** are found to be more challenging that pain management.

Management of other symptoms, usually **breathlessness**, **secretions** and **behaviour** are more challenging than pain management.

About **47%** of initial ZBI-12 >17



Based on the initial rating of the first 360 PCOC documentation

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Challenges in Care Provision - Nursing

Top 3 areas that nurses find challenging to manage:

Home Palliative nurses	Home Nursing nurses
Family/Caregiver - No/incompetent caregiver - Neglect - Poor support for caregiver - Psychoemotional distress (anxious, differing opinions) Refractory symptoms Practical matters: Complex wounds, challenging nursing procedures & manoeuvring the financial assistance schemes	Family/Caregiver - Anxious family - Demanding family - Not prepared for end-of-life care Refractory symptoms Prognostication

Challenges in Care Provision - Administrative

Significant operational work required in ensuring access to various claims:

- Medisave
- Medifund
- Disability schemes

Differential access to

- Medisave between home medical and home nursing
- Subvention claims in Transition between services

Role of ACP

Only **15.6%** of admissions had a known ACP.

Useful tool to start end-of-life conversations
- Check patient and family's understanding of illness
- Understand patient's values and preferences

It is an on-going conversation about preferences, never a once off decision

Uncertain Prognosis

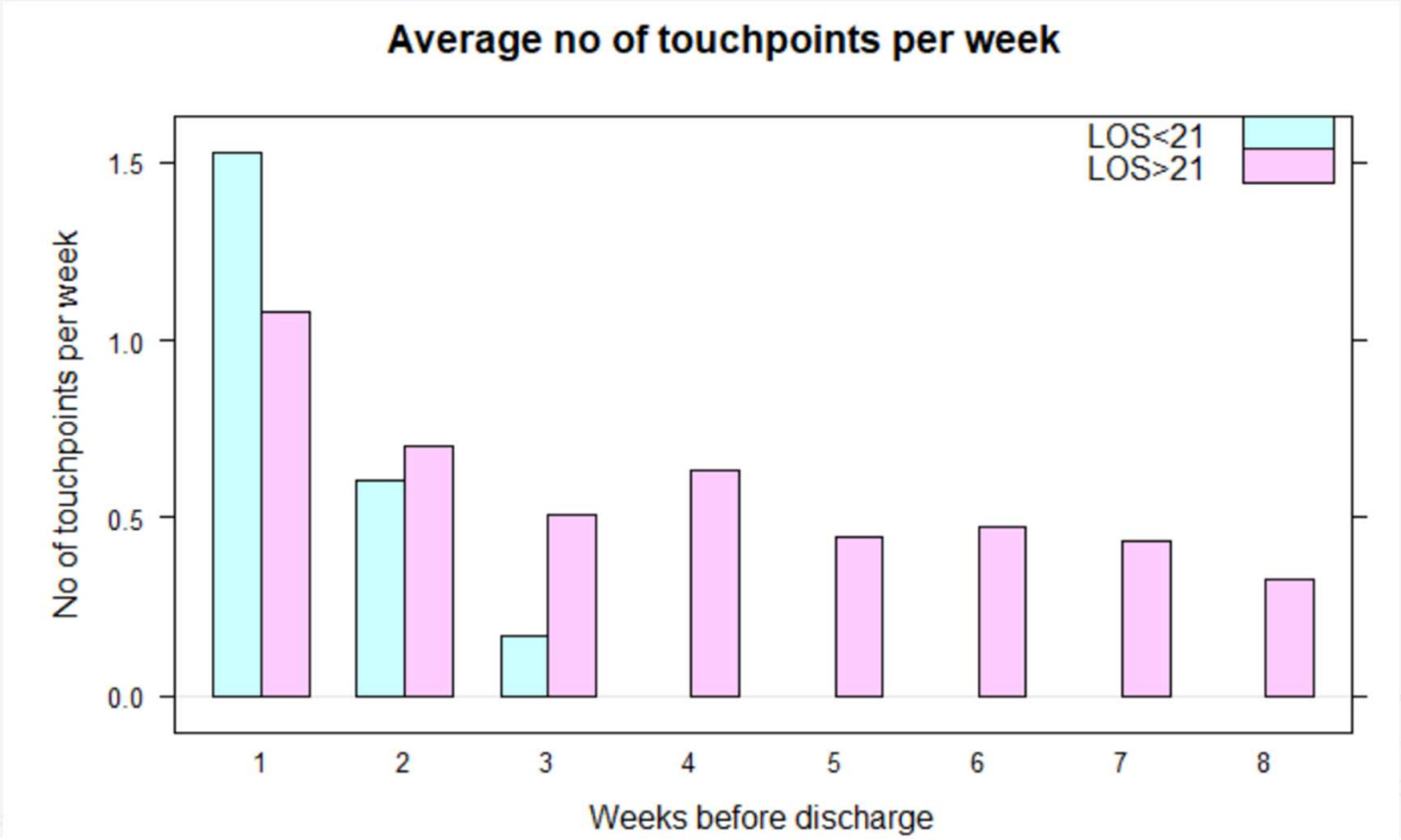
Challenges in Prognostication

LOS	Min	Max	Mean	>7 days (%)	>30 days (%)
Urgent (n=66)	0	449	32.4	28 (42.4)	12 (18.2)
TD (n=27)	0	85	8.8	6 (22.2)	1 (3.7)

*urgent = contact within 48 hours
TD = contact within 24 hours

Resource Utilization in the Weeks Prior to Discharge

Resource Utilization (physical home visits and video consults)



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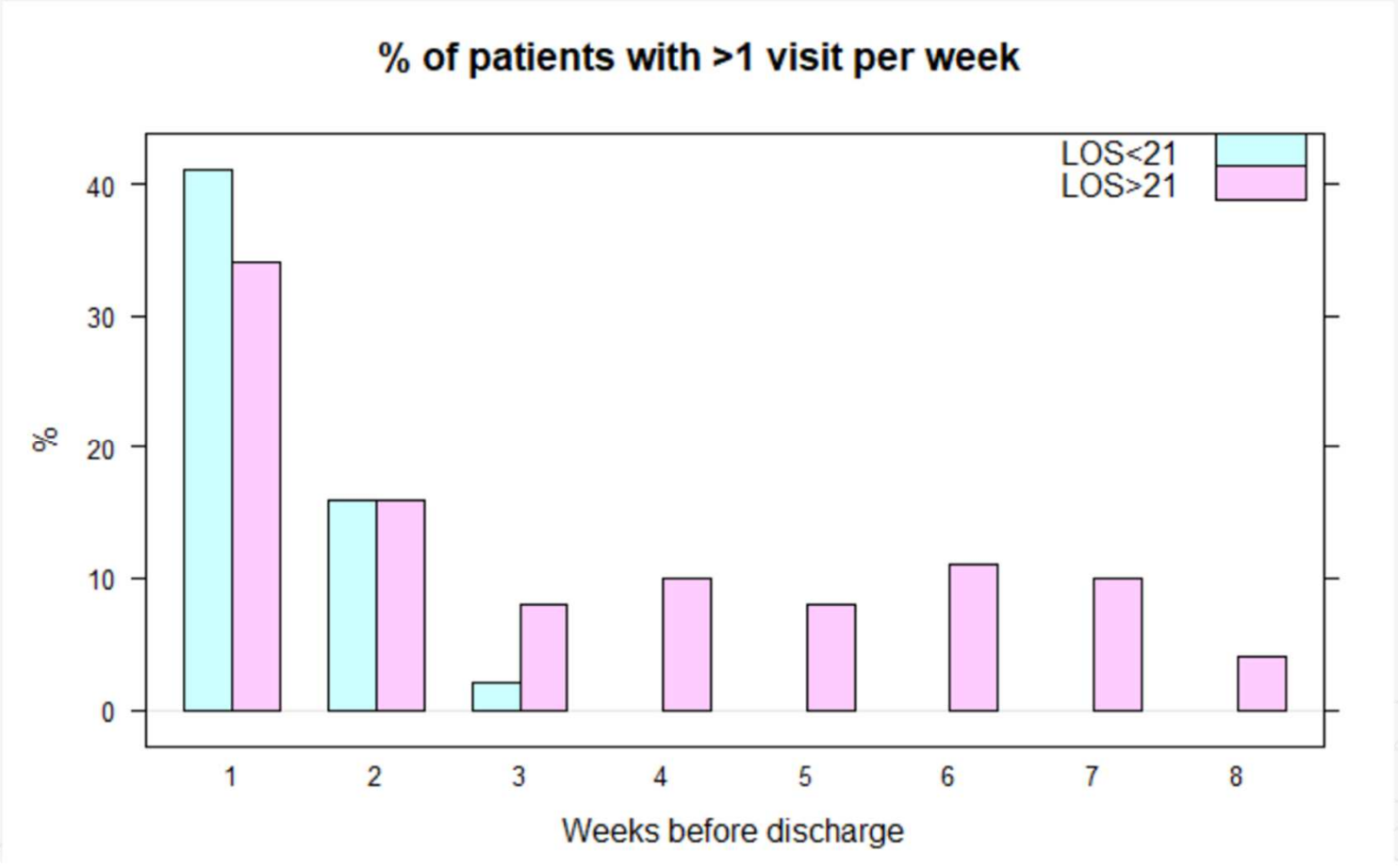

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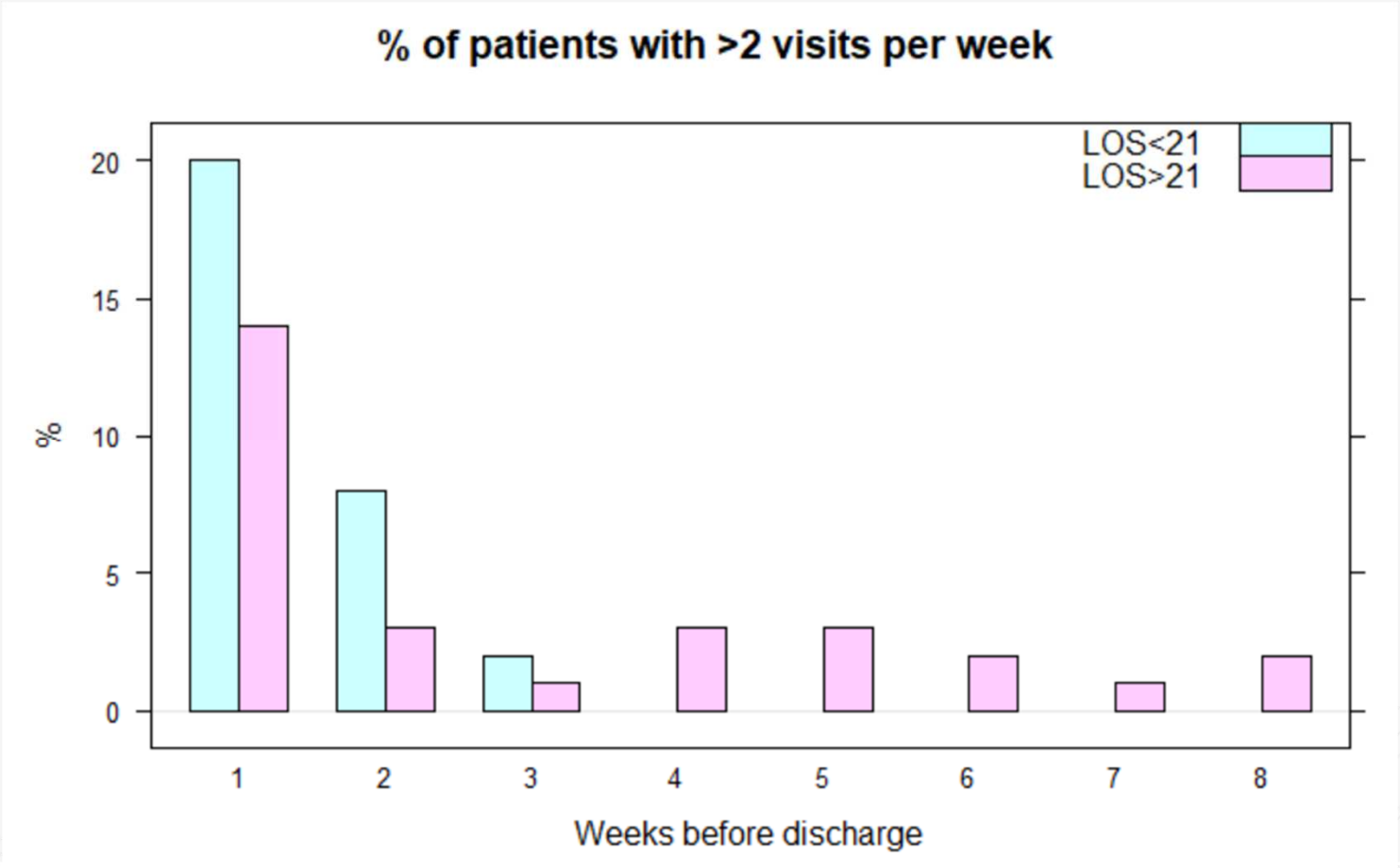

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Working Towards Care Integration

Care Integration

1. Alignment in philosophy of care among care providers
2. Respect for each other
3. Approachable team
4. Effective and efficient communication on patient's and providers' concerns

Working Towards Care Integration

1. **Alignment in philosophy of care among care providers**

*"I think it is your **philosophy of care**... So, if you are, you know, **you are on the same wavelength**. So, **when I say the approach to care is person-centred, right, I expect a certain thing**. (...) And therefore, **when you have an agency that has the same vocabulary and the same philosophy, and of care, and the same understanding of the depth of this concept, it's so much easier to work with them**."*

Working Towards Care Integration

2. Respect for each other

*"So, I think that **it was really, the staff accessibility to us, being able to communicate and so we will do this email thing, or even the office, you know, or it's just easy to communicate** rather than, you know, have to be so official, blah, blah, blah, you know. So, I think that, for us, definitely, is **the ease of communication**. (...) so **there is a respect in terms of how we work with each other compared to like, certain instances, you know, we are quite hierarchical in our organization.**"*

Working Towards Care Integration

3. Approachable team

*"(…) so one thing is, er **the (ViP) team is quite approachable**. Even if there is certain things that we are unsure of, we need to check in with them, quite responsive. **And you know, there is no harsh tones.. from them** that you know, "How come you don't know certain things all that and it has already been disseminated?"*

Working Towards Care Integration

4. Effective and efficient communication on patient's and providers' concerns

*"Because now, at least at this era, **we can reach them via phone, and then we can sometime we can Tiger text, so I thought that is very good already**, very good already. So, **at least we can do the handover**. I thought the handover and communication is the key that which this programme enable us to do so. And we also know we are, **we are handing over the patients to an entrusted team, that is some real reassurance to us lah**."*

Referrals: Home Medical/Nursing ↔ ViP

Referrals from SACH Home Medical	
Total	119
Urgent referrals	21
Total number enrolled	84
Total number enrolled as Shared Care	35 (11.4% of total enrolment)
Mean LOS for Shared Care	129.5 days (2 – 391)

Selection criteria for Shared Care
- Same admission criteria as ViP
- Patients and families who are keen to continue care at home

Barriers to referral
- Has not had any admissions in the last 1 year
- Frail with no end organ failure diagnosis but potential for acute deterioration or sudden death

In conclusion …

Conclusion

1. With challenges in prognosis and "uncertain recovery" just proceed with "parallel planning" rather than wait.	ACP and "serious illness conversations" in order to plan for contingencies – which includes - Emergency contact numbers for decline - Practical steps for symptom control
2. Common pathway in dying means that we need to be prepared to handle common symptoms	Protocols for common symptoms and equipment Caregiver education and support e.g. feeding issues at EOL
3. Do not underestimate the work in building "networks of care" • RHS and the community • "Specialist Pall Care Providers" and the "Generalists"	Communication tools e.g. Tiger Connect Access to EMR Role clarity as to what each team does

Conclusion

4. Making care affordable and seamless does require administrative and operational efforts

In order to scale the work, IT support and streamlined processes need to be worked out.

Much more work is required to address the aspirational goals of good palliative care.
And we are still working on it.

"Caring for the dying is a gift …"

Report of the Lancet Commission on the Value of Death: bringing death back into life
Lancet 2022; 399: 837–84