Supplementary File - Six Connected Protocols:

The Phases and Protocols of the Cancer Care Transition Program in the Health Care System of Iran

The process begins with the discharge of the cancer patient from the hospital. After referral to the hospital's discharge-home care unit (protocol A, pre-discharge phase), patients are transferred through two routes. The first route involves the patients who are discharged from the hospital and return home directly. According to the primary assessment of the follow-up nurse in the hospital's discharge-home care unit, concluding that no care provision by home health care centers is needed (Protocol C1, post-discharge phase). However, the second group consists of the patients who need home health care services and are referred to a home health care center (Protocol B, pre-discharge phase).

After the patient's referral to the home health care center, triage should be performed to determine the patient's level of care and the priority of his/her home visits. These evaluations are done based on either nursing or medical criteria or both (Protocol A, transitional care phase). After the triage, comprehensive patient-centered services, including supportive care, specialty-palliative care or end-of-life care tailored to the patient's level of care, are developed and provided during a 4-week care program. An experienced expert nurse, is the leader of this program in the home health care center (Protocol B, transitional care phase). At the level of supportive care services, patients' needs in regard with the disease, treatment, medication, nutrition, and daily activities are assessed to improve their quality of life (physical, emotional, mental, social, and education needs). The patients receive home health care services based on their needs. At the levels of the specialty-palliative care and the end-of-life care, advanced home health care services are provided to the patient and his/her family with the aim of reducing the symptoms such as pain as well as a peaceful death. At every level of care, team working and interdisciplinary cooperation between the health care providers is essential, and the nurse is responsible for coordination within the home health care team. The type of care and the health care services provided may change as the disease progresses or the patient's condition deteriorates. For instance, patients receiving supportive care services do not need specialty-palliative care or advanced care. But, patients who are receiving specialty-palliative care or advanced care may need supportive care depending on their conditions. If, after the 4-week care program, the patient's clinical condition improves in line with the objectives of the care program and he/she and his/her family is prepared for discharge, the patient would be discharged from the home health care center (Protocol C2, post-discharge). On the contrary, if after the 4-week care program, the patient's condition is not stable, the patient would not be discharged from the center, and the patient's care program and care goals are reviewed in the center and the next care program would be started immediately. However, if the patient's clinical condition deteriorates after the 4-week care program, he/she will be referred to a medical center (hospital). In addition, during the period of receiving home health care services, whenever the patient's condition deteriorates at any stage, the patient is referred to the hospital by the home health care center. This process requires periodic evaluations, and patient and family telephone follow-ups via health care center's telephone system. This care process continues until the patient and his/her family achieves relative or complete independence in the daily life or until the patient passes away.

Pre-Discharge Phase

Definition: The Pre-Discharge phase begins after the patient is discharged from the hospital ward and lasts until the end of the admission to the hospital's home care unit.

Hospital's discharge-home care unit: This unit performs three major activities through a follow-up nurse:

1. Examining the patient before discharge from the hospital and extracting the list of patient's needs and problems,

2. Evaluating the patient and determining his/her needs for transition care through home health care centers at the community level
3. Patient's follow up

The telephone consultation system of this unit should be active 24 hours/7 days and the records of the patients who have been visited in this medical center by the follow-up nurse should be available electronically to all the staff of the hospital's discharge-home care unit and they must be able to use it while providing health care services via telephone consultation.

Protocol A: Pre-discharge phase in the hospital's discharge-home care unit

- Interview with the patient and his/her family (the pre-discharge interview)
- Creating a file for patient's follow-up and recording the patient's health care information
- The patient's file should be made electronically available at the medical center to the staff of the hospital's discharge-home care unit, who must be able to use it for telephone consultation at any time of the day or night if necessary.
- Assessing the care ability and the health knowledge of the patient and his/her family
- Preparing a list of the patients' needs and problems
- Training the patient and his/her family based on patient-centered care, self-care and family empowerment

Protocol B: Pre-discharge phase - Primary assessment of the patient and referral process

- Determining the patient's need for transitional home health care based on the nursing criteria, medical criteria or both
- **Nursing criteria:** Palliative Performance Scale: PPSV2 (scores below 70% = the patient needs transition care by home health care centers at the community level)
- **Medical criteria:** Issuing referral letter by the responsible physician at hospital
- **Medical and nursing criteria:** Both criteria are available and an estimation of the results of both criteria is used.
- An introduction of home health care centers and how to provide services for the patient and his/her family
- The patient needs transitional home health care. Then, the patient and family receive education and training such as reminders for the clinic's appointment and adherence to medication and diet. Afterwards, a written consent is obtained from them and a referral letter is issued by the follow-up nurse at the hospital's discharge-home care unit. Next, the patient is referred to the nearest home health care center at the community level with a summary of medical record and the results of the evaluation made by the follow-up nurse.
- The summary of the medical record and the results of the evaluations are submitted to the electronic platform of the home health care center.

- The patient does not need to receive transitional care from the home health care center. At first the necessary training was provided to the patient and family (reminding the time to go to the hospital clinic, following the medication and diet instructions, disease management and symptoms and self-care) and prepared a list of warning signs and symptoms related to the disease and training the patient and family caregiver to manage problems. Next, the patient refers to the post-discharge phase to receive follow-up services.

Post-discharge phase after hospital

Definition: After discharge from hospital, if the patient does not need transitional care through home health care centers in the community after discharge from the hospital, he/she enters the post-discharge phase.

Protocol C1: Post-discharge phase after hospital: (Patient's Follow-up Protocol)

- Following up patient's clinical condition after hospital discharge via three phone calls during a 4-week period by the follow-up nurse, using the telephone consultation system:

A: Periodic telephone follow-ups via telephone consultation system to check the problems and needs of the patient and family after discharge from hospital
B: Recording the patient's needs and problems at home by the patient or his/her family
C: Following up the patient and his/her family's training at home (checking if the medication and diet are followed, and the disease and symptom management and self-care are done as ordered.)
D: Following up on the warning signs and symptoms of the disease and training the patient and family to manage the problems.

Time for telephone follow-ups:

- The first phone call is made during the first 48 to 72 hours after the patient's discharge.
- The second phone call is made 10 to 12 days after the first call (day 12 to 15 after the discharge) and the third call is made 14 days after the second phone call (day 26 to 28 after the discharge).
- In addition to the periodic telephone follow-ups made by the follow-up nurse, the patient and his/her family can call to the follow-up nurse, if needed, through telephone consultation system, at any given time within 4- week after the discharge from the hospital or later.
- The content and the duration of telephone conversations are recorded.
- After the patient's discharge from the hospital, the home visit program can be planned and implemented based on the priority of the patient's needs and hospital resources.

Transitional Care Phase
Definition: After discharge from hospital, the patient enters this phase if he/she needs continuity of care and transfer care through home health care centers in the community.

Protocol A: The patient's triage to check the level of care and the priority of home visit

The patient's triage is done in the home health care center to check the level of patient care and to determine the time of home visits based on the nursing criteria, medical criteria, or both.
-Determining the patient's needs based on the nursing criteria, the medical criteria, or both:

A: *Determining the patient's needs based on the nursing criteria:* Determining the level of home health care based on the Palliative Performance Scale (PPSV2) and the priority of home visits based on the Edmonton Symptom Assessment Scale (ESAS)
B: *Determining the patient's needs based on the medical criteria:* Issuing a referral letter from the responsible physician at hospital or the physician at home health care center
C: *Determining the patient's needs based on the medical and nursing criteria:* Both criteria are available and the results of both criteria are applied together.
-Based on the results of the triage, using the PPSV2 criterion, the patient is assigned to one of the three levels of care, including supportive care (the scores of 40-60%), specialty-palliative care or the end-of-life care (the scores of 0-30%).
-Based on the results of the triage, using the Edmonton criterion, the priority of the patient's home visits is determined in three levels, including an emergency visit (high priority, a score of 7 or more), a regular visit (moderate priority, a score of 4 to 6) and a non-emergency visit (low priority, a score of 0 to 3).

Protocol B: Providing comprehensive and patient-centered health care services at home

- Forming a medical file for the patient's follow-up and recording medical records of the patient in the electronic platform of the home health care center
- A home visit program is developed concurrently with the patient's telephone follow-up by the palliative health care team at the home health care center for a period of 4-week according to the level of the patient care and the priority of home visits. An experienced nurse in coordination with the patient and his/her family is the leader of this program and team.
- For the patients at the level of the specialty-palliative care and the end-of-life care and those do not need active treatments in the hospital, a written order of the patient's primary responsible physician to fully delegate care to the home health care center's physician would facilitate the development of the home health care program.
- The patient's home visits are performed according to the needs of the patient and his/her family by the palliative health care team or by an experienced nurse individually from the home health care center.
- The telephone consultation system of the home health care center must provide 24 hours/7 days response to the questions of patients and their families. The content and the duration of telephone conversations are recorded.
- The health care plan is evaluated and its results are followed as below:

A: In case the 4-week program is over and the patient's condition is stable (PPSV2 score: 70-100%), the patient will be discharged from the home health care center.

B: In case the 4-week program is over and the patient's condition is not stable, home health care services will be extended by revising the previous program.

C: If the 4-week program ends and the patient's condition deteriorates, the patient will be referred to the hospital.

- After the patient is discharged from the home health care center, he/she enters the post-discharge phase.

Post-Discharge phase after discharge from the home health care center

If after the 4-week care program, the patient's clinical condition improves for the purposes of the care program and the patient and his family are ready to leave the home care center, the patient will be discharged from this center.

Protocol C2: Post-discharge phase after discharge from the home health care center

- A periodic 4-week telephone follow-up is done via the telephone consultation system of the home health care center by the follow-up nurse to check the patient's needs and problems after discharge from the center.
- The first telephone call is made during the first 48 to 72 hours after the patient's discharge from the home health care center.
- The second phone call is made 10 to 12 days after the first call (day 12 to 15 after the discharge) and the third call is made 14 days after the second phone call (day 26 to 28 after the discharge).
- In addition to the periodic telephone follow-ups by the follow-up nurse, the patient and his/her family can call to the follow-up nurse, in case of necessity, through telephone consultation system, at any time within 4-week after the discharge from the home health care center or later.
- The content and the duration of telephone conversations are recorded.
- After the patient's discharge from the home health care center, home visits are planned and implemented based on the priority of the patient's needs, the family's request and the center's facilities.

- If the patient's condition deteriorates after discharge from the home health care center, he/she will receive the necessary health care from the home health care center with a new program or will be referred to the hospital if necessary.

Supplementary File- Table 2

Table 2. Categories, Subcategories and Quotations of the Qualitative Results

Category	Subcategory	Quotations
Integrated services for the continuity of care	Universal access of clients to health services	"One of the goals of the health care system is to ensure access to services for all people and in accordance with their needs. All people should benefit from specialty and health care services….Care and services should be community-oriented" (Participant 2, Policymaker)
	Integrated palliative care at different prevention levels	"It is necessary to provide integrated services at all levels of prevention. The public sector is the main provider of this type of care in the country, which also provides a significant part of secondary and tertiary health services such as palliative care and rehabilitation services in addition to the primary health care (Participant 1, Policymaker).
	Development of guidelines for transferring to home	"For the referral and care transition of cancer patients from the hospital to home, the transition procedure must be considered at the time of discharge from the hospital. When the patient is discharged, it should be determined what kind of services he/she needs according to a previously set procedure and guideline and based on his/her needs. For example, under what circumstances do patients need home care? And also how should they receive these services? "(Participant 8, Expert of home care in the Ministry of Health)
Holistic care	Providing comprehensive care	"At home, we can provide all kinds of services such as physical, mental, spiritual and end-of-life care for cancer patients. All the members of the care team such as the home care nurse, the physician, the psychologist, the priest, etc. cooperate to provide care for the cancer patient and family." (Participant 5, Researcher in the Ministry of Health)
	Interpersonal and interdisciplinary collaboration in the health care team	"Care provision is a team work and it is essential that different disciplines work together to provide services to patients. If experts of different health disciplines who provide services to patients work separately and without establishing communication, the patient cannot receive all the services necessary for addressing his/her needs…. No one can be expert in all fields." (Participant 13, Home health care nurse).
Care standardization	Developing clinical guidelines	"Patients mostly deal with the nurse, so we have to use a similar set of guidelines to provide services for the patient, in order not to confuse the patient." (Participant 9, Home health care nurse)
	Developing home care service packages	"Providing any kind of services should be based on service packages. With these service packages, job descriptions are clear for everyone on the treatment team and everyone performs his/her

		duties according to the items mentioned in these packages." (Participant 1, Policy maker)
	Periodic monitoring	"The quality of services provided for cancer patients should be assessed according to standard guidelines. This is done dynamically and continuously through periodic assessments." (Participant 15, Nurse) “Services provided at each level should be evaluated to achieve care goals and the desired quality of care and, if necessary, reviewed according to the patient's level of need.” (Participant 14, Nurse)
The use of telemedicine	Electronic platform of care transition system	"From the very beginning of the procedure of discharging a cancer patient from the hospital, there must be integrated software or an electronic system, to record all the stages of patients’ discharge and transfer to home or a home care center." (Participant 11, Home health care services coordinator)
	Registering patients’ electronic medical records on the system	"Upon the patient’s arrival at the home care center, a file should be created consisting of the patient’s demographic information, other data on his/her condition, administered medications and medical documents. For easy and fast access to medical information and the services provided for cancer patients, it is necessary to create a common file for each disease containing the disease, treatment procedure and other problems and data on the patient, to facilitate quick access to the patient’s medical records and his/her clinical and Para-clinical documents in case of patient’s referral and transfer to a care center such as a home care centers, urban and rural comprehensive health centers, etc." (Participant 4, Physician)
	Integrated access of the care transition staff to the system	"The data in the patient’s file for home care program should be linked to the patient's electronic medical record, and the staff responsible for hospital discharge and home care centers should have access to the patient’s file, so that any of them can easily access it at any given time or even forward it to each other and share the data..... The existence of these electronic records can improve service provision and prevent the confusion of the service provider team"(Participant 13, Home health care nurse)
	Establishing a telephone consultation system on the electronic platform	"Having a 24/7 response system for families, through the access of nurses and an experienced care team to hospital records in regard with patients’ problems can be an important step in reducing patients’ care problems. For example, a patient who is discharged from the hospital should be supported by someone. There should be a person who provides round-the-clock consultation to the patient and his/her family or even visits the patient in person." (Participant 21, Head of the home health care center) “In some cases, my patient had a problem that I did not know what to do at that moment. If there was a place I could call and give guidance, it would reduce the mental burden of that moment a lot, and I would not have to take my patient to the hospital, for example, for a leaking catheter”.(Participant 23, Family caregiver)
Transparency of rules	Establishing a legal framework for home care	"It is important to know what services can a cancer patient receive from home care centers, what types of care should be provided by the family, according to what criteria can the patient and family use the services, and according to which rules the patient is discharged, or in case the patient passes away at home, how should the death certificate be issued. There should be rules and guidelines for all the above." (Participant 3, Physician)
	Rules for entering the patient’s house	"Since the care is provided at patient's home, appropriate measures must be taken to prevent harm to the patient, the family and the

		staff. Ensuring the knowledge of home care staff, their use of a valid hospital ID card, written permission to enter the family's home, clarifying the type of services upon arrival at home and making previous coordination are all the things to consider while entering the a house" (Participant 4, Physician)
	Rules in case of errors	"Sometimes, during medical and nursing care, there is a possibility of error and negligence. In such cases, having a series of rules for further monitoring and supervision as well as finding the cause of error can prevent and reduce the incidence of errors." (Participant 2, Policy maker)
Care provision process	Assessment of the patient and family	"In order to provide services, all dimensions must be considered... It is necessary and essential that the care program be developed and implemented in consultation with the patient and his family. For example, the care program should be developed based on the needs of the cancer patients, and the financial status and the education level of the care seeker and his/her family." (Participant 17, Home health care nurse)
	Involving the patient and family in the care process	"The participation and cooperation of the patient and the family, especially the latter, can have a great impact on the improvement and development of the care plan. For example, it can be very effective in learning the provided trainings or even on the care procedure" (Participant 7, Faculty member)
	Identifying the existing and the potential problems of the patient and family	"In order to design a care plan, the problems of the patient and his/her family must be identified and prioritized, according to which it would be determined which level of care is needed for the patient and which problem has priority over the others." (Participant 13, Home health care nurse)
	Planning based on the abilities of the family for caring	"Before providing services and a care program, the patient's care ability should be measured, based on which the care program should be developed. If the developed program is beyond the capacity of the patient and his/her family, we will not achieve the predetermined goals." (Participant 6, Home health care nurse)
	Evaluating the care program along with the patient and family	"The services provided at each level should be evaluated in order to achieve the care goals and the desired quality of care, and if necessary, should be revised according to the evaluation feedback." (Participant 9, Home health care nurse)
	Training the patient and family with focus on the self-care and empowerment	"Training should be offered based on self-care with the aim of increasing the quality of life. Cancer patients and their families have many educational needs, and of course, training should be offered within their educational capacity and easy to understand so that it will be usable for everyone at any age with any level of education. This training should start from the time the patient is in the hospital and must continue... "(Participant 24, Faculty member)