

Case study analysis of end of life care development: A social movement perspective

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Abstract

Background

The modern hospice movement is often recognised as a social movement. However, such understanding is primarily based on historic reflection and this approach has lacked theoretical exploration. The modern hospice movement has not been examined by way of any social movement theory.

Aim

This study addressed the theoretical gap in understanding the end of life care (EoLC) development in Macao China.

Focusing on the Chinese socio-cultural context, this study explored the EoLC movement through the social movement theory, the Framing Perspective, as proposed by Snow and Benford in 1988.

Methods

A case study approach was conducted. Semi-structured interviews were held between 2012 and 2013, with pioneers (n = 11) of the EoLC in Macao. Thematic analysis was adopted to analyse the interviews.

Results

The EoLC development in Macao can be understood as a social movement. The Framing Perspective analysis illuminated that there was both growth and stagnation of the EoLC movement. Three themes emerged: 1) the suffering of people at the end of their lives was considered as a social problem needed to be addressed urgently, 2) the incoherent EoLC strategies developed by pioneers indicated the lack of internal ideological cohesion within the movement, 3) external constraints contributed to the stagnation of the movement.

Conclusions

The Framing Perspective provided a theoretical way to understand the emergence of EoLC; offering a novel perspective to conceptualise the modern hospice movement. This sociological and theoretical lens opened up new ways for future research to study the emergence of EoLC in different socio-cultural contexts.

Background

While the modern hospice movement is acknowledged and referred to as a social movement [1], there is a lack of exploration of the emergence of end of life care (EoLC) from a theoretical, social movement perspective. The conceptualisation of the modern hospice movement mainly concerns the establishment of the dissemination of the principles of hospice care [2–4], and the establishment of hospices and related EoLC services [5–10]. Several studies have investigated the development of EoLC in countries with a range of different socio-cultural backgrounds [11–16]. However, most available literature discussed issues pertinent to the practical and conceptual introduction of EoLC, and there is a notable lack of discussion on the theoretical underpinning of EoLC initiatives. Taking into consideration the overall lack of systematic examination EoLC as a social movement, and targeting this knowledge gap [12–14, 16–27], a social movement theory, the Framing Perspective, is used to examine data to analyse the emergence and stagnation of EoLC in Macao. Such a perspective enables a systemic and theoretical examination of the EoLC in the Chinese socio-cultural environment of Macao.

Methods

Study design

The qualitative case study model proffered by Robert Stake [28–30] was adopted in examining the emergence of EoLC in Macao, and developing a theoretical understanding of the EoLC establishment from a social movement perspective. The *'EoLC within the context of Macao'* was determined as 'the case', in order to reinforce the focus of enquiry for the present study.

Participants and recruitment

Participants recruited for this study were pioneers, including initiators, developers and nurse educators, who had been substantially involved in the establishment of EoLC in Macao; they were considered as the people best able to give insights to the phenomenon of the study.

Inclusion of nurse educators was mainly because they were found to have substantially involved in introducing and developing EoLC education in Macao [31–33].

Participants of this study were therefore recruited from: i) the inpatient hospice, ii) the community EoLC service and iii) a nurse education sector, where Macao's public promotion of the concept of EoLC and the introduction of palliative and EoLC first began.

Six participants (two initiators, three nurse educators and a hospice developer) were approached and recruited for this study by way of purposive sampling. Five more potential participants were identified by snowball sampling.

A total of 11 participants were recruited, with verbal and written informed consent being obtained from all participants.

Data collection

Semi-structured, in-depth interviews were conducted with the participants. In keeping the quality and relevance of the materials generated through interviews [28, 34], a semi-structured interview guide with

five open-ended questions was developed.

Data analysis

A thematic analysis approach [35] was adopted to structure the analytical process for the study. The process of data immersion during analysis facilitated the first author to determine that, the Framing Perspective [2–4] was a suitable theoretical framework to examine the emergence of the EoLC in Macao, and to aid the development of a theoretical understanding of the EoLC movement in Macao. The computer-assisted data management software (QSR NVivo version 11) was used to manage and facilitate the analysis of the collected data.

Reflexivity

Reflexivity of the first author in this study was informed by the position as an ‘insider’ as well as an ‘outsider’. The recognition of this joint researcher position illuminated the first author’s reflexivity during the research process, in that the first author was aware of how her experiences, or lack of them, might contribute to the construction of meanings, from structuring research questions, facilitating interviews, to handling, interpreting and analysing the collected research data [36, 37].

Rigour

The current study had adopted the position of quality assessment for case study, advised by Thomas [38], to ensure the quality and robustness of this research. The first author had kept clear documentation with regards to every step taken in conducting this study. The study had also provided participants with their interview transcripts, allowing them to confirm their responses and to make amendments should they see the need to do so. In offering this option to the participants, the study intended to safeguard participants’ confidentiality, but also wished to ensure the quality of the data [39, 40].

Results

Problem conceptualisation: the suffering of people as experienced at the end of their lives

The rise of a social movement usually intends to change a problematic situation (the grievance) identified by the movement’s adherents [2, 3, 41]. The rise of the EoLC movement in Macao, was found to have stemmed from one particularly problematic situation identified by the initiators of Macao, that was the suffering people experienced at the end of their lives. While the study found that the three initiators of the ‘EoLC in Macao’ having different personal and professional experiences related to end of life situations, they had reached consensus and conceptualised the same problem. However, the attribution of the problem was found to be different amongst the three initiators. According to the Framing Perspective, framing denotes an active and dynamic process of meaning construction exhibiting through the process of ‘core framing tasks’. The three core framing tasks encompass diagnostic framing, prognostic framing and motivational framing [2]. The consensus of a problematic situation (the

grievance) is often attained without complication, the attributional consensus, which is the consensus of the diagnostic frames, is usually more complicated [2]. The misalignment of diagnostic frames was evident in the EoLC movement as the three initiators varied; a variation which subsequently led to the incoherent solutions (prognostic frames) in establishing EoLC in Macao. The various solutions developed by initiators corresponded with the different diagnostic frames conceived by the initiators, a phenomenon explained by the Framing Perspective as a result of diagnostic framing is often projected onto prognostic framing, leading to different solutions developed by social movement initiators. Emerged from the data, the varied solutions developed by initiators included the establishment of an in-patient EoLC service, a community home visiting service and nursing and public educational programmes in promoting the concept of EoLC in Macao. Table 1 below summarises the various diagnostic and prognostic frames conceptualised by the three end of life initiators in Macao.

Table 1

Diagnostic and prognostic frames conceptualised within the end of life care movement in Macao.

	Diagnostic Frames	Prognostic Frames	Prognostic Approaches
Hospice Initiator	Absence of clinical EoLC	To alleviate suffering at the end of life	Establishing the first hospice
Community EoLC Initiator	Abandonment of the dying Absence of community EoLC to address abandonment of the dying	To alleviate suffering at the end of life To promote acceptance of death	Establishing the first EoLC home visit service
Nursing Education Initiator	Personal encounter of EoL experience Separation of life from death in nursing education	To promote acceptance of death	Constructing the EoLC concept in the nursing field and public sphere

As shown in Table 1, the diagnostic frames conceptualised by the three initiators reflect their individual interpretations of the grievance. The prognostic frames conceptualised, though appearing to be both overlapping and synchronised, yielded significantly different approaches. In the case of EoLC in Macao, whilst the articulation of frames, by EoLC initiators, was based on the shared grievance, the meanings rendered to those frames were diverse. This diversity was particularly visible amongst the diagnostic and prognostic frames, thereby contributing to the incoherence of internal frames.

Diversified solutions: intra-movement frame disputes

Suggested by Snow and Benford [2], an intra-movement frame dispute is the fragmentation of goals and/or strategies amongst different individuals/ groups, within one movement. Although intra-movement conflict is recognised as a universal and common feature of social movements, it would limit movement mobilisation. Intra-movement conflict was observed in the case of EoLC in Macao. Whilst

initiators shared a unified vision of the grievance, their framing efforts in terms of the problems (diagnostic frames) contributed to this grievance differed. As a result, the solutions for these prognostic frame problems remained segregated from one another (see Table 1). The diverse prognostic approaches developed as a result could be theorised as intra-movement frame disputes. Despite possible structural differences, social movements should have “cohesion and continuity over time” (p. 24) [42]. In the case of EoLC in Macao, the Framing Perspective has illuminated a fundamental issue: the lack of collectiveness informed by the absence of joint action amongst the initiators and developers in the development of EoLC. This lack of collectiveness - the lack of internal frame cohesion - implies that the EoLC in Macao was not a full social movement. Further, the lack of internal frame cohesion is suggested by this study to be one of the main contributors to the lack of advances in, or development of, EoLC in Macao.

The lack of external frame cohesion

Drawing on the Framing Perspective, conceptual constraint is the main contributor to the lack of external frame cohesion. The frames proposed by EoLC initiators were found to be in conflict with the extant cultural belief of life preservation. The conflicting nature between EoLC and the extant cultural element of life preservation has challenged the introduction of EoLC from the start, mainly because the ideologies conceptualised by initiators of EoLC were in complete contrast with the cultural beliefs held by the public of Macao.

“... They feel that no resuscitation equals giving up on life.

Yes, so when the patient is not for resuscitation, relatives will feel they are sending the patient to a place with no medical treatment.

Relatives will find it very difficult to see past their obligations.

They have not really understood the service of palliative care.

So their thoughts are normal.” (Developer, Hospice)

Evident in the above quote is a clear correlation between the cultural expectations of sustaining life through resuscitation. Within the context of EoLC, a link was established between the idea of no treatment and no resuscitation; as a result, EoLC was being conceptualised as a way of abandoning the dying relatives. These findings lend support to existing research that, amongst Chinese patients and families, making a decision for the complete withdrawal of resuscitative measures was deemed unacceptable, due to the existing filial obligations; as a result, basic life support medications were still commonly given regardless of resuscitation status [43, 44].

End of life care was being conceptualised/perceived as a form of abandonment of the dying, contrasting the external cultural beliefs held by people in Macao.

According to the Framing Perspective, the more compatibility that exists between the proffered meanings (frames) of a social movement and the existing cultural narrations, the more acceptable and popular the movement becomes [45]. In Macao, the connection of EoLC and no resuscitation was therefore unable to

align with the existing cultural expectations of life preservation, thereby inhibiting the acceptance of EoLC.

In the studies of social movements, it is well established that one of the biggest challenges for social movement initiators is the promotion of frames, that are often established in contradiction to the dominant culture, in which the movement is embedded [46]. In the case of EoLC in Macao, complete alignment between extant cultural values, and frames proffered by EoLC, could be difficult to achieve due to the substantial cultural divergence between the two variables. Nevertheless, the issue of frame misalignment is, in one way or another, attributed and heightened by the negligence of initiators to take into account this cultural divergence, when in the beginning stage of frame articulation for the EoLC in the case of Macao.

Put forward by Benford and Snow [41], the frame alignment processes are strategies adopted to help social movement to negotiate frames, in order to garner agreement from potential supporters, these processes are involved strategically, as social movement begins to establish frames, and potentially enhance movement efficacy from the start. With respect to the initiation of EoLC in Macao, initiators had not involved any of the framing processes in generating frames at the beginning stage of the initiative. The frames underpinned the initiation of EoLC were predominantly grounded in the three initiators' interpretations of the degree of a person's suffering experienced at the end of life. Initiators did not contemplate the extant cultural element, the desire and expectation to preserve life, when developing the initial frames for the EoLC movement.

Discussion

The Framing Perspective has: i) enabled the theorisation of intra-movement frame disputes, which had contributed to the understanding of the limited development of the EoLC in Macao, and ii) explained why the EoLC in Macao failed to meet the criteria of being cohesive and collective in a social movement. Both of these significant points indicate that EoLC in Macao was not a full social movement and further reinforced its limited degree of development. However, the Framing Perspective was unable to fully facilitate the investigation of the case of EoLC in Macao, in particular, problems remain regarding: a) how initiators came to devise incoherent strategies and b) how the diversity had continued without any observable collaboration between initiators and developers. Nevertheless, the focus on frame alignment within the Framing Perspective has aided in explaining and theorising the lack of internal as well as external frame cohesion within the EoLC movement of Macao. Further, the consideration of framing processes upon movement initiation is not appropriate, mainly because the ideologies supported by the EoLC initiative are substantially different from the existing cultural values associated with life preservation. To consider integrating the life preserving belief into EoLC might appear to be both unrealistic, and also unattainable, in the case of Macao. Therefore, initiators of EoLC in Macao perhaps had no other way to introduce the movement except by disregarding the extant cultural values.

The EoLC in Macao epitomises a type of social movement that is different from the types suggested by Snow and Benford [2], Snow et al. [4] and Snow et al. [3], in that the current structure of framing processes informed by the Framing Perspective only offers a limited understanding of social movements that are developed via frames that are exclusively based on the version of reality in accordance with their initiators' interpretations. Given the example of the EoLC movement in Macao, the study argued that the understanding of this type of movement is important. The current study is informed by the fact there are social movements, like the EoLC movement of Macao, where not only are the proposed frames opposed to certain mainstream values, but the integration of proposed frames with the mainstream values is impossible.

Implications

Despite the modern hospice movement that was initiated in the UK always being known as a social movement, there is only limited evidence examining the modern hospice movement from such a theoretical perspective.

Focusing on the EoLC in Macao, this study has provided a new way to examine the development of EoLC by way of a social movement theory: the Framing Perspective.

The findings of this study have broadened the understanding of the development of EoLC in Macao in the social movement sense. Whilst the Framing Perspective informed the consequential relationship between the diverse strategies in developing EoLC and their negative impact on EoLC, the Framing Perspective was unable to fully explain the phenomenon wherein the EoLC in Macao was developed upon the versions of reality in accordance with initiator's individual interpretations of the grievance. Further, the Framing Perspective was unable to explore how initiators had come to devise incoherent strategies in establishing EoLC, and how the diversity had continued, with no observable collaboration between initiators and developers. The use of the Framing Perspective has to an extent limited the understanding of the development of EoLC if and when perceived from a social movement perspective. This limitation again provides an opportunity for future research to consider other social movement theories in exploring the development of EoLC, not merely in Macao but also in other cultural contexts.

Conclusion

This study develops an understanding of the development of EoLC in the specific socio-cultural context of Macao at both the theoretical and experiential level. This research makes an important contribution in illustrating and understanding the development of the modern hospice movement in the Chinese context of Macao. Despite claims internationally that the hospice is a social movement [1, 7] there has been limited empirical and theoretical basis to support the claim. This research provides empirical evidence examining the mobilisation of the modern hospice movement from a theoretical social movement perspective. The social movement theory of the Framing Perspective [2–4] enables key facets of the development of EoLC to be explained and understood. The elements that have facilitated/inhibited the mobilisation of the social movement of the modern day hospice are valuable to understand for those

seeking to develop or adapt hospice services around the globe. The lens of the social movement theory of the Framing Perspective as applied to the understanding of EoLC in the Chinese socio-cultural environment brings a unique dimension to the current understandings of the hospice development pertinent for international consideration.

Abbreviations

EoLC: End of Life Care.

Declarations

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Ethics approval and consent to participate

The study was approved by the Research Ethics Committee of the School of Health in Social Science, University of Edinburgh, 23rd November 2012. Under the Ethics Framework of the College of Humanities and Social Sciences, University of Edinburgh, the study was undertaken in conformity with the Declaration of Helsinki. Informed consent was obtained from every participant in the form of signature and their anonymity was preserved.

Consent for publication

Not applicable.

Availability of data and materials

The audio-taped and transcribed interviews are not publicly available to protect participants' confidentiality. Raw data may be obtained from the corresponding author on reasonable request.

Competing interests

The authors declare no competing interests.

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Contributions

KIT designed the study. KIT collected data. KIT analysed data and interpreted results. EH-S and SR supported data analysis and the interpretation of results. KIT wrote the manuscript.

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