Social Relationships and Community End of Life Care in Hong Kong: A Three-stage Model of Social Capital Development

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Abstract

End-of-life (EOL) care is a crucial public health issue in Hong Kong, and one in which the community social service sector has become increasingly involved, as healthcare policy in the country shifts towards greater emphasis on social relationships in non-medical forms of EOL care. This study used abductive grounded theory methodology to illustrate the complex dynamics and mechanisms involved in social relationships between dying people (and their families), volunteers, and professionals in community-based social service agencies in Hong Kong. The aims are a) to better understand how social relationships influence the experiences of dying people and their families, and b) to engage theoretically with concepts of social capital and compassionate communities to explicate the dynamic and relational processes involved in this phenomenon. Fourteen in-depth interviews with practitioners and two service users affiliated with two community-based EOL care agencies in Hong Kong were interviewed. Findings inform a parsimonious three-stage model of social capital development in which relationships between service agency workers and families address a key precondition of social capital through establishing trust, facilitating the accessibility of social capital through cultivating mutuality, and mobilising social capital through collaborating in community EOL care. These processes in turn mitigate community detachment in the EOL experience. Lastly, this study elucidates policy and practice implications related to both health promotion and community engagement in the care of dying people and their families in Hong Kong communities.

Keywords: social relationship; social capital; compassionate communities; community end-of-life-care; dynamical mechanisms

Introduction

Improving palliative care, hospice care, and end-of-life (EOL) care is a global public health concern and response to population aging. A palliative care approach improves the quality of life of patients and their families who are facing problems associated with a life-threatening illness (World Health Organisation, 2018), and hospice care approaches emphasise addressing physical, psychological, social, and spiritual needs through professional and volunteer support in different settings (Worldwide Hospice Palliative Care Alliance, 2020). EOL care focuses more on providing these kinds of supports to people with a prognosis of 12 month or less (NHS, 2022; World Health Organisation, 2021).

Like other industrialised societies worldwide, Hong Kong's long-term care policy for older people strives to improve the quality of dying, through policy, public spending, and death education (Elderly Commission, 2017). Notably, Hong Kong's strategic service framework for palliative care specifically references an expectation around generating social-relational resources to improve psychosocial aspects of death quality (Hospital Authority, 2017).

However, a deep-rooted culture of death denial in this region, in which talking about death is believed to attract bad luck, still hampers efforts to promote death literacy (Chan, Lee &Woo, 2020). Hong Kong neighbourhoods also usually have low social capital (Fung & Hung, 2014). Neighbours rarely talk directly with their neighbours (Forrest, La Grange & Yip, 2002) and residents of high-density housing tend to act in cold or impersonal ways to those outside the family network (Tang et al., 2019), albeit with some positional variation between individuals.

Moreover, standard palliative care for dying people in Hong Kong remains grounded in a medicalised approach, resulting in specialist services, a focus on hospital-based care, and a significant focus on people with cancer (Lam, 2019). In this context, the term "EOL care" tends to be used among practitioners and advocates to signify and prompt a shift towards more socially oriented care at the community level (Chan & Chow, 2019). As such, we use this term in the present study to foreground the role of social agencies and their relations to and with dying persons and their family members.

The theoretical concept of *compassionate communities* has been used by palliative care advocates, researchers, and policymakers across the globe to highlight how collaborative social relationships in communities can enhance both the social atmosphere and formal supports surrounding dying persons and their caregivers (s) (Abel & Kellehear, 2016). In contrast, theorisation of how dying persons and their families develop *social capital* around their interface with formal services is still underdeveloped (Sawyer et al., 2019). Sociologically informed research that uses social capital theory as an analytic lens can provide important insight into how the processes and mechanisms of social relationships shape EOL care and dying experiences in compassionate communities. Specifically, a social capital lens can illuminate the resources embedded in social relationships and interactions within networks (Lin, 2001). As such, in this study we adopt and further enrich a theoretical model of social capital to analyse the capitalisation process (Li, 2015).

Highlighting the importance of community and social relationships in healthcare in discussions of palliative and EOL care (Holt-Lunstad et al., 2015), the social model of compassionate communities emphasises community participation, collaboration, and resilience to guarantee human rights in EOL care experiences (Abel & Kellehear, 2022). The theorisation of social capital development in community EOL care provides a systematic understanding of how the community connects and supports dying people and their families through social relationship development (Sawyer & Sallnow, 2022). It is vital to generate insights to reduce socio-cultural barriers to accessing EOL care among dying people and their families in Hong Kong (Chan, Lee, &Woo, 2020).

Background: Social Capital Theory

Lin (2001) developed a notion of social capital as an organised, measurable, and operationalised concept, extending beyond a focus on closed networks and socio-cultural aspects of the concept (as with Bourdieu, 1986) or on open structures (as with Putnam 2000). Echoing Coleman (1988) and Burt (1992), Lin posits social capital as a feature of social structure encompassing social relationships as embedded resources that facilitate the flow of opportunities, information, and informal social credentials to and between network actors (2001). Lin envisions a process of *capitalisation* - accessing and mobilising social capital - that occurs once *preconditions* are met, and which results in expressive and instrumental *outcomes* (Lin, 2001). Using this lens, one can consider compassionate communities initiatives as trying, among other things, to access social capital through improving death literacy within communities (Gott et al., 2018; Sallnow, 2018).

In dialogue with Lin's theoretical model (including pre-conditions, capitalisation, and outcomes of social capital; 2001), and grounded in empirical data, the present study develops an aligned, three-stage model that explicates the dynamic, relational processes, and mechanisms towards the front end of Lin’s model - between pre-conditions and capitalisation (Tavory & Timmermans, 2019). The specific focus is on social relationships between key institutional network actors (in this case, social service agency staff and volunteers) and dying persons and their families.

Methodology and Design

Abductive Grounded Theory Methodology (Abductive GTM)

This research investigates the relational processes and mechanisms within supportive relationships between social agency practitioners or volunteers and clients, theorised as shaping the community EOL experience of dying people and their families in Hong Kong. GTM (Glaser & Strauss, 1967), which emphasises theorising a basic social process, has been used to study palliative care experiences (e.g., Sandgren, 2017). Through elements such as theoretical coding, GTM is helpful for engaging theoretically with data and exploring social processes (Glaser, 2005). Abductive GTM promotes researcher responsivity to the data as well as inductively grounded theorisation; contrary to dominant assumptions, however, it is not always completely devoid of deductive elements (Bryant, 2017; Timmermans & Tavory, 2012). An abductive approach to GTM in this study was influenced by pragmatism. It relies on different approaches to the relationship between theory, observation, and method, rather than starting with as little theory as possible (Tavory & Timmermans, 2019). Specifically, it encourages a rule-governed iteration between data collection and analysis to new knowlege (Reichertz, 2019).

Setting

Data were collected from practitioners and volunteers of two non-profit agencies in Hong Kong: PARACLETE, which primarily handles EOL and bereavement cases (including one of their programs, "Hospice at Home" that focuses on community EOL care), and which operates through the S.K.H Holy Carpenter Church District Elderly Community Centre, and Life Rainbow, which operates through the Hong Kong Society of Rehabilitation (HKSR). Both are experienced social service operators in Hong Kong providing community support for dying persons and their families, and both emphasise non-medical, social-psychological support for dying persons and their families.

Participant Recruitment, Sampling, and Data Collection

In-person, semi-structured qualitative interviews conducted by the first author commenced in 2019 after obtaining approval from the university Research Ethics Board. Sixteen participants were recruited because of their involvement with either PARACLETE (June to July 2019, six social workers and three volunteers) or the Life Rainbow project (August to December 2019, one social worker, one nurse, four volunteers, one former and one current service user). Recruitment of volunteers, and staff (i.e., case managers) was designed to better understand the relational dynamics in community EOL care. The decision to include service users was guided by theoretical sampling considerations (consistent with grounded theory) and aimed to further develop the emerging core categories through adding new conceptual properties of their mediated EOL care experience until theoretical saturation was reached. Interview topics explored aspects of the mediated EOL care experience from practitioner and service user perspectives (see sample interview questions in Appendix One). Interviews conducted in Cantonese were transcribed verbatim and translated into English. See Table 1 for additional details about participants.

Table 1. Summary of Interview Participants

Interview #	Role in community end-of-life care (1=PARACLETE; 2=Hospice at home; 3=Life Rainbow)	Interview period (1=June to July 2019; 2= August to December 2019)	Gender	Years providing or receiving service	Age	Educational level
S1	Social Worker[1]	1	M	5	31 – 40	College or above
S2	Social Worker[1]	1	F	5	31 – 40	College or above
S3	Social Worker[1]	1	F	0.5	<30	College or above
S4	Social Worker[1]	1	M	10	41 – 50	College or above
S5	Social Worker[2]	1	F	4	31 – 40	College or above
S6	Social Worker[2]	1	M	0.5	31 – 40	College or above
S7	Volunteer[2]	1	M	3	41 – 50	College or above
S8	Volunteer[2]	1	M	3	41 – 50	College or above
S9	Volunteer[2]	1	F	5	51 – 60	High school
S10	Social Worker[3]	2	F	3	<30	College or above
S11	Nurse[3]	2	F	3	31 – 40	College or above
S12	Volunteer[3]	2	F	3	51 – 60	High

						school
S13	Volunteer[3]	2	F	3	51 – 60	High school
S14	Volunteer[3]	2	M	3	51 – 60	High school
U15	Former Service User[3] (Carer)	2	F	1	51 – 60	College or above
U16	Current Service User[3] (Patient)	2	F	1	>71	Primary school or below

GTM – Iterative Process and Analysis

In GTM, iterative-cyclical inquiry facilitates uncovering social processes related to the core categories, with abductive consideration given to various evidence and arguments when evolving theory (Strübing, 2007). Fundamental components of GTM analysis included both open and theoretical coding (towards theoretical saturation), developing categories, memo writing (to clarify conceptual connection between categories), theoretical sampling (Bryant, 2017), and constant comparison. The software NVivo 11 was used to manage the data and maintain the continuity of GTM coding and analysis.

Theoretical sensitivity was centred through this process, promoting conceptual and theoretical innovation while assessing the fit of the theory to the context (Bryant, 2017). As such, Lin's (2001) theorisation of capitalisation was an initial conceptual observation or starting point for this study, as stated earlier. This primary theorisation of capitalisation is about developing bonding and bridging capital towards instrumental and expressive outcomes (Lin, 2001). After the initial few interviews (with PARACLETE staff), the first author derived a tentative working proposition that in the context of EOL care in the community, capitalisation may involve a dynamic relational process between different network actors instead of simply a bonding and bridging construction (while keeping an open mind to emergent categories in the data about the dynamics of social relationships). The analysis worked in back-and-forth between data and theory to clarify conceptual connections, and the first author observed that trust was a good working hypothesis to understand the development of social relationships in EOL care (Tavory & Timmermans, 2019). The conceptualisation turned to how trust leads to collaboration in mediated EOL care experience. Therefore, the categories of trust, mutuality, and collaboration in subsequent theoretical sampling with an additional group of practitioners and service users from Life Rainbow. The three-stage model of social capital development in community EOL care emerged because of theoretical coding with these additional data.

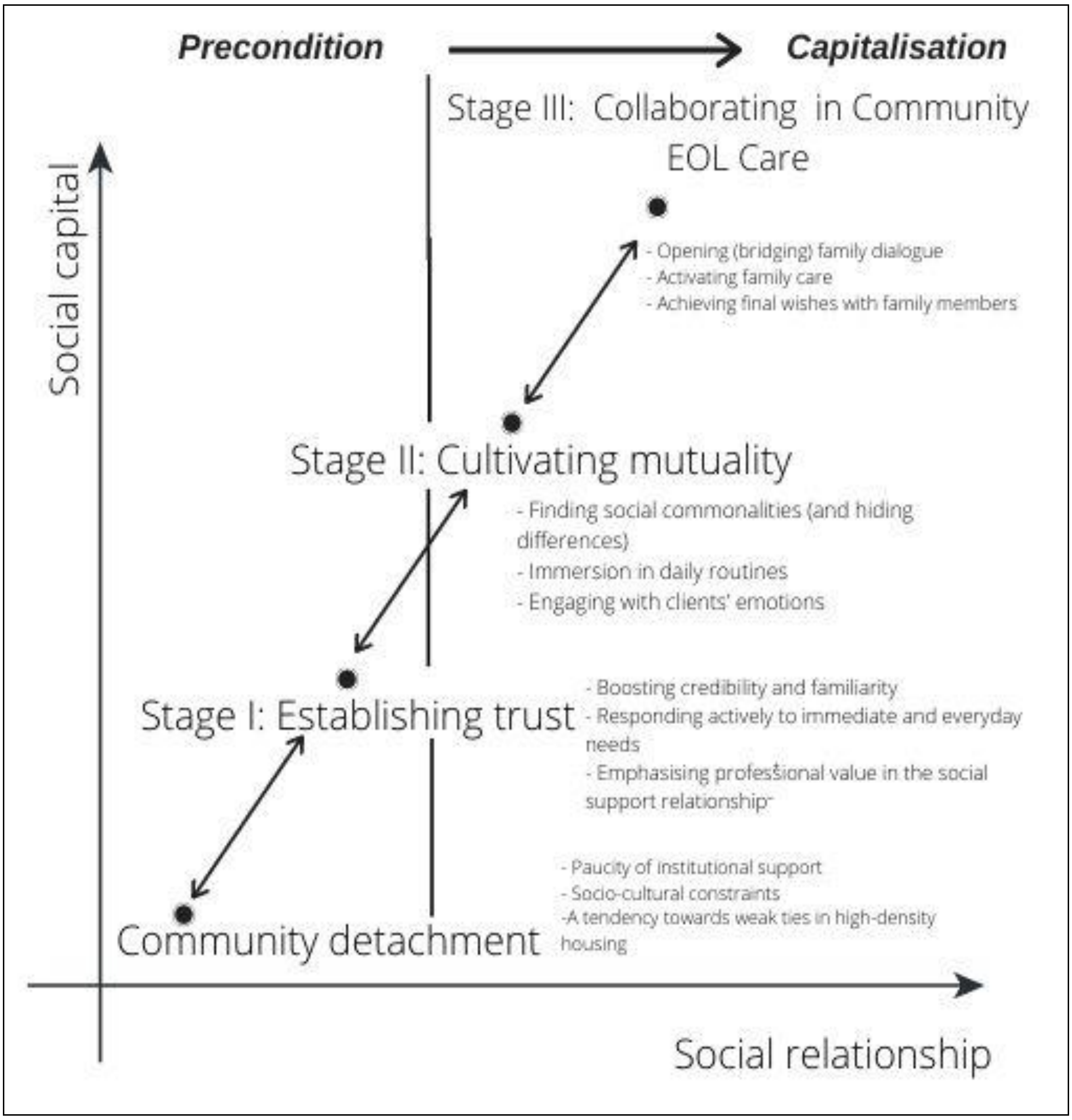
Findings

After presenting an overview and visualisation of the model below, we explicate how the model's components were identified in the data, with illustrative examples.

A three-stage model of social capital development in community EOL care (overview)

Figure 1 explicates how social capital is dynamically built and activated as relationships build between community practitioners and dying persons and their families, shifting from preconditions into capitalisation. Initially, dying persons and their families typically face community detachment without sufficient relational support and community resources. As community practitioners start providing supportive service and resources, ideally these actors start establishing trust, which forms the essential precondition for capitalisation. In terms of capitalisation, access to social capital starts to occur as mutuality is cultivated – specifically as the relationship shifts from one-way service provision to more continuous mutual exchanges over time in community EOL care. Then, collaborative care signals a shift towards mobilising social capital through even in-depth exchange and interaction between practitioners, dying persons, and family members.

Figure 1. A three-stage model of social capital development in community EOL care



Community Detachment: The Starting Point

When the structural and positional contexts are less favourable, dying persons and families have limited opportunities to access the resource of social capital, and there may be more inequalities or disadvantages in this regard (Lin, 2001). In our theorisation, community detachment refers to the unfavourable context of social isolation typically faced by older and dying persons and their families in the EOL period in Hong Kong – others have connected this to loss of agency and identity, decreased choice, and distance from original social lives in their communities (Horsfall et al., 2017). In the cultural background (death denial and taboo) in Hong Kong society, community and social institutions actively avoid taking extra care of dying persons and their families. Moreover, community detachment exacerbates tangible unmet needs for community support; under these conditions, dying persons and their families face greater difficulties.

The analysis highlights three particular social conditions that generate community detachment for those at the end of life: 1) a paucity of institutional support, 2) socio-cultural constraints, and 3) a tendency towards weak ties in high-density housing. First, participants emphasised how public, social, and professional services lack compassion and are not 'user-friendly' for dying people and their family members. A former service user described the uncompassionate service arrangement at the public mortuary:

> A client [family member] needed to claim the dead body at the public mortuary. The public mortuary staff called the client to ask him/her to arrive at the public mortuary around 8 am, [even though it would not open until] 9 am. It is just because they have to relieve the staff's workload in the public mortuary [by making sure all the clients arrive on time to claim the bodies]. I think to ask a bereaved person to wait outside the public mortuary an hour

> before the working hours is not a reasonable request. (s3)

Second, participants in this study emphasised how socio-cultural constraints, in particular the death taboo in Hong Kong society, limit access to both formal and informal community care, and mean that dying persons and their families rarely actively seek out help, because they are uncomfortable talking about their experience and accepting their needs for assistance. EOL tends to be viewed as a personal and family issue rather than a social or public issue that should be addressed within the community. A practitioner described obstacles to expanding awareness of life and death in the general public:

> … people still cannot perceive death as part of the average human life cycle. I think nowadays, and the community members cannot accept [this]. As we are currently running some events to educate the public, there are quite a lot of people who participate, and their reaction to the course isn't too adverse. They also seem to talk about the topic of death more often. However, although people do attend the event and there is hardly any free space left, it is always the same group of people who are attending. That’s why, in my opinion, education nowadays is not widely transmitted to different sectors within our society. And our [Hong Kong] society still does not have the motivation to address the question – “Why do I have to talk about death?” (s4)

Third, participants emphasised how Hongkongers are generally indifferent to EOL care needs in their neighbourhoods as they do not want to "bother" each other. For one practitioner, for example, weak and emotionally distant ties between neighbours limit the development of community resilience to support community members facing death:

> Overall, in Hong Kong, the culture of helping your neighbour (the relation between an individual and their neighbourhood) is very fragile. Most people are just playing with their smartphones and can't be bothered to care about other things. So, when they came across a dying issue, they would not have the determination to ask for help. If someone passed away in one's housing estate, no one would necessarily want to get involved with the bereaved person… (s1)

This same participant explained how detachment, manifesting through apparent neighbour indifference or lack of compassion (compounded by the death taboo) means that bereaved persons might for instance, in conversations with co-workers, conceal their bereavement status (and the death of their family member) from others.

A Precondition: Establishing Trust with Dying Persons and their Families

Trusting relationships (Lin, 2001; Putnam, 2000) between social agencies, dying persons, and their families were positioned by participants as vital for mitigating community detachment. Such relationships can help community members access decision-making information, caregiving supports, and acceptance and compassion; they may also, in our model, generate opportunities to access social capital. However, community members do not always trust that social agencies can be helpful. As such, trust is one of the core goals of community EOL care. Principally, trust hinges on how the parties in social interactions interpret the meanings of behaviours and actions. The data from this study indicate how establishing trust through relationship with dying persons and their families involves three types of social agency practices in community EOL care: 1) boosting credibility and familiarity, 2) responding actively to immediate and everyday needs, and 3) emphasising professional value in the social support relationship.

First, boosting credibility keeps the agency image consistently professional and demonstrates the agency's value and mission to clients. Practitioners tried to transform the relationship towards "open awareness" - when all the actors can openly discuss EOL (Glaser & Strauss, 1960). One of the strategies is providing clients and families with clear information about the practitioners before the first home visit (i.e., when they phone to confirm the timing of that visit). The goal of the first phone call is essentially to arrive at a particular definition of the situation about the mutual expectation in the home visit (Goffman, 1959). When the practitioners (usually a social worker with one or two volunteers) arrive at the home, they use this information to open the conversation and begin needs assessment. One volunteer describes their approach to a first-time home visit:

> The one who refers the client to us is usually the social worker … someone from the organisation would contact [the client]. So, I would explain to them thoroughly what I am going to do during the interview/visit. Then I go to their house, and we would also make disclaimers about the fact that the service is free of charge. (s2)

Second, participants spoke of responding actively to a comprehensive range of needs. As the social agency helps them solve various challenges, dying persons and their family members are more likely to accept the social agency as a reliable and trustworthy partner. Trust, in turn, directly facilitates further contacts and sharing in community EOL care. Practitioners also position themselves as sincerely trying their best to help humanise the everyday lives of dying persons (conveying they 'care about' clients through recognizing these needs). One long-time volunteer explained:

> I remember my first case was to serve an older man. The whole process lasted about just more than half a year. He was still capable of walking at the beginning, but in the end, he couldn't walk. In the end, the older man was

> waiting to pass away in the hospital. At that time, I went to visit him every day. I was there so often to the extent even the doctor and the nurses … could recognise me and remember my name. They frequently asked me, "Are you revisiting the old man today?" Every day just before dinner time, I would go to visit the older man. I remember once, and I asked the older man whether he liked the food provided by the hospital. He said no. And I said to him, "Shall I bring you some food from outside next time?" [paid by the client] … Every day...the older man...waited for me to go out to have dinner with him outside (to eat out). I was pushing his wheelchair and took him to a restaurant. (s9)

Third, emphasising professional value in the social support relationship is a vital impression management strategy to communicate to users that social agency support relies solely on altruism and philanthropic interests (Goffman, 1959). Participants spoke of their work in ways that illustrated how the agency positions itself discursively to appear to "blur" the boundary between formal and informal spheres of caring labour and naturalise emotional labour. For example, volunteers are instructed to help, but also to remember their ‘professional’ principles. Practitioners positioned the service to clients and families as altruistic and philanthropic, sincere and informal, but also emphasised their non-profit status, and the need to avoid private monetary and material giving. Such communications serve to professionalise the support relationship. As one practitioner noted:

> Concerning the trust establishment, I believe we strive to make the relationship the purest one [possible]. We provide service. That's all. Besides, the hospital introduces services to the clients beforehand. I think that made [clients] more comfortable. They may have a certain level of trust in us. (s6)

In sum, establishing trusting relationships means dying persons and their families recognise the reliable, helpful, and relatively resourceful role of practitioners, become more open to seeking help and accepting service-based interventions. Relationships developed to this point provide ground to progress capitalisation through a mutual exchange relationship.

Cultivating Mutuality

Recognising another person as reliable and trustworthy based on one-way social service support provision is a starting point for further development of the service agency-client relationship in community EOL care. The data from this study indicate how cultivating mutuality manifests in these relationships through 1) finding social commonalities (and hiding differences), 2) immersion in daily routines, and 3) engaging with clients' emotions.

First, practitioners often attempted to identify commonalities with clients and families in term of demographic and cultural backgrounds; such commonalities can generate common conversation topics of interest in the service-client relationship. For instance, one participant expressed achieving "resonance" in conversation - a subjective feeling connected to a similar socio-historical, cultural, socio-demographic, or leisure background. They believed purposively magnifying a sense of resonance could help make the client comfortable with sharing their personal stories, thoughts, and challenges about death and dying. A practitioner shared her observation about the implications of social status in this regard, in the community EOL care service:

> Age can [have an] effect on the service. If the volunteer is young, [it may] bring the client more happiness and hope [because they can deliver a more energetic and carefree feeling to the client]. But a middle-aged volunteer can open up more conversation on topics, such as cooking. I remember a case. The volunteer was a homemaker. In the visitation, the volunteer talked with the client about cooking skills. They talked about how to improve the recipe for shredded chicken. They enjoyed discussing how to keep the chicken meat tender after cooking. Our [younger aged] social worker colleague can’t talk about this topic because we don’t know this topic [how to cook]. The volunteer also suggested the client use a fork to help to make the dish. We learned those homemaker volunteers could open conversation on this kind of topic, which motivated the client to see us again. We rely on this kind of

> volunteer force very much because they really can help the client talk about the topics of everyday life, instead of repeatedly asking about their health condition. As a homemaker, our clients wish to experience things they like. They were keen on knowing how to finish a dish within 30 minutes as they enjoy cooking for their family members. We believe that this kind of topic is essential to a person at the end of their lives. (s5)

Agencies even appeared to specifically maximise the chances of cultivating mutuality by carefully matching particular volunteers and clients.

Hiding differences is an alternative way to establish social commonalities that was also identified in these data. Practitioners expressed particular concern about differences in values between themselves and clients, that might threaten the trust relationship. Thus, agencies emphasised to volunteers the need to focus on listening to clients rather than sharing their own experiences. A practitioner related what she called a ‘classic example’ of a client with final stage lung cancer, who was very proud and opinionated, with a masculine mindset. In her interactions with him, she, in essence, feigned interest, to build a sense of mutuality in the client:

> I knew he liked chatting with educated people about global issues, cultural things...For me, I decided, I tried to ingratiate myself with him by accepting most of what he said, and pretending I knew much about the topics. I wasn’t

> familiar with those topics. (s13)

A second mechanism for cultivating mutuality was evident in practitioners' accounts of actively participating or sharing in the daily routines of dying persons and their families. This is a way for the clients and practitioners to gradually come to know each other in a different way, creating a more stable and more reciprocal relationship. It also appeared to be mutually beneficial since practitioners themselves tended to enjoy these interactions. Practitioners spoke of 'hanging out' with families and explained how helping out with day-to-day activities strengthened relationships. A volunteer described how day to day activities (sharing lunch) contributed to his sense of a reciprocal relationship:

> I remember I met a case. She is an old lady. She lived near my home. Sometimes, she phoned me and asked me to have lunch together for the sake of convenience. I often went to her house and had lunch with her. She asked me to buy whatever I liked to eat before visiting her. After lunch, I helped her clean the dishes. In summer, it was sweltering when washing the dishes. She helped wipe my sweat off. I felt as if she were a mother who was caring for me. I didn't think we were beyond the relationship between volunteer and service user. I thought we were in a close relationship. (s9)

Third, engaging with clients' emotions was another mechanism that practitioners described as cultivating a mutual relationship. As described in more detail in another publication (author citation removed), the data indicated how engaging with clients' emotions to cultivate mutuality largely focused on encouraging clients to 'release' emotion. Various strategies were predicated on the assumption that continuous support over time helps build up the relationship as a secure, shared space, wherein clients can be encouraged to release and share emotions. Participants identified various communication processes (i.e., showing readiness, acceptance, understanding, and response) to help clients express their feelings during in-home service visits. This was seen to be of therapeutic benefit but also further strengthening the relationship. In particular, participants emphasised the role of non-judgmental, active, and wholehearted listening, that conveys empathy, respect, acceptance, and compassion to the other's emotional experience. In this regard, one volunteer shared the advantage of being a "listening stranger" in the relationship:

> We [the volunteer in the "hospice at home" project] listen to the client's story carefully because many Hongkongers do not have an opportunity to express their feelings and emotions [even with family members]. A client living alone often showed me his anger in the home visitation because he felt nobody could help him [to reverse his physical condition]. Therefore, he was indifferent to any supportive service we provided in EOL care. He reduced his anger through

> a continuous conversation when he realised I was carefully listening to his story… (s6).

The practice of being a "listening stranger" can encourage clients to talk under an additional layer of protection, based on the professional ethos of respecting privacy. This can build mutuality, as clients release emotional burdens with a trusted ‘acquaintance’ who keeps the conversation confidential (Granovetter, 1973).

Practitioners are tasked, through the philosophy of palliative care and the mission of their agency, to address the emotional needs and distress expressed by dying persons and their families. In responding, these practitioners further cultivate mutuality and service users may accept them as a kind of 'fictive kin' (Funk, 2019). Moreover, both clients and practitioners may come to share their thoughts and feelings (despite earlier exhortations against this), express care for each other in their interactions, and develop a sense of familiarity. In the practitioners' interpretations, expression of caring from service users can signal that mutuality has been successfully cultivated. For example, because of mutual concern, one family member was worried about a care routine that meant the agency volunteer had to remain until midnight (s9).

In sum, cultivating mutuality involves enriching trusting relationships through continuous information, resource, and emotional exchange, resulting in recognition of interdependence and mutual understanding of situations (Brown, 2015; Goffman, 1959).

Collaborating in Community EOL Care

Compassionate, collaborative community EOL care, from an organisational perspective, is an ideal form of care provision which recognises how care is inextricably linked to shared values, needs, and expectations of family and community members (Pfaff & Markaki, 2017). The short service time frame for EOL care (due to prognosis and eligibility) makes collaboration imperative. Three mechanisms for fostering collaboration were identified from the data: 1) opening (bridging) family dialogue 2) activating family care (e.g., deploying expert status, reorganising caring routines), and 3) achieving final wishes with family members.

First, practitioners focused on opening and actively ‘bridging’ emotionally honest dialogue within the family of dying persons, especially those with lower family social capital or greater family ‘ambivalence.’ When trust and mutuality are developed in the service relationship, and practitioners are recognised as trustful companions, practitioners can encourage the family to talk about EOL care arrangements. This, it was believed, can represent an "ice-breaking" moment for many families. At other times, practitioners tried to facilitate family communication by relaying information between family members, encouraging family communication, and even using their "professional status" as a power source to promote family dialogue or to help align family member's different opinions. A former service user shared how her older sister’s maid was instructed about how to provide care for her mother at her sister’s home:

> My mother had fallen and suffered from pneumonia. She was no longer able to walk. I then considered finding a physical therapist to help my mother. The staff of the Life Rainbow project helped me arrange an occupational therapist and a physical therapist to evaluate my mother. I expected they [the professionals] could teach the maid [who was hired by her elder sister and only listened to the instructions from her elder sister] to understand the skillsets to take care of my mother, such as lifting and transfer techniques. I felt the recommendations from a third-party professional are more convincing. It is critical to my family because no one in my family listens to me. (c15)

Second, agency staff believed they could foster collaboration more actively and directly through enabling the family to provide more and better EOL care. Having developed trust and mutuality was seen as a solid foundation in this regard. Recognising that family members often struggle with providing daily care, practitioners sought to identify the ‘right person’ in the family to provide care; they also sought to normalise EOL care within families, and to help families improve how they manage care routines (e.g., to provide better, more efficient care). For instance, according to one social worker (s10), one client's family members were comfortable with the agency nurse's suggestion to train their domestic maid to handle the client's ulcer wound, because of the nurse’s previous continuous service relationship and regular exchange of information with the family.

Third, achieving final wishes fosters collaboration through engaging the family more extensively beyond care per se towards activities designed to support the broader goal of the 'good death.' Practitioners, clients, and family members jointly identify a goal (which could be a final wish), conceptualise a feasible plan, and together implement the plan. One practitioner (S14) described working with the client (a dying woman whose mother had dementia) to successfully implement their “last party,” and helping to hide the illness from the client’s mother, as per their wishes that avoid the loss of children to death in Chinese culture.

Discussion

Findings from this study contribute to explicitly examining the complex social, interactional dynamics and mechanisms entailed in service-based relationships between dying persons, their family members, and their broader institutional network. That is, resources in social networks are activated primarily through direct and symbolic aspects of communication in social interactions between practitioners and clients. Through illuminating such social processes and mechanisms, we have contributed to theorising the relational, interactional experience of supporting and being supported, with potential implications for dying persons and their families in community EOL care in Hong Kong.

Theoretical implications

Our conceptualisation identified notable "signposts" in how relationships in mediated EOL care can progress sequentially from community detachment to trust (precondition), mutuality (accessibility), and collaboration (mobilisation). Conditions satisfied at one stage of the model signal that another stage of development may start (though there may potentially be some back-and-forth movement between stages). Throughout this sequence, agents enable each other to accumulate and activate more embedded relational resources. Evolving reciprocal and mutual relationships (between social agency workers and service users) need to occur before embedded relational resources can leverage a better quality of death in the community (Walshe et al., 2016). However, relationship development may cease at any stage of the sequence, for instance when clients decline to engage more deeply with practitioners.

Our findings confirm the critical role of institutional support (and social care intervention in particular) in maximising the impact of compassionate community development, helping dying persons and their family members improve the quality of life in EOL care collaboratively (Rosenberg et al., 2018; Walshe et al., 2016). Findings further show how this phenomenon relies on social capital processes manifesting at the micro-level to mobilise and build up networks for EOL care. Previous research emphasises how strategic investments in community engagement and capacity building can enhance social networks, promoting compassionate communities (Mills, Rosenberg & McInerney, 2015; Sallnow & Paul, 2015).

Social workers in this study acted as agents at the structural hole, which refers to the absence of a tie between two connections, to support weak ties in the network structure (Burt, 1992); visiting volunteers helped clients maintain close contact with the social workers. The division of organisational labour between the volunteers (visiting clients) and the social workers (overseeing the service and community resources) contributes to a stable network built on the triadic relationship between the volunteers, professional practitioners and clients in this context, which helps implement the functional aspects of the social network (Morris et al., 2017).

Findings also highlight how social capital can develop in community EOL relationships outside of more traditional, paternalistic medical and hospice-based settings, aligning with Sallnow's (2018) concept of "collective social capital" in compassionate communities. To some extent however, a service-provider/client power relation still existed in this study, especially between social workers and clients, as clients looked to the practitioners for access to knowledge and resources.

Implications for Practice

Findings emphasise the need for EOL care policy promoting social infrastructure that can facilitate compassionate community development through relational mechanisms and processes (Sallnow & Paul, 2015). Policymaking in the context of aging populations ideally entails not only efforts to strengthen informal social support networks but simultaneously to engage mainstream and institutional services (Abel et al., 2013; Leonard, Horsfall & Noonan, 2015). At the level of practice, our parsimonious model of relationship and social capital development can be used to help better engage potential service users and their family members by providing a clear processual understanding of practitioners' interventions.

Limitations

Our ability to examine data from service users and non-service users was limited in this study, due to social unrest in Hong Kong, followed by the COVID-19 virus, which constrained sampling and recruitment of this population. As such, our data are primarily grounded in practitioners' perspectives (volunteers and social workers).

Although participants' comments were analysed with attention to a Hong Kong socio-cultural context (and the original Cantonese data were analysed from this perspective), the data were translated into English for presentation. Although the first author is very familiar with Hong Kong language and context, and carefully translated the data and edited the translations line by line, there remained challenges in accurately representing the data in English language, in a way that retained the original meaning. As such, some subtleties might be lost in translation.

Conclusion

Further research into the dynamics and mechanisms of family-level relational resources (family social capital) may be critical to manifest another important aspect of the current theorisation more fully – specifically, data from the service users in this study indicate that family dynamics may provide additional influence and meaning to the EOL care experience (Alvarez, Kawachi & Romani, 2017). In addition, future research advancing the conceptualisation of social capital can contribute to and enhance theorisation of compassionate communities (Sallnow, Bunnin & Richardson, 2015; Sallnow & Paul, 2015).

The present study examined the processes and mechanisms involved in social relationships between dying people (and their families) and volunteers and professionals in community-based social service agencies. Our parsimonious, easy-to-understand theoretical model illustrates the processes and mechanisms of social capital development at the micro-level of relationships, with implications for shaping persons' dying experiences in compassionate communities in Hong Kong and more broadly.

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