

Social Relationships and Community End of Life Care in Hong Kong  
by  
Wing-sun Chan

A Thesis submitted to the Faculty of Graduate Studies of  
The University of Manitoba  
in partial fulfilment of the requirements of the degree of

Doctor of Philosophy

Department of Sociology and Criminology  
University of Manitoba  
Winnipeg

Copyright © 2020 by Wing-sun Chan

## **Abstract**

In Hong Kong, like other modern societies, death and dying are identified as a crucial public health issue. Given developments in the Hong Kong healthcare system, some of the work of caring for dying people and their families has shifted to cross-disciplinary collaboration in community settings. This trend corresponds with a growing policy and practice emphasis on social relationships in non-medical forms of community-based care for dying people and their families. In the present study, abductive grounded theory methodology was used to examine the complex dynamics and mechanisms involved in social relationships between dying people (and their families) and volunteers and professionals in community-based social service agencies. The goal was to contribute to knowledge about how social relationships influence the experiences of dying people and their families, and to explore and engage theoretically with the concept of social capital as a dynamic, relational process. Relationships between social service agency staff and medical professionals were also explored. Through contacts with two community-based end-of-life (EOL) service agencies in Hong Kong, qualitative data were collected using 14 in-depth interviews with practitioners and 2 service users. The findings were used to develop a clear and parsimonious three-stage model of relational social capital development. In this model, relationships between service agency workers and families can be seen as addressing a

key precondition of social capital through establishing trust, facilitating the accessibility of social capital through cultivating mutuality, and mobilizing social capital through fostering collaboration; all of these processes contribute to mitigating community detachment. Lastly, this study elucidates implications for policy and practice related to both health promotion and community engagement in the care of dying people and their families in Hong Kong communities.

## **Acknowledgements**

Firstly, I would like to express my sincere gratitude to my advisor Dr. Laura Funk for the continuous support of my Ph.D study and related research, for her patience, motivation, and immense knowledge. Her guidance helped me throughout the research and writing of this thesis.

Besides my advisor, I would like to thank the rest of my advisory committee: Dr. Daniel Albas, Dr. Christopher J. Fries, and Dr. Genevieve Thompson, for their insightful comments and encouragement, but also for the challenging questions they posed, which prompted me to broaden my research from various perspectives.

My sincere thanks also goes to Profs. Lori Wilkinson, Tracey Peter, and Sonia Bookman, who provided me support and encouragement during difficult stages of my Ph.D study.

Last but not the least, I would like to thank my family: Luresa, Kale, and Hazel for supporting me spiritually throughout writing this thesis and in my life in general.

## **List of Abbreviations**

End of Life Care (EOL)

## **List of Tables**

Table 3.1      Summary of participants interviewed in PARACLETE and the Life  
Rainbow community EOL care projects

## **List of Diagrams**

Diagram 7.1    Synthesizing Lin's (2001) conceptualization of social capital with  
findings from this study

Diagram 7.2    Lin's (2001) model on social capital

Diagram 7.3    The role of institutional support in compassionate community  
development

## Table of Contents

<b>Abstract</b> .....	<b>i</b>
<b>Acknowledgements</b> .....	<b>iii</b>
<b>List of Abbreviations</b> .....	<b>iv</b>
<b>List of Tables</b> .....	<b>iv</b>
<b>List of Diagrams</b> .....	<b>iv</b>
<b>Chapter One: Introduction</b> .....	<b>1</b>
I.    Background and Rationale .....	1
II.   Research Question and Significance.....	10
III.  Outline of the Dissertation .....	11
<b>Chapter Two: Literature Review</b> .....	<b>13</b>
Introduction.....	13
I.    Social Capital and Public Health .....	14
II.   Conceptualizing Social Capital: A Contested Sociological Concept .....	18
Closed networks and socio-cultural aspects of social capital: perspectives from Bourdieu and Coleman.....	19
From the effectiveness of closed structures to the importance of open structures of social capital: Putnam and Burt’s perspectives.....	25
Developing a theoretical model of social capital: Lin’s perspective on social capital.....	30
III.  Social Capital in the Hong Kong Context.....	35
<b>Chapter Three: Research Methodology</b> .....	<b>40</b>
Introduction.....	40
I.    Setting .....	42
II.   Participant Recruitment, Sampling and Data Collection .....	45
III.  GTM – Iterative Process and Analysis .....	53
IV.   Rigour .....	59
V.    GTM and Philosophical Assumptions .....	62
<b>Chapter Four: From Community Detachment to Establishing Trust</b> .....	<b>65</b>
Introduction.....	65
I.    Structural and Positional Variations in Conditions of Social Capital: Community Attachment-Detachment .....	66
A paucity of institutional support .....	68
A socio-cultural constraint: Death illiteracy and taboo in communities.....	74
Relational barriers and weak ties in high-density property markets.....	78
II.   Establishing Trust with Dying People and Their Families .....	83
Boosting credibility and familiarity .....	84
Responding actively to immediate, everyday needs .....	87

Purifying the support relationship.....	93
Outcomes of establishing trust between practitioners, dying persons and their families .....	97
III.    Establishing Trust while Respecting Boundaries: Collaborative Interactions with Medical Professionals in Community EOL Care.....	98
<b>Chapter Five: Cultivating Mutuality in Community End of Life Care.....</b>	<b>104</b>
Introduction.....	104
I.        The Process of Cultivating Mutuality .....	105
Finding social commonalities (and hiding differences).....	105
Immersion in routines: Participating in the daily routines of the client and family .....	110
Supporting actualization – the wishes of dying persons and their families .....	114
Engaging with clients’ emotions.....	118
II.      The Outcomes of Mutuality .....	124
Caring about the feelings of the practitioner.....	125
A sense of emotional security .....	127
Remaining estranged from the mutuality.....	129
III.    Cultivating Mutuality in Relationships with Medical Practitioners .....	131
<b>Chapter Six: Fostering Collaborative Community EOL Care.....</b>	<b>138</b>
Introduction.....	138
I.        Fostering Collaboration for Community EOL Care in Families .....	141
Opening (Bridging) family dialogue.....	143
Activating family to provide more intensive and appropriate EOL care...	148
Achieving final wishes with family members .....	150
II.      Fostering Collaboration across Medical and Social Domains .....	153
Linking up care resources in communities .....	154
Establishing ways of working together.....	156
Mobilizing joint effort towards a specific operational goal.....	159
<b>Chapter Seven: Discussion and Conclusion .....</b>	<b>165</b>
Introduction.....	165
I.        Summary of Key Findings .....	165
II.      Theoretical Implications .....	172
Additional “ingredients” important for conceptualizing social capital.....	173
Theorizing compassionate communities in relation to social capital .....	177
Social capital and social-medical collaboration in EOL care .....	182
III.    Implications for Practice .....	183
IV.    Limitations, Future Research Directions, and Conclusion .....	186

<b>References .....</b>	<b>190</b>
<b>Appendix 1: Interview Questions .....</b>	<b>231</b>
<b>Appendix 2: Sample of Memos .....</b>	<b>234</b>
<b>Appendix 3: Categories in the study .....</b>	<b>238</b>

## **Chapter One: Introduction**

### **I. Background and Rationale**

An important global public health challenge is how to address the demands associated with soaring numbers of dying populations in the context of the population aging, a phenomenon that is particularly pronounced in industrialized nations. According to the United Nations (2017), the global population aged 60 years or over was 962 million in 2017; more than twice the number in 1980 when there were 382 million older persons worldwide. Hong Kong, like other industrialized societies around the world, now strives to find ways to improve the quality of dying, for instance through implementing a national palliative care policy and framework, increasing public spending on healthcare service and training resources, and raising public awareness of palliative care (The Economist Intelligence Unit, 2015). Although countries adopt various strategies to address the needs of dying persons in their populations, particularly salient is the development of palliative care models, programs and services designed to support dying.

Current literature on supportive services for dying people and their families use terms such as palliative care, hospice care, and end of life (EOL) care. However, specific usage varies depending on each country's policy and service context (World

Palliative Care Alliance, 2014). The terms sometimes define a particular service, and sometimes a broader philosophy of or approach to care. In terms of the more comprehensive philosophy or approach, palliative care aims to treat or manage pain and other physical symptoms to improve the quality of life of dying persons as well as help with psychological, social and spiritual needs in both dying persons and their families, including bereavement (World Palliative Care Alliance, 2014). EOL care (which is a kind of palliative care often focuses on the last month of life) aims to help dying persons to live and die with dignity and, as such, it goes beyond medical-oriented interventions to other forms of support, such as help with legal matters, and bereavement care (World Palliative Care Alliance, 2014). A hospice care approach for terminally ill patients further emphasizes how dying people can get the most out of the time they have left to achieve an active dying experience in physical, psychological, social, and spiritual dimensions through the support of health professionals and volunteers (World Palliative Care Alliance, 2014).

In Hong Kong, the history of standard care services for dying people appear to be grounded in a palliative care approach (Hospital Authority, 2018). However, the terms palliative care and hospice care are used interchangeably in the Hong Kong medical sector (Liu, 2006) to refer to both palliative treatments (medicines, therapies, other specialist supports) and hospice services, including those offered in both hospitals and

care homes (Hong Kong Hospital Authority, 2018; Marie Curie, 2018). In Hong Kong, “EOL care” indicates a distinct departure from more medicalized forms of palliative care towards more socially oriented care (Jockey Club End-of-Life Community Care Project, 2018). As such, in this study I use the term “EOL care” because my broad interest is with the implications of social relationships within care networks for the experience of dying and bereavement at the community level (i.e., outside the hospital [palliative care] and care home settings [hospice care]).

From the 1980s to the early 1990s, the first hospice and palliative care units were established in public and private hospitals in Hong Kong (Heaven of Hope Hospital, 2006; Thompson, 2009; Society for the Promotion of Hospice Care, 2018). In general, such services require a referral and are open to all terminally ill patients (not restricted to the estimated time to death). In the mid-1990s, the first certificate course in hospice nursing was introduced (Thompson, 2009). More recently, from 2007 to 2012, the Li Ka Shing Foundation<sup>1</sup> initiated a hospice support service designed for dying people and their families in ten public hospitals (Hospital Authority, 2012; McCombie, 2008).

As in many other developed countries, palliative care delivery in Hong Kong has been moving slowly away from hospitalization towards community settings since the

---

<sup>1</sup> The Li Ka Shing Foundation (李嘉誠基金會) is a Hong Kong-based charitable organization founded in 1980 by Hong Kong entrepreneur Mr. Li Ka-shing.

1980s. In 1986, the Society for the Promotion of Hospice Care<sup>2</sup> was established as the first organization outside the hospital for supporting dying people and their families in Hong Kong (Society for the Promotion of Hospice Care, 2018). It has also been slowly adopting more holistic, less medicalized approaches to EOL care delivery. For instance, it initiated the Jockey Club “Home for Hospice” project in late 2016 to pilot a holistic care home service model (Society for the Promotion of Hospice Care, 2018).

Overall, the development and implementation of EOL care services in Hong Kong lags far behind other economically developed countries; these services are less sophisticated in terms of their legal, operational and organizational, and socio-cultural aspects (Chung, 2017). For example, the Fire Service Department is still legally obligated to perform resuscitation, if the situation requires, even on patients with EOL care documentation<sup>3</sup> (Chung, 2017). Barriers like this limit the development of community EOL care and thus continue to promote hospital death.

Until recently, community palliative care in Hong Kong mainly relied on palliative home care and community nurse services from general hospitals to provide multidisciplinary medical specialist support (through consultation, home visits) for dying people and their families in the community (Liu, 2006). However, in 2015, the

---

<sup>2</sup> The Society brought together professionals, volunteers, family, and friends who shared an interest in caring for dying people.

<sup>3</sup> E.g., Advance Directives (AD), Advance Care Planning (ACP), and Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR).

Hong Kong Jockey Club Charities Trust initiated a project to expand professional EOL care to address psychosocial needs at the community level. This involves enhancing the capacity of community-based service providers to deliver EOL care, and raising public awareness (Jockey Club End-of-Life Community Care Project, 2018).

Relational Confucianism, as part of the traditional culture normative in dominant Chinese ethnic groups, infuses ordinary social relationships in Hong Kong. It also shapes death and dying experiences in families and communities (King, 1985; Thompson, 2017). Relational Confucianism prioritizes some core aspects of Confucian philosophy relevant to social relationships and ordinary social interaction, such as filial piety, fate, and harmony (Mak, 2007). As such, the definition of a good death in Hong Kong emphasizes relational wellbeing over personal wellbeing (Mak, 2007). This cultural context informs a palliative care practice that differs from the Western model, which emphasizes personal choice and autonomy. In this context, it is particularly essential to understand how social relationships influence the experience of dying and family relationships within Hong Kong Chinese ethnic groups.

Compared to other developed Asian countries with significant proportions of ethnic Chinese populations (such as Singapore and Taiwan<sup>4</sup>), however, the progression of palliative care, hospice care, and EOL care in Hong Kong has been slower. For

---

<sup>4</sup> Singapore saw its first doctor trained in palliative care in the late 1980s (Lien Centre for Palliative Care, 2011), and Taiwan introduced hospice-palliative care in 1983 (Chen, 2015).

instance, both Singapore and Taiwan have developed sophisticated holistic social care models to address hospice and palliative needs in different socio-cultural contexts. Reflecting these efforts, in 2015, the Quality of Death Index<sup>5</sup> ranked Taiwan as the 6<sup>th</sup> in the world, and Singapore as the 12<sup>th</sup>; Canada as the 11<sup>th</sup>, and Hong Kong was 22<sup>nd</sup> (The Economist Intelligence Unit, 2015). This ranking reflects, among other things, lower levels of overall health care spending, reduced availability of research-based policy evaluation, and diminished capacity to deliver palliative care services in Hong Kong (The Economist Intelligence Unit, 2015).

The Hong Kong government has more recently signaled its intent to shift palliative care from hospitals to community settings. In 2018, the Hong Kong Chief Executive initiated a public consultation on palliative care policy and service development in both hospital and community settings (Chief Executive's 2018 Policy Address; Government of Hong Kong SAR, 2017). In 2017, the Hong Kong Hospital Authority published a strategic service framework for palliative care<sup>6</sup> which explicitly highlights the importance of medical-social community collaboration – with NGOs and patients' groups – and mobilizing community resources (both formal and informal carers<sup>7</sup>) for

---

<sup>5</sup> The Quality of Death Index is a standard constructed by the Economist Intelligence Unit (EIU) research team to examine the quality of support for people facing death across the world. The index includes aspects of the palliative and healthcare environment, human resources, affordability of care, quality of care, and community engagement (The Economist Intelligence Unit, 2015).

<sup>6</sup> This is part of a broader strategy for improving EOL care service organization, coordination and governance, in part as a response to the aging population in Hong Kong (Hospital Authority, 2017).

<sup>7</sup> In Hong Kong social services, formal carers refer to care services directly subverted or partially subverted by the Hong Kong Social Welfare Department. Informal carers refer to family members, relatives and friends, and members of the general public, who take care of people (often older adults) in the community (Hong Kong Social Welfare Department, 2020).

enhancing the quality of death (Hong Kong Hospital Authority, 2017).

In light of this new policy direction, effectively developing services to support dying people and their families requires an enhanced understanding of how communities support dying people and their families. Currently in Hong Kong, palliative care services mainly manage patient's physical and psychological needs as well as provide psychosocial support for families who are heavily involved in caring for patients in the hospital setting (Liu, 2006). Yet when dying people are discharged home, support relies profoundly on collaboration between dying people, their families, and other informal social network and community members. Key community agents, such as family members, neighbours, friends and other non-kin have an essential ancillary role in closely working with dying people and their family carers in providing physical, psychological, social and spiritual support (Broese van Groenou & De Boer, 2016).

Likewise, given current trends towards these more holistic and collaborative approaches to compassionate-based community-based EOL in Hong Kong, research on how social relationships (both informal and more formalized) operate when people die in the community is particularly timely. Some research has already begun to explore, for instance, processes around engaging and receiving help through and within relationships with neighbours, friends, mutual-help support groups, and family

members (Broom, 2015; Horsfall, Yardley, Leonard, Noonan, & Rosenberg, 2015; World Palliative Care Alliance, 2014). In the present study, qualitative data are used to examine the relational dynamics and mechanisms of social relationships between dying persons/their families, and both volunteers and professionals, with an interest in how these might shape the quality of care and death/dying experiences. This knowledge can help guide stakeholders to conceptualize and develop user-centered EOL service and policy at the community level. Moreover, this research also addresses a gap in current public health discussions - in particular, the current dearth of theorization about community-based relational engagement in EOL care (Dempers & Gott, 2017).

Sociologically informed research that draws on *social capital*,<sup>8</sup> used as an analytic lens, can provide particular insight into how resources manifested and exchanged in social relationships shape EOL care and death/dying experiences. Social capital generally refers to resources embedded in social relationships and interactions within networks (Lin, 2001). In light of recent calls to apply theoretical frameworks to improve EOL care (Olivere, Monroe & Payne, 2011; Zaman, Inbadas, Whitelaw & Clark, 2017), social capital is currently a popular concept in community EOL care arenas (Clark, Gardiner, & Barnes, 2016; Gott et al., 2018; Horsfall, Yardley, Leonard, Noonan, & Rosenberg, 2015), yet has rarely been explicitly theorized. In the present

---

<sup>8</sup> This will be further discussed in the literature review.

study, I develop an empirically grounded conceptualization of social, relational resources (and risks) that shape care for dying people and their families. The findings can also help understand how mediated social relationships in particular (e.g., that involve institutional intervention) contribute to experiential outcomes related to EOL care in the context of Chinese society.

Distinct from the larger body of research on social relationships and dying in hospital settings (e.g., Mak, 2007), in this study I focus on social, relational processes and mechanisms in the community, through interviews with actors (service providers and families) involved in EOL care in Hong Kong communities. This focus includes the process through which social relationships in EOL care develop, and the symbolic and interactional mechanisms facilitating shifts from trusting relationships to collaborative EOL care. Relationships in hospital settings mainly centre on top-down clinical interventions between professionals (e.g., physicians, nurses, psychiatrists, nutritionists, physical and occupational therapists, pharmacists, and so on) and dying people and their families (Broom, 2015; Liu, 2006). Moreover, public health research on community EOL care tends to examine formal care practices used in different locations and socio-cultural contexts, while under-theorizing social processes and mechanisms (Wegleitner, Heimerl & Kellehear, 2015). In contrast, in the present study I theorize the relatively more reciprocal and collaborative relationships that develop

between dying people/their families and other pseudo-formal actors or network members (volunteers and workers in social service agencies) to improve dying through community EOL care. By developing a meso-level theorization of community collaboration in EOL care which emphasizes groups and their interaction order (Fine, 2012), this research addresses a theoretical gap in knowledge about relational mechanisms in community EOL care. Indeed, the theoretical notion of a *compassionate community* is an emerging and increasingly popular concept in public health, highlighting the importance of collaboration for care (Abel, 2018; Horsfall, Noonan, & Leonard, 2012; Kellehear, 2005; Russell, 2017), yet this concept remains particularly abstract in public health arenas.

## **II. Research Question and Significance**

The focus of this study is on the processual and dynamic aspects of social relationships and networks in community EOL care; in this sense, social relationships are viewed as sites through which both *community* and *compassion* might manifest, to improve experiences of dying and bereavement. The central research question is: How do social relational processes and mechanisms operate in mediated, service-based relationships in community EOL care? Moreover, my other aim is to ascertain whether the lens of social capital could be helpful in developing a grounded meso-level theorization not only of the resources entailed in these relationships, but also of

the strategies used by dying persons/family members and community service providers to create supportive connections.

Addressing current concerns in the international public health community about the promotion and implementation of EOL care in communities, I engaged with current conceptualizations of social capital and compassionate communities to guide this study. The hope is that this research can inform future directions for policy development in care for dying people and their families in Hong Kong communities.

### **III. Outline of the Dissertation**

Following this introductory chapter, in Chapter 2, I provide a brief overview of current theoretical conceptualizations of social capital, and outline how social capital has entered into the public health dialogue in Hong Kong. In Chapter 3, I will discuss the methodology (abductive Grounded Theory) and design used in this study, as well as discuss some of the more challenging aspects of study recruitment. The next three chapters (4 through 6) present the analytic findings. Specifically, in Chapter 4 I present the conceptual categories of *community detachment* and *establishing trust*, with a focus on how community EOL care agencies position themselves as intervening to mitigate community detachment and help dying persons and families access support, by establishing trust with clients/families (as well as with medical professionals – relationships involving a distinctly different balance of power).

Chapter 5 will address how these mediated forms of social relationships with clients/families in community EOL care shift towards the more in-depth process of *cultivating mutuality*, with particular outcomes. Chapter 6 addresses the social processes through which these relationships further develop, in ideal scenarios, as professionals seek to foster and accomplish *collaborative EOL care* with clients/family members (and medical professionals).

The last chapter (7) presents a theoretical integration that synthesizes the conceptualization of social capital in community EOL care, as well as extending the theorization of compassionate communities. This final chapter also discusses implications for policy around community engagement in the care of dying people and their families in Hong Kong communities, and future research directions.

## **Chapter Two: Literature Review**

### **Introduction**

Through its focus on resources in social relationships and networks, the concept of social capital offers a useful analytic framework to understand relational experiences of dying people and their families at the community level, as well as how communities take care of dying people and their families more broadly (Aldrich, 2017; Lewis, DiGiacomo, Luckett, Davidson & Currow, 2013; Whitfield & LaBrie, 2017). The term relational experiences acknowledges how the social order of experiences is actively co-constituted by relational subjects in social networks (Donati & Archer, 2015). However, current public health literature lacks a meso-level theorization of the processes through which social and relational resources might shape community EOL care (Lewis, DiGiacomo, Luckett, Davidson & Currow, 2013). Within sociological literature, social capital has been a heavily debated concept over the past several decades, and various definitions and elaborations have been established by different “schools” of thought (Häuberer, 2011). In this chapter, I describe critical theoretical gaps in public health discussions of community EOL care and review and assess the relevance and potential usefulness of dominant conceptualizations of social capital. Drawing on recent literature connecting social capital and EOL care, I focus on how the concept might help illustrate the social relational resources that shape dying experiences.

## **I. Social Capital and Public Health**

The concept of social capital sheds light on patterns of civic collaboration in studies of entrepreneurship, organizational behavior, educational attainment, job-seeking behaviors, disaster restoration, and in particular, in public health (Farkas, 2003; Hawkins & Maurer, 2009; Lin, 2001; Kawachi, Subramanian, & Kim, 2008; Kilduff & Brass, 2010; Svendsen & Svendsen, 2004; Thornton, Ribeiro-Soriano & Urbano, 2011). The concept can illustrate the structures and patterns of social relations and offers a common language to drive the development of social policy (Halpern, 2005). In public health literature, the concept of social capital has been used in relation to public health interventions at multiple levels, considered variably as either the direct target of response, as a channel/mediator, or as a segmenting variable (Villalonga-Olives, Wind & Kawachi, 2018). Broad appreciation for social capital theory is evident in both public health and social policy fields concerning community EOL care (Aldrich, 2017; Halpern, 2005; Lewis, DiGiacomo, Lockett, Davidson & Currow, 2013; Moore & Kawachi, 2017; Woolcock, 2000). Indeed, health promotion and public health approaches to community EOL care start deliberating a various range of practices in different localities, emphasizing the importance of social relational resources (including connections and cooperation between community stakeholders and across formal and informal care networks, not limited on the discussion of social capital) for various

health and social policy outcomes (Bainbridge, Brazil, Krueger, Ploeg & Taniguchi, 2010; Dempers & Gott, 2017; Kellehear, 2005; Pesut et al., 2018; Pesut et al., 2017; Rosenberg, Horsfall, Leonard, & Noonan, 2015; Sallnow & Paul, 2015; Sawyer, Sallnow, Kupeli, Stone & Sampson, 2019; Wegleitner, Heimerl & Kellehear, 2015). In this regard, the concept of “compassionate communities”<sup>9</sup> has been used to highlight how collaborative social relationships can strengthen community EOL care, through enhancing the social atmosphere and institutional environment for the dying person and his/her caregiver(s) (Abel & Kellehear, 2016; Kellehear, 2005). To achieve this goal, community agents must strengthen social capital (Abel et al., 2011). For instance, in one well-developed compassionate community in Kerala, India, volunteer neighbourhood networks identify chronically ill people and facilitate liaison with formal services (Abel et al., 2011). In this regard, Abel et al. (2013) coined the notion of “the circle of care” around an ill person – a caring network,<sup>10</sup> including community members and service delivery organizations. Notably, in one study in Australia, most formal EOL service providers remained at the margin of the circle of care (Leonard, Horsfall, Rosenberg, and Noonan, 2018). Importantly, barriers to building social capital

---

<sup>9</sup> According to Kellehear (2005), compassionate communities: 1) embed ethical compassion into local health policies; 2) meet the unique needs of those living with life-threatening illnesses, and with loss; 3) demonstrate commitment to local social and cultural differences; 4) involve grief and palliative care services in local government policy and planning; 5) offer access to a broad variety of supportive experiences, interactions, and communication; and 6) provide easy access to grief and palliative care services (p.87-91).

<sup>10</sup> In the construction of the circle of care, people may use a model that involves a person, the inner caring network, the outer caring network, community, service delivery, and policy from the core to the periphery of the circle of care (Abel et al., 2013).

in community EOL care relate to insufficiencies in community awareness and caring capacity, coordination between informal and professional services, and from paternalistic service principles (Rosenberg, Horsfall, Leonard & Noonan, 2015). In this regard, the latter authors recommend community development strategies that help build up experiential and practical knowledge of EOL care in the community, strengthening informal care networks (Rosenberg, Horsfall, Leonard & Noonan, 2015).

As such, compassionate communities are envisioned as having frequent, sophisticated participation by and within voluntary groups, mutual collaboration between people and institutions (both within and between communities), and as activating and addressing structural holes<sup>11</sup> and bonding and bridging ties (Burt, 2001; Putman, 1993; Kellehear, 2005; Woolcock, 2001). The resource that exists in a compassionate community - an interactive interdependency and reciprocity between laypeople and professionals - has been identified as a collective kind of social capital (Gott et al., 2018; Sallnow, 2018). Sallnow (2018) argues that that the conceptualization of social capital in EOL care needs to redress power dynamics within provider-recipient relationships and create space for reciprocal and mutual relations (Sallnow, 2018).

A few studies tentatively suggest that enhanced social capital strengthens the support of dying people and their families as well as the quality of this support (Horsfall,

---

<sup>11</sup> A gap between two individuals with complementary resources or information (Burt, 2017).

Noonan & Leonard; 2012; Johansson, Leonard, & Noonan, 2012). Thus, health promotion leaders posit social capital as a necessary resource for dying people and their families to achieve a good death (being socially active in dying) in the community (Borgstrom, 2015; 2016; Králová, 2015). Although not explicitly using a social capital lens, other studies have investigated the role of social networks in the care of the dying people and their families, as well as those that may be disadvantaged in this regard. For instance, Lewis, DiGiacomo, Currow & Davidson (2014) found that socioeconomically underprivileged persons are disadvantaged in terms of their access to informal care networks due to issues such as family conflict and crisis. Besides, Collins (2017) found that some older widowers had very restricted personal communities, leading to more limited and inconsistent access to formal care practical supports.

Overall, the concept of social capital has been used in current public health literature on community EOL care to explore the resources involved in neighbourhood relationships, volunteering, and institutional collaboration, as well as implications for the quality of care and quality of death/dying and bereavement in communities (Kellehear, 2005; Wegleitner, Heimerl, & Kellehear, 2015). To date, however, this literature is still under-developed methodologically and theoretically. It has not provided a distinct and useful meso-level theorization of how social relational processes and mechanisms operate in mediated, service-based relationships in community EOL

care; specific examples of how people access and mobilize social capital resources are also poorly explored. There is also little research engaging with these issues in the contemporary Hong Kong context. With the data collected and the guidance of theoretical sampling, this research will address this gap and provide a basis for theorizing how resources in social relationships be developed and mobilized in community EOL care in Hong Kong. Also, it provides insights into how these resources are developed and mobilized. As a preface to this work, in the following section, I highlight the essential characteristics and properties of social capital as a sociological concept and address the suitability of existing models to guide the exploration of social capital in community EOL care in Hong Kong.

## **II. Conceptualizing Social Capital: A Contested Sociological Concept**

Social capital was first introduced by economist Glenn C. Loury<sup>12</sup> in 1977 to identify how social resources affect the development of human capital; his focus was on racial differences in personal income in the US in the 1970s. The concept was a response to the current discursive emphasis on supply and demand, human capital and equal opportunity (Lin, 2001; Loury, 1977; Portes 1998). Afterward, scholars began deliberating how relational mechanisms such as network, norms, and trust facilitate

---

<sup>12</sup> Loury (1977) defined social capital thusly: “an individual’s social origin has an obvious and important effect on the amount of resources that is ultimately invested in his or her development. It may thus be useful to employ a concept of ‘social capital’ to represent the consequences of social position in facilitating acquisition of the standard human capital characteristics” (p.176).

cooperation for the acquisition of public economic goods (Hayami, 2009).

A sociological consensus about the properties of social capital, or even its exact definition, has not been reached since this early introduction of the concept (Bourdieu, 1986; Lin, 2001; Portes, 1998). However, as it is most generally understood today, social capital refers typically to resources embedded in the social relationships and interactions within networks (Lin, 2001). In relation to EOL care, for example, social connections and interpersonal trust could improve the circulation of information, improving access to government resources as well as the provision of local services in communities, alongside building civic trust and cohesion more generally (Lewis, DiGiacomo, Lockett, Davidson & Currow, 2013). Yet how social capital can be observed and analyzed, and how the concept can be theoretically elaborated, is still in debate (Häuberer, 2011). Below, I highlight several vital conceptualizations of social capital and propose a synthesis, with a focus on illustrating how the concept might advance our understanding of community EOL care.

### **Closed networks and socio-cultural aspects of social capital: perspectives from Bourdieu and Coleman**

One dominant conceptualization of social capital emphasizes the role of closed networks and socio-economic and cultural contexts. First, a Bourdieusian conceptualization, drawn from his theory of practice, illustrates how the reproduction

of social class occurs, extending beyond the focus on economic capital found in the Marxian tradition (Fries, 2009). Together with economic and cultural capital, social capital interplays with doxa (the position of the field), illusio (the collective belief in the rules of the social game), field (the structure), and habitus (agency) (Bourdieu, 1977; Walther, 2014) to reproduce social class (Harker, Bourdieu, Mahar & Wilkes, 1990).

Bourdieu defined social capital thusly:

The aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition, or to membership in a group (Bourdieu 1986, p.248).

Bourdieu (1986) elaborates that the volume of social capital depends in part on the size of the network and connections the agent can effectively mobilize. Individuals may differ regarding the amount and the quality of social capital (Bourdieu, 1986), as well as strategies to access and accumulate the social capital embedded in social relationships. Social capital also relies highly on intensive exchange and recognition in formal institutions, such as being a member of a formal social group, club, or organization (Bourdieu, 1986). To achieve formal membership, individuals have to access and invest in economic capital (money) and cultural capital (education) (Bourdieu, 1984; 1986). Furthermore, social capital is closely intertwined with economic and cultural capital (Bourdieu, 1986; Fries, 2009). For instance, one study reported that second-generation Turkish immigrants in Germany, France, Sweden, and

the Netherlands<sup>13</sup> were more likely to succeed in the labour market when they accumulated not only economic and cultural but also social capital - social skills and support from parents and others in their social networks (Crul, Schneider, Keskiner & Lelie, 2017).

Social capital builds up when individuals start interacting and constructing social networks, such as family, kinship, as well as connections to informal and formal institutions (Bourdieu, 1986). Practices and their meaning in social networks are of importance to the accumulation of social capital. Practices might entail strategic investment in the network of social associates (Bourdieu, 1986) or embodying the rites of social institutions, which indicate or mark crucial moments (Bourdieu, 1986). For example, in the construction of social relationships (guanxi) in the modern Chinese society, Chinese people are used to giving gifts to the people with whom they want to engage for different purposes (Gold, Guthrie, & Wank, 2002). The gift-giving strategy builds connections with different persons, across formal and informal institutions. Those social connections, in the culture of guanxi, help accumulate social capital for future rewards, such as joint ventures (Wilson & Brennan, 2010).

Moreover, as a social relationship plays out, it enacts a set of durable obligations that transform those relationships (Bourdieu, 1986) and which maintain continuous

---

<sup>13</sup> They compared three labor market sectors (corporate law, corporate business and education) across four countries.

exchanges of various forms of capital. For example, to keep a valid membership in a formal organization (social capital), people may need to pay membership fees regularly (economic capital) or attend key organizational events (cultural capital). Sometimes, the individual has to spend more economic (money) and cultural (disposition) capital than she/he expects when she/he has a lower ability to make a profit in the exchange (Bourdieu, 1986). Through such exchanges in social networks, social capital is produced and reproduced.

In the Bourdieusian conceptualization of interplay between structure and agency, social capital explains mechanisms of the social class reproduction through individuals' social networks and relationships. As such, this conceptualization helps explore the socio-economic and cultural features that may be implicated in how social relationships influence community EOL care, and who can access sufficient quantity and quality of social capital (Lewis, DiGiacomo, Lockett, Davidson & Currow, 2013).

With a focus on closed network structures like Bourdieu, Coleman offers a sociological account of educational achievement and social inequality in American society which likewise extends beyond economic explanations to emphasize human capital or capacity (Coleman, 1987; 1988a; 1993; Coleman & Hoffer, 1987; Schmid, 2002; 2016). For instance, social capital "inside or outside the family" might influence children's cognitive development and educational outcomes (Coleman, 1988).

However, departing from Bourdieu, Coleman engages with a structural-functionalist perspective and rational choice theory,<sup>14</sup> which emphasizes the influence of structure (such as family and community networks) on agency (such as decision-making) (Häuberer, 2011). Coleman (1988) also emphasizes the specificity of the function of social capital in social life; social capital is productive insofar it helps to achieve a specific goal (Häuberer, 2011; Lin, 2001; Porto, 1998). Moreover, he also offers a rich elaboration of the conceptual association between social capital, family, and social networks in the context of US education (Coleman, 1987).

As noted, Coleman's conceptualization of social capital rests on rational choice theory. It also relies on the notion of embeddedness coined by Polanyi (1957), used to recognize the function and implications of interactions between actors and relational networks for generating trust and creating as well as enforcing norms (Coleman, 1988; Granovetter, 1985; Woolcock, 1998).

Coleman (1988) differentiates social from physical capital (which helps change materials into tools to facilitate production) and human capital (which enhances and modifies a person's skills and capacities). Although social capital involves social structure, it is "defined by its function" (p. 98) in terms of how it maximizes the utility of social relationships and promotes mutually obligating actions towards specific

---

<sup>14</sup> Rational choice theory emphasizes how an individual maximizes utility by rationally choosing the best solution for her/his preferred purpose(s) (Häuberer, 2011).

purposes/goals (Coleman, 1988). More specifically, social capital facilitates:

...certain actions of actors—whether personal or corporate actors—within the structure. Like other forms of capital, social capital is productive, making possible the achievement of certain ends that in its absence would not be possible. Like physical capital and human capital, social capital is not completely fungible but may be specific to certain activities. A given form of social capital that is valuable in facilitating certain actions may be useless or even harmful to others (Coleman, 1988, p.98).

However, an actor can rationally and purposively choose either to or not to fulfill an obligation; thus, social capital is dependent on expectations of the return of personal benefit (Coleman, 1988).

Coleman further posits social capital as generated through a) the enforcement of group norms in action; b) the relations of mutual reciprocity in a group (i.e., expectations and obligations of return, help or exchange); c) trustworthiness among group members (more common in closed network structure); d) authority relations and rights of control (i.e., when somebody chooses to transfer her/his rights of control of the action to another); e) the “information potential” or the capacity of the group<sup>15</sup>; and f) an appropriate organizational structure which effectively socializes members.<sup>16</sup> Four factors are proposed to influence social capital: closure (relations between all embedded actors), stability (enforced by organizational structures and positions), ideology (which

---

<sup>15</sup> For example, a housewife wants to stand out at the cutting edge of fashion trends but does not have enough time to achieve this. She can acquire information about the latest fashion from her friend who may be more immersed or knowledgeable, if she has these kinds of friends (Katz & Lazarsfeld, 1955).

<sup>16</sup> For example, a volunteer association usually promotes the internalization of philanthropy (Brown & Ferris, 2007).

awakens the desire to act in the interest of someone or something else), and welfare (which may reduce motivation to collaborate: Coleman, 1988).

Although Coleman's conceptualization suggests the possibility of empirical operationalization and tangibly demonstrates how social capital emerges and interacts with different aspects of stratification, it too faces several fundamental critiques, including its vagueness concerning the distribution between human and social capital (Portes, 1998). It also neglects the power of weak, diffuse ties for information flow, innovation, and for counter-balancing the tendency for conservatism and other harmful outcomes in closed networks (Burt, 2001; Field et al., 2000; Kolankiewicz, 1996; Portes, 1998; Schuller, Baron & Field, 2001). Also, Coleman's conceptualization has been critiqued for idealizing the functional benefits of conventional gender-differentiated family forms and stigmatizing non-conventional forms (Bruegel, 2005; Coleman, 1988; 1997; Edwards, Franklin & Holland, 2003).

### **From the effectiveness of closed structures to the importance of open structures of social capital: Putnam and Burt's perspectives**

Here, I turn to the work of Robert Putnam, who argues that social networks contain a value for individuals, much like physical and human capital; he also proposes that social contact influences the productivity of individuals and groups and their ability to reach collective goals effectively (Putnam, 1995). For Putnam, social capital is similar

to civic virtue and political participation and reflects societal quality (Putnam, 2000). More specifically, he defines social capital as “features of social organization, such as trust, norms, and networks, that can improve the efficiency of society by facilitating coordinated actions” (Putnam, 1993: p.167). The features and dynamics of social capital are illustrated using the concept of mutual trust, depicted as a lubricant of civic life, and as promoting the probability of cooperation in groups and communities (Häuberer, 2011; McLean, Schultz & Steger, 2002; Putnam, 2000). In this way, higher levels of cooperation foster higher levels of trust<sup>17</sup> (Häuberer, 2011). In Putnam’s conceptualization, mutual trust stems from formal and informal groups in civil society (i.e., the network for engagement<sup>18</sup>), and norms of reciprocity (similar to Coleman’s conceptualization).

Putnam emphasizes that social capital can (but does not always) lead to clear benefits, including cooperation among individuals in the community for common goals (Putnam, 1993a), as well as individual interests through the operation of reciprocal relationships. For example, people secure jobs more often through personal contacts

---

<sup>17</sup> Misztal (2005) argued that trust-building in modern civil society is about more than cooperation - that it is connected to the type of interaction, such as civility (in “encounter” relationships), sociability (in “exchange” relationships), and intimacy (in “pure” relationships). Also, formality and informality should be also considered when conceptualizing social trust (Misztal, 2000; 2005). Misztal (2001) believed the self-coordinated and informal cooperation suggested by Putnam neglects the role of state in the process of building social trust.

<sup>18</sup> This includes horizontal groups that bring people of the same status and power together, such as neighborhood associations and sports clubs, which facilitate communication and improve information flow and trust (Putnam, 1993). It also includes vertical groups or linkages among individuals that are different in their positions in hierarchy and dependency (Putnam, 1993). These linkages allow individuals to leverage resources and information (Woolcock, 2001) yet may be more unstable and imbalanced in terms of power.

than advertisements (Isham, Kelly & Ramaswamy, 2002). Putnam also emphasizes that people need to continuously use social capital to achieve these public and private goods because this fosters mutual trust, which is the basis of social capital (Putnam, 1993a; 1993b). In other words, the stock of social capital has a cumulative and self-enhancing effect realized through continuous use (Montgomery, 2000; Putnam, 1993b).

Putnam further distinguishes between different types of connectedness in social networks. Bonding social capital refers to resources drawn from the intensive connectedness involved in more homogenous similar social networks (McPherson, Smith-Lovin & Cook, 2001), and bridging social capital emphasizes resources stemming from external ties of networks (Adler & Kwon, 2002; Putnam & Goss, 2002).

Putnam's conceptualization is perhaps most frequently cited with community EOL care and may reflect the dominant conceptual understanding in these circles of social connection and community participation (Kellehear, 2005). Yet Putnam's conceptualization has been critiqued as insufficient to illuminate the connection between civic engagement and participation in social institutions<sup>19</sup> (Levi, 1996). There is insufficient evidence to support Putnam's strong claims about the connection between formal institutional social networks and civic engagement, especially membership in voluntary organizations (Dowley & Silver, 2002; Häuberer, 2011). Moreover, Putnam

---

<sup>19</sup> Moreover, the critique identified the association of social capital and democratic as problematic because it cannot provide a model of how society legitimizes the rules of a political institution that citizens support on trust, which leads to democratic process (Misztal, 2001).

overlooks the implications of informal social networks in different settings,<sup>20</sup> for civic engagement (Häuberer, 2011). Furthermore, Putnam's social capital index<sup>21</sup> seems to combine various aspects of social life (often measured indirectly), which are causally connected but may be problematic in terms of empirical operationalization (Häuberer, 2011; Lin, 2001). These weaknesses require particular scrutiny before using this conceptualization to understand social connections and community EOL care.

Both Coleman and Putnam's conceptualizations direct the attention to how networks are structurally configured. Coleman focuses on the benefits of closed structures; Putnam highlights open structures yet does not comprehensively address their bridging function. In this respect, Burt (1992; 2005) has further elaborated on open-structure social networks, drawing on organizational behavior and network analysis. He also discusses how social capital facilitates the flow of resources between different networks through brokerage practices, which will be defined further below (Burt, 2005).

Burt's conceptualization of social capital is embedded in his structural theory of action, which elaborates individuals as actors positioned within social structures who perceive actions as improving their wellbeing (motivation) and balance the probability

---

<sup>20</sup> Campbell (2000) found that social capital in informal networks of friends and within neighborhoods leads to positive health-promoting activities. Putnam's apolitical consideration of social capital omitted structural constraints on civic participation in the context of global capitalism (Boggs, 2002; Boutilier, 2017; Navarro, 2002; Paterson, 2000).

<sup>21</sup> In Putnam's social capital indices, some indicators come from different kinds of "indirect" measurements of social capital, such as community organization life, engagement in public affairs and community volunteerism from US public statistics (Häuberer, 2011; Sabatini, 2005).

of success in comparison with alternatives (evaluation) (Burt, 1982). In this model, social capital refers to the resources or content of social relationships between actors, which could be used within this structure of action to achieve specific goals (Häuberer, 2011). Relationships include those with “friends, colleagues, and more general contacts through whom you receive opportunities to use your financial and human capital” (Burt, 1992; p.9). Importantly, related actors possess social capital mutually (Burt, 1992). As multiple contacts unfold in relationships, social capital in network structures forms gradually (Burt, 1992).

In terms of the structural features of networks, Burt theorizes that networks do not only link individuals<sup>22</sup> but also subgroups<sup>23</sup> (1992); Burt was also interested in aspects such as the density and transitivity of the network<sup>24</sup> as well as structural holes<sup>25</sup> and brokerage. Burt’s conceptualization extends from closed to opened structures but has been critiqued mainly because of its overemphasis on the latter; indeed, Burt (2004) even claims that closed network structures might not bring benefit to network actors (Coleman [1990] likewise highlights the drawback of closed structures). In contrast, Putnam advances both bonding (closed structure) and bridging (open structure) aspects

---

<sup>22</sup> The network of individuals (ego-network) consists of a set of actors and the ego actor has a direct relation to the actors. For instance, a family relation usually exists in the ego network. If the father is at the centre of the network, he often has direct contacts with his spouse and children (Odella, 2006).

<sup>23</sup> There are two types of subgroups, and *cliques* consist of actors that have intensive intimate face-to-face contacts and good collaboration (Burt, 1978).

<sup>24</sup> Network density refers to the extent that the actors connect with each other in a network system in average (Burt, 1982). Transitivity refers to the size of the relation (tie, edge, or link) connecting two nodes in the network (Burt, 1982).

<sup>25</sup> Structural holes refer to weak relations in the networks (Burt, 2001).

to depict two different ways that social capital circulates in a social network.

Burt's conceptualization also has limited scope and usage, because it focuses on individual benefit (career assets) rather than civic benefit (Schuller, Baron & Field 2000). Since it is based on general mathematical linear modeling, the model actually may not be able to deal with the variety of network functions to the same end, nor the different impacts on different social units (Abbott, 1998; Schuller, Baron & Field 2000). Since the present research project is concerned with the implications of social connections for quality of community EOL care, Burt's conceptualization would need to be expanded to develop its most promising features – structural holes and open networks - in a way that is more relevant to this research. Also, Burt's mathematical linear modeling would be less helpful for exploring the processual and dynamic aspects of social capital.

### **Developing a theoretical model of social capital: Lin's perspective on social capital**

The above social capital theorists lack a clear common ground or platform for conceptual synthesis (Häuberer, 2011; Portes, 1999). More recently, however, Nan Lin (2001) has developed the notion of social capital to a higher conceptual and theoretical level. Like Coleman and Burt, Lin also posits social capital as a feature of social structure encompassing social relationships and their embedded resources. He also views social capital as an investment with expected economic returns in the marketplace.

Social relationships facilitate the flow of opportunities, information, and informal social credentials to network actors, helping actors position themselves strategically in the hierarchy (2001). Lin notes, however, that some social ties are more influential than others (i.e., among actors that have more power and resources: 2001).

Moreover, Lin explains how social ties could reinforce social identity and public recognition, which also help maintain positive mental health (Lin, Ensel & Vaughn, 1981; Lin, Ye & Ensel, 1999). Lin's discussion emphasizes open network structures (2001); he argues that network closure might create exclusion of non-members and fail to make good use of the strength of weak ties (Lin, 2001).

Lin's conceptualization is primarily grounded in neo-capital theory<sup>26</sup> in which capital is a part of the surplus-value that is captured by capitalists and re-invested to generate additional surplus value (Lin, 2001). It also represents the investment in the production and circulation of commodities with an expected return in the marketplace (Lin, 2001). Lin conceptualizes capitalist society as a set of hierarchies between labourers and capitalists, within which actors mobilize upward or downward (Lin, 2001). In this sense, capitalists and laborers are all active agents in the capital

---

<sup>26</sup> Different from the classical view of capital by Marx (focusing on the relations of production, the ownership of means of production, the commodity, and the consumption of commodities), neo-capital theory emphasizes the process associated with the labourer, the labourer as an investor, and the labourer as motivated to acquire skill and knowledge as reward (beside wage) (Lin, 2001).

accumulation process, and (social) capital can be mobilized to help labourers succeed in capitalist society.

Lin proposes that valued resources are embedded in social structures where position, authority, rule, and occupant form a hierarchy related to the distribution of valued resources, the number of positions, the level of authority, and the number of occupants (Lin, 2001). Moreover, the interaction among network actors usually occurs between actors with similar characteristics of resource and lifestyle (Kossinets & Watts, 2009; Lin, 2001). Last but not least, actors are believed to be motivated to maintain or gain their resources through purposive actions.

In terms of cultural capital, Lin's conceptualization generally aligns with the Bourdieusian one. Lin admits that the dominant class can invest in the reproduction of symbols and meanings (cultural capital) to generate a return (2001). However, he notes that no perfect relation between economic and cultural capital can be assumed (1999; 2001); instead, network construction sometimes determines how much social capital can be accessed. Lin (1999) conceptualizes social capital as intersecting aspects of structure and action – in particular, structural embeddedness (e.g., the distance between ties, their location, strength), opportunity/accessibility, and action-oriented (use) aspects.

Lin's conceptualization is explicit, parsimonious, internally consistent, and testable (Häuberer, 2011). Going beyond other social capital theorists, he has refined the concept with attention to preconditions, and the expressive and instrumental outcomes of accessed and mobilized social capital<sup>27</sup> through what he terms "capitalization" (discussed in Chapter Seven) (Lin, 2001). Critics focus mainly on operational problems specific to proposed measurement tools, which accord primacy to strong ties and frequent contacts and tend to overlook network members lacking in positions (Häuberer, 2011; Lin, Fu & Hsung 2001; Kalish & Robins, 2006; Van der Gaag 2005; Van der Gaag, Snijders & Flap, 2008). However, Lin's conceptualization may not represent the dynamic social process involved in the cultivation of social capital. It may tend to support neo-liberal perspectives (impersonal purposive, and mechanical) towards social relationships (Rankin, 2002).

In conclusion, the experience of dying is fundamentally a relational, processual, and dynamic one (Broom, 2015). However, public health literature on EOL care has not consolidated an adequate meso-level theorization (which emphasizes the group and its interaction order), of social capital in relation to dying experiences. Instead, this field still uncritically and rather mechanically applies the concept of social capital to denote

---

<sup>27</sup> For the preconditions of accessing social capital, Lin (2001) suggested cultural societal aspects (norms of reciprocity, generated trust), collective assets (economy, technology, and historical background), and individual characteristics (age, gender, and ethnicity). For the structures of informal/formal networks, he proposed network size, range, openness/structural holes, and closure/density. In terms of resources for expressive and instrumental action, he suggested this also has a cultural societal aspect (norms of reciprocity, generated trust).

social support at a neighbourhood level. A more sophisticated and nuanced application of the concept of social capital can help examine how the resources embedded in social relationships can be developed and mobilized, and theorize movement from preconditions towards capitalization in social capital development. The present abductive grounded theory study thus was informed broadly by Lin's conceptualization of social capital –used as a tentative “starting point” (while remaining open to discoveries and alternate interpretations). Lin's conceptualization is used because it clarifies how social networks and relationships can help achieve individual goals (Lin, 2001); dying well at home is such an individual goal (Abel & Kellehear, 2016). Lin's unit of analysis emphasizes the area located between micro and meso-levels, which helps explore social capital processes within neighborhoods and communities (Lin, 2005; 2008). Moreover, Lin's conceptualization, like others, are structural conceptualizations of social capital that overall have not widely addressed issues of dynamics, mechanism, and process (Portes, 1998). As such, this research will engage a qualitative methodology to develop a dynamic and processual understanding of social capital, and how social networks and social resources<sup>28</sup> shape EOL care, using evidence from a Hong Kong community. This inquiry can enrich the conceptualization

---

<sup>28</sup> Lee, Árnason, Nightingale & Shucksmith (2005) pinpointed the importance of social processes in relation to the relationship between continuity and change in rural development. Dudwick, Kuehnast, Jones & Woolcock, (2006) and Swann & Morgan (2002) also stated that a qualitative approach can help explore the mechanistic and processual dimensions of social capital.

of social capital as well as contribute to the public health literature on community EOL care more broadly (Kellehear, 2001; Swann and Morgan, 2002).

### **III. Social Capital in the Hong Kong Context**

In Hong Kong, social capital is generally built through community development, such as volunteering, collaboration, and social action (Leung, 2010). Notably, community development processes are heavily mediated by social workers. In 2018-2019, the Hong Kong government spent about 50.9% of total government expenditure on social services, with 32.4% of this spending directed to social welfare (Hong Kong Legislative Council Secretariat, 2018). In Hong Kong, there is a mixed model of universal health service provision, but a selective approach to social security,<sup>29</sup> through means-testing (Ting, 2010).

Most active attempts to build social capital, in this context, are mediated mainly through social work agencies and non-government organizations (NGOs). For instance, faith-based groups have increasingly been developing social welfare NGOs to tackle social problems related to housing, neighborhood stability, and public trust; they also implement government-initiated projects and interventions (Chan, 2005; Hung, Leung & Ng, 2010; Ting, 2010). Every NGO has an advisory or directory board and often recruit board members from the community. As increasing numbers

---

<sup>29</sup> The Hong Kong welfare system primarily opts to support people below a certain level of income, through means-testing.

of community members join the boards of those NGOs, connections between the Hong Kong government and communities become more intertwined (Ting, 2010).

Moreover, at a micro-level, social workers often apply socio-political theories in their case-based and group work towards the goal of social justice, with the guidance of the social work code of ethics.<sup>30</sup> Service users (and likely board members) are in these ways socialized into civic-oriented citizenship (Ting, 2010). Social workers may further facilitate and activate community assets and relational resources by participating in social planning, locality development, and social action (Ting, 2010). As citizens build resourceful relationships within their communities (bonding ties), they may have higher confidence and access more opportunities to communicate with people of different social statuses, who may possess different kinds of resources (bridging and linking) (Lee, 2010).

Social workers tend to view their work as building social capital through community engagement and civic renewal, facilitating policy formulation and implementation, and mobilizing social care networks (Leung, 2010). In their praxis, social workers attempt to create relationships among local interested stakeholders, provide essential supporting resources, encourage bridging and integration of people

---

<sup>30</sup> Ting (2010) identified that the basic values and beliefs of social worker highlighted in the Social Workers Registration Board as: development of norms of trust, reciprocity, respect, mutual support, and strengthening interpersonal relationships for the betterment of individuals, families, communities and society.

of different backgrounds, and build up cohesion among members of the same social group (Leung, 2010). As this work strengthens the bottom-up motivation of community members, it is hoped this will gradually enhance the responsiveness of policy to citizens as well as societal cohesion (Leung, 2010).

For instance, bridging, as praxis, describes how social workers encourage in-group members to learn new knowledge about out-group members to reduce negative images (Chong and Ng, 2010; Pettigrew, 1998). This makes the in-group members establish a temporary and initial acceptance of the out-group in collaboration, which serves as a precursor for future attitudinal change (Chong and Ng, 2010; Pettigrew, 1998). With increasing intensity of reciprocal exchange, both in-group and out-group members start building up affective ties and friendship (Chong and Ng, 2010; Pettigrew, 1998). Finally, both groups try to adopt alternative views of the social world, learned from each other (Chong and Ng, 2010; Pettigrew, 1998). Through this praxis, social workers believe their intervention can play an important role in establishing a substantial foundation of social capital<sup>31</sup> (Fung & Hung, 2016).

Bridging praxis, as with other efforts to build social capital, are viewed by Lee

---

<sup>31</sup> Chong and Ng (2010) used a Community Investment and Inclusion Fund (CIIF) project "Elder Shop Corner" to illustrate bridging. The elders operated the Elder Shop as a traditional corner, giving neighbors a drop-in place, where the much valued Chinese traditional soup is served and where the elders, along with women and youth volunteers, operate voluntary or fee-paying community services teams for their community. This project provided many regular opportunities for seniors to interact and work with customers from different backgrounds. This successfully reduced negative stereotypes about older people in mainstream Hong Kong society, enhancing mutual understanding.

(2010) and Roger (1995) as strengthening community health in Hong Kong; for instance, community members can access health-related information more efficiently, and social relationships can create a supportive and normative environment to address barriers to healthy lifestyles as well as having more direct benefits for health.

In sum, social capital in Hong Kong is built in part through social work praxis and delivery; as such, there is a critical need to consider the everyday work of social workers in service delivery in community EOL care (the latter is also increasingly mediated by social service, in alignment with the government's current policy direction, as previously stated).

In conclusion, in this chapter, I briefly reviewed existing public health and EOL care literature that engaged with the concept of social capital and provided a comprehensive theoretical background for my subsequent analysis of social capital and community EOL care in this study. In particular, my research addresses the relational dynamics and mechanisms involved in the development of social relationships to enhance the quality of death. Lin's conceptual model of social capital, alongside other concepts such as compassionate communities and the circle of care, are promising conceptual tools in this regard. Lastly, I emphasized how social capital development in Hong Kong relies on the social service sector intervention (and social work praxis). Taken together, this material provides the reader with the starting point

for the present study; in the next chapter, I will discuss the research methodology, before moving on to present findings.

## **Chapter Three: Research Methodology**

### **Introduction**

In this chapter, I introduce the research methodology used for this study and explain how it guided the data collection, analysis and theoretical development through the abductive approach of grounded theory, which is based on Peirce's philosophy (Rodrigues, 2011). After highlighting the essential features of grounded theory methodology (GTM), I describe how I collected data through interviews with the staff and clients of two non-profit, community-based EOL service organizations – organizations which offer support, education and facilitate mutual help groups for dying persons, their families, and the general public (among other services). I conclude this chapter by illustrating how the empirical data were analyzed.

This research investigates the relational (particularly reciprocal and interactional) mechanisms and dynamics of social relationships that shape the community EOL experience of dying people and their families in Hong Kong. In particular, the focus is on the supportive relationships that develop between social agency practitioners or volunteers and clients, and between social agency practitioners and medical professionals. Qualitative methods are well suited to exploring the complex mechanisms involved in mobilizing social capital to shape experiences of compassion and community over time for dying people and their families (Dudwick, Kuehnast,

Jones & Woolcock, 2006; Swann & Morgan, 2002). Several vital dimensions frequently discussed in the notion of social capital, such as trust, cooperation, and cohesion, are arguably difficult to assess using standardized quantitative measurement tools. Grounded theory methodology (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1990) has been used effectively to study the complexities of palliative care experiences (Kuziemsky, Downing, Black & Lau, 2007; Sandgren, 2017; Sandgren, Thulesius, Petersson & Fridlund, 2007; Stiel et al., 2010; Tan, Ng, Subramaniam, Lim & Loh, 2012); indeed, it was developed and used in Glaser and Strauss' early work on death and dying (Glaser & Strauss, 1967; 1968; 1980). This inductive methodology is designed to develop theories of social interactions and processes more broadly. GTM emphasizes the discovery and elaboration of basic social processes (BSP) through theoretical coding around a core category (Glaser, 2005). BSPs represent process and change over time, often through stages, as these are associated with different patterns of behaviours or interactions, such as dying trajectories. The stages may or may not be strictly determined by aspects of social structure, or even be immediately perceived by the actors themselves (Glaser, 2005). GTM seeks to elaborate not only such stages but also the conditions and consequences associated with each stage (Glaser, 2005).

Grounded theory methodology allowed me to remain responsive to the data and to facilitate inductive theorization of the social relationships surrounding dying people and

their families in the community. To help move the work beyond description and to engage theoretical sensitivity<sup>32</sup>, I used an abductive approach (and social capital as an analytic lens), which prioritizes inductive analysis but retains some deductive elements (Bryant, 2009; 2017; Timmermans & Tavory, 2012). This section below will highlight further details about the setting, data collection, and analysis strategies.

## **I. Setting**

This research is based in Hong Kong, a city at the south-eastern tip of China. As of 2019, Hong Kong has a population of approximately 7.52 million. People of Chinese descent (92% as of mid-2016) comprise the vast majority of the population (GovHK, 2020). Other significant national groups represented in the population include the Philippines (196,546 people), Indonesia (174,105 people), and India (34,217 people) (GovHK, 2020). In terms of language, Cantonese (88.9%) is the major language spoken in Hong Kong (GovHK, 2020), and other commonly spoken languages include Putonghua (1.9% of the popu), other Chinese dialects (3.1%), English (4.3%), and other languages (1.9%) (GovHK, 2020). In 2019, Hong Kong had 52,900 births and 48,500 deaths (Hong Kong Census and Statistics Department, 2020); population growth is almost stagnant, and population aging increasing, due to a particularly low fertility rate.

The present research focuses primarily on in-depth data collected from

---

<sup>32</sup> For details, please refer to Glaser (1978).

practitioners and volunteers of one nonprofit agency that, in 2004, was established as the first community EOL mutual support group service in Hong Kong (PARACLETE).<sup>33,34</sup> The staff of another project, called Life Rainbow, were also included; this project is part of the Hong Kong Society of Rehabilitation (HKSR). To a lesser extent, former users (bereaved family members) and current users (dying persons) were also theoretically sampled (more details are provided later in this chapter).

PARACLETE was established by a community centre for older adults and sponsored by Hong Kong Jockey Club. It is based in Hung Hom, an east Kowloon district community. PARACLETE constitutes part of the social relationships and networks of its service users - dying people and their families. Although the geographic base of the institution and service is in eastern Kowloon, the service is for terminally ill people and their families in any Hong Kong district. There is only one support group operating. There are around 50 core volunteers in a total of 163. Service users can self-refer or be referred by their doctor; they are from diverse demographic and clinical or community service<sup>35</sup> backgrounds. Services available through PARACLETE include

---

<sup>33</sup> This is one of the EOL care service projects provided by SKH Holy Carpenter Church District Elderly Community Centre. Another project is called “Hospice at home” home care support service. Most of the service users were referred to PARACLETE. The service target group is terminally ill older people and their families (Jockey Club End-of-Life Community Care Project, 2018)

<sup>34</sup> The service manager of the project “PARACLETE” is a personal friend. He also oversees other community EOL care services in SKH Holy Carpenter Church District Elderly Community Centre.

<sup>35</sup> The users may be receiving help from existing formal services in the community provided by the Hong Kong Social Service Department, and subvented NGOs. In Hong Kong, the formal subvented service by Hong Kong Social Welfare Department could be provided by Integrated Family Service Centres (65 Centres), District Elderly Community Centres (41 Centres), Neighbourhood Elderly Centres (169 Centres), and Community Centres (13 Centres) (Hong Kong Social Welfare Department, 2018).

funeral service consultation and accompaniment, peer mutual emotional support, life education at the community level for dying people and their family members, and volunteer development (SKH Holy Carpenter Church District Elderly Community Centre, 2018). Distinct from some of PARACLETE's standard bereavement services, "Hospice at Home" is a funded project to provide EOL support specifically for dying persons and their families. Volunteers meet regularly at different social events hosted by the service provider throughout a year. More broadly, PARACLETE has established networks with hospitals, mass media, religious groups, funeral service providers, artists, and universities (Centre for Excellence in Social Service, 2015). By 2015, PARACLETE had served over 30,000 people (Centre for Excellence in Social Service, 2015).

The newer, "Life Rainbow" End-of-Life Community Care Project was officially launched on 1 January 2016, to provide community support for persons in late stages of illness and their family members at home. Up until 2020, the project has served 316 clients, with help from 60 active volunteers, managed by 7 project staff.<sup>36</sup> The project's catchment area centers around the East District of Hong Kong Island. Service users mainly come from the existing participants of the HKSR service centre in eastern Hong Kong Island, and through referral by the public hospitals in the Hong Kong East

---

<sup>36</sup> The project personnel include one project manager, two social workers, one nurse, two project officers, and one program worker.

cluster.<sup>37</sup> Life Rainbow's specific aims are to formulate an integrative, collaborative partnership model of community-based EOL care with a particular emphasis on mobilizing medical-social collaboration to address tangible, physical, and psychosocial needs of dying persons and their families. This is important to note because the aims of this specific organization likely explain why medical-social cooperation in community EOL care emerged as a salient category (as will be discussed later). This project was also likely to be a good fit to represent the current policy and practice direction in Hong Kong EOL care. As such, I decided to reach out to recruit through this project as a compatible supplement to PARACLETE, in theoretical sampling.

## **II. Participant Recruitment, Sampling and Data Collection**

In-person, semi-structured, in-depth qualitative interviewing<sup>38</sup> and grounded theory methodology (GTM) were employed in this study. Data collection commenced in 2019 after obtaining approval from the Psychology/Sociology Research Ethics Board (REB) of the University of Manitoba.

Between June 2019 and December 2019, two primary groups of participants were recruited based on their involvement with either PARACLETE or the Life Rainbow project. First and most primarily, I recruited both volunteers and organizers

---

<sup>37</sup> This refers to the Eastern and Wanchai Districts of Hong Kong Island and outlying Islands (excluding Lantau Island). Currently, this includes Pamela Youde Nethersole Eastern Hospital and Ruttonjee Hospital.

<sup>38</sup> Please refer to Appendix 1 for interview questions.

(practitioners) from both organizations (n=14), intending to learn from them to understand better the relational dynamics in community EOL care and how this shapes the death and dying experiences of service users (dying people and their families). Second, I also conducted a smaller, limited number of interviews with former and current users (n=2) to further develop the emerging conceptual framework. On average, interviews were approximately one hour in length and conducted at a quiet and safe (public/private) location as preferred by interviewees.<sup>39</sup> To reach theoretical saturation, GTM suggests the researcher uses an appropriate amount of data to generate the core category and BSP (Glaser & Strauss, 1967). However, the amount of data needed entirely depends on the progression of the emergence of the core category and BSP and the implementation of theoretical coding and theoretical sampling<sup>40</sup> (Glaser & Strauss, 1967).

Interview #	Role in community EOL care	Gender	Years providing or receiving service
S001	Social Worker (PARACLETE)	M	5
S002	Social Worker (PARACLETE)	F	5
S003	Social Worker (PARACLETE)	F	0.5
S004	Social Worker (PARACLETE)	M	10
S005	Social Worker (PARACLETE “Hospice at home”)	F	4

<sup>39</sup> Most of the interviewees preferred a quiet room at the service centres.

<sup>40</sup> Theoretical sampling is based on using theoretical sensitivity, adjusted research questions, working hypotheses, and emerging categories to achieve saturation (Glaser & Strauss, 1967).

S006	Social Worker (PARACLETE “Hospice at home”)	M	0.5
S007	Volunteer (PARACLETE “Hospice at home”)	M	3
S008	Volunteer (PARACLETE “Hospice at home”)	M	3
S009	Volunteer (PARACLETE “Hospice at home”)	F	5
S010	Social Worker (Life Rainbow)	F	3
S011	Nurse (Life Rainbow)	F	3
S012	Volunteer (Life Rainbow)	F	3
S013	Volunteer (Life Rainbow)	F	3
S014	Volunteer (Life Rainbow)	M	3
U015	Former Service User (Life Rainbow)	F	1 year
U016	Current Service User (Life Rainbow)	F	1 year

Table 3.1 Summary of participants interviewed in PARACLETE and the Life Rainbow community EOL care projects

In total, 16 participants were interviewed. Of note is that this project faced considerable recruitment challenges - in particular, the significant social movement and unrest in Hong Kong following the June 12, 2019, anti-extradition law amendment.<sup>41</sup> Following this amendment, various actions of the Hong Kong government escalated the situation. Feedback from within Hong Kong civil society was and continues to be intense and long-lasting, and included frequent protests in different districts, sit-ins at the Hong Kong International Airport, general strikes, blockades of major highways, clashes between protesters and counter-protesters, and

---

<sup>41</sup> After June 9, 2019, 1.03 million people in Hong Kong joined in various protests against the extradition law amendment. The Hong Kong government insisted the second reading debate on the bill be resumed on 12 June. Protesters finally stopped the second reading of the bill by surrounding the legislative complex. Riot police dispersed protesters using controversial methods such as kettling, firing tear gas, bean bag rounds and rubber bullets, allegedly assaulting journalists in the process.

so on. Reinforced police suppression tactics and what many viewed as a ruthless response<sup>42</sup> from the Hong Kong government towards this social movement, has led to an almost irreconcilable social situation. In January 2020, the situation shifted in focus slightly, as protests increasingly took the form of public pressures on the Hong Kong government to adopt substantial measures to reduce the risks to public health in Hong Kong, after the outbreak of the COVID-19 in mainland China.

These social conditions (political unrest and COVID-19) have significantly influenced sample recruitment for this study. Firstly, the interviews were challenging to arrange because the social and political unrest diverted much of the attention and effort of workers within the whole social service sector, who became concerned about how to maintain their service routines and relationships with their clients during this period of social unrest. Anxieties, in general, were high at this time, and social service workers had relatively less time, capacity, or interest in assisting with research recruitment or participating in interviews themselves. This, in turn, affected my ability to promote the study to and connect with potential client participants, as did the fact that evenings no longer were viewed as a suitable time to conduct interviews, since most of the social confrontations and demonstrations escalated at night time.<sup>43</sup> In addition, the general erosion of trust and cohesion in Hong Kong society and

---

<sup>42</sup> The Hong Kong government resisted the movement by escalating severe punishment, violence and suppression, with a 'no compromise' attitude towards protestors.

<sup>43</sup> Most of the protests in different districts were at night time.

heightened anxiety among the general public during this time (who were worried about community chaos) likely also reduced the motivation of service users to share their personal experiences with me/participate in this study. Although I could have extended the period of recruitment in order to compensate for the slowed recruitment, following the outbreak of COVID-19<sup>44</sup> in Hong Kong in January 2020, I had to cease data collection and recruitment altogether following guidelines issued by the Hong Kong government to reduce the risk of community-level transmission of the virus (they discouraged social gatherings).

It should be noted that even in ideal social conditions, this population is challenging to recruit, merely because they are experiencing a difficult emotional time (dying and bereavement) in a cultural context in which talking about death/dying is still considered taboo. As an example of the latter, one former service user from PARACLETE initially agreed to meet, and after I explained the project in more detail, he declined an interview. Although stating that “being a bereaved old man is a ‘shameful’ experience, and he did not want to recall it anymore.”

Due to the unforeseen social circumstances noted above, I needed to adjust this research in terms of goals and design. My difficulties in recruiting service users, in particular, mean that these findings rely on the experience of practitioners. Inevitably,

---

<sup>44</sup> Originally, it was also called “Wuhan Coronavirus” or “Wuhan virus” as the first place of the outbreak of COVID-19 is in Wuhan city, Hubei Province, China in December of 2019.

there were constraints on my abilities to implement theoretical sampling. Due to the social unrest,<sup>45</sup> I was also more conscious of not wanting participants to experience inconvenience through participating in the interview and found that it was preferable to limit the interviews to around one hour. Nonetheless, I was able to collect essential data regarding several aspects of practitioners' relationships with clients, to help in the elaboration of a model of social relationships in community EOL care.

In terms of practitioner recruitment, social workers affiliated with each agency/project helped distribute a one-page study advertisement handout to other organizers and volunteers. Interested participants then contacted me directly. The interview was audio-recorded with participant consent and transcribed verbatim. A general interview guide is attached (Appendix 1). The overall aim of the interviews was to explore the ways in which relationships operate to shape the practice and experience of community EOL care. In addition, I conducted the interviews in Cantonese, which is the mother tongue of all the informants. I audio-recorded the interviews and they were transcribed verbatim in Chinese. I translated the excerpts I include in this dissertation, into English<sup>46</sup>.

---

<sup>45</sup> Social actions might happen in daytime, such as blocking highways, interrupting the train service, etc.

<sup>46</sup> To do this, I first organized most illustrative excerpts from the transcripts into different tables for different chapters. I placed the original interview content and the translation side by side. I acknowledged that the complexities involved in the translation may have an influence on the accuracy of the data. However, the emphasis on GTM in moving towards the abstraction of data conceptualization, may mitigate this issue somewhat (Glaser, 2007). For example, in the further phases of analysis, I emphasized concepts developed from the data rather than the precise accuracy of specific

As noted above, my initial goal was to conduct several retrospective interviews with former and current service users (dying persons and bereaved<sup>47</sup> family members who received service from one of these two agencies), to understand how families' social networks and relationships (including but not limited to community care and the self-help group), supported them and their deceased family member through dying and bereavement experiences at the community level. Social workers affiliated with both groups did distribute a one-page study advertisement handout to former service users. Interested participants were invited to contact me directly. The interviews (conducted with two participants, as noted above) were tape-recorded with participant consent and transcribed verbatim. Questions are outlined in Appendix 1.

The engagement of the two specific service agencies in this research means that the knowledge generated in this study is grounded primarily in practitioners' scopes of practice, agency mission and goals, and is targeted to their understanding of relationships with dying persons/families who used or accessed community EOL care. As such, my analysis and interpretation of the findings considers how social relationships shape dying and bereavement experiences, in the context of specific

---

details of the translation. The main concern posed by the translation is in representing the analysis and concepts to the English-language reader.

<sup>47</sup> To be sensitive to the needs of bereaved persons while trying to maintain accuracy of recall, my 'rule of thumb' was to interview those in the post-bereavement period (approx. 3 to 6 months after the family member's death: Bentley & O'Connor, 2015), unless service users expressed a preference or need to wait longer.

community intervention. Indeed, community intervention (formal service) represents an aspect of social capital. It is also possible that people accessing services from one of these agencies may have been facing more significant challenges around EOL care than those in the general population (thus motivating their participation).

As noted earlier, contextual challenges limited my recruitment of current and former service users (my goal was 30). In the course of data collection, I adjusted the sampling strategy to focus on interviewing many of the staff I could reach in PARACLETE and Life Rainbow projects to gain an in-depth understanding of these services. In the absence of garnering first-hand data from the users about their experiences, I encouraged the staff to illustrate their service insights with concrete examples to help me explore the social process involved in the community EOL care service. Eight interviews with service providers/professionals were supplemented by six interviews with volunteers working in the two agencies/projects. Using the same strategy, I encouraged them to supplement their insights with concrete examples from their service experience to help me explore processes pertinent to the influence of social relationships in community EOL care.

Although my Findings chapters identify a theme of medical-social cooperation in community EOL care, it is essential to note that I could not arrange interviews with medical professionals to develop theoretical understanding grounded in a medical

perspective on the practice of collaborating with social agencies in community EOL care. Informally, however, my interpretation of this theme benefitted from a conversation I had with a Chief of Service at one Hong Kong area hospital (who was involved in a pilot EOL care project). Though this is not cited or used as data, this informal meeting provided me insight which helped me interpret the data from practitioners about medical-social cooperation in community EOL care.

### **III. GTM – Iterative Process and Analysis**

The use of GTM to discover the significant categories from data is a process of category identification and integration. Although traditionally in GTM the research question is less clearly specified (Glaser & Strauss, 1967), I believe we do not enter research with an ultimately “empty mind” and without pre-existing theoretical assumptions. I planned to keep my mind open throughout the research inquiry and be open to different possibilities and variations. The research question focuses this inquiry on the social and relational mechanisms involved in community EOL care. Therefore, the research question in this regard is a starting point to develop a better fitting question as appropriate through the research process, for instance, as emerging categories from the data are explored in the preliminary analysis (such as the first one or two interviews). After the primary two interviews, I heard the practitioners repeatedly emphasize the issue of trust in service delivery. As such, I tried to re-organize the interview questions

to more fully probing the matter of trust and how it helps facilitates community EOL care. I also encouraged the interviewees to use some real-life experiences as examples to illustrate the dynamics of social relationships and trust in community EOL care.

Particularly in the preliminary analysis, open coding was used to summarize what categories “emerged” in the interviews to inform the theoretical coding (Glaser, 1978). Theoretical coding helped me sharpen my research focus, interview questions and sampling strategy as needed through the data collection period. Initially, my research question focused on the influence of social relationships on community EOL care. After the first round of interviews with practitioners in PARACLETE, my initial theoretical coding centered on trust and mutuality. As such, in the second round of interviews (with practitioners in Life Rainbow), I sought to elicit more information from participants about the social process of trust, mutuality, and collaboration.

Throughout the analysis process, I used the fundamental components of grounded theory methodology - coding, developing categories, memo writing, theoretical sampling, constant comparative method, and theoretical saturation. For instance, coding develops particular statements in the interviews (and observations, if used) into more abstract interpretations (Charmaz, 2006). Open coding provides a good starting point to identify the initial understanding of a social phenomenon (Strauss and Corbin, 1998). The goal is to let the essential themes emerge from the

data (Glaser, 1992). Commonly, the analyst attaches a conceptual label to almost every line of the interview transcript to identify what has been said (Charmaz, 2006).

The labels can also associate jointly with the interview context or use the interviewee's own words (known as *in vivo* codes). (Glaser and Strauss, 1978).

The next phase of the coding process is a more abstract one known as focused coding or selective coding. Focused coding uses a code to represent the fittest indication about several lines or paragraphs in the interview transcript. This can verify the adequacy of the properties of an initial concept and test towards the development of a core category (Glaser and Strauss, 1978; Strauss and Corbin, 1998).

Developing categories generally happens through the coding process. For instance, after coding the first two interview transcripts, I identified some issues of importance to participants, such as "community detachment", and "trust issues." These repeatedly occurred in the data and, as such, are assigned a conceptual label, towards understanding these as social phenomena (Strauss and Corbin, 1998). When different concepts share the same or similar features, the researcher can pull them together to form more abstract categories, which are the typical building blocks interlinking with each other to form a theory. The core category is a different category that serves as the core of a developed theory and summarizes the situation under study. All the significant categories should associate with the core category, which

should frequently occur in the data (Strauss and Corbin, 1998). For example, in this study, I synthesized the core categories of “establishing trust,” “cultivating mutuality,” and “fostering collaborative community EOL care” into the core category of “the process of social relationships in Hong Kong community EOL care” (Appendix 3).

The process of coding and developing categories was supported by writing memos. Memos are simply a set of notes which continuously support the researcher and provide a record of thoughts and ideas (Charmaz, 2006). Memos (Appendix 2) helped me reflect on the interviews, codes, and categories in the analysis process by entering into a dialogue with the collected data. I found writing memos right after my coding process and revisiting and reflecting on these later, to be particularly important (Charmaz, 2006). For example, when I revisited a memo about my first categorization of “establishing trust,” I was stimulated to think about whether there is any development process of trust and community end of life care. This question drove me to observe the data later on to verify my working research questions.

As noted, GT data collection is ideally guided by theoretical sampling, after the first round of the data collection. Theoretical sampling helps “to maximize opportunities to discover variations among concepts and to densify categories regarding their properties and dimensions” (Strauss and Corbin, 1998; see also Corbin & Strauss,

1990b; Glaser, 2005). In this study, I periodically reassessed the suitability of my sample according to emerging vital concepts (theoretical codes), and responded as best I could given the recruitment mentioned above challenges. With some caveats, however, I did find that data from the later interviews were proving less helpful in terms of providing additional information that would develop or refine my theorization – suggesting some degree of theoretical saturation had been reached (Glaser and Strauss, 1967; 1976; Morse, 2010).

This is, of course, impacted by the constraints mentioned above – in particular, that I could only interview two service users, limiting the theorization from this perspective and making it impossible to follow up with additional participants on issues raised by the two service users (such as about family interaction in community EOL care<sup>48</sup>). Notably, however, after the two service user interviews<sup>49</sup>, I carefully compared these participants' data with my existing categories, and codes, and felt reasonably confident that the three categories I had developed to date had reached sufficient theoretical saturation (Morse, 2010).

In line with GTM, I also utilized the constant comparative method to help generate the theoretical properties of a category from the data. According to Glaser (2008), this

---

<sup>48</sup> I noted several potential theoretical directions from the service user data, such as the relationship between family dynamics of division of labour of caring work, and the variations of family social capital. This has stimulated my interest in further theoretical exploration in another research project in the future specifically on caring work and family relationships.

<sup>49</sup> This is not a strategic arrangement. I was only able to recruit two service users at the final stage of data collection.

includes (1) comparing incidents applicable to each category; (2) integrating categories and their properties; (3) delimiting the theory; and (4) writing the theory (See also Charmaz, 2014).

GTM offers several recommendations about generating concepts and theories; importantly, it is not limited to either induction or deduction (Bryant, 2009). Preferably, the abductive discovery aspect of GTM helps the theory achieve a maximum of fit, work, relevance, and modifiability (Glaser, 1978; Reichertz, 2007). Through a recursive process of double-fitting data and theories (in this case, this includes the concept of social capital), the abductive analysis was used to help explain the empirical data (Timmermans & Tavory, 2012). GTM offers a useful guide for starting with a general question (e.g., “how do social relationships influence the experience of dying people and their families in the community in Hong Kong?”) and proceeding to discover a theory that specifies the BSP found in the research. Throughout the data collection and analysis process, my research question changed only slightly. In particular, I was conscious that I could not talk about the experience of non-service users, non-mediated experiences (e.g., without social agency intervention). Also, I could not theorize the influence of all types of social relationships on EOL in the community, given some of my recruitment and sampling limitations. As such, I adjusted my original research question to focus on the meditated experience of EOL care in the

community, as per the flexibility provided by the abductive feature of GTM.

Still, in the course of data collection and analysis, I gained a deeper understanding of the mechanisms and dynamics of these particular types of social relationships on community EOL care in Hong Kong – and how these involve trust, mutuality, and collaboration between the social agencies, social workers, volunteers, service users, and medical professional.

#### **IV. Rigour**

GTM has emphasized that evaluations of research rigour differ from those used in quantitative social science research (e.g., validity, reliability) and draws attention to aspects of credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Other qualitative researchers have considered features such as worthy topics, rich rigor, sincerity, credibility, resonance, significant contribution, ethical, and meaningful coherence (as per Tracy, 2010). GTM suggests some closely related principles, precisely, that quality research requires constant attention to the refit and emergent fit of the generated category, data, and emerging theory (Glaser, 1978; Glaser & Strauss, 1967). Moreover, GTM expects the generated theory can attain relevance (another aspect of quality) by allowing the core problem and BSP to “emerge” throughout the inquiry, rather than “forcing” the data to pre-existing assumptions and categories (Glaser, 1978). Furthermore, GTM emphasizes the criteria of work and

modifiability throughout the analysis (Glaser, 1978).

Concerning refit and emergent fit issues, I needed to make sure the emerged categories fit all the data, and the developed category fits the pre-existent category (Glaser, 1978). For example, data from the 5<sup>th</sup> and 6<sup>th</sup> interviews indicated a new dimension related to trust – specifically, the further development of trust in social relationships, which no longer remains at the stage of the one-way provision of service. Instead, these data indicated more of a mutual exchange. Although I still categorized those incidences related to “trust” in vivo coding, I eventually differentiated the new dimension into a new category (“cultivating mutuality”). This was because the new category could explain the developmental trajectory of social relationships with a better fit to the data, which emphasized the nature of mutual exchange in the relationship.

The criteria of relevance meant that I attempted to avoid forcing the data into the conceptualization of social capital in the initial stages of research. Although I had explored a vast amount of literature related to social capital in community EOL care, I often alerted myself that I could not force the analysis to “verify” pre-existing conceptualizations of social capital at the beginning of the research, but needed to allow the core problems and processes to emerge (Glaser, 1978). In the analysis, I discovered a lot of information about the dynamics and mechanisms through which relationships develop in ways that affect community EOL care. When the data touched on concepts

related to social capital early in this research, I held back and waited for the whole picture emerge through coding, theorization, and theoretical sampling.

The generated theory must not only fit and be relevant, but must work throughout the research; for instance, it must be able to explain what happened, predict what will happen, and interpret what is happening (Glaser, 1978). I strived to avoid using “pet” theories, concepts, or hypotheses. Even though I embrace Lin’s (2001) conceptualization of social capital in the literature review, I distanced myself from it throughout the research by critically examining its strengths and weaknesses, and remaining open to possibilities in my conceptualization. To help my theorization work, I listened to what the informants said to carefully to discover the core issues, and test my conceptual and theoretical integration in the interviews.<sup>50</sup>

Lastly, modifiability – the adaptability of the analysis to variations in the data - was facilitated using computer software (Nvivo 12.0 and Freemind). This software helped me handle the modification of codes and theorization throughout the research. In the open coding stage (using Nvivo), I tried to understand the data and let core problems and issues emerge, knowing that my initial categorizations may not fit all the data later. I used memo writing<sup>51</sup> to record the reasons and justification for the existing

---

<sup>50</sup> I tried to integrate my articulation of my hypothetical understanding from my data-in-hand from participant experiences in the interview questioning. For example, data from earlier interviews, which established the concept of trust in social relationships, led me to ask subsequent participants about this more directly, to explore whether “establishing trust” fully explains what was happening when practitioners’ engage with service users in community EOL care.

<sup>51</sup>Corbin and Strauss (1990) have also suggested that grounded theory researchers should be able to

classification and coding, including any changes. I repeatedly read through these memos to consider whether the current coding is still valid for new data. Practically, I managed all these records (i.e., codes, memos, and transcripts) in the Nvivo software. In building up more theoretical coding, I often used Freemind, which is a mind-mapping visualization computer software<sup>52</sup>. In developing the theoretical aspects of this analysis, it had sufficient flexibility to adjust when facing variations and new possibilities in my study.

## **V. GTM and Philosophical Assumptions**

GTM was established to challenge the prevailing social research methodology at the time that relied on hypothesis testing (Bryant & Charmaz, 2007; Glaser & Strauss, 1967). Since then, it has become clear that Glaser's GTM is firmly rooted in a positivist epistemology, even as Glaser discourages dialogue about ontology and epistemology (Charmaz, 2014). Others contributing to the subsequent development of GTM have claimed that critical realism, constructivism, and pragmatism are potential philosophical positions that can be applied to GTM (Bryant, 2009; Charmaz, 2014; Webster, 2016).

---

provide a reasonable amount of information (e.g., audit trail) to justify decisions made about sampling, conceptualization, analysis, and interpretation. The researcher often is required to refer back to memos written during the process of coding and theoretical sampling (Charmaz, 2014).

<sup>52</sup> This is a free computer software allow users change the structure of mapping by simply dragging the items. The link of the software is ([http://freemind.sourceforge.net/wiki/index.php/Main\\_Page](http://freemind.sourceforge.net/wiki/index.php/Main_Page)).

In this research, I adopt a pragmatic grounded theory (PGT) perspective, similar to Bryant (2009; 2016). I believe that the GTM does not discover “truth” because all knowledge is provisional, and the value of the research outcome is in its usefulness in a particular context (Dewey, 1917). I also believe that abductive inquiry<sup>53</sup> derived from pragmatism can strengthen GTM by explicitly encouraging iteration between data collection and analysis, such as using theoretical sampling to confirm or falsify the initial ideas in the earlier stage of study (Bryant, 2009; Strübing, 2007), and centering theoretical sensitivity for conceptual and theoretical innovation to maintain the fit of the theory to the context (Bryant, 2009; Strübing, 2007; Timmermans & Tavory, 2012). Moreover, in PGT, the iterative-cyclical inquiry practice facilitates the discovery of the basic social process related to the core categories with an abductive consideration of a variety of evidence and arguments when evolving theory (Strübing, 2007). I believe PGT helps theorize grounded knowledge about how social relationships influencing the experience of dying people and their families change over time, which can help establish a solid foundation for future studies and applied intervention.

In sum, since the current policy development direction of EOL care in Hong Kong

---

<sup>53</sup> Abduction could be defined as a process in which “something unintelligible is discovered in the data, and on the basis of the mental design of a new rule, the rule is discovered or invented and, at the same time, it also becomes clear what the case is” (Reichert, 2007, p.219). It is similar to what Glaser characterizes as “theoretical sensitivity,” an ability to be “sensitive to theoretical issues while scrutinizing the data” (Glaser, 1978).

shifts part of service from the hospital to community, a higher number of people will stay in the community at their last stage of life. Community capacity, and the quality of social relationships, thus, becomes especially important to support dying people and their family members in this setting. I have explored the mechanisms and dynamics of mediated, service-oriented social relationships in community EOL care for dying people and their families in Hong Kong. This analysis, presented in the following chapters, was guided by GTM and an abductive approach, and engages with, and responds to, current literature on social capital. I ultimately aim to fill a theoretical gap about the mechanisms and dynamics involved in how social capital operates in community EOL care; findings can also be used to inform public health conceptualizations of compassionate communities as well as service and policy recommendations on how to improve current community EOL care in Hong Kong.

## Chapter Four: From Community Detachment to Establishing Trust

### Introduction

Within these data, the core matter concerning social relationships<sup>54</sup> and community EOL care in Hong Kong is how to help community members facing death access compassionate support from formal and informal community sources,<sup>55</sup> especially given socio-cultural barriers to accepting death and dying in Hong Kong communities<sup>56</sup> (Chung & Yeoh, 2019). In this chapter, I start by exploring how death in Hong Kong communities is embedded in an overarching context of community detachment,<sup>57</sup> resulting from institutional, socio-cultural, and inter-personal conditions. The extent of community detachment can also be conceptualized as an aspect of structural (and positional) variation in the conditions of social capital<sup>58</sup> of

---

<sup>54</sup> Social relationships in this study mainly refers to the social connections in the community providing instrumental support in community EOL care.

<sup>55</sup> Formal community sources of support refer to specialized social welfare service in the community. Informal community sources of support refer to informal social groups, such as mutual support groups and voluntarism.

<sup>56</sup> Chung and Yeoh (2019) outline six barriers of facing death in Hong Kong communities: 1) the general reluctance among the general public to discuss death; 2) Misconceptions and myths about death and dying; 3) An interpretation of filial piety as the practice of “doing everything possible”; 4) inadequate understanding of ethical principles behind a “good death”; 5) Misinformation about palliative care practice; and 6) A local concern over the impact of home death on property price.

<sup>57</sup> This concept stems from discussions of “social death” as usually existing before the physical death (Sweeting & Gilhooly, 1997). Králová (2015) conceptualizes “social death” involving a loss of social identity, a loss of social connectedness, and losses associated with disintegration of the body. Borgstrom (2016) elaborates this notion about how dying people living in institutions become distanced from their previous social lives and relationships, together with isolating and de-personalizing activities in care homes (Froggatt, 2011). Some emphasize the loss of identity and personal agency (personhood) (Borgstrom, 2015).

<sup>58</sup> Re: structural variation of social capital: Lin, Cook & Burt (2001) stated that a structure may be characterized by many elements, such as economy, technology, and participation in social, cultural, and political realms. Within a given social structure, individuals may occupy different positions in social, cultural, political, and economic strata. Both structural (between structure) and positional (within structure) variations may be hypothesized to affect the richness or poorness of various social ingredients.

dying persons. Under detachment conditions, their families are likely to face difficulties in accessing and mobilizing social capital (Lin, Cook & Burt, 2001), and dying persons and their families typically turn ‘inwards’ to deal with pressing needs and challenges at the EOL. Yet as community EOL care agencies provide support addressing their needs, dying persons and their families gain comfort with and begin to trust the service providers. Drawing on Lin’s (2001) conceptualization, this trust becomes an essential “precondition” for building stronger social relationships and mutuality in community EOL care. Based on the accounts of practitioners, in this chapter, I further analyze how community EOL care agencies intervene to mitigate community detachment and help dying persons and families access support, by establishing trust with them, especially its processual, dynamic, and sometimes strategic aspects. Moreover, I examine agency workers’ practices of establishing trust with medical professionals, which, as outlined in the subsequent chapter, builds towards further collaboration. Lastly, I will end this chapter by discussing the implications of successfully establishing trust, as a precondition for further access to social capital through cultivating mutuality in community EOL care.

## **I. Structural and Positional Variations in Conditions of Social Capital:**

### **Community Attachment-Detachment**

For dying persons and their families, informal social relationships influencing

community EOL care develop near the EOL or even after death, and these relationships usually directly respond to the emergent needs of the dying persons and their family members (Payne, Smith & Dean, 1999; Zapart, Kenny, Hall, Servis & Wiley, 2007). Community detachment-attachment may directly affect the quality of dying experiences among dying persons and their families (Lewis et al., 2013; Whitfield, 2018). Borrowing from attachment theory, I refer to community attachment as existing when dying persons and their families are embedded in a cohesive, reciprocal, and resourceful social-relational condition (Ainsworth, 1991). If community attachment exists, dying people who have sufficient resources may not need any external support (Abel et al., 2013). However, dying people with lower socioeconomic status may have a limited network, and low relational support; this can erode quality of end of life care (Lewis, DiGiacomo, Currow, & Davidson, 2014). Community detachment, in this study, describes the social isolation faced by dying persons and their families in the EOL period – others have connected this to loss of agency and identity, decreased choice, and distance from original social lives in their communities (Borgstrom, 2015; Horsfall, Leonard, Rosenberg, & Noonan, 2017; Králová, 2015). Particularly when both structural and positional conditions of social capital are less favourable, dying persons and families may have limited opportunities to construct and maintain social capital (Lin, Cook & Burt, 2001). This contributes to

different disadvantages in terms of the distribution and mobilization of social capital (Lin, Cook & Burt, 2001) one outcome can include social isolation (McPherson, Smith-Lovin & Brashears, 2006).

Community detachment (here encompassing both formal and informal relationships, and their connection), in these data, is shaped by three social conditions: the paucity of (and uncompassionate) institutional support; socio-cultural constraints (related to death illiteracy and taboos), and relational barriers and weak ties in high-density property markets. Community detachment exacerbates tangible unmet needs for community support; under these conditions, dying persons and their families face considerable difficulties in handling death and dying in the community.

### **A paucity of institutional support**

Participants in this study explained how recent changes to the quality and extent of service in the community in Hong Kong means that those institutional arrangements alone may be insufficient (or uncompassionate) to take care of the dying people and their family members. Sometimes, the needs of dying persons and their family members may be subverted or suppressed by professional, emotionally detached civil and social service protocols (Cain, 2012), which may symbolically communicate community reluctance about the needs of dying persons and their family members. For instance, the structures and processes involved in public, social, and

professional services were described as lacking compassion and not being ‘user-friendly’ for dying people and their family members. In addition, the relative lack of such formal, institutional support can contribute to emotional hardship among those seeking formal community-based support, or even a lack of desire to seek help. One social worker described the situation, emphasizing both the challenges of system navigation, the lack of bereavement supports, and how interactions with government services can generate adverse outcomes:

I think when dealing with grief, different departments in the government should have a consensus. For example, one would call to various government departments to gather information about how to handle their significant other’s bereavement support. However, the government always overlooks the emotional state and the needs of mourning. Indeed, the response from the government often [even] hurts the bereaved person’s feelings, which makes them very upset, especially in such situations where they need the most support. (s3)

An apparent lack of compassion (perhaps with both symbolic and more direct manifestations) among those working in civil and social services contributes to the community detachment of dying persons. The organization of case management arrangements<sup>59</sup> in social services and unsympathetic attitudes of many public and professional services professionals can also contribute to feelings of helplessness and

---

<sup>59</sup> Case managers provide one-stop support services for persons with specific needs so as to co-ordinate and arrange appropriate welfare services for them (Hong Kong Social Welfare Department, 2019).

community detachment among people in grief. One practitioner referred to how mainstream services close case files too early, meaning that bereaved persons who wish to return have to repeat assessment procedures, requiring them to relive painful experiences to receive help repeatedly. The practitioner further added:

This is also the reason why they are losing confidence in the mainstream service and avoid seeking help from the government. Assuming that the client would also go to see the [service] psychiatrist, the whole appointment might only last for 10 minutes. They have to make quite a lot of emotional preparation [be familiar with the environment and conversation in the medical consultation] before seeing the psychiatrist. But a 10-minute meeting is often just the case [Many clients often told that they could not even open the topic about the real problem of their emotion in the meeting]. Therefore, when many bereaved people use mainstream service, they have gone through a lot of unpleasant experiences. This is another example of an uncompassionate response from the government department treating bereaved people in the community. (s3)

This same practitioner provided another example, describing service at the public mortuary:

There was a client [family member] who needed to claim the dead body at the public mortuary. The staff at the public mortuary 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 workload of the staff 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. However, the government thinks this kind of request is fair. I believe this is one of the biggest discrete obstacles in the current mainstream service. (s3)

A former service user revealed her unpleasant experience in picking up a dead body, which was compounded by what she interpreted as the 'uncaring' stance of her brother:

There was a lot of stuff to handle after my Mom passed away. For example, I needed to go to the public mortuary to pick up the dead body [because her Mother did not die at the hospital]. I remember I went [with her elder brother] to the gate of the public mortuary. It did not open yet. I, therefore, queued outside. The wind is blowing and cold. Although I wore a thick jacket, I still felt freezing. I kept jumping when I felt cold. I thought my brother was not caring because he kept looking at me occasionally [he was sitting in his car]. Maybe he got used to being a boss [a not caring mindset], he never asked me to stay in the car or brought me one more jacket. Even worse, I stood in the chilly weather for 35 minutes, and he did not actively ask me to take turns until the public mortuary opened. I stood in that cold wind for 35 minutes that morning. (c15)

Indeed, some civil, social, and professional services may not be user-friendly; the procedures by which to access support are unclear and complicated. Becoming entangled in complicated procedures can contribute to the stress of grief. The same practitioner, as cited above, explained further:

Because there are lots of specific [post-death tasks], for example, residential issues, financial support, change of property holder in the bank, heritage...when querying the government for information, the government might handle each case without much attention paid or even just referring the case to another department indifferently again and again. There is not a

specific counter or place (for the applicant/bereaved person) to seek direction to apply for a particular service. Of course, in some cases, there will be staff; for instance, the police officers or civil servants, who know how to make the whole application process proceed smoothly. However, there is not an explicit instruction and system for different departments in the government to work on, to provide better support for bereaved persons, so that the services offered could be improved. The services they provide at the moment cannot effectively help bereaved people calmly accept the death of their beloved. For example, (if the government does not issue the death certificate immediately, the bereaved person cannot apply for any financial support.) Even more, an individual cannot change the contact details or use for any internet support unless the dead person's death certificate is issued. (s3)

User-unfriendly services could affect the experience of dying persons. A practitioner shared her observations about dying persons that may not have the opportunity to participate in group events facilitated by the agency when clients/families face challenges engaging with mainstream social services:

Talking about how to bring community support and resource to our clients, we hope we can bring those to our clients as much as possible. I have an example. A client was at the end of her life. She rarely came out to meet people because only her husband took care of her (he was too old and weak to bring his wife out frequently, but also, he did not access related service information). Because of joining our EOL care program, she could participate in our eight-session art therapy workshop. She could have a certain level of social life in the community though she is at the end of life stage. (s10)

User-unfriendly services are also difficult to access, eroding the support that can be accessed by dying people and their family members, as well as bereaved people. A

second practitioner shared the following observation about service:

If there were more information and resources provided by our society that one could get access to if there were services that provide direct support to the carers. I believe maybe it would be (a lot better). Perhaps there are indeed some sectors or organizations that were providing such service, but I don't think that the individual could get access to these resources. (s2)

User-unfriendly service exacerbates community detachment and social isolation in the EOL stage as well, and clients may be less able to address basic needs in their everyday life. A practitioner shared his experience of his client facing a user-unfriendly bank service:

...I encountered a case which is an old lady. She received the Comprehensive Social Security Assistance (CSSA) monthly. But she was used to keeping all her money in a metal box at home. One day, she asked me to help her keep her key to the lock of her metal box. I refused her request reasonably because I could not have any financial relationship with the client. I asked her why she did not deposit her money to the bank. She answered that she felt very annoying to withdraw money every month, due to she had difficulty to walk. Although she had a daughter, her daughter was not living with her. She was also afraid of the situation that her daughter stole her money. I then explained my view to her patiently and hoped she could change her decision... (s14)

In the EOL stage, dying persons still strive to complete many tangible everyday tasks; in this way, user-unfriendly services can hamper their abilities to maintain their ordinary social lives (and identities).

In sum, the paucity of institutional support (social, civil, and professional services), alongside symbolic and material effects stemming from their apparent lack of compassion or user-friendliness, reflects a broader condition of community detachment, in which people cannot appropriately recognize and/or address their EOL care needs. Another property of community detachment, socio-cultural constraints, will be discussed in the next section.

### **A socio-cultural constraint: Death illiteracy and taboo in communities**

Contributing to community detachment, socio-cultural constraints represent a second aspect shaping structural variation in social capital; in the present context, these constraints operate by working to limit access to both formal and informal community EOL care. These socio-cultural constraints include a lack of knowledge about death in the community and taboos around talking about death. Socio-cultural constraints mean that dying persons and their families tend to seek help passively because they are uncomfortable talking about their experience and accepting their needs for assistance. Therefore, dying persons and their families, as well as the community, construct EOL as a personal and family issue. They do not think the EOL care issue is a social issue that should be addressed in the community. A practitioner described the cultural context surrounding death in the community:

When knowledge about death and dying is low in the community, community members rarely talk about death matters. [Community members are not] free to express their feelings and needs. Compassion cannot develop at the community level. Moreover, Life-and-Death education is not being emphasized enough in our society. It is rare for us to hear people discussing Life and Death issues in our [Hong Kong] society - especially teenagers and youngsters. In many cases, when facing the death of a relative/loved, a child does not know how to deal with the problem. There isn't anyone by their side to teach them how to solve the problem. More importantly, they do not have enough information. Most of the time, they do not have any ideas... and they tend to have lots of queries, which leads them to irrationally speculate about the reasons for the death of their beloved. Eventually, it became a difficulty for them. Therefore, this is one of the bereaved persons' most significant needs in our society. For instance, a child would always be told not to cry, at a funeral – [that] their decedents won't be happy if they complained. However, this is keeping the child from expressing his/her sorrow. Many adults were yelling at the funeral as well, but the child never has this chance to cry and to express their feelings. Whenever I witness the problem, my heartaches. And I would question myself, "Why the adults at the funeral would ask a child to suppress his/her feelings?" "Don't cry, and you must stay strong." This kind of traditional concepts often affects how a child responds to death... (s3)

As dying persons, their families, and the broader community are inclined to suppress their feelings, recognize needs, and avoid information about death and dying, this contributes to community detachment. Dying persons and their families hide their needs and feelings about death and dying because they think others may not accept these; they perceive it is still a taboo in the community. Moreover, community members may suppress compassion and abstain from offering support to the dying persons and their families, since they are unsure whether dying persons and their families are ready to talk about the issue.

Although social agencies do attempt to increase public awareness of death and dying matters in the community, open receptivity to such education in Hong Kong is still low. Different social institutions still feel unable to support the expansion of knowledge at the community level. Another 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)

This practitioner also qualified their earlier statement about the excellent turnout at educational events by mentioning that this was only for free events. Moreover, the practitioner added that despite some level of interest in the community to attend events, “such level of interest is [not] high enough to motivate them to talk about their...they cannot see the necessity of talking about death in their daily life” (s4).

Similar to other modern Chinese societies in which people embrace Confucian ethics (Lee, 2009), death and dying matters are still relatively “taboo” in the community, and the dominant orientation towards death is one of denial. As the

practitioner explained below, this can contribute to misunderstandings and/or the proliferation of alternative interpretations of death rituals. This misunderstanding not only can make funeral arrangements confusing and inconsistent but can contribute to suspicion towards more traditional, ritualistic practices:

(If we looked at the impact of the social norm on the service), firstly, the traditional Chinese social norm, for example, taboos on death. I am not saying that Western countries don't have any taboos about death. But in terms of taboos about death, the Chinese people have a unique way of thinking, which includes...to try not to mention death during one's lifetime. Many people don't [even] care much about the meaning behind the procedure of a funeral, such as 'placing the ashes of the dead' or 'ashes scattering.' Additionally, (many people may not even acknowledge this process or how they would want to be treated when they pass away). I can share with you about the case I saw today, with a Chinese family<sup>60</sup>...they weren't as familiar with the Chinese style funeral as one would expect, for example, some people say you must conduct a regular ritual for three years after one's beloved passed away. Others say three weeks; there are lots of different versions, and different people perform the ceremony in their style. One client said that his/her beloved passed away for seven days.<sup>61</sup> But in fact, "the ritual of 7 days" and "the returning of the soul" are two completely different matters. But the client was relatively anxious, so they stayed at the hotel on that night, on purpose. Indeed, such an example showed how severely the client was scared of their decedent. Still, it also signifies the misconceptions of many Chinese people about such "nonsensical" views on traditional Chinese style funerals. If such social norms heavily influence society, we have to aware of this so that we spend more time clearing up their suspicion. (s1)

---

<sup>60</sup> Hong Kong Chinese tend to accept "utilitarianistic familism" in the family structure of "modified nuclear family" (Chan & Lee, 1995; Lau, 1981). In contrast, mainland Chinese tend to accept organizational *guanxi* (personal connection) (Chen & Chen, 2004). In Chinese ethics there are aspects of some Confucian ethos of benevolence, *ren lun*, filial piety, etc, but the organization of social relationships are quite different, especially after the Cultural Revolution in mainland China and marketization in Hong Kong and Taiwan (King, 1985). The influence of *danwei* (the Chinese work unit system) on the organization of social relationships is still very significant (Pan & Ruan, 1995; Ruan, 1998).

<sup>61</sup> Chinese people believe that a decedent's soul would return to their body on the 7th day after death.

Another practitioner explained how the death taboo hinders the dissemination of information about death and dying in the community, and described the challenges of opening up conversations on death and dying matters in public venues:

The way society treated life and death education was completely different from the other mainstream service. If it was normal...such as fundraising for older adults. Many shopping centers would let you use their space willingly, but there weren't many who would let you use their stage to talk about funerals. When we were preparing for a talk about topics related to death in 2015 around 2014. It was a challenging job to find a space. None of the shopping centers let us use their space for promotion. We had to do it at a university. That's why the publicity of Life and Death education, it is a relatively challenging job. It is even more difficult for us to promote basic (fundamental) knowledge. For example, to explain to people about what "placing the ashes" is... (s1)

The above illustrates how the socio-cultural context in Hong Kong limits people's abilities and willingness to talk about death and dying among the general public. Without an open and supportive atmosphere to recognize the physical, psychological, social, spiritual needs in EOL care, dying persons and their families tend to restrain their expression of needs in the course of EOL, contributing to community detachment. The next section will draw on practitioners' interviews to explain how relational barriers represent another condition (with positional variation) that can further contribute to community detachment.

### **Relational barriers and weak ties in high-density property markets**

In Hong Kong communities, neighbourhood-level social relationships in private housing tend to be thin and fragile, compared with the one in public housing estates (La Grange, 2011; Lee and Yip, 2006). Similar to the observations made in western literature, one of the participants in the present study (s7) explained that neighbours frequently change within the current Hong Kong private property market, which is also high-density (e.g., many apartment buildings) (Sampson, 1988). Neighbours in contemporary Hong Kong private properties are unused to sharing a lot with strangers and rarely talk directly with their neighbours (Forrest, La Grange & Yip, 2002; Yau, 2010). With the cultural features of the Hong Kong Chinese people, Hong Kong people living in high-density housing tend to be cold and impersonal to outsiders of the family network (Kan, 1978; Lau, 1982; Mitchell, 1971), albeit with some positional variation between individuals. As such, neighbourhoods in Hong Kong usually have low social capital (Fung & Hung, 2014; Lum et al., 2016). People are generally indifferent to the EOL care issue in the neighbourhoods as they do not want to “bother” each other.

As a result of low neighbourhood social capital, people do not appear to be heavily involved or invested in the dying experiences of their neighbours. According to one practitioner, weak, emotionally distant ties between neighbours limits the development of community resilience to support community members facing death:

Overall in Hong Kong, the culture of helping out your neighbour (the relation between an individual and their neighbourhood) is very fragile. Most people are just playing with their smartphone, 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... However, this kind of action is leading to the isolation of bereaved persons. Nowadays, one would not even try to know about their neighbour' when something related to death happened, and the inter-neighborhood relationship would only become worse. People become more indifferent to these topics...(s1)

This participant explained how detachment manifests, since apparent neighbour indifference or lack of compassion (likely compounded by the death taboo), means that bereaved persons might, in conversations with coworkers for instance, conceal their bereavement status (and the death of their family member) from others. Neighbourly indifference and community detachment more broadly may be exacerbated in situations of death and dying because dying persons and their families are reluctant to share or show their vulnerabilities and challenges with their neighbours (this is elaborated further in the next chapter).

It is possible, however, that some dying persons do not want to contact neighbours because of their personal preference. A current service user (a dying person) shared her perspective:

I don't like hanging out with the mature ladies about my building. Maybe I was living in the most former type of public housing in Hong Kong, which is a seven-floor building<sup>62</sup>, only has a shared bathroom and kitchen each floor. I want to keep my privacy because I heard a lot of others' private stuff in those public areas. I felt not comfortable at all. Moreover, the topic that the old ladies in my building love chatting is about their daughters-in-law. I hate talking about this kind of matter because most of the time, they bad-mouth their daughters-in-law. I can't get used to this topic at all. (c15)

Although this participant appeared to have isolated herself from her neighbours because she sought to avoid the topic and content of their discussions, she may have been reluctant to discuss other more emotional reasons for her lack of connection. She rarely talked with her neighbours about her own EOL care expectations; she may, however, have benefitted from talking to someone, if not a neighbour.

Relational barriers also shape access to formal sources of support. Sometimes, dying people's resistance to addressing death-related issues (i.e., the internalization of socio-cultural constraints) generates a reluctance to develop ties with practitioners. This can be compounded by navigational burdens (related to the quality of institutional support processes). A practitioner described her experience in an attempt to provide compassionate EOL care:

I remember I encountered a client. He needed the in-home meal service [under the Integrated Home Care Service]. But the application procedure of this

---

<sup>62</sup> It refers to the public housing in Resettlement Area in 1970s in Hong Kong. This is the first generation of Hong Kong public housing built in the early development stage of new towns in Hong Kong. The most obvious feature is the seven-floor building and shared bathroom and kitchen at each floor. His observation is similar to the literature (Lee and Yip, 2006).

service, you need to declare and provide a lot of things. Because his physical condition was deteriorating, we persuaded him to apply for the service through these annoying application procedures. We stayed with him during the home visit from the staff handling the meal service application. Unfortunately, he got angry and refused the application during the home visit due to the annoying and endless provision of documents [that was required]. I understood his frustration and asked him how I can help him with the phone call several days later. He said he needed nothing. Occasionally in a phone call, I realized his chair in the bath was broken. I proposed him to visit him to take a look at that chair. He refused. Then, I told him that I had helped him order a chair to replace the broken one, and the chair will be delivered to his home shortly. I want to express I am staying with him no matter what we rarely meet. After this, I invited him to go high tea in Repulse Bay [a very famous seafront area of high tea in Sai Kung]. He was pleased to accept this invitation. I met him was at his EOL stage when it was three months before he died. I remembered the last time I met him, when is the last week before he died. He told me that he wanted to have a buttered toast and a cup of hot almond milk. I bought it for him promptly. I felt sad because I could not do much for him. After all, he suppressed his needs until the very last period. (s10)

This experience clearly illustrates the complex, relational, and contextual nature of community attachment-detachment. It illustratives effects on EOL experiences that are similar to the potential impacts of neighbourhood indifference.

In sum, both structural and positional variation contributing to community attachment-detachment limits dying persons and their families' opportunities to construct and maintain social capital to handle EOL care. Community detachment may reduce community-level resilience. It inhibits the development of trusting social relationships for persons facing death, and erodes the quality of death, dying persons' abilities to create personalized death experiences, and bereavement coping. Targeted

community support can mitigate the effects of community detachment for dying persons and their families by facilitating support to address personal needs related to care work, information and system navigation, and emotions and coping.

Paradoxically, however, dying persons and families usually find it harder to accept community-based support in the context of community detachment, which erodes resilience and trust. Through coordinated practices, community support agencies can help by generating a kind of replacement social capital – by building trust with both community members and other professional institutions. This will be illustrated in the following sections.

## **II. Establishing Trust with Dying People and Their Families**

Relationships between social agencies and dying persons and their families are vital for improving EOL and bereavement experiences because they can assist community members in accessing decision-making information, caregiving supports, as well as space where acceptance and compassion (for clients) can be actively demonstrated; these relationships are based on trust (Lin, 2001). Community members not only need to accept their needs for help, but trust that social agencies can provide this help; as such, trust is one of the core goals of community EOL care, and trusting relationships between the practitioners and clients generate an opportunity for accessing social capital. Principally, trust hinges on how the parties in social

interactions interpret the meanings of behaviours and actions. Building trust (and relationship) with dying persons and their families involves three significant types of practices that social agencies often use in different stages of community EOL care: boosting credibility and familiarity, responding actively to immediate, everyday needs, and purifying the support relationship.

### **Boosting credibility and familiarity**

Social agencies view their initial contacts with the dying person and her/his family seriously because they believe these first impressions determine how well the service will go, hence the outcome of the service. If community members do not initially trust the service, they may stop using it. As such, practitioners use several strategies to boost the credibility of their social agency when making primary contacts with service users.

The first strategy is to provide 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). In the phone conversation, the staff clearly describes the practitioner and the social agency, the purposes of home visitation, and the expected outcomes of the visit. In this way, they actively set the stage for (and control expectations for) the home visit. During the phone call, the staff also asks for initial background information from the client or family. The goal of this 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 practitioners (usually a social worker with one or two volunteers) arrive at the home, they use this information to open up the conversation and begin needs assessment. One volunteer described their approach to a first-time home visit:

The one who refers the client to us is usually the social worker ... someone from the organization 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)

Clients interviewed in this study usually believed the practitioners and the service were professional in their manner of systematically providing service information. This professionalism conveys an image that the providers are legitimate, professional, and qualified to manage EOL matters in communities. It emphasizes the practitioners' contribution and suppresses any potential contradictory information, an activity Goffman calls "dramatic realization" (Goffman, 1959). Moreover, emphasizing that the service is free of charge does not only provide reassurance to clients who may have financial concerns but also demonstrates the pure intentions of the service's mission (a point that will be returned to in a later section). All those in the first home visit are involved in a performance that sets a pattern of appropriate

conduct which must be enacted and portrayed to give it a 'stamp of reality' realized in the social interaction (Goffman, 1959).

The second strategy to maximize credibility is to send well trained/qualified and experienced practitioners to the first home visit. In part, this is because these practitioners can most effectively understand and respond to service users' emotions, for instance (see next section), contributing to trust. For example, one service manager described how they usually assigned a professional social worker and two volunteers to attend the first visit. In part, this was so they could better observe, assess, and respond to social welfare and emotional needs. However, it had the added benefit of reassuring clients that they are "in good hands."

The third strategy moves beyond the initial visit to ensure continuity (e.g., present the same practitioners repeatedly) in the first several home visits. Social agencies usually arrange for one team of practitioners to follow the same case, to build up both credibility and familiarity. When service users, over time, become more familiar with both the agency and the practitioners, this facilitates the establishment of trust, as one practitioner explained:

I could not have a rough idea of how to get along with the client unless I have got in touch with them at least 3 to 4 times. For example, there was a time that I went to visit the client, an old lady. She only started to say 'hi' to me on my 3rd, 4th visit. Trust is something that could be formed gradually... in my

experience, in many cases, the client wouldn't give you many reactions on the 1st or 2nd visit, but on the 3rd visit, they would gradually become less wary (for example, they would be willing to talk more at the start of the visit). They would react to the things that you have told them. So, I think time is an essential factor to form a trusting relationship with the client. (s7)

This excerpt reveals how the relationship enters a place of “open awareness” (Glaser & Strauss, 1960). The practitioner continuously engaged the client until the client accepted him as a volunteer and interactional actor after several home visits and conversations. This illustrates how trust is established in community EOL care, a situation in which the transitional status between life and death heavily depends on timing (Glaser & Strauss, 1971).

In sum, to boost credibility, practitioners strove to project a consistently professional, expert image, demonstrating the value and mission of the agency to clients, as part of developing a trusting relationship. The next section will elaborate on how practitioners build trust by recognizing and responding to clients' needs.

### **Responding actively to immediate, everyday needs**

In the context of community detachment, dying persons and their families can face considerable social and economic challenges, such as ensuring sufficient help with the caring routine, being able to afford the purchase or rental of tools or equipment, and finding information about community resources. The second type of practice social agencies uses to establish trust with the service users is to respond

actively to a comprehensive range of needs. Symbolically, this conveys to dying persons and their families,= that their whole being is recognized and understood; active responses also facilitate a sense of being ‘cared about’ and respected (Funk, Stajduhar & Cloutier-Fisher, 2011; Funk & Stajduhar, 2013; Stajduhar et al., 2011).

This experience is expressed, for instance, in the following quote from one practitioner:

Regarding the importance of listening to them and staying by their side, in my experience, listening allows us to hear the patient's needs and his/her families' needs. ...I think the most crucial point is that you can form a relationship with the client and his/her family, especially when you were able to win their trust. Only under such a relationship [circumstance], they will talk about their needs and thoughts. After listening to their feelings, we would then report to the [planners], and the planners would eventually follow up the case. During our next visit, [I learn] that they feel that sense of support by the government because their needs received a suitable reply from us. I think such a vital attending and listening phase could even further help them to go through the pre-death period and so that it could become a meaningful period ... after fulfilling their needs, they can focus on thinking about how to spend their time meaningfully, even more, they could do something useful. Therefore, their thoughts don't have to be restricted by some real needs. (s7)

As the social agency helps them solve various challenges, dying persons and their family members are more likely to accept the social agency (and practitioner) as a reliable and trustworthy partner. Trust, in turn, directly facilitates further contacts and sharing in community EOL care. Practitioners also positioned themselves as sincerely trying their best to help humanize 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 wasn't able to 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 recognize 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. Because throughout the project, we have to learn how to push the wheelchair properly, so I am quite good at pushing the older man's wheelchair. So I could easily take the older man outside to get some food. (s9)

This excerpt shows a transition of "the definition of situation" over time, and as trust is established in the relationship (Goffman, 1959; Misztal, 2001). At first, the older man could walk, so did not need any help. As he experienced declining mobility, the practitioner actively helped him to maintain the continuity of some normal routines, such as having dinner outside. The preservation of normal routine, with the help of the practitioner, presumably promoted client comfort. A new, emergent definition of the situation hinges on the predictability of the practitioner's supportive role to a frail person, the interaction order, and the client's trust intentions to the relationship in the

situation (Misztal, 2001).

Another practitioner shared her experience on how to build a trusting relationship with a dying client through helping to recognize their immediate, everyday needs. This involved bringing the client and his wife to a park regularly (something he enjoyed), a way of knowing the wife's hardship and providing her with a brief respite:

My first client was an old man who lived in Quarry Bay [a small residential community in the Hong Kong Island]. He is a patient of Parkinson's disease. My colleague and I regularly visited him every Tuesday. We brought him to a park nearby to take a walk. We helped push his wheelchair. The client waited to meet us because he changed his clothes before we came every time. His wife also fondly anticipated our visit because she could take a rest when we helped take care of her husband in the session. And she felt released because she knew here are people sharing her hardship. (s12)

This practitioner paid sincere attention to the challenges in the client's everyday life and offered timely support to them as part of their caring routine. Although the nature of attention and support provided here may appear subtle compared to managing physical symptoms, these kinds of social interactions help develop a stable, trusting relationship.

To address a comprehensive range of everyday needs, practitioners attempt to play a coordinating (or case management style) role, including directly helping with daily caring routines, providing accurate information about EOL care, and linking the

client and family up to community resources. Through offering practical and prompt help with caring work, from personal care to funeral arrangements, practitioners strive to reduce the burden faced by dying persons and their families, during often desperate circumstances surrounding EOL and bereavement. For example, the volunteer quoted above spoke of helping the client (who had now moved to a care home) clean his dentures during the visit:

There was a time that I could always remember - I was washing the older man's dentures. Because the doctor mentioned to the older man once, and I was there when it happened, that the artificial teeth must be washed and cleaned every day, and after wiping the teeth, they had to be soaked in water. At that time, I had no experience in washing dentures, but I would do it anyway because I knew if I had to take care of a patient who could pass away at any time, I must deal with these kinds of jobs as well. (s9)

Cleaning dentures is a intimate caring routine. That the practitioner managed to convince the client to accept her help in this regard may indicate they had been successful in establishing at least an initial level of trust; from this, the involvement of the practitioner in this task itself could contribute to further trust.

Moreover, providing useful information and resources (for an unmet need) helps dying persons and their families address different questions and make decisions. One practitioner explained how their networks of connection and information, in this way, contributed to building trust with clients and families, both through bolstering

professional credibility as well as being able to respond to needs actively:

...We have community resources built up in our service project that we can bring to our clients. For example, we have professional information about how to clean pressure ulcer wounds. We have a formal referral mechanism to introduce our clients to community nurse service [a formal service of the Hong Kong Hospital Authority]. We can directly make an appointment on behalf of our clients if they need the service. We organize a variety of supporting groups and workshops for EOL caregivers to help them release their stress, teach them how to push the wheelchair correctly. Also, when we realize clients are having economic difficulties, we can help them apply for special subsidies. Overall, we have the [professional] position to bring the community resources to the clients if they need it. (s10)

Social agencies providing community EOL care, and their professionals, have a well-developed institutional network of community resources; as such, they extend or broaden the clients' existing social networks as they actively respond users' needs in a coordinating role, linking up dying persons and families with other existing resources and information. A former service user (bereaved caregiver) shared her appreciation of the help she received from the agency:

I did contact different service centers, and I chose to go to this centre because it is near to my mother's home. Also, the staff in this centre are incredibly helpful. I often asked them when I encountered any questions about how to improve the caring work for my mother. They often looked for the resource, which may help me, such as some professional service referral [home visit service of the physical therapist and occupational therapist]. (c15)

Once the unmet needs (the community detachment) are addressed, clients start to

believe that the agency is capable of handling their difficulties, and they are more comfortable and willing to share their concerns and wishes. The client and the practitioner establish a closer and deeper trusting relationship.

### **Purifying the support relationship**

The third strategy for gaining the trust of dying persons and their family members is purifying the social support relationship. The primary goal of this practice is to communicate to users that the support from the social agencies purely relies on altruism and philanthropic interests (e.g., to enhance the quality of death in the community). The service positions itself discursively, in ways that align with broader phenomena that similarly appear to “blur” the boundary between formal and informal spheres of caring labour, and to naturalize emotional labour (Johnson, 2015; Milligan, 2000; Power & Skinner, 2019). Moreover, purifying the relationship can be seen as a kind of impression management strategy (Goffman, 1959), as illustrated below. As such, practitioners emphasize the value and image of the service (as altruistic and philanthropic) and try to avoid misunderstandings. They emphasize sincerity, avoiding any private monetary and material giving, their non-profit status, and informality to purify the support relationship.

This ‘pure’ relational status has a twofold meaning. Practitioners need to enforce the ‘pure’ value and mission of community EOL care in their service content, while

also demonstrating, to the client, their 'pure' compassion and care. For instance, the following practitioner spoke of prioritizing the client's needs above his own needs (in this case, his need to keep his clothes clean, when helping to clean a client's kitchen):

I thought to put more effort in, is the essence. Only this can serve the clients. For example, I followed a social worker to visit a client. I carefully observed his furnishings at his home, especially the kitchen. I found that there was a stick umbrella. I reminded myself that I must remember to bring that umbrella when going out with him on a rainy day. I also noticed the kitchen is dirty. I cleaned the kitchen every time I visited him. I remember I wore white jeans at that time. I was afraid my jeans were stained, so I used a big black garbage bag to cover them when cleaning. I realized that he knew what I was doing. (s6)

Providers are seen to demonstrate sincere effort though these kinds of gestures are essential in purifying social relationships between formal agency workers and dying persons/their families.

Practitioners also strive to avoid any private monetary and material exchanges in their interactions with service users. One example of this is that agencies recommend that volunteers do not buy snacks for the clients with their own money. Such policies reinforce the professional credibility of the service (as above), but also, from the agency perspective, can mitigate the risk of mistrust. Relationships that involve money and gifts are problematic because different clients may have different expectations of the norms of private exchange. This could lead to situations that end up eroding client trust. One practitioner explained:

The existence of volunteers makes the relationship complicated.... Before the visit, we brief the volunteers never to have any monetary relationship with the clients. For example, if the client wants you to play mah-jong with her/him, don't gamble with the client. We also remind the volunteer never to buy a gift for the client because it makes the client get confused. They may think why do I have a gift this time, but I don't have a gift the next time. The best is to make the relationship the purest one - the volunteer visiting the client is just bringing love and care to the client. (s5)

The agency strives to uphold a singular focus on providing support and care based on only compassion and its mission. Indeed, in communicating about their mission, practitioners aim to 'purify' their service objective; to pare it down, in other words, to the focus on helping dying persons and their family members achieve a better dying experience. For instance:

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

Emphasizing the status of the agency as a non-profit professional service is also an important message to convey to dying persons, their families, and referring organizations, to enhance the image of the service as trustworthy and reliable. This role realization process informs what information practitioners should emphasize and what they should keep secret to maintain the expected interaction (Goffman, 1959).

Charity funds fully support agency projects, and practitioners believed this non-profit status is beneficial when engaging service users. Practitioners collect no fees from the client or family, for instance. The reliance on volunteers by the agency further supports their attempts to emphasize their pure or altruistic, orientation (e.g., these workers are unpaid). However, as noted above, the agency strives to further ‘uncomplicate’ the relationship between volunteers and clients (suggesting that gift exchange, for instance, sullies the purity of this relationship).

Paradoxically, in some instances, however, ‘purity’ is achieved by introducing a degree of informality (as opposed to professionalism) into the connections with service users – especially those who might be resistant to service. In the bereavement care service, practitioners sometimes want to maintain contact with bereaved family members, to follow up for several months. However, bereaved people may refuse this follow up. In these instances, practitioners try to create opportunities to maintain a more informal social relationship with these individuals. The social worker may ask them to watch a movie in a workshop, and even, in this case, giving donated gifts. One practitioner explained how this relational strategy (a shift in ‘tone’) is used:

With regards to the people refusing [bereavement] service, we intend not to end the follow-up immediately because we believe that those people may have a more extensive service need. Therefore, we change the tone. For example, we invite them to attend [agency-hosted] social gatherings regularly.

Sometimes, we inform them we have some sponsored gifts for eligible people, such as soup coupons and adult diapers. We usually use these kinds of tactics to engage the patients in the palliative ward (i.e. lung failure and dementia) who don't have a sense that they are at the end stage of their life so that they don't have a strong desire to use our service. (s5)

Practitioners who spoke about this commented that the clients feel more comfortable with the informality of connection to the service, who might otherwise be reluctant to access 'formal' services as a service user or wish to move past the social identities of a 'bereaved' person. The tone of the relationship, in this case, shifts to a "pure" but informal form of connection between community members.

In community EOL care, establishing trust is an essential precondition in accessing and mobilizing social capital. The processes and strategies of boosting credibility, responding actively to comprehensive needs, and purifying the support relationship work to establish trust and mitigate the effects of community detachment for those experiencing dying and bereavement.

### **Outcomes of establishing trust between practitioners, dying persons and their families**

Establishing trusting relationships helps dying persons and their families to recognize the role of practitioners in the intervention, regarding the social workers and volunteers as reliable, helpful and relatively resourceful. They become more open to seeking help from the practitioners when they need it, and accepting of service-

based interventions. Relationships developed to this point provide a fundamental ground to progress to another level - the mutual exchange relationship (discussed in next chapter). If dying persons and their families do not develop trust, they might cease contact with the practitioners, and the practitioners could help no farther. In the next section, I will illustrate a parallel process through which agency workers strive to establish trust with medical professionals in community EOL care.

### **III. Establishing Trust while Respecting Boundaries: Collaborative Interactions with Medical Professionals in Community EOL Care**

Social agencies coordinate between medical professionals and the community of service users, and also need to build trust with medical professionals (e.g., doctors and nurses in palliative wards and geriatric units). Medical professionals generally welcome the introduction of psychosocial intervention that EOL care provides but may be concerned about obligations and liabilities, as they must adhere to strict administrative and legal protocols. Therefore, social agencies need to be careful in the initial adjustment period of cooperation and strive to work out a clear position and roles to establish trust. Extending the idea of relational ‘purity’ raised in the previous section, here is an example of how one practitioner tried to connect with medical professionals to implement community EOL care in the new service boundary, by keeping the relationship ‘clear and simple’:

With regards to establishing trust, at the very beginning, a university professor [who is the director of a community EOL care project in the university who takes care of the impact assessment of our project] helped us align with the senior management of the hospital [in the West New Territories]. We met many physicians of the oncology department, palliative ward, hospice center, and geriatric department. ... we worked with the palliative ward and found that the potential is highest [here]. Their primary concern is the role of the nurse in both parties if there is any overlap. (s5)

The social agency was very aware of the role overlap with the existing in-hospital service. The agency wanted to avoid any possibility of making organizational and role conflict in the initial stage of engagement because they know the hospital is very concerned about it, from the perspective of hospital resource management. They strove to remain open and communicate well with different units in the hospital, which have an interest in their service. They deferred further discussion with the group that expressed reservation. They tried to keep the relationship clear, pure and straightforward, to provide social support to the EOL patients in the existing workflow in the hospital, apart from the medical intervention.

A nurse in “Life Rainbow” project reported fewer challenges in building relationships with hospital-based providers in their service boundary, because the Hong Kong Hospital Authority had endorsed collaboration. They also had prior experience of successfully engaging with hospitals in Advance Care Planning. They, too, however, strove to emphasize these medical-social collaboration relationships as

clear, simple, and pure by emphasizing their own goal of effectively delivering EOL care and maximizing benefits for clients. A nurse practitioner in an EOL care service explained how the outcomes of their collaboration with one hospital were perceived by the senior management of another hospital, who then approached them about extending their partnership model:

In a cross-disciplinary forum on late-stage care, I presented our phase one service working with Pamela Youde Nethersole Eastern Hospital. The senior management of Ruttonjee Hospital [in the service district next to that of Pamela Youde Nethersole Eastern Hospital] appreciated our service outcomes and impacts very much. They thought the medical-social collaboration [to support the Advance Care Planning scheme] could lead to a synergy of mutual help in the service delivery. That is the primary reason Ruttonjee Hospital approached us. We are currently adjusting the workflow with them to achieve higher effectiveness because we are just starting working with them. (s11)

Both social agencies in the present study strove to maintain a consistent discursive focus on collaboration towards enhancing the quality of death and sought to integrate their service within the current workflow of particular hospital units. In doing so, they sought to convince medical professionals that their social support service agency was a reliable partner in the goal of responding to the unmet needs of the dying persons and their families.

Moreover, the agency employees spoke of carefully respecting the authority of the medical professional in their working relationships. For instance, they avoided

making excessive recommendations for matters beyond their service scope or asking irrelevant questions to medical professionals. In this regard, the concern is less about establishing trust than about fear of disrupting the current power imbalance (and incurring antipathy from the medical professionals, which would damage the working relationship). One nurse concluded with her practice wisdom for establishing trust with medical professionals:

For the essence of cross-disciplinary collaboration [in the community EOL care], I still think mutual respect is the most crucial factor. I know the boundary in the collaborative relationship with the Hong Kong Hospital Authority. I know what I can do and what I must not. I also clearly know how to seek help appropriately from the right department. All in all, communication is the foundation in the [cross-disciplinary] collaboration.  
(s11)

Although this nurse emphasized mutual respect as an element of success in the cross-disciplinary cooperation, her talk belies the uni-dimensional rather than mutual application of ‘respect.’ In this way, the implicit meaning of ‘trust’ in relationships with medical professionals emerges as more about the latter’s trust in social agency professionals not to overstep their boundaries. This reflects the particular power imbalance in these relationships, in contrast to providers’ relationships with clients and families.

In conclusion, in this chapter, I illustrated the broader landscape of death, dying

and community EOL care in Hong Kong communities, drawing on participant accounts and my interpretations to conclude that dying persons and their families are usually detached from informal and formal relationships within their community; this detachment stems from systemic navigational barriers, internalized socio-cultural taboos and lack of knowledge, and apparent neighbourhood and institutional indifference. From the perspective of non-profit community EOL service agencies, this context generates unmet needs that could be addressed through service. In this chapter, I also elaborated on the essential social process of establishing trust, which is the first step to mitigate the effects of community detachment for dying persons and their families. Establishing trust helps service users recognize their ongoing needs for help and to access services. It encourages continuous exchange and communication that benefits these relationships, helping to mobilize social capital to enhance the quality of death (Bolt, Verbeek, Meijers, & van der Steen, 2019; Gittel & Vidal, 1998; Rostila, 2011; Tonkiss, 2000; Woolcock & Narayan, 2000). Trust in collaborative relationships between social agency providers and hospital professionals is also a fundamentally vital component from an agency perspective, but one that takes on the distinctive character of 'respecting boundaries,' due to the power imbalances involved in these relationships (Carroll, Santucci, Kang & Feudtner, 2007; Fukui, Fujita, Ikezaki, Nakatani, & Tsujimura, 2019). Moreover, the benefits of

trusting relationships between social agency providers and hospital professionals are not as immediately apparent to service users but are more indirect. These relationships are essential, however, when considering community-level social capital and resilience to help support dying and bereavement experiences.

## **Chapter Five: Cultivating Mutuality in Community End of Life Care**

### **Introduction**

In this chapter, I will further illustrate how social relationships - between social agency practitioners and dying persons/their families, and between social agency practitioners and medical professionals - influence community EOL care through cultivating and nurturing mutuality. Mutuality here extends conceptually beyond trust, based on its conceptualization within social capital theory as a shared relational feeling of being together and co-creating something towards the same goal (Bourdieu, 1986; Brown, 2015). In other words, mutuality, in this study, progresses past the stage of viewing another person as reliable and trustworthy based on one-way support provision (as typifies many service connections). Rather, mutuality illustrates social bonding as trusting relationships become closer and deeper through continuous exchange and further collaboration, as well as mutual understanding of social situations (Goffman, 1959; Misztal, 2013; Pahl, 2007; Putnam, 2000). Cultivating mutuality through impression management is a vital process in creating a collective experience within community EOL care settings (Goffman, 1959; Magasi, Buono, Yancy, Ramirez, & Grady, 2019). The process engages complementary relational aspects such as recognition, participation, respect, and care (Alexander & Charles, 2009; Brown, 2016; Lewis et al., 2013; Putnam, 2000), although it often entails an

asymmetry<sup>63</sup> in social transactions (Lin, 2001b). In this chapter, I will discuss the processual, dynamic, and sometimes strategic aspects and outcomes of cultivating mutuality in community EOL care.

## **I. The Process of Cultivating Mutuality**

After practitioners, dying persons, and their families consolidated trusting relationships, they progressed to a mutual exchange relationship. The practice-based processes entailed in cultivating mutuality consist of finding social commonalities (and hiding differences); immersion in daily routines; supporting actualization; and engaging with clients' emotions. These will be discussed here, in turn.

### **Finding social commonalities (and hiding differences)**

When practitioners connected with dying persons who were using their services, they intentionally oriented their interactions to identify (and even construct) common social features, related to life background, demographic characteristics, and social identity (Goffman, 1963). They believed this was particularly important in the context of the limited time they often had to spend with these clients (due to their prognosis).

---

<sup>63</sup> Lin (2001b) conceptualized this kind of active attempt to manipulate the situation to be a kind of asymmetric social exchange in the maintenance of social relationship (Guanxi) towards an expressive or instrumental outcome. Asymmetric social exchange occurs as the social relationship is often in the state of imbalance of favor over time (Lin, 2001b). Particularly, in the Chinese relational context, the social relationship is based on a sentimental basis. That means the affective component of social relationship “*Renqing*” (人情) becomes one of the critical factors to a successful mobilization of social capital (Barbalet, 2017). Moreover, the social exchange tends to be asymmetric while in a social relationship is facing power-dependence and uncertainties in the transaction (Cook, Cheshire & Gerbasi, 2006).

A social worker expressed the importance of age similarities when matching volunteers with clients:

Sometimes age matters in communication. Similar age, gender, and religious background can lead to a different implication in the service. For example, a 40-year-old lady matched with a same-age female client. The resonance is tremendous. The client is willing to share much more with the volunteer, which is different from the sharing content with other types of volunteers. (s2)

This practitioner articulated how sharing similar age, gender, and social identities have direct benefits because it can generate common conversation topics of interest to both client and volunteer (the latter important because volunteers are unpaid). This conversational experience of what the participant calls “resonance,” represents a subjective feeling connected to the similar socio-historical and cultural background (Schwadel & Stout, 2012). The enhancement of the sense of “resonance” in conversation would motivate the client to share their personal stories, thoughts, and challenges about EOL care. The continuous building up of subsequent exchanges of personal matters would help organize the social order of interaction in EOL care. This means that the interactional actors find it easier to identify roles and expected responses in interactions, as they build up more points of symbolic reference for a particular performance based on emphasizing appropriate impressions of social identities and social attributes (Goffman, 1959). This also builds mutuality in

relationships where trust has already been established (Goffman, 1959; 1963).

As well as shared demographic characteristics shared social identity was also positioned as an active basis for reinforcing social commonalities. 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 social worker colleague [the younger aged colleagues] definitely 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)

In this way, a blend of age or life stage and social identity (e.g., homemaker), has implications for finding social commonalities. In another example, a practitioner described capitalizing on the age and social identity of retired persons to establish

commonalities:

Some [volunteers] are retired people, [which leads to similarities] in the topics that they chat about with the clients. For example, they talk about the historical features in old Hong Kong society [between the 1950s and 1980s]. Some retired people respond to this kind of topic well because they know it well. In this sense, I believe that conversation between volunteers and clients of similar ages can help increase the client's quality of life. (s6)

Hiding differences is an alternative way to establish social commonalities (Goffman, 1963). In particular, practitioners were often concerned about differences in values. One social worker described how she strove to mitigate the potential influence of value differences among volunteers and service users in-home visitation:

For value discrepancies between the service and the volunteer, I believe communication [to the volunteer] is the most important. For example, a social worker partnered with a volunteer in a home visit. Beforehand, the social worker clearly explained the service goal to the volunteer. Moreover, we requested that the volunteer listens to the client carefully in the first visit. During the visit, the social worker might make small gestures to remind the volunteer to keep looking carefully to the client's needs. After the visit, the social worker debriefed the volunteer about their performance and how to improve. For experienced volunteers, we would remind them how to intervene better in [future opportunities to exchange experiences]. While some experienced volunteers get familiar with the ways of handling, the social worker alternatively keeps listening to the volunteer's intervention. (s5)

In this case, the social worker appeared to be mitigating the potential for value differences to emerge in interactions between the volunteer and client, by

emphasizing, to the volunteer, the need to remain focused on listening in this case, rather than sharing their own experiences. In these situations, the focus shifts from one of cultivating mutuality through mutual sharing, to needing to protect trust and strategically help the client “pass” as socially acceptable in the interaction (Goffman, 1963).

In other cases, practitioners also appeared to specifically maximize the chances that practitioners, dying persons, and their families can cultivate mutuality, as in the following quote from a social worker:

For volunteer recruitment and organization, we rely very much on ‘matching.’ We make use of different combinations of volunteers, according to their time availability, experience, etc. (s2)

Alternatively, some practitioners, even at times, also attempted to maximize the commonality by feigning similarity. 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. Although he respected educated people, he assumed they shared his perspectives, but this practitioner did not. In her interactions with him, she, in essence, feigned interest, in the interest of building 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)

The practitioner viewed creating a shared experience in this way as a viable strategy for moving towards mutuality<sup>64</sup>. Although the practitioner may not agree with what the client says and thinks, she believed it was worth doing because she believed it would benefit the client's psychosocial wellness (a top priority in community EOL care). This role idealization process facilitates a sense of homophily by controlling what information practitioners emphasize about themselves and what is kept secret or unrevealed (Goffman, 1959; McPherson, Smith-Lovin & Cook, 2001).

### **Immersion in routines: Participating in the daily routines of the client and family**

The practitioners that I interviewed also cultivated mutuality by actively participating (sharing) in the daily routines of dying persons and their families. Through this intervention, the service users get to know the practitioners and build up a stable relationship with them. It also appeared mutually beneficial, as practitioners tended to enjoy these interactions. Immersion involved properties such

---

<sup>64</sup> Lin (1977) discussed the theoretical insights in research on communication effects, which is related to the construction of social networks. He highlighted a conceptual framework of studying communication effects with four elements: 1) encounter; 2) exchange; 3) influence; and 4) adaption and control (Lin, 1973). In the elaboration, he emphasized adaptation and control of communication, as one of the essential components in the communication effects on social network formation, is to reduce the discrepancy between the expected effect and the actual effect on the receiving participant. He stated that manipulation of presence-absence, intensity, extensity, redundancy, and value associations are exercised in the formation and structure of information, meanings, and influence for further communication (Lin, 1977). Lin's conceptualization informs my analysis that cultivating mutuality, sometimes, involves strategic manipulation.

as: hanging out, helping with caring routines, and being “listening stranger.” The practitioners sometimes described just “hanging out” with service users. For instance, in the following example, 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)

After practitioners formed a first stable relationship of trust with service users, they usually attempted to participate in some way in their caring routines. However, this was, in part, about starting to assess and address their needs for help (ranging from accompaniment to care coordination). Indeed, dying persons and their family members also tried to communicate their needs to practitioners. One participant described an example:

I went with [client] to see the doctor. I chatted with him, and we touched on the topic of how other people can help you. He said he wanted to have a new wheelchair. The next day, I helped to place a request to the rehabilitation equipment borrowing service to get a wheelchair. The new wheelchair would make his day because it was a tangible tool that would make it more

convenient to go to see a doctor. (s9)

Another practitioner shared how they immersed themselves in accurately assessing and addressing the needs of dying persons:

Many clients felt they don't have dignity at the end of life. For example, they need to ask somebody to help turn on an air conditioner. They think they are incapable. Sometimes, they are boiling and sweaty but don't want to trouble their family members to turn on the air conditioner. Although they might just say turning on the air conditioner is wasting electricity. When we realize they have this kind of need, we will talk with their family members. (s8)

In community EOL care, one of the most important routine needs of the dying patient and their families is the caring work of everyday life. Practitioners often suggest improved techniques or equipment to reduce the caring burden. The clients, from their perspective, tended to be willing to share their thoughts, needs, and feelings.

Sharing feelings and thoughts can be part of important family routines during EOL care. Yet not all dying persons get used to sharing all of their inner emotions and thoughts with their families. This may be because of holding grudges, self-esteem issues, lack of communication skills, or bad family relationships (Kellehear, 2014).

As such, practitioners described their own or the volunteers' roles as that of a kind of "listening stranger" to address the emotions of service users at the EOL, which can be conceptualized as part of their immersion in family routine. The "stranger" is recognized in a group but remain distant from the group members (Simmel,

1908/1950, p.402). They believed that dying persons and their families appreciate sharing their feelings with them because of their status as, simultaneously, both trusted practitioners and strangers. One participant thought that though service volunteers or neighbourhood members could serve similar functions in this regard, that volunteers have a particular advantage:

Sometimes, clients and their family members don't want to talk with their neighborhood about the challenges and problems facing them at the end of life, because they believe those are embarrassing. They don't want to show those issues to others. So [instead] they often talk about their hard feelings to the volunteers because they see that volunteers are outsiders but reliable to keep secrets. This is their concern instead. (s8)

Moreover, privacy within the neighbourhood is often a primary consideration for clients in sharing their personal feelings. Although some participants spoke of neighbourhood bonding in this study, even neighbour relationships may sometimes be viewed as too close and familiar by dying persons, particularly when it comes to sharing their emotions from their inner worlds, thoughts, and feelings. Dying persons and their families may feel embarrassed about sharing their troubles with their neighbours. "Listening strangers" who have established trust can thus have a unique role in encouraging the clients to talk with them under an additional layer of protection (and for this reason, practitioners emphasize, to clients, their professional ethos of concern for respecting privacy). For example, the practitioners showed their

readiness (willingness to listen), acceptance (nonjudgmental mind), understanding (empathy to the client's situation), and response (thinking about solutions to address the needs) to help clients express their feelings during in-home visits. These processes are favorable for building up mutuality in the social relationship, even when the actors do not share many objective commonalities (Simmel, 1908/1950, p.402).

### **Supporting actualization – the wishes of dying persons and their families**

In cultivating mutuality, community EOL care practitioners also offered service, which they characterized as fulfilling the desires of both the dying persons and their family members and carers. Practitioners provided resources and support to help clients, for instance, to do what they want at their end of life. The activities of 'wish-granting' in particular offered a pivotal opportunity for practitioners, dying persons, and families to work together towards what is viewed as a common goal. Mutuality is strengthened when the interacting parties engage in this more profound form of exchange in the process of actualization, which maintains normalcy in the social interaction (Goffman, 1959). However, some of the granted goals are guided by the practitioners. For example, both projects had some resources to help clients enact their legacy, so practitioners may prompt their clients to engage in this. Importantly, the dying persons and families who use this service are actively predisposed to accept this form of help and acknowledge their own needs for assistance. What occurs, therefore

is the cultivation of a mutual understanding - of each other in the relationship, and of the tasks at hand - through smoothly tuning the exchange, and interpretations of the symbolic meaning of the relationship, towards a sense of “anchored relations” (Blumer, 1969; Goffman, 1972).

The wish-granting activity may appear trivial, for instance, just bringing the dying person to a Chinese restaurant for Dim Sum. But in other cases, practitioners also help dying persons to complete a unique or more ritualized task. Here is one volunteer’s description of helping the dying person to write their life story, as a way to pass his life experience on to his family members:

The volunteers are used to improve the clients to make their memorial book to pass down their life stories. I think all of this only happens after we have addressed their real needs. After they made the monument books, they could tell anybody their own stories. They felt happy with that because they thought they were being respected and appreciated. (s7)

Though not stated here, this likely helps the dying person achieve a sense of immortality through the written word. The feeling of being respected as an individual is an added benefit in a situation in which dying persons may feel precarious in their identity. What is noteworthy in this example is that the idea for this arises with the practitioners; as such, in this sense, it represents only an ‘imagined wish’ in the mind that the wish has not been expressed by the client, initially. In other words,

practitioners envision the activity as fulfilling a wish they believe the client has on some level but does not know how to express.

Supporting the actualization of the wishes of dying persons and their families can cultivate mutuality. At least, the client and the family members can share some of their ideas and wishes. A former service user described how the service helped her to coordinate a final birthday party for her dying mother in a home visit:

Last year [2018] was my mother's 90-year-old [her last birthday]. I raised an idea [to the project nurse in a home visit] to organize a birthday party to celebrate. The project nurse told me that she could help arrange a professional photographer service for us to take family photos at the party. I was pleased to hear that. Also, she helped organize an outing activity for our family to go to the Peak. I did not join because I am not available, but my family members went with my mother at that time. (c15)

In the home visit, this participant was pleased that the practitioner could provide this additional support to help her actualize her idea of hosting a birthday party for her mother. A sense of mutuality (she was willing to share her thoughts, and promptly received a positive response) can be posited as having occurred in the interaction.

Through impression management mechanisms in this above-mentioned social interaction, the client altered their perception of the situation (i.e. transiting into the EOL care experience) and reinforced the supporting role of the practitioners, for whom it is crucial that the client should accept their needs (Glaser & Strauss, 1980;

Goffman, 1959). Such interactional dynamics cultivate a social exchange relationship (Putnam, 2001).

Practitioners provide resourceful support for family carers, to help them occasionally step away from the caring role through doing something on her/his own (e.g., granting a wish expressed by some carers). A social worker described a time they helped grant one carer's stated wish to attend the opera:

...Another example is that we regularly support the carers to do what they want, like taking a rest from the caring routines. A carer said she wants to watch Chinese opera. So, my colleague thought about how to create a chance to let her go out for several hours. My colleague instructed her to tell her husband that she needed to pick up a blanket in the service centre. The volunteers and I brought her to watch Chinese opera then. Over time, she shared that she likes singing Chinese opera very much. She chose her husband because he allowed her to sing. We saw that she was another person at that time because she energetically introduced the details of the Chinese opera. We genuinely felt that a lot of carers give up their quality of life because of the caring routines. Therefore, this kind of support - engaging in 'playful activities' with them - is also one of our primary tasks (s5)

After considering the feasibility and priority of this option, the practitioners, in this case, encouraged the wife to tell a "white lie" to her husband to preserve their relationship, since the practitioners and the wife knew the husband could take care of himself in a short period (e.g., in an afternoon). The practitioners were mutually complicit in helping her meet her wish, which likely strengthens mutuality. In addition, the secret keeping of the "white lie" between the wife and the practitioners

promoted a sense of mutuality. In Goffman's (1956) terms, they constitute a 'team' and as much carry "something of the sweet guilt of conspirators" (p.105).

### **Engaging with clients' emotions**

Service agencies also try to address the emotional needs and distress of dying persons and their families. This activity is embedded as part of the philosophy of palliative care, and in so doing, these practitioners cultivate mutuality. Again, mutuality, in this sense, refers to concentrated forms of exchange based on an established trust relationship (Mauss, 1922). Developing mutuality actively mitigates community detachment that can exacerbate emotional distress already faced by dying persons and families at the end of life. Engaging with clients' emotions in a way that cultivates mutuality entails: encouraging clients to 'release' emotion, demonstrating emotional involvement, and actively listening.

From practitioners' perspectives, encouraging clients to release emotions is a fundamental task (and art). Rather than continuously asking them about their needs, practitioners aim to support clients to tackle everyday challenges; it is hoped that continuous support in this regard, over time, helps build up the relationship as a secure shared space in which clients can be encouraged to release emotions through sharing them with the practitioner. One practitioner also described how they would help make funeral arrangements, and how this contributed to security in bereavement:

For example, the volunteer's support in funeral arrangements makes the client feel secure. Firstly, the clients met us before; they usually think we are reliable. With this social relationship, they believe the whole thing is becoming stable, less frightening, and less stressful, such as when handling the probate requisition procedures, tidying up the remains. Individually, clients felt there is somebody trustworthy who can listen to their feeling because some clients trembled when feeling frightened in the course of these procedures. Usually, the volunteers brief the client clearly about what would be going on in the funeral arrangements, such as in the funeral parlor. This kind of information means a lot of support for the clients. (s2)

Finishing funeral tasks, for clients, includes the completion of rituals and is wrapped up with the process of coping with the grief, fear, stress, at what can be an uncertain time. Accompanying clients extends beyond the professional's involvement in providing information and support; the practitioner actively encouraged clients to release their grief, fear, and stress, and to start talking about their own emotional needs. As a normative relational shift towards releasing emotions is established, practitioners can also more actively respond to emotional needs. Mutuality can also manifest through the often intense nature of dialogue that can be entailed in this process over time.

Practitioners were skilled in making users feel they are receiving compassionate support through displays of their emotional involvement to build up the sense of mutuality in the relationship. One practitioner explained:

I think when running this kind of service, one has to be emotionally sensitive and passionate so that the user could have that sense of being looking after and being supported. Especially for a patient who is dying soon. You could only selflessly take care of her with this in mind. (s9)

The reference to ‘selflessness’ in this excerpt harkens back to the ‘purification’ of the service provider-client relationship discussed in the previous chapter. Still, it extends here to the sense of full involvement and commitment of the practitioner to the emotional needs of the other. This can lead to the relationship becoming more supportive. A practitioner of Life Rainbow talked about the practical implication of showing a sense of emotional involvement and commitment:

In my opinion, how to open the client’s heart is to let the client accept her/his own needs. I think showing our sincerity with patience is essential. For instance, the client may say a lot of things we may not agree with. So, the first step is to listen to all she/he talks [not to judge], then understand why she/he says so. (s13)

Echoing the “selflessness” of practitioners, a sense of full involvement and commitment helps cultivate mutuality. With involvement in and commitment to the relationship, and sensing practitioners’ sincerity, client may be willing to have a more in-depth exchange, such as emotional exchange, with practitioners. As such, clients wanted to talk about their thoughts and emotions with the practitioners.

Emotional involvement is closely tied to listening actively; through non-judgmental, active, and wholehearted listening, practitioners attempted to convey

empathy, respect, acceptance, and compassion (e.g., emotional involvement) to the emotional experience of the other. One practitioner described how empathetic listening is connected to cultivating mutuality:

The reason why the client is putting their trust in us is that he/she won't talk to others, because they think that we are like a semi-professional practitioner. So they are scared to talk about it to the others. But they don't mind talking to a social worker. When they are working with us, you help them to accept the death of their relatives. They hope that someone can understand their feelings... They don't know how to release their emotion, broadly speaking, such as mental health. (s1)

In particular, bereaved clients might be afraid of sharing their feeling and distress related to EOL and death with others (as noted above). Therefore, the “semi-professional” status (these agencies being positioned almost at the intersection of formal and informal sectors) bolsters credibility and trustfulness for the clients. In turn, this encourages bereaved persons to talk freely about death, facilitating further, ever more intensive dialogue or verbal exchange, facilitating, for the bereaved persons, a sense that they are being understood.

Practitioners believed that the most powerful way to encourage dying persons and their family members to talk about or share their emotions is to show interest. Through deferential listening that validates identities, practitioners provide role identity support, which essentially recognizes or reaffirms high status as a prestige or moral right (Goffman, 1959; McCall & Simmons, 1966). The following quote from

one practitioner highlighted the importance of providing these identify-affirming opportunities, given the broader context of community (and in this specific case, family) detachment:

... we are willing to listen to their story carefully. A lot of Hong Kong people don't have a chance to talk with others about their deep feelings. I remember I encountered a client who was angry with us because he felt that we couldn't help him tangibly. Therefore, he didn't have any interest in our service, say escorting to attend a medical appointment, or providing information. But, when we continuously talked with him, we gradually understood what he had been doing, such as his job. We realized that he is the elite (an engineer). Further, as we listened to him, he felt less angry with us. We learned that this client usually did not have a chance to express his negative emotions as his family members had moved out. We used this listening technique to establish trust with him. At least, he knew that we were not liars. (s6)

An 80-year-old current service user of Life Rainbow also explained how, at one point, she struggled with whether or not to talk to her children about her wishes for their involvement in her EOL care. She described her interaction with a trusted agency practitioner who listened to her concern and responded encouragingly:

In-home visits, we chat a lot of ordinary topics, such as my health condition. But I enjoyed talking very much because I felt the love and care in the conversation [in terms of the practitioner's attitude, tone, and passion]... I remember one time I asked her [the practitioner] if I should talk about my expectations about EOL care to my children. She said it is lovely to talk about that before you need EOL care in the very last moment. She said the most important thing is that you have your wish to speak about this topic and ask your children to follow your wishes. I felt released and encouraged. I also

appreciated her [the practitioner's] kindness and sincerity very much after hearing her reply. I also thought we were in an excellent relationship. (c16)

In this sense, a sense of mutuality, from the user's perspective, can be straightforwardly cultivated in a regular home visit. The client believed the practitioner appropriately and actively responded to the most pertinent issue in their mind. The client recognized this as a relationship and may be willing to share more, in turn. To sum up, engaging with clients' emotional needs is a typical process in the practice of community EOL care, which can cultivate mutuality.

In this section, I analyzed the process of cultivating mutuality through practitioners' strategies such as finding commonalities, immersion in routines, supporting actualization (granting wishes), and engaging with client's emotions, engaging with sociological concepts of dramaturgical analysis. Cultivating mutuality represents an extension of trust in the development of the social relationship in EOL care (Giddens, 1984). Through the cultivation process, bonding social relationships become more profound and more reliable through the culmination of continuous exchange (Lin, Cook & Burt, 2001; Putnam, 2001). The EOL care actors build mutual understanding of the perception of situation and construct their interactional roles through deeper exchange and interpretation of interactional feedback from the other (Blumer, 1969; Goffman, 1959). The cultivated mutuality also serves as a basis for mobilizing social capital. This will be discussed further in the next chapter.

## **II. The Outcomes of Mutuality**

Practitioners spoke about how service users who have been receiving service for a continuous period, gradually accept them as a kind of ‘fictive kin’ (Funk, 2019), which signals a form of mutuality has established. At this point, both clients and practitioners tended to share their thoughts and feelings, take care of each other in their interactions, and manifest a sense of familiarity in the relationship. Practitioners also interpreted expressions of caring from service users as providing feedback that signals that mutuality has been successfully cultivated. The response indicates emotionally supportive mutual exchange between the practitioners and service users in a way that goes beyond the one-way provision of assistance (including emotional support) and service users’ acknowledgment of the presence of the practitioners (in the establishing trust stage). Fictive kin-type ties cultivated during a higher level of social interaction and impression management in EOL care signal the generation of a new mutual understanding of the perception of situation. Both parties realize their interdependence and joint creation of a better dying experience. Interpreting such outcomes or “tie-signs” of mutuality help to determine whether the service relationship will develop into a collaborative relationship of the community of EOL care (Goffman, 1972). Three specific results of cultivating mutuality identified in this research are presented in more detail below, including two which are favourable:

caring about the feelings of the practitioner, and a sense of emotional security; and one which is unfavourable: remaining estranged from the mutuality.

### **Caring about the feelings of the practitioner**

Practitioners described how dying persons and their families attended to the sentiments of the practitioners; for instance, not wanting practitioners to suffer difficult emotions when taking care of them. One volunteer remembered a time that a client expressed regret for taking up the volunteer's time in-home visitation, and added:

I hear from the clients; sometimes, they feel they are troubling the volunteers. They were afraid of holding up our time. I perceive this as a kind of feedback about our caring. I also felt they have started trusting us. In those moments, I restate that taking care of you is our core responsibility. Please don't think it is holding up our time. (s6)

In this quote, the volunteer actively interpreted client apology as a positive sign signaling their mutuality, rather than, for instance, a sign that the client's self-worth is faltering, or that they might be depressed.

Another volunteer shared two stories from her practice about users who expressed care for her feelings. The first one is about a dying person who suggested that she return home after a late-night visit.

I remember I visited one client until very late at night. He reminded me that it was time to leave and take care of myself. I thought their care [indicated] excellent feedback about our work. I felt comfortable with that. Because of mutual concern, I felt our social relationship got more in-depth, going beyond a relationship between volunteer and service user. (s9)

Though it is possible that this concern for self-care masked other intentions (e.g., that the client was tired and no longer wished the practitioner to be present), in the practitioner's interpretation, at least, it was well-received and signaled mutuality.

In a second example, a dying person encouraged this volunteer to apply ointment on a mosquito bite:

Talking about how to build up a relationship with the client, my experience is like this. I encountered a client who is a Chaozhou person<sup>65</sup>. I intended to talk with him about Chaozhou topics. I spoke about the history, customs, and landscapes of Chaozhou. In the conversation with him, I got some feedback from him as well. For example, I got bitten by a mosquito when I was visiting him; I told him I felt very itchy. He gave me a bottle of medicated oil and asked me to apply it. [Again] I felt the social relationship got more in-depth, going beyond a relationship between volunteer and service user. (s9)

Caring about the feeling of the practitioner is symbolic of the outcome of cultivating mutuality because it signals the relationship is moving beyond a one-way emotional connection from the practitioner to the client, towards a sense of relational connection or belonging. In this situation above, the client started noticing and trying to address the needs of the practitioner. Compared with the initial stage of

---

<sup>65</sup> The culture in this geographic region is commonly very male-centric/dominated

engagement, this reflects a significantly deeper involvement in terms of the relational exchange. In the next section, I will discuss how emotional security can also be viewed as an outcome of cultivating mutuality in community EOL care service relationships.

### **A sense of emotional security**

Another outcome of cultivating mutuality, according to practitioners, is that the dying persons and their families signal that they are emotionally secure<sup>66</sup> when the practitioners are present. In these situations, clients/families perceive that the practitioners can provide reliable, holistic support (Funk, Allan & Stajduhar, 2009).

Security in community EOL care is multidimensional and includes the security of timely access to needed care, services, and information. One social worker shared his observation after he finished a case:

We had an experience where the client showed us that they trusted us very much when our volunteer was with them. I believe our role is being with clients at the hardest moment in her/his life. Although their condition may not be stable all the time, we could see the client noticeably improve in terms of voice, emotion, and self-confidence. (s1)

The client referred to here was less worried and uncertain in the context of timely

---

<sup>66</sup> The notion of emotional security extends beyond trust and has the properties of 1) feeling secure that care services will be provided by competent professionals; 2) feeling secure in their timely access to needed care, services, and information; 3) and feeling secure in their own identity and self-worth as a caregiver and individual (Funk, Allan & Stajduhar, 2009).

care, service, and information pertinent to the needs at the EOL stage. The client cognitively recognizes the support relationship, and the client regained some self-confidence. This signals an extension of the trust relationship.

Notably, this same participant described helping a bereaved person with funeral arrangements:

When some reliable people stand with the bereaved person, the bereaved person is often stable. It is because there is a person who is familiar with death and dying. They feel the support. I believe the function of volunteers in the service is not only about accompanying the clients, but also stabilizing psychosocial and spiritual distress. After finishing all the tasks, the client gradually realizes own their psychosocial and spiritual needs and difficulties.  
(s1)

Feeling emotionally secure might be particularly important when family support is lacking. When the client feels accompanied by competent professionals, they can handle situations with less struggle and distress. In this sense, security might manifest when bereaved persons feel comfortable articulating psychosocial and spiritual needs related to their own identities (e.g., a mother, a woman, an employer, etc.) in the support relationship. Moreover, mutuality, in this sense, manifests as both parties in the interaction feel secure in their identities (Goffman, 1959). The excerpts above illustrated how voice, emotional tone, and other cues, interpreted as symbols indicating an actor's emotional state and self-confidence, can entail processes through

which workers' identities, too, are reinforced (e.g. workers recognize they have done the job, when it is apparent that clients' emotional state shifts).

### **Remaining estranged from the mutuality**

Sometimes, attempts to cultivate mutuality may lead to unfavourable (and unsuccessful) outcomes. The client might remain estranged from mutuality, despite practitioners' attempts. Practitioners interpret this as hampering the further development of collaborative EOL care. A practitioner shared his experience of such an unfavourable outcome, which he attributed to the clients' preference for more professionalized or tangible sources of support:

There are some clients who I have visited four to five times, who are still [seems to be] feeling I am cheating them. So, they sometimes talked to me that they needed a social worker instead of volunteers. For example, I visited a client for five to six times. When I went to visit the client, our conversation remained at the level of simple question-and-answer until the visit was over. I encountered another one, too, who said he needed a social worker for tangible support, instead of chatting with us [the client thought talking is useless]. (s7)

When the client remains estranged from the relationship in this way, even though they might trust the volunteer, the relationship does not develop towards bonding or mutuality.

Time limitations (due to referral timing and EOL situations) and physical constraints of clients also contribute to remaining estranged from mutuality. A social

worker described difficulties in cultivating mutuality in relationship with the clients:

Sometimes, there is a situation that the case is at the very final stage of life when referring to us. We actually cannot do much for them. Say, I received a case today. The client's condition is precarious. He needs to be admitted to the hospital frequently. What we expect is the hospital can provide more support for him, until the condition becomes stable. Then he can return home. Then we can continue the follow-up. In some dementia cases, what we can do is focus on caring routines. The relationship with this kind of family is not as deep as the ordinary one [in which both the clients and the practitioners can jointly build up different experiences together]. But I cannot say that we do not have a trusting relationship in the continuous follow-up. I can only feel the outcome is unfavourable [in terms of the potential for intervention]. (s10)

A client's unstable physical condition and/or receiving the case too late can hamper opportunities to cultivate mutuality through support provision (even trust may be challenging to establish). Thus, the service relationship remains at a superficial level of interaction because of how the client orients to the communication under these conditions, and because practical constraints limit the focus to immediate (often physical) needs. In these situations, service relationships do not develop into more collaborative relationships that can more fully enhance the quality of care.

In sum, when clients express care about the feelings of the practitioner and convey a sense of emotional security, these are positive signals demonstrating that both practitioners and clients are actively engaging in the social exchange, in the "anchored relationship" (Goffman, 1972). When successfully developed from a

trusting relationship, mutuality can be a favorable resource leading to more collaborative relationships.

In the previous chapter, I deliberated the category of establishing trust in medical-social collaboration, as a precondition of accessing social capital in these relationships (cultivating mutuality). When the medical-social collaboration cumulates a certain level of trust, how to make good use of this relational resource to enhance the quality of EOL care becomes the critical question in the relationship. In the last section of the present chapter, I will address how social agency practitioners cultivate a more limited, instrumental form of mutuality in relationships with medical agencies and professionals.

### **III. Cultivating Mutuality in Relationships with Medical Practitioners**

Medical-social collaboration can be complicated no matter the issue but maybe especially difficult in community EOL care. Health and social professionals may prioritize different specific considerations or have distinct concerns about the implications for their agency in terms of liability, administrative support, and risk management. Compared with the mutuality and depth of bonding that can be achieved in relationships with clients and families in the “home visit,” relationships between medical and social professionals are grounded in case handling (instrumental outcome) instead of affective benefits (expressive outcome) (Lin, Cook & Burt,

2001). My analysis of the data from some participants in this study suggests that medical-social mutuality, which denotes a relational status in which both medical and social service professionals respond to each other on a similar or equal level of interdependence (Brown, 2016). If it can be achieved, this may help leverage collaboration not only by reinforcing this common operational goal but also by modeling a base from which to develop further collaboration. Cultivating a sense of mutuality between medical and social professionals, just as with clients, entails some performative strategies on the part of social care professionals – most notably, ingratiation behaviours, which enhance the potential that actors of different statuses attribute likeability to the other (Jones & Pittman, 1982). In this section, I will outline how the practitioners cultivate medical-social mutuality through the multi-disciplinary meeting, explicitly drawing on the experience of PARACLETE practitioners.

The critical site or opportunity for cultivating mutuality among medical and social professionals involved in community EOL care is the multi-disciplinary case meeting, which plays an essential role through the mutual exchange of information. This meeting is a regular and formal occasion in which physicians, nurses, and social workers discuss the progress of community EOL care cases, identify professional needs (i.e., case handling), and how to coordinate to address client (and family) needs jointly. For instance, one professional might invite others to help follow-up with the

case. One social worker described the multi-disciplinary case meeting this way:

Every month, we meet the physicians in Tuen Mun Hospital. In the meeting, we report the cases we are handling because all of us want to see the condition of the clients. If we encountered any challenges and difficulties in the case handling, we deliberate deeply on how to handle it better and provide more support, with joint efforts. For example, facing a case involving difficulties of engagement, the hospital would inform us when they will next attend their medical appointment. We can encounter them outside the medical consultation room. We also circulate information about our service events, which the hospital helps us disseminate among the patients. (s5)

The scope of this multi-disciplinary case meeting is instrumental because the hospital wants to follow-up on the EOL patients in the program better after discharge. Indeed, social-medical mutuality between professionals, in contrast to the “home visit”, is more limited, and is tied to a kind of professional mutual exchange about improving case handling. To the extent that this can be achieved, the benefits, according to social agency practitioners, include improved case coordination, for instance, through enhanced contact and communication between the social service and the hospital.

This will be discussed further below.

Professionals collaborate and coordinate their activities during the multi-disciplinary case meeting by brainstorming long-term comprehensive solutions and envisioning how different parties can support each other in the case follow-up routines. A social worker described how different professionals collaborate through

mutual support; accurately, one meeting was described, in which professionals became concerned when they realized they were having issues contacting a client:

I think the regular meeting can show collaboration, particularly [considering] the division of labor. Earlier, the community nurse couldn't find the client. But we knew that client very well and could contact him quickly. We also felt strange that we [then] also couldn't reach him either. We all knew his physical condition was worsening, [so] we felt worried. Since we had his son's contact, we contacted his son afterward. When his son went to the client's home, he found that the client had fainted at home. The client was sent to the hospital immediately to receive further medical care. Because of the collaborative relationship between the hospital and us, we can provide timely support for the client. We believe this kind of mutual aid can enhance the service on both sides (s5)

This social worker emphasized the instrumental benefits of medical-social collaboration or mutuality. Through mutually supporting the goal of quality client care, the multi-disciplinary meeting can provide an opportunity to identify "short cuts" in otherwise convoluted case handling routines, especially in emergencies. In the meeting, both medical and social service professionals are encouraged to exchange information, knowledge, and insights towards a greater shared understanding of the cases and service rationales of each other. In this way, "doing favours" facilitates ingratiation (Jones & Pittman, 1982). Cognitive understandings of professional boundaries and respect that are established in the trusting relationship provide a platform on which both parties can share their information, knowledge, and

practice wisdom.

Stimulated by regular case meetings and through ongoing collaborative action on particular cases, different professionals can develop an appreciation of their own mutually supportive roles and functions, with the outcome of more significant efforts towards active coordination (even if the physician might take the lead in some cases). This self-enhancing communication helped reduce the power discrepancy between two professionals by increasing interdependence (Jones & Pittman, 1982). However, social agency practitioners face a distinct power imbalance in relationships with medical professionals; in response, social professionals might emphasize more performative aspects of mutuality (i.e., emphasizing collaboration to nurture a sense of mutuality in the other through “opinion conformity”) (Freidson, 1990; Jones & Pittman, 1982). A social worker shared their experience of coordination during a case meeting:

We respect the physicians’ viewpoints very much. We also tried to align our voices in the regular meeting. If we know the physicians use a particular view, we will keep consistent with their viewpoint afterward. (s5)

This excerpt indicates how social workers actively work to achieve a sense of mutuality through opinion conformity (Jones & Pittman, 1982). At the same time, it raises questions about the extent to which physicians themselves might or might not

likewise strive to align their voices with those of the less powerful professionals on the team.

In sum, the social process of cultivating mutuality with both service users and medical professionals, as outlined in this chapter, builds on and extends trusting social relationships in community EOL care. Mutuality, where it can be achieved, is essential for activating social capital in community EOL care relationships. Ideally, mutuality can be cultivated with service users through social-psychological processes rooted in frequent, cumulative dialogue, and interaction. In trusting relationships with service users, practitioners strive to find social commonalities, embed themselves in daily caring routines, grant the wishes of dying persons and their families, and actively engage with clients' emotions. Cultivating mutuality through these activities can solidify, extend, and transform trusting relationships, as signified, for practitioners, by clients' efforts demonstrating caring about the feelings of the practitioner and feeling emotionally secure. These indicate the relationship has shifted from a one-way provision of compassion, care, and support for the dying persons and their families to one more fully entailing mutual exchange, especially in terms of emotional and cognitive dimensions. However, in some situations, ongoing dialogue with service users may not successfully cultivate mutuality. The client may remain estranged from mutuality, meaning that both parties remain at a superficial level of

exchange. Even worse, relationships with clients become weakened and tense.

In social agency professionals' relationships with medical providers, mutuality is more limited to the instrumental goal of case handling, but can also be viewed as stemming from the praxis of trust in established (albeit fundamentally hierarchical) relationships between medical and social service professionals; most salient in this regard is the multi-disciplinary meeting. In the next chapter, I will further analyze the process through which practitioners build on mutuality with both service users and medical professionals to foster their vision of collaborative community EOL care, which can be viewed as mobilizing and activating social capital within these established social relationships to enhance the quality of death in the community.

## **Chapter Six: Fostering Collaborative Community EOL Care**

### **Introduction**

In the past two chapters, I have illustrated how social agencies develop relationships with service users and medical professionals; these relationships are the basis of community EOL care. Social agency staff builds up the precondition of access to social capital by establishing trust in relationships and then facilitate access to social capital by cultivating mutuality in these relationships. In this chapter I will focus on how social agency workers foster collaborative community EOL care to enhance the quality of death, and in doing so, I complete my articulation of a grounded conceptual model of social capital in community EOL care.

Collaborative community EOL care is an organizational form of care provision in which care is inextricably linked to shared values, needs, and expectations of clients, families and healthcare providers (Brito-Pons, & Librada-Flores, 2018; Dyess, Prestia, Levene, & Gonzalez, 2020; Flores, Molina, Osuna, Vargas, & Vicuña, 2018; Pfaff, & Markaki, 2017). This ideal model of healthcare practice typically involves both compassion and collaboration in a harmonious combination (Kellehear, 2013), and is concerned about supporting the patient and family-centered care (Altimier, 2015; Pfaff & Markaki, 2017). As Kellehear (2005) articulates, collaborative community EOL care requires profound dedication to the production of social capital.

Enacting compassionate, collaborative community EOL care requires that social agency workers leverage collaborative partnerships with clients (and their family members), as well as with medical practitioners; the result is a higher, more synergistic level of holistic support (Saunders, 1991), wherein the collaboration can help generate new resources to enhance the quality of EOL within a short service time frame (due to the prognosis). Social agency workers develop social relationships through sociability interaction (in exchange relationships), which is a fundamental way to develop social capital up from a casual encounter in the community (Lin, 2002; Misztal, 2005). Trust and mutuality – the consolidated basis of social connections - leverage such partnerships (Hyypä & Mäki, 2003; Lin, Cook & Burt, 2001; Misztal, 2013; Onyx & Bullen, 2000). For example, clients develop clear understandings that the practitioners are trustworthy partners engaged with them in co-developing EOL care experiences, and that clients can access different resources and support embeddedness in the established relationship.

Notably, in community EOL care, these collaborations usually address issues in both the dying person and the family, and family members tend to be viewed as the most important “ingredient” in the EOL care relationship (Alvarez, Kawachi & Romani, 2017; Gale, Kenyon, MacArthur, Jolly & Hope, 2018; Wegleitner, Schuchter, & Prieth, 2018). Practitioners in the present study likewise identified

family support as the core issue in the holistic care of dying persons in community settings. Collaboration, in this setting, seeks to engage family members in greater participation in EOL care through facilitating, organizing and mobilizing based on developed (trusting, with mutuality) social connections. By doing so, the community can effectively deliver care to dying persons and their families (Kellehear, 2013; Pfaff & Markaki, 2017), mitigating community detachment.

However, participants in this study acknowledged that there are variations in the levels of family engagement, depending on different qualities and types of family relationships, for instance. Internally, some families may not themselves be rooted in relationships of mutuality, shared values, and in-depth communication. Fostering collaborative relationships with family members is a substantial focus for practitioners, even in these situations, yet might look different (e.g., be focused more on discussions about long-term care plans). In other situations, fostering collaboration with families might entail processes such as re-organizing care routines, and in these situations, practitioners and families may decide to work together to meet the final wishes and needs of dying persons and their families. Moreover, social agency workers' more professional collaborations with medical professionals tend to entail the development of a systematic workflow and work norms towards better quality EOL care (Badger, Plumridge, Hewison, Shaw, Thomas & Clifford, 2012; Boucher,

2016; Oishi & Murtagh, 2014).

In this chapter, I will sociologically analyse the dynamic, and sometimes strategic, social processes through which collaborative EOL care between social agency practitioners and family members can be fostered. Three processes were identified in the data from this study: opening (bridging) family dialogue, activating family care (e.g., deploying expert status, reorganizing caring routines), and achieving final wishes with family members. Regarding medical-social collaborations, in this chapter, I will also illustrate how social agency workers leverage collaboration with medical agencies and professionals to formulate a systematic, holistic community EOL care workflow and work norms towards a better quality of practice. These processes consist of: linking up care resources in communities, establishing ways of working together and mobilizing joint effort towards a specific operational goal.

### **I. Fostering Collaboration for Community EOL Care in Families**

In community EOL care, collaboration is facilitated by the shared commitment to addressing the needs of the entire family (in palliative care philosophy, this is reflected in the idea that the family, not just the dying person, is the unit of care) (Abel et al., 2013). One volunteer practitioner emphasized how the family is of importance in the delivery of community EOL care. However, they prioritized the role of the family in this case as providers of EOL care (rather than as recipients):

Family is of most concern to enhance the quality of EOL care. Community support, to some extent, is limited for dying persons. Family is the most fundamental resource of support for EOL care. Volunteers cannot go on home visits every day. Hence, I feel family and community is a complimentary relationship. More importantly, the collaboration between family and volunteers can make the dying person happier and more meaningful. (s7)

As family members of dying persons are positioned as the primary “players” in community EOL care (and in the context of a system with limited formal resources), fostering collaboration with families is regarded as one the most effective ways to enhance the quality of dying experience. In particular, many needs of dying persons stem from, and/or are closely associated with family relationships. An 80-year-old current service user of Life Rainbow shared her ultimate goal of talking about death and dying matters, which is still closely related to her children.

Regarding my end of life care matters and funeral arrangements, I don’t find it difficult to talk with my children [after the encouragement from the social worker]. But I am waiting for the right timing to do so...I think the most challenging part about this is to wait for all of my children gathering together [the life in Hong Kong is extremely fast and busy, so the whole family rarely can attend family gatherings regularly] and pleasant dialogue atmosphere as well. I am still waiting for this opportunity [to deliver my thoughts to my children]. (u16)

In that example, the current service user was keen to find the right timing and pleasant

atmosphere to talk about her thoughts of death and dying matters with her children.

Her ultimate goal (directly delivering her ideas of EOL care and funeral arrangements to her children) was closely associated with her family relationship. Moreover, her goal seemed to be very simple and straightforward. This is of profound importance to achieve a better quality of EOL care.

Fostering collaboration in the family setting, as it emerged in participant interviews in this study, could be differentiated into three levels, varying according to the depth of family participation. They are opening family dialogue, re-organizing the caring routine, and achieving final wishes. These will be discussed below.

### **Opening (Bridging) family dialogue**

Dialogue is the primary level of collaboration fostered among the family of dying persons, especially among those whose families have a lower level of familial social capital.<sup>67</sup> Familial social capital refers to aspects of internal family relationships grounded in symbolic exchanges, such as giving, receiving, and reciprocating (Prandini, 2014). Families with lower social capital are believed to more

---

<sup>67</sup> Prandini (2014) lists (based on the analysis of Italian population statistics) possible familial network factors shaping familial social capital. They are: 1) reduced size of care-sharing networks; 2) emergence of “sandwich-squeeze“ families, with adult members caring simultaneously for older and the younger generations; 3) need of aging adult members (parents) for care; 4) grandmothers increasingly overwhelmed by care responsibilities, given the simultaneous needs to help grandchildren and to be cared for because of their aging; 5) increasing numbers of caregivers but decreasing numbers of cared-for families of elderly people; 6) increasing numbers of cared-for families with children and employed mothers; 7) older helpers; 8) fewer caregivers and fewer cared-for families; 9) increasing financial help, mostly for younger families; 10) increasing help for children; 11) less time and help for adults; 12) more women engaged in care practices.

commonly encounter “ambivalence<sup>68</sup>” (De Carlo & Widmer, 2011; Maio, Fincham, Regalia & Paleari, 2003; Prandini, 2014). Through engaging those families in particular in joint discussion, practitioners position their work as attempting to facilitate communication about EOL care matters among family members of a dying person. When trust and mutuality have developed in the previous service relationship, the dying person and her/his core family caregivers are accustomed to the presence of the practitioners and recognize them as trustful companions. Then, practitioners encourage the family to talk about EOL care arrangements, which represents an “ice-breaking” moment for many families with lower familial social capital. One practitioner shared their experience of “opening” (initiating) a family dialogue about the long-term care of a widow, with her adult children:

I observed the client [an old gentleman] at the end of his life, and his [older] wife ... I was not worried about who took care of the client [his wife had done an excellent job]. However, my social worker colleague and I were concerned about how to facilitate the children’s responsibilities for taking care of the wife when she became bereaved, as the two daughters were living in Canada. Recently, they came back to arrange their father’s funeral ceremony... The most important task is to open a discussion among the family members. The children do not treat me as a stranger because they know who I am. One time, I had chatted with one of them on the phone when I was visiting the client’s home. She [the daughter] knows the general workflow of our home visit and how the visit helps her mother... On the day I met the daughters, we were

---

<sup>68</sup> A situation when the normative expectation of family obligation does not match the individual expectation (De Carlo & Widmer, 2011). In modern societies, ambivalence stems from conflicts, power relationships, and interpersonal stress in familial relationships (Beck & Beck, 1999; Widmar, 1999). These family relationships are not fully cooperative or conflictual (Widmer, 1999).

familiar with each other. Although I did not have much time to talk very profoundly in our discussion [this was during a routine service visit], I felt that we did not have any reservation and difficulty to start the conversation about their mother's care. We exchanged the ideas and views [about the long-term care of the mother] effectively in the discussion. (s13)

Through their previous communications with the client and the family, this practitioner believed that the family members valued the practitioner's viewpoints. The practitioner also found that by engaging in family discussion in this case, the future long-term care of the bereaved mother was directly enhanced. The practitioner positioned herself in this encounter as activating some level of family support through dialogue, and as bringing to the attention of the children (who live at a distance and do not actively share the caring work) and valuable firsthand information about their mother's condition and needs.

To open broader, emotionally open dialogue between and among family members directly, in the hopes of fostering collaboration, practitioners also at times sought to build what they called "bridges" of communication between family members. In other words, practitioners try to facilitate communication between the family members and the dying person towards the end of life. For example, one practitioner spoke of assisting family members in expressing love to a dying father:

I believe expressing appreciation to the dying person is the most important [in EOL care]. However, sometimes the style of communication among the children makes it difficult for them to show love to their dying father. My role is bridging up their communication to help them express love. I think it is a good thing (s12)

Bridging communication between family members was believed by practitioners to serve an essential role at the client's EOL, even when this was merely facilitating family expressions of regret or appreciation. For this same practitioner, the importance of this was tied to her personal experience in this regard:

I recognize that we [practitioners] have a role in helping enhance the client's family relationships. Maybe the family has not had a chance to express their love for the dying person clearly. With our help [telling the dying person what the family members think and encouraging family members to express their gratitude directly], they usually can say thank you or sorry to the dying person at the end of life. That helps the family release a lot. I have a personal experience with my father (with this), so I feel it is crucial in EOL care. (s12)

The same practitioner further elaborated on their role in actively serving as a bridge in a slightly different sense of the term – through providing regular phone updates to family members who lived abroad.

Successfully relaying information between family members and encouraging family communication is premised on service relationships of trust and previous patterns of mutual exchange. In these relationships with service providers, family members feel more comfortable sharing their more personal emotions and thoughts with the practitioner and accept the practitioner's role in helping convey this to the dying person. Collaboration, in this sense, involves the family member and the

practitioner's co-creation of a 'good death' – based on the condition of saying “final words” to the dying person.

Invoking a neutral yet “professional status” was one strategy used by practitioners to help open family dialogue, especially when some family members remained skeptical of other family members' plans for the dying person. In these situations, a professional, as an authority, exert their power in interactions, facilitating family consensus. A former service user shared how her elder sister's maid was instructed about how to provide care for her mother at her elder 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)

This kind of intervention (which involves ‘lending power’) was regarded by practitioners as more critical when families themselves tend to have more distrustful and conflictual, rather than cohesive relationships. Usually, this approach (third-party professional intervention in family dialogue) was used when practitioners viewed it as essential to ensure that all family members worked together to perform caring

obligations<sup>69</sup>.

### **Activating family to provide more intensive and appropriate EOL care**

Beyond opening and bridging family dialogue, social agency staff believed they can foster collaboration through actively helping to enable the family to provide more, and better, EOL care; the success of this hinges on having developed trust and mutuality. Professionals in this study recognized that family members often struggle with providing care daily, and sought to help them improve how they manage care routines (e.g., to provide better, more efficient care). In this regard, practitioners spoke of needing to find the “right person” in the family to deliver care-related information and skills. This enacts the bridging function of social capital and helps normalize EOL care within dying persons’ families (Lewis et al., 2013; Sawyer, Sallnow, Kupeli, Stone, & Sampson, 2019).

In particular, practitioners spoke of developing family members’ professional skillset, imparting them with accurate information and practical support to handle care. This action specifically addressed informational needs to activate the family members to provide better EOL care routines. A social worker in one community

---

<sup>69</sup> The complexity of this case is that the client did not live with her dying mother, but had been the major EOL carer in the family for a decade. Her siblings (especially her elder brother and sister) possessed resources to handle the caring work, but had come to rely on the client. The client did not have great power to mobilize familial relational resources. For example, her dying mother was living in the client’s elder sister’s home. Other siblings did not prioritize the caring work, and often did not return messages from the client about caring arrangements. Given this client’s imbalanced power in her family, she needed to borrow the authority from professional to mobilize the familial resources to share the caring work collectively.

EOL care program spoke about helping a client's family members care for the client's pressure ulcer wound:

Another case is about a client who often sat uncomfortably because he had a pressure ulcer wound. The domestic maid helping to take care of him did not notice this wound and did not know how to take care of the wound either. ... the wound got worse day by day. Realizing this, we asked our nurse colleague to visit this family to help them find a solution. The nurse firstly spoke with the caregiver, and we taught all the family members how to clean the wound. With our provision of information and skills, the wound recovered quickly... during the visits, the nurse reminded the family members how to take care of the wound carefully and pay attention to the client's sleeping posture...[and] the nurse asked the family members took a photo of the wound every day. We decided if we should provide further support based on wound recovery. (s10)

With the trust and mutuality developed through the previous service relationship, the social worker learned about this problem as a result of her regular exchange of information with the client's family members. All parties accepted the nurse's training and monitoring of the family members and the domestic maid as a feasible and reliable solution (ensuring compliance to recommendations requiring them to re-organize the care routines). Through ongoing communication (photos of the wound), the family also helped the nurse assess progress in the healing; collaboration had been effectively fostered in this process.

As well as building on established relationships and trust, professionals deployed their professional/expert status, to reinforce specific messages, when re-organizing the

caring routines. Professionals viewed themselves as intervening in relationships between clients and family members, or between family members and privately hired staff, to provide expert recommendations to re-organize caring routines. One former service user described how the nurse helped reinforce the maid to handle her mother's pressure ulcer wound:

One time, a nurse in the hospital gave me a special tape to treat the injury of pressure ulcers. Initially, the nurse said this tape could be changed every two or three days. My mother was using a diaper and had a heavy dose of Diuretics. Therefore, the tape needed to be changed once it got wet...I asked the maid to take a photo of the wound and send it to me every day. But she often forgot to do so. Occasionally, the social agency program nurse told me that she wanted to look at the recovery of my mother's wound. I asked the nurse if she can do me a favour - to speak to the maid and reinforce with her the importance of taking photos [of the wound] every day. In this situation, I felt she helped me a lot in handling my mother's wound [monitoring the maid to use the special tape appropriately]. The recovery is finally apparent. (c15)

In this way, the social agency nurse engaged collaboratively with the family member is not just the re-organization of the caring routines, but in their reinforcement (including the work of the privately hired maid).

### **Achieving final wishes with family members**

In the previous chapter, "supporting actualization – the wishes of dying persons and their families" highlights how practitioners themselves provide tangible support to help actualize the wishes of dying persons and their families. In contrast, in this

chapter, “achieving final wishes” represents a higher-order aspect of collaboration that engages family more extensively towards activities designed to support the broader goal of the ‘good death.’ In this process, practitioners, clients, and family members *jointly* identify the goal (which could be a final wish), conceptualize a feasible plan, and *together* implement this plan. One practitioner described how she helped a dying person watch his daughter’s wedding ceremony:

I encountered a client whose daughter was getting married. However, the client’s physical condition is not good enough to attend the wedding ceremony in-person [the client revealed more than once that he wanted to join her daughter’s wedding ceremony]. We communicated with the ward manager and the physicians to allow our staff to remain in the ward outside of visiting hours. We used a computer to help the client watch the live-stream of the wedding ceremony to help finish his final wish. (s10)

Although the practitioners recognized the need for the client to attend his daughter’s wedding ceremony, they encouraged the family members to arrange live broadcasting of the ceremony at the wedding venue. Family members agreed it was worth trying to achieve his final wish. At the ward, the practitioners remained with the client to help set up the equipment to receive live broadcasting. Through collaboration between the practitioners and the family members, the client experienced a real-time wedding ceremony even though he was physically too weak to attend in-person.

Practitioners also worked together with dying persons to create memories for

family members. Another practitioner described collaborating with the client to organize one last party:

I think dying persons know they have limited time, so they are keen on finishing their final wishes before they die. I remember a client. She was initially a caregiver of her mother... overtime, she (the client) was diagnosed with cancer. She died earlier than her mother. One time, the client told us that she wanted to send her mother to a residential care home, to have more time to face the disease and finish her final wish. She did not tell her mother about her illness. In her last month of life, she said to us that she wanted to have a decent meal with her mother, but was very concerned about keeping her health condition secret. Therefore, we reserved a room in the hospital and brought the food there. We also arranged a car to bring her mother to the venue. We treated it as a party to celebrate something with the client and her mother. I remembered I help her to take some photos and videos to leave some video clips for her mother...After the party, I helped edit the images to make her complexion better. (s14)

The client, having identified her final wishes (to have a final good last meal with her mother), worked closely with the practitioner to implement the “party” (and was complicit in keeping the illness secret from her mother). Distinct from Western culture, nondisclosure is a culturally specific Chinese family relational practice for handling “bad news” from/to their loved ones, to protect other family members from distress (Mak, 2001; Tse, Chong & Fok, 2003). In this example above, the situation is complicated. The daughter perceived she would die earlier than her mother with dementia. In Chinese culture, loss of children to death (“white hair sends dark hair away”) is taboo; it is not a culturally natural order of life; in this case, parents of the

deceased child often do not even attend the funeral (Yick & Gupta, 2002). The client in this example did not want to increase her mother's emotional burden, so decided to keep her situation secret. Moreover, the practitioners respected the client's decision to not tell her mother about her condition.

In these kinds of ways, practitioners characterized their role in fostering collaboration as helping dying persons and their families to enhance the quality of death. In the context of complex family relationships, practitioners strove to foster collaborative opportunities both with and between family members, by opening family dialogue and bridging communication, activating families through deploying expert status and re-organizing care routines, and collaboratively achieving final wishes. In the next section, I will discuss how practitioners promote collaboration in relationships with medical professionals, again to enhance the quality of death.

## **II. Fostering Collaboration across Medical and Social Domains**

When trust and mutuality have been developed between medical professionals and social service practitioners (i.e., through multi-disciplinary case meetings), collaboration for community EOL care represents closer, more thorough inter-disciplinary exchange and coordination to establish a smooth workflow, work norms, and finish particular tasks. In this section, I will discuss three properties of fostering collaboration with medical professionals. They are linking up care resources in

communities, establishing ways of working together, and mobilizing joint effort towards a specific operational goal.

### **Linking up care resources in communities**

Collaborative teams crossing medical and social sectors can access a more comprehensive understanding of different care-related resources in communities, enhancing navigational support that can be accessed by clients (Kellehear, 2005).

Through developed social connections and expanded networks, teams can collaborate to refer clients to specific resources. Medical practitioners might, for instance, seek the expertise of a social service practitioner to strengthen their existing EOL care-related work in the community. With those supports, clients and family members can enact their own identities within their dying experience, instead of being limited to the identity of a ‘patient’ waiting for palliative treatments (Hockey & Draper, 2005; Mellor & Shilling, 1993). One social agency practitioner described one referral from the community nurse to the social worker to provide a patient escort service for a dying person:

The community nurse observed a client in the community who needed to have a follow-up with medical monitoring or support. For instance, the client did not have a capable person at home to help draw the blood sample or measure specific health indicators. The community nurse contacted us directly. They hoped we could arrange an escort service for the client at the date of follow up treatment. Although calling an ambulance is one way to enter the hospital, the

client would spend a significantly longer waiting time to go to the specialist clinic. (s5)

In this case, the result is that the hospital could reach community-dwelling patients more easily, with the help of the social service. Familiarity among professionals about the specific features of different services can enhance the dying person's functional support network. This linking or bridging of various care-related resources in the community strengthens overall service, in a mutually beneficial way (Sallnow, 2018).

As such, clients can become more autonomous in making decisions about their own EOL care (commonly identified as a feature of a 'good death' in contemporary societies) (Borgstrom, 2015). Presumably, this also opens up space for dying experiences to move beyond medical and professional control (Crawford, 1980; Kellehear, 2004).

Social service agency workers operate in other ways to link up or bridge different care-related services and therapies to enhance the quality of life of dying persons and their family members (Bartkus & Davis, 2010; Daly & Silver, 2008; Day, 2007). One community EOL nurse talked about how the social service program helps clients connect to community services:

We try to bring community resources to our [end of life care] clients. For example, support for cleaning wounds, referral to community nursing service. We help the client make an appointment as well. Moreover, we organize a

workshop for the caregivers of dying persons to release their stress. We also disseminate practical information and knowledge, such as how to push a wheelchair safely. Furthermore, we try to coordinate different kinds of resources to support the clients, which the clients may not be able to reach by themselves. If we encounter clients who have some economic difficulties, we help them apply for special subsidies. Therefore, we can bridge up different resources in the community to help our clients. (s11)

In other words, the social service agency tried to facilitate connection (access) to resources in the community and channel them to their clients. In this way, existing services could effectively reach potential clients, and clients' needs are more fully met. By so doing, clients access more community resources; a way of re-connecting with their own community towards their EOL and improving their well-being during this time (Lewis et al., 2013; Morris, Payne, Ockenden, & Hill, 2017)

### **Establishing ways of working together**

Fostering collaborative community EOL care also involves creating ways of working together; both medical and social service practitioners aligned their practice so that their work is a joint effort that also effectively draws on the complementary strengths of both medical and social services (Abrahm, 2001; Gwyther et al., 2005; Lee et al., 2019). For instance, social service practitioners might rely on medical practitioners as a backup when medical issues arise for their home-based clients. A social worker explained how he handled medical-related inquiries when establishing trust with a client:

With in-home visits, if we observe that the client has any needs, we can provide support promptly. And, if the client needs [medical] professional knowledge, we usually get further information through the hospital. This [collaboration experience] is the way we build up trust with our clients. (s6)

This social worker often engaged the hospital he closely worked with as a collaborative resource.

One of the principles of community EOL care is to enhance the quality of the dying person's social and family lives in communities. For example, clients might be encouraged to use their time in the community to visit their family members.

Although clients may need to enter a hospital palliative ward temporarily, the goal is that if their physical conditions improve again, they are encouraged to go home and enjoy their lives. Without effective collaboration with the hospital, these kinds of transitions are not smooth or coordinated. One PARACLETE social worker spoke about this idea of "workflow" or smooth functioning of community EOL care, and reinforced the sense of a division between medical and social responsibilities in the following excerpt:

Among our social worker and volunteer colleagues, we have sufficient training in knowing different symptoms of different diseases. They need to pay close attention to those in their practice. For the bigger picture [e.g., medical signs and management], we do not have much professional knowledge. When we realize this kind of problem, we usually encourage them to go back to the hospital. It is because our project [Paraclete] does not emphasize that our clients must choose to insist on dying at home. Instead, what we treasure is

providing opportunities for our clients to stay in their communities when their conditions are acceptable. Typically, the clients need to go back to the hospital to receive further professional care once their physical conditions are no longer allowable. (s5)

Having established trust and a sense of mutuality with staff at particular palliative wards in hospitals, social agency practitioners referred clients back to the hospital for further professional medical care to handle symptoms. They were more confident in addressing the social aspects of clients' lives in communities. This collaborative care united community efforts with palliative care to take a better care of "the whole person" and shift some power away from more medicalized conceptualizations of death and dying, as both parties recognize that dying involves both symptom management and maintaining social life (Kellehear & O'Connor, 2008).

Under the limitations of the new Hong Kong healthcare system, medical practitioners cannot do regular follow-up visits and monitor or even reach clients' family members when clients return to the community. They know little about the client's everyday lives or caregiver needs. Yet this knowledge is essential for their practice. As such, medical practitioners also sought to build up collaborative norms to work with social services, since social service practitioners can contact the client and their family members to go through those matters during home visits (Kellehear, 2013). In this way, the structure of the health care system reinforces medical-social distinctions while also creating the functional requirement for collaboration between

these sectors to reduce the drawbacks of “medical dominance” and encourage the “constructive medicalization” in EOL care (Broom & Woodward, 1996).

The same PARACLETE social worker quoted above described the community nurse’s expectation about addressing the emotional needs of a client’s husband when the client was readmitted to the hospital:

Sometimes, the community nurse knows that a client [that we both know] came to the hospital. And the condition of the client was getting worse. Since the nurse in the hospital had rarely met the client’s husband, this nurse expected us to help find him and provide more support for him, especially emotional and bereavement support. We had often encountered this client’s husband in the in-home visit. That’s why I feel there is a robust collaborative relationship between the hospital and our project in case handling. (s5)

The excerpt revealed an ordinary practice that fosters collaborative community EOL care - working together to close a service gap in the existing healthcare system. The hospital cannot reach the client’s family members if they do not accompany the client to the hospital. However, the social service practitioners can effectively reach these family members in their daily service routines, to support them. In the next section, I will discuss the third property of fostering collaborative care - mobilizing joint effort towards a clear shared operational goal.

### **Mobilizing joint effort towards a specific operational goal**

In 2015, the Hong Kong Hospital Authority updated its guidelines on Life-

Sustaining Treatment (LST) in terminally ill persons; a new section on Advance Care Planning (ACP) was added, recommending that ACP be initiated in several situations<sup>70</sup>, and with the consent of the individual terminally ill person (Tse, 2018). Quality communication is a prerequisite to ACP<sup>71</sup> discussions. However, medical professionals' training, skillset, and time demands make it challenging for them to initiate and have these discussions with dying persons and their family members.

One of the functions of the project "Life Rainbow" is to aid in ACP discussions, which the hospitals appreciate, since this helps in obtaining documentation about the client's values and preferences (information required on the form for the ACP scheme), which is also the shared goal of the social agency. As such, ACP represents an illustrative case example of mobilizing joint effort towards a specific operational goal.

Life Rainbow practitioners believe that completing the ACP form could enhance client autonomy in EOL decisions. A social worker in "Life Rainbow" referred to the feedback they receive from physicians:

---

<sup>70</sup> Specifically, following the diagnosis of a life-limiting condition with a rapid downhill course, early cognitive decline in dementia, significant disease progression, discontinuation of disease-targeted treatments, transition to palliative care, recovery from an acute severe episode of a chronic disease, following multiple hospital admissions, or when the patient becomes institutionalized (Hospital Authority, 2015; Tse, 2018).

<sup>71</sup> The scope of the discussion includes anticipated progression and prognosis of the illness, treatment options available and the benefits and risks, the patient's preferences and values regarding medical and personal care, and views and concerns of family members (Tse, 2018).

Recently, the physicians in Ruttonjee Hospital heard that we could help fill in the section of personal value in the ACP form. They [the physicians] know that this section is challenging to complete [because it is very time consuming and requires the helper to have high sensitivity]. Therefore, they hope we [the social workers] can help their team out to facilitate the patients to complete the whole section about psychosocial and personal value. (s10)

The nurse of “Life Rainbow” elaborated further on their role collaborating with hospitals, which has stemmed from the ACP scheme:

Now we are closely working with Ruttonjee Hospital on the ACP scheme. I think this is an excellent example of medical-social collaboration. We have joined the partnership for just a few months [from June to July in 2019]. On the ACP form ... there is a section on the client’s values. The medical practitioners cannot finish this section in a short time [it involves a tremendous amount of time to make sense of the client’s values and orientation]. The hospital, therefore, invited us to attend the first meeting between the client and the physician. We could listen to the conversation about the medical information section. In the second meeting, we [the social workers] usually talk with the client and their family members a day before the client meets the physician. We can manage to make sense of the client’s values, especially the information helpful to complete the ACP form. Then, when the client meets the physician, we will go through the section on personal values together and complete the form. In these few months, we have completed over ten forms from the ACP scheme with this collaboration model. (s11)

This organized example of medical-social collaboration is instrumentally driven by the need to complete the ACP form, yet can benefit the care of dying persons and their family members. The collaboration model, in this case, entails a clear division of labor between the physicians and the social workers, however. The shared operational goal (as mandated by the ACP scheme) is to encourage the clients and their family

members to participate in EOL care decision-making actively.

Social service practitioners involved in this collaboration actively promoted it.

For instance, the same social worker above explained:

Although we do not have formal meetings with the hospital, we regularly exchange practical wisdom and insights into the work of “Life Rainbow” with the nurses in the hospital. Say, we would show the photos of how the clients did exercise, or how the clients hang out [to improve the quality of life near the end of life] to let them know what we have done in last year. We also invited the client’s family members or our clients to share their experience of receiving the service. And also, we let the physicians know how other physicians collaborate with us ...in completing the ACP form. We further hope to foster the physicians to join this collaboration model, educate them to refer their patients to our project actively. (s10)

The social worker pinpointed the positive outcomes and implications of this kind of structured collaboration. For instance, physicians and nurses would learn more about the non-clinical role of social workers, and social connections in the community, in EOL care and ACP. The shared operational goal might be further consolidated through collaboration, thereby improving communication and social relationships between medical professionals and dying persons (and their family members).

In conclusion, this chapter has described the phase of mobilizing social capital through the practices of fostering collaborative care for and with dying persons and their families in the community. Building on trust and mutuality, the major actors in

community EOL care (social and medical practitioners, dying persons, family members) engage and consolidate a collaborative relationship towards a goal that jointly enhances the quality of death in the community, through re-connecting the dying experience with their own everyday life (Mellor & Shilling, 1993). Ideally, the consolidated relationship increases the participation of all parties, in complementary ways, in the dying experience. In family settings, the mutual collaboration between clients, their family members, and practitioners enhance family capacity to face death and dying matters in the community. Practices that foster cooperation in this regard are opening and bridging family dialogue, activating family to provide more and better EOL care, and jointly achieving final wishes with family members.

In practice settings, medical and social service practitioners build on mutual supportive relationships to collaborate in their service routines. Collaboration here is fostered by linking up care resources in communities, establishing ways of working together, and mobilizing joint effort towards a specific operational goal. From the perspectives of the study participants, community EOL care is conceptualized as promoting community attachment (mitigating detachment), as practitioners respond to needs and encourage dying persons and their family members to accept such needs. Through a collaborative care model, medical dominance can be more effectively mitigated (Broom & Woodward, 1996; Kellehear, 2013). The social processes include

establishing trust, cultivating mutuality, and fostering collaboration. The next chapter will discuss the theoretical implications from the findings of this study, which pertain to social capital, compassionate communities, as well as the broader policy and practice concerning the more comprehensive body of literature in this area.

## **Chapter Seven: Discussion and Conclusion**

### **Introduction**

Using grounded theory methodology, I analyzed qualitative data from in-depth interviews with practitioners (volunteers and employees), and to a lesser extent, from former and current service users affiliated with two community EOL care agencies in Hong Kong. The findings, presented in Chapters 4 through 6, illuminate the social processes and mechanisms involved in developing mediated, service-based relationships in community EOL care. In this final chapter, after briefly summarizing the key findings in this regard, I will discuss the significance for theory and practice relevant to community EOL care in Hong Kong. The findings provide a clear, parsimonious, three-stage model of relational social capital development (addressing a key precondition through establishing trust, facilitating accessibility through cultivating mutuality, and moving to mobilization through fostering collaboration). I will conclude this chapter and my dissertation by reflecting on the limitations as well as the strengths of this research and propose several directions for future research in this field.

### **I. Summary of Key Findings**

Through this research I strive to address one core issue - the influence of social relationships on the experience of EOL care. It shows that the quality of EOL

experience obviously improves through extracting the support and resources embedded in the client-practitioner social relationships, and activating the support and resources in the existing family, kinship, and friendship connections. This echoes the sociological discussion about the connections with others, both within and outside of our families, are one of the crucial determinants of a good death and more manageable bereavement (Glaser & Strauss, 1966; 1980; Kellehear, 2013; Lewis et al., 2013). This study, therefore, examines explicitly the complex social, interactional dynamics (processes) and mechanisms (strategies) entailed in service-based relationships between dying persons, their family members, and their broader social network (with a focus on community organizations), as well as relationships between social service agency workers and medical professionals (the latter having a more indirect effect on the quality of death and bereavement). Findings from this study have illustrated how resources in social networks are activated, especially through direct and symbolic aspects of communication in social interactions between practitioners and clients, and between social and medical professionals. As such, these findings illuminate these social processes and mechanisms in ways that allow us to theorize the relational, interactional experience of both supporting and being supported, as well as the potential implications for dying persons and their families in community EOL care in Hong Kong.

In establishing the relational context of EOL service – community detachment – Chapter 4 presented participants’ characterization of current social conditions as unfavourable and isolating for dying persons and their family members (this detachment included institutional, socio-cultural, and inter-personal dimensions). The findings then highlighted the process of service-based relationship development in the Hong Kong community EOL care as consisting of three major stages. Firstly, in interactions with dying persons and their family members, practitioners attempted to *establish trust* through boosting credibility and familiarity, responding actively to immediate everyday needs, and purifying the support relationship. Establishing trust can be viewed as a fundamental social process to engage dying persons and their family members and initiate community EOL care, which is the first step to mitigate the effects of community detachment for dying persons and their families, and to address a key precondition of social capital. My analysis of the interview data presented previously indicates how trust encourages continuous exchange and communication that benefits these relationships, which eventually helps to mobilize social capital to enhance the quality of death (Bolt, Verbeek, Meijers, & van der Steen, 2019; Gittell & Vidal, 1998; Rostila, 2011; Tonkiss, 2000; Woolcock & Narayan, 2000).

From participants’ perspectives, the outcome of establishing trust is that dying

persons and their family members welcome or accept service-based intervention; these relationships also represent a foundation for further relational development. In particular, Chapter 5 illustrated how social relationships - between social agency practitioners and dying persons/their families, and between social agency practitioners and medical professionals – in community EOL care develop through a further process of *cultivating mutuality*. In this stage, relationships progress beyond trust to a more intensive, continuous, and even mutual sense of exchange. The agents in these relationships have greater access to embedded relational resources in this stage, and thus mutuality, where it can be achieved, is essential for accessing and later activating social capital in community EOL care relationships.

Ideally, mutuality can be cultivated with service users through social-psychological processes rooted in frequent, cumulative dialogue and interaction. In trusting relationships with service users, practitioners strive to find social commonalities, embed themselves in daily caring routines, grant the wishes of dying persons and their families, and engage with clients' emotions. Cultivating mutuality through these activities can solidify and transform trusting relationships, as signified by clients' efforts demonstrating caring about the feelings of the practitioner and a sense of emotional security. These indicate the relationship has shifted from a one-way provision of compassion, care, and support for the dying persons and their

families to one more fully entailing mutual exchange, especially in terms of emotional and cognitive dimensions. Cultivating mutuality manifests relationality, rather than individualism, as the foundation of EOL care; in this way professionals strategically utilize continuous dynamic interactions between different social actors, believed to be key to improving EOL care experiences (Abel, Bowra, Walter & Howarth, 2011; Horsfall, Noonan, & Leonard, 2012; Horsfall, Leonard, Rosenberg & Noonan, 2017; Lewis et al., 2013; Mills, Rosenberg & McInerney, 2015; Sallnow, Richardson, Murray & Kellehear, 2016). However, another possible outcome is a client may remain estranged from mutuality, and both parties remain at a superficial level of exchange. Even worse, relationships with clients may become weakened and tense.

Chapter 6 described how social agency workers further built on mutuality, where it existed, to *foster collaborative care*, with the ultimate goal of enhancing the quality of death in the community and mitigate the negative impacts of community detachment. This represents the mobilization of social capital. Practitioners, in relationships with clients (and their family members) and practitioners, and with medical professionals, attempted to foster and leverage collaboration for improved case management and intervention outcomes. At this stage, relationships approximate partnerships, and social agency workers aim to promote family participation in community EOL care. The work involves facilitating, organizing, and mobilizing

based on the mutuality entailed in established, ongoing, trusting interactions with service users and medical professionals over time. Fostering collaborative care consists of opening (bridging) family dialogue, activating family to provide more, and better, EOL care, and jointly achieving final wishes with family members.

Fostering collaborative care reflects two crucial features of these higher- order service-based relationships in EOL care. First, the collaborative goals suggested by clients tend to pertain to everyday, ordinary wishes grounded in family relations; fundamentally, they are about enjoying family life, restoring broken family relationships, and conversations between family members. Indirectly, such wishes highlight the importance of family relationships as a determinant of a ‘good death.’ Second, the role of professionals - social workers - is perhaps most salient at the stage of fostering collaborative care, which involves more bridging and linking functions, which may be more suited to professional skills and knowledge. In addition, professionals deploy their expertise in specific ways to assist clients with family-related challenges. Volunteers, at this stage, may continue developing the agency’s bonds with clients, but may be less well-suited to the process of fostering collaboration.

Overall, the findings from this study help us understand the social context in which relationships in community EOL care progressively develop, while also

delineating specific features of this relational development, as social agency workers strive to activate social connections around the dying persons and their family members. This context including social situational, socio-cultural, and interpersonal features represents an aspect of structural variation, even as there may also be positional variation at the individual or family level (Sawyer, Sallnow, Kupeli, Stone & Sampson, 2019). In the local social conditions of Hong Kong, this context, characterized here as that of community detachment, primarily presents a structural barrier both for developing relationships as well as promoting quality EOL care. Dying persons and their family members in this context find it difficult to share their feelings with others, feel supported by community members and institutions, and mobilize social network resources. Nonetheless, it is important to acknowledge the potential for contextual variation between Hong Kong and other regions, and to consider how these might shape relational processes and social capital development in different ways, with implications for community EOL care.

Equally if not more important, this study delineates the progressive features of relationships in EOL care situations. Relationships, as characterized by participants in this study, generally progressed, over time and with mutual effort, along a three-stage developmental sequence, from establishing trust to cultivating mutuality, to fostering collaborative care. This finding echoes Sallnow and Paul's (2015) *spectrum of*

*engagement* in EOL care, which outlines steps towards achieving more effective health and social outcomes, through a range of progressive categories such as information, consultation, co-production, collaboration, and empowerment. Specifically, engagement progresses through relational development that involves the accumulation and activation of relational resources, such as volunteer support from the community, interdisciplinary acceptance between professionals, and advocacy with officials and policy-makers (Baugher, 2015; Pfaff & Markaki, 2017; Sallnow, 2018). However, in community EOL care, sometimes the exchange is more asymmetric than would be ideal in models of collaborative relationships – for instance, most support flows in the direction of practitioner to client (Lin, 2001b; Lin, Cook & Burt, 2001; Misztal, 2013). A broader understanding of social exchange in community EOL care recognizes how dependence, commitment, and power in the relationship determine the balance of social exchange (Cook, Cheshire & Gerbasi, 2006). This finding suggests the need for future research to explore how various strategies and tactics in both symmetric and asymmetric social interactions shape negotiations, service-based interventions and outcomes (Vasconcellos-Silva, Rivera & Siebeneichler, 2007).

## **II. Theoretical Implications**

Relationship development can be considered a vital “ingredient” to mitigate

community detachment in EOL care. The findings from this study provide a meso-level (i.e., bridging interpersonal and community levels) theorization about the processes and mechanisms involved in specific interactions between practitioners and dying persons and their families, as well as between social agency workers and medical professionals. In this section, I will elaborate on how the findings from this study provide further theoretical understanding in terms of the conceptualization of both social capital and compassionate communities in community EOL care.

### **Additional “ingredients” important for conceptualizing social capital**

In this study, I adopted the lens of social capital to help with theorizing the relationships among practitioners, dying persons, and family members, as well as between social agencies and medical professionals. After reviewing the literature, I concluded that Lin’s conceptualization could be a particularly useful framework in this regard (Häuberer, 2011). It is my position that an abductive, substantive theory can be synthesized using Lin’s conceptualization of social capital. I have visually modeled this in Diagram 7.1.

First of all, Lin’s model (1999) identifies trust (along with collective assets and structural/positional variation) as an important precondition for accessing and mobilizing social capital. Similar to Lin and particularly to Putnam (2001), the findings from the present study identify trust as a paramount precondition for

developing social capital. In the localized setting of community EOL care, the emphasis has been on how “general trust” is established through joining and participating in voluntary associations (e.g., Putnam, 2001). Findings from the present study indicate how establishing trust – between service users and service providers - is processual, dynamic, and sometimes strategic. It includes clients’ interactional feedback about the practitioners’ efforts to boost credibility, actively respond to immediate needs, and purify the support relationship. The processual and dynamic features of establishing trust are, I believe, essential when considering Lin’s conceptualization of this precondition for social capital.

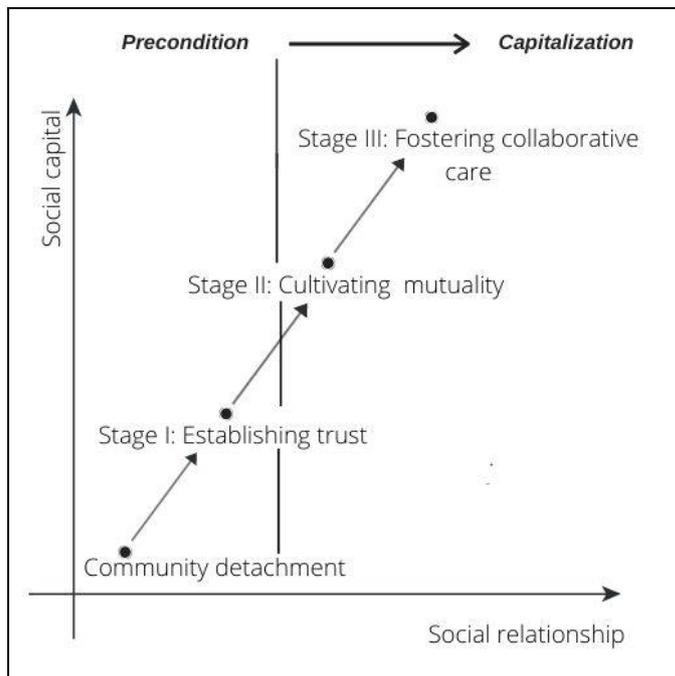


Diagram 7.1  
Synthesizing Lin’s (2001)  
conceptualization of social  
capital with findings from this  
study

Second, the findings from this study aid in theorizing how “preconditions” (like trust) inform a broader process of “capitalization” in Lin’s framework, sometimes also referred to as “linking up” (see Diagram 7.1; Lin, 2001); a process envisioned as

involving both access to and use of social capital (Lin, 2001). Although capitalization is noted as a key process, Lin's overall model leans towards a more static presentation (see Diagram 7.2). It has not represented the dynamic social process involved in the cultivation of social capital. In the present study I sought to add a more complex understanding of "linking up" as a dynamic process. For instance, the process of cultivating mutuality (Chapter 5) can help us understand how social capital comes to manifest in the process wherein relational trust progresses into a more collaborative care relationship. Specifically, service user agents in trusting relationships with agency workers, through cultivating mutuality, can be viewed as accessing and further developing social capital. Importantly, cultivating mutuality involves highly strategic and situational management of social situations, the interaction order, and behaviours in interaction. Dramaturgical analysis may be a good conceptual tool to better understand the strategies, processes, and mechanisms involved in cultivating mutuality. The outcomes of mutuality - caring about the feelings of the practitioner, and feeling emotionally secure - manifest in these relationships, going beyond the one-way provision of embedded resources (Chapter 4) to approximate more continuous mutual exchanges over time. The relational agents build up a sense of belonging to the social connection. However, attempts to cultivate mutuality might not be sufficient. Instead, some relationships remain estranged from mutuality. In

these situations, the clients chose not to develop the social relationship further towards more in-depth social exchange. This situation, from the practitioners' perspective, might limit the clients' accessibility to social capital, especially given the limited time available to develop a more in-depth relationships and a higher-order collaboration towards shared goals in EOL care.

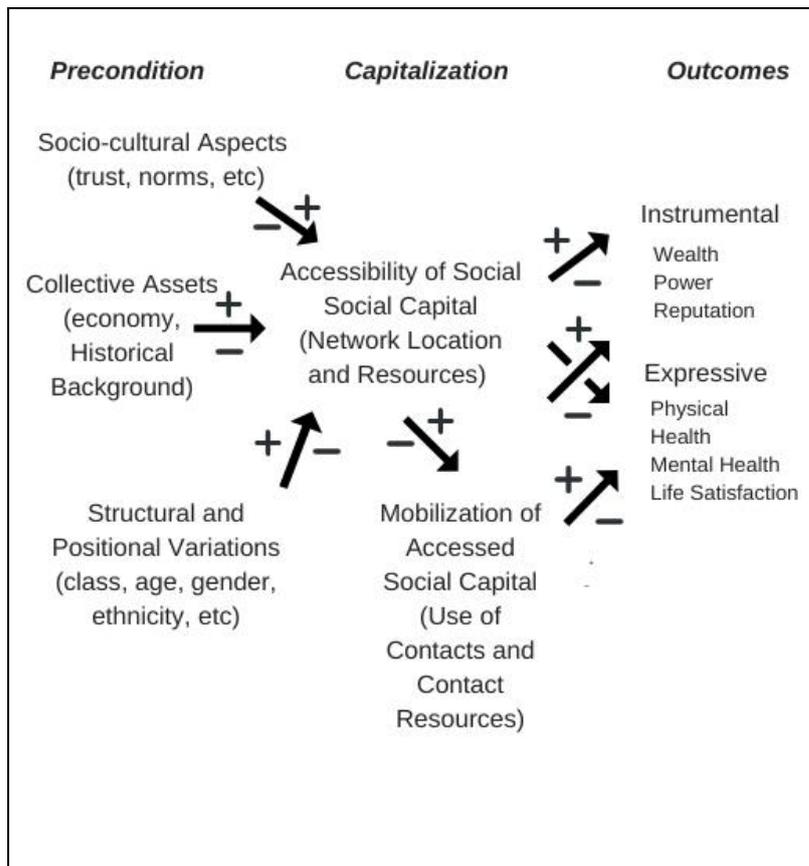


Diagram 7.2 Lin's (2001) model of social capital

Thirdly, in this study, I developed a substantive, grounded theory that delineates the close connection between the precondition of trust, and both the accessibility to and mobilization of social capital. Lin (2001) proposed that future studies may attempt to demonstrate such connections, and to articulate the causal sequence through which embedded resources constrain and enable individual action. In the

present study, my conceptualization identified how relationships progress from community detachment, to trust (precondition), mutuality (accessibility), and collaboration (mobilization). Where the condition is satisfied at one stage, another stage of development may start. Throughout this development sequence, the agents enable each other to access and activate more embedded relational resources towards a better experience of community EOL care.

In sum, I have identified three supplements or refinements to Lin's conceptual framework: 1) that establishing trust is not only a fundamental precondition but is a dynamic process, rather than static, in the context of social relationships; 2) that cultivating mutuality is a key process that connects established trust to the broader 'capitalization' of social capital, and 3) that there is perhaps a sequential or even developmental connection between different categories in the framework. Ultimately, however, I believe Lin's conceptual framework needs further research to achieve the best-fit explanation of the processes and mechanisms in community EOL care. There are other concepts that might also be useful, and in the next section I will deliberate whether the concept of compassionate communities might be helpful in further attempts to develop grounded theory.

### **Theorizing compassionate communities in relation to social capital**

The notion of compassionate communities was introduced in what is called "the

third wave” of public health advocacy, which emphasizes the inclusion of issues related to death, dying, and loss into health promotion activities and frameworks (Kellehear, 2004). Recently, public health scholars have begun to connect the concept of compassionate communities to the concept of social capital (Abel, 2018; Horsfall, Noonan, & Leonard, 2012; Kellehear, 2005). This conversation usually revolves around how to make good use of the resources and capacity embedded in community social networks (including informal networks) to improve EOL care (Abel, Bowra, Walter & Howarth, 2011; Horsfall, Leonard, Rosenberg, & Noonan, 2017; Rosenberg, Horsfall, Leonard & Noonan, 2015). In other words, social network resources, viewed with a compassionate community lens, are seen as having a vital function for achieving adequate, health-promoting community EOL care (Horsfall, Noonan & Leonard, 2012). In this section, I engage my findings in dialogue with the existing literature on compassionate communities. I will discuss the specific role of institutional support in developing compassionate communities, the relevance of “collective social capital,” and the contribution of (and need to understand better) social-medical collaboration in EOL care.

The findings of this study confirm the critical role of institutional support in compassionate community development, which relies on social capital processes to mobilize community members and institutions and build up support networks for

EOL care (Kellehear, 2013). Previous literature emphasizes how strategic investments in community engagement and capacity building can enhance social networks, promoting compassionate communities (Abel, Bowra, Walter & Howarth, 2011; Horsfall, Noonan, & Leonard, 2012; Horsfall, Leonard, Rosenberg & Noonan, 2017; Lewis et al., 2013; Mills, Rosenberg & McInerney, 2015; Sallnow, Richardson, Murray & Kellehear, 2016). Institutional (formal, organizational) support can help dying persons and their family members build up linking relationships in EOL care (Rosenberg, Horsfall, Leonard & Noonan, 2018; Rosenberg, Horsfall, Leonard & Noonan, 2015).

In the present study, social workers, volunteers, and clients (dying persons and their family members) could be viewed as jointly constructing a triadic relationship. In both of the community-based agencies that participated in this study, social workers served in the role of the case manager, overseeing clients' needs, connecting them to resources, managing the volunteers, and so on. In this sense, they acted as an agent at the structural hole,<sup>72</sup> providing support to the weak ties in the network structure (Burt, 2004). Volunteers themselves played a vital role in building up bonding connections with the clients, through accompanying, listening actively, and offering emotional support. In practice, although the volunteers regularly visited the

---

<sup>72</sup> A structural hole exists when an actor provides the only connection between other actors (Burt, 1992).

clients, the clients maintain close contact with the social workers, who channel different community resources to them (see Diagram 7.3) and deploy their professional expertise in particular ways. The division of organizational labour between the volunteers (visiting clients) and the social workers (overseeing the service and community resources) involves a form of interdependence that can help stabilize the network structure. This dynamic triadic relationship within the context of institutional support puts the function of the social network into practice.

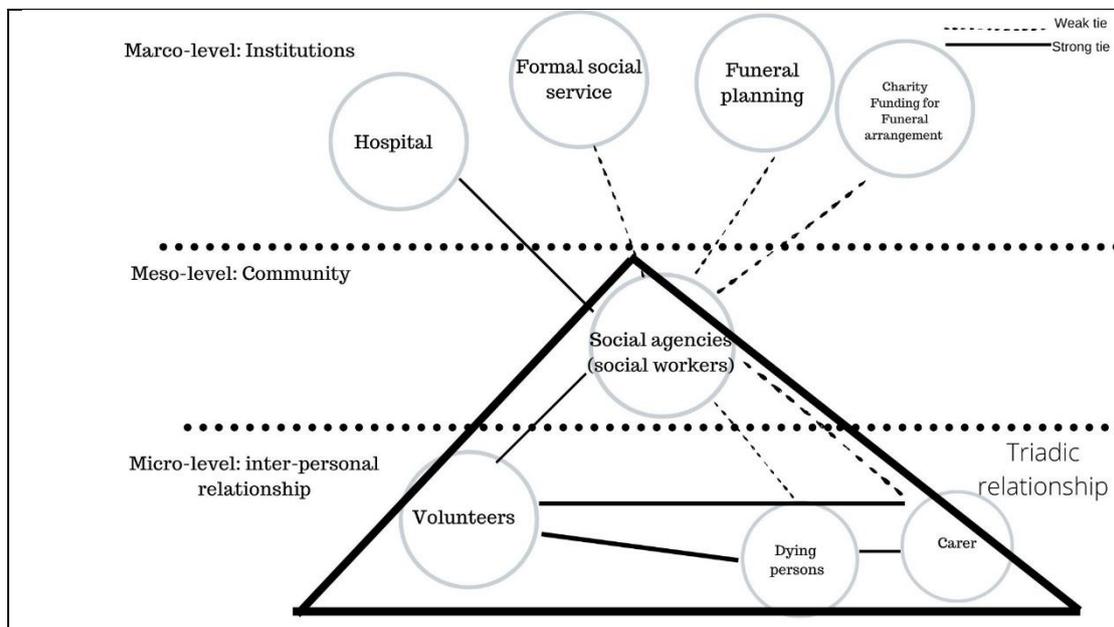


Diagram 7.3 The role of institutional support in the compassionate community development

Moreover, this study highlights how social capital development in community EOL relationships can occur outside of the traditional, more paternalistic relationship between dying persons and hospice<sup>73</sup>. Sallnow (2018) identified how “collective social capital” in compassionate communities redresses the power dynamics within

<sup>73</sup> In Hong Kong, hospice still refers to the medical oriented palliative care model, which has been discussed in Chapter 1.

provider-recipient relationships and creates space for reciprocal and mutual relations to emerge. The present study indicates the sequence or process of this emergence; specifically, the evolving reciprocal and mutual relationships (between social agency workers and service users) that needs to occur before embedded relational resources can be leveraged towards improving the quality of death in the community. In the details of the interaction, to some extent a subtle power relation still existed between social workers and clients, however. In this way professional images and interventions have implications for the EOL care experience.

The juxtaposition of the present study with Sallnow (2018) suggests two possible approaches to develop compassionate communities and meaningful community participation in EOL care. Sallnow developed an understanding of the social process of developing the capacity of community members (2018). In the present study, I identify how social networks around the dying persons and their family members are activated in the context of relationships mediated by institutional support. Considered together, these two studies demonstrate the potential of substantive theories of compassionate community development that are informed by the lens of social capital.

## **Social capital and social-medical collaboration in EOL care**

One of the core components of compassionate communities is how dying persons, their families, and the community are empowered to better handle death and dying, which is primarily a medicalized experience in modern society (Kellehear, 2007; Mellor, 1992; Mellor & Shilling, 1993; Wagleitner, Kellehear & Heimerl, 2015). In compassionate communities, collaboration between social and medical professionals is important to enhance quality of death (Pesut et al., 2018; Pesut et al., 2017). Since collaboration between different EOL care professionals generates the resources embedded in these relationships, the present study also uses the concept of social capital to theorize the phenomenon of *social-medical collaboration* in EOL care. Inter-disciplinary trust and partnership/teamwork are essential in cross-sector collaboration between professionals (Blacker & Deveau, 2010; Danielsen, Sand, Rosland & Førland, 2018). To have the most impact on community health outcomes, medical professionals from hospitals and hospices rely heavily on social agencies to help clients navigate access to resources and information (Pesut et al., 2018; Pesut et al., 2017; Bainbridge, Brazil, Krueger, Ploeg & Taniguchi, 2010). As such, the present study highlights the processes and interactional features of social-medical collaboration. For instance, being transparent and straightforward in cross-disciplinary interactions is identified as a vital element for reducing uncertainties and mitigating

administrative concerns in the early stage of relationship development between professionals.

Moreover, through the more performative aspects entailed in medical-social mutuality, professionals build teamwork through actively recognizing the relationship, as well as through more regular and formal knowledge and information exchange. In established relationships, facilitating collaboration entails a more distinct division of labour, ways to work together, and a shared mission and goals. However, further research is needed to learn how this sequential development of social-medical collaboration might work in different countries and socio-cultural contexts. Moreover, in the present study, the subtle power imbalance between medical and social professionals still appeared to be shaping approaches to, and the meaning of relationships in this context.

The findings of this study can help inform our understanding of how compassionate communities develop through the social capital processes reflected in institutionally mediated service relationships. This information could guide future development of interventions and has practical implications, as discussed in the next section.

### **III. Implications for Practice**

During a time in which the Hong Kong government appears to be concerned about

how to enhance EOL care in communities, findings from the present study can help inform policy related to community engagement in the care of dying people and their families in Hong Kong communities, institutionally mediated interventions made at earlier stages of the disease process could make it easier for dying persons and their family members to recognize their needs, and provide an opportunity for the first connection to community supports; at a population level over time, earlier intervention could work to reduce community detachment. Moreover, to address the general lack of community awareness of death/death literacy, additional funding and services should be put on those aspects to mitigate these aspects of community detachment.

At the organizational (operational service) level, I would recommend a roadmap for practitioners in engaging and developing relationships with clients. Especially in the Hong Kong context, relationality is a strong determinant of EOL care which emphasizes the actualization of personhood among dying persons; the latter requires improving dying persons' social networks and creating opportunities for continuous intersubjective interaction among community network members (Ellis, 2013; Kong, 2017). In this regard, the findings from this study provide a parsimonious, easy to understand three-stage model of relationship and social capital development (establishing trust, cultivating mutuality, and fostering collaboration). Using this model, practitioners can think about how to engage potential service users and their family

members, as well as the medical professionals, in the provision of community EOL care.

At the policy level, notions of social capital and compassionate community are useful to guide future policy development related to EOL care in Hong Kong. Social capital draws attention to the circulation and exchange of resources in relationships, identifying points of policy intervention. For instance, policymakers could encourage the development of social networks and infrastructure, and target responses to enable the building of social capital. They also could measure how the outcomes of quality of death related to social capital (e.g., trust, mutuality, and collaboration) to assist with policy and program evaluation (Halpern, 2005).

At the same time, the notion of compassionate communities, which emphasizes the power of collective effort and shared goals between individuals, families, and institutions (Kellehear, 2005), draws attention to the broader context of policy advocacy in Hong Kong. Other research indicates how the collective effort of compassionate communities can activate social networks and support dying persons and their families (Grindrod, 2020; Horsfall, Leonard, Noonan & Rosenberg, 2013; Labonte, 1999; Morris, Payne, Ockenden & Hill, 2017). As such, policymakers might consider how to promote the strengths of informal social support networks through policy, while also engaging formal, institutional service (Abel et al., 2013; Leonard,

Horsfall, & Noonan, 2015). In other words, a compassionate community does not solely rely on informal agents; institutional supports are also an important component.

Overall, in Hong Kong, community-based EOL care is still at the early stage of development (Hospital Authority, 2017). The Hong Kong government has an opportunity to take reference from the experience of other countries and to engage with existing theories and conceptual models to enhance the quality of death and bereavement in the community. This study suggests that understanding social relationship development is a previously underestimated component of both social capital and compassionate community EOL care.

#### **IV. Limitations, Future Research Directions, and Conclusion**

In this study, I sought to explore the complex dynamics and mechanisms of relationships between dying people/their families and formal network actors, as well as between the social service agencies and medical professionals. Three stages of development of these relationships in community EOL care were delineated, from the perspectives of those interviewed: establishing trust, cultivating mutuality, and fostering collaborative care. One fundamental limitation of this study concerns the sampling; ideally, I would have examined data from practitioners alongside and in comparison to that of service users and non-service users. However, as outlined in the methodology chapter, the social unrest in Hong Kong during the data collection

period, followed by the COVID-19 virus, severely constrained sampling and recruitment. As such, the data are primarily grounded in the perspectives of practitioners (volunteers and social workers). This means the analysis was inclined towards examining a mediated experience<sup>74</sup> of community EOL care. Relatedly, I was unable to access the perspective of medical professionals in the data collection because I could not establish rapport with the Hong Kong Hospital Authority (the gatekeeper). Through interviewing medical professionals, I might have gained more comprehensive insights about fundamental concerns and challenges in the relational development of medical-social collaboration in community EOL care.

Another critical challenge in this study was that the translation and linguistic presentation of data were particularly complicated. Although participants' comments are understood as grounded within a Hong Kong socio-cultural context (and analyzed from this perspective), the data needed to be translated into English, for presentation.<sup>75</sup> Although I am personally very familiar with the Hong Kong language and context, a main issue was how to accurately translate and represent the data in English in a way that retains the original meaning. For example, though I translated

---

<sup>74</sup> Refers to the social relationship with institutional actors involved.

<sup>75</sup> This has been mentioned in the methodology chapter. The translation may not have a huge effect on the theorization because to some extent the abstraction of theorization mitigates this translation effect, with the use of grounded theory methodology.

the data line-for-line before editing, some of the subtleties might still be lost in translation.

Several future research directions are indicated in this study. For instance, future research into how family relationships shape the quality of death would be promising, as most of the community EOL care goals identified by participants in the present study appeared to pertain to this – for instance, clients were seen as generally wanting to restore family relationships at the EOL stage, or make use of the family relational resources to achieve final wishes. In this process, the dynamics and mechanisms involved in family-level relational resources (family social capital) may be critical. This study also indicates the conceptual and theoretical convergence between symbolic interactionism, or other relational theorizations (e.g., Donati & Archer, 2015; Crossley, 2010; Emirbayer, 1997) and social capital in EOL care. This is also a significant future direction for scholarship.

Future sociologically informed research that advances theorization of compassionate communities (Sallnow, Bunnin & Richardson, 2015) in ways that engage with the conceptualization of social capital could also be fruitful (Hunter, Neiger, & West, 2011; Logan, Thornton, Kane & Breen, 2018; Wegleitner, Schuchter & Prieth, 2018). The present study represents an attempt to open these more

theoretical dialogues; as such, it may serve as a useful scholarly reference for future endeavours in this promising research area.

## References

- Abbott, A. (1988). Transcending general linear reality. *Sociological Theory*, 6(2), 169-186.
- Abel, J. (2018). Compassionate communities and end-of-life care. *Clinical Medicine*, 18(1), 6-8.
- Abel, J., & Kellehear, A. (2016). Palliative care reimagined: A needed shift. *BMJ Supportive & Palliative Care*, 6, 21-26.
- Abel, J., Bowra, J., Walter, T., & Howarth, G. (2011). Compassionate community networks: supporting home dying. *BMJ Supportive & Palliative Care*, 1(2), 129-133.
- Abel, J., Walter, T., Carey, L. B., Rosenberg, J., Noonan, K., Horsfall, D., Leonard, R., Rumbold, B. & Morris, D. (2013). Circles of care: Should community development redefine the practice of palliative care? *BMJ Supportive & Palliative Care*, 3, 383-388.
- Abrahm, J. L. (2011). Advances in palliative medicine and end-of-life care. *Annual Review of Medicine*, 62, 187-199.
- Adler, P. S., & Kwon, S. W. (2002). Social capital: Prospects for a new concept. *Academy of Management Review*, 27(1), 17-40.
- Ainsworth, M. D. S. (1991). Attachments and other affectional bonds across the life

- cycle. In C. M. Parkes, J. Stevenson-Hinde, & P. Marris (Eds.), *Attachment across the Life Cycle* (pp. 33-51). London: Routledge.
- Aldrich, D. P. (2017). The importance of social capital in building community resilience. In Yan W. & Galloway, W. (Eds.), *Rethinking Resilience, Adaptation and Transformation in a Time of Change* (pp. 357-364). Cham, Switzerland: Springer.
- Alexander, C., & Charles, G. (2009). Caring, mutuality and reciprocity in social worker—client relationships: Rethinking principles of practice. *Journal of Social Work*, 9(1), 5-22.
- Altimier, L. (2015). Compassionate family care framework: a new collaborative compassionate care model for NICU families and caregivers. *Newborn and Infant Nursing Reviews*, 15(1), 33-41.
- Alvarez, E. C., Kawachi, I., & Romani, J. R. (2017). Family social capital and health— a systematic review and redirection. *Sociology of Health & Illness*, 39(1), 5-29.
- Badger, F., Plumridge, G., Hewison, A., Shaw, K. L., Thomas, K., & Clifford, C. (2012). An evaluation of the impact of the Gold Standards Framework on collaboration in end-of-life care in nursing homes. A qualitative and quantitative evaluation. *International Journal of Nursing Studies*, 49(5), 586-595.
- Bainbridge, D., Brazil, K., Krueger, P., Ploeg, J., & Taniguchi, A. (2010). A proposed

- systems approach to the evaluation of integrated palliative care. *BMC Palliative Care*, 9(1), 8.
- Barbarlet, J. (2017). Dyadic characteristics of guanxi and their consequences. *Journal for the Theory of Social Behaviour*, 47(3), 332-347.
- Bartkus, V. O., & Davis, J. H. (Eds.). (2010). *Social capital: Reaching out, reaching in*. Northampton, MA: Edward Elgar.
- Baughner, J. E. (2015). Pathways through grief to hospice volunteering. *Qualitative Sociology*, 38(3), 305-326.
- Beck, U., & Beck-Gernsheim, E. (1999). *The Normal Chaos of Love*. Cambridge: Polity Press.
- Bentley, B., & O'Connor, M. (2015). Conducting research interviews with bereaved family carers: When do we ask? *Journal of Palliative Medicine*, 18(3), 241–245.
- Bentley, B., & O'Connor, M. (2015). Conducting research interviews with bereaved family carers: When do we ask? *Journal of Palliative Medicine*, 18(3), 241–245.
- Blacker, S., & Deveau, C. (2010). Social work and interprofessional collaboration in palliative care. *Progress in Palliative Care*, 18(4), 237-243.
- Blunden, A. (2004). Social solidarity versus “social capital.” *The Ethical Politics*

*Home Page*. Retrieved from:

<https://www.ethicalpolitics.org/ablunden/pdfs/social.pdf>

- Boggs, C. (2002). Social capital as political fantasy. In McLean, S, Schultz, D. & Steger, M. (Eds.), *Social Capital: Critical perspectives on community and "bowling alone"* (pp.183-202). New York: New York University Press.
- Bolt, S. R., Verbeek, L., Meijers, J. M., & van der Steen, J. T. (2019). Families' experiences with end-of-life care in nursing homes and associations with dying peacefully with dementia. *Journal of the American Medical Directors Association*, 20(3), 268-272.
- Borgstrom, E. (2015). Planning for an (un) certain future: choice within English end-of-life care. *Current Sociology*, 63(5), 700-713.
- Borgstrom, E. (2015). Social death in end-of-life care policy. *Contemporary Social Science*, 10(3), 272-283.
- Borgstrom, E. (2016). Social death. *QJM: An International Journal of Medicine*, 110(1), 5-7.
- Boucher, N. A. (2016). Direct engagement with communities and interprofessional learning to factor culture into end-of-life health care delivery. *American Journal of Public Health*, 106(6), 996-1001.
- Bourdieu, P. (1977). *Outline of a Theory of Practice*. Cambridge, UK: Cambridge

University Press.

Bourdieu, P. (1984). *Distinction: A social critique of the judgement of taste*. London:

Routledge & Kegan Paul.

Bourdieu, P. (1985). The social space and the genesis of groups. *Information*, 24(2), 195-220.

Bourdieu, P. (1986) The forms of capital. In: Richardson, J. (Ed.), *Handbook of Theory and Research for the Sociology of Education*. Westport, CT: Greenwood Press.

Bourdieu, P. (1986). The forms of capital. In J.G. Richardson (Eds.), *Handbook of Theory and Research for the Sociology of Education* (pp. 241–258). New York: Greenwood.

Boutilier, R. (2017). *Stakeholder Politics: Social capital, sustainable development, and the corporation*. Stanford: Stanford University Press.

Brito-Pons, G., & Librada-Flores, S. (2018). Compassion in palliative care: a review. *Current Opinion in Supportive and Palliative Care*, 12(4), 472-479.

Broese van Groenou, M. I., & De Boer, A. (2016). Providing informal care in a changing society. *European Journal of Ageing*, 13(3), 271–279.

Broom, A. (2015). *Dying: A social perspective on the EOL*. London: Ashgate.

Broom, D. H., & Woodward, R. V. (1996). Medicalisation reconsidered: toward a

collaborative approach to care. *Sociology of Health & Illness*, 18(3), 357-378.

Brown, B. (2015). Towards a critical understanding of mutuality in mental healthcare:

Relationships, power and social capital. *Journal of Psychiatric and Mental Health Nursing*, 22, 829-835.

Brown, B. J. (2016). Mutuality in health care: Review, concept analysis and ways

forward. *Journal of Clinical Nursing*, 25(9-10), 1464-1475.

Brown, E., & Ferris, J. M. (2007). Social capital and philanthropy: An analysis of the

impact of social capital on individual giving and volunteering. *Nonprofit and Voluntary Sector Quarterly*, 36(1), 85-99.

Bruegel, I. (2005). Social capital and feminist critique. In Franklin, J (Ed.), *Women*

*and Social Capital*. Families & Social Capital ESRC Research Group, London.

Retrieved from

[https://www.lsbu.ac.uk/\\_data/assets/pdf\\_file/0007/9439/women-social-capital-families-research-working-paper.pdf](https://www.lsbu.ac.uk/_data/assets/pdf_file/0007/9439/women-social-capital-families-research-working-paper.pdf)

Bryant, A. (2009). Grounded theory and pragmatism: The curious case of Anselm

Strauss. *Forum: Qualitative Social Research*, 10(3). Retrieved from

<http://www.qualitative-research.net/index.php/fqs/article/view/1358>

Bryant, A. (2017). *Grounded Theory and Grounded Theorizing: Pragmatism in*

*research practice*. New York: Oxford University Press.

- Bryant, A., & Charmaz, K. (2007). Grounded theory in historical perspective: An epistemological account. In Bryant, A., & Charmaz, K. (Eds.) *The Sage Handbook of Grounded Theory* (pp. 29-57). London: SAGE.
- Burt, R. S. (1978). Cohesion versus structural equivalence as a basis for network subgroups. *Sociological Methods & Research*, 7(2), 189-212.
- Burt, R. S. (1982). *Toward a Structural Theory of Action: Network models of social structure, perception and action*. New York: Academic Press.
- Burt, R. S. (1992). *Structural Holes: The social structure of competition*. Cambridge, MA: Harvard University Press.
- Burt, R. S. (2001). Closure as social capital. In Dubos, R. (Ed.), *Social Capital: Theory and research* (pp.31-56). New York: Routledge.
- Burt, R. S. (2004). Structural holes and good ideas. *American Journal of Sociology*, 110(2), 349-399.
- Burt, R. S. (2005). *Brokerage and Closure: An introduction to social capital*. Oxford: Oxford University Press.
- Cain, C. L. (2012). Integrating dark humor and compassion: Identities and presentations of self in the front and back regions of hospice. *Journal of Contemporary Ethnography*, 41(6), 668-694.
- Campbell, C. (2000). Social capital and health: Contextualizing health promotion

- within local community networks. In Baron, S., Field, J. & Schuller, T. (Eds.), *Social Capital: Critical perspectives* (pp. 182-196). Oxford: Oxford University Press.
- Carroll, J. M., Santucci, G., Kang, T. I., & Feudtner, C. (2007). Partners in pediatric palliative care: a program to enhance collaboration between hospital and community palliative care services. *American Journal of Hospice and Palliative Medicine*, 24(3), 191-195.
- Chan, C. (2005). *Study on the Third Sector Landscape in Hong Kong*. Central Policy Unit, Hong Kong Special Administrative Region. Retrieved from [https://www.pico.gov.hk/doc/en/research\\_reports/3rd\\_ch01.pdf](https://www.pico.gov.hk/doc/en/research_reports/3rd_ch01.pdf)
- Chan, H., & Lee, R. P. (1995). Hong Kong families: At the crossroads of modernism and traditionalism. *Journal of Comparative Family Studies*, 26(1), 83-99.
- Charmaz, K. (2014). *Constructing Grounded Theory*. London: Sage.
- Chen, X. P., & Chen, C. C. (2004). On the intricacies of the Chinese guanxi: A process model of guanxi development. *Asia Pacific Journal of Management*, 21(3), 305-324.
- Chong, A.M. & Ng, G.F. (2010). Bridging social capital - Theories and practice. In S.H. Ng, Stephen Y. Cheung & Brahm Prakash (Eds.), *Social Capital in Hong Kong: Connectivities and Social Enterprise* (p. 75-98). Hong Kong: City

University of Hong Kong Press.

Chung, R & Yeoh, E. (2019). Policy directions for end-of-life care in Hong Kong. In

I. Chan, C. Fong, E. Wong, V. Lou, & C. Chan (Eds.), *The Foundation of*

*Community Based End-of-Life Care in Hong Kong* (pp. 41-56). Hong Kong:

The Jockey Club End-of-Life Community Care Project.

Coleman, J. S. (1987). Families and schools. *Educational Researcher*, 16(6), 32-38.

Coleman, J. S. (1988). "Social capital" and schools. *The Education Digest*, 53(8), 6-9.

Coleman, J. S. (1993). Equality and achievement in education. *British Journal of*

*Educational Studies*, 41(4), 438-440.

Coleman, J. S., & Hoffer, T. (1987). *Public and Private High Schools: The impact of*

*communities* (Vol. 41). New York: Basic Books.

Cook, K, Cheshire, C. & Gerbasi, A. (2006). Power-dependence and exchange theory.

In Peter Burke (Ed.), *Contemporary Social Psychological Theories* (pp. 194-

216).: Stanford, CA.: Stanford University Press.

Crawford, R. (1980). Healthism and the medicalization of everyday life. *International*

*Journal of Health Services*, 10(3), 365-388.

Crossley, N. (2010). *Towards relational sociology*. London: Routledge.

Crul, M., Schneider, J., Keskiner, E., & Lelie, F. (2017). The multiplier effect: how

the accumulation of cultural and social capital explains steep upward social

- mobility of children of low-educated immigrants. *Ethnic and Racial Studies*, 40(2), 321-338.
- Daly, M., & Silver, H. (2008). Social exclusion and social capital: A comparison and critique. *Theory and society*, 37(6), 537-566.
- Danielsen, B. V., Sand, A. M., Rosland, J. H., & Førland, O. (2018). Experiences and challenges of home care nurses and general practitioners in home-based palliative care—a qualitative study. *BMC Palliative Care*, 17(1), 95.
- Day, R. (2007). Information connecting people with services: the information and referral role of community service organisations. *Australasian Public Libraries and Information Services*, 20(3), 103.
- De Carlo, I., & Widmer, E. D. (2011). The fabric of trust in families: inherited or achieved? In *Families and Kinship in Contemporary Europe* (pp. 216-233). London: Palgrave Macmillan.
- Dempers, C., & Gott, M. (2017). Which public health approach to palliative care? An integrative literature review. *Progress in Palliative Care*, 25(1), 1-10.
- Desan, M. H. (2013). Bourdieu, Marx, and capital: A critique of the extension model. *Sociological Theory*, 31(4), 318-342.
- Dewey, J. (1917). The need for a recovery of philosophy. In Dewey, J. (Ed.), *Creative Intelligence: Essays in the pragmatic attitude* (pp.3-69). New York: Holt.

Donati, P., & Archer, M. S. (2015). *The relational subject*. Cambridge, UK:

Cambridge University Press.

Donati, P., & Archer, M. S. (2015). *The relational subject*. Cambridge, UK:

Cambridge University Press.

Dowley, K. M., & Silver, B. D. (2002). Social capital, ethnicity and support for democracy in the post-communist states. *Europe-Asia Studies*, 54(4), 505-527.

Dudwick, N., Kuehnast, K., Jones, V. & Woolcock, M. (2006). *Analyzing social capital in context: a guide to using qualitative methods and data*. Washington,

D.C.: World Bank Institute.

Dyess, S. M., Prestia, A. S., Levene, R., & Gonzalez, F. (2020). An interdisciplinary framework for palliative and hospice education and practice. *Journal of Holistic Nursing*. Published online in advance of print at:

<https://doi.org/10.1177/0898010119899496>

Edwards, R., Franklin, J. & Holland J. (2003). *Families and Social Capital: Exploring the issues*. Families & Social Capital ESRC Research Group, London South

Bank University. Retrieved from

<http://www.payonline.lsbu.ac.uk/ahs/downloads/families/familieswp1.pdf>

Ellis, J. (2013). Thinking beyond rupture: continuity and relationality in everyday illness and dying experience. *Mortality*, 18(3), 251-269.

- Emirbayer, M. (1997). Manifesto for a relational sociology. *American journal of sociology*, 103(2), 281-317.
- Farkas, G. (2003). Cognitive skills and noncognitive traits and behaviors in stratification processes. *Annual Review of Sociology*, 29(1), 541-562.
- Fine, G. A. (2012). Group culture and the interaction order: Local sociology on the meso-level. *Annual Review of Sociology*, 38, 159-179.
- Flora, J. L. (1998). Social capital and communities of place. *Rural Sociology*, 63(4), 481-506.
- Flores, S. L., Molina, E. H., Osuna, J. B., Vargas, R. M., & Vicuña, M. N. (2018). All with You: a new method for developing compassionate communities-experiences in Spain and Latin-America. *Annals of Palliative Medicine*, 7, S15-S31.
- Forrest, R., La Grange, A., & Ngai-Ming, Y. (2002). Neighbourhood in a high rise, high density city: some observations on contemporary Hong Kong. *The Sociological Review*, 50(2), 215-240.
- Freidson, E. (1990). The centrality of professionalism to health care. *Jurimetrics*, 431-445.
- Fries, C. J. (2009). Bourdieu's reflexive sociology as a theoretical basis for mixed methods research: An application to complementary and alternative

- medicine. *Journal of Mixed Methods Research*, 3(4), 326-348.
- Froggatt, K. (2001). Life and death in English nursing homes: sequestration or transition? *Ageing & Society*, 21(3), 319-332.
- Fukui, S., Fujita, J., Ikezaki, S., Nakatani, E., & Tsujimura, M. (2019). Effect of a multidisciplinary end-of-life educational intervention on health and social care professionals: A cluster randomized controlled trial. *PloS One*, 14(8), e0219589.
- Fung, K. K., & Hung, S. L. (2014). Strengthening a community of poverty in an affluent society: strategies to build social capital in Tin Shui Wai North in Hong Kong. *Community Development Journal*, 49(3), 441-457.
- Funk, L. M. (2019) Fictive kin. In Gu, D., & Dupre, M.E. (Eds.,) *Encyclopedia of Gerontology and Population Aging*. Springer Publishing, Cham.
- [https://doi.org/10.1007/978-3-319-69892-2\\_16-1](https://doi.org/10.1007/978-3-319-69892-2_16-1)
- Funk, L.M., & Stajduhar, K.I. (2013). Analysis and proposed model of family caregivers' relationships with home health providers and perceptions of the quality of formal services. *Journal of Applied Gerontology*, 23(5), 318–28.
- Funk, L.M., Stajduhar, K., & Cloutier-Fisher, D. (2011). Exploring family caregivers' rationales for nonuse of formal home health services when caring for a dying family member. *Home Health Care Management and Practice*, 23(5), 318–28.
- Gale, N. K., Kenyon, S., MacArthur, C., Jolly, K., & Hope, L. (2018). Synthetic

social support: Theorizing lay health worker interventions. *Social Science & Medicine*, 196, 96-105.

Giddens, A. (1984). *The Constitution of Society: Outline of the theory of structuration*. Los Angeles: University of California Press.

Gittel, R., & Vidal, A. (1998). *Community Organizing: Building Social Capital as a Development Strategy*. Thousand Oaks, CA: Sage.

Glaser, B. (1992). *Basics of Grounded Theory Analysis: Emergence vs. Forcing*. Mill Valley, CA: Sociology Press.

Glaser, B. (2005). Basic social process. *Grounded Theory Review*, 4(3). Retrieved from <http://groundedtheoryreview.com/2005/06/22/1533/>

Glaser, B. (2008). The constant comparative method of qualitative analysis. *Grounded Theory Review*, 3 (7). Retrieved from <http://groundedtheoryreview.com/2008/11/29/the-constant-comparative-method-of-qualitative-analysis-1/>

Glaser, B. G. & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for qualitative research*. New York: Aldine De Gruyter.

Glaser, B. G. (1978). *Theoretical Sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.

Glaser, B. G. (1998). *Gerund Grounded Theory: The basic social process*

*dissertation*. Mill Valley, Ca.: Sociology Press.

Glaser, B. G. (2007). Remodeling grounded theory. *Historical Social Research*, Supplement, 19, 47-68.

Glaser, B. G., & Strauss, A. L. (1960). *Awareness of Dying*. New York: Routledge.

Glaser, B. G., & Strauss, A. L. (1980). *Time for Dying*. Chicago: Aldine Publishing.

Glaser, B. G., & Strauss, A. L. (2011). *Status Passage*. New York: Aldine.

Glaser, B.G. (1998). *Doing Grounded Theory: Issues and discussions*. Mill Valley, CA: Sociology Press.

Glaser, B.G. (2005). *Staying open: The use of theoretical codes in grounded theory*.

Grounded Theory Review, 1(5). Retrieved from

<http://groundedtheoryreview.com/2005/11/21/1487/>

Goffman, E. (1959). *The Presentation of Self in Everyday Life*. New York: Doubleday.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. London: Penguin.

Goffman, E. (1972). *Relations in Public: Microstudies of the public order*. New York: Basic Books.

Gott, M., Wiles, J., Moeke-Maxwell, T., Black, S., Williams, L., Kerse, N., &

Trussardi, G. (2018). What is the role of community at the EOL for people

dying in advanced age? A qualitative study with bereaved family carers. *Palliative Medicine*, 32(1), 268-275.

GovHK. (2020). *Hong Kong – The Facts*. Retrieved from <https://www.gov.hk/en/about/abouthk/facts.htm>

Grindrod, A. (2020). Choice depends on options: A public health framework incorporating the social determinants of dying to create options at end of life. *Progress in Palliative Care*, 28(2), 1-7.

Gwyther, L. P., Altilio, T., Blacker, S., Christ, G., Csikai, E. L., Hooyman, N., Kramer, B., Linton, J. M., Raymer, M., & Howe, J. (2005). Social work competencies in palliative and end-of-life care. *Journal of Social Work in End-of-Life & Palliative Care*, 1(1), 87-120.

Halpern, D. (2005). *Social Capital*. Cambridge: Polity.

Hammersley, M. (1992). *What's Wrong with Ethnography? Methodological explorations*. London: Routledge.

Harker, R., Bourdieu, P., Mahar, C., & Wilkes, C. (Eds.) (1990). *An Introduction to the Work of Pierre Bourdieu: The practice of theory*. New York: Palgrave Macmillan.

Häuberer, J. (2011). *Social Capital Theory: Towards a Methodological Foundation*. Wiesbaden: VS Research.

Hawkins, R. L., & Maurer, K. (2009). Bonding, bridging and linking: How social capital operated in New Orleans following Hurricane Katrina. *British Journal of Social Work*, 40(6), 1777-1793.

Hayami, Y. (2009). Social capital, human capital and the community mechanism: toward a conceptual framework for economists. *Journal of Development Studies*, 45(1), 96-123.

Hockey, J., & Draper, J. (2005). Beyond the womb and the tomb: Identity, (dis)embodiment and the life course. *Body & Society*, 11(2), 41-57.

Hong Kong Census and Statistics Department. (2020). Demographics. Retrieved from <https://www.censtatd.gov.hk/hkstat/sub/so160.jsp>

Hong Kong Hospital Authority. (2015). *HA Guidelines on Life-Sustaining Treatment in the Terminally Ill*.

Hong Kong Legislative Council Secretariat. (2018). *Research brief on the 2018-2019 budget of Hong Kong Special Administrative Region*. Retrieved from <https://www.legco.gov.hk/research-publications/english/1718rb02-the-2018-2019-budget-20180412-e.pdf>

Hong Kong Social Welfare Department. (2019). *Case Management Service*. Retrieved from [https://www.swd.gov.hk/en/index/site\\_pubsvc/page\\_rehab/sub\\_listofserv/id\\_sup](https://www.swd.gov.hk/en/index/site_pubsvc/page_rehab/sub_listofserv/id_sup)

portcom/id\_cms/

Hong Kong Social Welfare Department. (2020). *Carer Support Service*. Retrieved

from

[https://www.swd.gov.hk/en/index/site\\_pubsvc/page\\_elderly/sub\\_csselderly/id\\_c](https://www.swd.gov.hk/en/index/site_pubsvc/page_elderly/sub_csselderly/id_c)

[arersuppo/](#)

Horsfall, D., Leonard, R., Noonan, K., & Rosenberg, J. (2013). Working together–

apart: Exploring the relationships between formal and informal care networks

for people dying at home. *Progress in Palliative Care*, 21(6), 331-336.

Horsfall, D., Leonard, R., Rosenberg, J. P., & Noonan, K. (2017). Home as a place of

caring and wellbeing? A qualitative study of informal carers and caring

networks lived experiences of providing in-home end-of-life care. *Health &*

*Place*, 46, 58-64.

Horsfall, D., Noonan, K., & Leonard, R. (2012). Bringing our dying home: How

caring for someone at EOL builds social capital and develops compassionate

communities. *Health Sociology Review*, 21(4), 373-382.

Horsfall, D., Yardley, A., Leonard, R., Noonan, K., & Rosenberg, J. P. (2015). *EOL*

*at Home: Co-creating an ecology of care*. Penrith, NSW: Western Sydney

University.

Hospital Authority. (2017). *Strategic Service Framework for Palliative Care*.

Retrieved from [https://www.ha.org.hk/haho/ho/ap/PCSSF\\_1.pdf](https://www.ha.org.hk/haho/ho/ap/PCSSF_1.pdf)

Hung, A.P., Leung, K.K. & Ng, S.H. (2010). Social capital in Hong Kong since 1997.

In S.H. Ng, Stephen Y. Cheung & Brahm Prakash (Eds.), *Social Capital in Hong Kong: Connectivities and Social Enterprise* (p. 99-120). Hong Kong: City University of Hong Kong Press.

Hunter, B. D., Neiger, B., & West, J. (2011). The importance of addressing social determinants of health at the local level: the case for social capital. *Health and Social Care in the Community*, 19(5), 522-530.

Hyypä, M. T., & Mäki, J. (2003). Social participation and health in a community rich in stock of social capital. *Health Education Research*, 18(6), 770-779.

Isham, J., Kelly, T., & Ramaswamy, S. (Eds.). (2002). *Social Capital and Economic Development: Well-being in developing countries*. Northampton, MA: Edward Elgar.

Johnson, E. K. (2015). The business of care: the moral labour of care workers. *Sociology of Health & Illness*, 37(1), 112-126.

Jones, E. E., & Pittman, T. S. (1982). Toward a general theory of strategic self-presentation. In J. Suls (Ed.), *Psychological perspectives on the self* (Vol. 1, pp. 231-262). Hillsdale, NJ: Erlbaum.

Kalish, Y., & Robins, G. (2006). Psychological predispositions and network structure:

The relationship between individual predispositions, structural holes and network closure. *Social Networks*, 28(1), 56-84.

Kan, A. W. (1978). A study of neighbourly interaction in public housing: The case of Hong Kong. *Housing in Hong Kong: A Multidisciplinary Study Hong Kong*. Heinemann Educational Books (Asia).

Katz, E. & Lazarsfeld, P.F. (1955). *Personal Influence: The part played by people in the flow of mass communications*. New York: The Free Press.

Kawachi, I, Subramanian, S., & Kim, D. (2008) Social capital and health. In Kawachi I., Subramanian S., Kim D. (Eds.) *Social Capital and Health* (pp.1-26). New York: Springer.

Kellehear, A. (2004). Third-wave public health? Compassion, community and end-of-life care. *International Journal of Applied Psychoanalytic Studies*, 1, 313-323.

Kellehear, A. (2005). *Compassionate Cities: Public health and end-of-life care*. London: Routledge.

Kellehear, A. (2007). The end of death in late modernity: An emerging public health challenge. *Critical Public Health*, 17(1), 71-79.

Kellehear, A. (2013). Compassionate communities: end-of-life care as everyone's responsibility. *QJM: An International Journal of Medicine*, 106(12), 1071-1075.

Kellehear, A. (2014). *The Inner Life of the Dying Person*. Columbia University Press.

Kellehear, A., & O'Connor, D. (2008). Health-promoting palliative care: a practice example. *Critical Public Health*, 18(1), 111-115.

Kilduff, M., & Brass, D. J. (2010). Organizational social network research: Core ideas and key debates. *Academy of Management Annals*, 4(1), 317-357.

King, A. Y. (1985). The individual and group in Confucianism: A relational perspective. In D. J. Munro (Ed.), *Individualism and Holism: Studies in Confucian and Taoist Values* (p.57-72). Michigan: Center for Chinese Studies, University of Michigan.

Kolankiewicz, G. (1996). Social capital and social change. *British Journal of Sociology*, 47 (3): 427-441.

Kong, S.S. (2017). *Solving the "Personhood Jigsaw Puzzle" in End-of-Life care*.

Retrieved from

[http://ageing.hku.hk/upload/file/eol/29%20ECSWR%202017\\_conference%20presentation\\_EOLcare\\_14apr2017.pdf](http://ageing.hku.hk/upload/file/eol/29%20ECSWR%202017_conference%20presentation_EOLcare_14apr2017.pdf)

Kossinets, G., & Watts, D. J. (2009). Origins of homophily in an evolving social network. *American Journal of Sociology*, 115(2), 405-450.

Krállová, J. (2015). What is social death? *Contemporary Social Science: Journal of the Academy of Social Sciences*, 10(3), 235-248

- Kuziemsky, C. E., Downing, G. M., Black, F. M., & Lau, F. (2007). A grounded theory guided approach to palliative care systems design. *International Journal of Medical Informatics*, 76, S141-S148.
- La Grange, A. (2011). Neighbourhood and class: A study of three neighbourhoods in Hong Kong. *Urban Studies*, 48(6), 1181-1200.
- Labonte, R. (1999). Social capital and community development: practitioner emptor. *Australian and New Zealand Journal of Public Health*, 23(4), 430-433.
- Lau, S.K. (1981). Chinese familism in an urban-industrial setting: The case of Hong Kong. *Journal of Marriage and the Family*, 43(4), 977-992.
- Lau, S.K. (1982). *Society and Politics in Hong Kong*. Hong Kong: Chinese University Press.
- Lee, A. (2010). Social capital and health. In S.H. Ng, Stephen Y. Cheung & Brahm Prakash (Eds.), *Social Capital in Hong Kong: Connectivities and Social Enterprise* (p. 155-180). Hong Kong: City University of Hong Kong Press.
- Lee, J., & Ngai-Ming, Y. (2006). Public housing and family life in East Asia: housing history and social change in Hong Kong, 1953-1990. *Journal of Family History*, 31(1), 66-82.
- Lee, J., Árnason, A., Nightingale, A., & Shucksmith, M. (2005). Networking: social capital and identities in European rural development. *Sociologia Ruralis*, 45(4),

269-283.

Lee, S. K. (2009). East Asian attitudes toward death—a search for the ways to help east asian elderly dying in contemporary America. *The Permanente Journal*, 13(3), 55.

Lee, V. H. F., Lam, T. C., Jing, H. M., Liu, F., Zhang, Y. S., Huang, J. J., & Lee, A. W. M. (2019). Integrative palliative cancer care in Hong Kong: an overview and an example from the East. *Clinical Oncology*, 31(8), 589-594.

Leonard, R., Horsfall, D., & Noonan, K. (2015). Identifying changes in the support networks of end-of-life carers using social network analysis. *BMJ Supportive & Palliative Care*, 5(2), 153-159.

Leung, J. C. (2010). Social capital and community: a review of international and Hong Kong development. In S.H. Ng, Stephen Y. Cheung & Brahm Prakash (Eds.), *Social Capital in Hong Kong: Connectivities and Social Enterprise* (p. 121-154). Hong Kong: City University of Hong Kong Press.

Levi, M. (1996). Social and unsocial capital: A review essay of Robert Putnam's *Making Democracy Work*. *Politics & Society*, 24(1), 45-55.

Lewis, J. M., DiGiacomo, M., Currow, D. C., & Davidson, P. M. (2014). Social capital in a lower socioeconomic palliative care population: a qualitative investigation of individual, community and civic networks and relations. *BMC*

*Palliative Care*, 13(1), 30.

Lewis, J. M., DiGiacomo, M., Luckett, T., Davidson, P. M., & Currow, D. C. (2013).

A social capital framework for palliative care: supporting health and well-being for people with life-limiting illness and their carers through social relations and networks. *Journal of Pain and Symptom Management*, 45(1), 92-103.

Lin, N. (1973). *The study of Human Communication*. Indianapolis: Bobbs-Merrill.

Lin, N. (2001b). Guanxi: a conceptual analysis. In So, A. Y., Lin, N., Poston, D., &

Poston, D. L. (Eds.), *The Chinese Triangle of Mainland China, Taiwan, and Hong Kong: Comparative institutional analyses* (No. 133) (pp.153-166).

London: Greenwood Publishing.

Lin, N. (2008). A network theory of social capital. In Castiglione, D., van Deth, J. &

Wolleb, G. (Eds.), *Handbook on Social Capital* (pp.50-69). New York: Oxford University Press.

Lin, N. (2001). *Social capital: A theory of social structure and action*. London:

Cambridge University Press.

Lin, N., Cook, K. S., & Burt, R. S. (Eds.). (2001). *Social capital: Theory and*

*research*. New York: Transaction Publishers.

Lin, N., Ensel, W. M., & Vaughn, J. C. (1981). Social resources and strength of ties:

Structural factors in occupational status attainment. *American Sociological*

*Review*, 46(4), 393-405.

- Lin, N., Fu, Y. & Hsung R.(2001). The position generator: Measurement techniques for investigations of social capital. In Lin, N & Cook, K (Eds.), *Social Capital: Theory and research* (pp.57-81). New York: Aldine de Gruyter.
- Lin, N., Ye, X., & Ensel, W. M. (1999). Social support and depressed mood: A structural analysis. *Journal of Health and Social Behavior*, 40(4), 344-359.
- Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic Inquiry*. Newbury Park CA: Sage.
- Liu, F. (2006). Community palliative care in Hong Kong. In Chow, A.Y.M & Chan, C.L.W. *death, dying and bereavement: A Hong Kong Chinese experience* (pp. 183-195). Hong Kong, Hong Kong University Press..
- Logan, E. L., Thornton, J. A., Kane, R. T., & Breen, L. J. (2018). Social support following bereavement: The role of beliefs, expectations, and support intentions. *Death Studies*, 42(8), 471-482.
- Loury, G. (1977). A dynamic theory of racial income differences. In Wallace, P. A., & LaMond, A. M. (Eds.), *Women, Minorities, and Employment Discrimination* (pp.86-153). Lexington, MA: D.C. Heath and Company.
- Lum, T. Y., Lou, V. W., Chen, Y., Wong, G. H., Luo, H., & Tong, T. L. (2016). Neighborhood support and aging-in-place preference among low-income elderly Chinese city-dwellers. *Journals of Gerontology Series B: Psychological*

*Sciences and Social Sciences*, 71(1), 98-105.

Magasi, S., Buono, S., Yancy, C. W., Ramirez, R. D., & Grady, K. L. (2019).

Preparedness and mutuality affect quality of life for patients with mechanical circulatory support and their caregivers: A qualitative analysis. *Circulation: Cardiovascular Quality and Outcomes*, 12(1), e004414.

Maio Gregory, R., Fincham Frank, D., Regalia, C., & Paleari, F. G. (2003).

Ambivalence and attachment in family relationship. In P. Karl & L. Kurt (Eds.), *Intergenerational Ambivalences: New Perspectives on Parent-Child Relations in Later Life* (Vol. 4, pp. 285-312). Bingley, UK: Emerald Group.

Mak, M. H. J. (2001). Awareness of dying: An experience of Chinese patients with terminal cancer. *OMEGA-Journal of Death and Dying*, 43(3), 259-279.

Mauss, M. (1922). *The Gift: Forms and functions of exchange in archaic societies*. London: Routledge.

McCall, G. J., & Simmons, J. L. (1966). *Identities and interactions*. New York: Free Press.

McLean, S. L., Schultz, D. A., & Steger, M. B. (Eds.). (2002). *Social capital: Critical perspectives on community and "bowling alone"*. New York: NYU Press.

McPherson, M., Smith-Lovin, L., & Brashears, M. E. (2006). Social isolation in America: Changes in core discussion networks over two decades. *American*

*Sociological Review*, 71(3), 353-375.

McPherson, M., Smith-Lovin, L., & Cook, J. M. (2001). Birds of a feather:

Homophily in social networks. *Annual Review of Sociology*, 27(1), 415-444.

Mellor, P. A. (1992). Death in high modernity: the contemporary presence and

absence of death. *The Sociological Review*, 40(S1), 11-30.

Mellor, P. A., & Shilling, C. (1993). Modernity, self-identity and the sequestration of

death. *Sociology*, 27(3), 411-431.

Milligan, C. (2000). 'Bearing the burden': Towards a restructured geography of

caring. *Area*, 32(1), 49-58.

Mills, J., Rosenberg, J. P., & McInerney, F. (2015). Building community capacity for

end of life: An investigation of community capacity and its implications for

health-promoting palliative care in the Australian Capital Territory. *Critical*

*Public Health*, 25(2), 218-230.

Misztal, B. (2013). *Trust in Modern Societies: The search for the bases of social*

*order*. John Wiley & Sons.

Misztal, B. A. (2000). *Informality: Social theory and contemporary practice*. London:

Routledge.

Misztal, B. A. (2001). Normality and trust in Goffman's theory of interaction

order. *Sociological Theory*, 19(3), 312-324.

- Misztal, B. A. (2001). Trust and cooperation: the democratic public sphere. *Journal of Sociology*, 37(4), 371-386.
- Misztal, B. A. (2005). The new importance of the relationship between formality and informality. *Feminist Theory*, 6(2), 173-194.
- Mitchell, R. E. (1971). Some social implications of high density housing. *American Sociological Review*, 18-29.
- Montgomery, J. (2000). Social capital as a policy resource. *Policy Sciences*, 33(3/4), 227-243.
- Moore, S., & Kawachi, I. (2017). Twenty years of social capital and health research: A glossary. *Journal of Epidemiology and Community Health*, 71(5), 513-517.
- Morris, S. M., Payne, S., Ockenden, N., & Hill, M. (2017). Hospice volunteers: bridging the gap to the community? *Health and Social Care in the Community*, 25(6), 1704-1713.
- Morse, J. M. (2010). Sampling in grounded theory. In Bryant, A., & Charmaz, K (Eds.), *The Sage Handbook of Grounded Theory* (pp. 229-244). Los Angeles: Sage.
- Navarro, V. (2002). A critique of social capital. *International Journal of Health Services*, 32(3), 423-432.
- Noonan, K., Horsfall, D., Leonard, R., & Rosenberg, J. (2016). Developing death

literacy. *Progress in Palliative Care*, 24(1), 31-35.

Odella, F. (2006). *Using ego-networks in surveys: Methodological and research*

*issues*. Proceedings from International Conference on Network Science:

Retrieved from

<https://pdfs.semanticscholar.org/72d1/72da8629a3c8e7b0f7fcf51c6a01b6e44dd>

[7.pdf](#)

Oishi, A., & Murtagh, F. E. (2014). The challenges of uncertainty and

interprofessional collaboration in palliative care for non-cancer patients in the

community: a systematic review of views from patients, carers and health-care

professionals. *Palliative Medicine*, 28(9), 1081-1098.

Onyx, J., & Bullen, P. (2000). Measuring social capital in five communities. *The*

*Journal of Applied Behavioral Science*, 36(1), 23-42.

Pahl, R. (2007). Friendship, trust and mutuality. In Haworth, J., & Hart, G.

(Eds.), *Well-Being* (pp. 256-270). London: Palgrave Macmillan.

Pan, Y. & Ruan, D. (1995). Family networks in urban China. *Zhejiang Academic*

*Journal*, 3, 66-71.

Payne, S., Smith, P., & Dean, S. (1999). Identifying the concerns of informal carers in

palliative care. *Palliative Medicine*, 13(1), 37-44.

Pesut, B., Duggleby, W., Warner, G., Fassbender, K., Antifeau, E., Hooper, B., ... &

- Sullivan, K. (2018). Volunteer navigation partnerships: Piloting a compassionate community approach to early palliative care. *BMC Palliative Care*, 17(1), 2.
- Pesut, B., Hooper, B., Jacobsen, M., Nielsen, B., Falk, M., & O'Connor, B. P. (2017). Nurse-led navigation to provide early palliative care in rural areas: a pilot study. *BMC Palliative Care*, 16(1), 37.
- Pettigrew, T.F. (1998). Intergroup contact theory. *Annual Review of Psychology*, 49, 65-85.
- Pfaff, K., & Markaki, A. (2017). Compassionate collaborative care: an integrative review of quality indicators in end-of-life care. *BMC Palliative Care*, 16(1), 65.
- Portes, A. (1998). Social capital: Its origins and applications in modern sociology. *Annual Review of Sociology*, 24(1), 1-24.
- Portes, A. (2000). The two meanings of social capital. *Sociological Forum*, 15(1), 1-12.
- Power, A. & Skinner, M. (2019). Voluntary sector and urban health systems. In V., Igor, L. A., Pearson, G. Asiki., G.DeVerteuil & A. Allen (Eds.), *Handbook of Global Urban Health* (1st ed) (pp. 134-148). London: Routledge.
- Prandini, R. (2014). Family relations as social capital. *Journal of Comparative Family Studies*, 45(2), 221-234.

- Putnam, R. (1993a). *Making democracy work: Civic traditions in modern Italy*.  
Princeton: Princeton University Press.
- Putnam, R. (1993b). The prosperous community. *The American Prospect*, 4(13), 35-42.
- Putnam, R. (1995). Tuning in, tuning out: The strange disappearance of social capital in America. *Political Science and Politics*, 28, 664-683.
- Putnam, R. (1996). Who killed civic America? *Prospect Magazine*. Retrieved from <https://www.prospectmagazine.co.uk/magazine/whokilledcivicamerica>
- Putnam, R. (2000). *Bowling Alone: The collapse and revival of American community*.  
New York: Simon Schuster.
- Putnam, R. and K.A. Goss (2002). Introduction. In R. Putnam (Ed.) *Democracies in Flux: The evolution of social capital in contemporary society* (pp. 1–19).  
Oxford: Oxford University Press.
- Putnam, R. D. (2000). Bowling alone: America's declining social capital. In *Culture and Politics* (pp. 223-234). New York: Palgrave Macmillan.
- Rankin, K. N. (2002). Social capital, microfinance, and the politics of development. *Feminist Economics*, 8(1), 1-24.
- Reichertz, J. (2007). Abduction: The logic of discovery of grounded theory. In Bryant, A., & Charmaz, K (Eds.), *The Sage Handbook of Grounded Theory* (pp.

214-228). Los Angeles: Sage.

Rodrigues, C. T. (2011). The method of scientific discovery in Peirce's philosophy:

Deduction, induction, and abduction. *Logica Universalis*, 5(1), 127-164.

Roger, E. (1995). *Diffusion of Innovation* (4th ed). New York: The Free Press.

Rosenberg, J. P., & Yates, P. M. (2010). Health promotion in palliative care: The case

for conceptual congruence. *Critical Public Health*, 20(2), 201-210.

Rosenberg, J. P., Horsfall, D., Leonard, R., & Noonan, K. (2015). Informal caring

networks for people at EOL: Building social capital in Australian

communities. *Health Sociology Review*, 24(1), 29-37.

Rosenberg, J. P., Horsfall, D., Leonard, R., & Noonan, K. (2018). Informal care

networks' views of palliative care services: Help or hindrance? *Death Studies*,

42(6), 362-370.

Rostila, M. (2011). The facets of social capital. *Journal for the Theory of Social*

*Behaviour*, 41(3), 308-326.

Ruan, D. (1998). The content of the General Social Survey discussion networks: an

exploration of General Social Survey discussion name generator in a Chinese

context. *Social Networks*, 20(3), 247-264.

Sabatini, F. (2005): The empirics of social capital and economic development: A

critical perspective. *MPRA Paper* No. 2366. Retrieved from <http://mpra.ub.uni->

[muenchen.de/2366/](https://muenchen.de/2366/)

Sallnow, E. S. (2018). *Collective Social Capital: A study of new public health and end-of-life care* (Doctoral thesis, University of Edinburgh, Scotland, UK).

Retrieved from <https://era.ed.ac.uk/handle/1842/33037>

Sallnow, L., & Paul, S. (2015). Understanding community engagement in end-of-life care: developing conceptual clarity. *Critical Public Health*, 25(2), 231-238.

Sallnow, L., Bunnin, A., & Richardson, H. (2015). Community development and hospices: A national UK perspective. In K. Wegleitner, K. Heimerl & A. Kellehear (Eds.,) *Compassionate Communities: Case Studies from Britain and Europe* (pp. 1-14). London: Routledge.

Sallnow, L., Richardson, H., Murray, S. A., & Kellehear, A. (2016). The impact of a new public health approach to end-of-life care: a systematic review. *Palliative Medicine*, 30(3), 200-211.

Sampson, R. (1988), Local friendship ties and community attachment in mass society. *American Sociological Review*, 53, 766–779.

Sandgren, A. (2017). Complexities in palliative cancer care: can grounded theories be useful to increase awareness? *Grounded Theory Review*, 16(1). Retrieved from <http://groundedtheoryreview.com/2017/06/23/complexities-in-palliative-cancer-care-can-grounded-theories-be-useful-to-increase-awareness/>

- Sandgren, A., Thulesius, H., Petersson, K., & Fridlund, B. (2007). "Doing Good Care"—a study of palliative home nursing care. *International Journal of Qualitative Studies on Health and Well-being*, 2(4), 227-235.
- Saunders, C. (1991). *Hospice and Palliative Care: An interdisciplinary approach*. London: Edward Arnold.
- Sawyer, J. M., Sallnow, L., Kupeli, N., Stone, P., & Sampson, E. L. (2019). Social networks, social capital and end-of-life care for people with dementia: a realist review. *BMJ Open*, 9, e030703. doi: 10.1136/bmjopen-2019-030703
- Schmid, A. A. (2016) Social capital: critical perspectives. *Journal of Economic Issues*, 36(3), 824-826.
- Schuller T. (2001). The complementary roles of human and social capital. *Canadian Journal of Policy Research*, 2(1), 18-24.
- Schuller, T. (2007). Reflections on the use of social capital. *Review of Social Economy*, 65(1), 11-28.
- Schuller, T., Baron, S., & Field, J. (2000). Social capital: A review and critique. In S. Baron, J. Field & T. Schuller (Eds.) *Social capital: Critical perspectives*. Oxford: Oxford University Press.
- Schwadel, P., & Stout, M. (2012). Age, period and cohort effects on social capital. *Social Forces*, 91(1), 233-252.

- Simmel, G. (1950). The stranger. (K. Wolff, Trans.). *The Sociology of Georg Simmel* (pp.402-409). New York: Free Press. (Original work published in 1908)
- Simmel, Georg. (1908). "Exkurs über den Fremden". In *Soziologie: Untersuchungen über die Formen der Vergesellschaftung*. Leipzig: Duncker & Humblot.
- Sobel, J. (2002). Can we trust social capital? *Journal of Economic Literature*, 40, 139-154.
- Stajduhar, K., Funk, L.M., Cohen, S.R., Williams, A., Bidgood, D., Allan, D., Norgrove, L., & Heyland, D. (2011). Bereaved family members' assessments of the quality of EOL care: What is important? *Journal of Palliative Care*, 27(4), 261–69.
- Stiel, S., Pestinger, M., Moser, A., Widdershoven, G., Lüke, U., Meyer, G., & Radbruch, L. (2010). The use of grounded theory in palliative care: methodological challenges and strategies. *Journal of Palliative Medicine*, 13(8), 997-1003.
- Stiel, S., Pestinger, M., Moser, A., Widdershoven, G., Lüke, U., Meyer, G., & Radbruch, L. (2010). The use of Grounded theory in palliative care: methodological challenges and strategies. *Journal of palliative medicine*, 13(8), 997-1003.
- Strauss, A. L. & Corbin, J. (1998) *Basics of Qualitative Research: Techniques and procedures for developing grounded theory* (2nd ed.). London: Sage.

- Strübing, J. (2007). Research as pragmatic problem-solving: the pragmatist roots of empirically-grounded theorizing. In Bryant, A., & Charmaz, K. (Eds.), *The Sage Handbook of Grounded Theory* (pp. 580-601). London: Sage.
- Svendsen, G. L. H., & Svendsen, G. T. (2004). *The Creation and Destruction of Social Capital: Entrepreneurship, co-operative movements, and institutions*. Northampton, MA: Edward Elgar.
- Swann, C. & Morgan A. (Eds.) (2002). *Social Capital for Health: Insights from qualitative research*. London: Health Development Agency.
- Sweeting, H., & Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health & Illness*, 19(1), 93-117.
- Tan, S. B., Ng, C. G., Subramaniam, P., Lim, E. J., & Loh, E. C. (2012). Inner peace in palliative care patients: a qualitative study using grounded theory. *BMJ Supportive & Palliative Care*, 2(Suppl 1), A37-A37.
- The Economist Intelligence Unit Limited. (2015). *The 2015 Quality of Death Index: Ranking palliative care across the world*. Retrieved from <https://eiuperspectives.economist.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf>
- Thomas, G., Guthrie, D. & Wank D.L (2002). An introduction to the study of guanxi. In Thomas, G., Guthrie, D. & Wank D.L. (Eds.), *Social Connections in China :*

- Institutions, culture, and the changing nature of guanxi* (pp.3-20). New York: Cambridge University Press.
- Thornton, P. H., Ribeiro-Soriano, D., & Urbano, D. (2011). Socio-cultural factors and entrepreneurial activity: An overview. *International Small Business Journal*, 29(2), 105-118.
- Timmermans, S. & Tavory, I. (2012). Theory construction in qualitative research: From grounded theory to abductive analysis. *Sociological Theory*, 30(3), 167-186.
- Ting, W.F. (2010) The Praxis of social capital. In S.H. Ng, Stephen Y. Cheung & Brahm Prakash (Eds.), *Social Capital in Hong Kong: Connectivities and Social Enterprise* (p. 37-74). Hong Kong: City University of Hong Kong Press.
- Tonkiss, F. (2000). Trust, social capital and economy. In *Trust and Civil Society* (pp. 72-89). Palgrave Macmillan, London.
- Tracy, S. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry*, 16(10), 837-851.
- Tse, C. Y., Chong, A., & Fok, S. Y. (2003). Breaking bad news: a Chinese perspective. *Palliative Medicine*, 17(4), 339-343.
- Tse, C.Y. (2018). Advance care planning and advance directives in Hong Kong: Concepts and developments. *Casebook on Ethical Decision-Making in End-of-*

*Life Care of Older Adult*. Retrieved from <http://www.ioa.cuhk.edu.hk/en-gb/casebook/backgrounders/advance-care-planning-and-advance-directives-in-hong-kong-concepts-and-developments>

United Nations. (2017). *World Population Ageing*. Retrieved from [https://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2017\\_Highlights.pdf](https://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2017_Highlights.pdf)

Van der Gaag, M. (2005). *Measurement of Individual Social Capital*. PhD. Thesis, University of Groningen. Retrieved from: <http://dissertations.ub.rug.nl/faculties/ppsw/2005/m.p.j.van.der.gaag/?pLanguage=en&pFullItemRecord=ON>, accessed 7.9.2009.

Van der Gaag, M., Snijders, T. A. B. & Flap, H. D. (2008) Position generator measures and their relationship to other social capital measures. In Lin, N. & Erickson, H, (Eds.), *Social capital: An international research program* (pp.185-205). Oxford: Oxford University Press.

Vasconcellos-Silva, P. R., Rivera, F. J. U., & Siebeneichler, F. B. (2007). Healthcare organizations, linguistic communities, and the emblematic model of palliative care. *Cadernos de Saude Publica*, 23, 1529-1538.

Villalonga-Olives, E., Wind, T. R., & Kawachi, I. (2018). Social capital interventions in public health: A systematic review. *Social Science & Medicine*, 212, 203-

218.

Walther, M. (2014). *Repatriation to France and Germany: A comparative study based on Bourdieu's theory of practice*. Wiesbaden: Springer Gabler.

Webster, M. D. (2016). Examining philosophy of technology using grounded theory methods. *Forum: Qualitative Social Research*, 17(2). Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/2481>

Wegleitner, K., Kellehear, A., & Heimerl, K. (Eds.). (2015). *Compassionate Communities: Case Studies from Britain and Europe*. London: Routledge.

Wegleitner, K., Schuchter, P., & Prieth, S. (2018). 'Ingredients' of a supportive web of caring relationships at the end of life: findings from a community research project in Austria. *Sociology of Health & Illness*, published online in advance of print. Retrieved from: <https://doi.org/10.1111/1467-9566.12738>

Whitfield, K. (2018). Community capacity development to enhance hospice palliative care in Alberta, Canada communities: Evidence demonstrating the value of a community engaged model. *Annals of Palliative Medicine*, 7(Suppl 1), AB001-AB001.

Whitfield, K. Y., & LaBrie, M. (2017). Community capacity in EOL care: Can a community development model address suffering and enhance well-being? In Phillips, R., & Wong, C. (Eds.). *Handbook of Community Well-Being*

- Research* (pp. 275-289). Netherlands: Springer.
- Widmer, E. D. (1999). Family contexts as cognitive networks: A structural approach of family relationships. *Personal Relationships*, 6(4), 487-503.
- Wilson, J., & Brennan, R. (2010). Doing business in China: is the importance of guanxi diminishing? *European Business Review*, 22(6), 652-665.
- Wong, O., & Chau, B. (2006). The evolving role of filial piety in eldercare in Hong Kong. *Asian Journal of Social Science*, 34(4), 600-617.
- Woolcock, M. (1998). Social capital and economic development: Toward a theoretical synthesis and policy framework. *Theory and Society*, 27(2), 151-208.
- Woolcock, M. (2001). The place of social capital in understanding social and economic outcomes. *Canadian Journal of Policy Research*, 2(1), 11-17.
- Woolcock, M., & Narayan, D. (2000). Social capital: Implications for development theory, research, and policy. *World Bank Research Observer*, 15(2), 225-249.
- World Palliative Care Alliance. (2014). *Global atlas of palliative care at the end of life*. Retrieved from <https://www.who.int/ncds/management/palliative-care/palliative-care-atlas/en/>
- Yau, Y. (2010). Sense of community and homeowner participation in housing management: A study of Hong Kong. *Urbani Izziv*, 21, 126-135.
- Yick, A. G., & Gupta, R. (2002). Chinese cultural dimensions of death, dying, and

bereavement: Focus group findings. *Journal of Cultural Diversity*, 9(2), 32.

Zapart, S., Kenny, P., Hall, J., Servis, B., & Wiley, S. (2007). Home-based palliative care in Sydney, Australia: the carer's perspective on the provision of informal care. *Health & Social Care in the Community*, 15(2), 97-107.

## Appendix 1: Interview Questions

### A. Social Workers

1. Can you tell me a bit about your involvement with this group? (How/why they became involved, how they see their role)
2. Can you tell me a bit more about the group itself? (Objectives, challenges, etc)
3. What are the major needs of EOL care in the community (e.g., Hung Hom district)?
4. Tell me how you think people experience of community at the EOL? What does it mean to be part of a community as a family member of a person at the EOL?
5. Can you tell me a bit more about the role of volunteers in the group? How is this envisioned, and handled by the service?
6. Besides volunteering, what other social connections does the service help establish in the community?
7. How might social connections improve community EOL care? (Probes: bonding, bridging etc)
8. What is challenging about establishing social connections for community EOL? Can you give examples? How do you deal with this?
9. How do you see your own role in facilitating social connections for group members? Can you give examples?
10. How do you synthesize social connections more broadly, such as between different professional and non-professional agents in the community?
11. Tell me how you think people experience compassion during the EOL? What does it mean to experience compassion during this time?
12. What social policy would improve the current community EOL care?

### B. Volunteers

1. Tell me about your involvement with the mutual help group? (Probes: how/why did you get involved, how often do you volunteer, etc.)
2. How do you think people experience community at the EOL? What does it mean to be part of a community as a family member of a person at the EOL?
3. What do you find the most meaningful about your role in this group, and why?
4. Tell me a bit about what you've observed among the members of the group over time – do they come to start helping each other or not? Why/why not?
5. How do you help in that process? When and how do you intervene? Can you give an

example?

6. What kind of relationships do you see in the group? How and why does this change?
7. In what ways does this group help members? Can you give me some examples?
8. Are there negative outcomes of the group? Why? Can you give me any examples?
9. What do you think about the importance of social relationship in the experience of dying people and their families? Could you raise example of your personal or service experience to illustrate that?
10. Among family and community connections, which do you think is more important in improving the dying experience? Why do you think so? Could you raise some examples to illustrate that?
11. In your opinion, which type of social relationship improves the dying experience most? Why and how?
12. In your opinion, which type of social relationship harms the dying experience most? Why and how?
13. What do you think are the most fundamental implication(s) of social relationship on dying experiences?
14. How do you think people experience compassion during the EOL? What does it mean to experience compassion during this time?

### C. Current/former service users

1. First, can you tell me a bit about your involvement in this group (Probes – how/why did you seek help).
2. Did you feel the group was helpful? (How/why note e.g., did it help improve relationships, which ones; how else did it help)
3. How did you and your family member experience community while [your family member] was dying? What does it mean to be part of a community as a family member of a person at the EOL?
4. Before you came to the group, what were your social connections like? (Probes – size, types of connections, quality of connections, etc)
5. How were your family's social connections important in your family member's dying experience, if at all?
6. How important were these social connections to you as you experienced the dying of your family member?
7. Can you talk about what it was like, generally, going through this and providing care for your family member? (Probe for talk about social relationships and connections)
8. How did you navigate different resources in your community to help your family

member?

9. Which people and connections helped you most in your experience of taking care of the dying family member? Why? How did they help? Which were not helpful?

10. How did you and your family member experience of compassion during the time your family member was dying? What does it mean to experience compassion during this time?

11. Reflecting back on your experience, what are your thoughts about the role of social and community connections, in helping dying persons and their families through this process?

## Appendix 2: Sample of Memos

//Establishment of trust with users\_information

Establishment of trust with users\_emotional support

Establishment of trust with users\_accompanying//

In the first-round interviews, Paraclete staff spoke about establishing trust as a vital element in their intervention. During establishing trust, information provision, emotional support and accompaniment were delineated as effective practices.

information provision: for instance,  
information about funeral procedures

emotional support: for instance,  
skillful listening

accompanying: for instance,  
physically going along with bereaved clients

This work creates common experience, making the client feel secure and stable, and addressing tangible needs.

[20190621] This is also a potential direction in research on how social capital is created among users and volunteers. What are the socio-psychological processes in this area, how does this happen, are the interesting questions to be explored. The data has shown there are several determinants affecting the creation of trust.

I observed that "establishing trust" is a potential category within the data because all participants spoke of their experience of this in service provision. However, how service users conceive of this "help" from the volunteers, and how those helping behaviors can transmit or transform into the social psychological concept of "trust" might help us address how social capital is formed, in terms of the development of reciprocity and norms in the interpersonal relationship.

Sometimes, helping behaviours need to be controlled and managed because the volunteers need to consider their "role in the relationship". They tried not to "overact" in the support relationship. For example, they had a sense they should not

be 'more' than the client's family members and relatives. Doing so may have negative implications such as destroying the supportive relationship with the users.

But, in terms of the sequence of events, providing support and creating trust are the beginning of relational support. But, what is the "outcome" of this relationship, for instance, a stable emotional status? New norms for facing death in the family? This needs clarification in the coming interviews.

Emergent questions:

1. Why do participants believe a stranger and an encounter relationship can help them resolve their death and dying challenges in families, which are regarded as a personal issue in modern society?
2. Since social relationships should be a "reciprocal", what is the property of "social exchange" in the cultivation of helping relationships in this context?
3. What is the meaning of an "inclusive" dying experience based on the establishment of relational support?

Theoretical propositions:

1. Level of familiarity -ve ----> reciprocity (bridging relationship)
2. Material and non-material provision of help +ve--> feasibility of creating common experience +ve --> level of trust (bonding relationship)

//20190808//

In the second round of interviews, 4 interviews were done with two staff and two volunteers. Participants again spoke of how to establish trust with users.

Similar to the first round of interviews, the staff and volunteers make use of tactics of providing information and tangible support, emotional support, and accompanying. In addition, this time, the volunteers suggested two more dimensions or aspects of trust establishment - the timing of trust establishment and purifying the relationship. The former is about the duration of exchange and the temporal implication of exchange. For example, 'accompaniment' works until the user accept your presence in the relationship. This may take 3-4 visits. When the client gets worse, the family members often need more support, and trust also can establish more effectively during these more intensive exchanges.

In terms of purifying the relationship, the experiences of volunteers with community intervention suggests that they intentionally want to make the

relationship between the volunteers and users become a service provision relationship. The relationship does not involve any money, benefits and so on. With this "pure relationship" which is constructed as about altruism and social care, the users and their family members often have less reservation when receiving their help. Therefore, trust often can be easily established when the users and family members' needs can be responded to several times.

//Date: 25/8/2019

Core category: Establishing Trust

This category emerged from the data from volunteers and staff's interviews. They were talking about how to "engage" the users and the professional partners. What they first did is let the users and partners recognize them. Knowing their position and rationale, Paraclete wanted to enter into their daily routines (as 'users and partners'). In the interviews, participants mentioned that permission to enter the users' and professional partners' routine is not easy. Users (and professional partners) were often defensive, initially. How to open the conversation, how to try to let them believe the mutuality (next step) were believed to be important procedures in any collaboration.

In existing theoretical discussions of social capital, trust is one of the pre-conditions for the access and mobilization of social capital, according to Lin's model. With trust, people can build up ties and relationships with other people. The implications of this of tie building accumulates along with positive continuous exchanges. Moving towards expressive and instrumental outcomes.

Paraclete's staff and volunteers appear to make good use of strategies to promote quick engagement, along the trajectory of dying, with the dying people and their family members. I am not saying that trust cannot be established in the absence of any of these strategies. Some dying persons and their family members might find somebody in community they trust to support them. Rather, what Paraclete's staff said is that the intervention is more effective (i.e. don't need to wait until the "white knight" to come, by luck) to engage all the clients they encountered and help them manage their risk of distress in the dying process, which has limited time.

Conceptually, establishing trust could involve two dimensions. Firstly, trust towards the users. Secondly, trust towards professionals. After all, it is a "bridging" relationship, and Paraclete does not have a lot of exchange in the beginning;

Paraclete staff also do not have much common experience with those parties. Rather, the niche is that those parties need people to help them out to achieve a good death in community. Paraclete grasp the opportunity to be the agent linking up professionals and service users. Paraclete staff also made good use of their role and position to bridge up the resources to help both parties respectively.

Keeping transparent is one of the tactics.

Keeping responsive is one of the tactics.

Keeping reliable is one of the tactics.

Being kind is a core principle.

Being non-judgmental is a core principle.

When the users and partners recognize the relationship and acquire further resources from the relationship, this means their trust becomes established; it is about moving on to the next aspect of relationship, the mutuality.

### Appendix 3: Categories in the study

<b>Core category: the process of social relationships in Hong Kong community EOL care</b> Categories /Properties	1	2	3	4	5	6
<b>I. Community Detachment</b>						
1. A paucity of institutional support	S3	S3	S10	S2	S14	C15
2. A socio-cultural constraint: Death illiteracy and taboo in communities	S3	S4	S1	S1		
3. <u>Relational barriers and weak ties in high-density property markets</u>	S1	C15	S10			
<b>II. Establishing trust with dying people and their families</b>						
4. Boosting credibility and familiarity	S2	S2	S7			
5. Responding actively to immediate, everyday needs	S7	S9	S12	S9	C15	
6. Purifying the support relationship	S6	S5	S6	S5		
<b>III. Establishing trust while respecting boundaries: collaborative interactions with medical professionals in community EOL care</b>						
7. The ‘clear and simple’ relationship	S5	S11	S11			
<b>IV. The process of cultivating mutuality</b>						
8. Finding social commonalities (and hiding differences)	S2	S5	S6	S5	S2	S13
9. Immersion in routines: Participating in the daily routines of the client and family	S9	S9	S8	S8		
10. Supporting actualization – the wishes of dying persons and their families	S7	S5	C15			
11. Engaging with clients’ emotions	S9	S1	S6	C16	S8	
<b>V. The outcomes of mutuality</b>						
12. Caring about the feelings of the practitioner	S6	S9	S9			

13. A sense of emotional security	S1	S1	S2			
14. Remaining estrangement from the mutuality	S7	S10				
<b>VI. Performing medical-social mutuality</b>						
15. Doing the multi-disciplinary case meeting	S5	S5				
<b>VII. Fostering collaborative community EOL care in family</b>						
16. Opening and bridging family dialogue in families with lower familial social capital	S13	S12	S12	S12	C15	
17. Activating family to provide more, and appropriate, EOL care	S10	C15				
18. Achieving final wishes with family members	S10	S14				
<b>VIII. Fostering collaborative community EOL care in medical-social collaboration</b>						
19. Linking up care resources in communities	S5	S11				
20. Establishing ways of working together	S6	S5	S5			
21. Mobilizing joint effort towards a specific operational goal	S10	S11	S10			