

賽馬會安寧頌



Jockey Club End-of-Life Community Care Project

Press Conference

Public Survey on End-of-Life Care in Hong Kong 2023

策劃及捐助 Initiated and Funded by:



香港賽馬會慈善信託基金
The Hong Kong Jockey Club Charities Trust
同心同步同進 RIDING HIGH TOGETHER

合作夥伴 Project Partner:



Number of Deaths in 2022

- **67.1 million around the world**
(Ritchie & Mathieu, 2023)

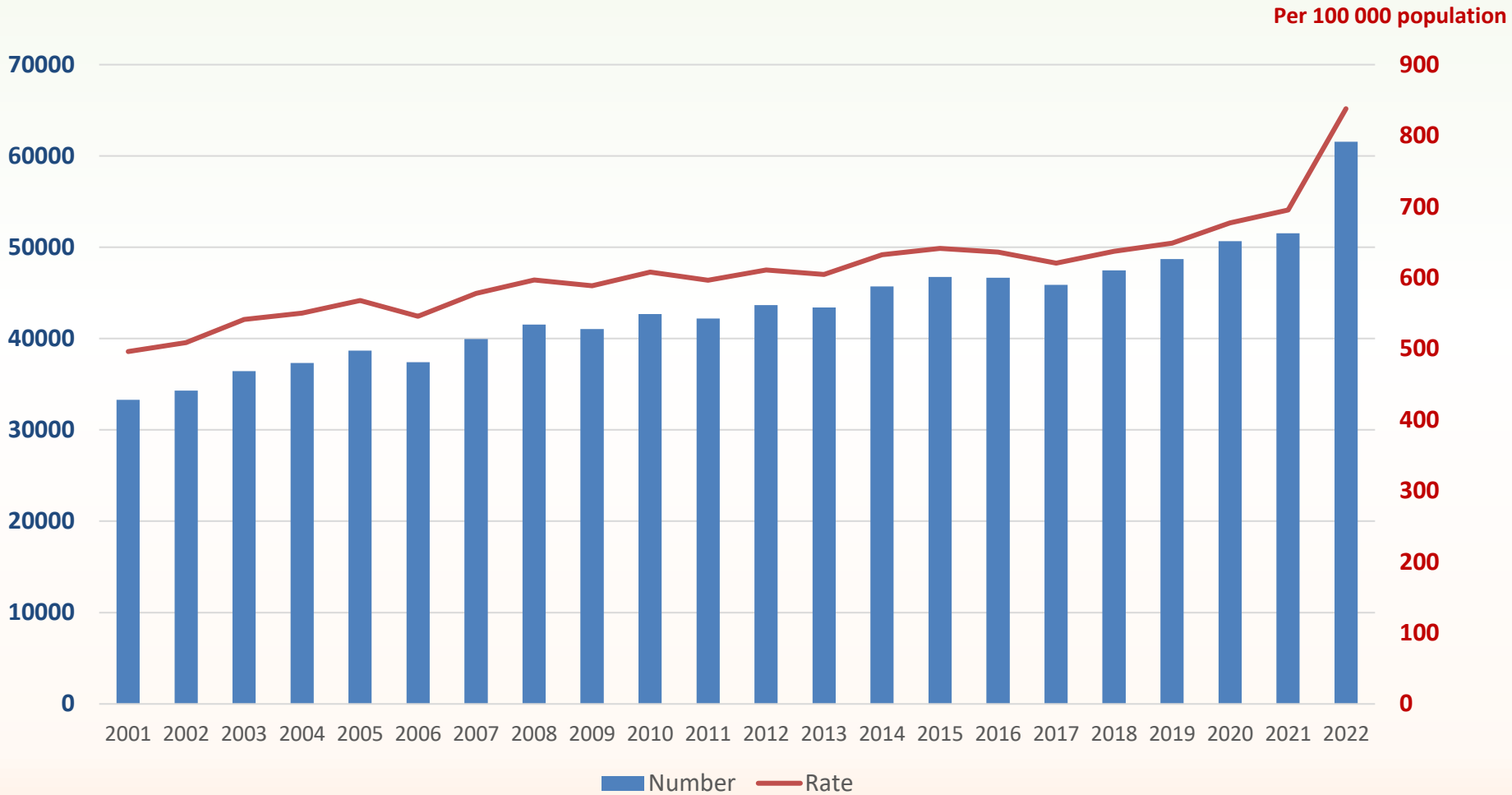
(2.13 deaths per second)



- **61 557 in Hong Kong** (Centre for
Health Protection, 2023)

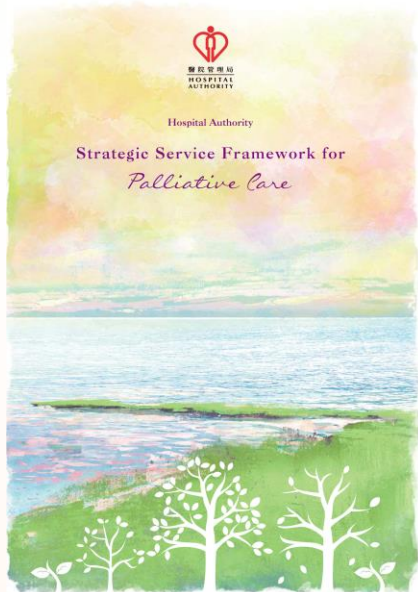
(7.03 deaths per hour)

Increasing number of deaths and death rates



Hong Kong Scenario

Aug, 2017



Strategic Service Framework for Palliative Care

Sept 2019



Public Consultation on End-of-life Care: Legislative Proposals on Advance Directives and Dying in Place

July 2020



Nov, 2023

Advance Decision on Life-sustaining Treatment Bill

C3259

Advance Decision on Life-sustaining Treatment Bill

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The Advance Decision on Life-sustaining Treatment Bill

The Third Batch of End-of-life Care in Mainland China (July 14, 2023)

《关于开展第三批安宁疗护试点工作的通知》解读

发布时间：2023-07-14 来源：老龄健康司



近日，国家卫生健康委办公厅印发《关于开展第三批安宁疗护试点工作的通知》（以下简称《通知》）。现解读如下：

一、印发《通知》的背景

为提高疾病终末期患者的生命质量，自2017年起，国家卫生健康委先后启动两批安宁疗护试点工作。多年来，国家安宁疗护试点地区建立完善政策措施，不断深入宣传倡导，持续扩大服务供给，试点工作取得积极进展。根据《中共中央国务院关于加强新时代老龄工作的意见》关于“稳步扩大安宁疗护试点”的要求，为进一步推动安宁疗护发展，在前两批安宁疗护试点工作的基础上，国家卫生健康委继续扩大试点范围，开展第三批安宁疗护试点工作。

二、《通知》的主要内容

一是确定试点地区。在各地推荐的基础上，确定北京市、浙江省、湖南省为第三批国家安宁疗护试点省（市），天津市南开区等61个市（区）为第三批国家安宁疗护试点市（区）。

二是明确试点任务。《通知》提出四项任务，第一，**建设服务体系。**要求到2025年，在每个国家安宁疗护试点市（区），每个县（市、区）至少设立1个安宁疗护病区，在有条件的社区卫生服务中心和乡镇卫生院设立安宁疗护病床，建立覆盖试点地区全域、城乡兼顾的安宁疗护服务体系。第二，**完善支持政策。**要求构建价格体系、探索支付制度、加大资金支持、建立转诊机制、制定标准规范、保障药物配备。第三，**壮大服务队伍。**要求汇聚专家资源、组建多学科团队、加强教育培训、完善激励机制。第四，**开展宣传教育。**要求加强对领导干部、医疗行业人员、在校师生和社会公众的宣传教育。（<http://www.nhc.gov.cn/lijks/tggg/202307/52149be8ad1344558fe469dd495f2c0a.shtml>）

Jockey Club End-of-life

Community Care Project (JCECC)

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Jockey Club End-of-Life Community Care Project

In 2016, the Jockey Club Charities Trust initiated the Jockey Club End-of-Life Community Care Project (“JCECC”), aimed at enhancing the end-of-life (EoL) care in Hong Kong to improve the quality of life of older people with terminal illness by developing viable community-based service models to complement the existing service provisions in a coordinated manner



2016



2019



2022

Jockey Club End-of-life Community Care Project (JCECC)

End-of-Life Care Systems
 安寧服務系統

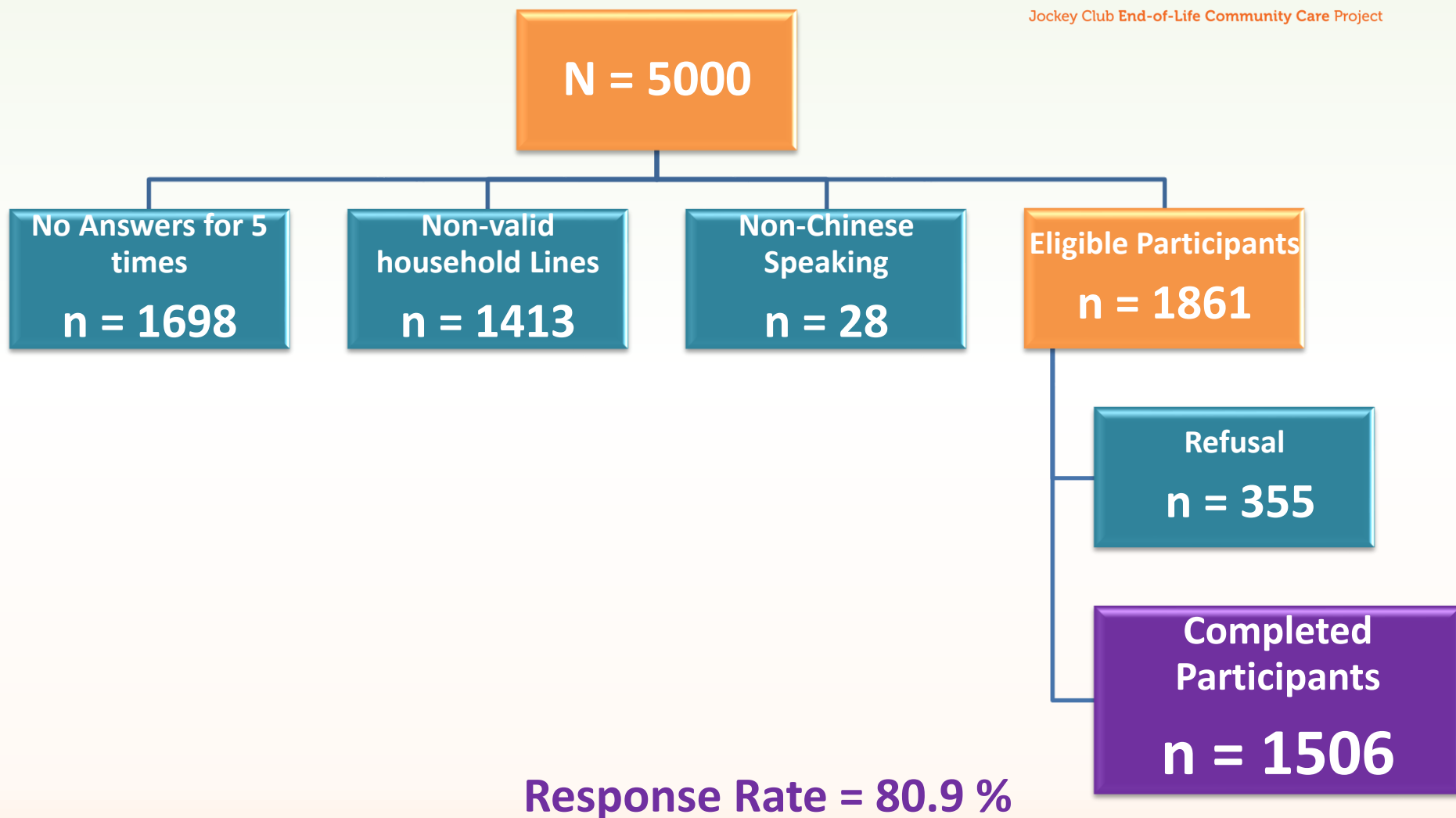
Project Components
 項目內容



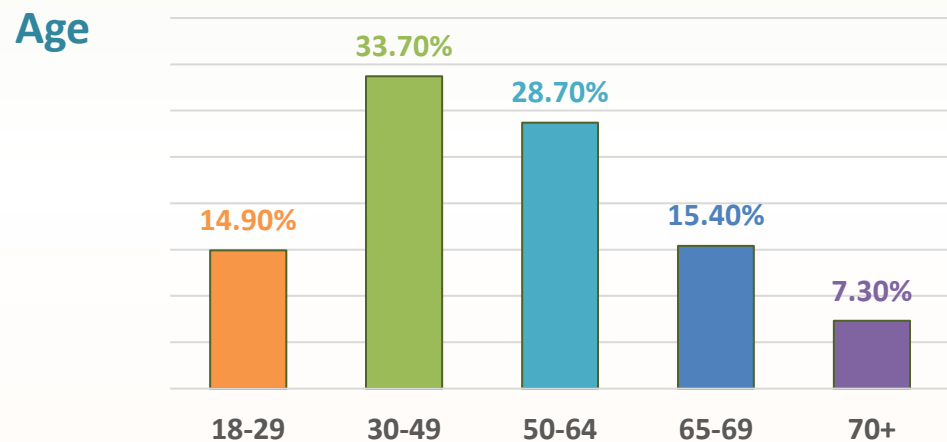
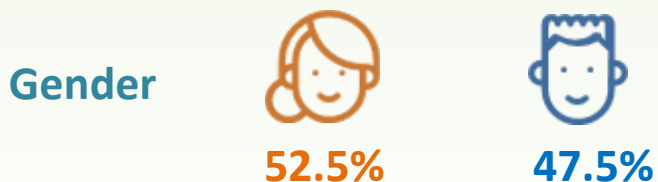
The Study

- **Method:**
 - A random-sample household telephone survey
 - Social Policy Research Limited was entrusted
- **Participants:**
 - Cantonese-speaking Hong Kong residents aged 18 or above
- **Duration:**
 - July 17 to October 12, 2023
- **Objectives of the Study:**
 - To understand the needs and strategies for public education on end-of-life care
 - knowledge and attitude of the general public on end-of-life care

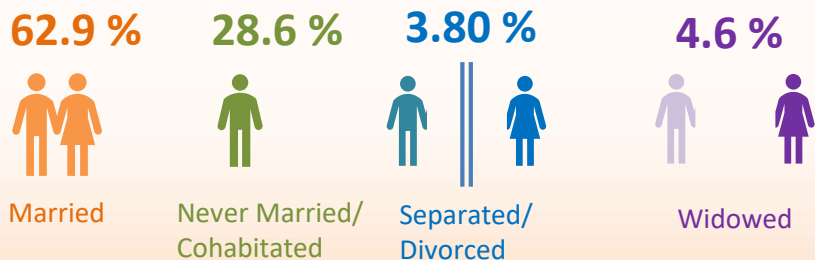
Participants



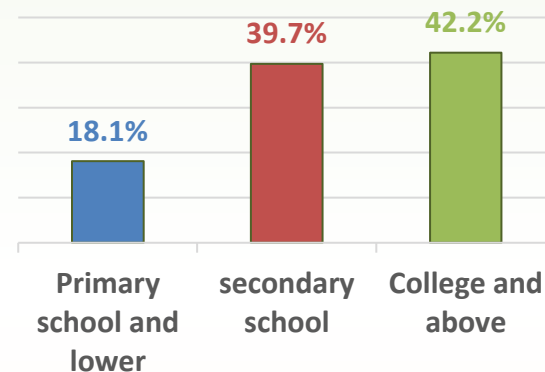
Participants (N = 1506)



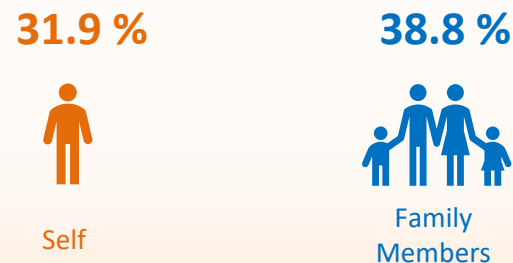
Marital Status



Education Level



Has Chronic/ Life-threatening Illness

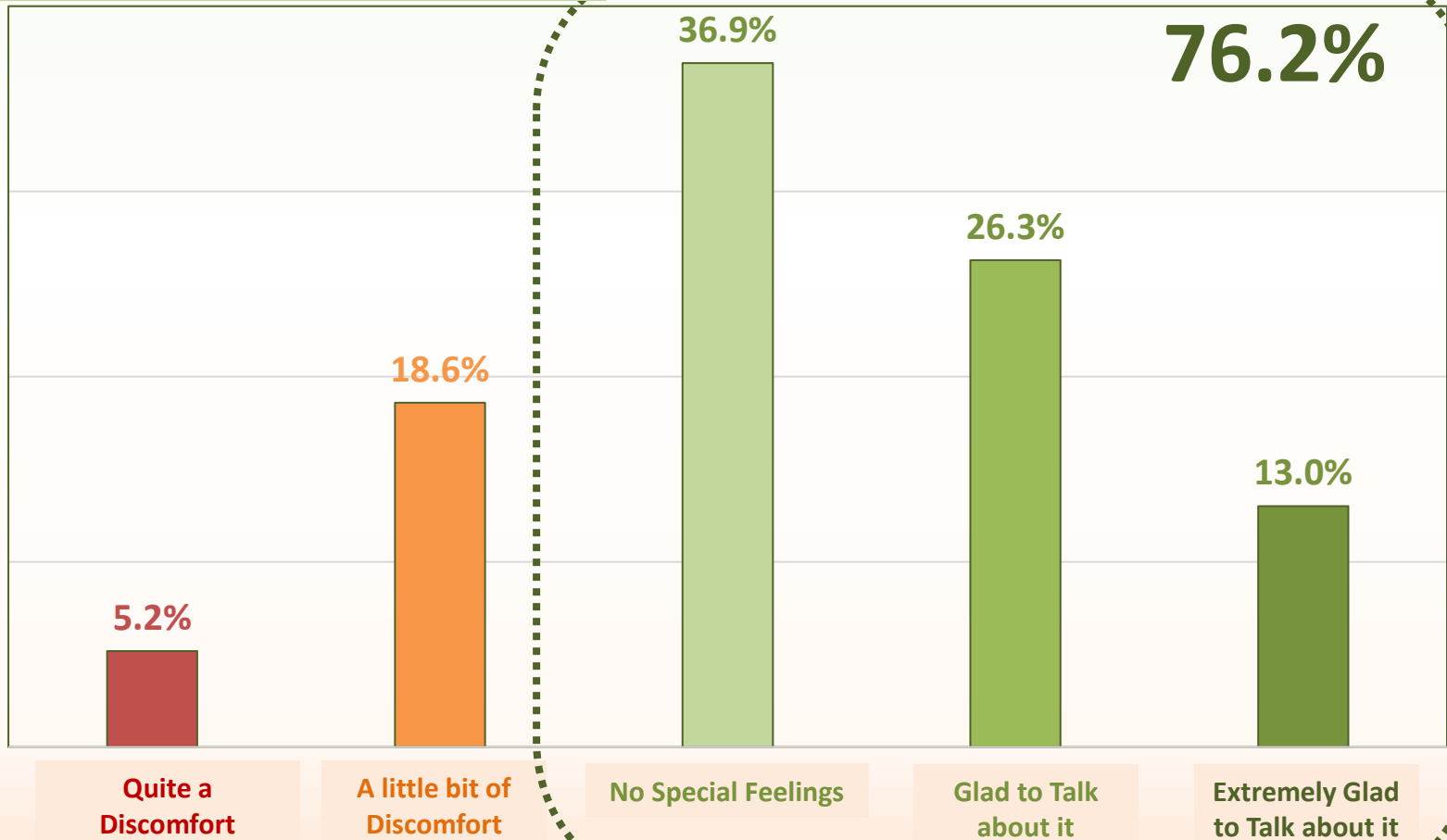


#1

**Death is not necessary a taboo topic
and EoLC can be a family discussion
topic**

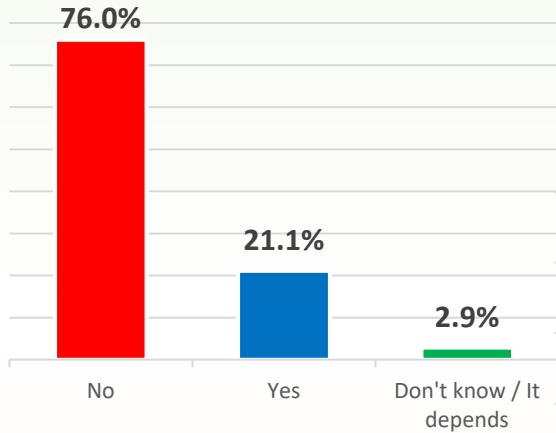
Level of Comfort in Talking about Life and Death (N = 1506)

More than 75% of the participants expressed no discomfort in talking about life and death topic

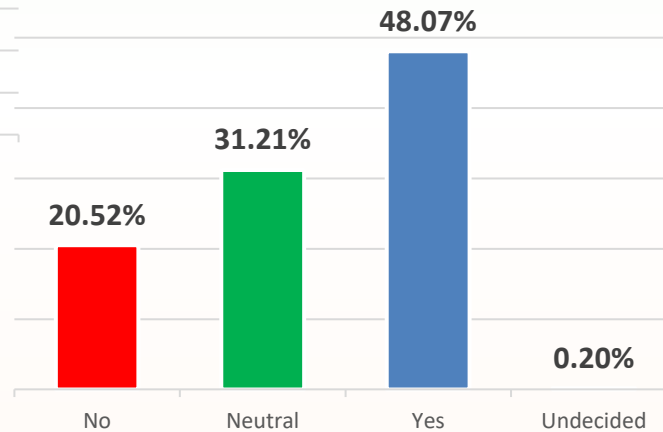


Acceptance of Deaths happened in Living Place (N = 1506)

Move to a unit with deaths happened

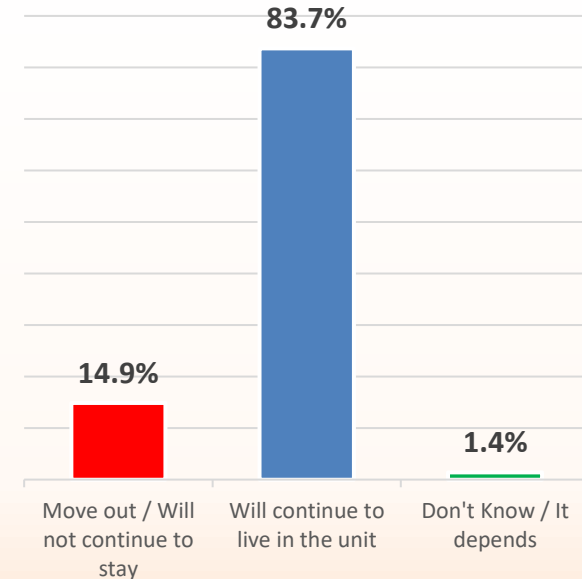


Support family members dying at home



About 20% don't mind staying in the house with death happened, and up to more than 80% if it is the death of the family

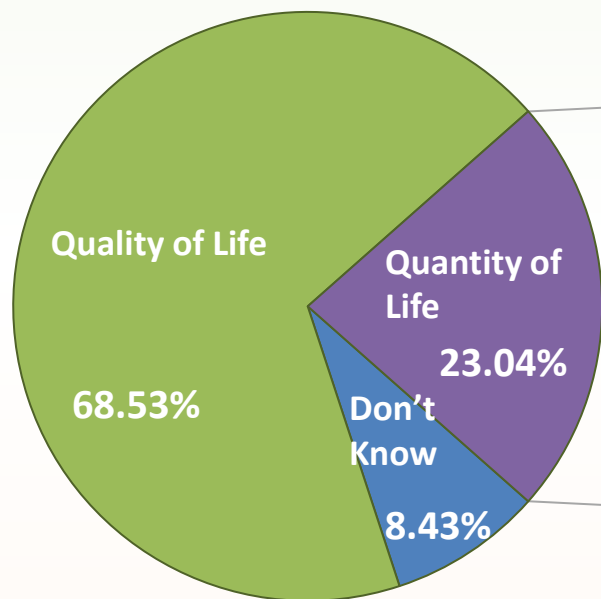
After a family member died at home



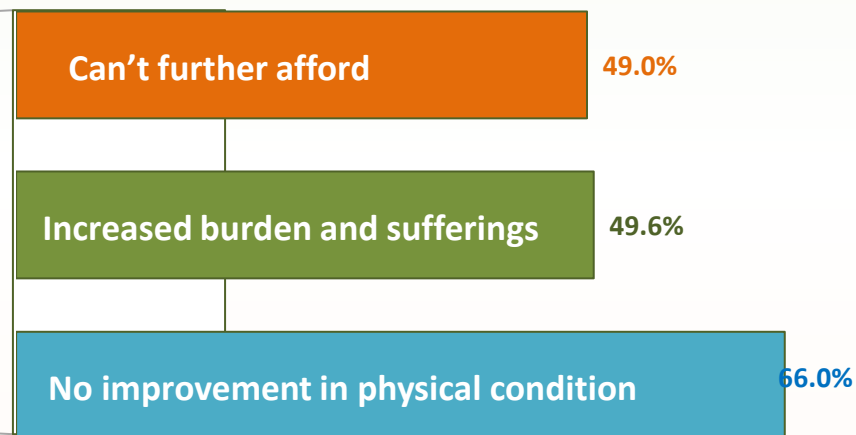
Quality and Quantity of Life

(N=1506)

Preferred Goal of Care at the End-of-life



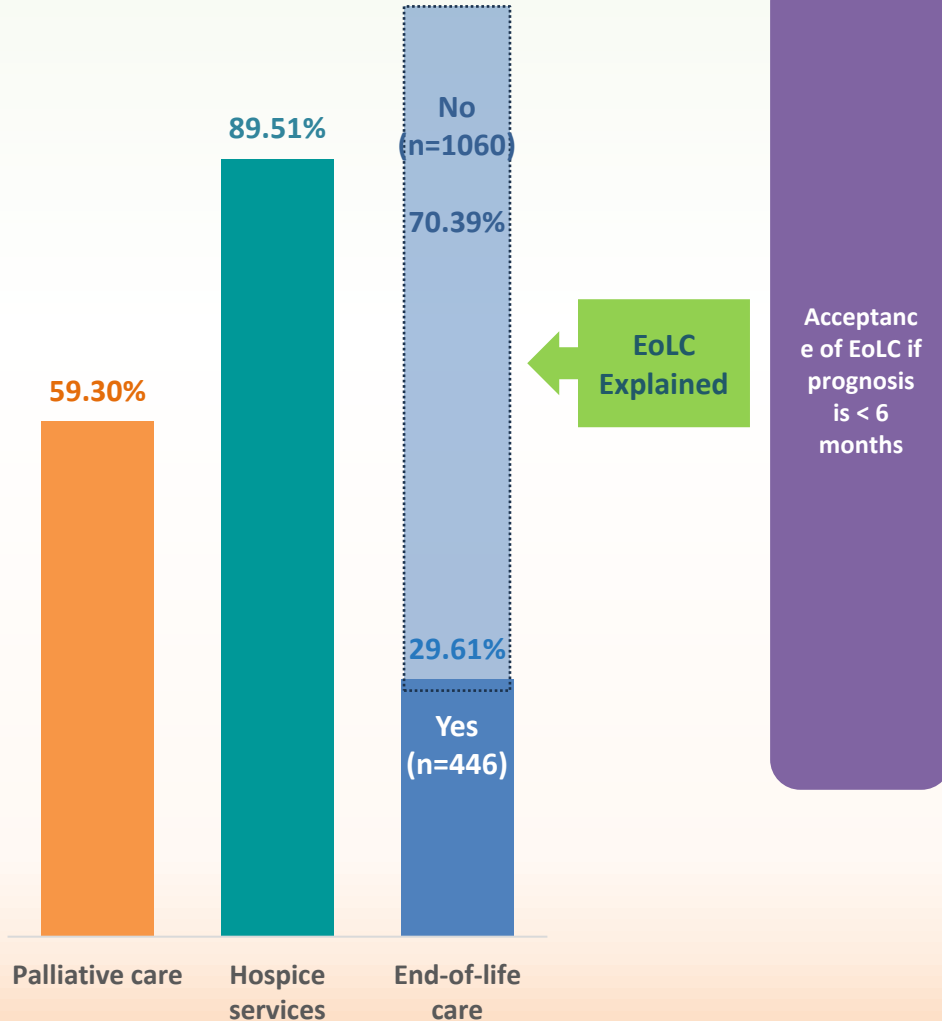
Consider change from Quantity to Quality of Life (n=347, multiple answers)



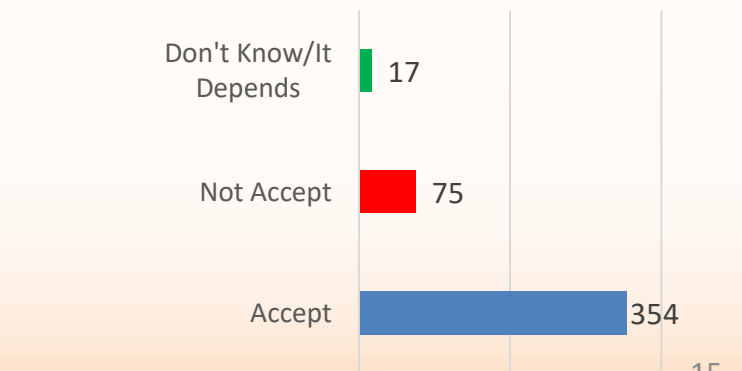
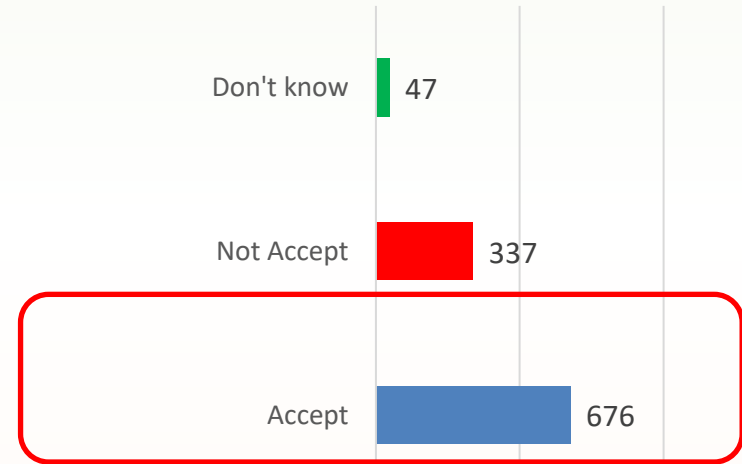
Nearly 70% of the respondents preferred treatment that could improve their quality of life

Heard of EoLC-related Terms and Acceptance of EoLC (N = 1506)

Heard of ...



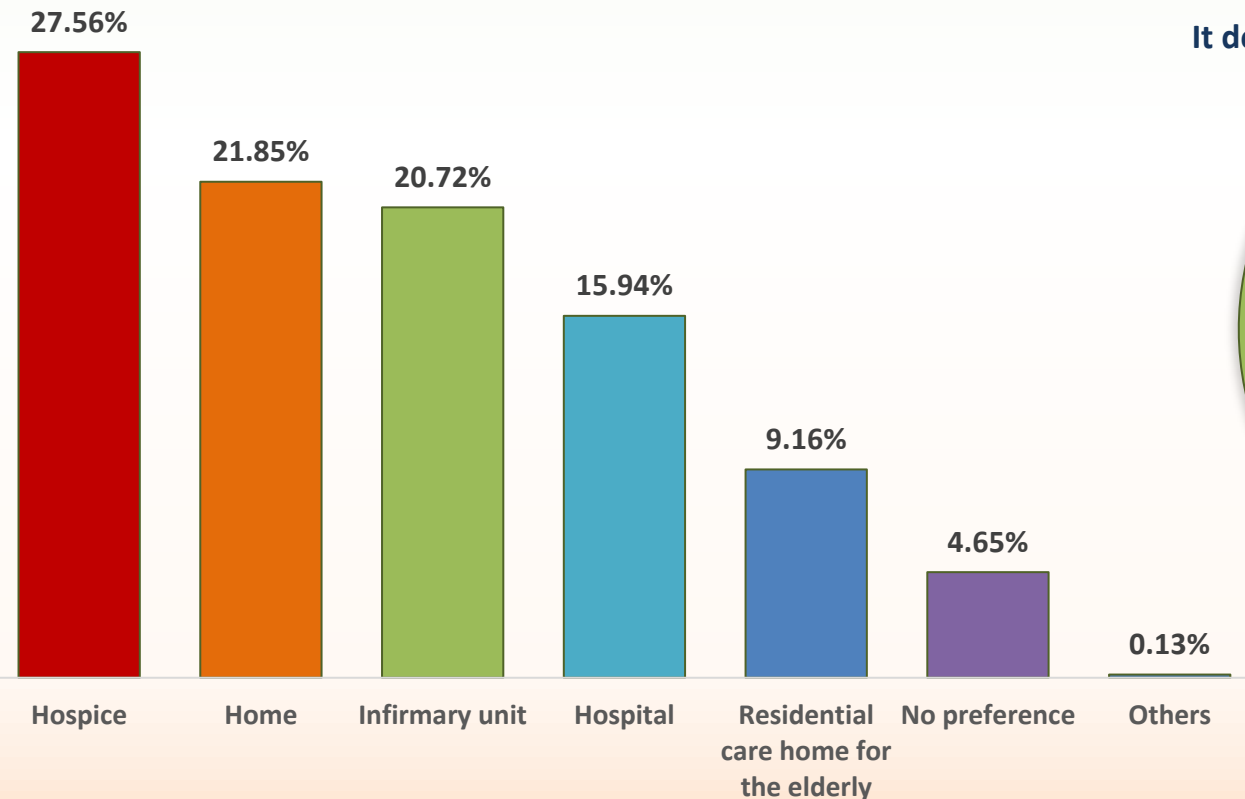
About 2/3 of those who have not heard of EoLC will opt for it after learning about it



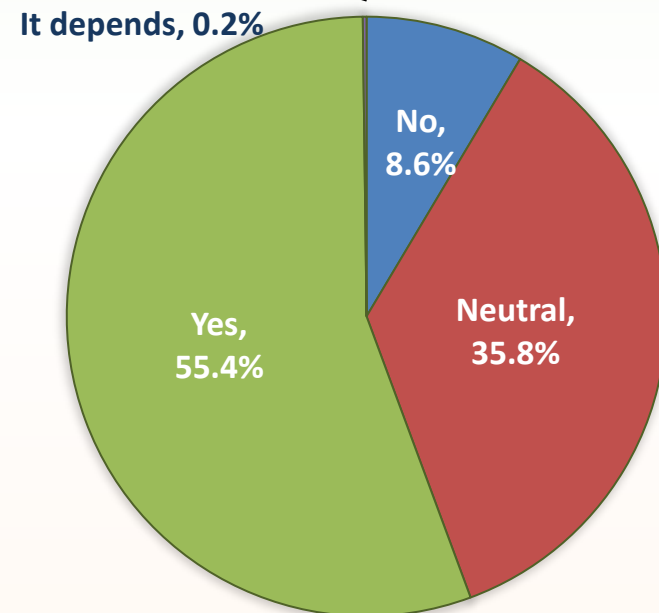
Preferred Location of EoLC (N = 1506)

One in four of the respondents preferred to be cared for at hospice and one in five preferred to be cared for at home

Preference for Self

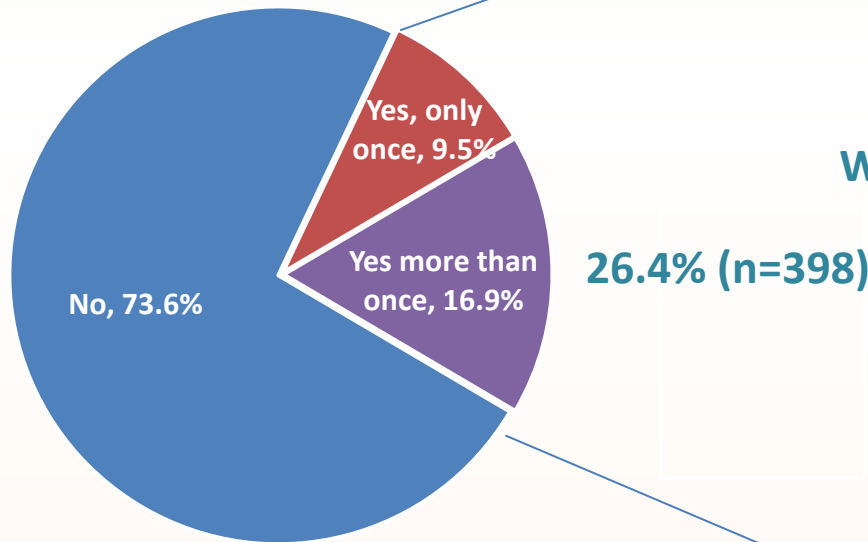


Support for family having EoLC at Home

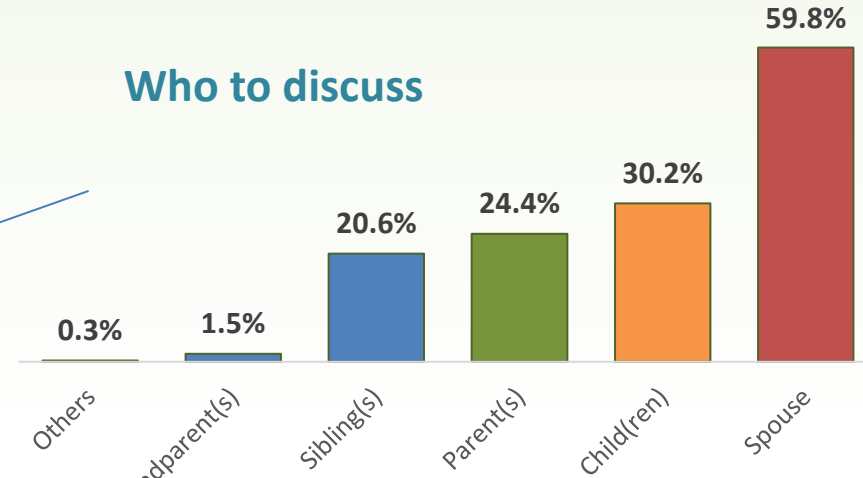


Family Discussion on Personal EoLC (N = 1506)

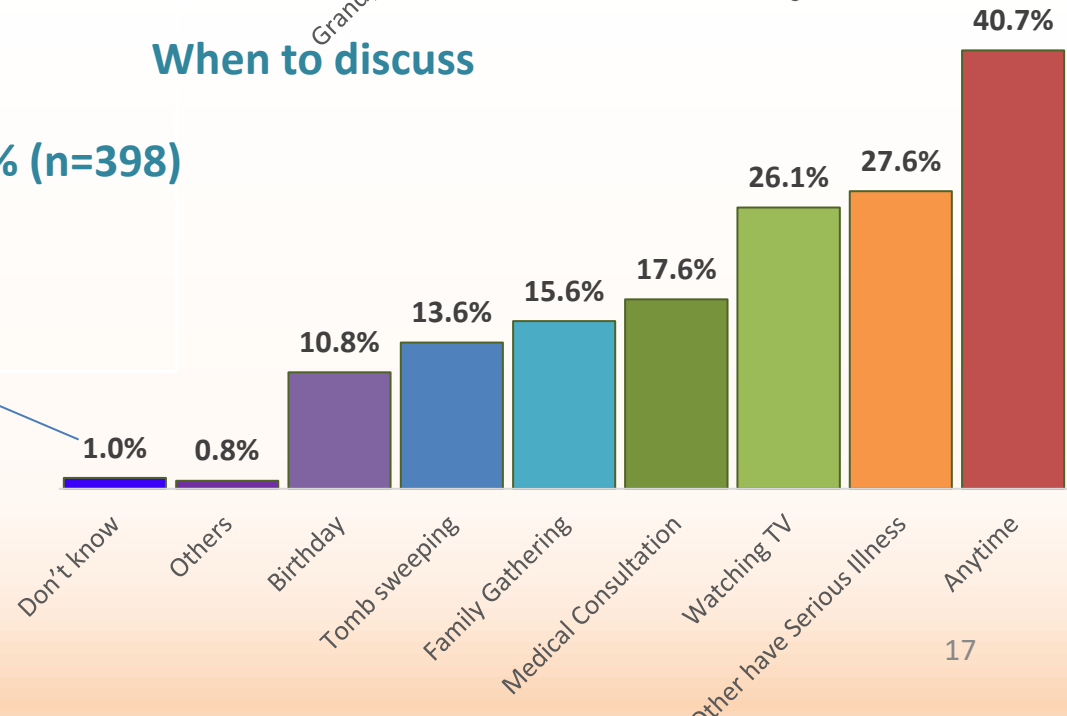
More than 25% of the respondents had discussed personal or familial EoLC with their family.



Who to discuss

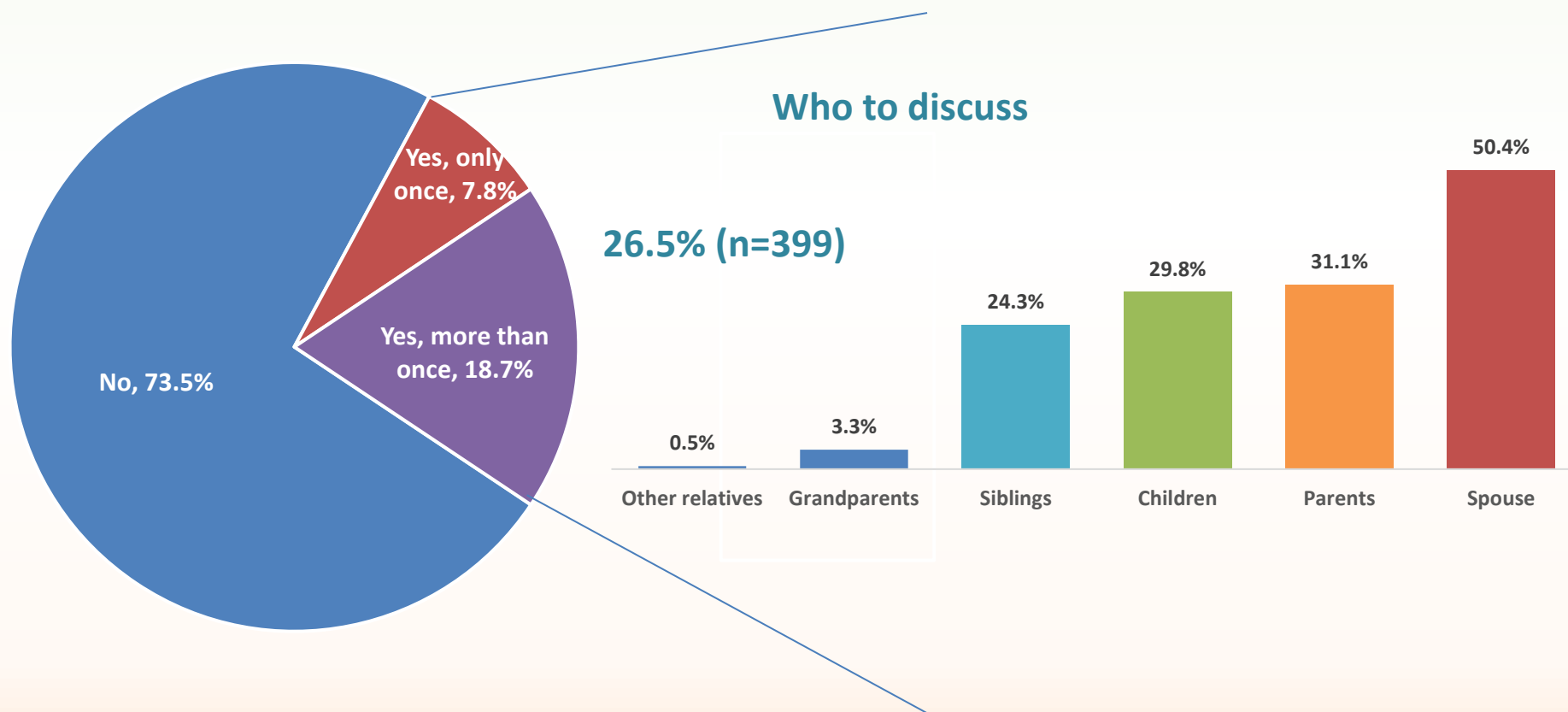


When to discuss



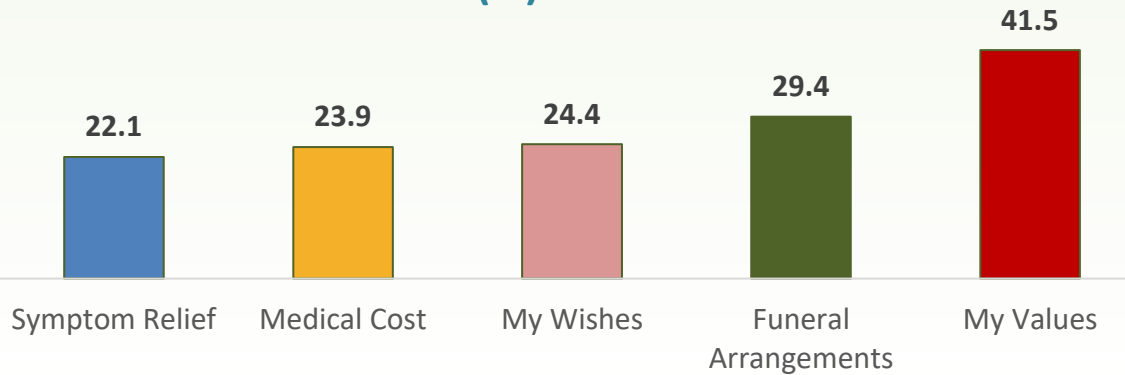
Family Discussion on Family Member's EoLC (N = 1506)

More than 25% of the respondents had discussed personal or familial EoLC with their family.



What to discuss and What's the impact (n = 398)

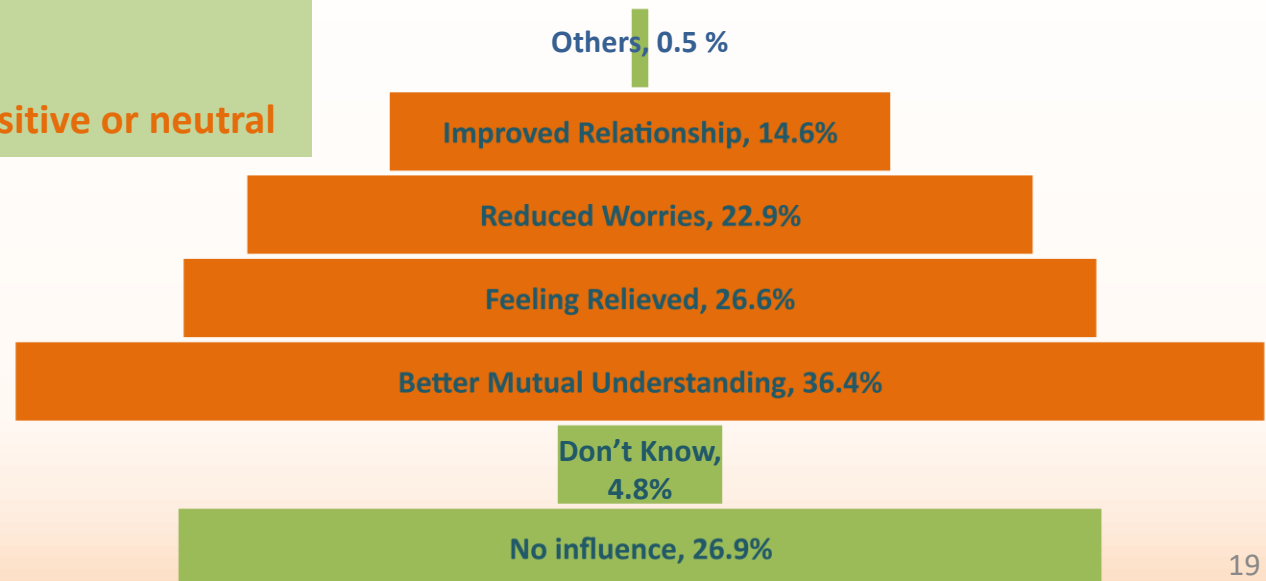
What are Discussed (%)



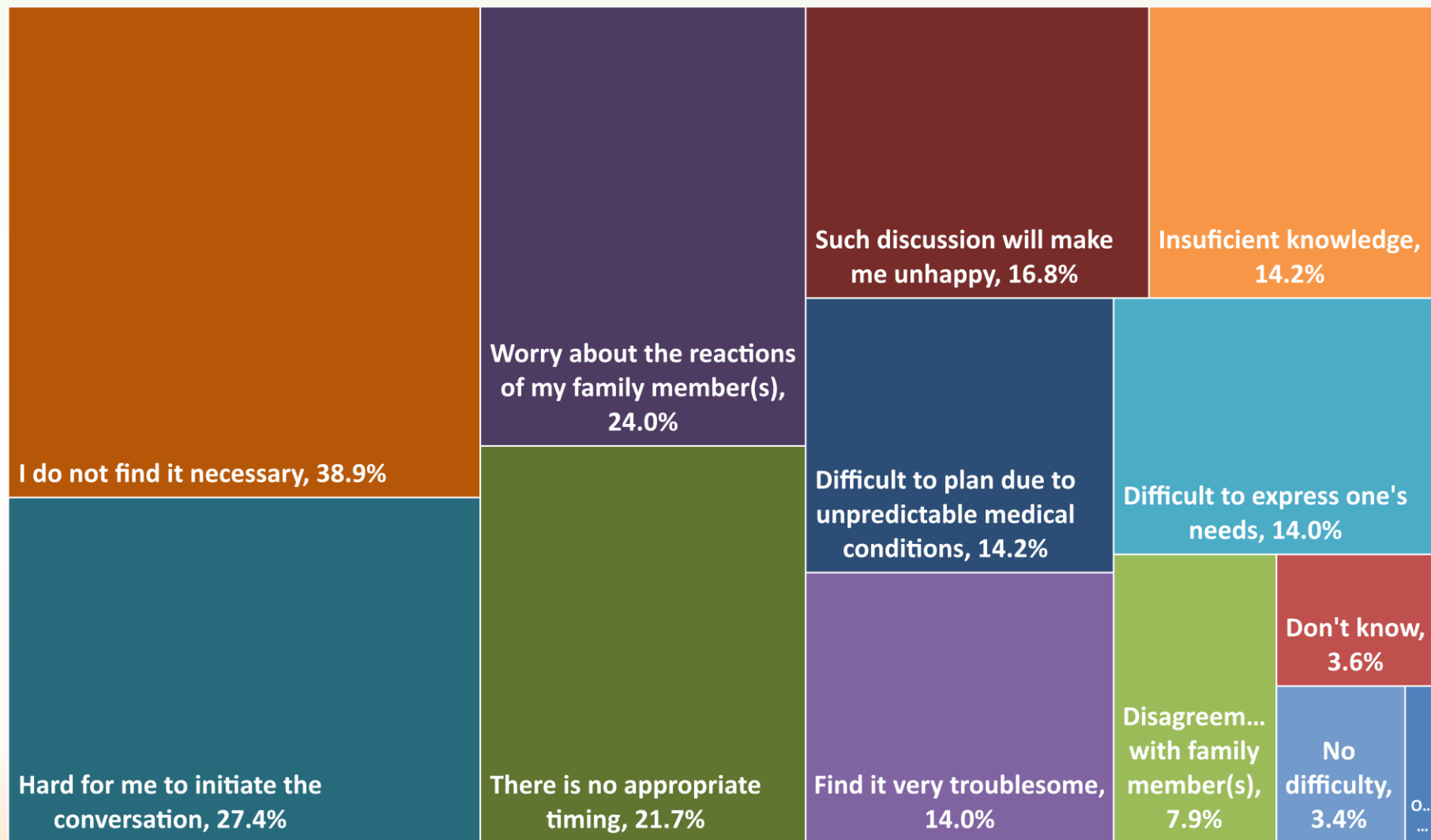
Family EoLC discussion mainly focused on values and practicality

Impact of Discussion

- No adverse effect, but positive or neutral



Reasons for Not Discussing Personal EoLC in Family (n = 529)



#2

Advance Care Planning and Advance Medical Directive discussion shall be promoted and individualized

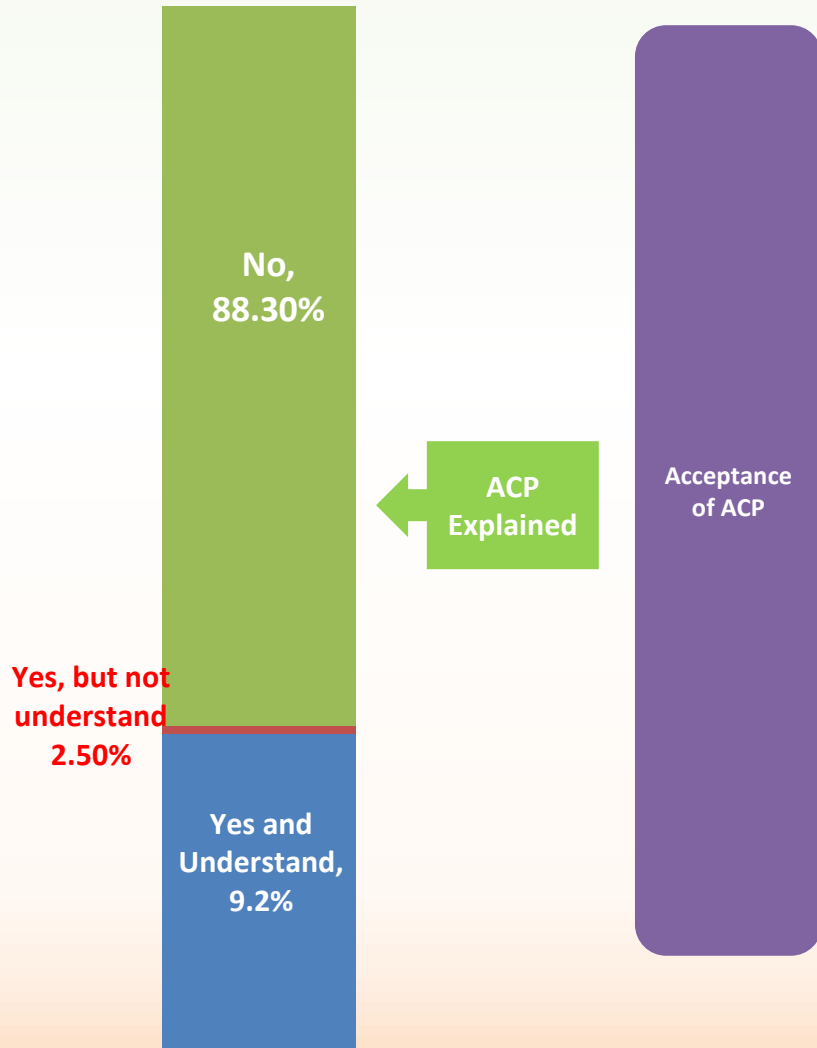
Advance Care Planning (ACP)

Advance care planning (ACP) refers to the process of communication among a patient with advanced progressive diseases, his/her health care providers, and his/her family members and caregivers regarding the kind of care that will be considered appropriate when the patient can no longer make those decisions. ACP is an overarching and preceding process for such decisions, based on the mentally competent adult patient's preferences and values, and the risks and benefits of individual treatment. (HA, 2020, p.21)

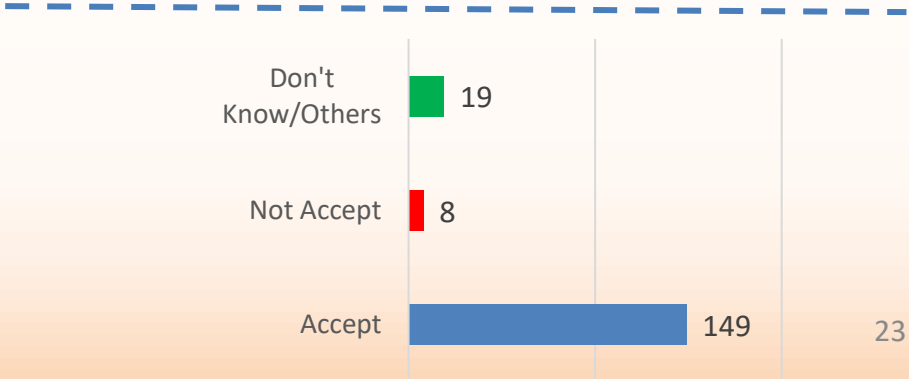
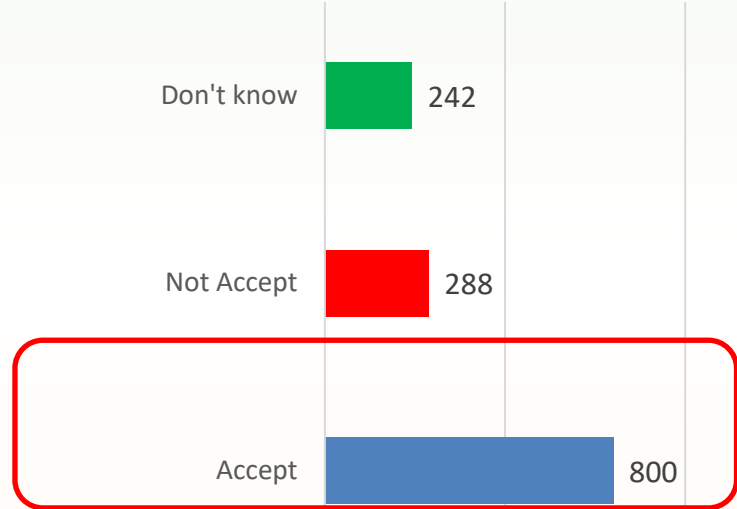
Heard of ACP and Acceptance

(N = 1506)

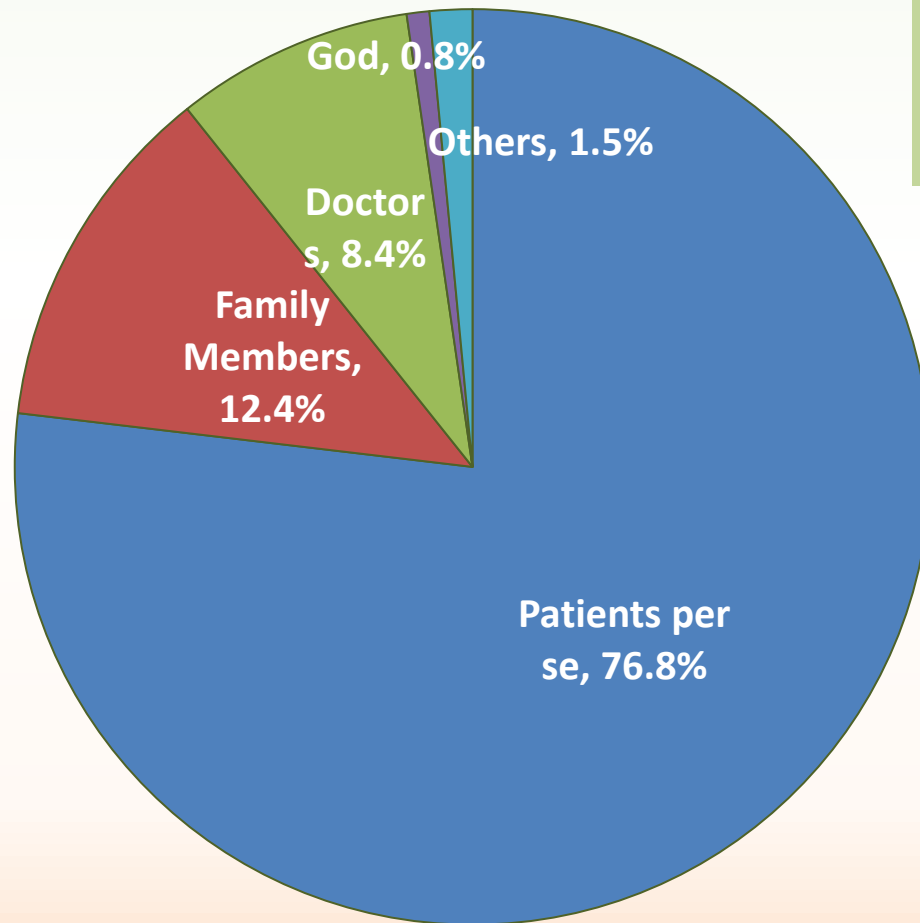
Heard of ACP



With information provided, more than 2/3 of those who have not heard of ACP will opt for it



Final decision maker for one's treatment in EoL (N = 1506)



Three out of four of the respondents thought they should be the final decision maker of their treatment in EoL

Most Appropriate Person to Discuss

ACP for oneself and family members

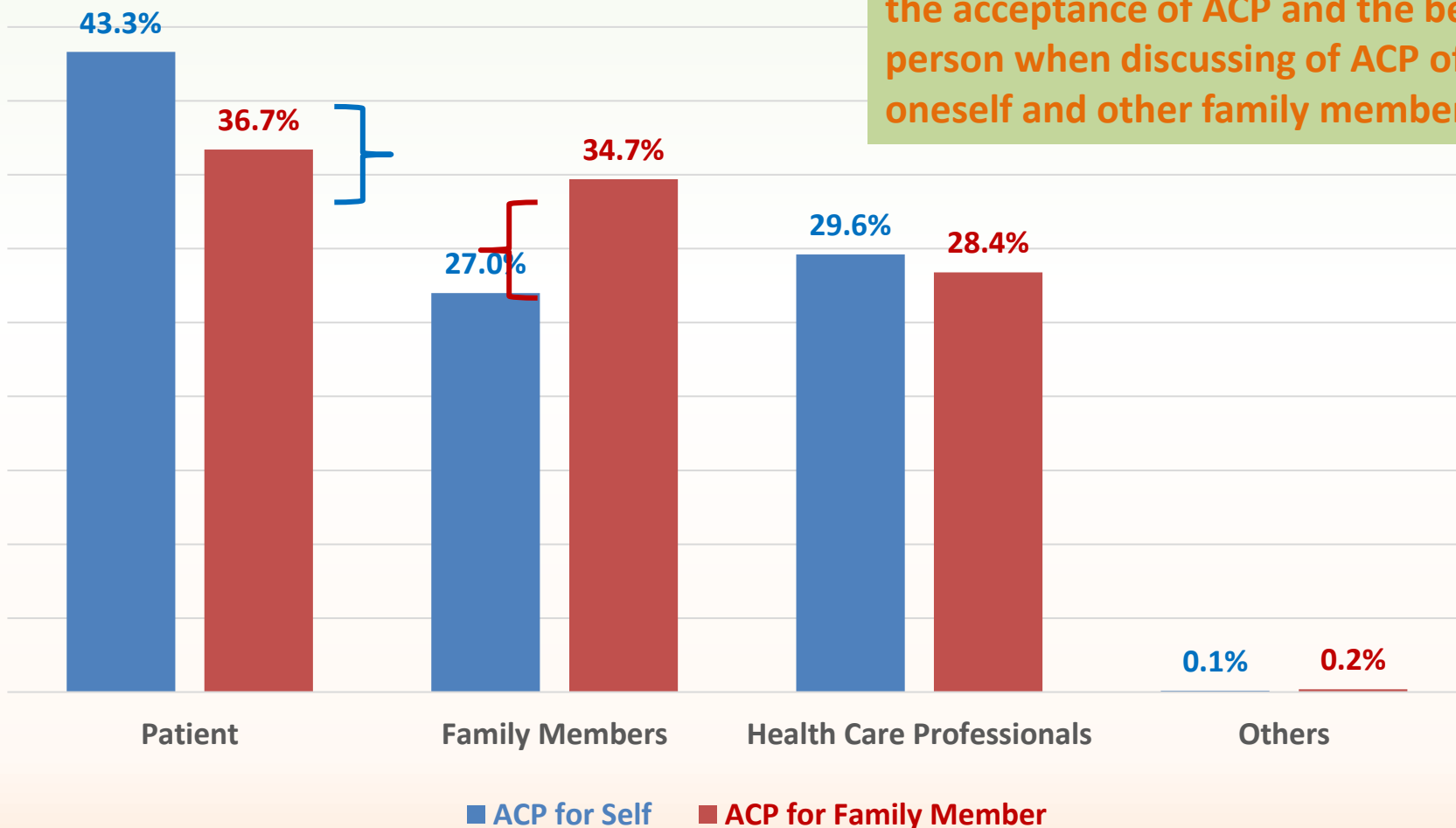
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Jockey Club End-of-Life Community Care Project

(n = 900)

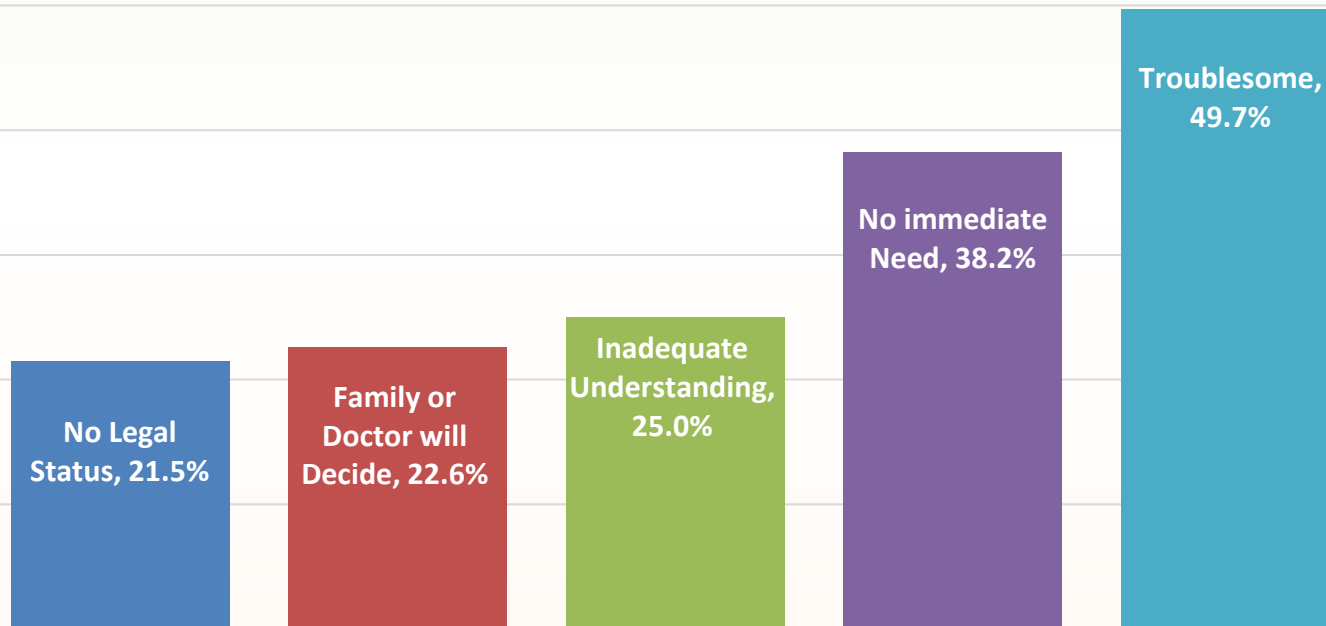
There are discrepancies between the acceptance of ACP and the best person when discussing of ACP of oneself and other family members.



Only for those who did not have ACP before and intended to do it after explanation (n=900)

Reasons for no intention for ACP (n=288)

Among those who do not have intention to establish “Advance Care Planning”, 49.7% considered the procedures to be complicated; 38.3% perceived no immediate need, and 25% with insufficient understanding.



Advance Medical Directive (AMD)

An AMD generally refers to a written statement in which a person indicates, while mentally capable, what life-sustaining treatment he/she would refuse when he/she is no longer capable of doing so.

(Legislative Council, 2023, p.1)

Heard of AMD and Acceptance

(N = 1506)

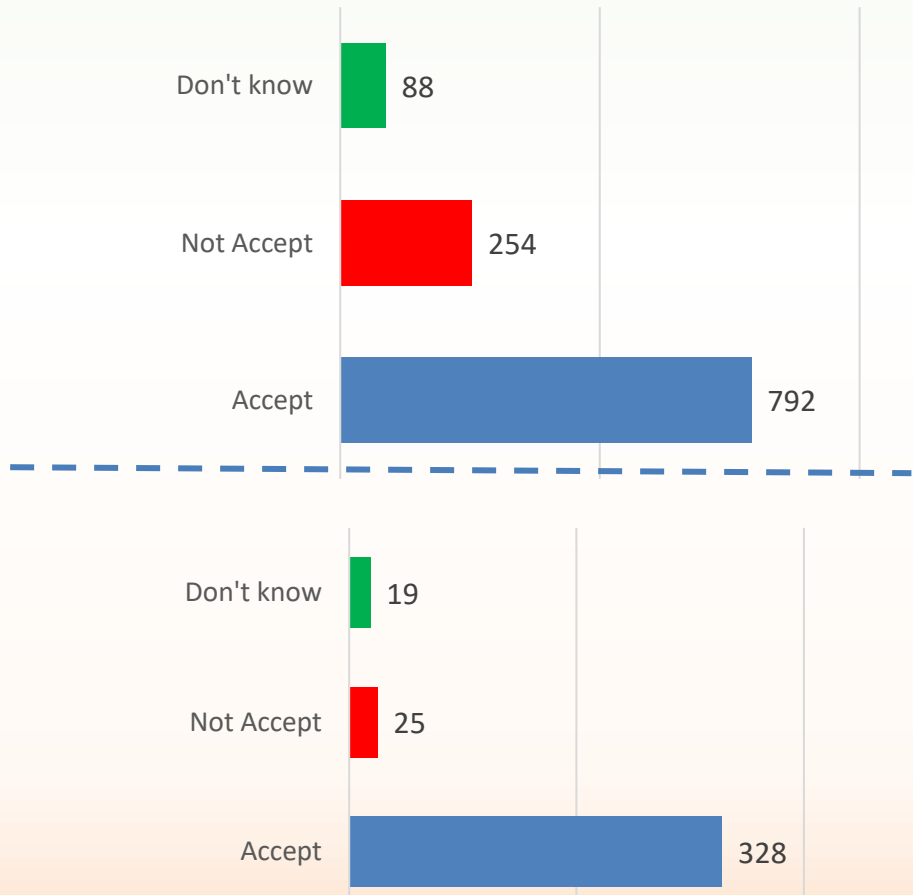
Heard of AMD



← AMD Explained

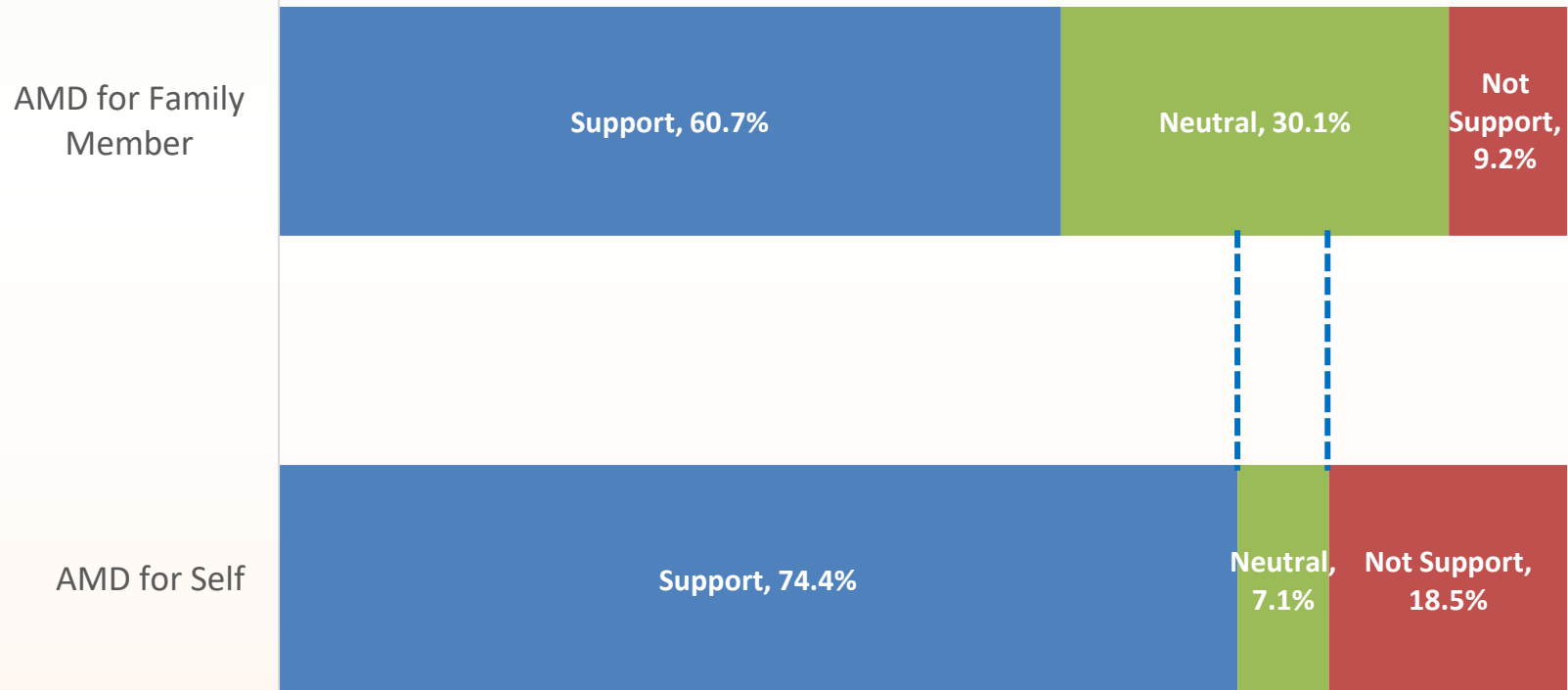
Though there were ¾ of the participants hadn't heard of AMD, 70% of them opted for it when the information was provided

Acceptance of AMD



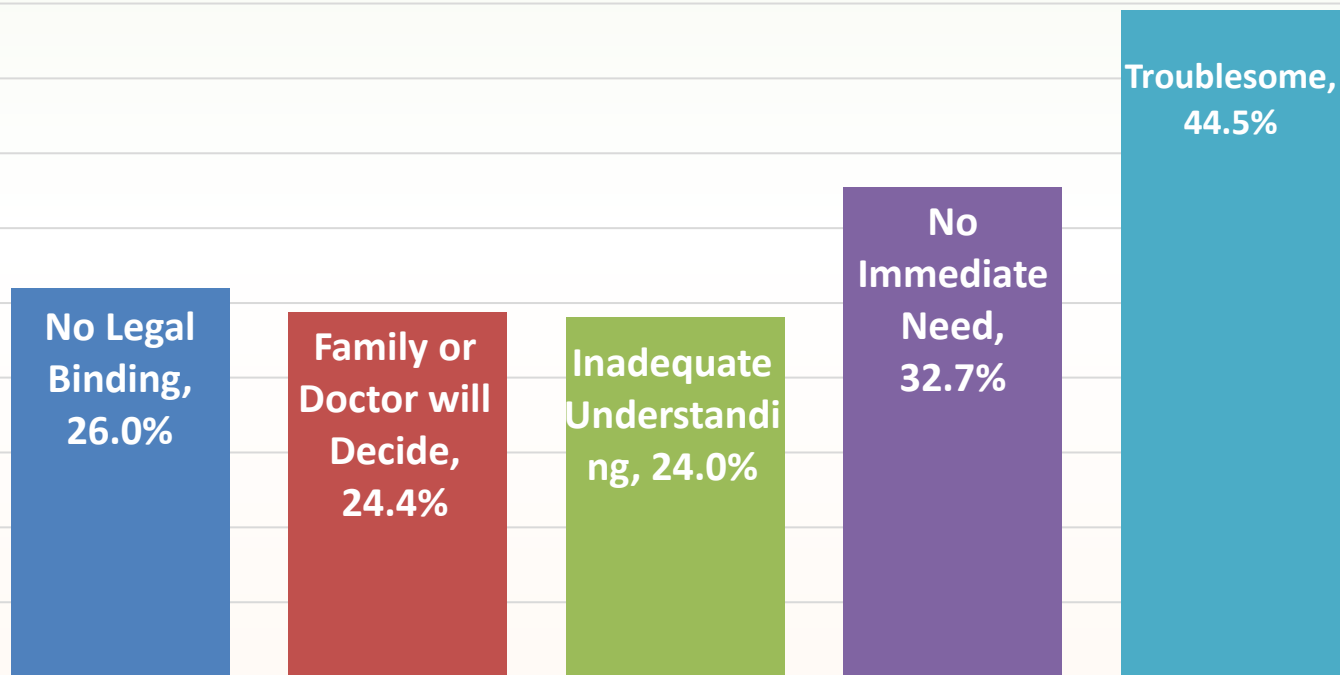
Intention for self and family for AMD (N = 1506)

About 75% and 60% of the participants agreed to have AMD for themselves and their family members, respectively

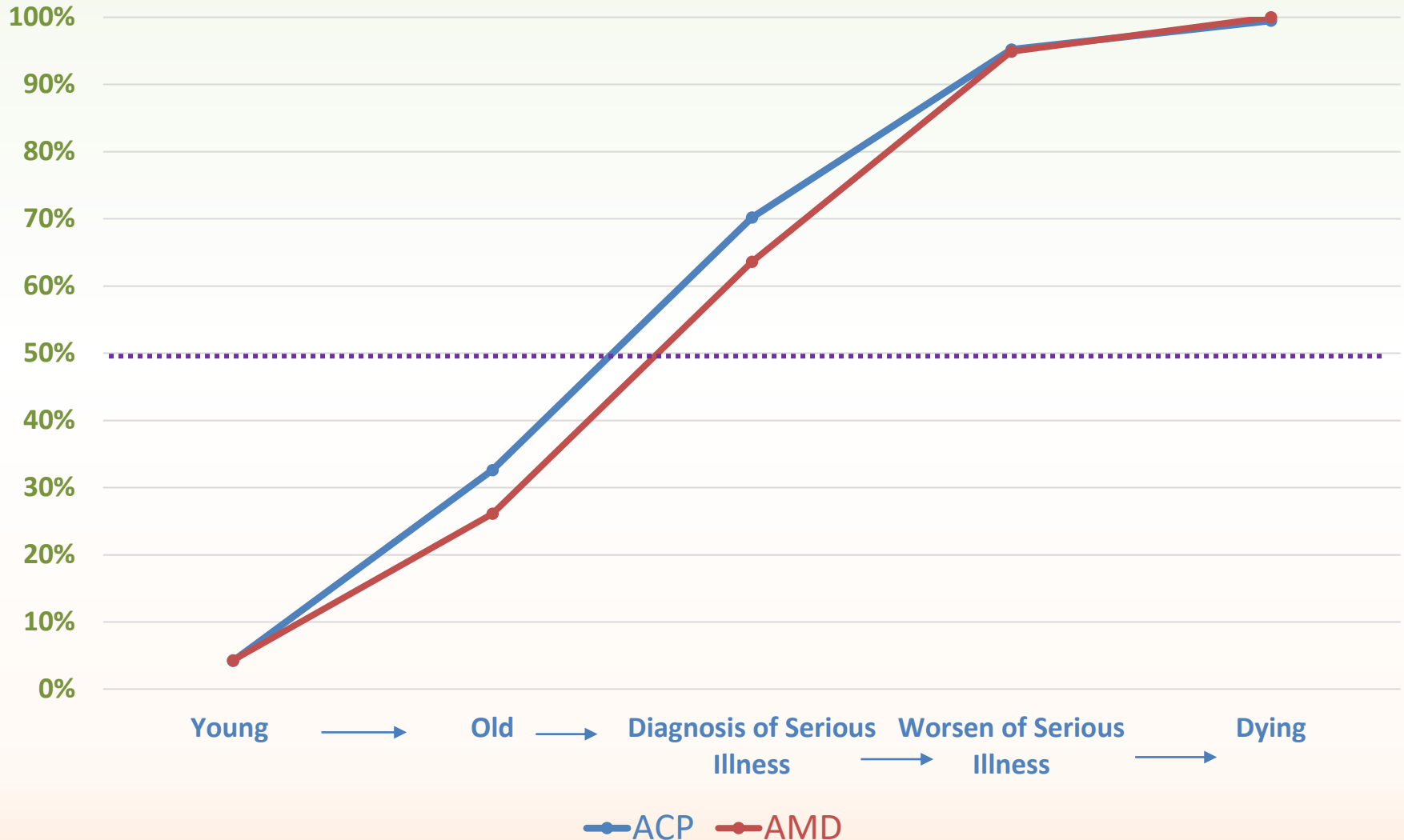


Reasons for no intention for AMD (n=254)

Among those who do not have intention to establish “Advance Medical Directive”, 44.5% considered the procedures to be complicated; 32.7% perceived no immediate need, and 26% believe it’s not legal binding.



Best Timing for ACP (n=900) and AMD (n=1065)



Only for those who did not have ACP before and intended to do it after explanation (n=900) and for those who did not have AMD before and intended to do it after explanation (n=1065)

#3 The timing is now

- Majority accept AMD
- The Advance Decision on Life-Sustaining Treatment Bill and relevant legislative amendments drafted by the HKSAR government is subject to second reading

Conclusions

- Death is not necessarily a taboo topic, and people are prepared to discuss the end-of-life care decision with family members. While the perceptions of end-of-life care and decision are different for self and family members, communications within family are needed
- With the information provided, they opted to accept the care and planning. Thus, this is the appropriate time for HKSAR Government to proceed the legislation of the related policy. In addition, public education and professional training should be strengthened

Case Sharing

Supplementary slides

End-of-Life Care (EoLC)

Palliative and end-of-life care is provided to people who have an incurable and progressive illness to improve their quality of life (Food and Health Bureau, 2019, p. 42)

Those who will choose EoLC after information provided (n=676 vs 830)

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More likely be

- **With chronic or life-threatening illness**
($B = .38, p = .001$)
- **Female** ($B = .22, p = .03$)
- **Married** ($B = .39, p = .001$), **widowed** ($B = .79, p = .003$)
[compared with Never married]
- **Age group of 50-64** ($B = .41, p = .02$),
65-69 ($B = .71, p < .001$), and **70+** ($B = .50, p = .04$)
[compared with 18-29]

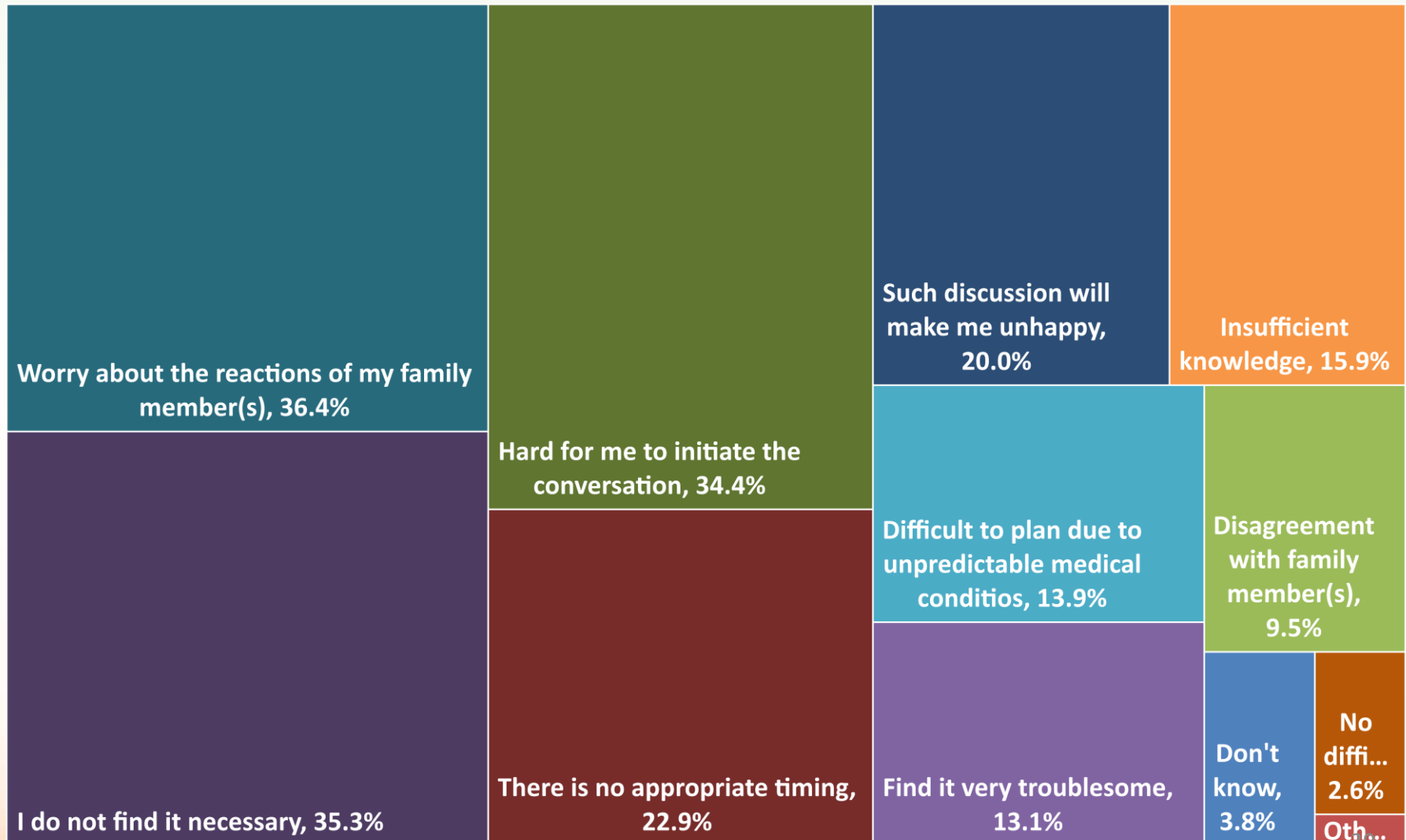
Religion, family members with chronic and life-threatening illness have no differences

Those who will choose EoLC after information provided (n=676 vs 830)

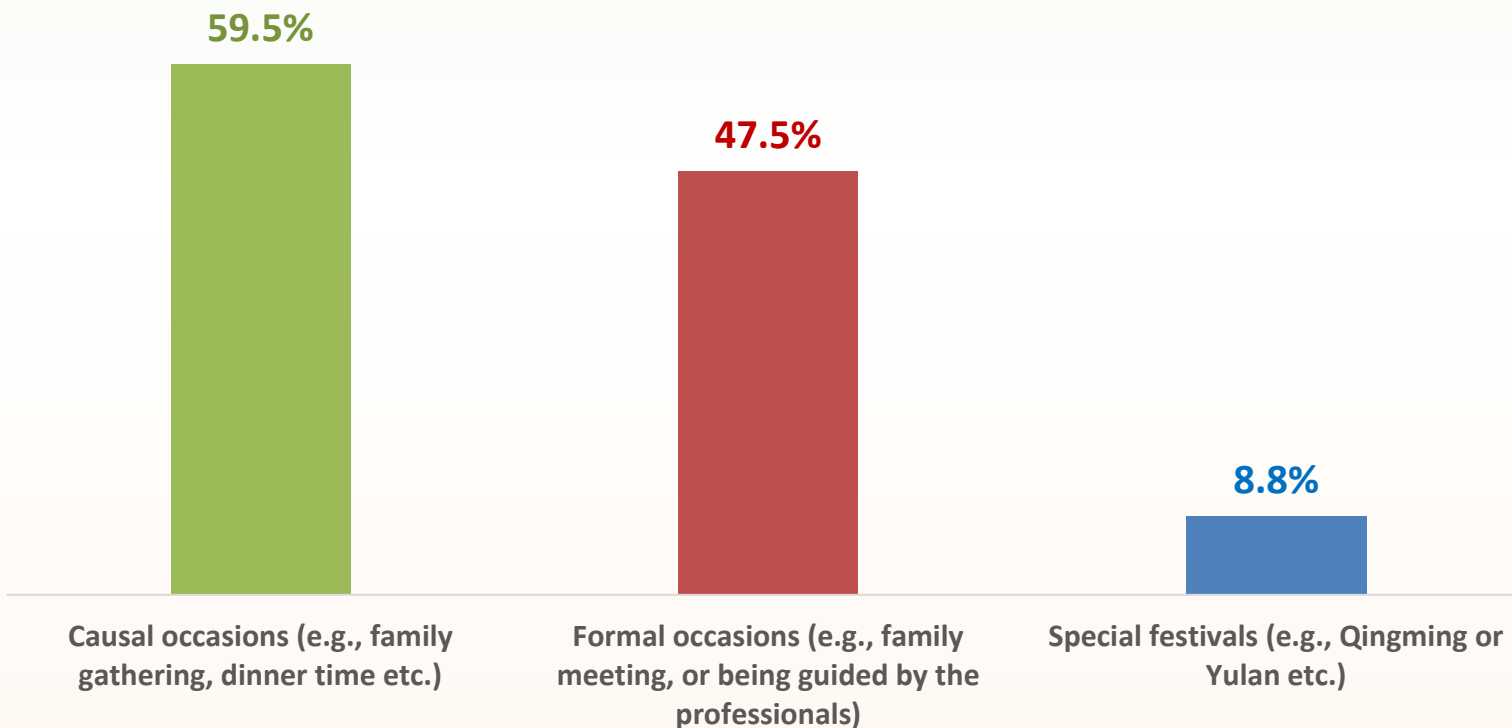
Less likely be

- **Have secondary education** ($B = -.35, p = .02$)
- **Or tertiary education** ($B = -.45, p = .002$)
[compared with Primary of below]

Reasons for Not Discussing Family Member's EoLC (n = 654)



Suitable Occasion for Family Discussion (N=1506)



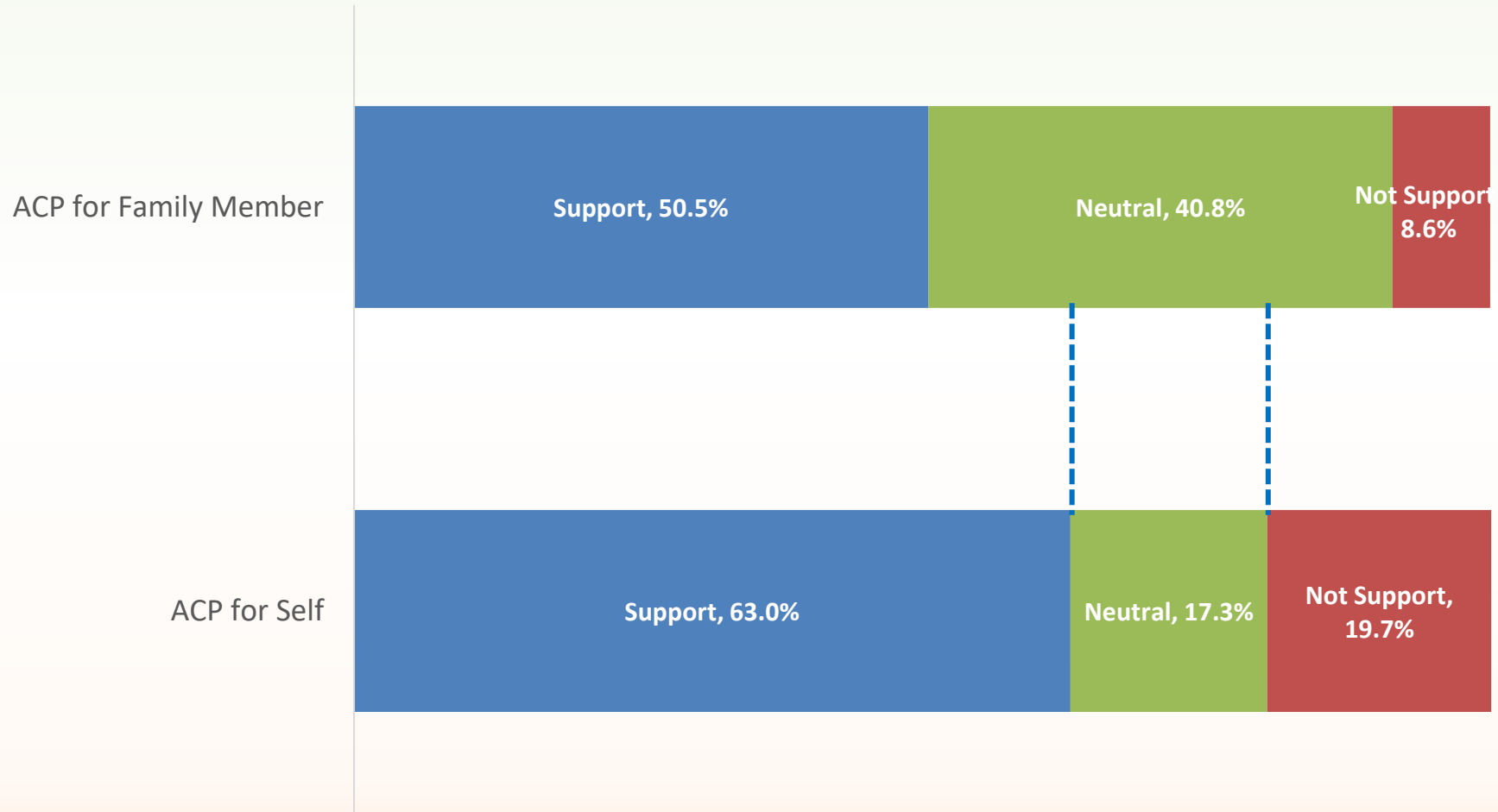
Those who will accept ACP after information provided (n=800 vs 288)

More likely be

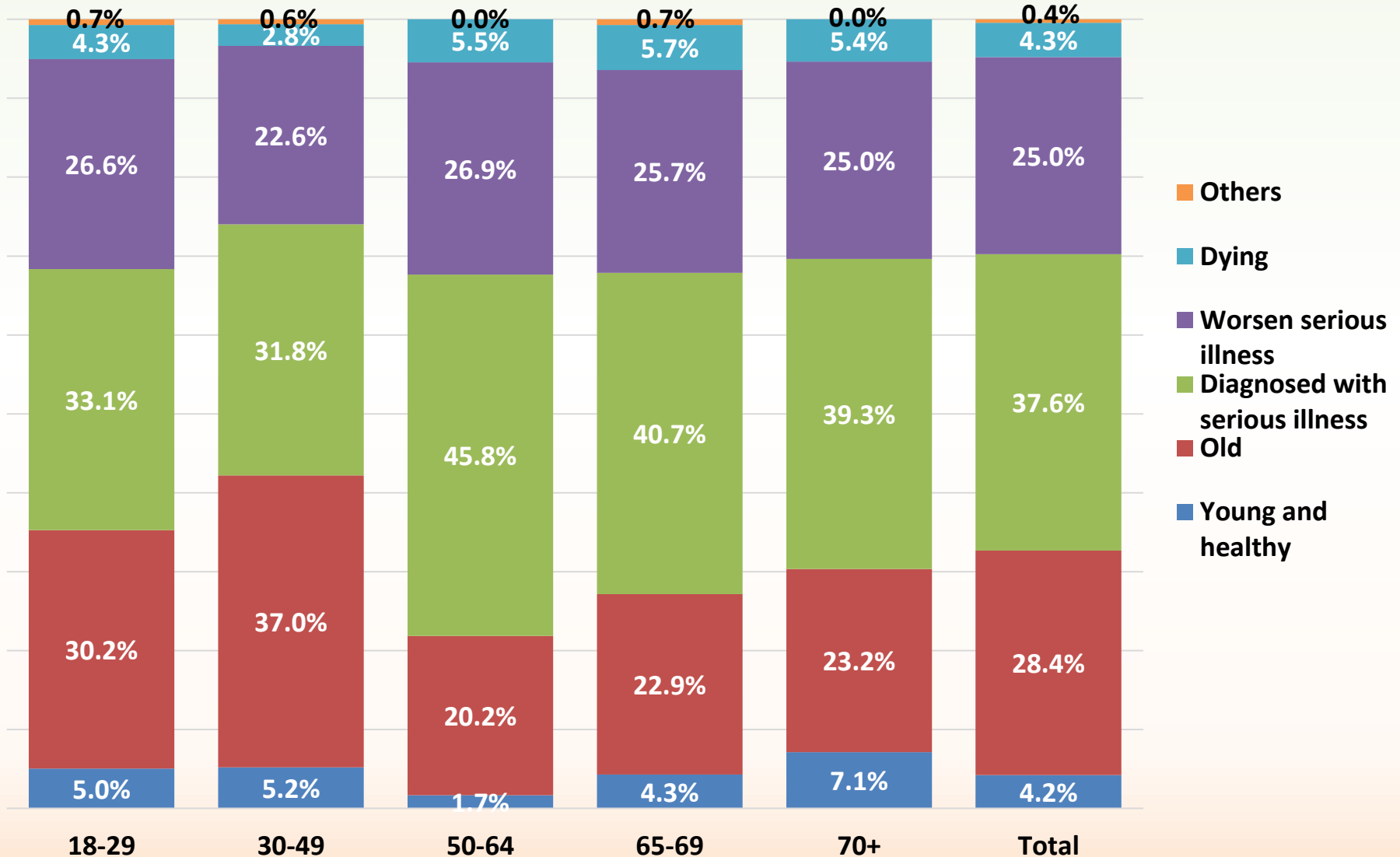
- **Female** ($B = .72, p < .001$)
- **With religion** ($B = .35, p = .02$)
- **Family members with chronic or life-threatening illness** ($B = .38, p = .01$)
- **With tertiary education** ($B = .71, p = .001$) [Compared with Primary school or lower]

Oneself with chronic and life-threatening illness, age group, marital status have no differences

Intention for self and family for ACP (N = 1506)

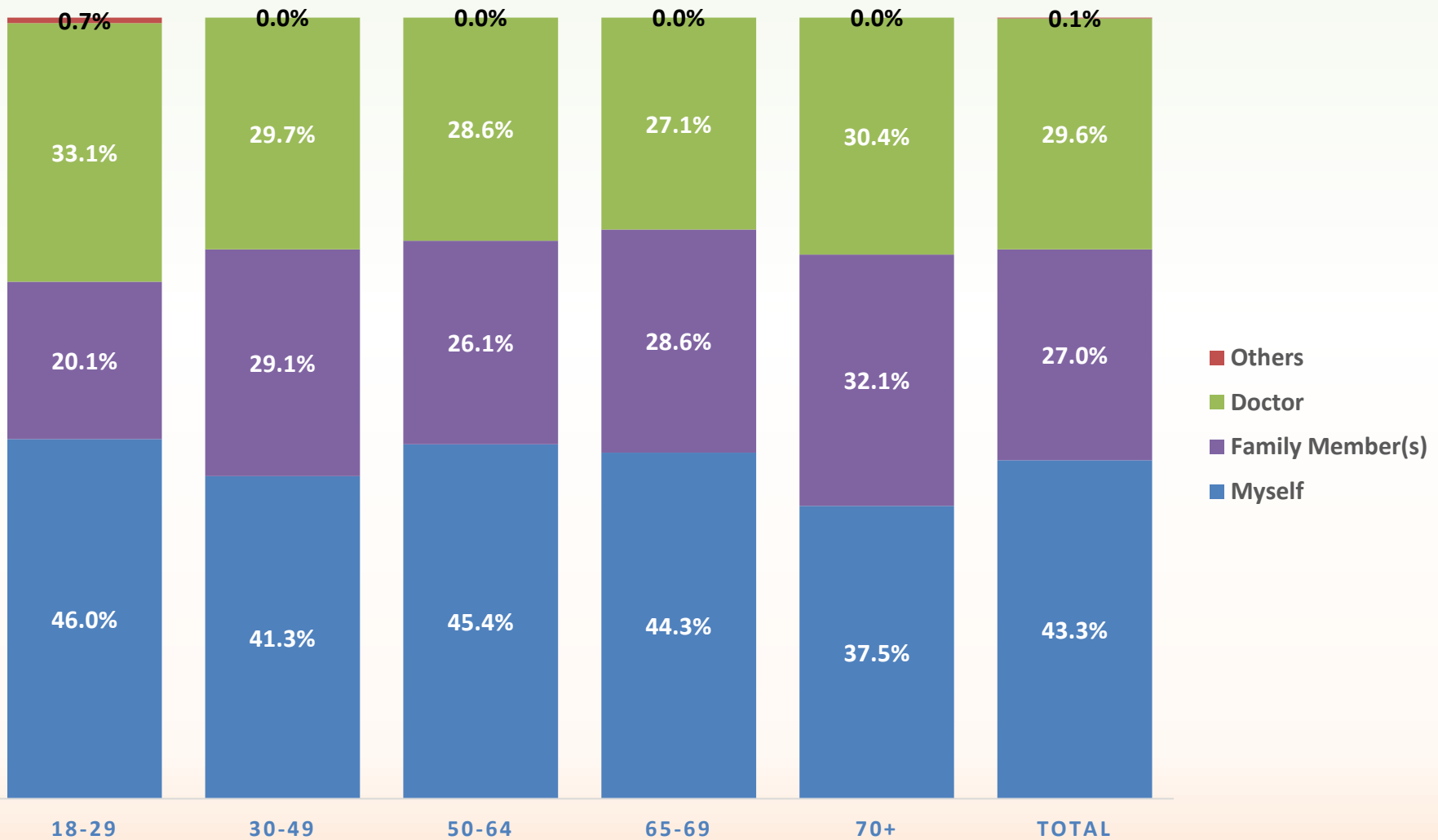


Best Timing for ACP (n = 900)



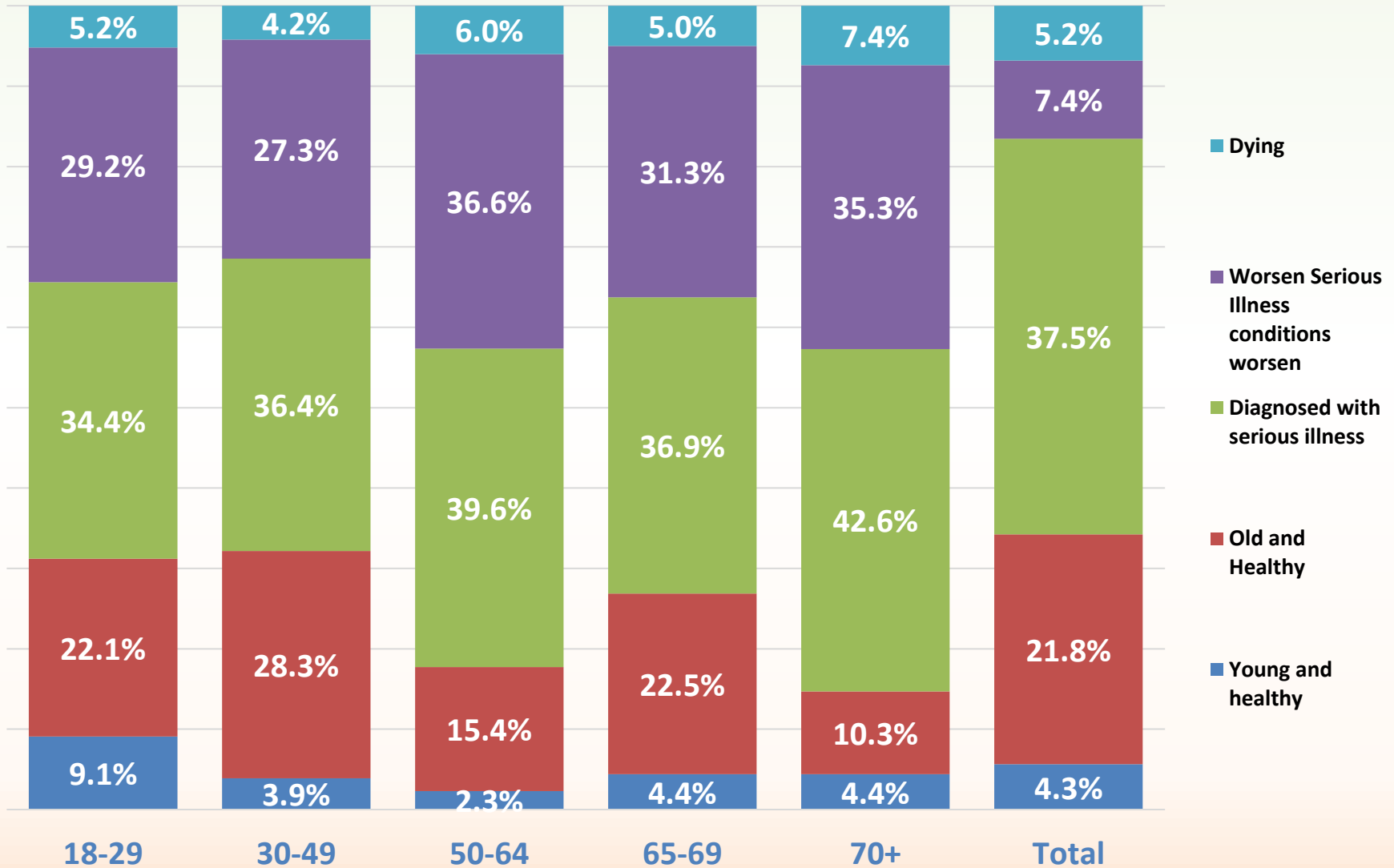
Only for those who did not have ACP before and intended to do it after explanation (n=900)

Most appropriate person to initiate an ACP discussion (n = 900)



Only for those who did not have ACP before and intended to do it after explanation (n=900)

Best Timing for AMD (n = 1065)



Only for those who did not have AMD before and intended to do it after explanation (n=1065)

Those have AMD and Chance of Revoke

- There were 28 respondents (1.86%) with an AMD
 - They all revealed to have a 50:50 chance to change the directives
- In a systematic review of 24 studies, 17 studies, more than 70% of patients' preference were stable over time (Auriemma et al., 2014).
- In the US, a study with 104 cancer patients, 81% had stable preference at 1st month and 68% at 2nd/3rd month. 32% changed at least once (Jabbarian et al, 2019)
- In Japan, the stability of the preferred place of death of older adults in three years was 40% (Kawaguchi et al, 2022)

- Public talks
- Public education programmes

[Online Learning Platform for Patients and Carers | JCECC](https://foss.hku.hk/jcecc/en/online-learning-patients-and-carers/)

[\(https://foss.hku.hk/jcecc/en/online-learning-patients-and-carers/\)](https://foss.hku.hk/jcecc/en/online-learning-patients-and-carers/)

Publications:



Learn more:



JCECC aimed at enhancing the quality of community end-of-life care ("EoLC") in Hong Kong. To provide capacity building for the public, patient and family, social and health care professionals, and to hold public education events.

The **JCECC Online Learning Platform** for Patients and Carers aims to provide a platform for them to learn essential end of life care knowledge including the concepts of palliative care, communication skills, self-care and community resources. The platform features various videos, contents and self-reflection exercises, with the goal of enhancing the EoLC knowledge of patient and carer and promoting a caring society.

Publications are available for community stakeholders use to discuss their EoLC decisions.



安寧照顧病人及照顧者網上學習平台

JCECC 賽馬會安寧頌計劃 - 安寧照顧病人及照顧者網上學習平台

賽馬會安寧頌晚期病人與照顧者網上學習平台旨在為晚期病人與照顧者提供一個地方學習基本的安寧照顧知識，包括安寧照顧概念、溝通技巧、自我關懷和社區資源，平台上載不同的影片、文字和自我反思練習，期望為推遲晚期病人與照顧者的安寧照顧知識，從而推動關愛社會。

故事篇

- 身心社靈，由生活入手
- 擁抱晚臨，心靈慰藉
- 自主、自決、自愛
- 平安三寶

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