Decision-making on locally advanced pancreatic cancer
a longitudinal interview study of patients and informal caregivers

A.C. (Anouk) van der Hout[1] , Ida J. Korfage[1], Marc G. Besselink[2,3]; Casper H.J. van Eijck[1], Thomas F. Stoop[2,3], Agnes van der Heide[1], Judith A.C. Rietjens[1,4] [1]Erasmus MC, University Medical Centre Rotterdam, Rotterdam, NL, [2]Amsterdam UMC, Amsterdam, NL, [3]Cancer Center Amsterdam, Amsterdam, NL, [4]Delft University of Technology, Delft, NL

Introduction

For patients with locally advanced pancreatic cancer (LAPC), surgical resection of the tumour is the only potentially curative treatment. However, only a few of them are eligible for surgery, and eligibility can only be determined after completion of chemotherapy. Given the substantial impact of surgery on quality of life and the uncertainty surrounding outcomes, shared decision-making is essential but challenging. We investigated how patients and their informal caregivers navigate decision-making about treatment of LAPC.

Methods

Study design
- Qualitative, longitudinal, semi-structured interviews

Participants
- Patients with LAPC (n=18) and/or their informal caregivers (n=18)
- Included in two academic hospitals in the Netherlands
- Purposive sampling

Analysis
- Thematic analysis[1]
- Theme development over time

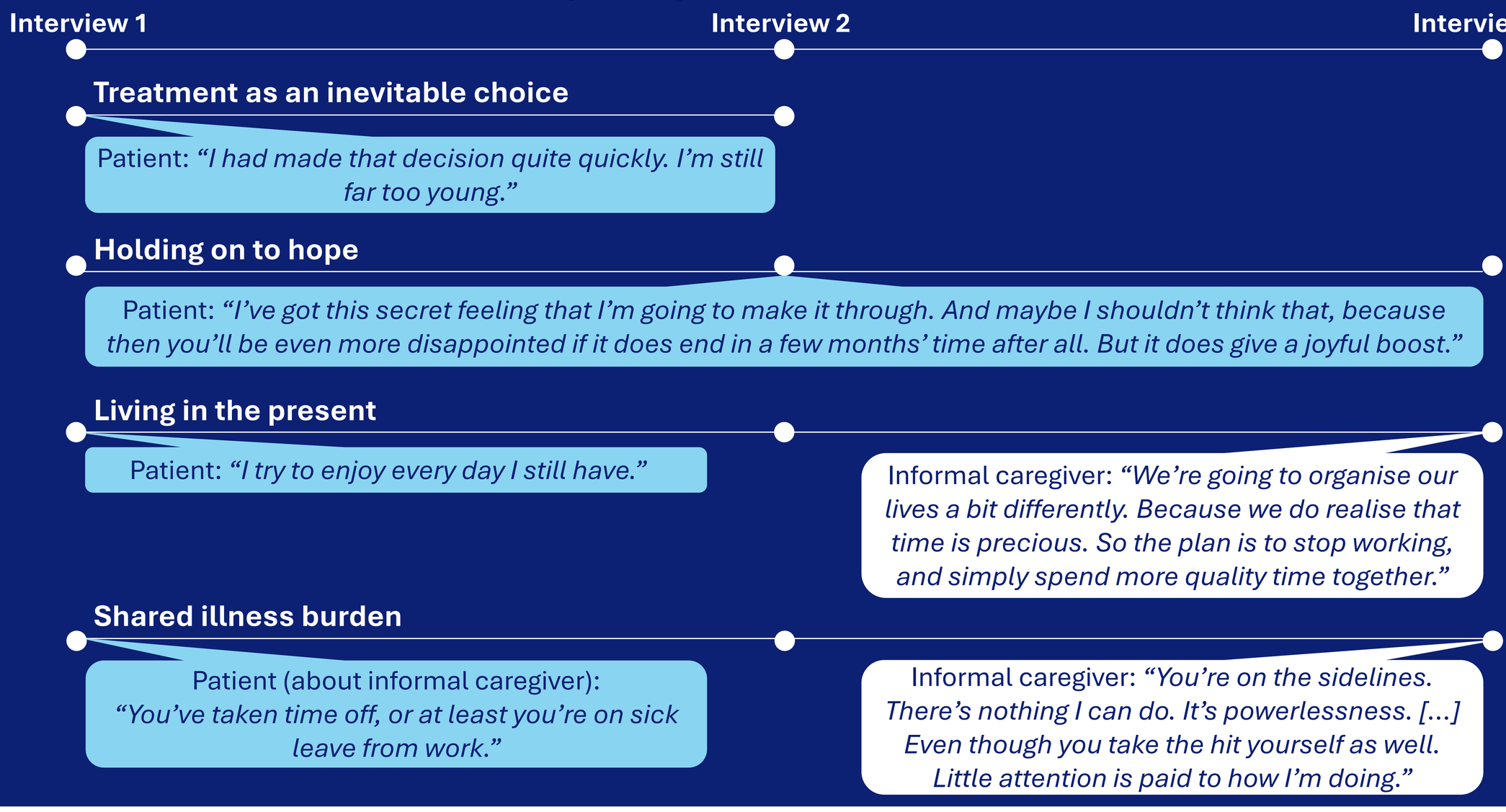
Interview timeline



Patient characteristics (n=18): median age 65 years, 61% female

Follow-up:
Interview 2: 6 patients died between interview 1 and 2 (1 interview conducted with bereaved informal caregiver); 3 dyads withdrew or were lost to follow-up
Interview 3: 1 dyad withdrew

Themes across the treatment trajectory



Discussion

Decision-making in LAPC is highly complex and emotionally laden. Many participants experienced treatment decisions not as genuine choices but as inevitable pathways, sustained by hope for cure and a focus on the present rather than long-term outcomes. Moreover, the illness and treatment of LAPC is also highly disruptive for the lives of informal caregivers. These findings underscore **the need for timely, ongoing, and experiential information provision that addresses quality of life implications for both patients and informal caregivers, and for shared decision-making approaches that acknowledge the relational and existential dimensions of living with LAPC.**

References: [1]Green & Thorogood (2018)



Find more information about the PREOPANC-4 study here:

Contact:
a.vanderhout@erasmusmc.nl

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