A Human Rights based approach for Palliative Care:
Towards Solutions for Public Health Palliative Care

3rd International Research Seminar
AIIHPC and EAPC Reference Group on
Public Health and Palliative Care

EAPC VZW Reference Group
Public Health & Palliative Care

AIIHPC
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Cost consequences of unscheduled emergency admissions in cancer patients in the last year of life

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This presentation reports the findings published in https://link.springer.com/article/10.1007/s00520-023-07633-6 .

Project Scope

Building upon the report of the Macmillan / NICR Partnership

Maximise the insights of the report's findings

Develop complementary health economics report'

Focus on length of stay*

Lessons from the process

*in the absence of other metrics for use around the content of care episodes

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Background

- Cancer is a leading cause of death worldwide[1].
- Overall, 4,316, just over 1 in 4 deaths 28%, in NI in 2015 had cancer recorded as cause of death GRO, 2017
- Whilst ‘death and dying are inevitable’[2], the moments leading to death create the causes and conditions for the development of meaning, thereby constructing a peaceful or traumatic transition.
- Palliative care underpins symptom management in the end-of-life and is considered a human right[3], since its absence can lead to unnecessary suffering[4].
- Palliative care access and 'in-home' procedures may prevent emergency admissions given the symbiotic relationship between primary and tertiary care[17].
- The appropriate method for controlling symptoms in some patients will be hospital-based, however, the difference between hospital visits indicating necessary care versus aggressive care varies[22].

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Quality, safety & length of stay

Indicators to identify healthcare systems delivering aggressive or poor-quality end-of-life care

- a short interval between last chemotherapy and death
- a high proportion of hospital deaths vs home deaths
- frequent emergency room visits
- **a high number of hospital and Intensive Care Unit ICU days near the end-of-life**
- hospital admission near to death

- A statistical model which simulated the cost of caring for English cancer patients in their last year of life found
  - a 10% reduction in emergency admissions
  - coupled with a 3-day reduction in length of stay
  - could equate to a saving of £104 million per year

Indicators of good quality care include

- Communication
- shared decision making
- advance directives and
- pain and symptom management

Non-standard reporting metrics *not reported here

REF:
1. Earle et al. 2003 2. Hatziandreu et al., 2008

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Objectives

- **Characterise cost implications of cancer patients accessing unscheduled inpatient care in the last year of life**
- **Analyse patient demographic and disease characteristics at diagnosis to determine factors influencing utilisation***

*other features considered in main report included rurality and socio-economic status showed no statistically significant relationship to admission

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Context

- Health economic evaluations are configured based on the assumptions made
- Data drives each assumption
- Data can often deviate from the real-world context
- That is bounded by accurate clinical coding, unseen changes in bed capacity or staffing and the types of services and their interconnectedness
- For which only some of the ‘data’ is accessible
- Analysis may or may not make use of all ‘data’ from the patient history as seen by clinical staff
- We meet where multiple realities intersect
    - An ‘average’ patient journey, from a data lens – yet acknowledging that in truth no patient is at all average

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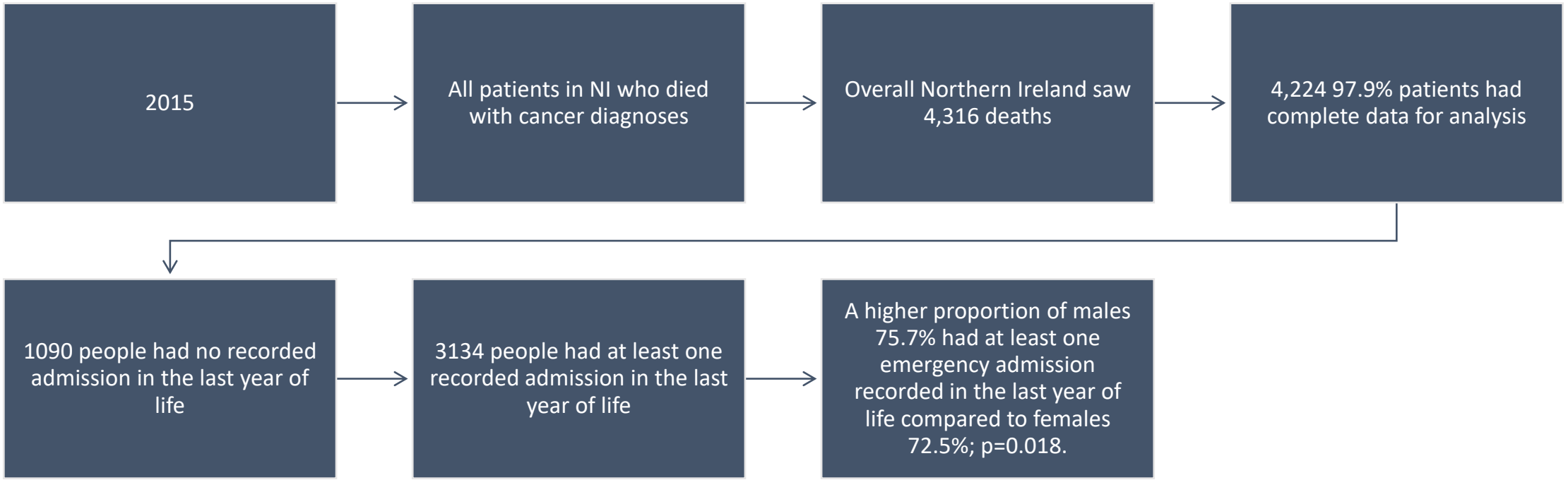
The data…



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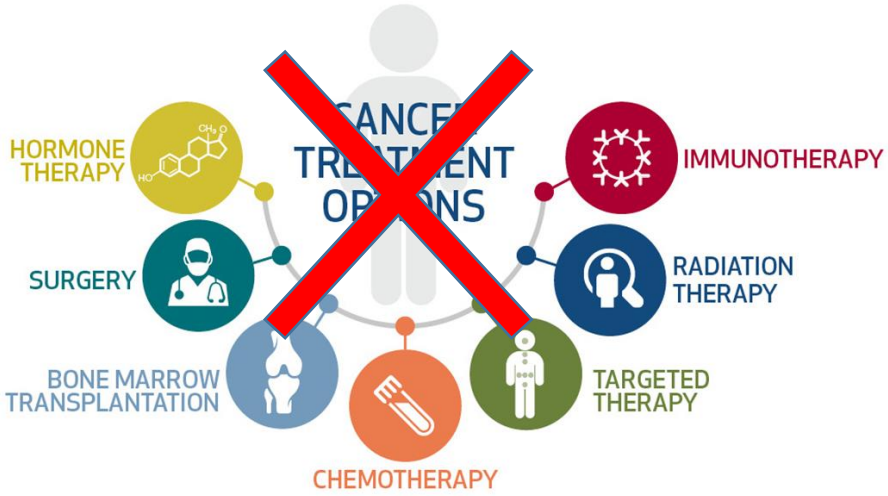
Costing Assumptions

Variable	Cost (£)	Assumption Description
Non-elective inpatient stays	Day 1 = 1,609	1,609 / day of admission[16]
	Day 2 (+) = 306	306 /excess bed day[16]
Inpatient – specialist palliative care (support)	119 / day	If a patient is not admitted under the care of a specialist palliative medicine consultant but is receiving support from a member of a specialist palliative care team, this is classed as specialist palliative care support and should be reported per bed day15.
Ambulance transfer[16]	236	Based on assumption that those with recorded admissions via ambulance or paramedic admission were provided with 'see and treat and convey' cost per incident included at 2015-16 rate (89 cases noted to have 'GP via ambulance'/ 'paramedic admission' as method of admission* from one hospital only)
GP referral	39.23	Where 'GP via ambulance' was recorded as method of admission *note use of source home confounds accuracy
A&E Cost	138	The unit cost for outpatient and A&E attendance is per attendance



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Results

	Days	Cost in GBP£*
Survival Average days from diagnosis to death	731	
Total Unscheduled Emergency Care Use	60,746	
Average Length of stay	19	
Length of stay only cost		26,408,656
Additional Palliative Care cost Estimated		1,322,328
Ambulance cost Inc. preceding GP referrals**		39,795
A&E Attendance Cost		836,004
Total Cost Unscheduled Care		**28,684,261**
Average Cost per patient		9,200

- No specific treatment costs were included
- *DOH Reference Costs for 2015/16

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Trend in preceding GP attendances…

- Admission 1 = 261 (4.3%)
- Admission 2 = 119 (1.9%)
- Admission 3 = 48 (0.8%
- Admission 4 = 25 (0.4%)
- Admission 5 = 19 (0.3%)
- Admission 6 = 2 (0.03%)
- Admission 7 = 4 (0.06%)
- Admission 8 = 0
- Admission 9 = 0
- Admission 10 = 0

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Admitted patient only data

	Cost per person							Inpatient days					
	n	Mean	Standard Deviation	Q1	Median	Q3	Max	Mean	Standard Deviation	Q1	Median	Q3	Max
Brain	83	7,587	5,635	3,437	6,199	10,585	32328	19	16	7	16	26	73
Breast	194	6,658	4,530	3,432	5,281	8,626	28962	16	14	6	12	21	69
Colorectal & Anus	364	7,565	5,700	3,675	5,893	9,871	42307	19	17	7	14	25	134
Connective Tissue	11	9,281	7,460	4,822	6,403	10,330	24372	24	21	11	14	30	66
Female Genital ex Ovarian	59	7,649	5,754	3,012	6,182	11,087	31597	20	19	6	14	30	99
Head & Neck	88	9,430	10,721	3,139	5,587	13,161	71768	25	30	6	14	35	170
Leukaemia	102	7,674	6,047	3,445	6,352	9,565	31597	20	19	7	16	27	99
Liver, Gallbladder & Bile Ducts	129	7,470	5,266	3,751	5,978	9,871	32141	19	16	8	14	25	86
Lung	788	7,224	5,418	3,445	6,089	9,259	69541	18	17	7	14	23	223
Lymphoma	123	10,062	8,256	4,516	8,086	13,543	48733	28	26	11	21	38	155
Melanoma	32	6,466	3,900	3,675	5,587	8,188	18133	16	12	8	13	21	55
Mesothelioma	33	6,532	3,930	3,683	5,587	7,848	18201	16	11	7	13	21	42
Myeloma	72	9,316	6,620	4,363	7,797	12,442	41389	25	21	10	19	31	131
NMSC	16	4,846	3,171	1,839	4,363	6,199	11690	11	10	2	9	16	32
Oesophagus & Stomach	238	7,300	5,079	3,445	5,893	9,918	28673	18	16	7	14	24	84
Other - small numbers	22	8,669	7,600	3,445	6,658	10,534	34963	23	25	7	16	28	110
Other Digestive	27	7,990	5,082	4,703	7,117	9,106	21975	20	15	11	18	26	62
Other Female Genital & Fallopian tube	13	8,620	5,938	3,445	7,440	13,543	20275	22	19	7	19	40	62
Ovarian	65	7,748	5,727	3,445	6,811	9,565	32957	20	17	7	17	27	77
Pancreas	170	7,164	4,808	3,445	6,199	8,885	25528	18	14	7	14	24	64
Prostate	189	8,024	6,831	3,445	6,505	9,565	47203	21	19	7	17	26	108
Retro Peritineum	12	9,317	6,228	4,006	8,129	12,740	19357	23	18	9	19	35	59
Small Intestine	12	10,807	8,045	5,230	7,500	13,008	28537	30	27	12	19	38	89
Unknown Primary	104	8,409	6,662	4,057	7,117	10,526	51487	21	20	9	19	28	164
Urinary Cancer	172	8,232	5,604	4,223	6,964	10,177	39332	21	17	9	17	28	113

*subject to corrections – not for reporting without explicit permission of the author

*LOS cost only

Admitted patient only data

		Cost per person							Inpatient days						
Age at Diagnosis	**n**	**Mean**	**Standard Deviation**	**Min**	**Q1**	**Median**	**Q3**	**Max**	**Mean**	**Standard Deviation**	**Min**	**Q1**	**Median**	**Q3**	**Max**
0 to 19	8	9,030	9,929	2,833	3,063	5,128	8,953	31,597	25.3	32.4	5.0	5.8	12.5	25.0	99.0
20 to 29	17	7,118	3,862	1,609	4,669	6,505	9,803	14,155	17.9	12.6	1.0	9.0	17.0	27.0	42.0
30 to 39	46	7,213	5,756	1,609	2,948	5,366	10,058	23,641	18.1	18.0	1.0	5.3	12.0	22.5	73.0
40 to 49	148	7,530	6,232	1,609	3,381	5,698	8,673	32,209	18.7	19.1	1.0	6.8	13.0	21.3	101.0
50 to 59	399	7,189	6,938	1,609	3,428	5,281	8,953	71,768	17.9	20.3	1.0	6.0	13.0	23.5	223.0
60 to 69	782	7,822	6,190	1,609	3,445	6,089	10,368	51,487	19.9	19.0	1.0	7.0	15.0	27.0	164.0
70 to 79	938	7,718	5,447	1,609	3,751	6,505	9,616	45,758	19.5	16.3	1.0	8.0	16.0	26.0	116.0
80 to 90	649	7,855	5,680	1,609	4,057	6,505	9,871	47,203	20.1	17.3	1.0	8.0	16.0	27.0	138.0
90+	131	7,399	5,606	1,609	3,445	5,893	9,259	41,389	18.9	17.7	1.0	7.0	14.0	24.5	131.0
Gender	**n**	**Mean**	**Standard Deviation**	**Min**	**Q1**	**Median**	**Q3**	**Max**	**Mean**	**Standard Deviation**	**Min**	**Q1**	**Median**	**Q3**	**Max**
Female	1389	7,632	5,490	1,609	3,734	6,199	9,871	41,389	19.2	16.7	1.0	7.0	15.0	26.0	131.0
Male	1707	7,720	6,313	1,609	3,445	6,199	9,871	71,768	19.6	19.0	1.0	7.0	15.0	26.0	223.0
Missing	22	6,932	4,019	1,609	3,522	5,417	10,534	14,036	17.2	12.4	1.0	7.3	13.0	27.3	41.0

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Admitted patient only data														
		Cost per person							Inpatient days					
Stage at Diagnosis	n	Mean	Standard Deviation	Min	Q1	Median	Q3	Max	Mean	Standard Deviation	Min	Q1	Median	Q3	Max
1	159	8,293	6,866	1,609	4,057	7,117	10,424	69,541	21.5	22.0	1.0	9.0	17.0	28.5	223.0
2	259	7,444	5,960	1,609	3,139	5,587	9,871	42,307	19.0	18.9	1.0	5.5	14.0	26.0	134.0
3	542	7,578	5,692	1,609	3,445	5,910	9,871	48,733	19.0	17.1	1.0	7.0	14.0	25.0	155.0
4	1198	7,377	5,821	1,609	3,445	5,978	9,259	71,768	18.4	17.4	1.0	7.0	14.0	24.0	170.0
Unknown	960	8,062	6,055	1,609	3,751	6,505	10,390	51,487	20.7	18.2	1.0	8.0	16.0	28.0	164.0

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1 in 4 patients with cancer admitted in the last year of life had a recorded Palliative care episode (2015)

		Inpatient days during last year of life	Average LOS w/ relative difference	Cost per person					
Palliative Care	**n**	**coefficient (linear regression)**	**19.5**	**Mean**	**Standard Deviation**	**Min**	**Q1**	**Median**	**Q3**	**Max**
No	2318	18.5	-1.0	6,959	5,403	1,609	3,139	5,587	8,953	69,541
Yes w/ further admissions after	251	+9.7	8.7	11,636	6,418	2,034	7,109	9,905	15,031	39,332
Yes - Last Admission & Died before Discharge	252	+3.2	2.2	8,203	5,630	1,728	4,474	7,134	10,398	45,758
Yes w/ No further admissions after	299	-0.8	-1.8	9,707	8,156	1,728	4,703	7,678	11,839	71,768

This reflects 1831 PCT attended discrete episodes of care, accounting for up to 11,112 days of palliative care input

So, what's useful within that?

Factors Influencing Length of Stay

	Variables analysed to explain effect on Length of stay	Adjusted R-squared	
		All deaths	In admitted cases only
model1	Gender	0.0010	
model2	Place of death	0.0336	
model3	ICD 10 Group	0.0133	
model4	Stage	-0.0005	
model5	Age at Diagnosis	0.0011	
model6	Age at Diagnosis + SES	-0.0001	
model_2	Survival time	0.0003	
model7	Gender + ICD10 Group + Stage + age + SES	0.0146	
model8	Gender + ICD10 Group + Stage + age + SES + Place of death	0.0449	
model9	Gender + ICD10 Group + Stage + age + SES + Place of death + Palliative care	0.2675	
model10	Gender + ICD10 Group + Stage + age + SES + place of death + palliative care + First hospital admission location	0.2848	
model11	Gender + ICD10 Group + Stage + age + SES + place of death + palliative care + First hospital admission location + age at death	0.3551	
model12	ICD10 Group + Stage + age + SES + place of death + palliative care + First hospital admission location + age at death + First Primary admission diagnosis	0.3765	
model13	Gender + ICD10 Group + Stage + age + SES + place of death + palliative care + First Primary admission diagnosis + age at death + First hospital admission location	0.3767	
model14	Gender + ICD10 Group + Stage + age + SES + place of death + palliative care + First Primary admission diagnosis + age at death + First hospital admission location + settlement + last admission primary diagnosis	**0.4127**	**0.1526**
model15	Gender + ICD 10 Group + Stage + age + SES + place of death + palliative care + First Primary admission diagnosis + age at death + First hospital admission location + settlement + last admission primary diagnosis + survival time	0.4126	0.1522

Statistically significant attributes as unclear predictors?

- Small intestinal disease
- Eye related procedures of several types

Statistically (almost) significant attributes as indicators of?

- Stage 4 disease at ddx

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Hypothetical savings

Mirroring approach of Hatziandreu et al 2008

	Reduction in mean Length of stay days (of x days)			
Reduction in % of emergency admissions	0	1	3	5
0	0	1,519,405	4,500,879	7,539,689
5	1,433,401	2,952,806	5,934,280	8,973,090
10	2,866,802	4,386,207	7,367,681	10,406,491
15	4,300,203	5,819,608	8,801,082	11,839,892
20	5,733,604	7,253,009	10,234,483	13,273,293
25	7,167,005	8,686,410	11,667,884	14,706,694

Recommendations and Conclusion

Findings emphasise the critical need for targeted interventions and service improvements

Particularly in areas with the highest unscheduled care utilisation, like lung and colorectal cancers.

Results emphasise the importance of data-driven decision-making to enhance end-of-life care quality and streamline healthcare services for cancer patients.

Specific need to enhance the Palliative care coding

Examine the impact of service transformations – Acute Oncology, revised community palliative care services.

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Cancer Focus NORTHERN IRELAND

DATA-CAN
The Health Data Research Hub for Cancer

HSC Public Health Agency

N. IRELAND Cancer Registry

MACMILLAN CANCER SUPPORT

November 17, 2023

How willing are people to help their neighbours in need of support?

A cross-sectional survey among the general public

Luc Deliens

END-OF-LIFE CARE RESEARCH GROUP

UNIVERSITEIT GENT VUB

BACKGROUND

Growing recognition: involving social connections to support people with care needs

Wider social networks can be a potential resource
& are already recognised as pivotal to sustainable healthcare systems

Support = Practical, emotional, spiritual or social

Robust foundation for community-based support models?
> Studying how willing people are to support their neighbours

Prior literature largely focused on kin carers & on topics ~~serious illness or dying~~

RESEARCH QUESTIONS

(1) How willing are people to provide practical and emotional support to their neighbours in need of support?

(2) Is there a difference in their willingness depending on the type of support tasks?

(3) Are personal characteristics, personal experiences with care, illness and death, religiousness, and perceived social support associated with people's willingness to provide practical and emotional support to their neighbours?

METHODOLOGY

Cross sectional survey design in 4 municipalities in Flanders, Belgium

4,400 questionnaires, responses on paper or online (↑ response rate)

Main outcome measure: 2 cases with 4 hypothetical types of support

- **Case 1**: person with minimal social support needs help
- **Case 2**: neighbour is a carer for his care-dependent and terminal spouse

Types of support: doing groceries, keeping company, mowing the lawn, cooking

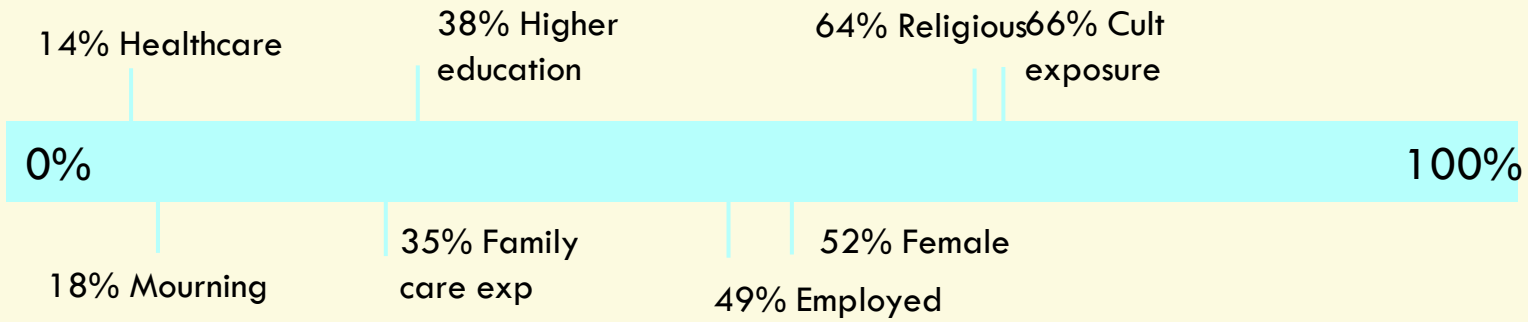
Willingness to support on a scale from 1 (definitely not) to 5 (definitely)

Multivariable linear regression controlling each IV for a set of confounders

RESULTS (1)

4,400 questionnaires sent; 1,851 used in data analyses (RR = 42%)

Sample:



Highest willingness for doing groceries in both cases

RESULTS (2)

Experiential exposure related to illness, death or dying > higher willingness

(e.g. cultural exposure to death & dying, having experience as family carer, having volunteered around serious illness, death & dying, mourning a loss)

Being female, religious
Feeling supported when in need
Higher self-estimated PC knowledge
Higher objective PC Knowledge

} Higher willingness to support neighbours

DISCUSSION (1)

People are willing to support their neighbours in need of help

Possible explanations:

- Support within the neighbourhood
- Practical support = public responsibility, nursing help = shared responsibility
- Family care research often does not elaborate on what ‘care’ is = interpretation

How to make use of this high willingness?

→ practical, emotional, spiritual & social support = part of care within communities

→ recognise their added value in both carers’ and care-recipients’ health

DISCUSSION (2)

Optimistic outlook about receiving support: Perceived reciprocal relationship

Potentially large support network → adds strength to community-based strategy of health promoting initiatives around illness, death & dying

Normalising EOL: experiences indeed associated with higher willingness

Making use of this potential: becomes imperative because of increasing strain on our HC systems

Interventions could increase people's experiences with illness, death & dying

CONTACT & QUESTIONS

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Questions?

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