

Uncertainty in palliative care: problem or solution?

Simon Etkind | University of Cambridge

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“Ah yes, we live in uncertain times,” I chip in.
“Life is a five-thousand-piece jigsaw puzzle
with no picture to follow.”

— Hendrik Groen, *The Secret Diary of Hendrik
Groen, 83¼ Years Old*

James

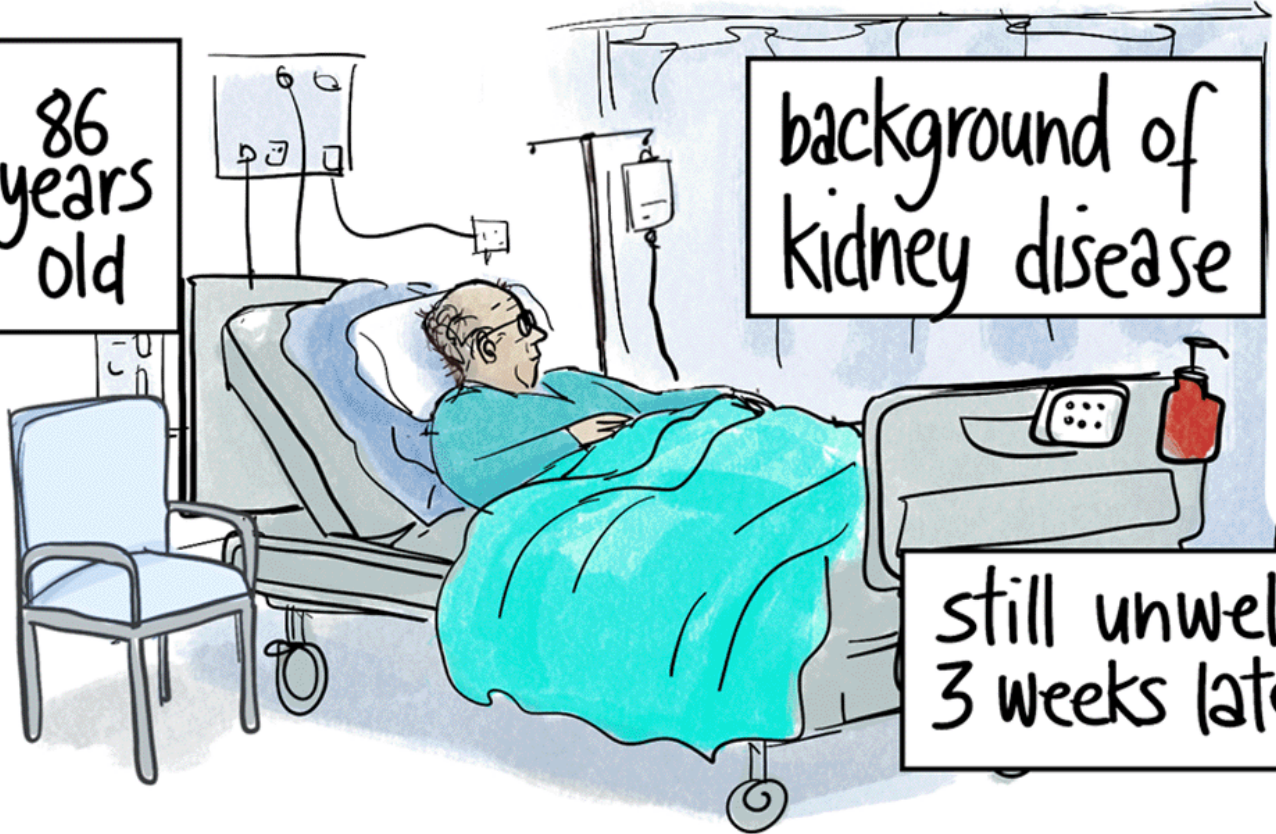
previously independent at home

recent surgery for colon cancer

86 years old

background of kidney disease

still unwell 3 weeks later



Part 1: what is uncertainty and why is it an issue?

Known Unknowns	Known knowns
Uncertainty	Knowledge
True unknown	Ignorance
Unknown Unknowns	Unknown knowns

What is uncertainty?

“known unknowns”

Incorporating:

Complexity

Unpredictability

Ambiguity

Lack of information

Personal

Practical

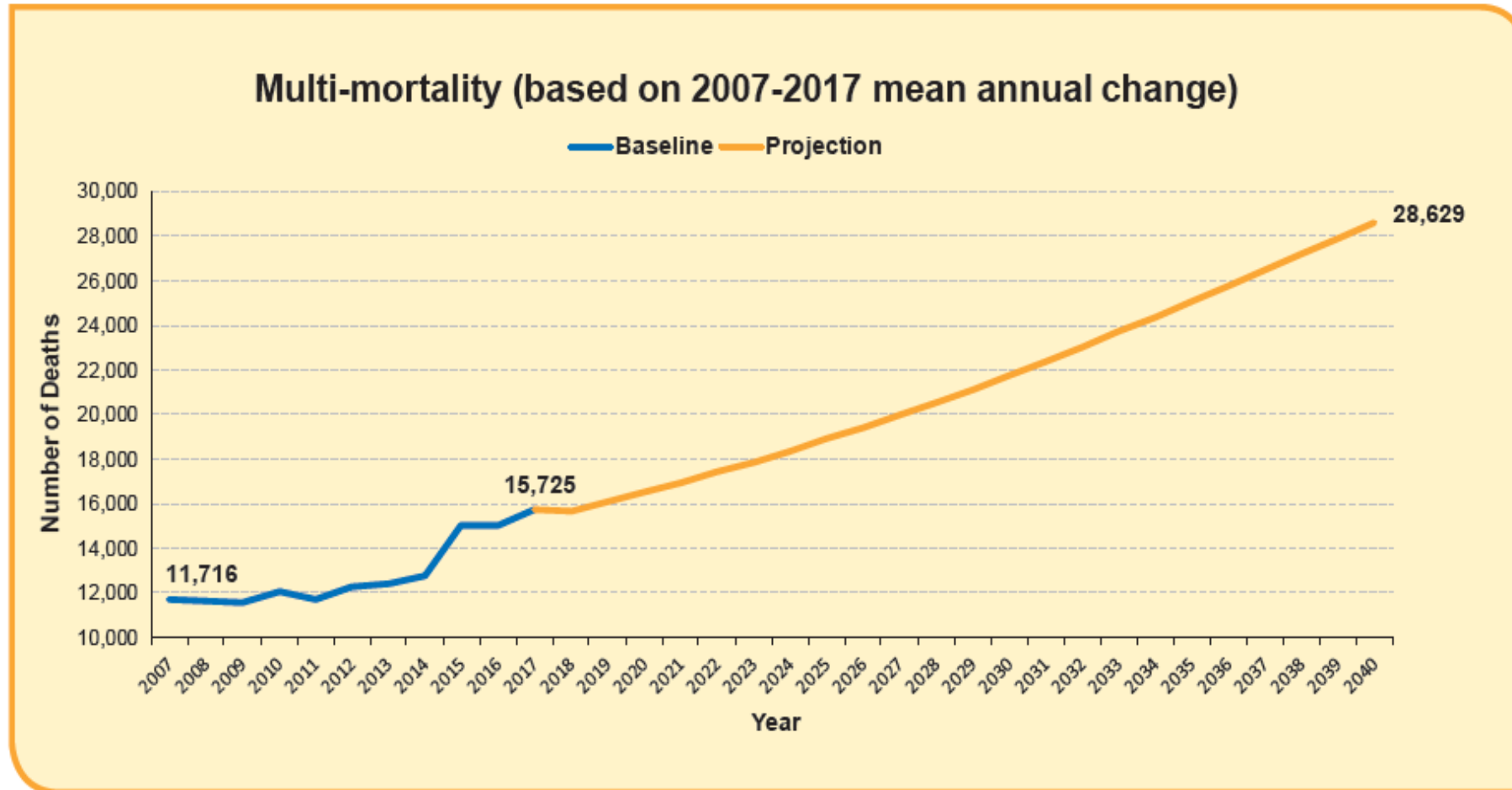
Scientific

Han PKJ, et al. Medical Decision Making. 2011;31(6):828-838.

Mishel, Merle H. "The measurement of uncertainty in illness." Nursing research (1981).

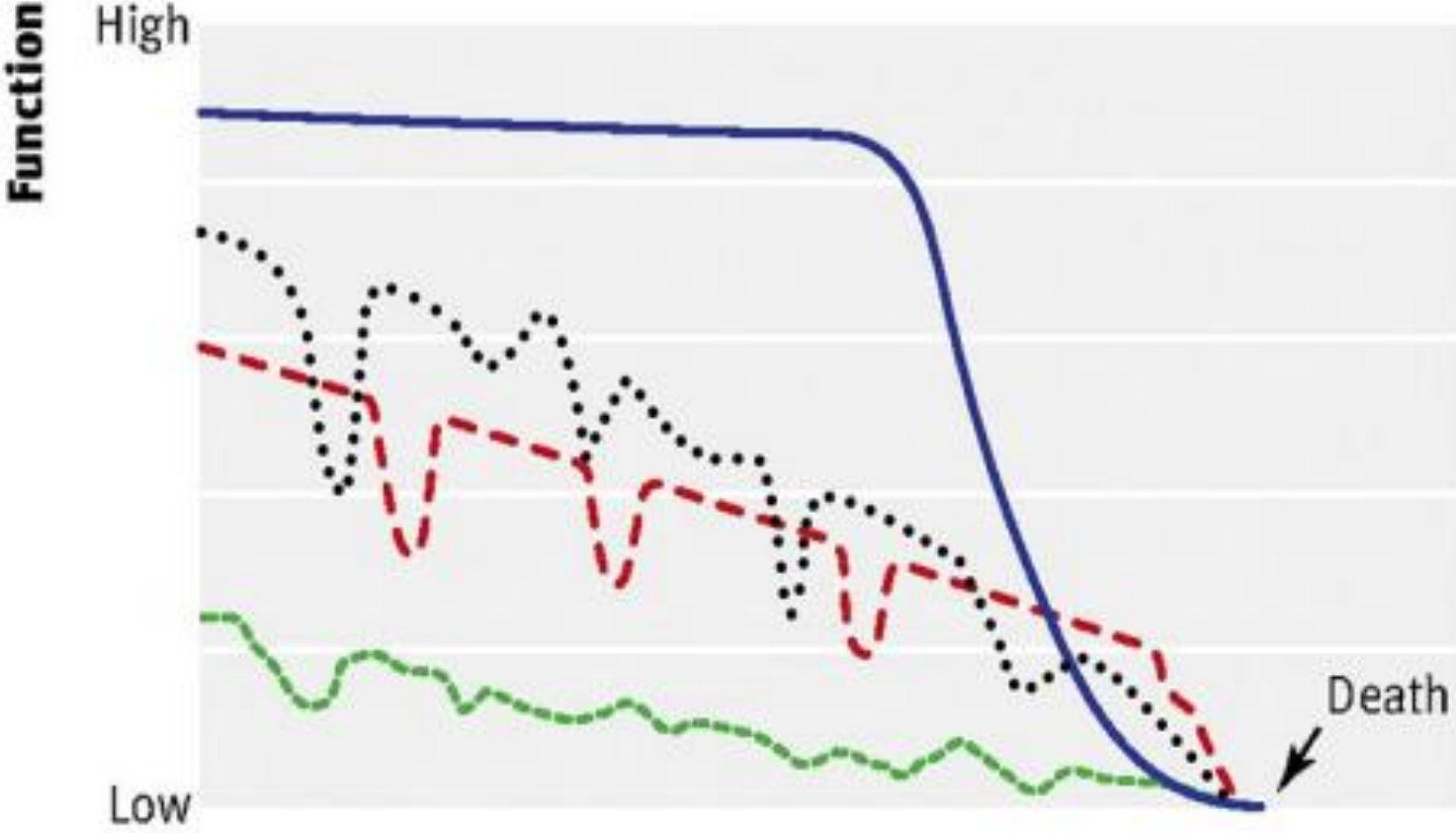
Rising multimorbidity

BMJ Open How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery



Complex illness trajectories

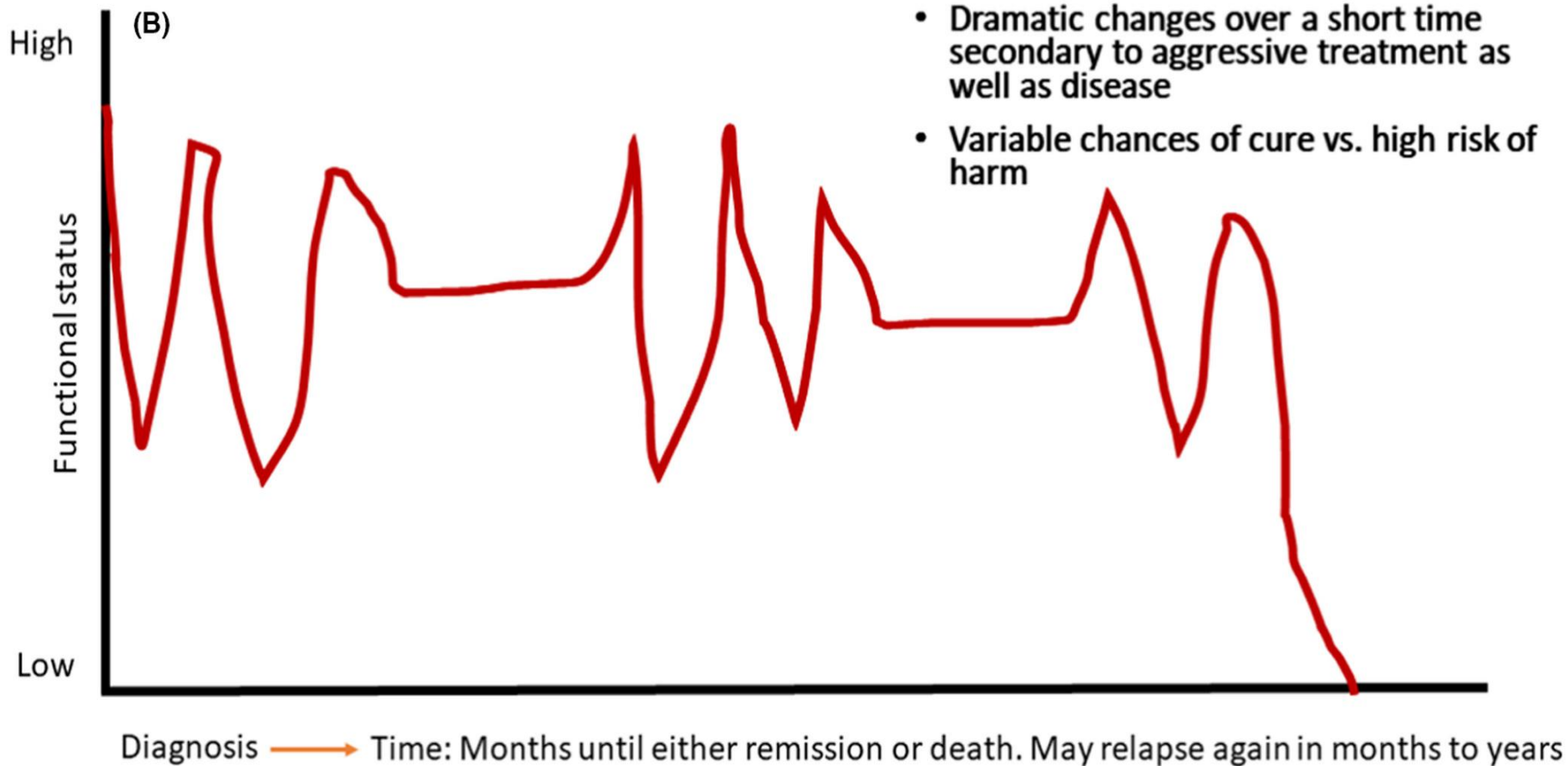
- Cancer
- Multimorbidity
- - - Organ failure
- - - Physical and cognitive frailty



Adapted from Murray, S.A et al. BMJ 2008;336:958-959

Time

New trajectories

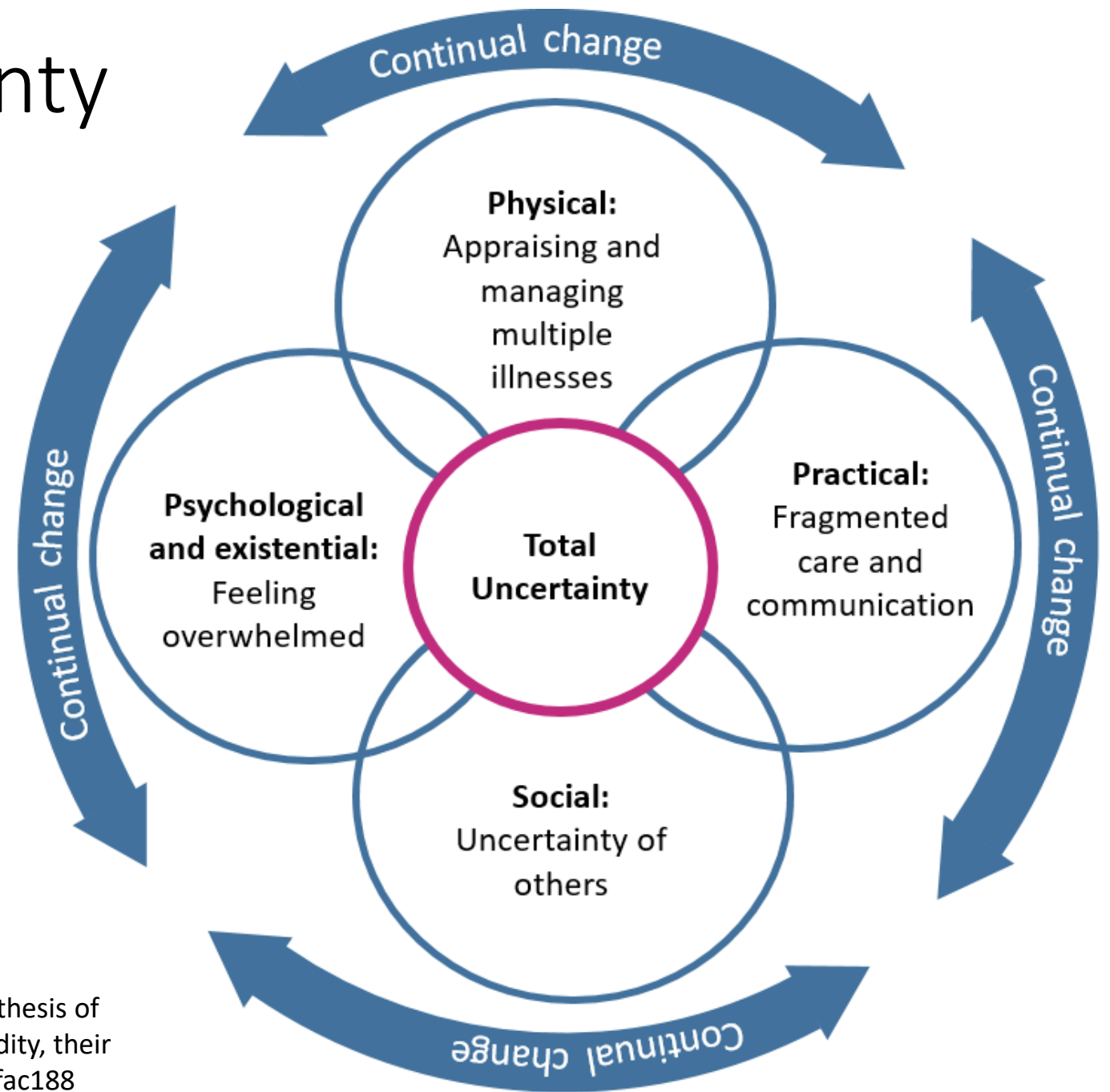


The effects of uncertainty

“So my experiences of dealing with uncertainty, I mean it’s a slightly difficult question because it’s kind of the air we breathe.



Etkind S et al. Total uncertainty: a systematic review and thematic synthesis of experiences of uncertainty in older people with advanced multimorbidity, their informal carers and health professionals. Age and Ageing 2022;51(8):afac188

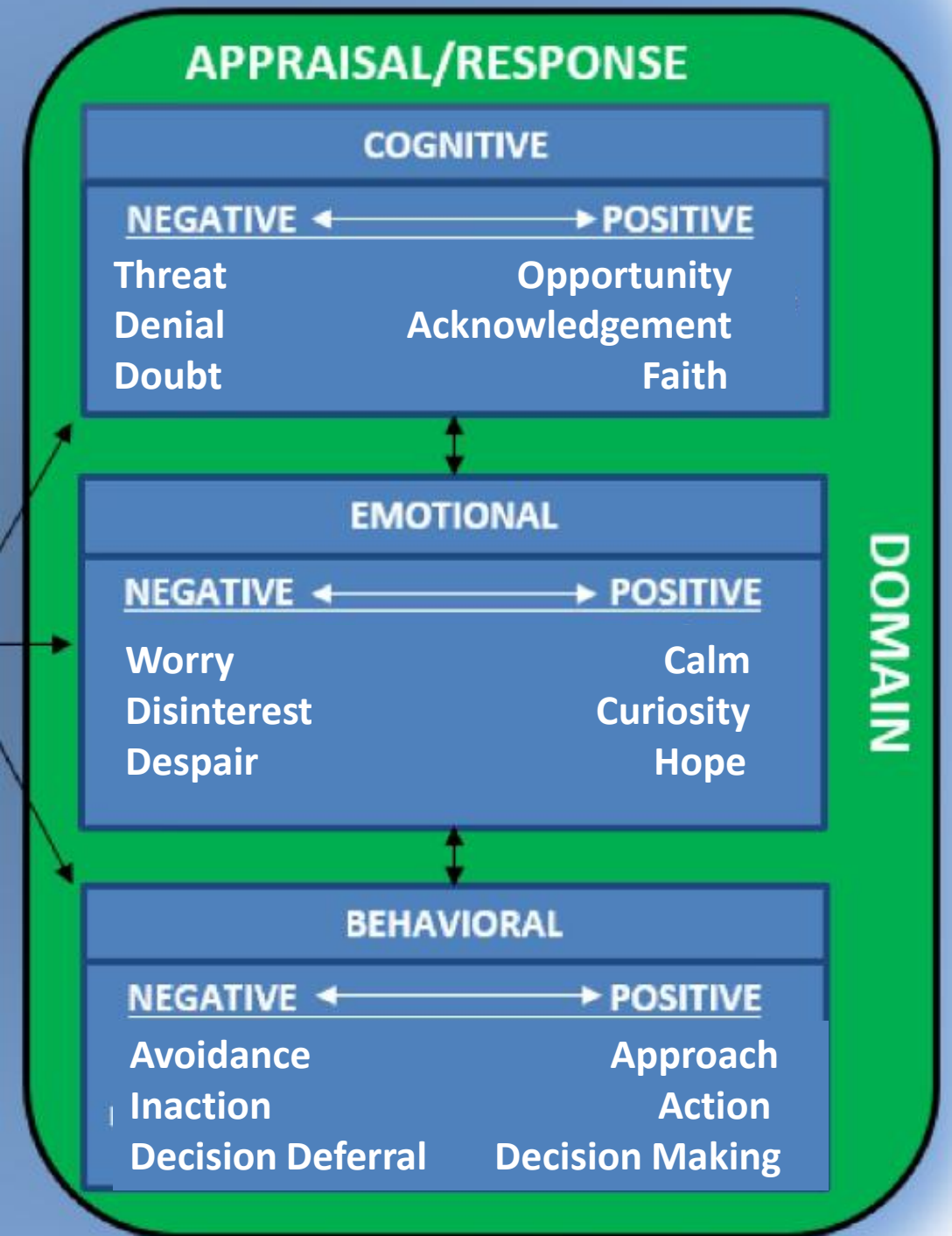


Part 2: Reframing uncertainty

Appraisal of
uncertainty is crucial




Appraisal mediates effects of uncertainty




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Review article

Tolerance of uncertainty: A systematic review of health and healthcare-related outcomes

Tania D. Strout^{a,*}, Marij Hillen^b, Caitlin Gutheil^c, Eric Anderson^c, Rebecca Hutchinson^{c,d}, Hannah Ward^e, Hannah Kay^f, Gregory J. Mills^g, Paul K.J. Han^c

^a Department of Emergency Medicine, Maine Medical Center, Tufts University School of Medicine, 47 Bramhall Street, Portland, ME, 04102, USA
^b Department of Medical Psychology, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands
^c Center for Outcomes Research and Evaluation, Maine Medical Center Research Institute, Portland, ME, USA
^d Hospice and Palliative Medicine, Maine Medical Center, Portland, ME, USA
^e University of Rochester, School of Medicine & Dentistry, Rochester, NY, USA



The difference appraisal makes

MPs to get historic vote on England and Wales assisted dying bill



“I believe we should have the right to see out our days surrounded by those we love and care for, knowing that when we are gone they can remember us as we would like to be remembered. I also believe that if we were able to spare them any unnecessary trauma and uncertainty, we would want to do that too.”

Uncertainty leaves space for hope

A photograph of a butterfly with white wings and a purple body, perched on a large, light-colored leaf. To the left of the butterfly is a large, vibrant purple flower. The background is a soft, out-of-focus green, suggesting a natural outdoor setting.

“Some families considered decision-making a negative concept and preferred uncertainty”¹

1. Higginson et al. The value of uncertainty in critical illness? An ethnographic study of patterns and conflicts in care and decision-making trajectories. *BMC Anesthesiol* 16, 11 (2015)

Uncertainty as an intellectual challenge



Future uncertainty permits (requires?) a focus on daily life:





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Supportive and Palliative Care Indicators Tool (SPICT™)



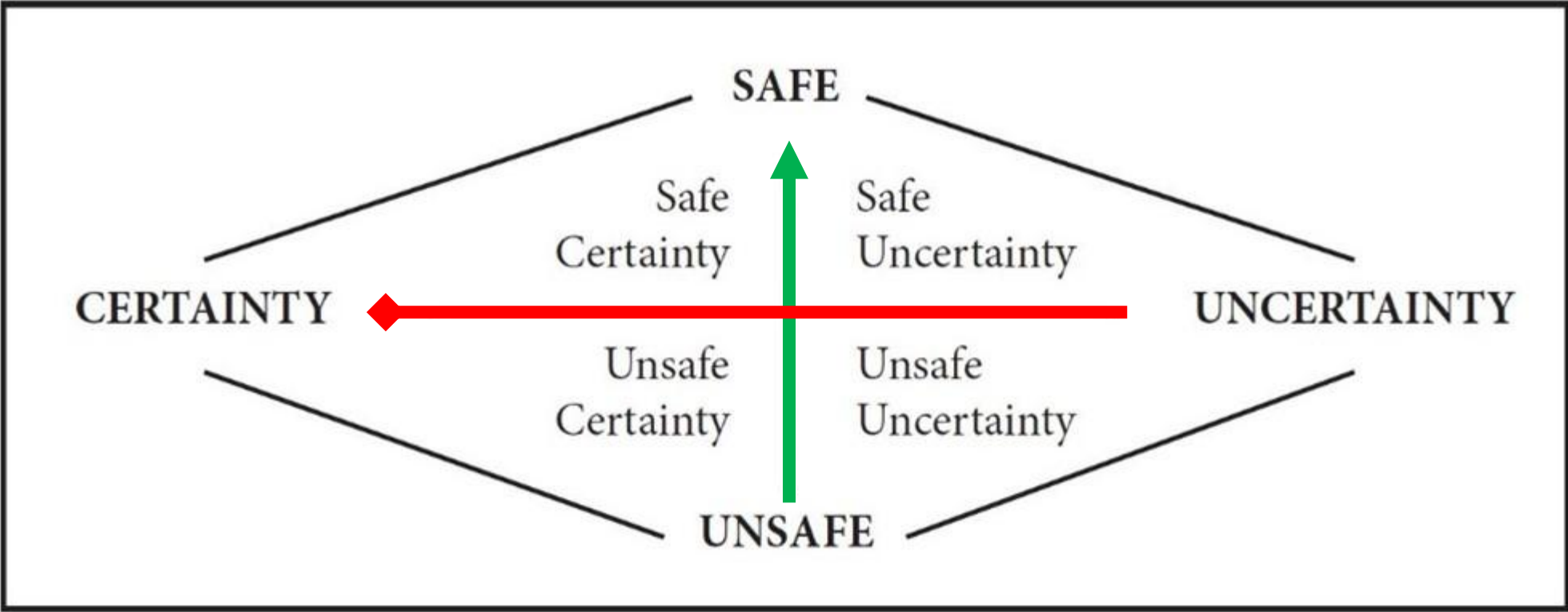
The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

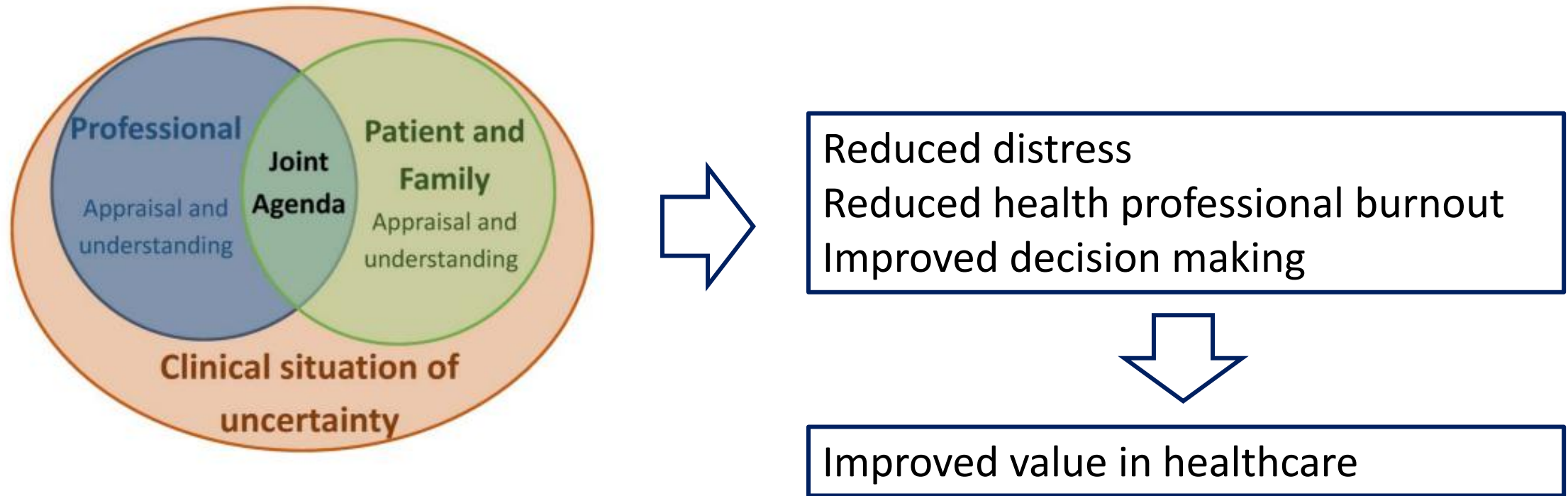
- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems. The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Uncertainty
can be a
barrier or a
trigger for
decisions
about care

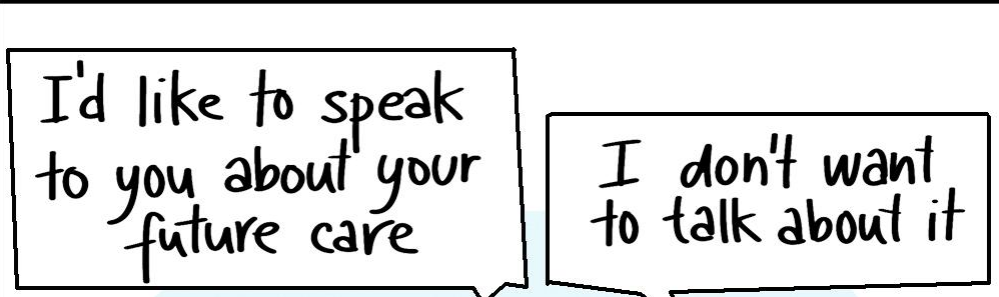
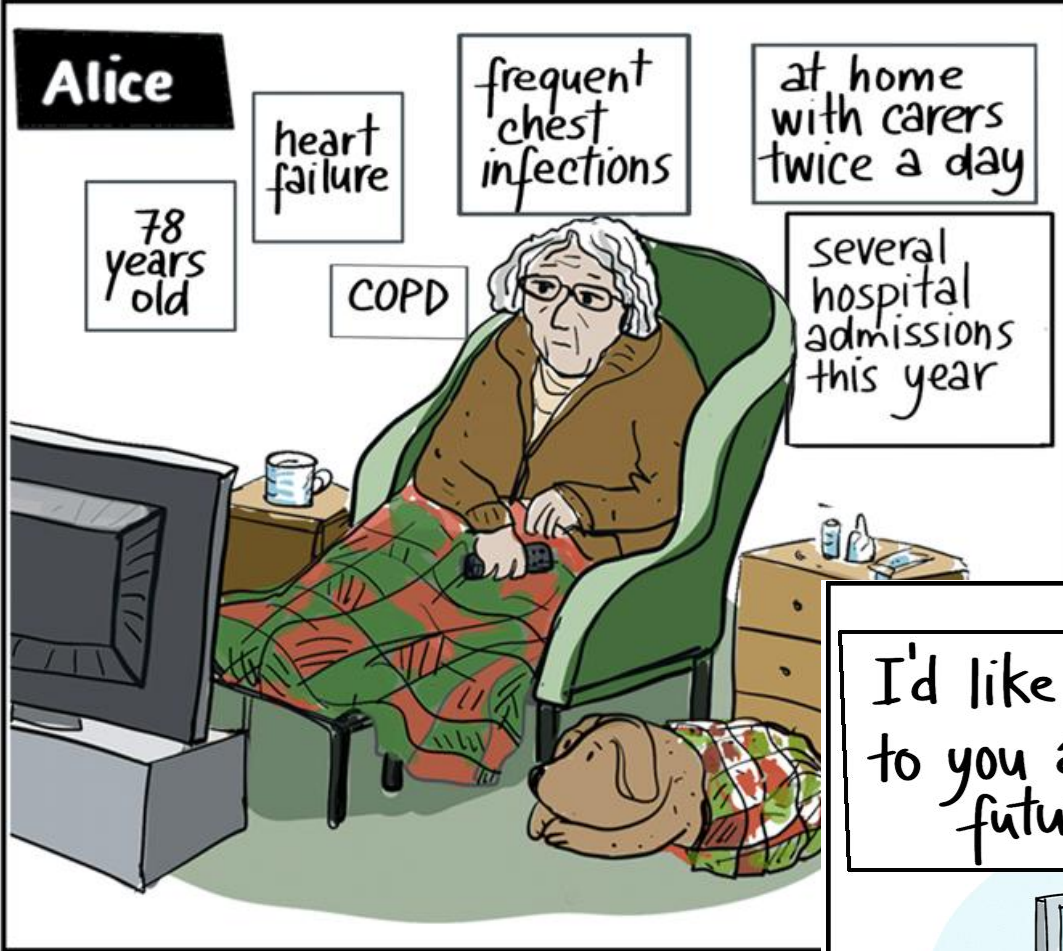
Part 3: Responding to uncertainty – what can we do?



What might be the benefits of addressing uncertainty?



- Etkind S & Koffman J. Approaches to managing uncertainty in people with life-limiting conditions: role of communication and palliative care. *PMJ* 2016;92(1089):412-7
- Kimbell B, Murray S A, Macpherson S, Boyd K. Embracing inherent uncertainty in advanced illness *BMJ* 2016; 354 :i3802
- Simpkin AL et al. Tolerating Uncertainty — The Next Medical Revolution? *N Engl J Med* 2016; 375: 1713–1715.
- Simpkin AL et al. Stress From Uncertainty and Resilience Among Depressed and Burned Out Residents: A Cross-Sectional Study. *Acad Pediatr.* 2018 Aug;18(6):698-704.
- Tinetti M et al. (2019) Challenges and strategies in patients' health priorities-aligned decision-making for older adults with multiple chronic conditions. *PLOS ONE* 14(6)



Individual responses to uncertainty: Avoiding and Addressing

RESEARCH

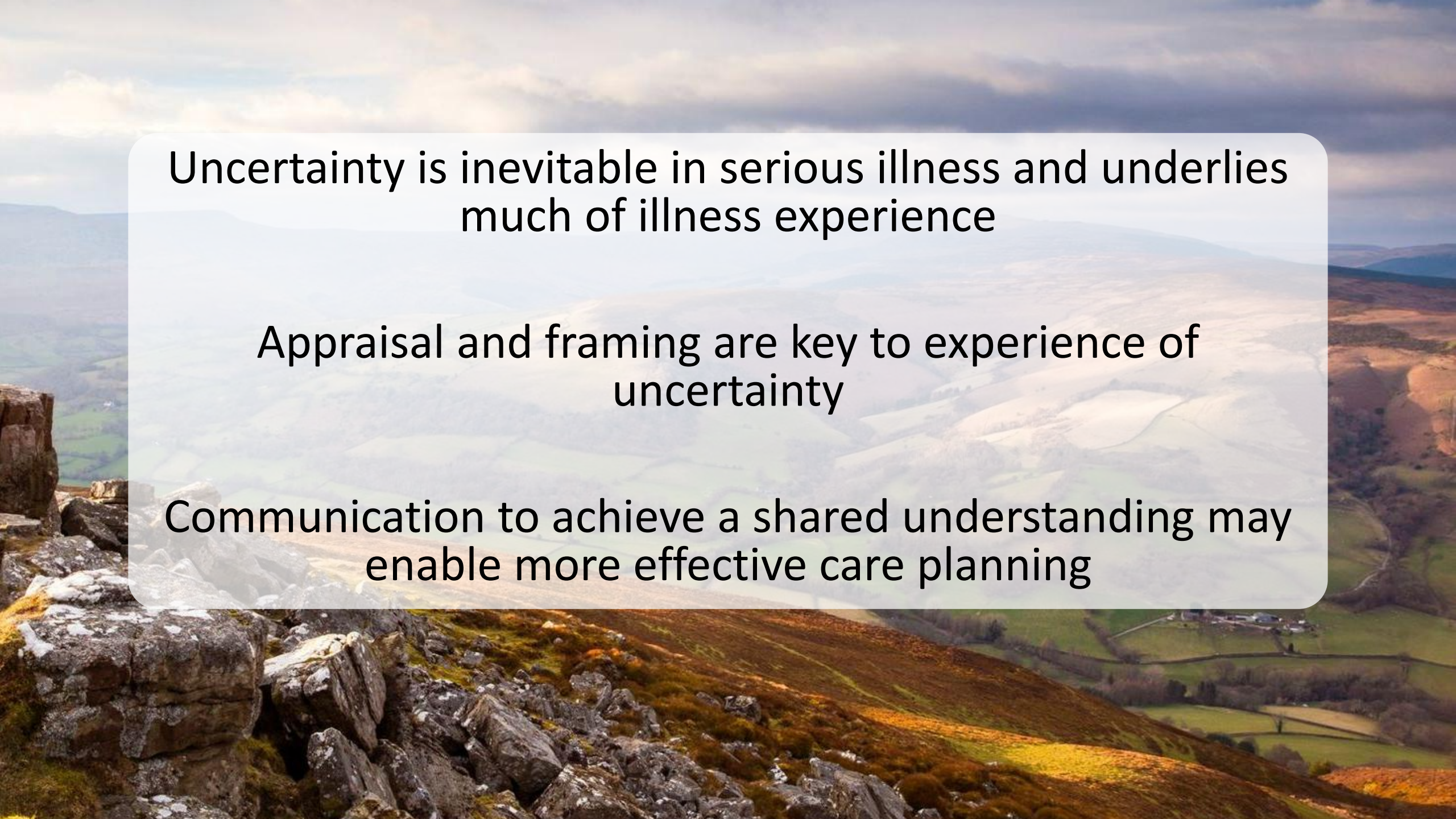
Open Access



Managing clinical uncertainty in older people towards the end of life: a systematic review of person-centred tools

Clare Ellis-Smith^{1*} , India Tunnard¹, Marsha Dawkins^{1,2}, Wei Gao¹, Irene J. Higginson^{1,3} and Catherine J. Evans^{1,4} on behalf of SPACE

“Communication of clinical uncertainty to patients and families had the least evidence and is challenging to do well.”

A scenic landscape featuring a rocky foreground on the left, rolling hills in the middle ground, and a cloudy sky. The text is overlaid on a semi-transparent white box.

Uncertainty is inevitable in serious illness and underlies much of illness experience

Appraisal and framing are key to experience of uncertainty

Communication to achieve a shared understanding may enable more effective care planning

