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Title

Combining realist evaluation and transformative evaluation to advance research in palliative care: The case of end of life companionship

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Abstract

Background: Palliative care requires innovative methods to understand what works, for whom, in what circumstances and why. Realist evaluation has become one prominent approach due to its preoccupation with building, and testing, causal theories to explain the influence of contextual factors on outcomes. Undertaking realist evaluation is not without challenges and may amplify issues of underrepresentation, disempower those working in palliative care, and produce results with poor ecological validity. Complementary approaches are needed which mitigate these challenges, whilst producing credible findings that advances knowledge.

Purpose: In this article it is outlined how realist evaluation provides a toolkit to advance research to explain, and empirically test, the complex contours of palliative care. Moreover, it is proposed that transformative evaluation can provide a catalyst to engage and empower those within palliative care, create the opportunity for care transformation, and produce more informed and authentic theories.

Discussion: Contemporary issues in palliative care pertain to the complexity of palliative care, the insufficiency of experimental designs alone, and the challenges of achieving inclusive research participation. In this article it is argued that theory led, participatory, opportunistic, and naturalistic approaches can provide an antidote to the issues in the literature. The combination also mitigates many methodological critiques of the individual approaches, by increasing the transformative potential of realist evaluation, and explanatory potential of transformative evaluation.

Keywords

Palliative care, end-of-life, volunteer, research methodology.

Key statements

What is already known about this topic?

- Palliative care is a complex service that is irreducible to its constituent parts
- There is a recognition that novel research methods are needed to respond to the enduring challenges that exist in palliative care research
- Realist evaluation is one methodological approach that is gaining momentum, but challenges exist with its application and the combination of novel methods is needed to overcome issues with representation and equitable research participation

What this paper adds?

- The current article provides a justification on the need for a research paradigm shift within palliative care, highlighting the issues of complexity, need for explanatory methods, and inclusive research participation
- A critical overview of realist evaluation and transformative evaluation is provided, illustrating their potential to advance the palliative care literature
- The complementary features of combining the approaches are described, emphasising how the critiques of each approach can be mitigated by employing both approaches

Implications for practice, theory, or policy

- Transformative evaluation, in tandem with realist evaluation, can be utilised to empower palliative care workers and access settings which are unique and unpredictable
- Tacit knowledge can be nurtured and combined with theory led analysis to enhance the rigour, and acceptability, of research
- Realist evaluation is a useful framework to pursue research that attempts to explain outcomes; and combining it with formative and collaborative approaches, like transformative evaluation, enhances its accessibility, inclusivity, and ecological validity

Introduction

The value of palliative care is well established, however, multiple research challenges are acknowledged (1). Palliative care is a complex system which is emergent, unpredictable, and prone to adaptations (2,3). For example, in the case of volunteering, role ambiguity, hesitancy about volunteering, and the partial appreciation of spiritual support in palliative care, all influence outcomes (4). Correspondingly, there have been calls to advance the understanding of how palliative care outcomes are produced, the mechanisms of success, and the role contextual factors play (5,6).

Unique issues in palliative care challenge the possibility of experimental designs to demonstrate effectiveness (7). Randomised control trials are often not feasible due to funding, barriers to recruitment, high attrition, missing data, and unease about randomisation (8,9). Although public involvement is growing, research that gives primacy to patients' needs is lacking (10). Traditional ethical boards also require procedures which risk removing agency from key groups, and subsequently results may not represent real life (1,11). Therefore, research is needed that empowers patients, is low burden, and inclusive. This is also likely to be more acceptable to clinicians, thus increasing the likelihood of more complete datasets (12).

Working with patients to establish priorities will also advance the measurement of outcomes (1). Illness-centric measures are well established compared to concepts like autonomy, human connection, acceptance, comfort, and dignity which are often used in practice, but have underdeveloped metrics (13,14). Research must be able to capture diverse and holistic outcomes in naturalistic settings to accurately appraise palliative care (15,16).

In addition, there is a lack of research which explores the practicalities of palliative care and little is known about why outcomes are variable (17), and the lived experiences of those using services (6,18). An enduring issue is the concern of gatekeepers omitting people from research, due to ethical concerns (10). This has resulted in research that is not an accurate representation of those utilising services (19,20). It is argued that people should be given the choice to participate in research and have their autonomy maintained (19). Correspondingly, researchers should increase the opportunity to contribute to research, frequent where people are, and

actively target marginalised groups (6,10,19). By increasing engagement, recruitment will be greater, crucial insight can be gathered, and research will be more responsive and representative of real life (19,21).

Combining complexity focused approaches like realist evaluation, and participatory approaches like transformative evaluation, may provide an antidote to some of the current methodological challenges (17). The following article critically introduces the two approaches and discusses their utility to resolve some of the current issues in palliative care. The complementary features of combining the approaches is illustrated with examples from one project, which aspired to understand how end of life volunteering works, for whom, in what circumstances and why.

Realist evaluation

Realist evaluation is a form of theory-driven evaluation that aspires to explain patterns of outcomes by building and testing theories related to mechanisms (22). Mechanisms in realist evaluation usually refer to an individual's responses to specific resources (23) which are not predetermined, but activated by contextual factors (24). The selection of methods should be based on their ability to develop and test explanatory ideas, therefore, there is no standardised format advocated (25). Nonetheless, the RAMESES reporting standards provide overarching principles and key components to ensure researchers demonstrate integrity (26).

Several schools of realism underpin realist evaluation, but the central premise is that what exists is not dependent on observation (27). This encourages the researcher to theorise about entities which are beyond observation, but cause outcomes (28). Depth ontology proposes that reality can be separated into three progressively basic layers and allows theorising to be intelligible. The empirical realm accounts for phenomena that can be experienced; the actual realm relates to how things occur regardless of human experience or interpretation; and the real domain concerns the causal properties of mechanisms (24) (Box 1). By acknowledging the influence of the

unobservable on observable outcomes, enquiry turns to what must exist for events to occur (28,29).

Box 1. An example of how realism philosophy may operate in end of life.

Empirical: Observable changes to wellbeing, distress, fright, loneliness, comfort, peace, suffering, achievement, relaxation, enjoyment.

Actual: Interaction with volunteers causing events such as friendship, advocacy, learning, companionship, presence, spiritual guidance, reflection, validation.

Real: Manifestations of the events may be caused by changes to emotions, beliefs, human bonding, distraction, personhood, remembrance, reconciliation.

The cycle of realist evaluation starts with generating initial programme theory. Programme theories are unique, practical, and accessible causal ideas developed by those with experience of services (30). The context, mechanism, outcome heuristic helps arrange data into causal configurations (23)(30) (Box 2). The task of evaluation is then to accumulate a refined understanding of how outcomes manifest in practice (31)(32). It is encouraged to employ established theoretical models to orientate the work using abstract labels and refine generalisable theory into specific contexts (33). Analysis essentially involves the researcher engaging in thought experiments to explore what must be true for X to exist which is known as retroduction (29)(28).

Methodological guidance is underdeveloped (34,35) which decreases realist evaluation's accessibility. Common challenges of realist evaluation include the esoteric nature of the approach, the difficulty in distinguishing context from mechanism, the burden of the approach, and the conflation of complex relationships (36–38). Methodological exchanges about realism do exist, but are largely alienating as they focus on philosophical debates which decreases the contribution to practice (37,39,40).

A critique of realist evaluation, pertinent to the challenges in palliative care research, relates to the risk of producing results that are 'bureaucratically driven' and abandon the potential for emancipatory functions (41). It is argued that the orientation of realist evaluation is, without modification, unable to attend to the concerns of those affected by services (38). An inherent tendency is to categorise outcomes and under acknowledge the consequences of provisions to the lives of those affected by them. The requirement to engage with people to co-theorise in formal interviews (42), and rely on the evaluator to provide an authoritative interpretation of mechanisms, may also cement disparities in palliative care and overlook the voice of patients who are marginalised.

Box 2. Initial programme theories of how end of life volunteering may work

If companions have appropriate attributes and provide a presence that is sensitive to the person's needs, then human connectedness improves levels of peace and comfort.

If companions possess a middle ground (unattached to the family or allied health professionals), and provide a person-centred experience, then people can resolve their concerns, increasing coping and acceptance.

If the medicalisation of death is present and the companion is viewed as a valued part of the team, they can provide practical and advocacy support. People are then empowered, and distress is eased, improving a sense of control and dignity.

If the companionship is present beyond the death experience, and companions provide wraparound support, then the recipient, through a sense of relief, has decreased guilt and an increased peace of mind.

If the companion has appropriate training and goals, and provides loving friendship, then changes to abandonment, forgiveness, acknowledgement, and distress improve living well until they die.

Transformative evaluation

Transformative evaluation is a participatory methodology based on appreciative enquiry, most significant change, and transformative learning (43). Evaluation is undertaken to empower professionals to define good practice, the outcomes of their work, and enhance the learning function of evaluation (44). The aspiration is to engage those within the system as learners and move from proving worth to collective action (45). Participatory methods could attenuate issues with recruiting people who are representative of real life (46). The need for authentic voices, participatory methods, and approaches which satisfy the right of those dying to participate in research is noted elsewhere (17).

Transformative evaluation draws on emancipatory aims in defining what reality is and how to capture it. Questions about historical, economic, socio-political, and moral climate need consideration to ensure marginal voices inform the research. This provides a greater balance and authenticity about a phenomenon of interest (47). A genuine collaborative, and cyclical, engagement with the voices of the service is therefore central to the approach. To achieve this, appreciative enquiry provides a toolkit which values the strengths of the group, and rejects a deficit approach to evaluation. This framing of research asks 'what works', stimulating a capacity building mindset therefore enhancing positivity (43).

The 'most significant change' technique provides the platform to realise the aims of transformative evaluation. The approach was developed to overcome issues with capturing outcomes that are hard to quantify (44). Those within the area of interest are consulted to generate brief accounts related to the elements that drive outcomes (48). The process involves inviting key personnel and training them on story generation, the research process, and ethics. During the training, collaborators devise a specific question to generate 'change stories' with the users of a service (Box 3). The group then meet and collectively reflect, analyse, and select key stories they have gathered to represent core domains which they collectively generate (Box 3). The approach is acceptable to stakeholders, real world, flexible, has practical use, is low burden, and sensitive to unexpected outcomes (49).

The critiques of transformative evaluation concern the appreciative underpinning, singular data source, lack of generalisability, and insufficient consultation with established theory to provide explanatory ideas. Focusing on positive stories alone has been perceived by professionals as biased (44). Utilising most significant change data alone has limitations and should be combined with other research methods (43). Although participatory methods are rising in popularity, it is unknown if research is genuinely able to minimise power, engage marginalised people, and encapsulate individual's values and experiences (46). Lastly, the aim of transformative evaluation is to produce ongoing learning and empower professionals to contribute to knowledge generation. A further critique is that many naturalistic approaches describe accounts without unpicking how outcomes are derived (32).

Box 3. An example of a Most Significant Change question which was generated by a group of volunteers in the current project, and illustrative stories generated to empirically test programme theory

Question: "Since I've been visiting, what do you think is the most important thing to you about our time together?"

1. "For many years I have lived alone and miss my husband. Though I have 6 children, who visit, when possible, they have lives of their own and I am quite lonely at times. Your companionship and the regular conversations we have, puts sparkle in my life. It helps my loneliness and prevents me from getting anxious and depressed. This makes my life so worthwhile with kind friends like you. During the two years of the pandemic, you have been my lifesaver, my anchor and hope in that stormy sea of sadness. I am now enjoying happier days seeing you in person"
2. "You are one of the most joyous people I know. Your regular, numerous phone calls have always lifted me up when I was very lonely, and I could talk to you for hours. Also, you usually find interesting things for everyone to do at the community centre. Your continuing kindness and caring as a companion cheer me up and lift my spirits when I feel low."
3. "Since I am a widow and live on my own, I am grateful for your friendship and regular phone calls, which was a lifeline during the many months of lockdown. This was one of the things that kept me going during the worst times. At the community centre, you have been doing raffles and quizzes, apart from arranging exercises, talks and musical afternoons, which broaden and stimulate the mind. I would be lost without you and I'm sure I speak for your other beneficiaries. To me you are a beacon of light shining God's love for us all."

The lack of explanation in naturalistic approaches limits the potential for portable ideas to be applied elsewhere (50).

Illustrative example

The Centre for The Art of Dying Well, in partnership with the St Vincent de Paul Society, England, and Wales, undertook a two year project which offered introductory training in end of life companionship to its members. A realist evaluation, combined with transformative evaluation, was utilised to appraise the impact of companionship on beneficiaries.

The phases of the research are outlined in Figure 1. Initial document analysis was done to concept mine/map the palliative care and volunteer landscape (n=8) (51). Documents were purposefully sampled for their ability to populate theory (52). The objective of the document analysis was to unearth interpretations about definitions, envisaged outcomes, key contexts, and implicit or explicit 'theories of change' (30). Participant observation (March 2021-May 2022) involved attending meetings and volunteer catch ups. These observations were useful proxies to the settings where companionship was taking place. Journaling was used to record and examine the interplay of observations, thoughts, questions, theoretical ideas, anxieties, and potential impositions on the data generated (53). The journal followed the broad processes involved in reflective practices to retrospectively think about experiences, self-evaluate the actions and feelings from the experiences using theoretical perspectives, and reorientate the results to influence emerging ideas about theory (54).

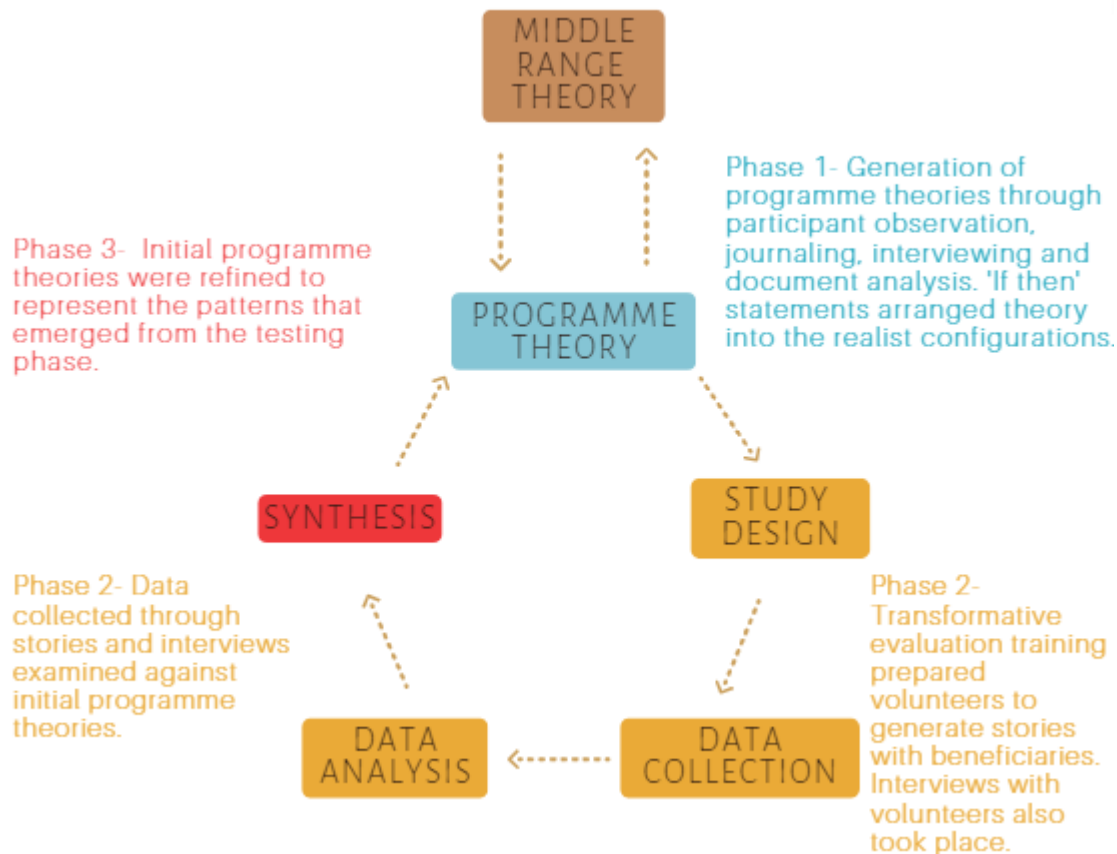


Figure 1: The research phases and data collection methods for the research

Semi-structured realist interviews with programme architects (n=6) were undertaken to glean ideas. The approach adopted a ‘teacher learner’ approach whereby the interviewee can teach the researcher about their experience of theory in action from the interviewer’s initial ideas (55).

Theory testing involved most significant change stories from patients generated by the volunteers who were trained in transformative evaluation. Alongside this, interviews with volunteers, written reflections from the project team, transcripts from volunteer catch ups, and extracts from a volunteer forum were also used to refute, confirm, or extend programme theory.

The context, mechanism, outcome heuristic helped arrange data into causal configurations (23). Initially analysis to develop programme theory employed the ‘if then’ or ‘if then because’ framework which alleviated issues with the conceptualisation of context and mechanism (56)(Box 2). Segments of documents and interview transcripts were read and appraised to see if outcomes, essential conditions, or theories of change were articulated. Each statement was also given a

theory label creating conceptual 'bins' (57). The next stage of the research will abstract findings to middle range theoretical models which allows for transferable learning (32).

Discussion

The use of realist evaluation in palliative care is growing (58), and there is increasing attention on methods that can complement 'complex adaptive system' methods to address current methodological challenges (36,59). Transformative evaluation and realist evaluation have similarities which make them congruent, offering one potential for methodological synergy (43,60,61).

Many approaches to generating programme theory are developed prior to entering applied settings and utilise individuals who are removed from practice, decreasing their ability to capture authentic findings (37,62). In contrast, transformative evaluation gives primacy to how phenomena play out in real time. The opportunistic generation of stories increases the potential for theory to uncover nuances which may not be articulated in formal interviews with programme architects (63,64).

Transformative evaluation values practice led conversations with the aim to inspire learning (44). This has implications which can strengthen the accessibility of realist evaluation. Empowering those within palliative care to engage in a critical dialogue about how practice works, from whom, in what circumstances overcomes several issues within realist evaluation. As the members of the community drive data generation and analysis, it increases the accessibility of realist theorising. Jargon is minimised and the burden of discerning context from mechanism is not emphasised. The most significant change approach focuses on how services change people's lives from the beneficiaries voice (49), which ensures causal explanation is at the foreground of collective discussions.

Realist evaluation can also bolster transformative evaluation by overcoming the limitation of exclusively using individual perspectives. Realist evaluation encourages consultation with a range of respondents, and the literature, to sensitise the researcher to theory areas (65). Although efforts must be made to ensure inclusivity is achieved, realist evaluation positions the researcher as the knowledge broker.

Realist evaluation addresses the limited transferability, questionable reliability of findings, and biased perspectives in transformative evaluation. The focus of transformative evaluation is on prudent changes to people's lives, learning, and empowerment, but it does not have the apparatus to make causal claims about how the historical, economic, and social contexts produce outcomes. Configurational causal analysis and use of theoretical models in realist evaluation provides the '*connective tissue*' to progress naturalistic data into transferable ideas about services (50).

Realism contends that real entities exist but can only be known through interpretation, metaphor, and discourse (66). Others have drawn parallels between realism and emancipatory paradigms (67) which may indicate why realist evaluation focuses on what works well (or not well), for whom, in what circumstances, and why. Although there is no need to defend sampling positive experiences in an emancipatory paradigm, realist evaluation encourages the use of mixed methods to validate findings (34). Therefore, the process of realist evaluation can employ transformative evaluation as one tool within a broader evaluation suite, increasing the credibility of findings from various methodological perspectives (68).

There are considerations when combining the approaches that need attention if integrity to both approaches can be maintained. Transformative evaluation requires a genuine commitment to reducing power differentials and involving participants as co-researchers. This challenge to transformative evaluation's core element is magnified in realist evaluation where the researcher is positioned as presiding over the incorporation of different perspectives (36). Subsequently, care must be taken to ensure the transformative training is culturally appropriate, minimises social desirability, and seeks out marginalised groups (49).

Conclusion

Contemporary research is needed that recognises how features like geography, resourcing, healthcare system organisation, service configuration, and the role of volunteering is diverse across palliative care (69). Furthermore, there is a need to explain how differences in settings, structures, continuity, and training influence the quality of care and the effect on patients (6). Lastly, research must be sensitive to

how palliative care can ensure equity of access and involve marginalised groups (6,19,69).

Realist evaluation has the potential to advance explanatory research, which addresses the complexity of palliative care, but may not address issues in research pertaining to inclusivity, empowerment, and transformative. We propose the use of realist evaluation, in combination with transformative evaluation, to advance palliative care research. Authors have advocated for realist approaches to be combined with naturalistic approaches (50,70), however, the combination is underexplored. Transformative evaluation provides realist evaluation the opportunity to empower individuals, gain access to the voice of the dying, decrease evaluative burden, and provide ongoing practical feedback (60). Realist evaluation offers transformative evaluation an explanatory framework to make portable causal claims about how outcomes are derived. We propose that, used together, realist evaluation and transformative evaluation, are also better aligned to the practical realities of palliative care than traditional research methods, and can address the current research priorities.

Declarations

Authorship

JD, SC, LB, MD, ABL, JC were major contributors to the design, acquisition, and interpretation of the work.

JD, LB, MF, SC, ABL were major contributors to the analysis of the data

JD, NB, SC, LB were major contributors to the drafting and revising of the work.

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Declaration of conflicts of interest

The authors declare that there is no conflict of interest.

Ethics

Although this is a methods paper, it does update the reader on phase 1 of the research project. All ethical clearance has been granted by Plymouth Marjon University ethics panel. All practices confirm with the World Medical Association Declaration of Helsinki.

Consent and data sharing

The research is ongoing, as such access to data can only be retrieved upon request from jdowney@marjon.ac.uk

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