



'Desired Care in the End of Life': implementing and evaluating a palliative care pathway in The Netherlands

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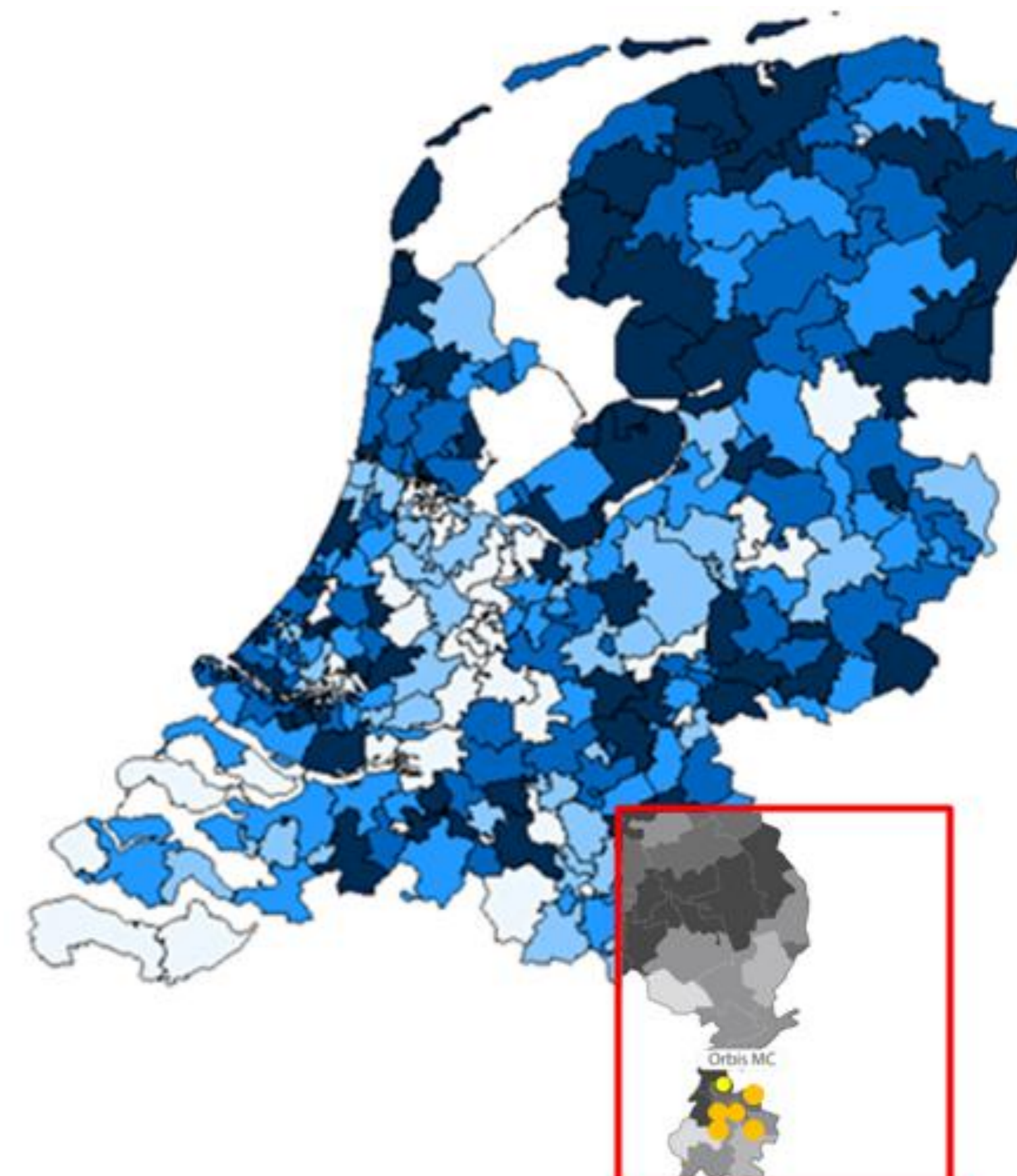
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Background

- In the Netherlands, in December 2015, a palliative care pathway was implemented
- 13 primary care facilities, 9 pharmacists, oncologists / geriatricians Zuyderland MC
- 8 core principles: 1) early identification ; 2) assessment of needs at intake; 3) weekly multi-disciplinary meetings; 4) timely shared decision making and multidisciplinary care planning; 5) medication reviews 6) good coordination and communication btw health care workers; 7) post-mortem interview with informal caregiver; and 8) continuous monitoring of outcomes.
- Question: "Does ACP in EOL care in Limburg (NL) increase experienced quality of care, death and dying and decrease unnecessary health care utilization?"

Aim: to evaluate the impact of the palliative care pathway in terms of GP proactivity, experienced quality of care, and of death and dying, (preferred) place of death, and health care utilization.



¹ Lo, C. ea. 2009 *Eur J Cancer*. 2009 Dec;45(18):3182-8.
² Munn, J.C. Ea. 2007, *J Am Geriatrics Society* 55,9:1371-79
³ Ingen, 2013.
http://patz.nu/images/vraag_antwoord/Vragenlijst_vwp_alg_gegevens.pdf
⁴ Pot, Dijk van, Deeg, 1995

Methods

- 13 PCFs intervention group; 8 additional PCFs control group
- Focus here on *effect evaluation* (a parallel process evaluation was carried out)

Question	Instrument	Timing
Patients and spouses involvement and 'fit' with care	FAMCARE ¹ (spouses)	6 weeks after death patient
Does ACP improve quality of dying process?	QOD-LTC ² (spouses)	6 weeks after death patient
Do GPs act more proactive?	PaTz ³ (GPs)	asap after death of each non-acute patient
Patients die in preferred place of death?	• QOD-LTC ² (spouses) • PaTz ³ (GPs)	• 6 weeks after death patient • asap after death of non-acute pts
Effect ACP on experienced burden of care for spouses	EDIZ ⁴ (spouses)	At intake (intervention group) and 6 weeks after death patient
Less burdensome care in the EoL?	care utilization profiles based on pts' EPR data	0,5y; 1y and 2y after start

Preliminary findings

Approximately **80 patients** have been included at the moment, of whom at least 17 have already passed away. Findings should be interpreted with this number in mind. Preliminary data point into direction of ⁵:

- Better experienced QoD**
- More patients die at usual place of residence**
- Proactive inclusion in pathway; GPs anticipate on death
- Bearable burden for informal care givers (ICGs)**
- ICGs report good quality of care
- More intense communication btw GPs and medical specialists and also with patients

⁵ details of a selection of outcomes (in bold) are shown at the right
⁶ *Personhood*: patient is kept clean, was able to maintain dignity, etc.; *Closure*: patient appeared at peace, accepted impending death; *Prep. tasks*: preferences expressed etc.

Experienced Quality of Dying

Domain ⁶	Intervention group (N=2)	Control group (N=14)
Personhood	4.60	4.38
Closure	4.50	3.86
Preparational tasks	4.38	3.57

Place of death

Outcome	Intervention group (N=12)	Control group (N=37)
% who died in preferred place of death	72.73	Too many missing
% who died in usual place of residence	76.92	59.46
% who died in hospital	0	13.51

Burden for ICGs

Outcome	Intervention group (N=2)	Control group (N=14)
Avg score on EDIZ (0-9) scale for 'pressure experienced by informal care givers'	4.60	4.38

