

Psychosocial Care and the Role of Clinical Psychologists in Palliative Care

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Abstract

Objectives: The aim of this study was to explore the works of clinical psychologists in palliative care in Taiwan. **Methods:** Clinical psychologists who were working or had experience in palliative care were recruited. A 2-stage qualitative method study was conducted, including semistructured interviews and a focus group. **Results:** The following 4 main themes were identified: (1) the essential nature of the psychologists' care were caring and company; (2) the dynamic process included psychological assessment, intervention, and evaluation based on psychological knowledge; (3) they needed to modify their care using an integrative framework, by setting practical goals and using techniques with flexibility; and (4) they faced external and internal challenges in this field. **Conclusion:** Clinical psychologists have beneficial contributions but have to modify psychosocial care based on the patients' needs and clinical situations.

Keywords

clinical psychologists, hospice, palliative care, end-of-life care, psychosocial care, Taiwan

Introduction

Palliative care is effective for patients at the end of life, with the aim to relieve suffering and improve their quality of life.¹ It addresses the multiple needs of patients with terminal illnesses and their families, including physical, psychological, social, and spiritual aspects, and is delivered by an interdisciplinary team of health care professionals. The terminal stage of disease has significant impact on patients' psychological well-being.^{2,3} Health care professionals should provide various levels of psychological care to patients and families. All professionals provide general screen and support; and mental health specialists, such as clinical psychologists and psychiatrists, provide advanced diagnoses and specific interventions and psychotherapy.⁴

Clinical psychologists have the specific psychological knowledge and skills to contribute to specialist psychological care for patients and families facing life-threatening diseases and death. The skill framework comprises 3 levels, including (1) basic skills in establishing and maintaining supportive relationships, (2) skills in undertaking specific psychological interventions for a clinical problem/disorder, and (3) advanced skills in devising and delivering individually tailored psychological interventions for complicated problems.⁵ Clinical psychologists can help patients to cope with illness, from being diagnosed and treated, through progression, and during the dying process, as well as after the patients' death with bereaved survivors.⁶ As part of an interdisciplinary team approach, clinical psychologists can collaborate with other professionals to

provide comprehensive and holistic care⁷ as well as provide consultation and educational training.⁸

The United Kingdom National Council for Hospice and Specialist Palliative Care Services suggests that clinical psychologists should be members of hospice and palliative care teams.⁹ They can deal with various kinds of psychosocial issues, including emotional, psychosomatic, behavioral, and family problems.¹⁰ A survey revealed that the most common psychological problems in terminal patients were depression, anxiety, and grief/bereavement, and that clinical psychologists were the first professionals that palliative care programs stated they would wish to hire.¹¹ However, there were not many clinical psychologists involved in palliative care in Europe in 2012.¹² Although the number of clinical psychologists has increased slowly, the number of patients and families who receive psychological care from clinical psychologists is still limited.^{10,13}

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In Taiwan, palliative care was established in 1990 and now includes inpatient wards, home care, and hospital-based palliative care teams. A national survey in 2007 showed only 1 full-time clinical psychologist worked in an oncology ward and few clinical psychologists provided psychological care in part-time positions or as volunteers.¹⁴ Recently, more clinical psychologists have engaged in palliative care and the Taiwan government has encouraged this through national health policy. This is a novel and challenging field for clinical psychologists.

Previous research has provided conceptual frameworks for the role of the clinical psychologist in this field,^{5-7,15} and there have been published surveys about their service in the United Kingdom¹⁶ and Japan.¹⁷ More evidence is needed, however, to understand their professional roles and the work processes of exactly how clinical psychologists provide psychosocial care for terminally ill patients, especially in Taiwanese culture. The aim of this study therefore was to explore the working experience of clinical psychologists in palliative care in Taiwan.

Methods

Participants

In Taiwan, clinical psychologists need to take clinical psychology master degree with 1-year internship in a psychiatric department and other medical setting and then are licensed by the Department of Health. Clinical psychologists were recruited, including those (1) presently working or who had work experience in a palliative care team, (2) with full-time or part-time positions, and (3) who were willing to accept an interview.

Procedure

Ethical approval was obtained from the institutional review board (IRB) of Chi-Mei Medical Center, Liouying, before the study began. Because of the small sample size of potential participants, we used snowball sampling to recruit clinical psychologists. We explained the goal and procedures of this study to potential participants, and they signed an informed consent if they were willing to participate. After interviews, we asked them to introduce us to other clinical psychologists who also worked in this field.

We used a 2-stage qualitative inquiry approach to gain an in-depth understanding of their experiences, using semistructured interviews first¹⁸ and a focus group second.¹⁹ The interview guide questions included the following: (1) the content of work: What is the main content of your work? (2) The work process: How do you provide psychological care and use specific skills, theories, or approaches? (3) Teamwork: How do you communicate and collaborate with other professionals and how do you provide sustained care? (4) Difficulties and strategies: What are the difficulties in your work and how do you solve these difficulties? (5) Educational needs: What are the specific educational needs for those working in this field?

For the second stage, a focus group was conducted. We analyzed the interviews, and an initial report was sent to all

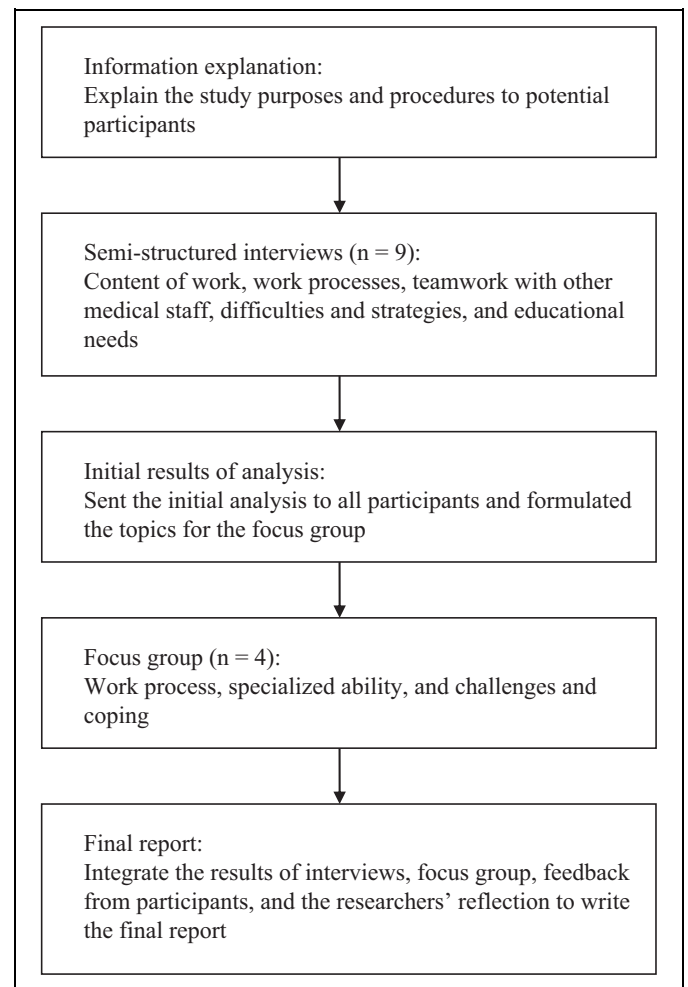


Figure 1. The Process of Research.

participants for verification and feedback. The feedback from the participants formulated the issues of the focus group, including (1) the work process, (2) specialized ability, and (3) challenges and coping. After the focus group, we again sent a report to all participants to elicit feedback. During the research process, the field notes and logbook of the researchers' reflections were also recorded. The data for qualitative analysis therefore included the interviews, focus group, feedback, and discussions from the participants as well as the researchers' records and reflections. The research process is presented in Figure 1.

Analysis

The researchers have more than 9 years combined clinical experience in oncology and palliative care. The first researcher (SYF) interviewed all participants and led the group discussion. Interviews and the focus group session were audiotaped and transcribed verbatim. ATLAS.ti 5.0 software was used to facilitate analysis, which was based on the principles of grounded theory.^{20,21} We read the verbatim repeatedly to familiarize ourselves with the data first and generate initial open coding from

Table 1. Participant Details.

Code	Gender	Department	Charge	Position	Years of experience working in hospice
A ^a	Male	Hospice ward	Ward, home care, hospital-based palliative care team	Full-time	1.25
B ^a	Female	Hospice ward	Ward, home care, hospital-based palliative care team	Full-time	4.5
C ^a	Female	Hospice ward	Ward, home care, hospital-based palliative care team	Full-time	2
D	Female	Department of family medicine	Ward, home care	Part-time	1
E ^a	Female	Department of psychiatry	Ward, home care	Part-time	3
F	Female	Department of psychiatry	Hospital-based palliative care team	Referral	1
G	Female	Department of psychiatry	Hospital-based palliative care team	Referral	0.5
H	Female	Department of psychiatry	Ward	Part-time	1
I	Male	Department of psychiatry	Ward, home care, hospital-based palliative care team	Part-time	1

^aAttended focus group.

the raw data. Then, we categorized the open coding into subcategories, linking coding at the levels of properties and dimensions. We searched for subthemes/themes that integrated concepts into core categories. In the next step, we reviewed the themes to determine whether there was a coherent pattern for formulating a thematic map and whether the thematic map could reflect the meaning of the data accurately. In the end, the report was written based on these analyses.

In order to enhance the reliability of analysis, the first (SYF) and second (WCL) researchers coded data independently and then compared results and combined them together. Any differences were discussed to achieve consensus. Regarding trustworthiness, we sent reports to all participants to ensure the accuracy of interpretation. The third author (IML), who has rich experience in the supervision of postgraduate clinical psychologist internships in palliative care, provided the external audit review of the analysis.²²

Results

A total of 10 eligible participants were contacted and 1 refused to participate (not wanting to reveal specific work experience); thus, 9 were recruited. The mean time of interview was 1 hour and 42 minutes. Four of the clinical psychologists participated in the focus group that lasted 3 hours. The others did not attend because of time constraints but still received the report and provided feedback. The mean time of work experience was 1.8 years. Three clinical psychologists had full-time positions in charge of a palliative care ward, home care, and hospital-based palliative care team concurrently. Of the 9 psychologists, 4 spent a fixed time every week in the wards and home care. The final 2 were members of a hospital-based palliative care team and only received referrals when needed (see Table 1). The following 4 main themes were identified: the nature of caring, the dynamic process based on psychological knowledge, the essential psychological care, and professional development and self-reflection.

The Nature of Caring

The clinical psychologists worked with patients having terminal illness and their families, who had psychological needs but

not necessarily mental illness. The sites the patients were cared for at included hospital wards, at the bedside, or in patients' homes, instead of in a psychotherapy room. The clinical psychologists and patients experienced genuine encounters in the clinical setting.

- D: It is hard to explain what I am doing. Definitely not traditional psychotherapy. It is OK without an office room and, in fact, I am not staying in the room and waiting for the patients. I am where the patients are, the bedside, the living room, or going out to a garden with a patient in a wheelchair.

The core aspects of the encounters were caring and companionship. The clinical psychologists tried to get close with the patients, be with them, and understand how they adjusted to their illnesses. In addition, the clinical psychologists felt neither that they were only helping nor focusing only on the psychopathological problems. They were providing companionship to the patients and families in going through the last journey of life. Most of the participants agreed that the clinical psychologists create an atmosphere of acceptance in which patients can express them easily as well as providing a space for dialogue between patients, families, and medical staff.

- A: When I meet a patient, there is a voice; he is a person, a whole person, and how can I get close with him, to be with him, be a companion to him, and let him feel that this companionship process is meaningful.
- F: The only thing that we can do is to be with them.

The Dynamic Caring Process Based on Psychological Knowledge

The clinical psychologists reported 5 main aspects of their work, including patients, families, the medical team, community education, and research (see Table 2). They spent most of their time in the direct psychological care of the patients and their families. In cooperating with the medical team, they contributed their psychological knowledge and skills toward caring for difficult patients and the families. They also provided

Table 2. The Content of Work.

Aspects	Content
Patient	(1) Disease: illness cognition, truth-telling, adjustment to illness, and disease progression (2) Emotions: negative feelings, such as depression, anxiety, helplessness, or hopelessness (3) Issues about death: death anxiety, preparation for dying, for example, do not resuscitate (DNR) order (4) Relationships with family: communication between patients and family members, unfinished business (5) Doctor-patient relationship: the communication bridge between patient and medical staff (6) Referral: based on patients' needs, refer patients to other specialists
Family	(1) Disease: adjustment and adaptation to patients' illness, including at the end-of-life and after death, especially children (2) Connection: organize for different family members to take care of patients (3) Emotions: negative feelings, anxiety, or depression (4) Doctor-patient relationship: the communication bridge between family and medical staff, family conferences (5) Preparation for dying, DNR order (6) Bereavement and grief counseling
Medical team	(1) Work together with other medical staff to care for patients: collect information and conduct assessments, refer to appropriate staff, attend case conferences, and coordinate the agreement of a care plan (2) Education training or sharing knowledge (3) Emotional support to other medical staff
Community Research	(1) To promote the popular acceptance of hospice palliative care by giving lectures or via publications (1) Research in hospice palliative care

educational training and emotional support to other staff. The content of their work varied depending on the clinical psychologists' time schedule, personal interests, and demands from their employing hospitals.

The caring process was dynamic and flexible based on the clinical situation. There was a certain pattern in the work process: at first, the clinical psychologists conducted assessments to understand patients' needs and problems; then they provided proper care and interventions based on the results of the assessments; finally, they evaluated the outcomes and modified their care or interventions. Patients' physical conditions and psychological status vary constantly and thus the 3 stages were cyclic in each visit.

C: It is hard to say whether I am assessing or conducting an intervention, there is no clear cut-off point. Maybe I am doing both at the same time. The patients didn't have a lot of time; I had to do several things in one session.

Assessment is a process that involves understanding a patient's physical and psychological status. The clinical psychologists collected information from families and medical staff before contacting patients. They also assessed and collected information from patients directly. There were 2 methods of assessment: standardized measures and clinical interviews. For standardized measures, they mentioned using the Distress Thermometer,²³ the Brief Symptom Rating Scale,²⁴ the Hospital Anxiety and Depression Scale,²⁵ and the Beck Anxiety & Depression Inventory.^{26,27} However, all of the participants expressed the weaknesses of standardized measures, including issues of reliability and validity, lack of flexibility, and whether it is worth the patients spending their last days filling in questionnaires rather than being with their loved

ones. All participants used clinical interviews for assessment. The contents included current disturbances, physical symptoms, emotional status, illness perceptions, ability, support system, positive activities, and more (see Table 3).

C, in group: I was like a recorder, recording patients' stories. I got information from patients directly, but I also got information from their families, physicians, and nurses. In the end, I had a complete picture about their life.

H: If I have a comprehensive framework to understand what's happening, what's going on, and not only that he had a disease or depression . . . we need to put the patient in his life in context.

Basic and advanced skills were mentioned as interventions. Basic skills included listening, empathy, unconditional acceptance, and support to create a warm, accepting, and supportive atmosphere. Advanced skills were specific psychotherapy techniques, such as cognitive-behavioral therapy, narrative therapy, life review, and existence therapy. They tried to ensure that their interventions were based on theoretical foundations with logical reasoning. After the case formulation and intervention, the clinical psychologists had to evaluate the outcomes, whether the target had been changed and whether they needed to modify or continue the interventions.

D: I spent a lot of time providing company, and the basic skills such as empathy and listening were necessary. I think clinical psychologists can create a space for narrative; patients can talk, express, and rearrange their lives.

Table 3. Assessment in Clinical Interviews.

Categories	Items
Current disturbances	The major disturbances or concerns in current life
Physical conditions	Physical symptoms, pain, consciousness level, performance status
Illness perceptions	Perceptions about the illness, medical treatment, disability, suffering, and death; whether they know their diagnosis and prognosis; thoughts about the future
Emotional status	Emotional reactions, negative feelings (eg, anxiety, depression, helplessness, and hopelessness), positive feelings (eg, happiness, calmness, and optimistic vision)
Ability	Coping strategies and flexible ability for adjustment, self-care ability
Support system	Relationships with caregivers and family members, family interaction and family functioning, other resources
Positive activities	Interests and hobbies, habits, any activities that patients enjoy
Other	Preparation for death, suicidal ideation, spiritual, or other needs
About family	Families' emotional reactions (eg, grief and self-blame), child-specific issues (eg, separation anxiety, truth-telling, and grief)

B, in group: I expect that I have a theoretical foundation to support me to do this or that, why I provided such an intervention, and what the expected effects would be.

The Essential Psychological Care

Clinical situations change rapidly, and psychological care needs to be modified. Therefore, the clinical psychologists use an integrative framework to understand patients comprehensively, changing from the viewpoint of psychopathology to adjustment. They focused not only on the psychological aspect but also on the whole person and not only on negative feelings or problems but also on positive experience and resources.

A: You cannot use a pathologic . . . or problem-oriented view to see the patients; you not only try to find out the problems and causes, but also use a broader, comprehensive view to organize what you see. You have to see the whole person in context.

Setting a practical goal was important. Considering the limited life expectancy of the patients, the clinical psychologists establish rapport with patients and families as early as possible. They reached out with the care to patients instead of waiting in the psychotherapy room. In addition, they realized the limitations that they may not achieve long-term goals due to life-limiting physical conditions. Setting an achievable short-term goal for each patient helped the clinical psychologists to provide proper care.

F: You have to realize your limitation, it is not easy to change something . . . they had certain life patterns throughout their whole lives, it is difficult to make big changes at the end-of-life . . . I would like to set a reasonable goal.

The clinical psychologists applied psychological techniques with some flexibility. It was difficult to utilize a specific technique completely without any modifications. The

modifications depended on many factors, such as patients' subjective concerns, physical conditions, time or space limits, relationships between patients and clinical psychologists, and available resources.

D: I did not follow a specific theory but used many skills from different theories. I combined several skills and theories based on the situations. I try to satisfy their needs immediately.

Professional Development and Self-Reflection

The clinical psychologists stated they required approximately 6 months to a year to adjust to this line of work. They faced external and internal challenges about the development of professionalism (see Table 4). The external challenges came from the patients, families, and medical team. Poor physical conditions and impending death may influence the patients' activities and abilities to cope. The patients and families might resist and reject the clinical psychologists' visit because of the stereotype associate with psychological care, stating they did not have any psychological problems or mental illness and did not need this service. In addition, team collaboration to establish mutual trust and formulate a care plan with consensus was another challenge.

Regarding internal challenges, the clinical psychologists reflected about their own professional ability, self-identify in this position, and the meaning of life. They thought about what the professional role meant in this field and whether they had the professional ability to provide care. These challenges involved the specific occupational identity associated with their role and functions in the team.

E: I feel anxious, anxiety about this role, because I am a clinical psychologist and I expect myself to be able to do something . . . it makes me feel anxious . . . In front of the patients, what is my role? Very professional? Can this professional (role) achieve some specific effects? Or is the profession itself a barrier?

Table 4. The Challenges in the Work.

External	Internal
(1) Limitations in patients' physical conditions and time	(1) How to collaborate with medical staff and the specific role of localization of clinical psychologists
(2) Interactions between patients' psychological well-being and physical problems	(2) Self-doubt about professional ability
(3) Rejection from patients, families, other medical staff	(3) Lack of supervision and peer discussion
(4) The consensus of a care plan among medical staff	(4) Keep balance between professional and humanity
(5) Trust between medical staff	(5) Helplessness: cannot change something, feeling like they cannot help the patients and families
(6) Lack of resources, for example, a private space	(6) Management of the impact of work on their emotions, life, and values

Witnessing the patients' suffering, the clinical psychologists also bore stress. For example, they felt helplessness, self-doubt about their work, and wondered whether they really could do something to help the patients and their families. Meanwhile, they also thought about the meaning and value of their own lives. In order to deal with these challenges, the clinical psychologists needed to have passion for the field, willing to engage in this work, having flexibility, willing to do self-introspection, and knowing how to set the boundaries between work and personal life. In addition, continuing self-learning, having peer group support, and receiving supervision could improve professional ability.

- D: I never know what the outcome is. It disturbs me and makes me feel helpless/useless. Patients died and families went home, then I didn't know anything (about the value or the outcomes of the work) . . . sometimes I felt depressed.
- G: Actually, what we can do is not as much, but rather we are the people who really get their help. Their life story enriches our lives.

Discussion

This study explored the working experience of clinical psychologists in palliative care in Taiwan. The nature of the encounters was primarily caring and involved providing company. Care is based on psychological knowledge and skills. Some transition to the role was needed, including changing from a psychopathological to an adjustment viewpoint, choosing small and practical goals instead of long-term outcomes, and modifying the therapeutic skills. Furthermore, the clinical psychologists dealt with external and internal challenges to develop their professionalism.

The clinical psychologists reflected about the nature of caring. Professional ability is important; however, the desire to get close and truly understand the patients is the foundation of caring, without which the clinical psychologists could not work with the patients and their families.

The clinical psychologists had multiple roles and functions in palliative care,^{5,10} and the main focuses were patients and families. Many factors may influence the process of psychological care, but the underlying structure is similar.²⁸ Patients' conditions may worsen day by day, and the psychologists may

not be certain how many sessions they will have with those patients. They established rapport immediately but, at the same time, collect information to understand patients' and families' concerns and assess the psychosocial needs as soon as possible. Regarding psychological assessment, standardized measures may not be suitable for terminally ill patients to complete, and thus the clinical psychologists used them as potential guidelines and applied some of the specific items in interviews. Clinical interviews were useful not only to elicit information but also to establish a therapeutic alliance.²⁹

An integrative framework for psychological care or intervention is necessary.³⁰ The clinical psychologists in this study tended to use various psychological theories and skills to satisfy patients' and families' needs and modified their interventions accordingly. Based on the problems, the clinical psychologists determined the levels of intervention.⁵ They formulated a workable care plan and also relayed the skills to the medical staff to care if the patients needed extra support; however, the psychologists would spend more time and effort when their patients needed advanced psychotherapy.¹⁵ They also organized external resources as a team, such as other medical professionals and the patients' social support system, to care together.⁷ After the interventions, they would evaluate the responses and advise other medical staff as to which interventions were carried out and how. The process is a dynamic and continuous loop.³¹

Similar to previous studies, the clinical psychologists in Taiwan faced multiple challenges from role and specialization team collaboration, the hospital system, and internal feelings and conflicts.³² They needed to establish their specific roles and functions in this field and develop their professional abilities. The important issues included assessing and creating case formulations; providing specific interventions and care that matched patients' needs and physical conditions; evaluating the outcomes of their interventions; and modifying psychological techniques in team-based collaboration in medical settings.³³

Specific training programs for clinical psychologists in palliative care are necessary.⁶ The education programs cover the core competences of clinical psychologists in end-of-life care, including the basics of palliative care, psychological assessment, psychotherapy, supervision and staff support, cultural sensitivity, ethics, and self-awareness and self-reflection.^{8,12} In addition, training including basic and advanced skills is

important. Junior clinical psychologists and other health practitioners can take basic levels and are supervised by a senior clinical psychologist. Furthermore, the improvement in self-care and peer support could help the clinical psychologists work in this field continuously. After this study was completed, the participants organized 3 series of Skype peer-supervision groups, each series lasting 7 sessions.³⁴

The limitations of this study should be acknowledged. First, palliative care is a developing field for clinical psychologists in Taiwan and diverse variables may influence their work. It is difficult to generalize the results to other countries. Second, we only explored the general working experience, but there are still many specific issues to investigate. Future studies could explore the most appropriate measures for terminally ill patients, the effects of specific interventions for certain problems, the collaboration between clinical psychologists and other medical staff, and the effectiveness and quality evaluation of psychological interventions.

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Declaration of Conflicting Interests

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