

# Capacitating a culture of compassion

through local community grief care by nurses

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Nurses are specialists in supporting the dying and death process. The supports for the dying vary widely from daily talking to establishing close relationships between the nurses and the family caregivers like caring for dying person.

Patients have various opportunities to meet nurses while living with their diseases. Nurses' healing presence has an effect on family caregiver's grief. Thus grief care provided by nurses could keep the negative impacts to a minimum on family caregiver's grief before and after the patient's death. To provide grief care does not necessarily need a special place and time, because it is intrinsic to nurses' everyday practice.

While grief care provided by nurses supports the family caregivers continually before and after the death that grief care might be not familiar to many people.

Creating grief care based on nursing knowledge and experience could potentially improve a local community's capacity for compassion by spreading grief care provided by nurses among the community. Bereavement support of these current times is needed because of weakened social ties. A community culture where communicating about bereavement is supported and making conscious connections with each other during times of grief would contribute to our health promotion, and build a more compassionate community.

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### PART1 Effects of bereavement

#### 1 Loss and Grief

We create many things in our lives for example material goods and houses, acquiring property, and cultivating human relationships. But, as time passes, the goods and human relationships would be lost because they are not forever. We have acquired something in a life cycle on the one hand and we have repeated loss on the other hand.

The emotion of having a loss experience is grief. Grief will become deeper when we lose important things that are essential for everyday life.

Grief is a reaction for many bereaved people, but some people develop traumatic or complicated grief. In those cases, medical care is needed. Expressions of our grief depended not only on personal factors, but also the influence of cultural affect, for example, community and social customs, religion, and social standards.



#### Effects of Bereavement on People

There is the death that is predicted and the death that is unexpected. An example of predicted death is by diseases. Examples of unpredicted death are by traffic accidents or natural disasters. But, the response to the death is different respectively.

Facing death is also different from person to person. The bereaved family member might be shocked if the death was not expected and they had no preparation as the death drew near; to face the death caused various stress-related reactions, for example, shock about sudden death, and anger.

Not being able to identify the body from natural disasters aggravated their grief because they felt there was no closure to the death. Bereaved families would continue to be terribly distressed by their grief in the case of the death from war or terrorism.

Moreover grief of the bereaved family was influenced by the nature and quality of relationship with the deceased. It would make a difference if it was a parent or child or a spouse, or sibling. In addition was the relationship positive or negative? Were they close or distant to the deceased? It should not be forgotten that pet lovers would also grieve deeply over the death of their pets.

#### Bereavement from a Disease

We can prepare for the death of someone we love if we have the time to spend with the loved one and understand the prognosis. The disease process and acceptance of the patient have varied effects on a family. The bereaved family has a second burden like a role in the family and a role in society, depending on family relationship. If that is the case then one could not expect to be supported by many people who may be nervous about the pending death.

Some bereaved family have regrets because of death from a disease. They would say, "I was very surprised. I had felt that he could have lived, yet...". In that case, the family was not to be able to believe medical specialists because they had some doubts about the death. Therefore medical specialists are important to predict the time of death from patient's condition so that family members can realistically prepare for the loved one's death.

Bereaved families are satisfied with the loved one's death if they are able to feel it was a good death, a peaceful death. But, it has a negative influence on family's grief process after the death when a family is shocked in the face of patient's agony in the terminal period. Then it is important for not only patients but also families to provide good terminal care and for patients to have adequate symptom management.

#### PART2 Grief Care

#### 1 What is Grief Care?

Sakaguchi (2010) indicated that grief care in a narrow sense is attitude, action, and activity by a person or group to intentionally support bereaved families after the patient's death; grief care in a wider sense is an act of helping the grief process of bereaved families which results in direct and intentional supports. Grief care is important to support mental health and also it secondarily affects the family relationship as they rebuild their daily life during the bereavement. The purpose of grief care is not only the prevention of illness and death due to the impact of bereavement but also to support the new daily life of a bereaved family in constructing new relationships.

#### Vision of grief care

World Health Organization (WHO) proposed a support system to help the family cope during the patient's illness and in their own bereavement. Accordingly, grief care is included in palliative care. It is important to offer grief care to the family from before and after the patient's death at home too.

#### Providing of Grief Care after the Death

#### Formal grief care

**Providers** 

Counselor, Medical specialist of a nurse or a doctor, Religious leader or Spiritual counselor Methods

Counseling, Home visiting, Telephone support, Support group, Memorial service

#### Informal grief care

Through conversation and reminiscence with other families and friends, specialists would ease grief of bereaved families in the informal situation. For example, it might become an important grief care for bereaved families to talk with nurses when the nurse meets them by chance.



### PART3 Grief Care for a Family Caregiver

#### Family Caregiver's Life after the Death

#### Negative effects on a family caregiver after the home death

- having mental and physical disease from suffering, anxiety, depression
- decreasing of social activity by stopping family caregiver's job and leisure
- ◆loss of emotional mainstay by the death of loved one
- ◆loss of all interest in daily life to have finished caring roles
- being shocked by having seen the death from so closeup at home

### Bereaved family caregiver's adaptation after the home death of their elders

Bereaved family caregivers feel grief but they might have a sense of security and satisfaction. But some bereaved families were distressed and had regret about the caring and shock from the death because they couldn't talk about it, as they had no close friends or family.

Figure 1 was the result of interviews of family caregivers caring for their dying elders at home. Initially the bereaved family caregivers held 'negative feelings resulting from their experience of care and bereavement'. However, they had

acquired 'the power to face daily life after the death', and they had started to move forward 'adapting to reality'.

Satisfaction with an elder's death at home and confidence in care provided the inner strength to face daily life after the death

While it is important to be supported by their families sometimes families are not able to provide that support. Therefore it is particularly important that bereaved families who have a deep sense of isolation know that there is someone who is watching out for them and tracking what is going on in their life (ONO, 2013a).

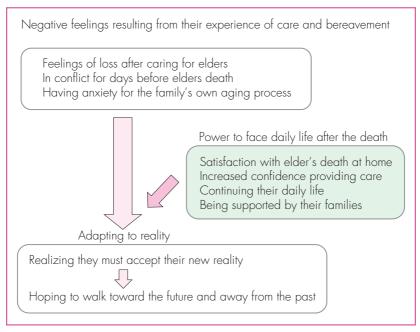


Figure 1. Bereaved family caregiver's adaptation after the home death of their elders (Ono, 2013a)

#### 2 Grief Care for Bereaved Family Caregivers by Nurses

Grief care provided by nurses has the role of providing highly empathic psychological care and appropriate social support, by sharing the bereavement experience with the family through continued involvement before and after the patient's death (Ono, 2013b).

Grief care can be understood to fall into in three periods as follows: grief care from beginning of home care to the terminal period, grief care at deathbed, grief care after the patient's death(Figure 2).

#### Outcome of grief care Grief care by nurse ◆Grief care from beginning of home ◆Family caregivers' outcome care to the terminal period Acquisition of positive feelings and Promotion of acceptance of death and alleviation of grief explanation of the death attendance Expansion of social roles system Prevention of illness and death due Support of continuation of family's care to influence of bereavement with respect to their intent Negative effect of grief care Empathize with family's intent ◆Grief care at deathbed ◆Nurses' outcome ◆Grief care after the patient's death Learning opportunity Grasping of state for resuming social Confidence in visiting nursing Deepening of trusting relations Sharing and support of family's at workplace experience of the patient's death Negative psychological effect Psychosocial support for rebuilding life

Figure 2. Grief care for bereaved Family caregivers by nurses Note. Revision based on ONO's original conceptual framework (2013b)

### Grief care from beginning of home care to the terminal period

### Promotion of acceptance of death and explanation of the death attendance system

Nurses explain the condition of patients and 'brink of death' to family caregivers so they can care for dying patients.

- ◆suggest they identify the person who the patient will want to see last or to be with as they die.
- prepare to care to dying patients, for example, burial clothes.

### Support of continuation of family's care with respect to their intent

- promote communication between family caregivers and medical specialists to determine the dying conditions
- support of family's care continuing their job and their hobby

#### Empathize with family's intent

Nurses hear family caregiver's anxiety and positive memories and provide empathy for the families' intent

#### Grief care at deathbed

Nurses provide death care in such a way that the bereaved family is satisfied. Then nurses consider how a bereaved family can get psychological supports.

#### Grief care after the patient's death

#### Grasping of the state for resuming social activities

It is to grasp if a bereaved family caregiver has resumed social activities turning their focus to make time for leisure and conversation with others.

### Sharing and support of family's experience of the patient's death

Nurses share the bereavement experience and supports positive feeling of a bereaved family for their future and patiently hear their desires and needs.

#### Psychosocial support for rebuilding life

- ◆ Nurses support bereaved families for rebuilding life and advise them about their living problems resulting from bereavement.
- ◆Nurses tell bereaved families to ask for help in their neighborhood if they have some hardships.
- ◆Nurses link bereaved families with social resource



#### Outcome of Grief Care

#### Family caregivers' outcome

#### Acquisition of positive feelings and alleviation of grief

Family caregivers acquire positive feelings, for example, their satisfaction of having cared for the patient and felt secure because of the presence of nurses.

#### Expansion of social roles

Family caregivers expand their social roles and grow as humans through grief care.

### Prevention of illness and death due to influence of bereavement

Family caregivers can prevent mental and physical illnesses and death under the influence of bereavement.

#### Negative effect of grief care

Family caregivers can be negatively influenced by nurses' supportive attempts.



#### Nurses' outcome

#### Learning opportunity

Nurses get an opportunity to reflect on nursing performed through grief care and grow personally and professionally.

#### Confidence in visiting nursing

Nurses gain confidence in their own nursing resulting from the satisfied state of family and feeling their work is worth doing.

#### Deepening of trusting relations at workplace

The process of discussing grief care in the workplace deepens the nurses trusting relations among their colleagues.

#### Negative psychological effect

Nurses experience negative psychological effects (e.g. fatigue, strain) in the face of the death and suffering of families.



# PART4 Grief Care by Nurses Working in the Local Community

Public health nurses and visiting nurses understand the local community because they are immersed in the community. They are nursing specialist supporting the local community. Then they are well informed about a policies and services of the municipality. One of the important roles of public health nurses and visiting nurses is to develop community care systems. As part of their nursing practice they could leverage or develop resources to increase resident's knowledge about grief and inspire motivation to participate in exchanges between residents, under the guidance and experiences of their nursing care.

Public health and visiting nurses sometimes feel the sadness and loneliness because of the trend toward nuclear families and the ensuing isolation. Nurses in the community have a role to make a community supporting care for bereavement care between residents, and to promote relationships between residents. As nurse's first step, nurses could become resources of grief care, then, it is important to promote a community grief care system.

For the future, nurses need to develop a compassionate community among themselves to support each other. Then from that strong center nurses consciously have to make an opportunity for residents to connect with support each other during their bereavement because there is less social connection among communities in Japan today.

#### PART5

### Nurses' Self-Care to Continue Best Nursing Practice

Nurses experience negative psychological effects by facing the suffering of bereaved families. Nurses must refresh and rejuvenate their inner state periodically.

They need to discuss this in the care team, to share an aim and methods of grief care in nurse's place of work. Toward that end, the 'death conference' is a very suitable method to use as an opportunity for psychological and emotional support for nurses.

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