

Using Realist Evaluation in Hospice Day Services to Understand Context, Mechanisms, and Outcomes of Social Support Interventions

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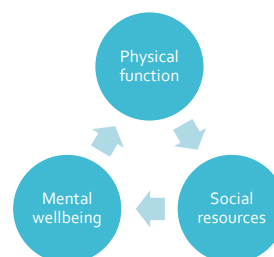
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Introduction

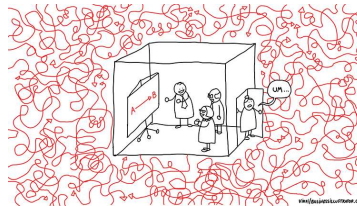
- Living with illness can mean less time and energy to invest in relationships
- Social networks grow smaller over time living with illness
- Physical and emotional isolation of being stuck at home
- Not all social support is helpful - unwanted support and ambivalent relationships can be highly stressful
- Increasing need for support to cope with (emotional, informational, practical, existential) demands of illness



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Methodology

- The social world is messy and complex
- Randomised *controlled* trials aren't always the best use of research resources
- 'Did it work?' an inappropriate question when health gains are not likely – *what is the intervention trying to achieve?*
- Realist evaluation draws on the strengths of different research methods
- Observable change emerges within a specific context from underlying forces - **context matters**
- Develops **explanations** of how and why an intervention 'works', for whom, in what circumstances, in what respects, to what extent....



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Data Collection

103

Online survey of hospice day services

A broad overview of service provision to inform next stages

9

Hospices involved in next steps

Using different locations for comparisons between hospice services and locations

19

Interviews with service-providers

People who design and deliver a service have underlying theories of why and how it 'works'

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Days' observation of hospice day services

Observations and fieldnotes led to deeper interviews and more insightful analysis

30

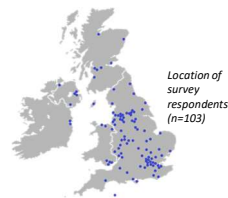
Patients recruited to observe outcomes

Need for progress on outcome measurement, feasibility and acceptability unclear

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Survey

- What hospice services facilitate social support for patients?
- 103 responses (49.5% response rate)
- Data collected Aug 2017-May 2018
- Mean 4.46 services
- A broad overview of services considered to offer social support



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Hospice Intervention

Hospice resources
(what interventions had in common)

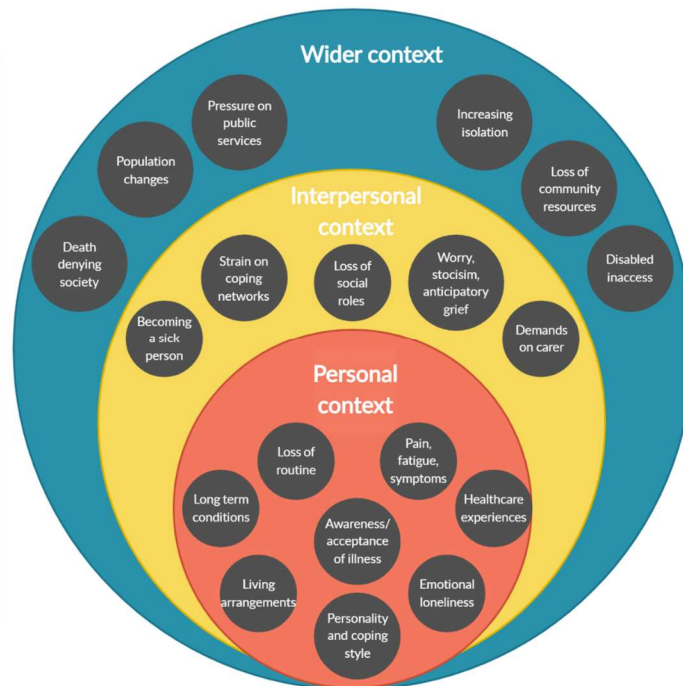
- Safe and accessible spaces
- Time-rich and experienced people
- Specialist components

Context => Mechanisms => Outcomes

"It's about giving them that safe space to talk... People always say they feel very safe, it's a relaxed environment but safe. And then there's the trust that they the patients build with each other, within the relationships that they've built. They are able to talk to each other and they help each other out."

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Patient Context



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Mechanisms

Autonomy

Choosing to be there and how to 'be' there
 Feeling safe, trusting support available
 Enjoying activities and atmosphere
 Aiming for something



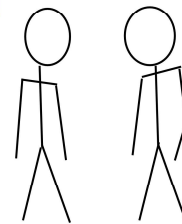
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Mechanisms

Companionship & social mealtimes
 Shared experiences, helpful advice
 New friendships and belonging
 A break from patient status

Familiarity

Autonomy



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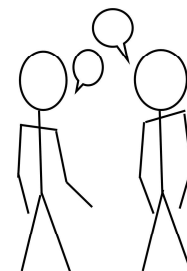
Mechanisms

Permission to talk honestly about losses since illness
 Acknowledging mortality without upset to family
 Seeing change in others, reappraising change in self
 Experiencing death of group members

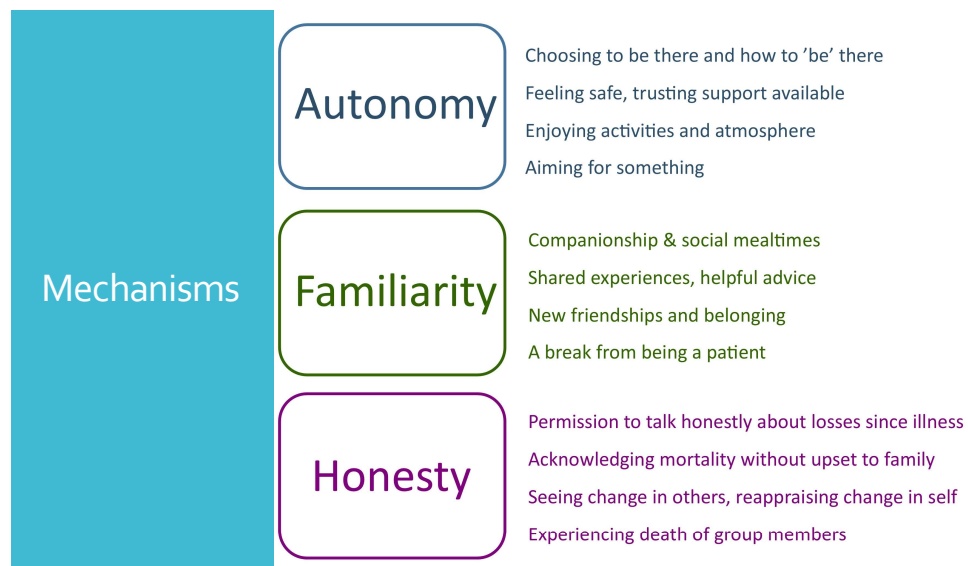
Honesty

Familiarity

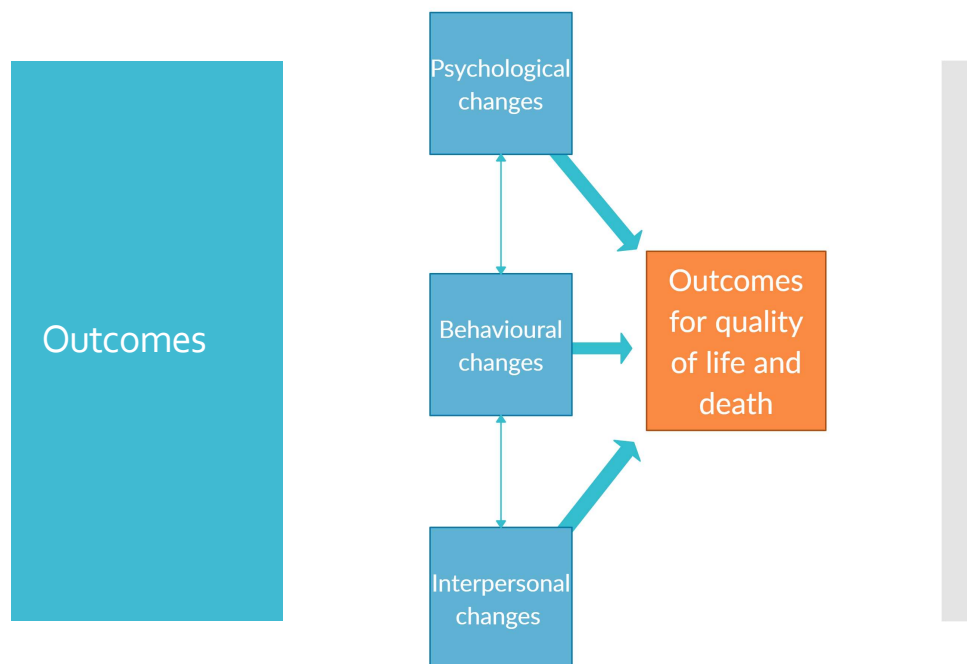
Autonomy



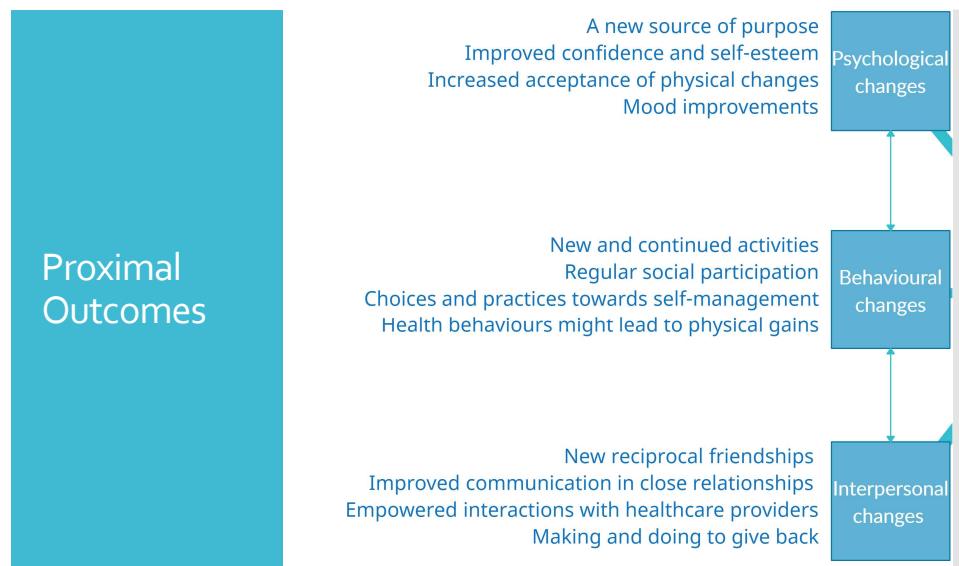
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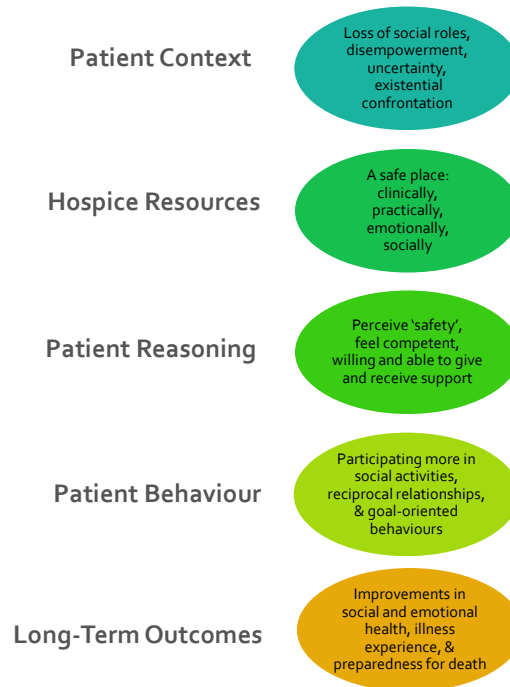


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Programme Theory



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Conclusion

- Palliative care patients can be at risk of emotional loneliness even if not socially isolated
- Beneficial social interventions are those that foster:
 - Autonomy in the experience
 - Relatedness between patients
 - And honesty around illness and mortality
- Outcomes lead to improved health (understood holistically) that enables better living & dying experiences for patients and their families
- Realist evaluation can give explanatory value – specifies the social aspects of interventions that could be relevant for their effectiveness
- A theory-driven understanding of intervention that is useful for both research and practice

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Thank you

To supervisors and funder

To hospice staff, volunteers and patients

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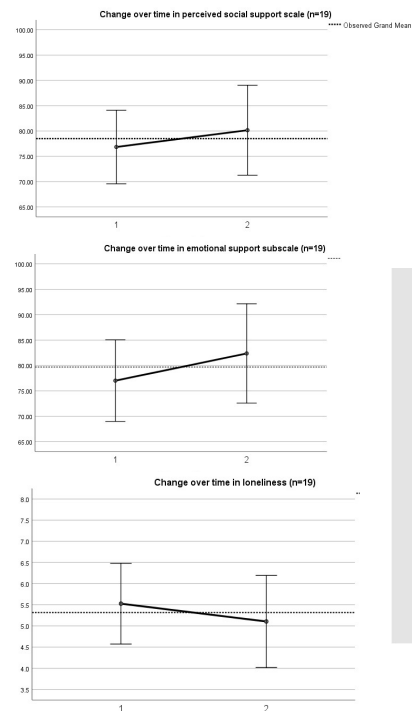


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Quantitative Results (n=19)

Quality of life: EQ-5D-5L
Perceived social support: MOS-SS, 19-items
Loneliness: UCLA, 3-item
Depression: BEDS, 6-item

- Perceived social support increased, but not significant ($p=0.267$)
- Larger change in emotional support subscale ($p=0.165$)
- Loneliness decreased over time ($p=0.104$)
- High variation in depression ($p=0.528$)
- Patients who lived alone reported greater improvement
- Recruitment was unpredictable
- Methods appeared acceptable to patients



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