

ENGAGEMENT ADDRESSING CAREGIVER STRESS IN A HOSPITAL SETTING

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In many lower and lower middle-income countries, critically ill patients in hospitals requiring lengthy stays are cared for by a combination of professional health workers and relatives or carers.

This is the case at the tertiary referral Hospital for Tropical Diseases, Ho Chi Minh City, where many patients are referred from the surrounding provinces. Many relatives or caregivers stay onsite during the patient's admission period to do the less technical caring such as feeding, bathing and basic physiotherapy. For some patients suffering diseases such as tetanus or brain infections their hospital stays may be weeks to months long. For many carers this is a particularly stressful experience.

The Public and Community Engagement team (PCE) at the Oxford University Clinical Research Unit (OUCRU) cooperated with the Hospital of Tropical Diseases (HTD), to conduct research about the main causes of stress and explore interventions to support carers of patients in the Intensive Care Unit (ICU) which has many of the longer stay patients. We identified the key causes of stress and needs of caregivers as follows:

- Their stress may be due to the critical conditions of their loved ones with a significant risk of mortality/death.
- The caregivers worry about the loneliness of the patients and that they are not be able to be close to the patients and take care of them continually.
- Some patients have no health insurance and the treatment cost is high for poor families. While staying in the hospital, the caregivers cannot go to work and do not have any income.
- They worry about other family members, especially their young children left at home with relatives.
- Sometimes, the caregivers also have chronic health problems such as diabetes, or cardiac problems.

Based on these findings, the PCE team and health workers from HTD developed engagement activities to support families and carers and provide them with important health information while they are at the hospital.

The activities included:

1. HEALTH TALKS
2. GROUP SESSIONS
3. HOSPITAL RADIO
4. SHORT PUBLIC HEALTH FILMS

1. HEALTH TALKS

Introduction and method

Carers often lacked basic knowledge about diseases, treatment and rehabilitation. Not understanding the cause or potential outcomes of the disease was a source of worry for some. To help give public health information in an informal and participatory way, we set up regular health talks. These talks are conducted by a doctor but include ice-breaker activities, games, and question and answer sessions to enable a relaxed atmosphere in which carers can ask the doctors their most pressing questions. At HTD, the talks are held in a public space, outside the carer's accommodation, and are supported by a senior doctor (the speaker), the PCE team, and the hospital's social workers. Typically, 30-40 people attend each talk which lasts about 50-60 minutes.

Topics

The topics and the focus of each of the talks are based on issues raised by carers in the research stage. These have included:

- Hand, foot and mouth diseases (during an outbreak in South Vietnam)
- Tetanus and vaccination
- Dengue fever
- Meningitis
- HIV
- Chicken pox
- Reducing stress for caregivers
- Hepatitis
- Measles

Reflection

A challenge for the health talks has been the context of the location of the talks. To ensure engagement of the carers, and due to a lack of facilities, the health talks have been conducted outdoors, near the waiting area for long-term caregivers. This enables the carers to actively participate in the health talks, but the weather often affects the ability to conduct the talks, especially during the rainy seasons. Despite this, the health talks have been very well attended by the caregivers and patients at HTD. After every health talk, participants often stay at the end and share their feedback with the facilitators or ask further questions. The feedback has been positive, with a large number having said that they love the activity, and that they find it is both enjoyable and informative at the same time. They really appreciate that the doctor is friendly and present to answer their questions, and have indicated that they would join future health talks on other topics.

2. GROUP SESSIONS

a. Introduction and method

This activity is based on the methods of 'social group work', this method helps individuals to enhance their social functioning through purposeful group experiences and to cope more effectively with their personal, group or community problems ¹. The objective is to work with groups of carers to help reduce stress and anxiety through positive interactions with a health worker and other group members.

The sessions are conducted with a facilitator, a health worker and about 8 carers, and consist of a time for carers to express their concerns, a session to help give them resources to cope with their stress, and an opportunity to speak with a health worker. Some techniques used in the sessions include art therapy, group consultations, and health education.

b. Using art as therapy

Art therapy is used as a creative process to improve and enhance the physical and emotional well-being of an individual. The purpose of the art therapy sessions within the study was to assist the carers of seriously ill patients be aware of their current emotions, and the stress they are experiencing, and to direct them to focus on a number of artistic processes to relieve the intensity of their emotions and anxiety during their time in the hospital.

Expressing emotions

During the early stage of a session, the facilitator invited caregivers to express their present emotions by free or doodle drawing on a piece of paper and then matching the intersection points until they found an image in their drawing. The result was that most of them expressed through their drawings both sadness and worry with unsmiling faces and tears in the eyes. They were invited to speak about their picture and shared their many concerns and worries. At the end of the group session, caregivers were invited to once again draw their emotions on a piece of paper. For most carers this second drawing was more joyful and had a peaceful face, and they reflected that the sessions had helped them trust the healthcare workers more and that some of their questions and concerns had been answered.

¹ Konopka, Gisela, (1963), Social Group Work: A helping process



The Carer cried and shared that when connecting the points, the result was a chicken, and it related to his grandson (patient) and wishes for his grandson to be able to come back home soon.

God's eyes

This art activity is a form of art therapy that focuses on using comforting textures and allowing for manageable exploration of uncomfortable emotions. There were various cut-offs of different fabric, textured material, wooden sticks, scissors and glue. During the art activity of creating a God's eye, the carers concentrated on doing a concrete activity and didn't think about their own worries. They relaxed their bodies and were stimulated by the sense of touch. They found that the softness of the wool and the motion of the continuous wrapping of the wool repeatedly also helped bring calm and relaxation; balancing their emotions.



A carer shared "I am very concentrated in doing this work in 15 minutes, I don't feel sad and stressed about the patient's status"

Rich pictures

In another group session, the carers illustrated their 'journeys to hospital' through rich picture exercises. A rich picture helps open group discussion and come to a shared understanding of the situation that the carers might face. The facilitators prepared the different art materials including pictures of symbols, icons, coloured card and wooden sticks. The journey can be expressed in each individual's own way and they choose the materials they wish to describe/reflect this journey – whether a drawn picture or collage. The goal is to create a common group picture to express their experiences or a particular point of view during the period they have cared for the ill relative.



In the beginning of the art activity, the carers identified stressors as including the uncomfortable accommodation for carers at the hospital and shared their negative emotions. However, at the end of the session, when the facilitator asked the group to use the different materials to describe their expectations of support which would help them reduce their stresses and worries, they expressed that they would like to have comfortable accommodation at the hospital for carers where they can feel safe and sleep well during their stay at the hospital

Some carers shared that they really enjoyed the process of art therapy as it helped them get to know the other group members, and to feel comfortable to share their worries or concerns. Many had stayed in the hospital for a long time, and sometimes they were bored, however, joining the art session helped them relax, and gave them an opportunity to express their emotions and other issues; and they felt that the doctors or psychologist had supported them.

c. Strategies

Among the strategies for dealing with stress, the facilitator discussed with the caregivers about different activities or approaches that may allow them to alleviate their negative emotions.

Examples of strategies we discussed with carers at HTD included:

- 1) *Doing your best within the current context:* It was stressed with the caregivers that no-one is a "perfect" caregiver. They needed to understand that they were doing the best they could and making the best decisions they were able to at any given time. They are

aware of the critical status of their loved one and they needed to trust the competency of the healthcare professionals within the ICU.

- 2) *Health diets:* We used printed pictures to demonstrate that eating healthy food was encouraged and that unhealthy behaviors were best avoided. The caregivers were encouraged to choose a healthy diet with nutritious food including fruit and vegetables, and to consider reducing their intake of caffeine and sugar, to avoid alcohol, cigarettes, and drugs, and instead ensure that they drank plenty of water.
- 3) *Getting adequate sleep can help with moods:* Encouraging them to aim for at least 7-8 hours of sleep per night, as sleep fuels the mind, as well as the body. Keeping a sense of humour, including the ability to laugh at oneself, can help the body fight stress.
- 4) *Breathing exercises:* The caregivers were shown ways to practice belly breathing as a simple way to reduce stress.
- 5) *Accepting support from others:* Acknowledging that it is acceptable to ask for and accept help in many forms - prayer, talking to family, friends or professionals. For instance, a friend or family member may be able to run an errand, pick up groceries, or cook a meal to assist. The caregivers may get emotional support by setting aside time each week for connecting, or having a walk with a friend. During the time staying in the hospital, a caregiver can ask for help from the other caregivers to buy things such as diapers, milk for the patient, or to take care of the patient when she/he needs to go home for a while. The other carers will understand their context and be willing to assist.
- 6) *Physical exercise:* The last way to reduce stress is by doing some physical exercises. The hospital grounds at HTD have a large space with nice gardens for people to take walks or exercise. The caregivers can walk around in the early morning to breathe clean air and contemplate the different flowers grown in the gardens.
- 7) *How to manage and accept bad news:* Bad news could include hearing that the patient is having difficulty breathing, or has low blood pressure, or that the patient's condition has deteriorated, or he/she had died. Discussing openly what bad news can entail, the carers can reflect and acknowledge how they respond to such news. In this session the discussion can explore how change occurs every moment of our lives through many events, experiences, changes in the external environment, or changes in our health. It is how we react to bad news and change that impacts on our health and stress levels. Keeping perspective and focusing on each day can help; such as the time they have with the patient during visiting time, maintaining their own health, following the evolution of the illness and trying to ask questions and understand the illness, and praying if they have a religion to calm their minds, can assist to prepare for the potential of changing contexts.
- 8) *Question and answer session with the doctor*
The activity was a direct conversation between the doctors and carers related to health messages and other concerns about the patients' condition and treatment. As the hospital was often crowded with patients, the doctor often did not have much time to

answer questions about the patients, and this caused additional concern for the carers about the patient's illness. This was a good opportunity for both sides to understand each other. The doctor explained information such as patient care skills such as self-hygiene, nutrition, discharge information, or the conditions of patients in the intensive care wards - including the reason for the long periods of unconsciousness experienced by the patient, and the physical and medical interventions required.

d. Reflection

After each session, the facilitator invited each individual in the group to share their reflections through asking the questions or selecting a photo which represented their feelings. They reflected that they understood that they could trust the healthcare practitioners of the hospital, and that it was important for them to also take care of their own health with healthy food, good walks, listening to music, belly breathing and praying. They understood that they would have better relationships with the healthcare workers and the other caregivers, and be able to help one another.

A carer shared: *"I practice breathing every night before sleeping and I feel I have a deeper sleep"*

Another carer said: *"When I hear the doctor's counselling, I feel more relaxed, I will try every day to talk more with my daughter during visiting time although she is unconscious. If she cannot survive I will be very sad but I should be courageous as I have to take care of the grandchild"*

The participants also expressed that they had gained ideas about the many ways of reducing their stress and improving their positive thinking from the health talk. With the support of the healthcare practitioners, they better understood about the illness of their relatives and were willing and able to cooperate with the healthcare practitioners to take care of their relatives during visiting times. The group had a positive interaction through the common activities such as drawing, sharing their worries and concerns, and through these sessions they enhanced their trust and were more open-minded in their support for each other when they were at hospital.

A carer shared: *"I have been in hospital over 2 months, and this is the first time I have a chance to ask a doctor. It helped the group better understand the treatment."*

Another carer expressed: *"The first time I saw the patient was tied in his wrist hand, I was suffered and angry. After listening a doctor explained, I understood that this way was to help the patient's seizures"*

3. HOSPITAL RADIO

Introduction and method

There is a hospital radio or loud speaker system throughout the hospital wards and public areas which is used for announcements. We worked with the hospital staff to create 1 hour 'radio shows' including music, short public health messages and personal messages sent to health workers or relatives. These shows were recorded in advance and played over the loudspeaker system between 5-6pm, which is when most outpatients had gone home, and carers staying at

the hospital had time to relax and listen. Individuals from the social work department were trained by professional MCs to present the shows.

Topics for the shows were chosen based on questionnaires with carers and current public health needs.

Topics:

- Dengue fever
- Foot – Hand – Mouth disease
- Protecting children rights
- Environmental sanitation (Reducing plastic use in daily life)
- COVID-19 (Prevention)
- Flu (Prevention)
- Measles (Treatment and nutrition for patients)
- Breastfeeding (Benefits)
- Meningitis (Treatment and nutrition for patients)
- Urinary tract infection and diarrhea
- Hepatitis (Prevention and treatment)
- High blood pressure
- Alzheimers (How to care for the patient at home)
- Heart failure (Nutrition and rest)
- Chickenpox and mumps
- Tetanus and vaccination
- Daily nutrition and the benefit of exercise
- Goiter (healthy diet with iodine)
- Rheumatoid arthritis
- Diabetes (daily healthy diet for patients)
- Occupational health and safety
- HIV (Prevention, care, and diet)
- Pneumonia (Treatment, care and diet)
- Tuberculosis (Treatment, care and diet)

Reflection

To clarify the impact of the hospital radio program, an evaluation resulted in 39 surveys completed by 3 doctors, 9 nurses, 10 patients and 14 care givers. Most comments were related to the quality of the sound system as it affects the understanding of the show. While there were 3 people who strongly did not support the hospital radio, there were some who wanted to extend the show an additional 30-45 minutes.

One HTD doctor shared that the programme is very helpful for HCWs, caregivers and patients. They like the radio programs and look forward to it each week, but sometimes miss the announcements if they are busy at this time. They would like to listen again and access it on

Facebook but the shows needed to be updated. The HCMC Department of Health has been happy to support the continuation of the hospital radio activity at HTD and encouraged other hospitals to follow and asked to collaborate with Youth Union in the future.

A social worker shared that the programme had always provided good topics for both healthcare workers and patients, especially the health information about diseases which was very useful for patients to understand how they take care of themselves at home. The accompanying songs helped healthcare workers release their stress after a long day working.

4. PUBLIC TELEVISION

Introduction and method

In recognition that carers spend many hours waiting in the hospital grounds, only being allowed on the wards at certain times, big screen televisions were set up in waiting areas, and a 'playlist' of short films and animations was developed with the aim of sharing public health information in an accessible manner. Most of the films were created by the PCE department and can be seen at: <https://www.youtube.com/channel/UCZS8dhcwJtD0tSJOzz1QP5g>

Topics

Examples of films being shown in waiting areas include:

1. A Patient's Story: an animation about a patient's road to recovery after leaving the ICU
2. Lan's story: a film about a patient recovering from a brain infection.
3. Rabies: an animation about the transmission of rabies and treatment of dog bites.

Reflection

The resources developed were accessible and in particular those related to Central Nervous System diseases and tetanus. The films related to patients recovering their health after discharge from hospital were inspiring and helped carers believe that the patients could recover to an extent if they took care of the patients well. It encouraged carers to trust in the treatment being received by the patient at the Hospital of Tropical Diseases.

A carer shared that whenever he was free, he went to watch the films being shown as it was useful information. He hoped that the films could be played regularly.

A healthcare worker shared that having the public television based in the carer's area supported healthcare workers to explain health information and carers also accepted the information as officially from the hospital,

CONCLUSION

Facilitating engagement with caregivers allowing for participation and expression of concerns and questions, can encourage an atmosphere of trust and respect for healthcare professionals, patients and their caregivers, and can be a highly effective way of sharing important health information.

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