

# A Qualitative Study of Long-term Care Leaders' Experiences of End-of-Life Care Provision at Long-term Care Facilities in Japan

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## Abstract

Several studies have highlighted the fact that long-term care facilities and caring staff are not ready for quality end-of-life care provision. The present study is aimed at shedding light on how caring staff provide care at the end of life and the emotions they experience in the provision of this care. Study participants were 4 long-term care leaders from different long-term care facilities. The subject for focus group discussion was end-of-life care at long-term care facilities. We used the KJ method (Kawakita Jiro's initials) as a qualitative research tool, which is widely employed in Japan. The emotions and experiences were organized into 9 groups (including 2 loner labels): 1) Active family involvement is important to successful end-of-life care; 2) Caring staff want to provide end-of-life care with compassion as well as logic; 3) Caring staff would rather avoid facing death or dealing with dying residents; 4) Caring staff are at a loss as to how to behave around the time of a resident's death; 5) There are language and psychological communication barriers among members of the end-of-life care team; 6) Caring staff get used to death through repetition; 7) End-of-life care for the elderly is challenging work. The loner labels were "A person who can remain calm and collected when facing the death of a resident" and "There are no complete manuals on providing end-of-life care due to the diversity in dying processes of elderly residents".

The present study reveals that long-term care leaders require a person who is able to remain composed in a demanding and emotional end-of-life care environment. Also, they thought that such a cool-headed person is best suited to tend to the needs of caring staff and residents' family and to promote communication among end-of-life care team.

**Keywords:** Caring staff; End-of-life care; Palliative care; Long-term care facility; Communication; Leader

## Introduction

Due to the aging of the population and longer life spans, end-of-life care for the elderly has become a major national concern in Japan [1,2]. Especially, the place of death is often regarded as an important parameter for the quality of the end-of-life [3]. Hospital deaths have become so common that they have now reached their peak ([www.mh1w.go.jp/toukei/saikin/hw/jinkou/suii03/deth5.html](http://www.mh1w.go.jp/toukei/saikin/hw/jinkou/suii03/deth5.html)).

According to health and social statistics from the Ministry of Health, Labor and Welfare ([www.mh1w.go.jp/toukei/saikin/hw/jinkou/suii03/deth5.html](http://www.mh1w.go.jp/toukei/saikin/hw/jinkou/suii03/deth5.html)), almost 80% of Japanese deaths occurred at a hospital in 2007. There are several reasons why so many Japanese people choose to die at hospital. First, Japanese people are more likely to prefer hospital regarding place of end-of-life care. Fukui et al. [4] suggested that 15% of the Japanese general population preferred hospital, while Escobar Pinzon et al. reported that 0.7% of the German people preferred it [5]. Second, Japan has not implemented policy measures to reduce the number of acute care hospitalizations as a means to reduce hospital death. For example, although a growing number of Japanese people now choose to outline advance directives, there is no legislation recognizing such legal documents [6]. Moreover, there are no standardized guidelines regarding end-of-life care for the elderly in Japan [2]. Third, the will of the elderly patients may change, or the patients may be reluctant to discuss death or to make a decision [6]. Hattori et al. also stated in their paper that the will of elderly patients may easily change considering the feelings of others [7].

However, due to rising health care costs and the insufficient number of hospital beds in Japan [8], hospitals no longer have the spare bed capacity to cope with the increasing demands of a rapidly-aging population. In addition, if given a choice, Japanese elderly people would rather spend the last few years of their life and pass away at a long-term care facility they are familiar with rather than in a hospital [9]. As a

result, we expect institutional end-of-life care for the elderly to become the focus of attention in Japan [2,6].

However, several studies have highlighted the fact that long-term care facilities and caring staff are not ready for quality end-of-life care provision in Japan [2,9-11]. First, there are three types of long-term care facilities in Japan: geriatric hospital, geriatric health services facility, and nursing home [10]. Geriatric health services facilities are long-term care facilities for the elderly that provide nursing care and rehabilitation services aimed at enabling the elderly who do not need hospitalization to return home, thereby assuming an intermediary position between geriatric hospitals and nursing homes. The geriatric health services facilities have only a full-time physician, and the nursing homes have only a part-time one. Thus, only a full- or a part-time physician makes it difficult for these facilities to maintain a 24-h emergency call system [10]. Second, long-term care facility managers disagree on whether or not they should provide end-of-life care. Opinions are clearly divergent regarding whether geriatric health services facilities should provide discharge support or end-of-life care for residents [11]. Third, caring staff tend to shy away from elderly patients who are facing imminent death. This behavior can be explained by the fact that caring staff enter the workforce with very limited exposure to death [1]. Further compounding the problem is the lack of access to death education programs.

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Studies carried out so far have mostly been based on quantitative data including questionnaires [1], but few have explored the underlying opinions and emotions of on-site staff. The present study is aimed at shedding light on how caring staff provide care at the end of life, the emotions they experience in the provision of this care, and what impact caring for dying elderly residents has on job satisfaction and burnout.

## Method

### The KJ method

We used the KJ method (Kawakita Jiro's initials) as a qualitative research tool. The concept and background of the method was explained elsewhere [12] (<http://mushin-kan.jp/>). In summary, the KJ method was created in the 1960s by the Japanese ethnologist Jiro Kawakita. In addition to studies in the field of ethnology [13], the KJ method is now widely employed in Japan as a tool for qualitative research and improvement of business operation. The method gathers information from the scene as it is, and is inspired from chaotic data itself. It is not based on fixed quantitative data and it does not verify a hypothesis but rather inspires a hypothesis itself (<http://mushin-kan.jp/>).

The KJ method allows for information and ideas to be synthesized into a conceptual visual map using labels [12,14]. The actual application of the KJ method involves four essential steps: 1) label making; 2) group organization; 3) illustration; 4) written or verbal explanation. Although this popular method is widely-used, there is only a very limited amount of literature explaining the standardized method procedure in detail. Therefore, both the author of the present study and a research assistant completed an eighteen-hour KJ method training course for researchers at Mushinkan KJ method training center in Kyoto (<http://mushin-kan.jp/>).

### Data collection and label making

We collected qualitative data through two-person or four-person discussions (Figure 1). First, two participants discussed end-of-life care at long-term care facilities for two hours, writing down all of the ideas and thoughts formulated during the discussion. Next, based upon these written notes, each participant drew up a complete list of all the

ideas and thoughts generated during the discussion. According to the empirical rule of the KJ method, if it seems that other ideas or thoughts could be gathered from further discussions with new participants, the 2-person discussion should be repeated with 2 new participants. Study participants were randomly recruited from a list of 84 long-term care leaders related to Nagoya University Hospital by letter, considering a diverse range of characteristics such as age, sex, workplace among the participants. And no one rejected our request for cooperation to the study. We did not include long-term care leaders of geriatric hospitals into the participants because we think that they are not well involved in hospital end-of-life care. We eventually stopped recruiting participants at 4 because we all felt that the two discussions had covered the widest possible range of opinions and information. In the end, all four participants took part in a final discussion on end-of-life care provision at long-term care facilities. We then transferred all of the participants' ideas and thoughts onto individual labels. All discussions were held in April of 2012. Study participants were 4 long-term care leaders from different long-term care facilities in Nagoya City (Table 1). All of them were skilled and experienced in providing end-of-life care.

### Abduction

In addition to the four participants, the first author and the research assistant took part in the present abduction. The exercise was performed in June 2012. Through the final discussion, we compiled a total of 113 labels reflecting the thoughts and experiences of the long-term care leaders on end-of-life care provision at long-term care facilities.

The KJ method allows selecting the number of labels carefully while saving time and labor. This procedure is called the multi-stage pick-up procedure. First, under the guidance of the author and the assistant, the four participants selected 34 out of 113 labels, using the procedure which works as follows: 1) Decide on a target number of labels, 2) Ask the participants to read the labels silently and memorize them to gain an overall impression, 3) get the participants to mark the labels they wish to keep 4) in a second round of pick-up, get the participants to mark the labels they wish to keep among the previously selected labels, 5) repeat this process until the resulting number of labels is close to the target number, 6) be extremely careful when making a final pick-up.

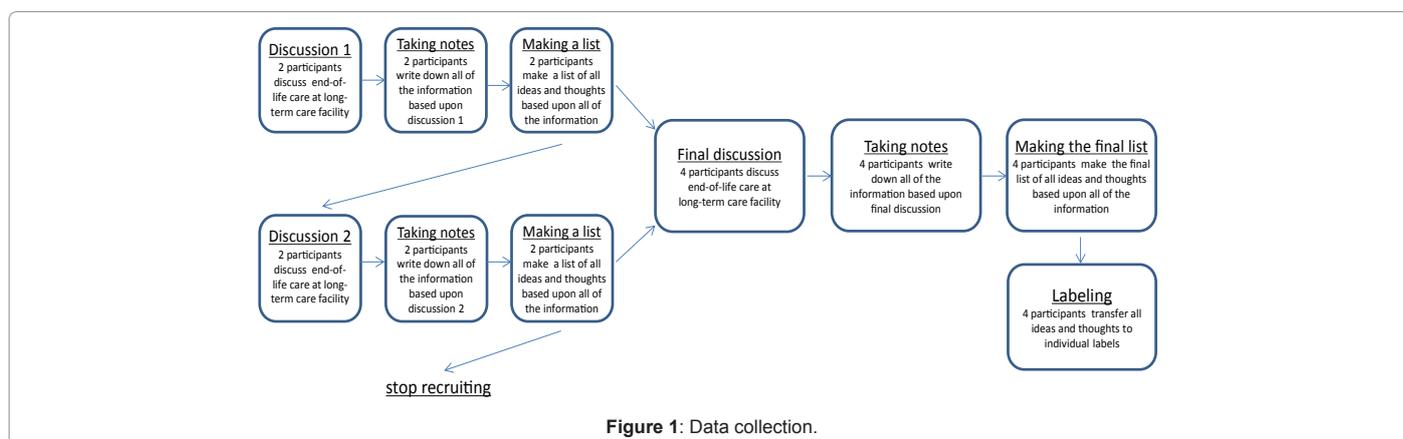


Figure 1: Data collection.

Participant	Age (year)	Sex	License	Facility type	Bed capacity
1	29	Male	Certified care worker	Nursing home	108
2	47	Female	Nurse	Geriatric health services facility	100
3	44	Male	Certified care worker	Nursing home	68
4	34	Female	Certified care worker	Geriatric health services facility	100

Table 1: Participants' Characteristics.

The target number of the multi-stage pick-up procedure is required to be more than twenty or one-fifth of all labels to assure the quality of study using the KJ method. (Figure 2).

Second, the author and the assistant organized the remaining 34 labels into groups using the following KJ method procedure: 1) read the labels silently to understand the entire image, 2) combine labels that share strong similarity of quality, 3) set aside any label that stands apart ('loner'), 4) make a 'first-step nameplate' for each group of labels, 5) again, read the loner labels and first-step nameplate labels silently and combine labels that share strong similarity of quality, 6) set aside any label that stands apart, 7) after further reflection, make a 'second-step nameplate' for each group of labels. When grouping the labels, we endeavored not to follow standardized, stereotypical perceptions. Because the KJ method treats a loner label as a group, as a result of group organization, we ended up with 9 groups (including 2 loner labels).

Third, we arranged the loner labels and the groups with nameplates on a large sheet of paper, devising a spatial patterning of the groups into a consistent unifying chart. We also created a catchphrase for each group in order to attract readers' attention.

Finally, to confirm the clarity and cohesion of the group arrangement to study participants, we added a title that captured the overall message of the illustration and the relationships among the organized groups and loner labels. We also added the explanation of the chart to interpret it effectively.

## Results

As shown in figure 3, the author and the assistant organized the 34 labels into groups using the KJ method procedure, and nine groups (including two loner labels) were extracted.

## Group organization

**Active family involvement is important to successful end-of-life care:** The labels "Carefully listening to the families' feelings is essential to quality end-of-life care (Participant 2)", and "I want families to be deeply involved in the end-of-life care process of their resident (Participant 3)" suggest that caring staff think that family involvement is an important factor toward successful end-of-life care for residents.

**Caring staff wants to provide end-of-life care with compassion as well as logic:** This group included the labels: "There is a gap between what caring staff can do and what they want to do (Participant 3)", and "Caring staff tend to think instinctively, but not logically (Participant 2)".

**Caring staff would rather avoid facing death or dealing with dying residents:** The first-step nameplate "Caring staff wish they didn't have to provide end-of-life care due to their negative feelings toward death", and the loner label "Caring staff think that if they avoid performing certain duties, other employees will do it for them" (Participant 2) suggested that caring staff would rather avoid facing death or dealing with dying residents.

**Caring staff is at a loss as to how to behave around the time of a resident's death:** The label "Caring staff do not know they can cry; most of them think that they should not do so (participant 2)" suggests that caring staff are at a loss as to how to express their emotions near or at the death of a resident. The label "Caring staff does not know how they should greet a bereaved family following the death of a resident (participant 2)" and the label "An increasing number of caring staff avoid approaching the residents' families (Participant 4)" suggests that caring staff are poorly experienced in (bereaved) family care. The first-step nameplate "Caring staff find it difficult to receive appreciative words from residents' (bereaved) families" is possibly related to the caring staff's lack of confidence in their ability to offer quality (bereaved) family care.

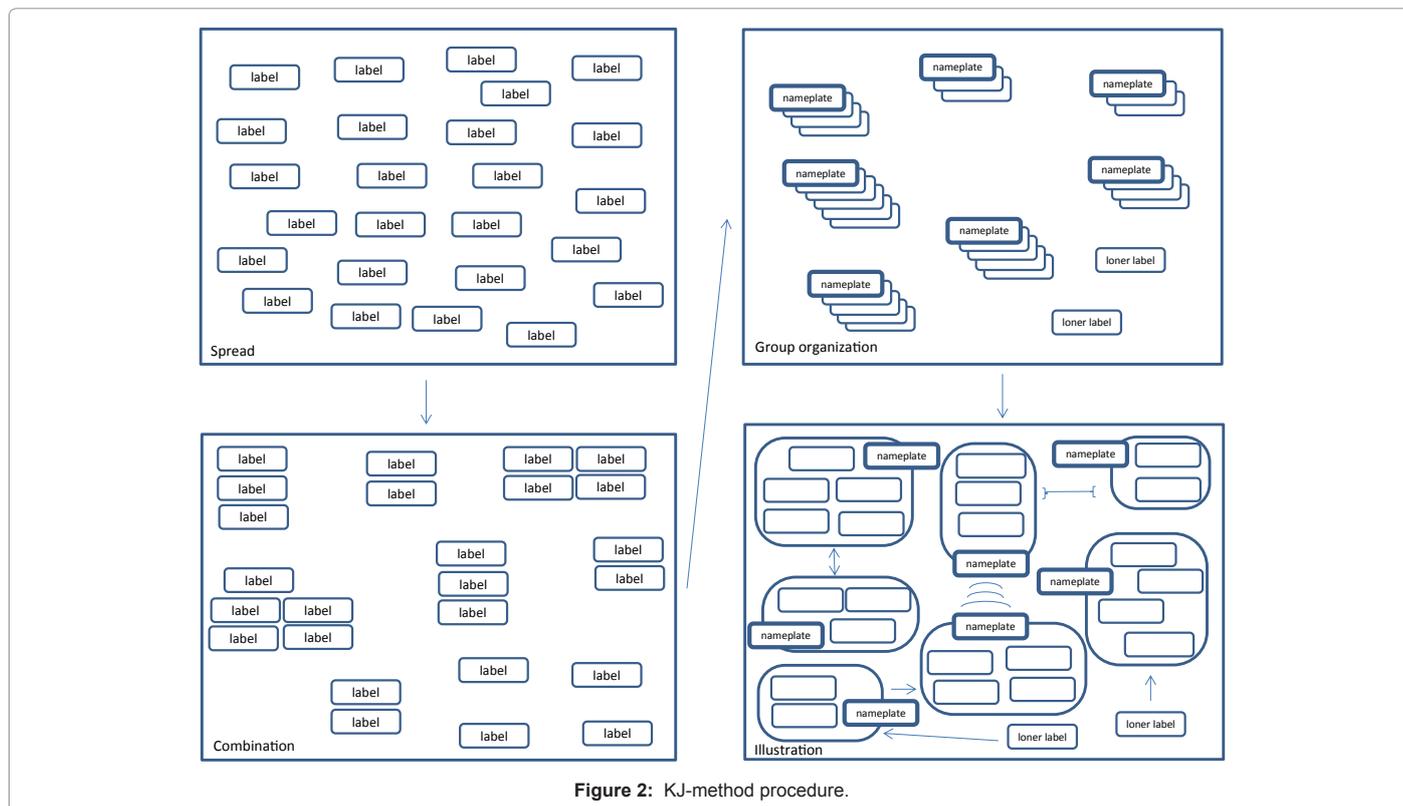
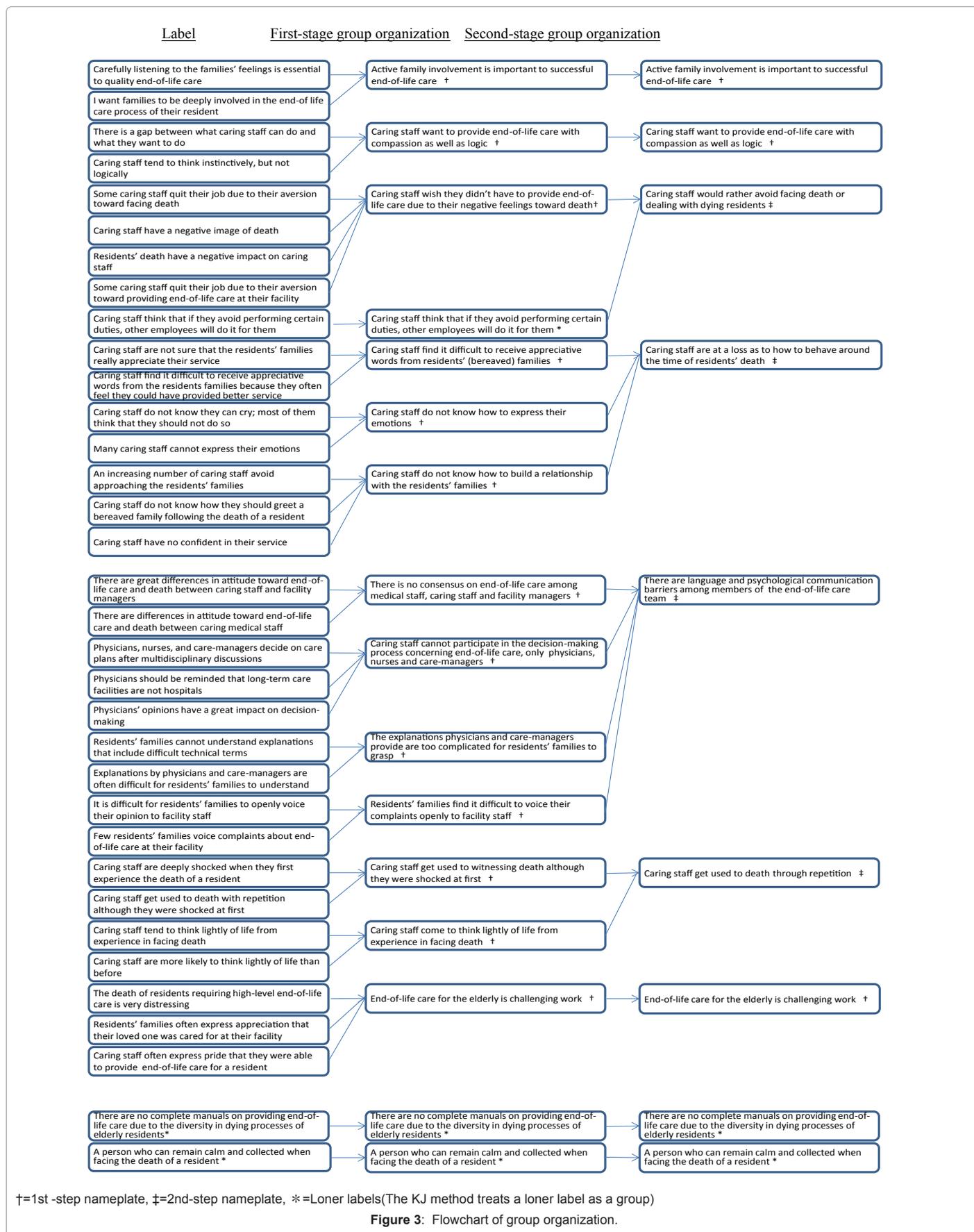


Figure 2: KJ-method procedure.



**There is language and psychological communication barriers among members of the end-of-life care team:** First-step nameplates included “There is no consensus on end-of-life care among medical staff, caring staff and facility managers”, “Caring staff cannot participate in the decision-making process concerning end-of-life care, only physicians, nurses and care-managers”, “The explanations physicians and care-managers provide are too complicated for residents’ families to grasp”, and “Residents’ families find it difficult to voice their complaints openly to facility staff”. These nameplates suggest that there are important language and psychological communication barriers between members of the end-of-life care team.

**Caring staff get used to death through repetition:** Although “Caring staff are deeply shocked when they first experience the death of a resident (Participant 1)”, two participants suggested that caring staff get accustomed to death through repetition and, as a result, tend to think lightly of life.

**End-of-life care for the elderly is challenging work:** Even though “The death of residents requiring high-level end-of-life care is very distressing (Participant 1)”, participant 1 indicated that caring staff and residents’ families often express satisfaction that their loved one passed away at their facilities.

**Loner labels:** The labels “A person who can remain calm and collected when facing the death of a resident (Participant 1)” and “There are no complete manuals on providing end-of-life care due to the diversity in dying processes of elderly residents (Participant 2)” were not placed into any group.

### Data interpretation

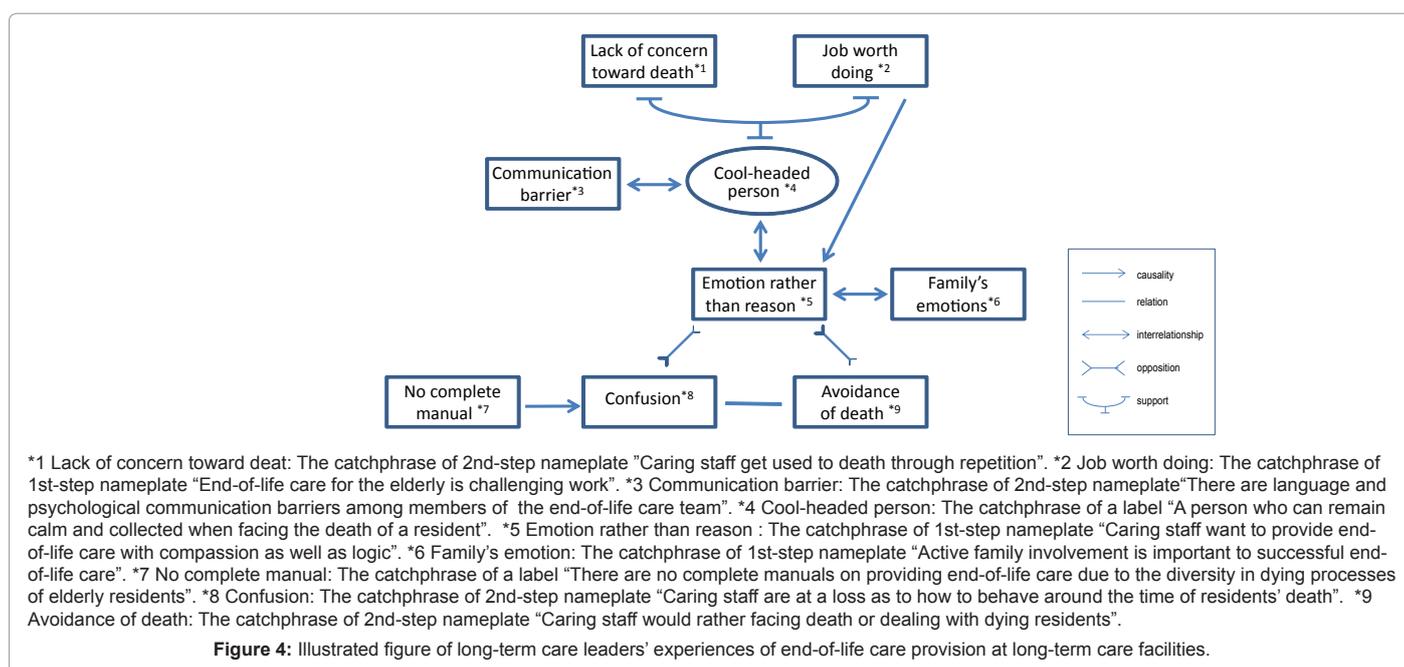
The following catchphrases were extracted: Lack of concern toward death; Job worth doing; Communication barrier; Cool-headed person; Emotion rather than reason; Family’s emotions; No complete manual; Confusion; Avoidance of death (Figure 4). The title of our illustrated figure is “Cool Head, but Warm Heart”, and the figure has “Cool-headed person” as the center.

Caring staff are often ill-prepared to face the challenges of caring for a dying resident and handling death. This is partly due to the fact that there are no comprehensive manuals concerning end-of-life care. Caring staff are thus often confused as to how they should behave or express their emotions and would therefore rather avoid having to deal with dying residents. However, caring staff do wish to provide compassionate end-of-life care, especially in order to honor the residents’ families’ wish for their elderly relative to spend the last days of life at their facility. Our illustration suggests that sound end-of-life care is dependent upon the ability to remain calm yet compassionate in the event of the death of a resident. Someone who maintains a “cool head” has the ability to appreciate the emotions of caring staff and residents’ families and to break language and psychological communication barriers among members of the end-of-life care team. However, unprepared and untrained caring staff gets accustomed to death with time and tend to think lightly of life; it is therefore essential that they receive some form of death education training from a knowledgeable person with a calm and composed attitude. This person plays a key coordinating role in the provision of successful and rewarding end-of-life care for elderly residents.

### Discussion

There is no consensus on whether long-term care facilities should provide end-of-life care for residents among the care team members in Japan. In fact, some facilities have a progressive policy towards end-of-life care provision while others have a regressive policy [1,11]. In addition, as our results suggest, there are no standardized guidelines regarding end-of-life care for the elderly in Japan [2]. Without social consensus about facility end-of-life care policy or standardized guidelines, caring staff may understandably be confused as to their role and responsibilities as a member of an end-of-life care team. Guidelines for end-of-life care of the elderly at long-term care facilities based on national consensus should be developed.

We found that some caring staff get used to death through repetition, while others would rather avoid dealing with dying residents and don’t know how to behave around the time of a resident’s death. Several



studies support our results, suggesting that staff require counseling on dealing with death and further education on end-of-life care [10,15-17]. However, to our knowledge, very few studies have highlighted the fact that caring staff get used to death through repetition. Further studies based on this new knowledge regarding staff behavior are required.

The present study also indicates that caring staff are generally desirous to provide compassionate end-of-life care. Zimmerman et al. [17] in fact suggested that caring staff prefer to stay involved with residents for whom they have been caring for years, rather than relinquish that responsibility to outsiders. Thus, because caring staff spend so much time with the residents, they often become emotionally involved with them and their family [18-24]. While a certain level of emotional attachment may certainly enhance the quality of the care they provide, caring staff should be aware that over-involvement may also possibly lead to burnouts [17,25].

Our results suggest that there is lack of communication among the members of the end-of-life care team. The position statement of the Japan Geriatric Society [26] suggests that a multidisciplinary approach to the care of dying patients is preferable. Also, we previously indicated that nurses and caring staff recognize the need for a cohesive end-of-life care team approach [10]. We think that promoting a multidisciplinary approach to end-of-life care is still a challenge in long-term care facilities.

In addition, our results suggest that some physicians or care-managers are not adequately prepared to explain the residents' condition to their family [6,27,28]. The development of medical interview training programs and communication tools to discuss end-of-life care may enhance communication and ultimately contribute to successful informed consent.

Our results suggest that long-term care leaders require a cool-headed person in their own facilities, implying that a person who is able to remain composed yet compassionate in a demanding and emotional environment is best suited to tend to the needs of caring staff and residents' family and to promote communication among the end-of-life care team. Drawing from literature [29,30] and our clinical experience, we believe that the most suited professionals to fill this coordinating role are nurses, care-managers, or long-term care leaders.

## Conclusion

We revealed that long-term care leaders require a person who is able to remain composed in a demanding and emotional end-of-life care environment. Also, they thought that the cool-headed person is best suited to tend to the needs of caring staff and residents' family and to promote communication among the end-of-life care team. We conclude that successful end-of-life care at long-term care facilities requires care coordination from a person capable of remaining calm yet compassionate under pressure, a person with a *cool head but a warm heart*.

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