

**A MIXED-METHODS PILOT STUDY OF SYMPTOM COMMUNICATION
IN ADVANCED CANCER: PATTERNS AND ASSOCIATING FACTORS**

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Abstract

Background

Improving patient-provider communication is a fundamental and cost-effective method to advance patient outcomes, including symptom management which is often the primary goal of care for patients with advanced cancer. Unfortunately, some studies revealed the poor quality of symptom communication among cancer patients and healthcare providers. While these evidences suggest important gaps in communication about symptoms with some of our most vulnerable patients, we know little about the patterns and associating factors of symptom communication.

Purpose and Specific Aims

The proposed 3-year pilot project aims to provide an enrich and systematic description of symptom communication by validating a newly developed typology of interaction patterns of symptom communication (TIPSC) between patients with advanced cancer, their caregivers, and healthcare providers and explore factors related to each interaction pattern. The specific aims are to: (1) validate TIPSC in Taiwanese advanced cancer population, (2) explore patients' /caregivers' experience and thoughts of symptom discussion in regard to their interaction patterns and symptom management, and (3) examine relationships between interaction patterns and (a) demographic factors, (b) symptom severity, (c) congruence in symptom assessment between patients/caregivers and providers, (d) patients'/caregivers' perceived ability to communicate with providers, and (e) patient/caregiver satisfaction.

Sampling

This pilot study plans to recruit about 50 patient/caregiver — oncologist dyads. The recruitment process contains three stages. First, medical oncologists who are currently in clinical practice at participating institutions and care for patients with solid tumors will be approached. Second, participating oncologists' patients will be recruited if they are: (1) currently a patient of a participating oncologist, (2) diagnosed with stage III or IV solid cancer, (3) aged 20 years or older, (4) able to tolerate an interview that will last approximately 30 minus, and (5) able to speak Chinese or Taiwanese. Finally, if applicable, adult caregivers who intent to join selected out-patient-department (OPD) visit with the patients will also be recruited.

Research Design

This is a mixed-methods study with a two-phase exploratory sequential design. The first phase is a qualitative descriptive study in which we will record patient/caregiver—oncologist OPD visits and conduct patient/caregiver interviews to address aim 1 and 2. Discourse and conversation analysis will be used to analyze the recorded visits and content analysis will be used to analyze the interviews. The second phase is a correlational study in which we use questionnaires to measure variables and examine their relationship with interaction patterns (aim 3). Descriptive statistics, binomial logistic regression, and linear regression will be used to analyze quantitative data.

Expecting Results

This is a pioneering study addressing the patterns and associating factors of symptom communication in Taiwanese patients with advanced cancer. Our findings will systematically map out the patient/caregiver—provider symptom communication and identify relationships between communication patterns and meaningful indicators. This proposed study is a critical step to understand patient/caregiver—provider communication regarding symptoms in order to pinpoint symptom management and communication barriers and design proper interventions in Taiwan.

Key words: Health communication, Symptom management, Mixed-methods design, Cancer Care, Advanced cancer

Background

Questionable quality of patient—provider communication is a worldwide issue which can negatively affect patient outcomes, satisfaction, quality of decision making, patient—provider relationship, and healthcare resource utilization and expenditures (1-4). Poor quality of communication also contributes to increasing medical error, adverse events, and patient aggression or violence behavior (5-8). While health communication has gained increasing attention in developed countries, **more studies done in Taiwan are needed because of the culture-specific communication needs and special communication challenges that Taiwanese healthcare providers have encountered**. For example, evidence shows that Taiwanese patients have lower health literacy compared to some developed countries which may affect their communication ability or efficacy (9-11). In addition, Taiwanese healthcare providers perceived lower communication openness compared to their counterpart in the U.S. (12). The escalating patient violence behavior toward healthcare providers also suggests ineffective patient-provider communication in Taiwan (9).

Among the multiple aspects of healthcare that can be affected by communication, **symptom management is one of the critical outcomes of patient—provider communication** (13-15). Indeed, symptom, perceived indicators of change in normal functioning as experienced by patients (16), is often the major topics of cancer patient—provider communication (17). In Taiwan, cancer remains the leading cause of death since 1982. It was estimated that there were more than 103 thousand newly diagnosed cancer patients in 2014 with considerable portion of them diagnosed with advanced stages (i.e., stage III or IV)(18). **While symptom management is one of the primary care goal for these advanced cancer patients, the quality of symptom communication is beyond satisfactory**. Cancer patients had either no chance to talk about or low motivation to discuss their severe symptoms (19-21). A study done in Taiwan have further revealed that the “fear of distracting the doctor” was a main barrier for cancer patients to report the symptom of fatigue (22). The ineffective symptom communication may prevent healthcare providers (HCP) from conducting accurate symptom evaluation and effective management. For example, HCP tended to underestimate patients’ symptoms which shows the incongruence of symptom evaluation between patients and HCP (23). Despite the poor quality of symptom communication, there is a lack of systematic and comprehensive understanding regarding patient—provider symptom communication. Specifically, few studies have considered (1) the theoretical underpinnings, (2) naturally occurring medical encounters, and (3) both patients’ and providers’ communication behavior. **In fact, to date, no published study exploring advanced cancer patient—provider symptom communication in Asia countries. Studies which explore symptom communication thoroughly is thus much-needed in order to fully map out and facilitate symptom communication in Taiwan.**

Purpose and Specific Aims

The purpose of this mixed methods study is to **provide an enrich and systematic description of symptom communication by validating a typology of interaction patterns regarding symptom communication (TIPSC) between patients with advanced cancer and their healthcare providers (HCP) and exploring factors related to each interaction pattern**. The specific aims are to:

1. Validate TIPSC in Taiwanese advanced cancer population in terms of how patients, caregivers, and HCP discuss symptoms during out-patient-department (OPD) visits.
2. Explore patients’/caregivers’ experience and thoughts of symptom discussion in regard to their interaction patterns and symptom experience.
3. Examine relationships between interaction patterns and (a) demographic variables: age and educational level, (b) symptom severity, (c) congruence in symptom assessment between patients/caregivers and HCP, (4) patients’/caregivers’ perceived ability to communicate with

HCP, and (5) patient/caregiver satisfaction.

Conceptual Underpinnings

The specific aims and research design of this proposed study are informed by two conceptual frameworks. **Aim one and two which seek to deductively explore interaction patterns of symptom communication are informed by a typology, TIPSC, developed by the applicant.** The applicant used qualitative methods to explore naturally occurring symptom discussions to establish this typology that describes eight interaction patterns of advanced cancer patient—provider symptom communication. These eight interaction patterns which reflects unique style of symptom communication are collaborative, explanatory, agentic, checklist, cross-purpose, empathic, admonishing, and diverging interactions (24). The definitions and exemplars of each interaction pattern are presented in table 1. Building on this typology developed in the U.S., the proposed study seeks to explore and categorize symptom communication in Taiwanese cancer population and, at the same time, verify or even expand the TIPSC. Once the qualitative verification of the TIPSC is established, we are able to quantitatively examine the relationship between interaction patterns and meaningful variables or outcomes which lead to our specific aim three.

While the proposed study does not intend to test the whole theory, specific aim three was informed by the Dual Process Theory of Supportive Message (DPT). DPT was firstly published by Burlison in 2008 with the main purpose of providing a systematic explanation about factors affecting communication and its outcomes (25). One of the important assumptions proposed by the DPT is: communicators' ability to handle the message (A) and their motivation (M) to discuss the topics mediates the relationship between quality of communication (Q) and communication outcomes (O). In the proposed study, we conceptualize the 'ability to handle the message' as **patients' perceived ability to communicate with providers** and 'motivation' as **symptom severity**. That is, we propose to explore the relationship between **TIPSC (Q)**, **patients' perceived ability to communicate with providers (A)**, **symptom severity (M)**, **congruence in symptom assessment between patients and providers (O)**, and **patient satisfaction (O)**. Figure 1 shows the modified conceptual framework.

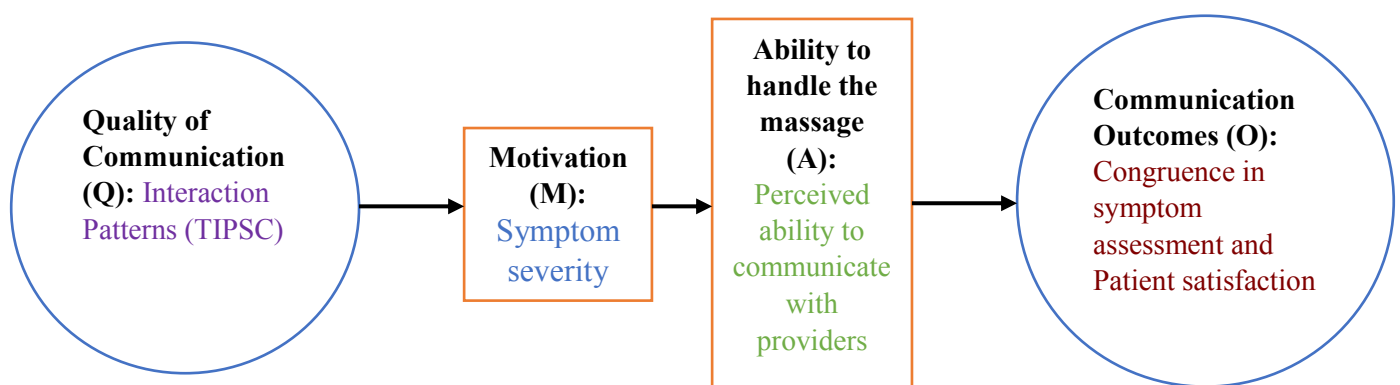


Figure 1. Modified Conceptual Framework of Dual Process Theory of Supportive Message

Table 1. Interaction Patterns, Defining Characteristics, and Exemplars

Interaction pattern	Defining characteristics	Exemplars [O] Oncologist, [P] Patient, [C] Caregiver
Collaborative	Patients/ caregivers and providers worked together to figure out the nature of a symptom or a course of action.	<p>O: But with the pain changing this much I am worried that the cancer might be growing, Mr. [Patient].</p> <p>P: Well, that's what I said to my wife, is I don't know this chemo's working.</p> <p>O: Right.</p> <p>P: It just seems to be growing.</p> <p>O: Right. I . . . I think so, too. You know, and I feel that -</p> <p>P: Can we . . . can we prove that through tests somehow?</p> <p>O: We can. It's not . . . if you think that it will help you decide that let's put this final chemo, you know, put to rest and know that it's not working then we'll do the scan. I . . . I don't know if we need the scan, Mr. [Patient], because, you know, everyone at home and we here who know you see the change. Right? You have never required a pain pill in clinic, right?</p> <p>P: Yeah.</p> <p>O: And so I think whether the scan shows growth that can be measured, you know, I don't know if . . . we need that. I think that I have enough evidence here for me to say that this chemo is not working.</p> <p>P: Oh, okay. Unless . . .</p> <p>O: Yeah, I think so.</p> <p>P: I'll go with the Lord...I have a lot of good faith for the Lord and I carry him with me everywhere I go. Along with my . . . along with my navy anchor. [Laughter]</p> <p>O: They go together, right?</p> <p>P: Yeah, why don't we just stop it.</p> <p>O: Yeah, because if I felt that it was just the tiredness or if you were having some side effects we would come up with some way to get through. But I think that, you know, and we'll have blood work, we'll have some tests there.</p> <p>P: Are you okay with that [to his wife]?</p> <p>C: Hmm?</p> <p>P: Are you okay with that?</p> <p>C: It's your decision. Your decision. I would say he was more tired this week than before.</p>
Explanatory	Providers gave factual information to patients and caregivers	<p>O: They [lymph nodes] are all less than 5 millimeters but they are new and they are increasing, which means that the cancer is spreading.</p> <p>P: [takes a breath, possibly a gasp]</p> <p>O: But none of them is more than 5 millimeters. What's going on in the liver. So, in the liver also there is the same thing. There is an increase in size and number of the [lymph nodes in the] liver. There is some fluid around your liver. Also in some area between -- the liver is covered by a capsule and there is some bleeding underneath the capsule from the old tumor dying. So there is some collection of fluid there. So, remember when you had that one instance where you had a tumor and you had a lot of pain in that area?</p> <p>P: Yes.</p> <p>O: That could have triggered the tumor dying and bleeding and stretching the capsule could have triggered your pain. And since then you haven't had any pain?</p> <p>P: No.</p>

		<p>O: So that probably is what happened that time when ... I first saw you and you ended up in the hospital afterwards. Now this is more pronounced so we can go back and say this is why you had the pain at the time. So, clearly the disease is growing and I don't want to go over each lesion because the. . . each lesion does not matter. The fact that the disease has increased in size and number tells me that we need to change course. You know, just the Gemcitabine alone might not be enough...</p>
Agentic	<p>Patients and/or caregivers were particularly vocal during discussions with providers and/or very involved in making treatment decisions.</p>	<p>P: ...My appetite, I want to eat. The problem I have doctor is. . . when I eat everything tastes bitter. O: I see. P: And it's hard to eat. It's hard - even when you want to eat it's hard to sustain yourself when you're trying to eat something and the food doesn't taste like food or you get that initial something sweet. And then, and on the back end as you swallow it or whatever, it's bitter. So I'm constantly getting this food don't taste like food, it's this bitterness that's going on. O: Are there any foods that you still enjoy or is this something that's everything? P: It's a lot of foods that I enjoy and those are the ones I go after. O: I see. P: But I still get this, like last night I had a little, I wanted to have a little piece of pizza, you know, just a taste of tomato sauce. O: Yeah. [keyboarding] P: And that kind of thing. And I couldn't eat it. It was just bitter. Um. . . that's a problem for me, one issue right now I don't know how to deal with. O: Okay. P: Because it's like I know to eat, my family is constantly on me about eating. And I know what you told me what I should be trying to do is the small meals. Okay. So those -- it's just the problem is when I do try to eat something it's. . . it's the taste. I don't have the taste that I would normally associate with those foods that I like. And so this is an issue. O: And that's probably the chemo. P: Yeah. This is an issue. I don't really know how to get around it. My wife says eat anyway. And I said - C: Well, it's so bitter it's disgusting. P: And I said, baby, it's hard to eat when. . . what you're eating is either doesn't have a taste that you normally associate it with so it's not as desirable as before.</p>
Checklist	<p>Providers asked a series of questions in rote fashion, as if they were "going down" a list.</p>	<p>O: Do you have an appetite? P: No. I'm not hungry. I... O: Stick out your tongue for me. Deep breaths. You were having regular bowel movements. P: Yeah, like every other day, too. O: Solid or loose? P: I'd say . . . solid. Yeah, solid. O: Pain here as I press? P: [Non verbal reply.] O: Fevers at all? P: None. O: Shaking, chills? P: None. I think for the most... C: So, he's not on [Emend]...Is he? It seems like...</p>

		P: I think they give me that on at the... O: You're getting ... a steroid. But you're not getting Emend.
Cross-purpose	Patients and/or caregivers and providers seemed to have differing agendas and failed to acknowledge the remarks of the other.	P: Because if I was to poke right in here...It's not a pain but it aches really hard. O: Hard. So have you been able to eat much? P: I don't eat at all. C: Well, he's. . . he eats very little. For a while he was hardly eating. Luckily he will drink the Glucerna. O: Okay. C: He'll drink that. And something like maybe oatmeal. O: Um hmm, okay. P: Cup of tea. O: Right. And you just don't have the appetite for it? C: Definitely. P: Don't have any taste there. O: We can control the pain because. . .
Empathic	Providers showed, or attempted to show, that they understood and cared about the emotions or experiences of the patients and/or caregivers.	P: And. . . um. . . I just discovered, what, about 3 days ago, my hair. O: This chemo started making your hair fall out? C: Um hmm. P: And I was very depressed. O: I'm sorry. P: I know it happens. It didn't happen the first time, the first time I had chemo. O: I know. P: So, I figured, you know, well okay, I'm one of the ones that it's not gonna happen to. But well, you know, this is a wig that I have on. My hair, starting from back here up to about right here is all gone. O: I'm sorry, [Patient]. P: Yeah. O: It's hard to tell because you always look good and this wig is so much like your real hair that it's very hard to tell. You know? And a lot of people, I know especially African Americans sometimes have all kinds of braids and they change their style so much that it's hard to, for people that don't know, to tell that this is all happening. P: Yeah. O: But I know you can tell and that must be upsetting and I'm sorry. So what to do, some of these chemos, the newer ones, they're stronger, they're better in some ways but then their side effects are also a little bit, you know, more. And as long as the other things that affect quality of life like, you know, eating and energy, you're not too badly affected, most patients say okay, I can wear a wig for a while. P: Right.
Admonishing	Providers cautioned patients and caregivers against behaviors thought not to be in the patients' best interest or gently scolded them for taking certain actions or voicing certain opinions.	O: . . . are you careful about when you take your pain medicine and driving? P: Well, . . . I find myself weaving sometimes. . . I don't like to drive with a lot of people because they tend to weave. Do you know what I mean? O: Well, you're not filling me with a lot of confidence here. C: But it's not a frequent occurrence when you're driving. P: Oh, no, it was happening on Easter...when I was going to [name of relative]. So... I got off on the wrong place, and I wound up on those 3 roundabouts...Have you ever been on roundabouts...?

		<p>O: I know what you mean, yeah...Well, that is a little scary...So how much driving are you doing since then?</p> <p>P: Oh, I drive, like to mah jong a couple of days a week and. . .</p> <p>O: Is that like a few blocks or is that halfway across the city?...What do you do that for?</p> <p>P: [Makes a fun noise]: Pow! [Chuckles] Slots.</p> <p>O: Do you have a friend that can go with you?</p> <p>P: Why? I have to take my car.</p> <p>O: I don't like this, what you're telling me about your driving, that's why.</p> <p>P: Oh. Well, basically I don't drive on the days that I'm really feeling blech. I know when to drive...And the people that want to pick me up, like my sister, believe me, I'm better off driving. [Chuckles] She's 85 years old and I think she's beginning to get a little flaky.</p> <p>O: Yeah, but she's not on pain medicine. That's what I'm concerned about.</p> <p>P: I never feel tired from it...I mean I go to bed at 2 o'clock in the morning.</p> <p>O: Well, I understand but it's like alcohol. You don't have to be falling down drunk to have decreased reflexes and maybe that's why you were weaving a little bit.</p> <p>P: ... I said my driving days are numbered if I feel like I did today...I'm not dumb.</p> <p>O: You've heard me and I know you're not dumb. So.</p>
Diverging	Providers and patients and/or caregivers expressed a disagreement.	<p>O: That could have been a different virus that led to your decreased immunity that led to your pneumonia, actually. That's probably the most likely thing.</p> <p>C: But generally that kind of stuff starts getting better after 3 or 4 days.</p> <p>O: Yes.</p> <p>C: If it's a virus.</p> <p>O: Right.</p> <p>C: And this wasn't getting better.</p> <p>O: I'll bet you anything it was a virus. You didn't think it was getting better because you got a subsequent pneumonia after the virus happened. And that's called a secondary super infection. That actually happens a lot. I. . . I personally think it came about because of an initial virus more than anything and I, personally myself don't think this has anything to do with the Everolimus. But prove me wrong -- I hope you don't because I don't want you to have anymore infections.</p> <p>C: We don't want to prove you wrong.</p> <p>O: I really do think you are tolerating very well. I see no reason to lower the dose. It's doing what we asked it to do...I'm not pushing surgery by any means but if it's something that you guys want to talk about then you guys should get together and talk about it.</p> <p>P: Thank you. We've been bothered all along about the. . . we saw Dr. [Name] first and then you...And we've seen you a couple of times since. And it just didn't seem like there was, you know, we came into this thing thinking you guys were a team. And we didn't feel that this team thing was a reality. That you had one. . . set. You know, you were definite on keeping me on this for ten years if it continued to work -</p>

O: oncologist, P: patient, C: caregiver

Research Design, Methods, and Procedures

Research Design

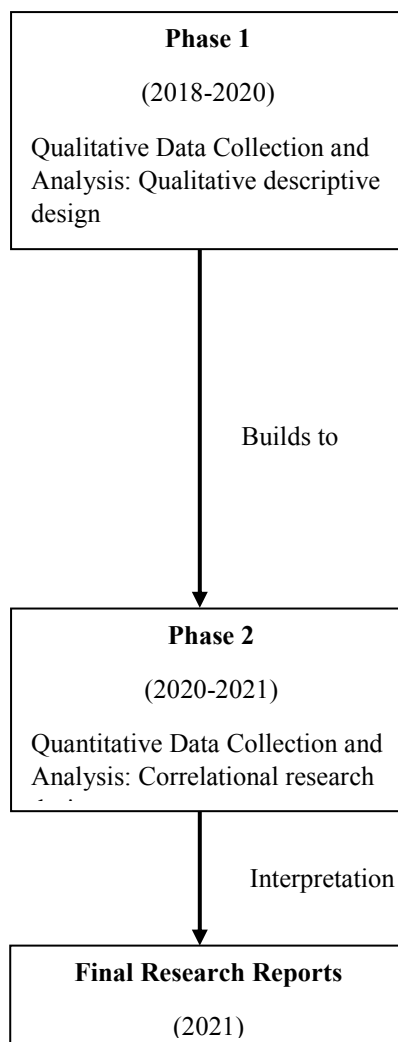
This is a **mixed-methods research project with exploratory sequential design** (Fig. 2). Mixed-methods study is an emerging type of research design which has gained increasing popularity in social science and medical research (26). It allows us to study and comprehend the phenomenon from multiple aspects. Because we are seeking to explore and describe the interested phenomenon in-depth and comprehensively, mixed-methods best address our research purpose. Exploratory sequential design is one of the major types of mixed-methods designs. It fits the specific aims which explore the unknown phenomenon first and then validate and test the exploratory findings in the following phases in order to generalize to larger population and make concrete suggestions. The following paragraph describes the exploratory sequential design according to the six key characteristics which are used to categorize and understand different mixed-methods designs (27).

1. **Number of study phases, type of implementation process, and stage of integration of approaches:** The proposed study include two study phases which are conducted sequentially. Primary qualitative data is collected and analyzed first (phase 1) to inform the following quantitative research (phase 2). The integration of qualitative and quantitative findings happens in the second phase as the analysis of the second phase will be conducted based on the findings from phase one.
2. **Theoretical perspective:** The exploratory sequential design includes dealing with both qualitative data and quantitative data and is supported by the pragmatism worldview. The pragmatism perspective appreciates both singular and multiple realities and emphasizes practicality. Pragmatism embraces abductive logic and is research question centered (26).
3. **Function of the research study:** The primary goal of the exploratory sequential design is to first explore the little-known area qualitatively and then enhance and generalize qualitative findings.
4. **Priority of methodological approach:** Qualitative method is the primary part of this study because the qualitative data collection and analysis builds to quantitative phase.

Conceptual Underpinnings

- Typology of Interaction Patterns Regarding Symptom Communication (TIPSC)

- Typology of Interaction Patterns Regarding Symptom Communication (TIPSC)
- Dual Process Theory of Supportive Message (DPT)



Specific Aims

Aim 1. Validating a newly established typology regarding interaction patterns of unstructured symptom discussion in Taiwanese advanced cancer population.

Aim 2: Exploring patients’ experience and thoughts of symptom discussion in regard to their interaction patterns and symptom experience.

Aim 3: Examine relationships between interaction patterns and (a) demographic variables, (b) symptom severity, (c) congruence in symptom assessment between patients/caregivers and providers, (d) patients’/caregivers’ perceived ability to communicate with providers, and (e) patient/caregiver satisfaction.

Procedures

- Recruiting oncologists, patients, and caregivers (collecting demographic information and scheduling an out-patient-department (OPD) visit to be recorded)
- Record 1 OPD visit
- Collect quantitative data: questionnaire measurements
- Schedule an 30-40 minutes interview
- Interview (Incentive will be provided after the interview)
- Analyze the recorded office visit using discourse and conversational analysis: determining interaction patterns
- Analyze the interview using content analysis: exploring patients’ experience regarding the recorded symptom communication
- Analyze quantitative data: the relationship between identified interaction patterns and questionnaire measurements
- Triangulation: compare the results from qualitative interview with the quantitative data to see how the data support or disagree with each other
- Drafting preliminary research report

Figure 2. Research Schema: Conceptual Underpinnings, Study Phases, and Corresponding Specific Aims and Procedures

Methods and Procedures

The method section describes sampling process and study methods of each phase.

Sampling. Because a qualitative study typically requires about 30-50 participants (28), the sample size of this pilot study is set to be 50. The two samples of phase one and two will include the exactly same individuals and same sample size which is about **50 patient/caregiver—physician dyads**, including about 50 patients, 10 physicians, and 50 caregivers, if applicable.

There are three steps of recruitment processes. First, physicians who are currently in clinical practice at National Taiwan University Hospital and care for patients with solid tumors will be recruited through study presentations at grand rounds, meetings, or personal contacts. A research assistant then meets with interested physicians for explaining the details of the study, consenting, and setting up following schedules for recruiting patients at OPD visits. Second, research assistants identify potential eligible patients by working closely with participating physicians and their clinic nurses. These potential eligible patients will be approached by their physicians, nurses, or research assistants. We include patients who are: (1) currently a patient of a participating physician, (2) diagnosed with advanced solid cancer (TNM stage III or IV), (3) aged 20 years or older, (4) able to tolerate an interview that will last approximately 30 minutes, and (5) able to speak Chinese or Taiwanese. Patients who (1) do not experience any symptoms, or (2) are hospitalized at recruitment are excluded. Finally, caregivers who will participate in the OPD visits with participating patient will be approached. Caregivers who are younger than 20 years old or cannot speak Chinese or Taiwanese will be excluded.

Recruitment process. Interested patients and their caregivers will receive a pamphlet regarding study information when research assistants explain study process, confirm participation, and arrange schedules. Signed written consents will be obtained from physicians, patients, and caregivers before data collection. Participated patients and caregivers are required to (1) provide an audio-recorded, unstructured OPD visit with their physicians, (2) complete 3 survey measurements (European Organization for Research and Treatment of Cancer, Perceived Efficacy in Patient-Physician Interactions scale, and The Chinese Patients' Satisfaction Scale), and (3) participate in a 30-40 minutes interview at home or a private room. On the other hand, participated physicians will complete European Organization for Research and Treatment of Cancer immediately after the recorded OPD visit. Figure 3 represents the recruitment and data collection process.

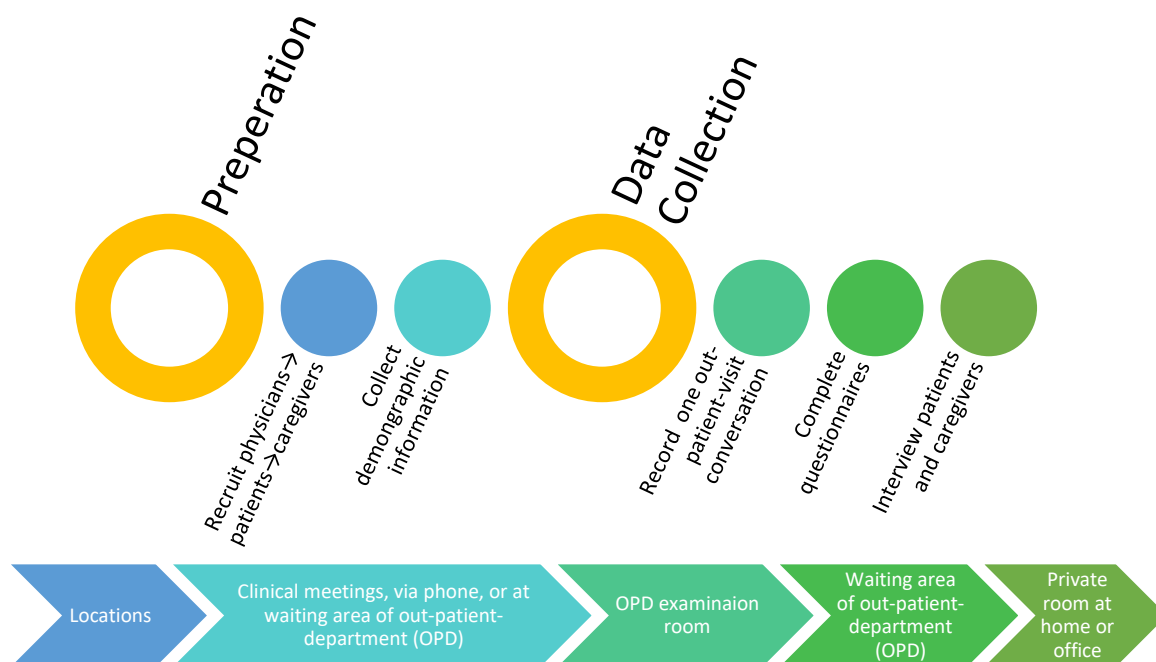


Fig 3. Recruitment and Data Collection Process

Table 2. Example Interview Guide (Patient version)

*[] 中文字會視每位病人在診間與醫師的對話內容而更動

今天的會談主要想了解您對於上次在診間、被錄音的那次會診的想法或感受。我們的重點尤其會放在當時您在診間溝通症狀時的一些內容；等一下我所問的問題都沒有所謂的正確答案，主要是以您的感覺為主。在開始之前，我很樂意回答您的任何問題。

1. 請回憶上次的會診，您在開始與醫師談話前是否有特別想討論的重點或問題？
2. 告訴我您對這次與醫師談話的任何感受、感想或印象最深刻的的事情。
3. 您與醫師曾討論[所有在診間討論提及的症狀]，請以你的話描述一下當時討論這些症狀的情形。
4. 在討論這些症狀的當下，您的感受是...？
5. 請問您當時還有任何症狀或問題是沒有被提及的嗎？為什麼？請多跟我描述這個[症狀或問題]。
6. 我們發現，您和醫師常以[以簡易方式說明某種互動模式]討論症狀，對於這種互動模式，您的想法或感受是...？
7. 依您的看法，這次的診間談話與平常的診間談話比較起來...？
8. 您覺得這次的談話有什麼優點或是可以改進的地方？

Phase 1: qualitative data collection and analysis. The qualitative phase is a qualitative descriptive study because we want to provide a fundamental and straightforward description regarding the validation of TIPSC (aim 1) and how patients experience and think about the interaction (aim 2).

On the day of the scheduled, audio-recorded office visit, a research assistant will first meet with the patient and caregiver for completing the survey measurements and then accompany them to the office, set up the recording device, and leave. The research assistant will collect the device and recordings after the visit and schedule a follow-up interview between 2 days to a week after the recorded visit. This 30-40 minutes follow-up interview will be conducted by the PI who is a certified oncology nurse with expertise in qualitative study, symptom management, and psycho-oncology. The PI will listen to the recorded visit before interviewing each patient in order to design individual-specific interview questions. Table 2 demonstrates example interview guide. All recorded visits and interviews will be transcribed verbatim.

Conversation analysis (CA) and discourse analysis (DA) will be used to analyze the transcripts of audio-recorded, naturally occurring OPD conversations as we want to understand patterns of symptom communication and verify the TIPSC (aim 1). CA and DA are selected because they allow us to focus on naturally occurring conversation and what is being accomplished in conversations (29-31). Particularly, CA considers talk-in-interaction as a co-constructive and collaborative process, which fits more with patient-centered and relationship-centered approaches to medical communication (32). CA and DA share similar assumptions and are firstly developed in sociology and linguistics before rapidly evolving in a wide range of disciplines including psychology and social medicine (31). While CA will provide analytic tools to (1) examine the talk turn by turn and (2) look for the related features of patient-provider symptom communication which is a unique sub-type of medical communication (33-36), Goodman's (2017) eight steps of conducting DA will guide the analysis steps of the current study.

Step 1: Deciding Appropriate Research Question. The researchers will focus on aim one which is appropriate for CA/DA because of its action-orientation.

Step 2: Picking Appropriated Data Source. The researchers will analyze naturally occurring OPD conversations which are idea for CA/DA as they are interaction-based.

Step 3: Generating a Corpus. 'Corpus' means 'the collection of all the appropriate data that will be analyzed.' While the researchers plan to record one OPD visit for 50 patient/caregiver—physician dyads, only conversations which contain discussions of symptoms will be included and analyzed.

Step 4: Transcribing Data. The data are primarily transcribed according to the conventions developed by Jefferson (37, 38), with slight modifications to those inapplicable to Mandarin Chinese characters. Jefferson's transcription conventions make it possible to capture the details of the talk—not only what was said, but also the way it is said. Pauses, rising/lower volume, or the change of intonation will be noted. Remarks on other verbal sounds—such as coughing and clearing throat—will be provided in italics inside double parentheses. The following software will be used to assist data transcription: Speechnotes, ELAN, and InqScribe.

Step 5: Preliminary Reading of the Data. The researchers will immerse themselves in the data and begin the first round of analysis including writing down initial thoughts about the data and categorize interactions into different patterns based on TIPSC. NVivo qualitative data analysis

software (version 11.4.1; QSR International Pty Ltd, 2017) and Microsoft Word will be used to aid the analysis

Step 6: Generating Results. The researchers use specific strategies or ‘discursive devices’ to enhance the analysis. Specifically, the researchers explore the following characteristics of each interaction type of TIPSC: turn-taking organization, sequence organization, and turn design (34, 35, 39, 40). These interrelated characteristics reflect different dimensions of patient-provider communication. First, we will examine how participants take turns and whether the interaction uses a special turn-taking organization. Looking at turn-taking, we will by default locally deal with pauses, overlaps, and interruptions. We will also, on overall level, explore whether the turns are equally distributed throughout the OPD visits by considering turn length and turn composition. For example, the interaction pattern identified as ‘agentic’ refers to the interaction in which patients and/or caregivers are particularly vocal during discussions, taking longer and complex turns; the pattern ‘checklist’ is organized by question-answer turn-taking organization with providers asking a series of questions in rote fashion. Second, with a focus on sequence organization, we will look at how particular courses of action are initiated and negotiated in sequences. Then, we will look at the turn design: how a turn is designed to perform certain action and how the turn is composed. That is, what the turns are doing and what linguistic elements, both syntactically and lexically, are selected to embody the actions. Lexical choice particularly draws researchers’ attention in prior research (41). Here we provide a data set from Heritage et al. (2007) to demonstrate the three dimensions turn by turn analysis.

01 DOC: -> And do you have any other medical problems?
 02 PAT: Uh No
 03 (7 s of silence)
 04 DOC: -> No heart disease?
 05 PAT: ((cough)) No.
 06 (1 s of silence)
 07 DOC: -> Any lung disease as far as you know?
 08 PAT: No.

(Heritage et al., 2007: 1430)

This spate of talk constitutes a prototypical turn-taking organization of doctor-patient communication—doctors posing questions and patients answering. The doctor’s turns are compositionally complex than the patient’s but relatively straightforward; the patient provides (negative) minimal responses. The turn organization represents a course of checklist symptom inquiry with patient indicating no problem. The doctor’s questions are all designed as yes-no questions in different syntactic formats with different lexical choices. All the questions communicate an expectation in favor of ‘no’ responses. The preference for ‘no’ answers is enforced by the use of the lexical item ‘any’ (instead of ‘some’) and ‘no’. Through an intervention study, it is shown that such question designs may lead to unmet concerns in office visits.

Step 7: Building a Case to Support the Findings. Similar to table one which was established in the preliminary study, the researchers refine definitions and pick best exemplars to describe each interaction patterns.

Step 8: Report Writing. Final research report and manuscripts will be established in this stage.

The standard content analysis will be used to analysis the follow-up interview because we want to provide a fundamental and low-interpretive description of how patients experience the

symptom discussions (42).

Phase 2: Quantitative data collection and analysis. The quantitative phase employs a correlational design because the aim of this phase is to examine the relationships between interaction patterns and variables including demographic variables, symptom severity, congruence in symptom assessment between patients/caregivers and physicians, patients' perceived ability to communicate with physicians, and patient/caregiver satisfaction (aim 3).

In addition to demographic information, three questionnaire measurements: **European Organization for Research and Treatment of Cancer (EORTC-QLQ C30)**, **Perceived Efficacy in Patient-Physician Interactions scale (PEPPI)**, and **The Chinese Patients' Satisfaction Scale (C-PSS)** will be used to collect data regarding symptom severity, perceived ability to process the information, and overall satisfaction, respectively. The oncologists are required to provide their own demographic information and EORTC-QLQ ratings after seeing each participated patient. Patients are required to provide information of demographic data, EORTC-QLQ C30, PEPPI, and Satisfaction scale. The demographic information will be collected at the time of recruitment while other questionnaires will be collected after the recorded office visits. More information regarding each questionnaire measurements are described below.

Symptom severity will be measured by **European Organization for Research and Treatment of Cancer (EORTC-QLQ C30, Taiwan Chinese version)**. The EORTC QLQ-C30 is a 30-item questionnaire developed by a group of scientists to evaluate functions, symptoms, and overall health-related quality of life of cancer patients. EORTC QLQ-C30 has been verified and widely applied in health-related research. Evaluators rate patients' functions, symptoms, and quality of life using 4-point Likert scales. The Taiwan Chinese version of the EORTC QLQ-C30 has been tested and shows good reliability and validity (43, 44). The reported Cronbach's alpha coefficient of most items was above 0.70 across studies. A 5-10—points difference of EORTC QLQ-C30 rating is considered a significant difference (45). That is, if the difference of EORTC QLQ-C30 rating between a patient/caregiver and a physician is greater than 5, it is defined as an incongruence symptom report.

Patients' perceived ability to communicate with providers will be measured by **Perceived Efficacy in Patient-Physician Interactions Scales (PEPPI-10, Chinese version)**. PEPPI-10 is a self-evaluated, 10-item instrument measuring patients' self-efficacy in "obtaining medical information and attention to their medical concerns from physicians (46)." Patients rate their confidence of interacting with physicians (e.g., get a doctor to pay attention to what you have to say) from "no confident (0)" to "extremely confident (10)". The Chinese version of PEPPI-10 shows good validity and reliability with the reported Cronbach's α coefficient of 0.907 (47).

Patients' overall satisfaction will be measured by the **Chinese Patients' Satisfaction Scale (C-PSS)**. C-PSS is a 27-item instrument which was developed to measure Chinese patients' satisfaction using a 5-point Likert scale. Patients rate their satisfaction from strongly disagree (1) to strongly agree (5) with higher scores represent better satisfaction. It is a reliable and valid tool with the reported Cronbach's alpha coefficient of all dimensions above 0.90 (48).

The major interaction patterns or combination of interaction patterns will be determined and dummy coded. Binomial Logistic Regression will be used to examine the relationship between interaction patterns and dichotomous variables (i.e., the congruence of symptom reports) while Linear Regression will be applied to examine the relationship between the interaction patterns and other variables, such as age, level of symptom severity, perceived communication ability, and satisfaction. The SPSS software will be used to organize the data and facilitate data analysis. Finally, combining and comparing the findings from the interviews and the results from the quantitative measurements enable us to do triangulation to fully map up the interaction behavior pertinent to symptom discussion.

Trustworthiness

To ensure the quality of study results and conclusions, five standards outlined by Miles and colleagues (2013) will serve as an evaluative framework. The standards are **confirmability, reliability, credibility, transferability, and utilization**.

Confirmability is the extent to which the findings are neutral, that is free of researcher bias, and thus can be confirmed by others. The strategies that will be used to ensure confirmability for the current study include the following: (1) The study processes, especially the analysis plan, will be explicitly described and documented, and (2) The research team will meet regularly to monitor the analytic processes and confirm study findings.

Reliability is whether the study processes remains consistent and stable over time and across researchers. Reliability is based on whether the researcher has taken care to ensure the quality and integrity of the research process. The strategies that will be used to ensure reliability are as follows: (1) Clear study aims have been established and the study design is explicit and consistent with the aims, and (2) The research team will meet regularly to ensure that all study procedures as outlined in this proposal are closely followed.

Credibility is the “truth value” of the findings – that is whether the study findings are authentic and thus make sense to people we study and to readers. The strategies that will be used to ensure credibility are as follows: (1) the researcher will obtain feedback on all codes and categories as they emerge from peer and qualitative research interest group, if available, and (2) **asking for selected participants’ feedback regarding study findings**. Specifically, researchers will mail preliminary findings to 3-5 participants who agreed to provide their feedback and then conduct phone interviews to examine if their experience is similar to or different than the study findings. The research group will meet to discuss patients’ feedback and modify the study findings accordingly.

Transferability is whether the study results can be generalized or transferred to other contexts, populations, or settings (49). Although it is similar to external validity or generalization in quantitative studies, they are different in that transferability invites the readers of the study to determine if the findings can apply or inform their understanding of the phenomenon by describing the participants and the study context fully. The strategy that will be used to ensure transferability is to clearly describe the study context, population and settings

Utilization describes the pragmatic value of the study. It is determined based on whether the study results can be applied to real world and advance the knowledge (50). The strategy that will be used to ensure utilization is asking for national and international health experts’ feedback regarding the usefulness of study findings by conducting expert panels. Specifically, **we have established collaboration relationship with Dr. Prigerson and her research team at Cornell Center for Research on End of Life Care and will invite Dr. Prigerson for online discussions and onsite visits**. Dr. Prigerson’s extensive knowledge and experience in cross-culture cancer care, decision making, and communication will not only help ensure the quality and utilization of the proposed study but also identify cultural differences which can inform future studies.

Innovations and Challenges

This is an innovative study because of its pioneering focus and unique design. First, this is one of the few studies focused on conceptualizing interactions patterns related to symptom communication. It is also the first study examining the possible factors related to interaction patterns of symptom communication. Such information can be used to conduct larger scale research and facilitate patient—provider communication and symptom management. **Second, part of the**

study design was informed by a communication theory. It is not common to see a healthcare study considering theories developed in communication field. Integrating knowledge established in different fields allow us to decipher researcher questions more efficiently and comprehensively. **Third, this proposed study address national issues based on international and interdisciplinary evidence and perspectives by (1) test a typology developed with U.S. population in Taiwan, (2) considering expert opinions from heterogeneous recourses, such as healthcare providers from Taiwan and other countries, patients, and caregivers when interpreting results.** Results will provide useful information regarding communicating symptoms with patients with diverse background.

Our study faces several possible challenges including the difficulties of recruiting physicians and advanced cancer patients because of physicians' limited time and the critical condition of patients with advanced cancer. Strategies designed to tackle these challenges including closely working with clinical experts, allowing reasonable recruitment duration, providing incentives, and interviewing patients/caregivers at a place of their choice.

Expecting Results

This will be a three-year study project starting from September, 2018. Table 3 shows study procedure and timeline. The expecting results of the research projects can be discussed in two categories: direct research results and indirect process results (table 4). The major **direct research results are: (1) the verified TIPSC and (2) a comprehensive map describing symptom communication including interaction patterns and associating factors.** The major **indirect process results which are the byproducts of the proposed research include (1) parameters establishment for larger scale quantitative studies, (2) establishment of a health communication lab, (3) international and interdisciplinary collaboration, and (4) international/national/ local conference presentations and journal publications** (i.e. practical results). The next paragraph describes the corresponding resources and strategies of achieving these indirect process results.

Parameters establishment for larger scale quantitative studies. As this pilot study is among the first to describe the relationship between interaction patterns and clinical outcomes, our findings can be used to calculate power and determine adequate sample sizes for future, larger scale quantitative studies.

Establishment of a health communication lab. The specific plan is to (1) conduct informational interviews in the campus with colleagues and students about suggestions and resources of beginning a lab, (2) recruit research team members and create training plans, (3) establish the lab culture and routines, such as missions, equipment and space, website, lab management systems, and regular meetings, (4) identify and securing collaboration opportunities by promoting the lab and research at research meetings and conferences, (5) networking other similar labs in Taiwan (e.g., language and communication lab at National Cheng Kung University) and other countries.

International and interdisciplinary collaboration. The strategy of working with diverse partners builds on the applicant's abundant global experience, including being members of professional organizations (e.g., Oncology Nursing Society, Communication, Medicine, and Ethics International Society), serving as a reviewer of a *Cancer Nursing*, and international collaboration experiences with Johns Hopkins University and Hospital, Indiana University and Cancer Center, Purdue University, and University of Rochester Medical Center. To achieve this goal, we first will continuously work with international experts and institutions by meeting online or onsite to brainstorm research ideas, refine study procedures, and generate joint recommendations. Specifically, as we mentioned earlier, the research team of Cornell Center for Research on End of Life Care have expressed their interest in collaborating on this and future projects. Other possible international collaboration institutions

include Behavioral Cooperative Oncology Group (BCOG) and Center for Symptom Management at Indiana University, Brian Lamb School of Communication at Purdue University, and Center for Health Communication at the University of Texas at Austin. Second, in addition to continuing the membership of professional organizations and reviewer service, the PI also plans to participate in more professional services, such as serving as a moderator in conferences or doing editorial service for journals.

International/national/ local conference presentations and journal publications. Research findings will be published in journals and presented in conferences, such as Oncology Nursing Society congress, European Society for Medical Oncology-Asia conference, and Asia Clinical Oncology Society conference. Table 5 demonstrates aforementioned practical results, including the number of conference presentations, and journal publications.

Conclusion

This study proposal focusing on patient-provider symptom communication in advanced cancer population is a groundbreaking study which addresses **not only an underexplored area in Taiwan but also two global research priorities in Cancer and Palliative Care: symptom management and communication (51-56)**. For instance, the 2014–2018 Oncology Nursing Society (ONS) Research Agenda Project Team identified eight high-priority cancer research areas including symptoms. Since 2001, managing physical and psychological symptoms in patients with cancer has consistently topped the ONS Research Agenda. The ONS Research Agenda Project Team also pointed out that studies enhancing communication in palliative care are a priority area for research (51, 52). Likewise, research focusing on using symptom management to improve HRQOL for patients with cancer has been a focus for National Institute for Nursing Research (NINR) for over 25 years. NINR has also stressed the importance of establishing effective patient—provider communication in order to promote health and decision-making regarding complex treatment and care options, especially in end-of-life care (54). In a European survey which obtained researchers' opinions from 36 countries found that symptom management, especially pain, was rated as the most active and most important research area in cancer end-of-life care (56). On the other hand, the quality of patient—provider communication is questionable and may link to several health issues, including patient outcomes, in Taiwan. Grounding on international evidence, this proposed study is a critical step to close knowledge gaps of symptom communication and management and identify local problems. Findings will inform relevant research, education, and clinical practice in Taiwan. Moreover, our findings will serve as a basis to transform healthcare in Taiwan by raising public awareness and facilitating expert discussions of issues related to patient—provider communication.

Conflict of Interest

The researchers declare that they have no conflict of interest. The research and development results ownership belongs to National Taiwan University.

Privacy and Confidentiality

All data will be de-identified by using heuristic methods. Electronic data will only be send using NTU or NTUH email system and be stored in the secure space at the network-attached storage system which can only be accessed with assigned username and password. Written information will be locked in PI's office at National Taiwan University.

	Year	2018		2019				2020				2021	
	Months	9	10-12	1-3	4-6	7-9	10-12	1-3	4-6	7-9	10-12	1-3	4-7
Phase 0. Obtain IRB approval		x											
Phase 0. Obtain questionnaire measurements		x											
Phase 0. Establish research team		x											
Phase 0. Recruit oncologists & patients			x	x	x								
Phase 1. Record 1 OPD visit & collect questionnaire measurements			x	x	x								
Phase 1. Interview				x	x	x							
Phase 1. Analyze recorded office visits					x	x	x	x	x				
Phase 1. Analyze interviews					x	x	x	x	x				
Phase 1. Check study trustworthiness: request selected participants' feedback on qualitative results									x	x			
Phase 2. Analyze quantitative data based on qualitative findings of recorded OPD visit									x	x	x		
Phase 2. Compare the qualitative findings of interview with the quantitative data (triangulation)										x	x	x	
Phase 2. Check study trustworthiness: request international experts' feedback on final results												x	
Phase 2. Report and Manuscript writing												x	x

*Abbreviation: Out-patient-department (OPD)

	Expecting direct research results	Expecting indirect process results
YEAR 1 (2018, 9—2019, 7)	<ul style="list-style-type: none"> ▪ Obtaining IRB approval ▪ Obtaining questionnaire measurements ▪ Finishing the recruitment of oncologists and patients 	<ul style="list-style-type: none"> ▪ Establishing research team: recruit members and establish regular meetings ▪ Training: recruitment strategies and research methodology (mixed-methods), interview skills ▪ Presenting methodology at local/national/international conferences ▪ Online international collaboration: study design
YEAR 2	<ul style="list-style-type: none"> ▪ Finishing collection of qualitative data: recorded 	<ul style="list-style-type: none"> ▪ Identifying and securing international collaboration opportunities

(2019, 8—2020, 7)	<p>office visits & interviews</p> <ul style="list-style-type: none"> ▪ Finishing collection of quantitative data: questionnaire measurements 	<ul style="list-style-type: none"> ▪ Training: data collection (qualitative and quantitative) and data analysis (discourse analysis method, content analysis method, usage of Nvivo) ▪ Presenting recruitment process and results at local/national/international conferences ▪ Online international collaboration: ensure study trustworthiness
YEAR 3 (2020, 8—2021, 7)	<ul style="list-style-type: none"> ▪ Completing the analysis of qualitative data: recorded office visits & interviews ▪ Completing the analysis of quantitative data: questionnaire measurements ▪ Triangulation 	<ul style="list-style-type: none"> ▪ Continuing international collaboration through on-site visits and email or online discussions ▪ Identifying conferences and journals for results dissemination ▪ Presenting preliminary results at local/national/international conferences ▪ Training: data analysis (descriptive and correlational statistics, triangulation, usage of SPSS) ▪ Onsite international collaboration: ensure study trustworthiness

Table 5. Practical Results				
		9, 2018—7,2019	8, 2019—7,2020	8, 2020—7,2021
Manuscripts	Journal	1 (methodology)	2 (discourse analysis results, content analysis results for patient)	3 (content analysis results for caregiver, quantitative results for patient and caregiver)
	Conference	1	2	3
Research Reports		1	1	1

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