

Practical wisdom of discharge planning nurses in the consensus building between cancer patients whose active treatment in coming to an end and their families: a qualitative descriptive study

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Practical wisdom of discharge planning nurses in the consensus building between cancer patients whose active treatment in coming to an end and their families: a qualitative descriptive study

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Abstract

Purpose: This study aims to identify the practical wisdom of discharge planning nurses (DPNs) in supporting the consensus-building process between cancer patients whose active treatment in coming to an end and their families.

Subjects and Methods: Semi-structured interviews using a face-to-face or web-based interview were conducted with 13 DPNs from six designated cancer hospitals in Japan. Qualitative descriptive analysis was used to analyse the interviews. The COREQ checklist was used to ensure reliability.

Findings: Five categories were identified as practical wisdom of DPNs who support the process of consensus building between cancer patients whose active treatment is coming to an end and their families: determination of the direction of discharge planning; building of relationships that allow patients and their families to express their intentions; sharing of patients' and their families' intentions among the involved parties; finding common ground that patients and their families can agree on; and constant review of the speed and timing of discharge planning.

Conclusion: The practical wisdom of DPNs supporting the process of consensus building between cancer patients whose active treatment in coming to an end and their families was clarified. Among them, review of the speed and timing of discharge planning was practical wisdom that DPNs exhibited continuously during the consensus building process and was considered to be a major characteristic of discharge support for cancer patients whose active treatment is coming to an end and their families. There is a need to enhance DPNs' educational programs by incorporating case study sessions, clinical conferences, and communication skills training.

KEY WORDS

discharge planning nurse, advanced cancer patient, decision making, consensus building, practical wisdom

Introduction

In Japan, medical costs are increasing due to the aging population and changes in the disease structure^{1,2)}. In addition, the average length of hospital stay in Japan is much longer than that in other countries³⁾. As a result of the national policy of functional differentiation of hospitals⁴⁾, it is becoming increasingly difficult

for a single hospital to provide complete cancer care from diagnosis to the end of life. Discharge planning is vital for facilitating appropriate decision making by patients and their families in healthcare settings⁵⁾ and is recommended to save medical costs by ensuring continuity of quality patient care and preventing prolonged hospitalisation and unnecessary

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readmissions⁶⁾.

Reportedly, cancer patients have a disease trajectory characterised by a rapid deterioration of their condition in the last 1–2 months of life, leading to death within a short period of time⁷⁾. As cancer progresses, and the risks of treatment outweigh the benefits to the patient, the physician will inform the patient and family that active treatment will end and recommend a move to palliative care. However, cancer patients hope to fight cancer until the last moment⁸⁾. As a result, cancer patients whose active treatment is coming to an end (hereafter referred to as “advanced cancer patients”) and their families who have been informed of this are unable to reconcile their feelings and are faced with overwhelming and important decisions to make about their treatment options and where to receive them.

In Canada, the role of the clinical nurse specialist in oncology palliative nursing is to collaborate with a team of specialists to provide referrals to community services and care planning⁹⁾. In Italy nurse case managers with palliative care experience have been reported to provide telephone follow-up for patients with advanced cancer in early palliative care¹⁰⁾. In Japan, there are also certified nurse specialists in cancer nursing, professionals who provide excellent nursing and decision-making support for cancer patients in their speciality¹¹⁾. The role of discharge Planning Nurses (DPNs), who are assigned to the discharge planning department is to support an agreed discharge of patients and their families where there are cancer or other factors that make it difficult for them to be discharged from the hospital¹²⁾. With increasingly diverse opinions, it is urgent to develop DPNs who can support the process of consensus building¹³⁾, in which everyone concerned can share the reasons for their opinions with each other and continue to search for the best solution.

The practical wisdom of nurses is the knowledge gained while consistently using skills and engaging in practice^{14,15)} and is something that is needed in clinical practice and guides decision-making¹⁶⁾. However, how DPNs actually think, judge, and act in clinical practice to support the process of consensus building with advanced cancer patients and their families is still unclear. Therefore, this study aims to identify the practical wisdom of DPNs in supporting the consensus-building process for advanced cancer patients and their

families.

Methods

1. Design

A qualitative descriptive approach¹⁷⁾ was adopted to provide a comprehensive description of the phenomenon. It sheds light on the actions and intentions of DPNs in the process of consensus building, particularly between patients and their families, between families, and between patients or their families and healthcare professionals. Thus, we adopt this approach in the context of discharge planning for advanced cancer patients.

2. Participants and recruitment

Participants were recruited from the discharge planning department of a designated cancer hospital in Japan. The first author was responsible for recruiting participants. They were recruited using the following criteria: nurses currently working in a coordinated cancer care hospital and coordinating and planning discharge planning for patients with advanced cancer. Cases were purposively sampled using opportunity sampling¹⁷⁻²⁰⁾. In a previous study, the ability of DPNs to build consensus with advanced cancer patients and their families did not differ according to the number of years of experience in the discharge planning departments²¹⁾.

3. Data collection

Semi-structured interviews using an interview guide were conducted between October 2019 and May 2021, with 13 DPNs who consented to the study; 11 of the 13 were face-to-face interviews and 2 were web interviews. The inclusion of web interviews did not impede data collection. The participants were asked to narrate a case wherein they had struggled to reach a consensus in supporting the discharge of a patient with advanced cancer, either between the patient and family, between family members, or between the patient or family and healthcare professionals. To elicit narratives about the DPN's thoughts, judgments, and actions, the researcher used an interview guide to ask questions such as ‘What was each patient's and family's understanding of the patient's medical condition and progress after discharge?’, ‘Where did you first see the problem in this case in providing discharge planning?’, ‘What were the intentions of the patient, family, and healthcare professionals?’ The narratives were recorded

on voice recorders with the consent of the participants, and notes were taken where necessary. The audio data were transcribed into a verbatim transcript.

Once the provisional categories had been generated, participants were asked additional questions in writing to obtain more detailed data on the actions and intentions of DPNs. Three participants were asked additional questions, and new data was added.

4. Data analysis

The analysis was carried out according to the methodology of Charmaz²². All coding was performed by the first author for each case. The first author read the transcribed text data carefully, extracted the parts that described the DPNs' actions and their intentions, including the background, in the process of consensus building with the patient and family and assigned names that were faithful to the data as initial codes. The initial codes were categorized, organized, and integrated according to their semantic content, and then codes for focalization were created from the initial codes. The focalization codes were organized and integrated to extract the subcategories. The subcategories were further organized and integrated at a higher level of abstraction to produce the final categories. After the analysis of the data of 11 persons had been completed, the data of two more persons were added, but no new categories were generated.

5. Trustworthiness

All the interviews were conducted by the first author, who holds a master's degree in health sciences, and is experienced in conducting interviews in qualitative research and in providing discharge planning to advanced cancer patients as a DPN. To ensure credibility, consistency, and corroboration¹⁸, interviews were conducted using an interview guide and member checking by three participants. During the analysis process, we sent tentative results to participants and asked them to comment on whether what they had said was correctly represented. The researchers followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist²³ to report research methods, research context, findings, analysis, and interpretation.

6. Ethical considerations

This study was approved by the Medical Ethics Review Committee of the Kanazawa University (Review No. 838). Participants were informed that they could

discontinue or refuse participation in the study at any time if they felt psychological distress or physical exhaustion from telling the case of an advanced cancer patient who they had assisted in discharge planning. The interviews were recorded with the participants' permission, and the content of the interviews was anonymized so that individuals could not be identified when transcribed verbatim.

Findings

1. Summary of participants

Thirteen participants were women, and their average age was 47.2 years (range: 34–59 years), with the mean number of nursing experience being 24.1 years (range: 11–38 years). The participants had an average of 4.2 years (range: 1.5–9 years) of experience in the discharge planning departments. The average length of the interviews was 52.7 minutes (range: 44–66 minutes), with a total of 15 case studies being discussed. None of the participants withdrew from the interviews at any point. (Table 1)

2. Practical wisdom of discharge planning nurses in the consensus building of advanced cancer patients and their Families

Five categories were generated from 21 subcategories in the analysis. They include determining the speed and timing of discharge planning, determining the direction of discharge planning, building relationships that allow patients and their families to express their intentions, sharing patient and family intentions among the involved parties, and finding a landing point that the patient and family can agree on. The categories and subcategories are shown in Table 2, and the relationships between the categories are shown in Figure 1.

In the explanations for each category that follows, the categories are highlighted in ***bold italics***, the subcategories in **bold**, and comments from the data are in *italics*.

Identifying the speed and timing of discharge planning

The DPNs confirmed the patient's medical condition with physicians and nurses to decide whether they could meet the patient and family and they were **determining the timing of starting discharge planning**.

Table 1 Participant characteristics

Participant	Gender	Age	Years of nursing experience	Years of discharge planning nursing experience	Hospital Locations
A	Female	59	38	8	Hokuriku region
B	Female	49	27	3.5	Tohoku region
C	Female	47	26	3.5	Tohoku region
D	Female	41	20	3	Hokuriku region
E	Female	53	25	7	Kanto region
F	Female	48	28	5	Hokuriku region
G	Female	48	24	3	Hokuriku region
H	Female	48	22	9	Kanto region
I	Female	50	28	1.5	Hokuriku region
J	Female	52	27	2.5	Hokuriku region
K	Female	50	26	2	Hokuriku region
L	Female	34	11	4	Kanto region
M	Female	35	11	3	Kanto region
Mean		47.2	24.1	4.2	

Some patients thought I was rushing them out of hospital because of my bedside visits, and I was told this explicitly. I try to ask the ward nurses when it is appropriate for me to come and talk to them and when it is appropriate for me to interact with the patient. (Participant G)

The DPNs were **always keep in mind the possibility that the patient's condition might deteriorate** and believed that they needed to hasten discharge planning for a patient with a limited time to live. On the contrary, the DPNs understood that it was natural for the family to have difficulty accepting the patient's severe condition, so they **waited for the patient and family to be able to decide where they want to be discharged to**. DPNs assessed the extent to which patients and their families accepted their illness and identified the timing of discussions about discharge from the hospital.

I understood that the patient's sons desire to continue treatment was due to their love for their mother, and I accepted it, but I kept in mind that, after all, it was pancreatic cancer, and there was a high possibility

that it would get much worse. I was watching the patient's progress, wondering what would happen to the family or the sons if the bilirubin level came down. (Participant H)

Determining the direction of discharge planning

Before meeting patients and their families, DPNs asked the health care professional about the **patient's prognosis and future treatment and the patients' and families' perceptions of the disease and the patient's social background**. When DPNs were aware of differences in perceptions among healthcare professionals, DPNs **set up a forum for healthcare professionals to discuss the direction of discharge planning**. They also requested that the physician to explain the risk of sudden changes in health condition to the family. The DPNs attend presentation on the disease to the patient and family to correct any differences in the physician's explanation and the patient's and family's perceptions. In this way, the DPNs were able to determine the direction of discharge planning.

Table 2 Categories and subcategories

Category	Subcategory
Determining the direction of discharge planning	Asking the health care professional about the patient's prognosis and future treatment
	Asking various professionals about the patient's and family's perceptions of the disease and their social background
	Setting up a forum for healthcare professionals to discuss the direction of discharge support
	Requesting that the physician explain the risk of possible sudden changes in health condition to the family
	Attending presentations on the disease to the patient and family
Identifying the speed and timing of discharge planning	Always keeping in mind the possibility that the patient's condition may deteriorate.
	Determining the timing of starting discharge planning
	Determining the timing of discussions about discharge from the hospital
	Assessing the extent to which the family accepts the illness
	Waiting for the patient and family to be able to decide where they want to be discharged to
Building relationships that allow patients and their families to express their intentions	Meeting patients and their families after receiving a referral from a person the patient or family trusts
	Going to the bedside to listen to what the patient is really thinking and feeling
	Assuring the patient and family that they can change their mind at any time
	Encouraging patients and their families to think together
Sharing patient and family intentions among the involved parties	Asking the patient and family how they would like to spend their remaining time .
	Assessing the differences in intentions between the healthcare team and patient and their families
	Holding discussions with the health care team to share information on patients and family differences in intentions
Finding a landing point that the patient and family can agree on	Informing the family of the patient's stated intentions
	Encouraging family members whose opinion differs from the patient's to reconsider
	Offering options that are acceptable to the patient and family members with different desires
	Providing patients and their families with strategies for coping with a deterioration in their condition after discharge

It is not possible to tell from the text of a physician's medical record alone how the physician explains the patient's condition to the family, and I think it is important to listen to the physician's explanation together with the patient and their family, because later when I ask the patient and their family what they think of the physician's explanation, they will be more likely to talk to me and I will be able to tell them what the physician wanted to say in a way that is easier for them to understand. (Participant J)

Building relationships that allow patients and their families to express their intentions

When the DPN met the patient and family for the first time, they met patients and their families after receiving a referral from a person the patient

or family trusts. At that point, the DPN explained that their role was to support the patient and family in deciding where to receive treatment and told the patient and family that they would encourage patients and their families to think together.

The family was confused by the shocking explanation concerning the disease. However, the patient's daughter was also very eager to do something for the patient and to make her feel as relaxed as possible, as her prognosis was very short. So, I talked to the family about the options available for the patient's future care, and how we could work together to find a way to deal with the limited medical resources available at her home. (Participant M)

To get patients to talk honestly, the DPNs often went

to the bedside to listen to what the patient is really thinking and feeling and gradually built a trusting relationship with the patient by listening to his values, past life, and thoughts about his family.

My role was listener of his story. I often went to his bedside asking, "How are you today?" I was in charge of discharge planning, but I did not reveal it, I try to get a glimpse of the patient's values, how they have lived their lives, how they feel about their homes and their families through daily conversation. (Participant H)

DPNs also assured the patients and their families that they could change their minds at any time so that the patients and families, who often feel obliged to do as they are told, could feel comfortable expressing their feelings.

I try to make it as easy as possible for the patient to say what they really feel. I would say, "If you want to change your mind please say so." There is no right answer and I explain that even if they think this is the best thing to do now, it's OK for them to change, even when talking about transferring to a different hospital. I tell them that it is natural to feel confused and if they tell me they have made a different decision, I will tell the physician for them. (Participant J)

Sharing patient and family intentions among the involved parties

After building relationships with patients and their families, the DPNs asked patients and their families how they would like to spend their remaining time, who had been given a harsh description of their condition. The DPNs reconciled information from the patient and family interviews with information from the providers to assessing the differences in the intentions between the healthcare team and patient and their families understand the differences between the healthcare professionals' perceptions and the patients' and families' intentions regarding post-discharge care. When DPNs identified differences in the intentions of patients and families and among family members, they held discussions with the health care team to share information on patients and family

differences in intentions. At the conference the DPNs also shared perceptions and the patient's current condition with the team.

I could predict that the patient would be shocked at being told about Best Supportive Care and that they would not easily accept it. So, I thought it was necessary to suggest a conference with medical staff to consider in advance how to deal with those aspects of BSC that would be most likely unacceptable to the patient. (Participant E).

Finding a landing point that the patient and family can agree on

The DPNs were informed the family of the patient's stated intentions who were unsure about continuing treatment or where to go for treatment after the physician had given them a grim account of the patients' condition, what the patient had told them. This provided an opportunity for the family to remember what the patient had said in the past and become aware of the patient's intentions.

When physicians give shocking explanations of the patient's condition, families often do not know what to do. At such times, if I say, "The patient said this", the family remembers the patient's intentions, saying, "Yes, they did used to say that." (Participant H)

DPNs communicated the wishes of patients with a bleak prognosis to family members whose thoughts differed from those of the patient and encouraging family members whose opinion differs from the patient. Conversely, DPNs not only prioritized the patient's wishes but also tried to understand the family members who wanted the patient to be treated in a place that did not match the patient's condition. Furthermore, DPNs approached hospitals that met the family's wishes, even if they thought it would be difficult for the hospital to accept the patient and waited for the family come to understand the patient's true condition. In the meantime, DPNs tried offering options that are acceptable to the patient and family members with different desire. They also provide patients and their families with strategies for coping with a deterioration in their condition after

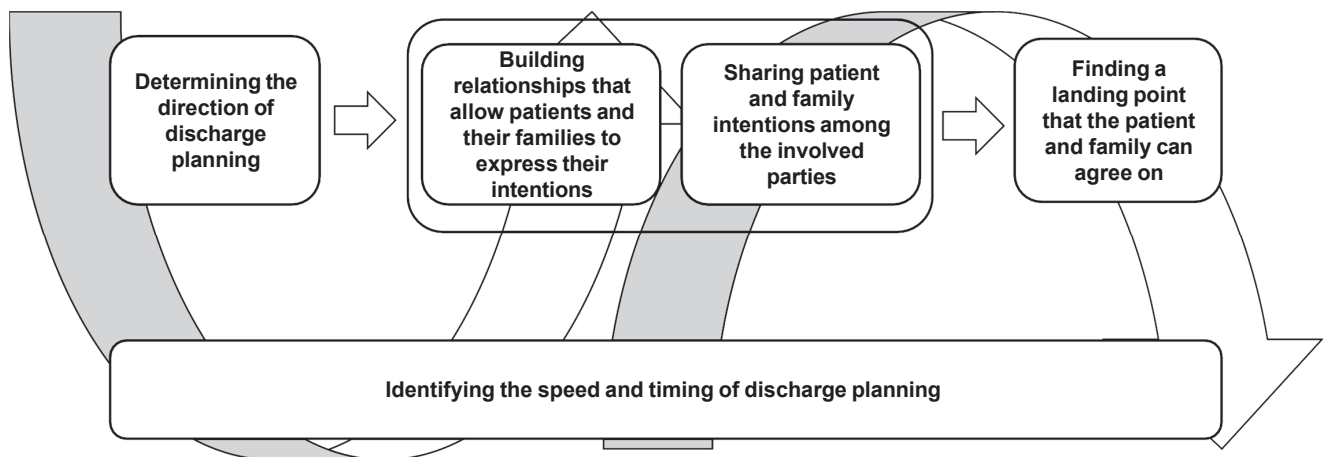


Figure 1 The relationships between the categories of practical wisdom of discharge planning nurses in supporting the consensus building process of advanced cancer patients and their families.

discharge.

If the family is not sure who to talk to about their symptoms after discharge, I tell them to talk to their home visit physician first, because the home visit physician and the hospital physician work well together, and if the home visit physician decides that they need help, the hospital will be contacted, so they don't need to worry. We also have a pre-discharge conference with the home care team, the hospital staff, the patient, and the family. (Participant D)

Discussion

1. Features of practical wisdom of DPNs in the consensus building of advanced cancer patients and their families

This study identifies the practical wisdom of DPNs in supporting the process of consensus building for people with advanced cancer and their families.

A feature of the disease in advanced cancer patients is that they carry on with daily life to some extent; however, once their condition deteriorates, they have a short time before they die⁷⁾. Cancer patients prefer to live, if possible, use all available treatments, and receive consistent care from the same physicians and nurses. Nonetheless, the desire to fight cancer varies significantly between patients and physicians and between patients and nurses⁸⁾. DPNs were continually assessing the speed and timing of discharge planning, faced with the ethical dilemma that they could not rush patients and families to make decisions²⁴⁾, despite the limited time available to them. The skills of anticipating

the course of illness¹⁴⁾ and interpreting the patient's situation are the heart of skilled clinical nursing²⁵⁾. Participants in this study, all of whom had more than 10 years of nursing experience, were considered to have used their skilled clinical knowledge to support discharge. The results of this study indicate that assessing the speed and timing of discharge planning is a key feature of the practical wisdom of DPNs in supporting the consensus-building process of advanced cancer patients and their families.

2. Implications for educational programs to assure the quality of discharge planning

When the DPNs sensed a discrepancy between the perceptions of physicians and nurses, they would set up a meeting to achieve a common consensus. They also suggested to the medical team to have a discussion when they identified differences in the patient's and families' intentions so that the perceptions and conditions of the patient and family could be shared among medical professionals. Different views on discharge in the medical team can hinder effective collaboration. However, a better understanding of the roles and expertise of team members could improve this process²⁶⁾. In order to determine the direction of discharge planning and share the patient's and family's intentions among the involved parties, it was considered effective for DPNs to encourage the medical team members to have open discussions.

For patient and family decision-making, it is important to ascertain agreement, where appropriate information is provided and explained by the medical profession, followed by a discussion to find the best

solution for the patient and family²⁷). For the patient to make a decision, a discussion about the patient's preferences regarding healthcare needs to be supported by the patient and an individual or medical profession that the patient trusts²⁸). The discussion also needs to be consistent with the person's readiness to talk about their healthcare and the amount of information they want to know about their health and prognosis²⁸). Families of people with cancer have had difficulties telling patients the truth and making decisions about the choice of place of care²⁹). Therefore, in these discussions, patients and families need to be able to express their intentions before making decisions³⁰). In this study, DPNs made frequent visits to the bedside and held a series of interviews with family members to hear the patients' true feelings. They built relationships that allowed patients and families to express their wishes by telling them that they would work together and that they could change their wishes at any time. Communication with patients and families is one of the difficulties faced by nurses caring for terminally ill cancer patients³¹). It has been noted that communication is the foundation of basic nursing practice and that communication in palliative care is challenging yet essential to patient care³²). The findings of this study suggest the need for communication skills training to be incorporated into the educational programs of DPNs.

Notably, in Japan, patients value harmony in family relationships and follow their family's decisions without expressing their own feelings³³). Additionally, in cases wherein the patients can express their own wishes, they prefer to make decisions with their physicians and family rather than on their own³⁴). Nurses face ethical dilemmas regarding advocacy when patients and families disagree in nursing practices³⁵). Reportedly, DPNs experience difficulties providing decision support to patients and families and supporting disagreements between the patients and family intentions³⁶). In this study, DPNs were to work with the patient and family to explore a landing point establishing agreement by informing the family of the patient's intentions with a limited prognosis and encouraging them to reconsider and by offer options that were acceptable to the family. Pre-bereavement support by nurses contributes positively to the bereaved family's experience of bereavement³⁷). In addition, via exploration with the

patient and family, an agreeable landing point was considered important as a deliberate engagement with the family to ensure that they have little or no regrets³⁸). The inclusion of an end-of-life care perspective in education programs for DPNs is necessary to support the consensus-building process for advanced cancer patients and their families.

Patients and their families feel more threatened and anxious about being discharged than being admitted to the hospital. Thus, professional judgement and skills are needed to carry out discharge planning³⁹). Education on multi-professional coordination and ethics between the parties concerned is provided in education courses for certified nurse specialists. Training in end-of-life care is also currently provided in the field of palliative care. However, advanced certification or training is not necessarily required as a qualification for discharge planning nurses and education depends on individual facilities and DPNs. Although national policies have increased the number of DPNs deployed⁶), educational programs to ensure their quality are still inadequate, and this is a challenge for the future. Based on the results of this study, it is suggested that DPNs would benefit from a more structured learning approach, as is provided to other nursing specialists including communication skills training through interactive role playing, detailed discharge planning case study analysis and specialist lectures to facilitate DPNs acquisition of practical wisdom.

Limitations

We were not able to ascertain the impact of the participants' professional qualifications in oncology nursing on the results of this study. In addition, participants in this study were limited to DPNs at designated cancer hospitals with no data from DPNs at other general hospitals.

Conclusion

The findings of this study revealed the practical wisdom of DPNs in supporting the consensus-building process of advanced cancer patients and their families. Among these categories, "Determining the speed and timing of discharge planning" which DPNs continuously practiced during the consensus-building process was a major characteristic of the practical wisdom of DPN, who

facilitated the consensus-building process in search of the best solution for advanced cancer patients and their families.

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積極的治療が困難になったがん患者とその家族の合意形成のプロセスを支える

退院支援看護師の実践的な知恵：質的記述的研究

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要 旨

目的：本研究は、積極的治療が困難になったがん患者とその家族の合意形成のプロセスを支える退院支援看護師の実践的な知恵を明らかにすることを目的とした。

対象および方法：国内 6 か所のがん診療連携拠点病院から募集された退院支援看護師 13 名を対象に、対面または Web による半構造化インタビューを実施した。インタビューの分析には質的記述分析を使用した。信頼性を確保するために COREQ チェックリストを使用した。

結果：積極的治療が困難になったがん患者とその家族の合意形成のプロセスを支える、退院支援看護師の実践的な知恵として、5 つのカテゴリーが抽出された。“退院支援の方向性の見定め”、“患者・家族が自身の意向を表明できるような関係性の構築”、“関係者間での患者や家族の意向の共有”、“患者・家族が納得できる着地点の探索”は、常に“退院支援のスピードとタイミングの見極め”をしながら行われていた。

結論：積極的治療が困難になったがん患者とその家族の合意形成のプロセスを支援する退院支援看護師の実践的な知恵が明らかになった。中でも、“退院支援のスピードとタイミングの見極め”は、退院支援看護師が患者や家族との合意形成のプロセスで継続的に実施している実践的な知恵であり、積極的治療が困難になったがん患者とその家族への退院支援の大きな特徴であると考えられた。事例検討会、クリニカルカンファレンス、コミュニケーションスキル研修などを取り入れた DPN の教育プログラムの充実が必要である。