



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

Patients' and Families' Perceptions of Palliative Care

Dr Bridget Johnston

Research Fellow

Centre for Health Policy and Management

13 September 2018

BACKGROUND AND MOTIVATION

Background

Preferences for palliative care

- Important to ensure resources are focused on services patients and their loved ones derive the greatest benefit from
- Different models + limited evidence
 - Delivery of palliative care services often influenced by national policy, funding arrangements and historical practices
- Evidence about preferences provides information about how services would best be delivered
- Caregivers may have different needs/preferences – important to balance these with patients' preferences

Background

Perceptions of palliative care

- A negative perception of palliative care is a common barrier to the introduction of a palliative care approach or the introduction of specialist palliative care (SPC) services.
- Perceptions of palliative care have also been shown to influence patients' preferences for place of care
- There is little empirical evidence, however, on the perceptions and preferences of Irish patients and their loved ones.
- Similarly, there is little data on what may influence their preferences.

Motivation

- **What works? For whom? What circumstances?**
- **Limited evidence about peoples' preferences**
 - What do they feel they need?
 - Similarities between patients and their family/friends
- **Identifying the factors that may influence preferences for care**
 - People may not understand the role of SPC services
 - Age, experience with SPC services, caregiver burden, etc.

Aim and Research Questions

Aim: To explore perceptions of palliative care among patients and family members accessing SPC services in Ireland and identify whether personal characteristics and geographical location are associated with expressed preferences for services.

The key questions:

1. Which characteristics of services and support are valued most by patients and their loved ones when living with a life-limiting illness?
2. How do perceptions and experiences of palliative care and hospice services, or other factors, influence these preferences?

METHODS

Methods

The International Access, Rights and Empowerment Plus (IARE+) Study

Study design

- Face-to-face survey
- Three regions across Ireland
- Preferences and perceptions of palliative care and hospice services
- Discrete choice experiment

Methods

Discrete Choice Experiments

- Participants make trade-offs between made-up scenarios
- Establish the importance of individual traits/characteristics of a service
 - What do they think the priorities are?
- Previously used in with people accessing palliative care
 - Day care, home care and over 65s

Example of a DCE Choice Card

Which of these trips to the cinema would you prefer?

	Scenario A	Scenario B
Type of film	A classic film	A new 3D release
Price	€5	€10
Distance from home	25 minutes	15 minutes

I would prefer: Scenario A

Scenario B

Example of DCE Choice Card

	Scenario A	Scenario B
Knowing whom to contact	I do not know whom to contact when I have questions or need advice and I can't find out	I know whom to contact when I have questions or need advice, but I often can't get the answers I need
Cost of care per month	All services are free	€200 per month
Access to palliative care services in community or hospital	Automatically when something happens to me, like my quality of life gets worse	When I may have a short time left to live
Impact of symptoms on my life	Symptoms significantly limit my ability to live the life I want	Symptoms somewhat limit my ability to live the life I want
Amount of help at home I need from family and friends	Around 40 hours per week	Around 20 hours a week
Arranging access to services	We have to find out about and arrange access to the services on our own	A healthcare professional provides information about services and helps us arrange access
How decisions are made	The doctors provide advice and I make the decisions about my care	The doctors looking after me make the decisions about my care
Place of care	I am cared for in the hospital as an inpatient	I am cared for in the hospice as an inpatient
I prefer:	Scenario A <input type="checkbox"/>	Scenario B <input type="checkbox"/>

Palliative Care Questions

Likert scale questions

1. Strongly Agree
2. Agree
3. Neither Agree nor Disagree
4. Disagree
5. Strongly Disagree

- _____ 1. Palliative care services are only available in the hospital or hospice.
- _____ 2. Palliative care can only be offered by specialist teams.
- _____ 3. Palliative care is as good as treatment from other hospital teams.
- _____ 4. Palliative care is for people who are at the end of life.
- _____ 5. Palliative care can provide support for family and friends.
- _____ 6. Palliative care means giving up.
- _____ 7. Palliative care means you get no treatment.
- _____ 8. Palliative care focuses on improving a person's quality of life.
- _____ 9. Palliative care causes people to die before their time.
- _____ 10. Palliative care is usually only offered to people who have been diagnosed with cancer.

Hospice Services Questions

Likert scale questions

1. Strongly Agree

2. Agree

3. Neither Agree nor Disagree

4. Disagree

5. Strongly Disagree

_____ 1. Hospices only provide inpatient care.

_____ 2. Hospices provide services at no cost.

_____ 3. The quality of treatment in the hospice is as good as in the hospital.

_____ 4. The hospice is for people who are at the end of life.

_____ 5. Being admitted to the hospice means you get no treatment.

_____ 6. The hospice can provide support for family and friends.

_____ 7. Services provided by the hospice focuses on improving quality of life

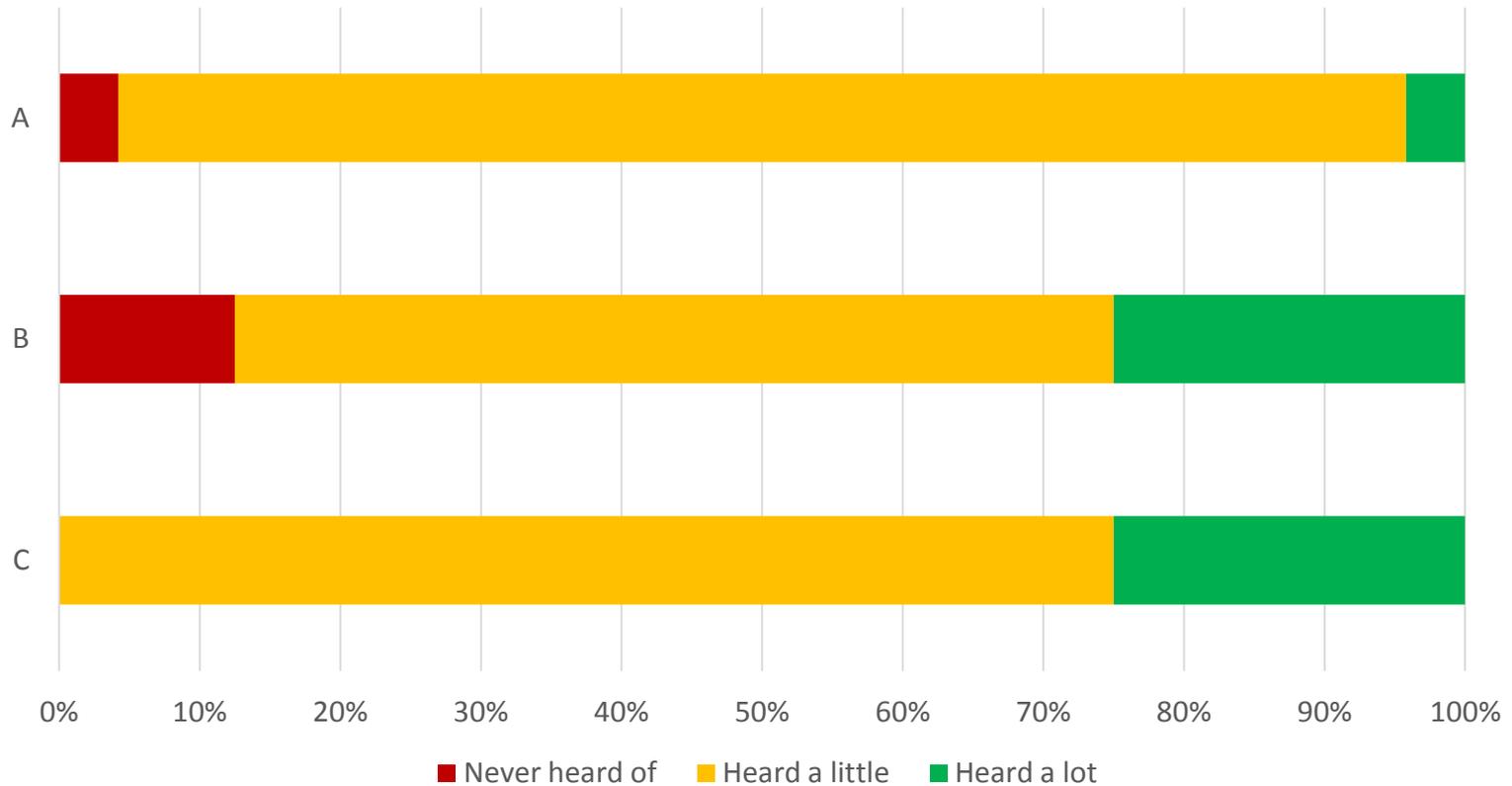
_____ 8. Being admitted to the hospice causes people to die before their time.

_____ 9. Treatment as an inpatient in the hospice is usually only offered to people who have been diagnosed with cancer.

KEY FINDINGS

Patients' Knowledge of Palliative Care

Regional differences



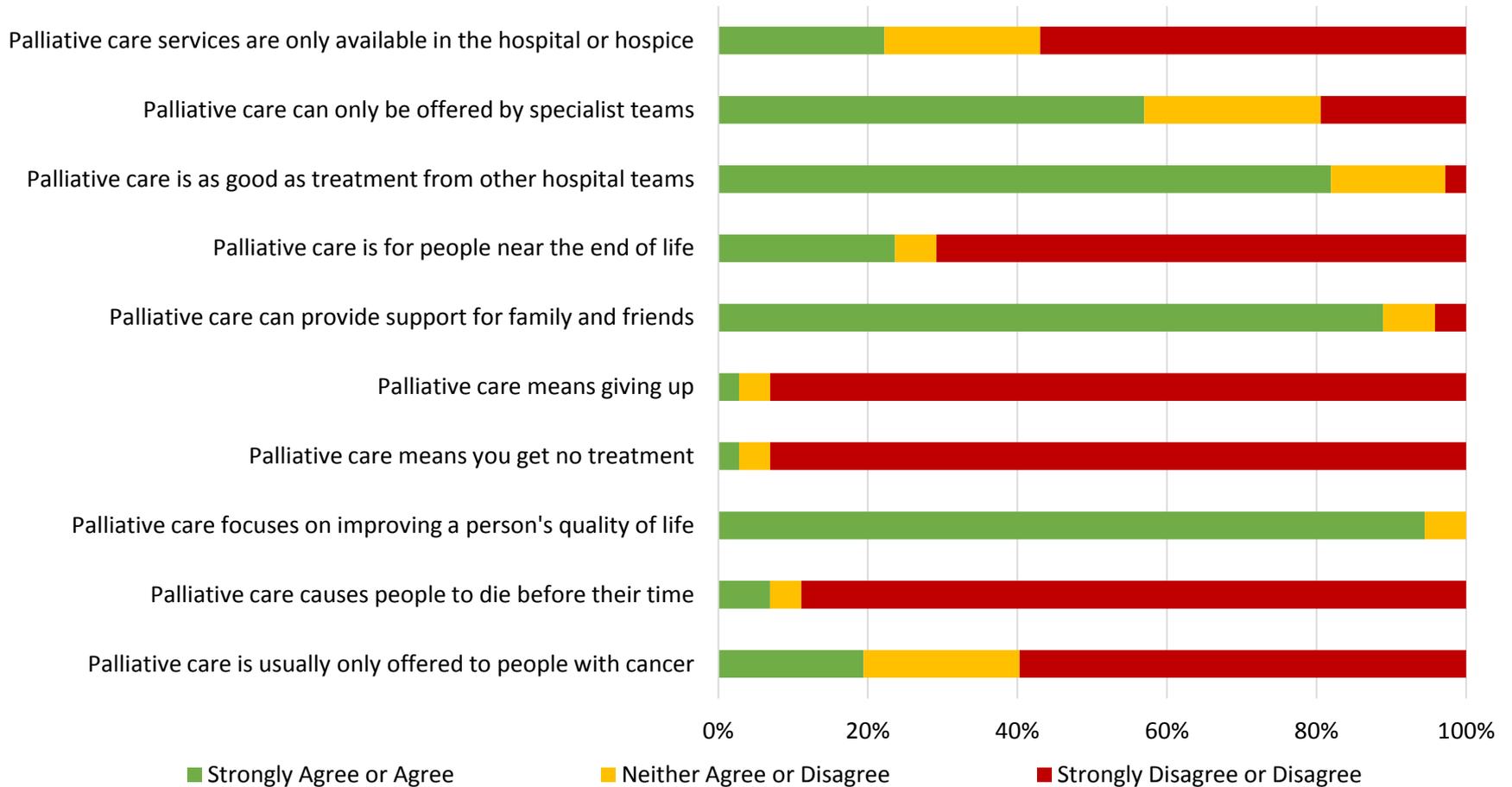
Patients' Experiences of Palliative Care

Regional differences

	Region A (n=26)		Region B (n=25)		Region C (n=24)		Total
	N	%	N	%	N	%	%
I know someone who used palliative care	4	16.7	10	41.7	8	33.3	36.0
I have used palliative care myself	19	79.2	19	79.2	24	100	44.0
From radio, television, newspaper or internet	0	-	0	-	1	4.2	2.7
From my family and friends	1	4.2	0	-	1	4.2	2.7
From others (specify)	2	8.3	0	-	1	4.2	1.3

Patients' Perceptions of Palliative Care

All participants



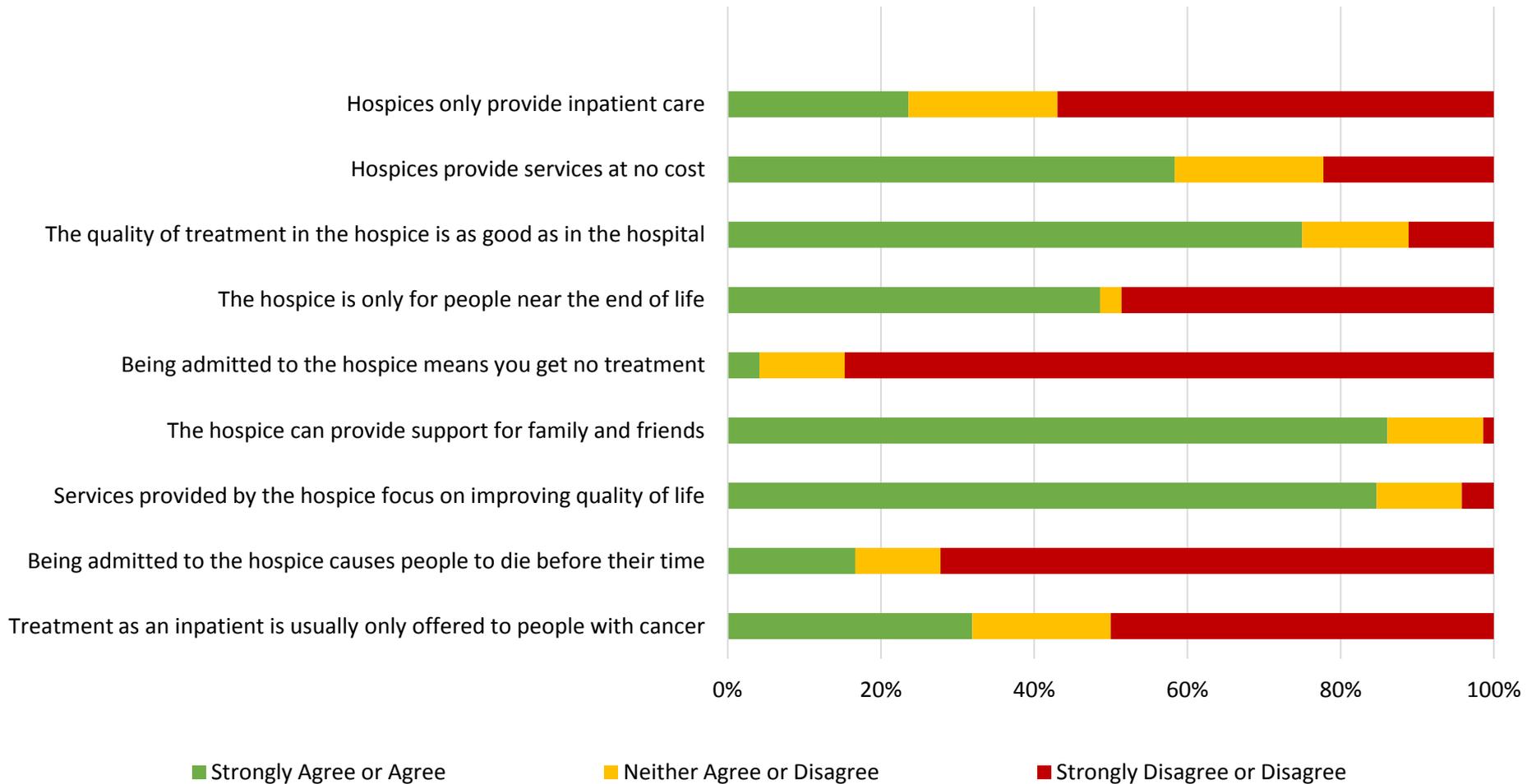
Patients' Experiences of Hospice

Regional differences

	Region A (n=26)		Region B (n=25)		Region C (n=24)		Total
	N	%	N	%	N	%	%
I know someone who used hospice services	8	30.8	8	32.0	11	45.8	36.0
I have used hospice services myself	25	96.2	3	12.0	5	20.8	44.0
From radio, television, newspaper or internet	0	-	0	-	2	8.3	2.7
From my family and friends	0	-	0	-	2	8.3	2.7
From others (specify)	0	-	1	4.0	0	-	1.3
I have not heard of hospice services	0	-	16	64.0	9	37.5	33.3

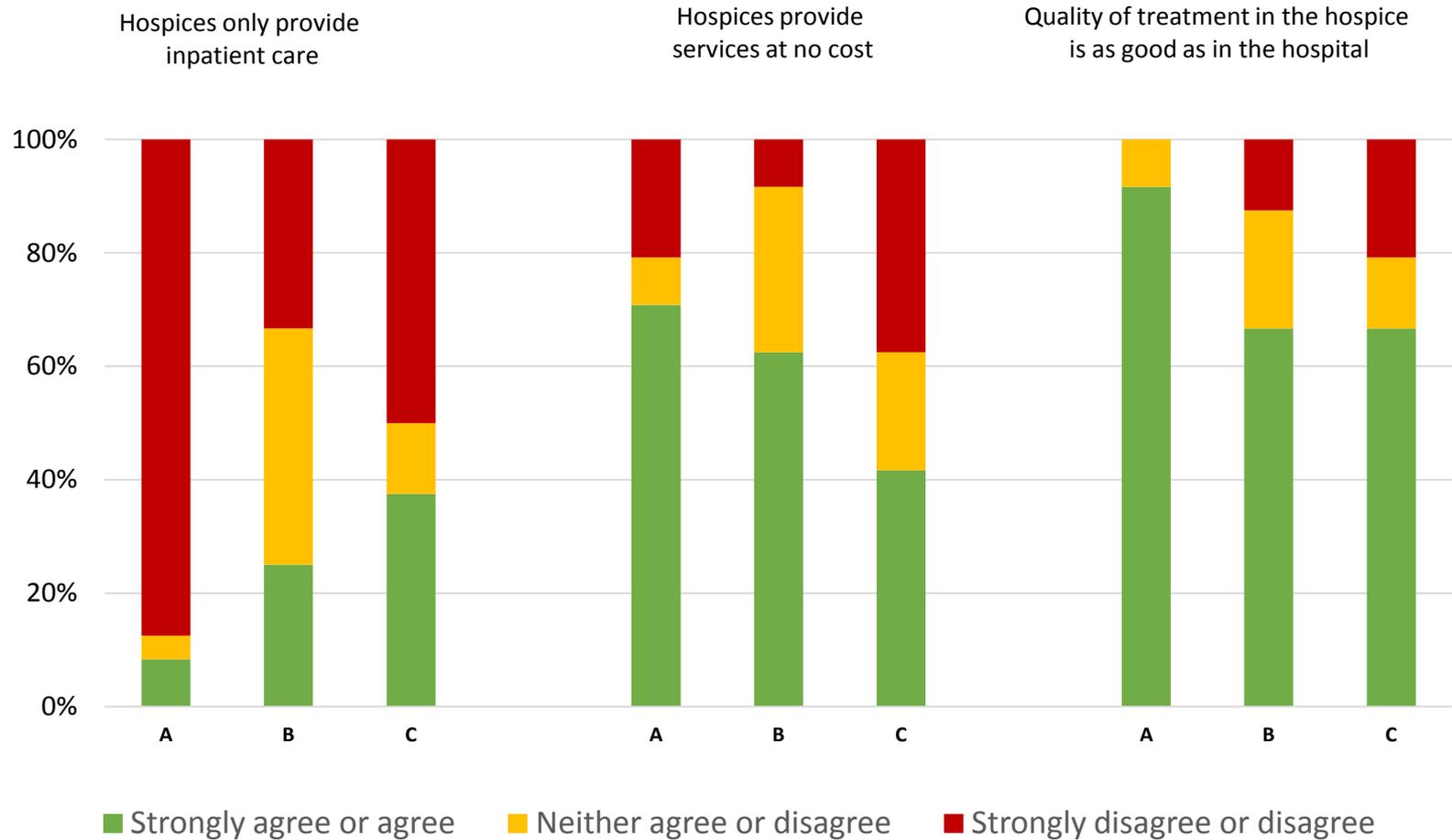
Patients' Perceptions of Hospice

All participants



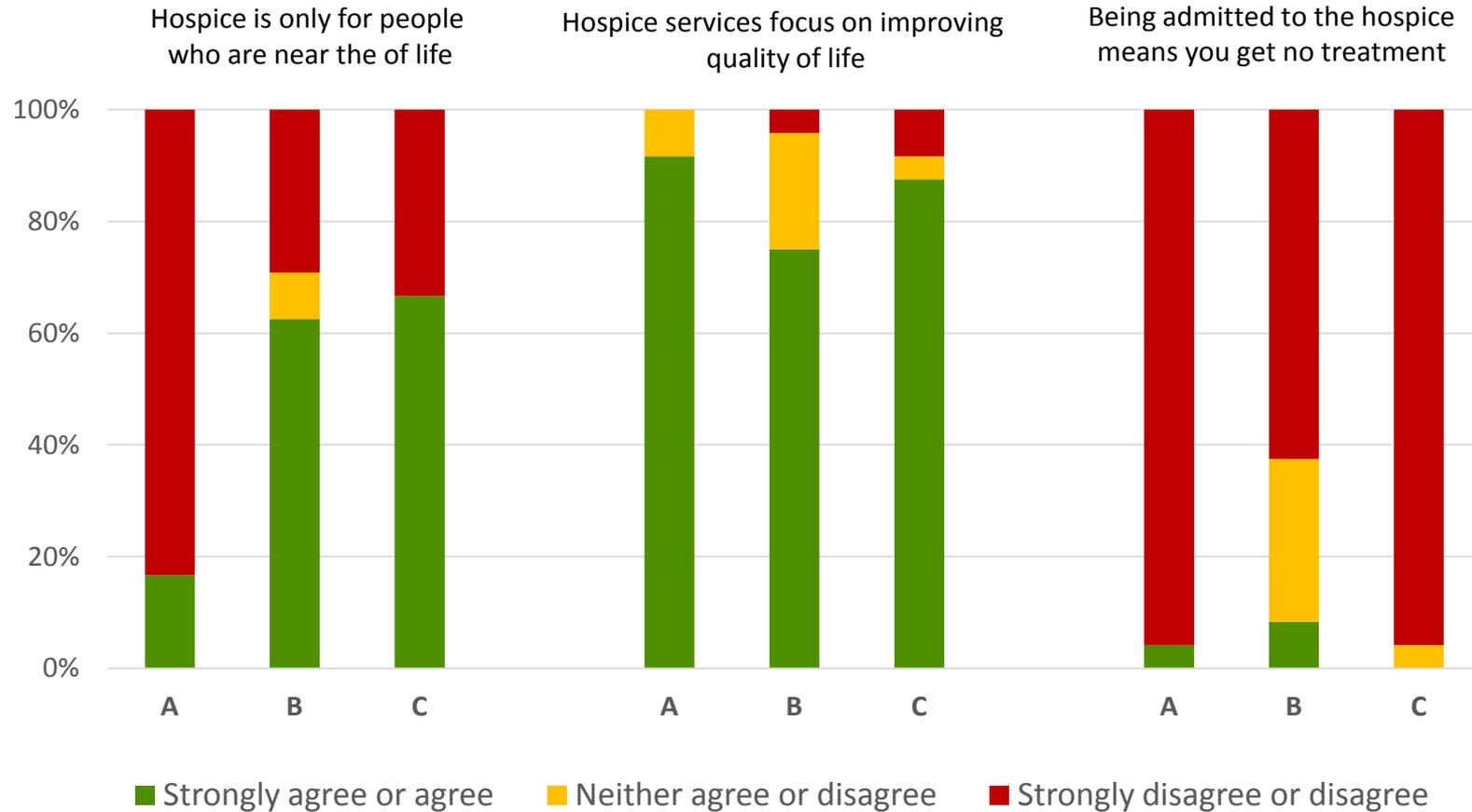
Patients' Perceptions of Hospice Services

Responses by Region

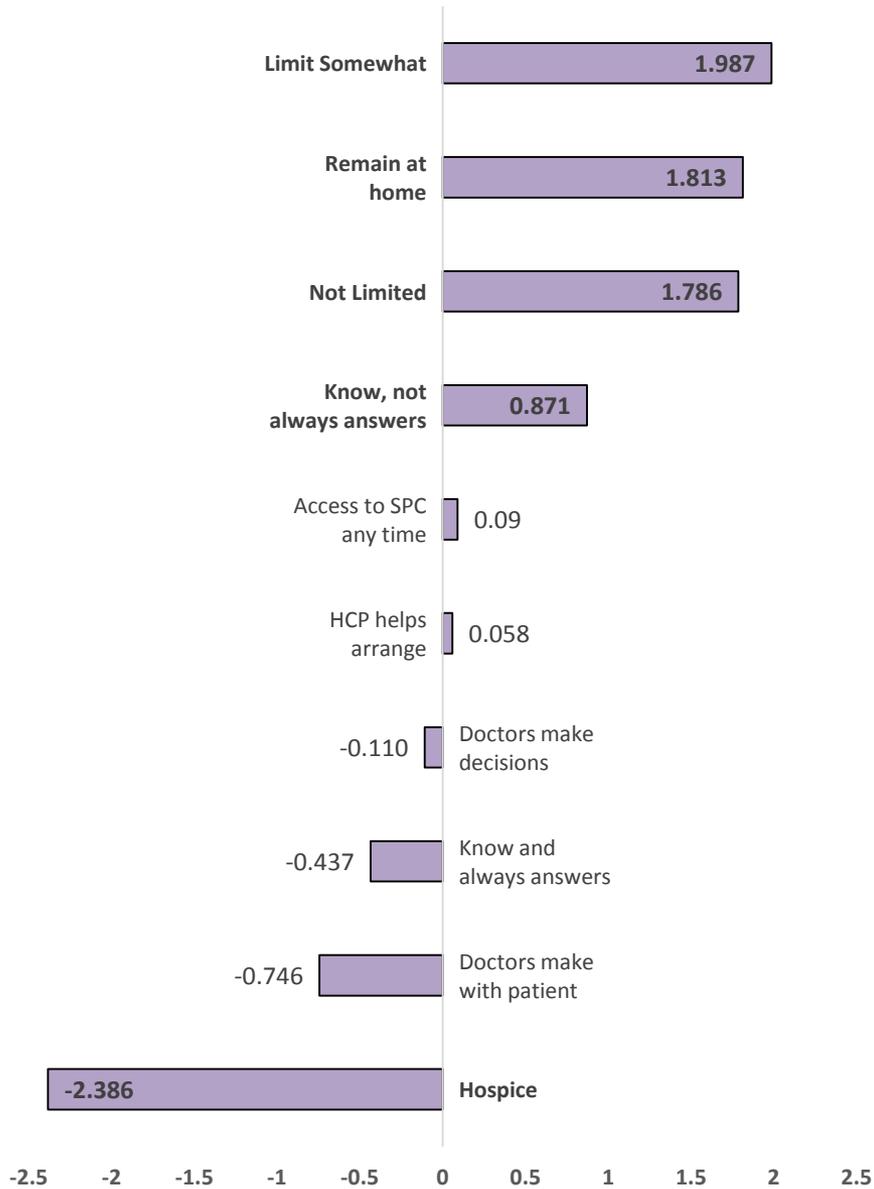


Patients' Perceptions of Hospice Services

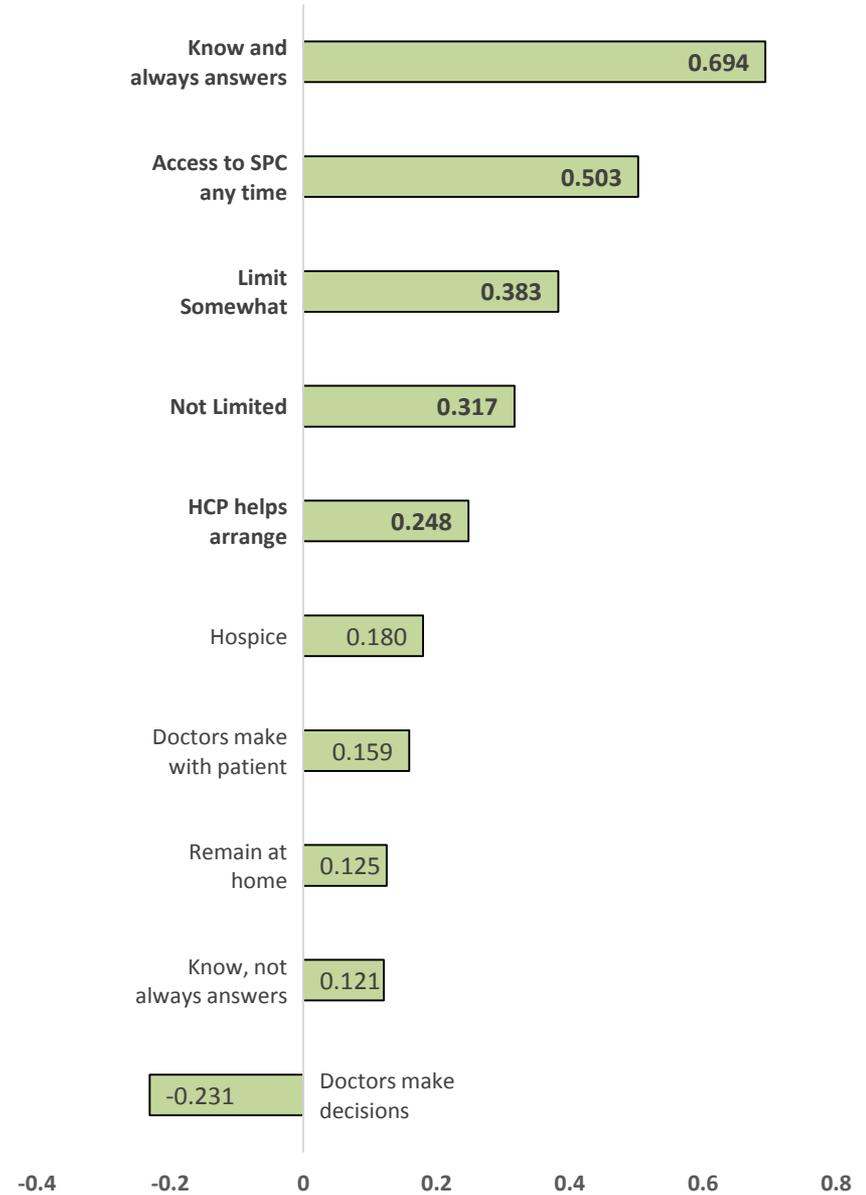
Responses by Region



Group 1



Group 2

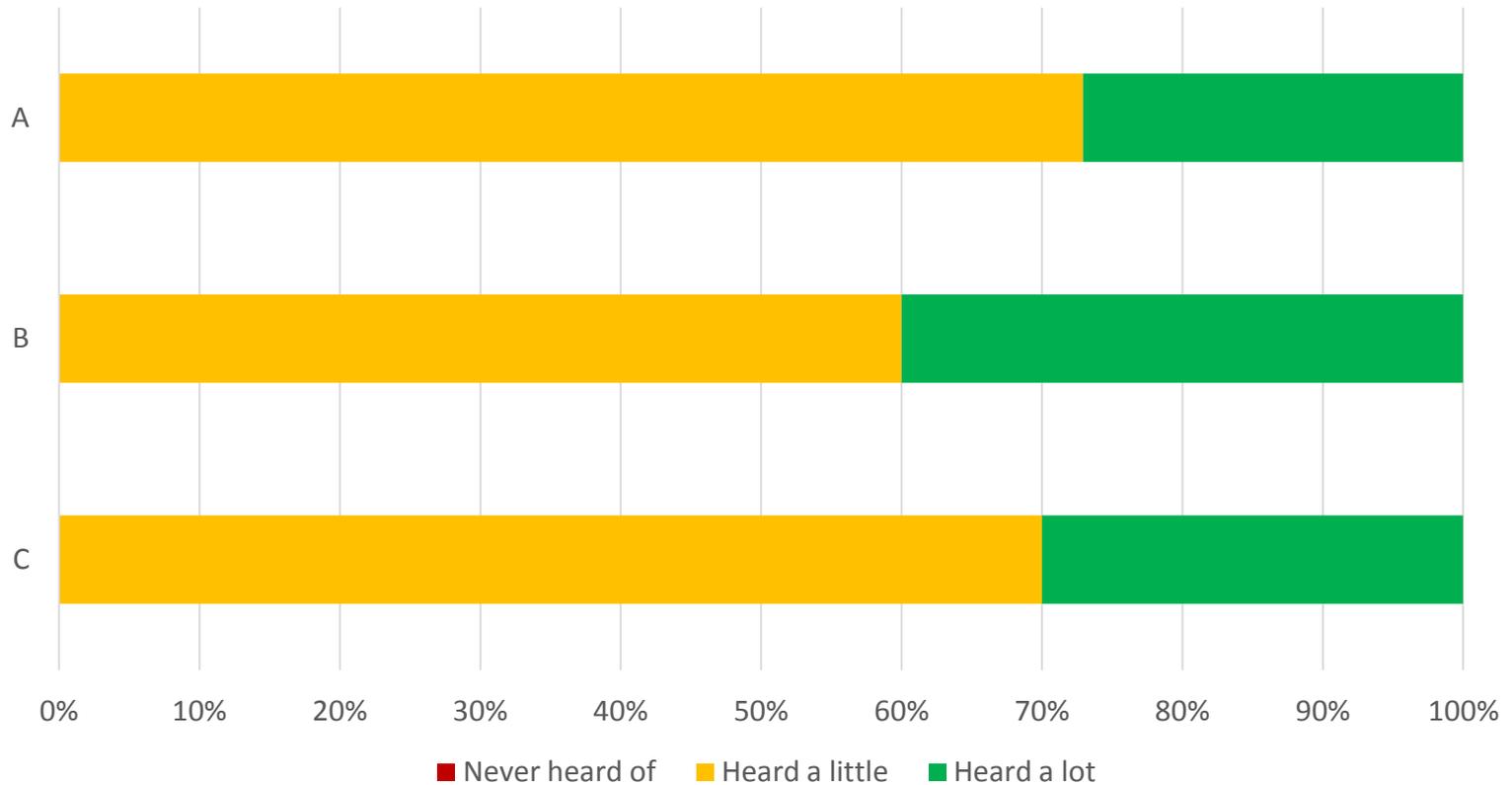


Reported Experience with SPC Services

	Group 1		Group 2		χ^2 test
	N	%	N	%	P-value
I know someone who used hospice services	7	33.3	17	37.8	0.727
I have used hospice services myself	5	23.8	22	48.9	0.054
From radio, television, newspaper or internet	1	4.8	1	2.2	0.575
From my family and friends	1	4.8	0	-	0.140
From others (specify)	0	-	1	2.2	0.491
I have not heard of hospice services	11	52.4	13	28.9	0.065

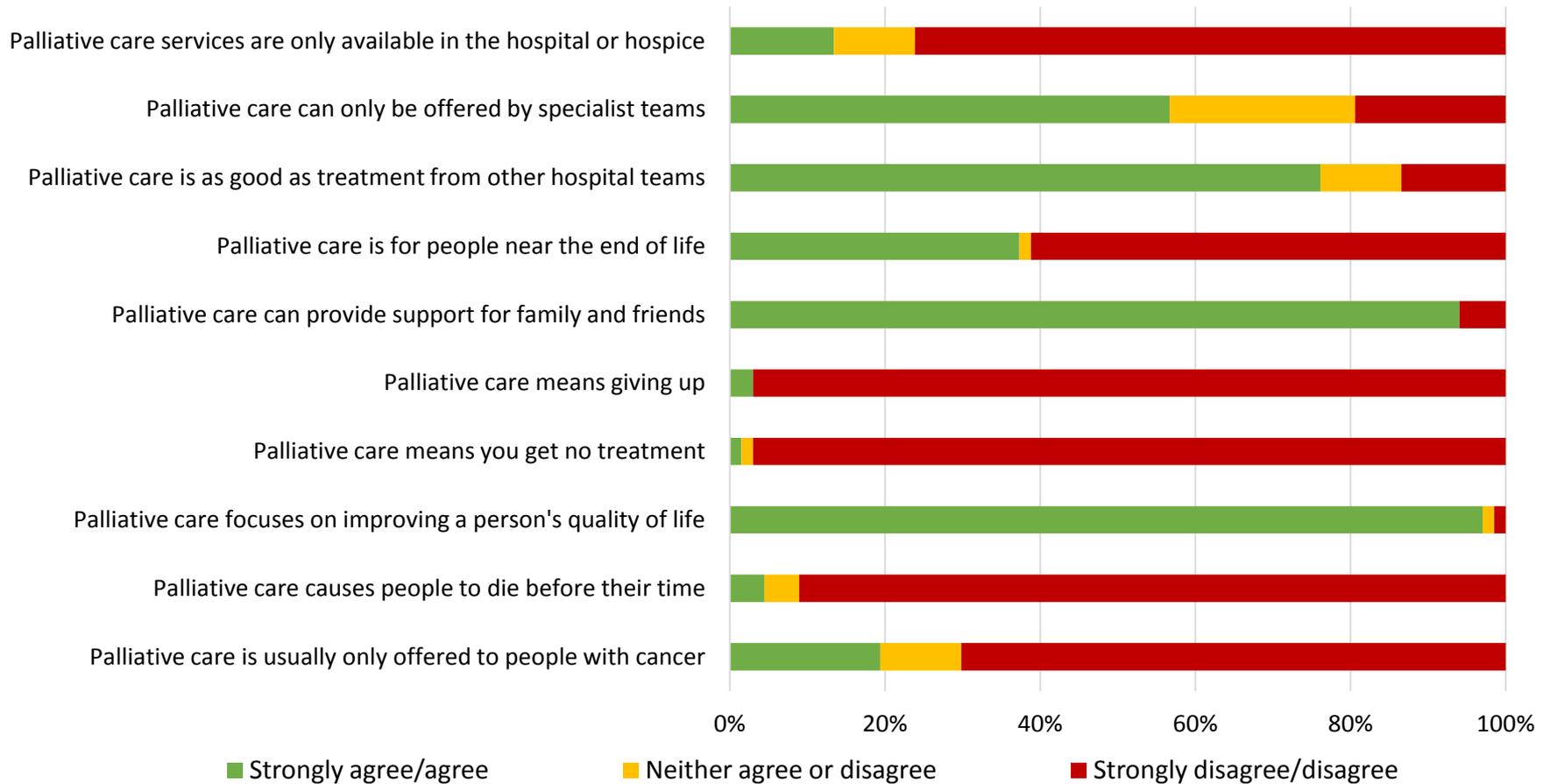
Loved Ones' Knowledge of Palliative Care

Regional differences



Loved Ones' Perceptions of Palliative Care

All participants



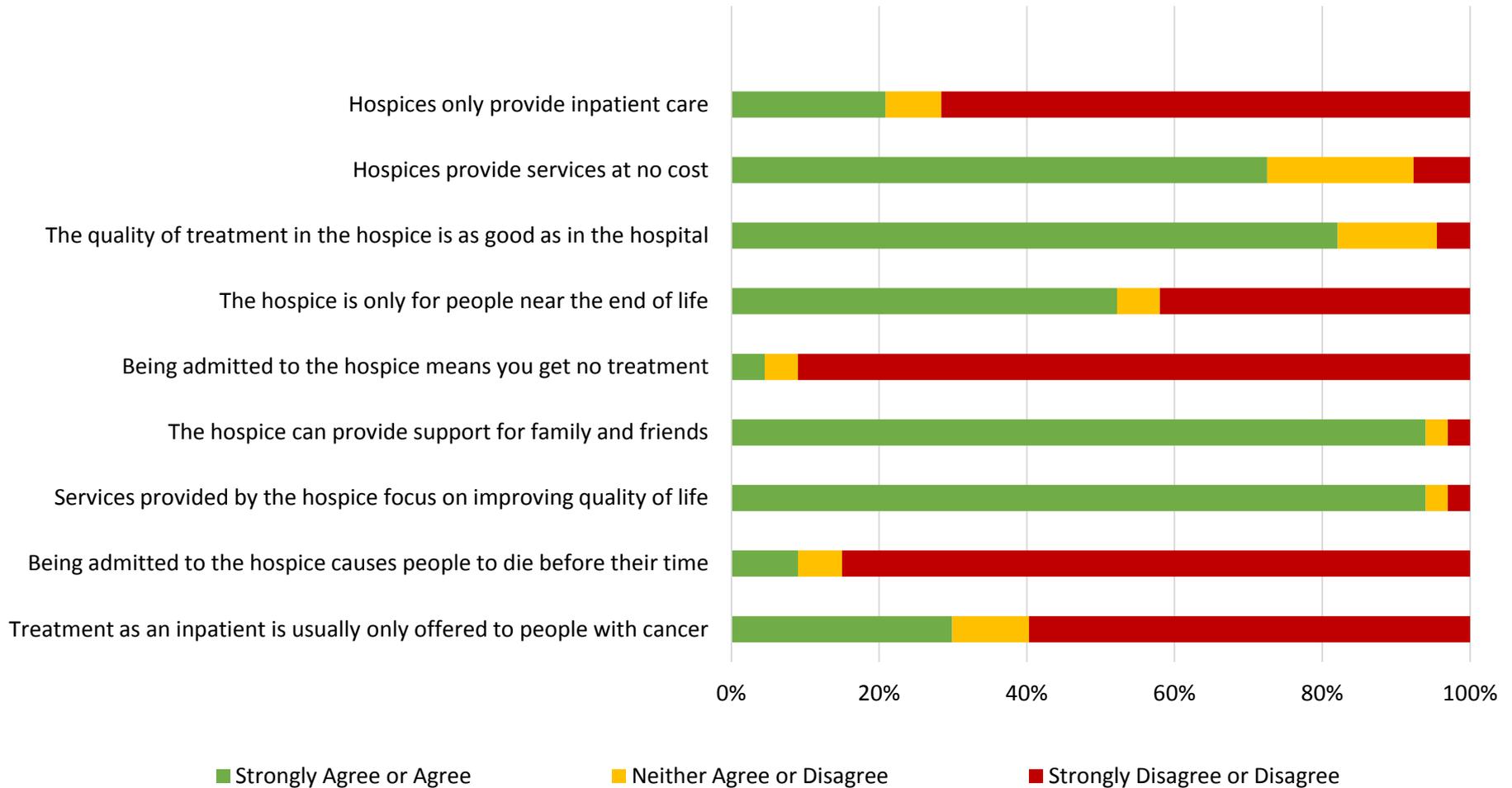
Loved Ones' Experiences of Hospice

Regional differences

	Region A (n=22)		Region B (n=25)		Region C (n=20)		Total
	N	%	N	%	N	%	%
I know someone who used hospice services	22	100	11	44.0	8	40.0	61.2
I have used hospice services myself	4	18.2	0	-	0	-	6.0
From radio, television, newspaper or internet	0	-	0	-	6	30.0	10.5
From my family and friends	0	-	2	8.0	6	30.0	11.9
From others (specify)	3	13.6	4	16.0	5	26.3	17.9
I have not heard of hospice services	0	-	13	52.0	2	10.0	24.6

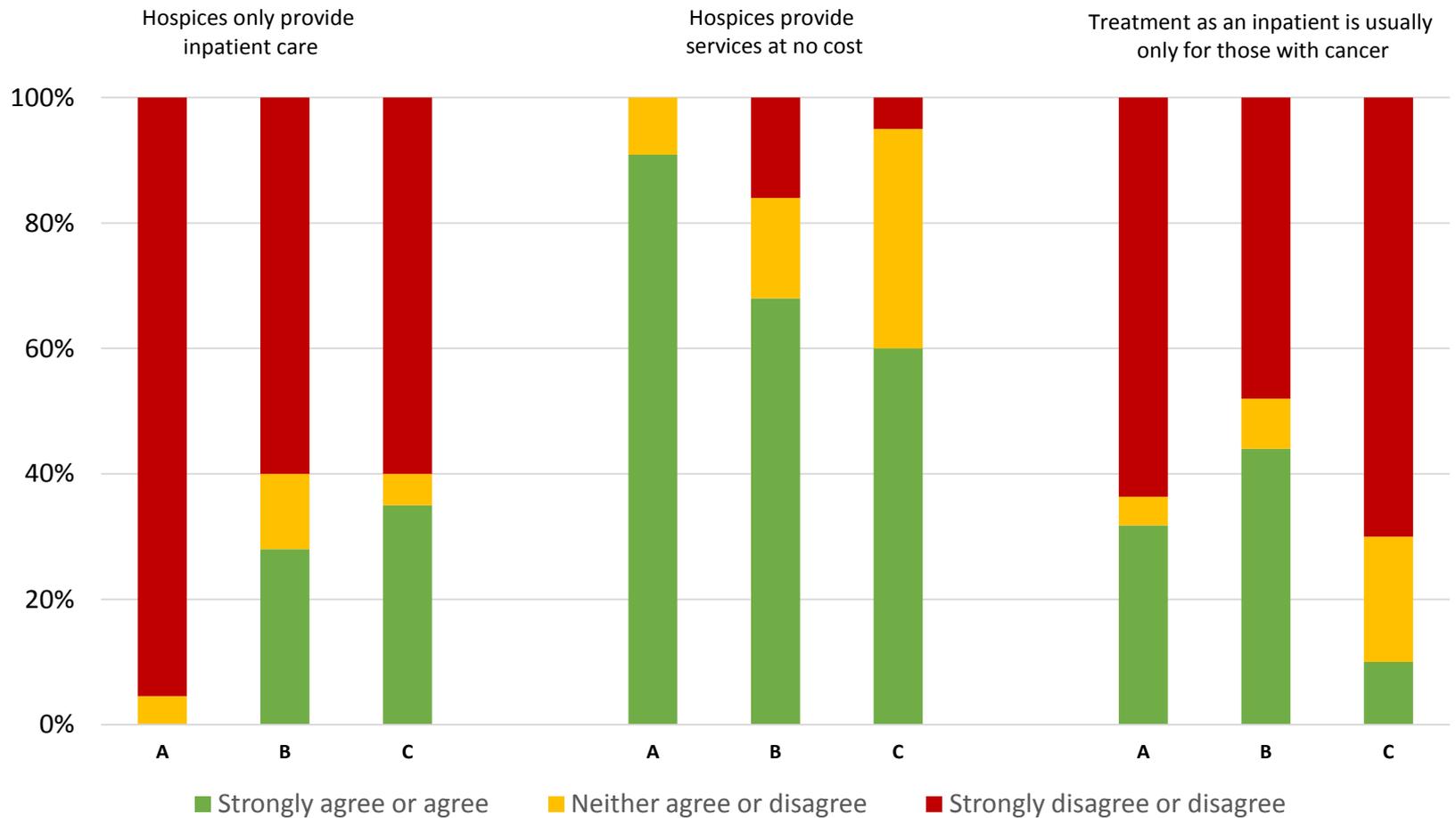
Loved Ones' Perceptions of Hospice

All participants

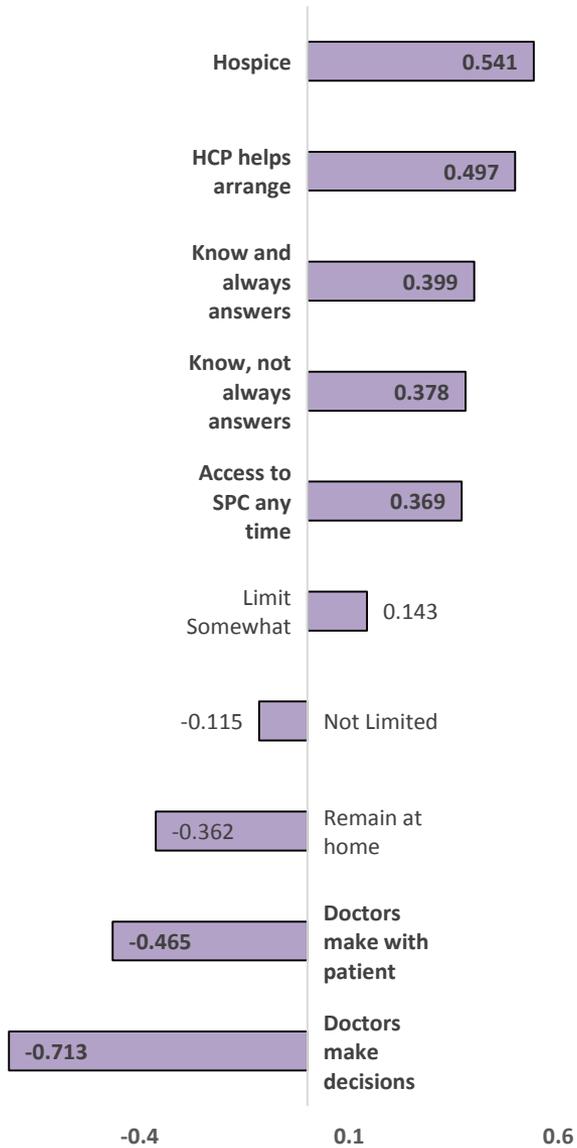


Loved Ones' Perceptions of Hospice

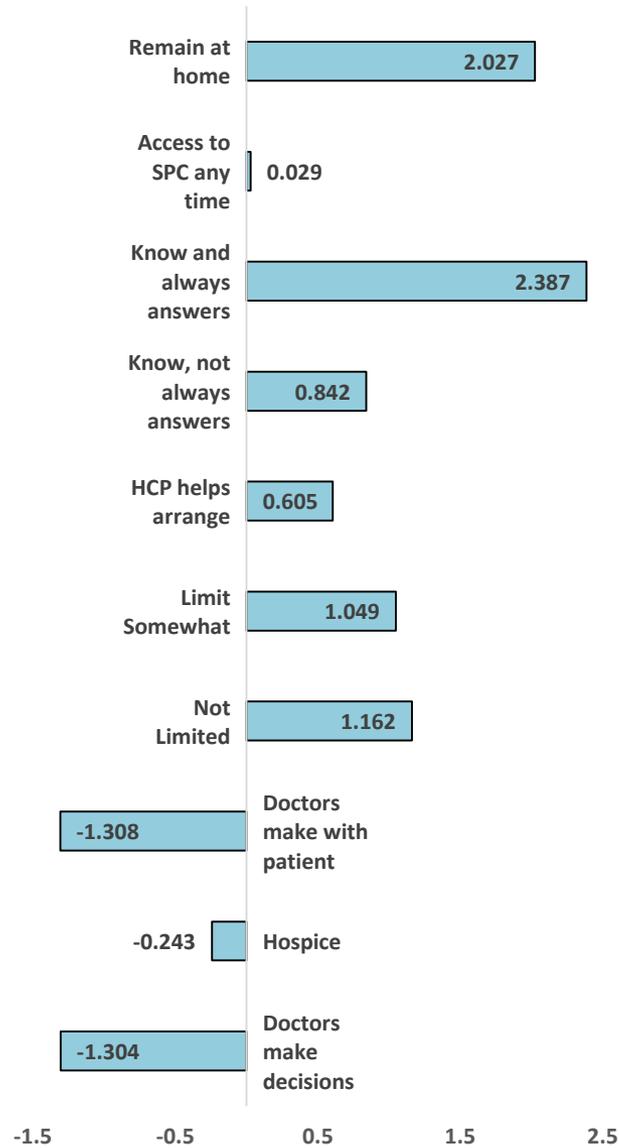
Regional differences



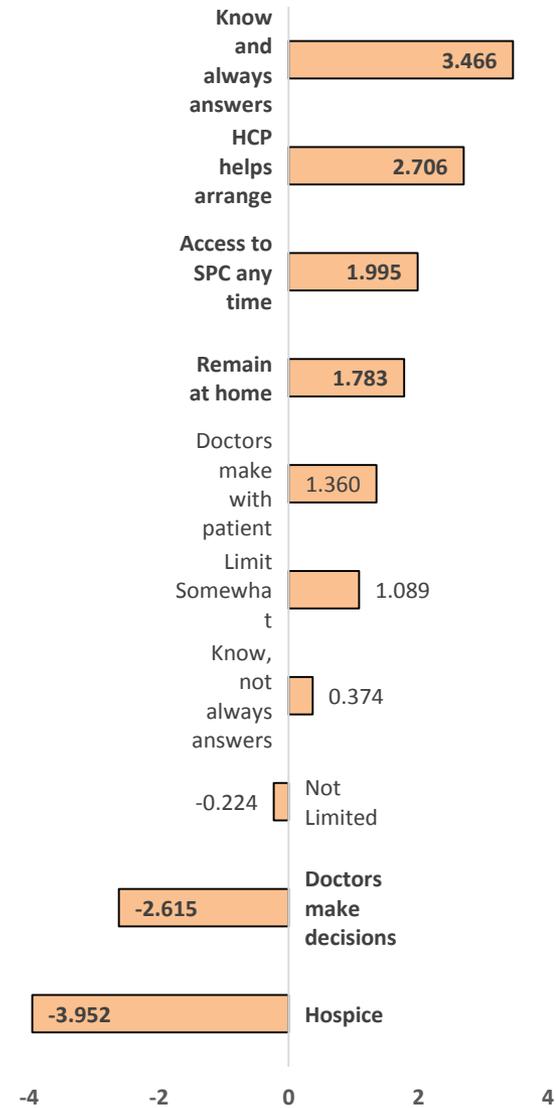
Group 1



Group 2



Group 3



Reported Experience with SPC Services

	Group 1		Group 2		Group 3		χ^2 test
	N	%	N	%	N	%	P-value
I know someone who used hospice services	19	61.3	13	65.0	9	56.3	0.866
I have used hospice services myself	2	6.5	1	5.0	1	6.3	0.976
From radio, television, newspaper or internet	5	16.1	2	10.0	0	-	0.230
From my family and friends	5	16.1	3	15.0	0	-	0.239
From others (specify)	5	16.1	6	30.0	1	6.3	0.171
I have not heard of hospice services	6	19.4	2	10.0	7	43.8	0.047

SUMMARY AND CONCLUSION

Summary

Perceptions of palliative care and hospice services

- Participants broadly understood the principles of palliative care, with 80% agreeing that palliative care was about quality of life and offering support to family and friends.
- However, many participants held incorrect assumptions about important aspects of service delivery.
 - Nearly 80% thought palliative care could only be provided by SPC teams, while 30% thought palliative care is only available in a hospice or hospital.
 - More than half thought SPC services are primarily for people who are near the end of life.
- Perceptions varied across the study regions and influenced expressed preferences.

Summary

Perceptions of palliative care and hospice services

- Surprising that a minority of patients (14%) did not realise they were using palliative care services.
 - Variation in reported usage across the study regions was statistically significant, with 80% of participants in Regions A and B stating they had used palliative care compared to 100% in Region C. These results likely reflect differences in terminology used across the settings.
- The findings show the challenges in asking about preferences for services which aren't defined in a consistent manner.
 - The need for a common language and definition of palliative care to improve knowledge among the public and health care professionals has been highlighted in previous research.

Concluding Thoughts

Perceptions of palliative care and hospice services

- Despite a long history of palliative care provision in Ireland, significant misperceptions exist, even among people accessing services.
- These data demonstrate there is an ongoing need to improve public awareness and understanding of palliative care and highlights the areas that should be prioritised.
- Appropriate knowledge about services is critical to helping people make informed choices about their care.



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

Thank You

