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Short Report

A Study of End-of-Life Care in the Community for Elderly People

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Abstract

Okinawans have been celebrating longevity and helping people in their community pass their dying moments at home. Traditional methods of dealing with birth and death and taking care of the spirits of the dead have been inherited from past generations.

This research was conducted in Okinawa from January 2005 to November 2005 using the Triangulation Method. The purpose of the research was to examine how elderly people hope to spend their last hours, and to investigate how communal care, including traditional local ways, should be organized most beneficially.

In the first investigation, 87 participants in the "group activities for elderly people" completed questionnaire. In the second investigation, ten people from a local elderly group, including trustees of the group, were interviewed using the Ethnography Method. In the third investigation, two facilities were studied in order to grasp the present situation of end-of life health care and terminal care using the Participant Observation Method,.

Questionnaires were processed statistically, interviews were analyzed qualitatively, and the following results were obtained: approaching death in a peaceful way, allowing individuals to decide how they want to die, thirdly, and letting people pass away with dignity. In order to meet above needs, elderly people must practice self-health management, maintain good relationships, and participating in *yuntaku* (Okinawan dialect for "chats"). Furthermore, it is important to establish support systems such as "*Yuntaku Net*" since the network has been showing the possibility of a new style of communal care for elderly people.

Keywords: End-of-Life Care, Elderly People

Ⅰ. Introduction

Okinawa, with its distinctive regional characteristics, has the highest rate of longevity in the world. Traditional methods of dealing with births and deaths and the care of the spirits of the dead, have been handed down from generation to generation. People celebrate long life and help those in their community to pass their dying moments at home. When dying outside of one's own home, it is customary to hold a "*NUJIFA*" ceremony to summon the soul back to the deceased's home. Many elderly people have died while staying in the hospital. However there has been little investigation about "*NUJIFA*" in relation to hospital deaths.

In the Okinawan belief system, death is considered as a rite of passage where the spirit and the body become separated from each other. Thus, when a person's death takes place outside his or her home and he body is brought home for the funeral, the spirit is believed to be left at the site where the death has taken place. To ensure the spirit's return home, the ritual called "*NUJIFA*" is performed at the site of death.

That is, the spirit is lured from the site of death and is taken back to the person's home. Generally, the "*NUJIFA*" is performed on the same day as the person's death. In some cases, however,

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it is performed on a later day. While the actual performances of the "*NUJIFA*" vary depending on the community, the meaning of the "*NUJIFA*" is basically the same throughout Okinawa. That is, in the culture of Okinawa, "NUJIFA" has a sense of grief care or spiritual care (Hamasaki, 2011).

The purpose of this research is to obtain basic data - for example, how elderly people hope to spend their last hours - in order to consider how end-of-life care, including traditional local styles of terminal care, can be best organized.

Ⅱ. Method

This research was carried out in A city, Okinawa, the survey was done from January to November of 2005. The author performed research using the Triangulation Method. The details are as follows:

(1) Research 1

In accordance with the Japanese Health Locus of Control Scale, questionnaires were given to participants of group activities for elderly people, in order to ascertain how they perceive health and illness. Out of 110 individuals who completed the questionnaires, 87 of these were then analyzed. The following areas were examined by this study:

①things which elderly people value highly and which allow them to approach the end of their lives in a way which reflects their way of life;

②The awareness of "*NUJIFA*" a traditional Okinawan ceremony, as an element of care for the spirit after death;

③The place where elderly people hope to be when they die.

(2) Research 2

Ten people from a local elderly people's group, including the trustees of the group, were interviewed about their experiences of terminal nursing care for elderly people and how they hoped to approach their own death. In accordance with Qualitative Content Analysis, the data was delineated, analyzed and then interpreted in order to understand the needs concerning end-of-life care for the elderly.

(3) Research 3

A Community Nursing Centre and other facilities took part in a study of end-of-life care provision, while the provision of terminal care was studied in two **Takuro-sho* (a small-sized multi-functional group home) using the Participant Observation Method.

**Takuro-sho* ; (ASAJINOSATO 2003)

Small sized facilities which mainly provide day care and short-term residential care for elderly people. In contrast to group homes, *Takuro-sho* don't normally provide long-term residential care but offer a wide range of services in a family-like environment.

Ⅲ. Ethical considerations

With regards to ethical considerations, protection of anonymity and privacy was explained and consent forms were obtained from subjects.

Ⅳ. Result and Discussion

(1) Research 1

The Subjects of the study included 87 elderly people (44 Men, 43 Women) over the age of 65 living in A-City, Okinawa, Japan. Their average age was 74.1±6.0 (Men 74.8±5.4, Women 73.4±6.6). Data was collected via interviews and a questionnaire at senior citizen events. The questionnaire consisted of Horike's (1988) Japanese version of the Health Locus of Control (JHLC) scales and their feelings concerning the "*NUJIFA*."

The JHLC scale includes a total of 25 questions: (1)Internal Health Locus of Control (IHLC) ; (2) Family Health Locus of Control (FHLC) ; (3) Supernatural Health Locus of Control (SHLC) ; (4)Chance Health Locus of Control (CHLC) ; and (5)Professional Health Locus of Control (PHLC) : With five questions for each item.All items utilized a 6-point, Likert-type format, ranging from "Strongly Disagree" (scored as one) to "Strongly Agree" (scored as six). The JHLC tests are scored ranging from 6 to 30.

The mean score of the JHLC scale is as follows. IHLCs: 26.45±2.59. FHLCs:24.13±3.53. PHLCs:22.32 ±3.52. CHLCs:16.44±4.60. SHLCs:14.56±4.61.

□The mean and standard deviations in elderly people were as follows,

Elderly people attribute their health and illness firstly, 'to themselves'; secondly, 'to important people' such as members of their families; next 'to professionals' such as doctors; then 'to luck and chance'; and finally 'to supernatural powers'. These results correspond to results found in preceding studies. (Fig1)

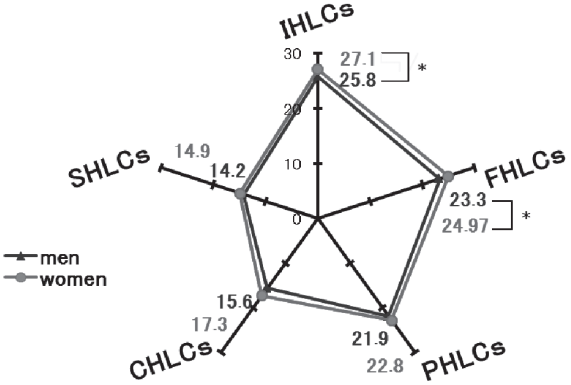

Fig1. The average score of JHLC scales *; p <.05 men/women by gender

"*NUJIFA*" is widely recognized in a positive context especially by women.

The results showed that 93.1% of elderly people knew of "*NUJIFA*" All women knew of "*NUJIFA*" and 74.4 % of the subjects affirmed the importance of "*NUJIFA*" In women it was especially important. Concerning the consciousness regarding the importance of "NUJIFA", the subjects were placed into a "positive group" and a "negative group". As a result, the positive-group had 48subjects (59.3%), the negative-group had 19subjects (23.4 %), and there were 14unknowns (17.3%). (Table.1.2.3.4)

These results suggested that "*NUJIFA*" and supernatural forces were widely accepted by older women in A City, Okinawa. In relation to the JHLC score, the group that affirmed the importance of "*NUJIFA*" had a high score in supernatural forces. It was suggested that there be a role of "*NUJIFA*" in generic care for elderly people who had a high SHLC score.

Table1. Do you know "*NUJIFA*"

	YES	NO
women (n=43)	43 (100%)	0
men (n=44)	38 (86.4%)	6 (13.6%)
total (n=87)	81 (93.1%)	6 (6.9%)

Table2. Consciousness as to the importance of "*NUJIFA*"

	very	some	little	not at all	unknown
women (n=43)	13 (30.1%)	19 (44.2%)	7 (16.3%)	2 (4.7%)	2 (4.7%)
men (n=38)	5 (13.2%)	11 (28.9%)	9 (23.7%)	1 (2.6%)	12 (31.6%)
total (n=81)	18 (22.2%)	30 (37.0%)	16 (19.8%)	3 (3.7%)	14 (17.3%)

Table3. Proportion of positive-negative group by gender

	positive group	negative group	unknown
women (n=43)	32 (74.4%)	9 (20.9%)	2 (4.7%)
men (n=38)	16 (42.1%)	10 (26.3%)	12 (31.6%)
total (n=81)	48 (59.3%)	19 (23.4%)	14 (17.3%)

Table4. The relevance of a mean and "NUJIFA" positive-negative group of JHLC scales (± SD)

	IHLC	FHLC	PHLC	CHLC	SHLC
Positive group (n=48)	27.35 ± 2.33	25.14 ± 3.31	23.21 ± 3.22	17.68 ± 4.50 *	16.02 ± 4.42 *
Negative group (n=19)	26.52 ± 2.04	23.28 ± 3.90	21.76 ± 4.17	14.30 ± 3.67	11.33 ± 3.78
unknown (n=14)	24.00 ± 2.27	22.44 ± 2.83	20.66 ± 2.78	15.50 ± 4.87	14.44 ± 4.23

n=81 *; p <.05

□88.5% of elderly people hope to be in their own homes during their final moments.

Participants cite being responsible for their own health management, maintaining good relationships, and taking part in sports and hobbies, as factors which help them to avoid becoming bedridden and to approach their last moments in a way which is in accordance with their wishes.

Research 2

The subjects of the study included 10elderly people (5Men, 5Women) over the age of 70 living in A-City, Okinawa, Japan. The average of which was 79.6.

The interview was performed 2or3 times per person. All of the members were experiencing the family's end-of-life care and about 15 examples of end-of-life care experiences were collected. The total interview time was 37hours and 30 minutes. The average time of one interview was about 100 minutes. The mean time of the interviews was 3hour and 45minutes. (Table5)

From 10 examples, 468 code extraction was carried out. The similarity of the code was examined and the reorganization integration of the categorical was performed. As a result, the following things became clear.

(1) the experience of end-of-life care consisted of six large categories. (Table6).

(2) Their end-of-life care wishes consisted of categories concerning『The elderly person's beliefs about the end-of-life』and『The elderly person's actions for the needs for the end-of-life』(Table7 and Table8).

The following factors have been highlighted as needs by elderly people in the provision of end-of-life care: firstly, to be able to approach death in a peaceful way; secondly, to allow individuals to decide by themselves how they want to die; thirdly, to allow people to pass away with dignity. In order to meet these needs elderly people practice the following: self-health management; the maintenance of good relationships; and enjoying Yuntaku (Okinawan dialect for 'chats').

Research 3

In 2005, a Community Nursing Centre in A City, enabled only two people to be nursed at home before they died, while at a *Takuro-sho*, with the help of the family and related workers, terminal nursing

Table5. The subjects who were interviewed, and an interview state

No	age	Sex	average of time minutes	Interview place	Family structure	The object of end-of-life care			
						Family relationship	Death age	place	disease
A	90	M	90	home	Marital	Wife	40	home	Cancer
						Father	50	home	sickness
B	86	W	90	home	Three or more	Grandfather	80	home	Senility
C	83	W	120	Coffee shop	Marital	Mother	89	home	Cancer
D	82	W	105	home	Oneself and a grandchild	Eldest son	57	Hospital	Cancer
E	77	W	80	home	Three or more	Mother	97	Welfare facilities	Cardiac failure
F	77	W	90	home	Marital	Mother-in-law	74	home	Stroke
						Father-in-law	77	home	Stroke
G	77	M	75	home	Three or more	Mother	104	Welfare facilities	Senility
H	76	M	130	home	Marital	Father	74	Hospital	After the operation
						Mother	88	home	Senility
I	75	M	90	home	Three or more	Father	76	home	Stroke
						Father-in-law	94	Welfare facilities	Pneumonia
J	73	M	105	home	Marital	Mother	80	Hospital	Stroke
						Father	90	home	Pneumonia

Table6. Realigned and consolidated categories for the experiences of sharing the last moment with passing family members

large category	mid category		breakdown category
1) Care provided mainly by family members	1. Family worked together	1	Most people died at home in the 1970's
		2	All family members provided elderly care
		3	Family members looked after a dying person
	2. Type of care given by family	4	Helped with daily routine
		5	Conversed with the elderly person
		6	Visited a nursing home everyday
		7	Provided post-death care
	3. Be with the dying person during the final moment	8	I have many experiences of being with family members when they passed away
		9	Death was a part of life
		10	I was there when my loved ones passed away
	4. Family decision	11	Decided to take an elderly person home from a nursing home/hospital
		12	Decision whether to bring an elderly person home was difficult
		13	Asked the elderly person if he/she wanted to go home
	5. Family bond	14	Bereaved family reminisce about the deceased
		15	Value on the family ties is important
		16	Parent-children bond is a fundamental factor for elderly care
		17	Family wished to provide end-of-life care
		18	Children should look after parents
2) Wishing for a peaceful death	6. Share the pain	19	I wanted to relieve the pain of my dying family member
		20	It was a shock to lose a family member
		21	It was hard to see a dying family member in pain
		22	The deceased looked peaceful
	7. Fulfill the dying person's desire	24	I wanted to fulfill the dying person's final wishes
		25	I couldn't take him/her home
		26	I wanted to do as much as possible
		27	My family member died surrounded by his/her family
	8. Accept death	28	I think the dying person understood the death could not be avoided
		29	I think the dying person thought the fate was unpredictable
		30	I think it becomes easier to accept death at a certain age
		31	It seemed the dying person was accepting death
		32	I felt that the dying person really lived a long life
	9. Pay the last respect	33	I paid the last respect to the deceased
		34	The person died a peaceful death
	10. Departure	35	The deceased looked peaceful in death
		36	Everyone goes to the “afterworld”
		37	The deceased believed in the “afterworld,” and so do I
		38	The deceased thought about the “afterworld,” and so do I
		39	The deceased thought about the bond with the "afterworld," and so do I
3) Utilizing medical resources	11. Help from doctors	40	Doctors came to the house
		41	Doctors gave advice
	12. Support from public health nurses	42	I had health care provider (s) among my relatives
		43	Public health nurses visited the house
		44	Public health nurses provided help
	13. Impact of medical resources	45	There was no hospital nearby
		46	The elderly person was taking over-the-counter medication
		47	Public health insurance system was not available

large category	mid category		breakdown category
4) Supporting each other in the community	14. Help from neighbours	48	Neighbours talked to me when I was caring for my family member
		49	Neighbours listened to me
		50	Neighbours offered guidance and helped with caring an elderly person
		51	Neighbours visited me
	15. Comfortable living environment	52	My dying family member loved nature
		53	I felt the healing power of nature
		54	The lifestyle was relaxed
		55	We lived in a familiar environment
		56	The relationships were generous and relaxed
	16. Experience of *yui-maru* (helping each other)	57	I was involved in the community
		58	Neighbours helped each other
	17. Close friends	59	I could be myself
		60	My friends encouraged me
		61	My friends supported me
		62	I had friends to enjoy chatting with
		63	My friends listened to me
		64	I had friends to spend time with
5) Fostering the cultural custom of celebrating departure	18. Share the good luck of longevity	65	I think it becomes easier to accept death at a certain age
		66	I felt that the dying person really lived a long life
		67	My family member had a longevity cerebration before they passed away
		68	I want to share the good luck of my family who enjoyed longevity
	19. Presence of afterworld	69	My family communicated with the afterworld, and so do I
		70	We live this world and afterworld
	20. Custom to pay respect to the deceased	71	I gave a gift to the deceased to take to the afterworld
		72	There have been rituals to respect the deceased
		73	There has been a practice of *nujifa* (*a traditional ritual*)
		74	I am aware of the customs of Okinawa
		75	I have experienced cultural rituals related to death
		76	We have a culture of *chimu* (*wholeheartedness*)
6) The way of life	21. Impressive strong will to stay alive	77	The family member was fighting against death
		78	The family member was trying hard until the last moment
	22. Ready to die	79	The family member anticipated death
		80	The family member gradually weakened
		81	The family member was ready to die
		82	The family member prepared to die
	23. Be a good person throughout our lives	83	I've had work to be devoted to (like my family member did)
		84	I've lived my life in a way I believe right (like my family member did)
		85	I am aware of my role in life (like my family member was)
	24. Self-care	86	I learned everyone has their own way of maintaining health
		87	I learned taking care of myself is important
		88	I learned believing in myself is important

Table7. Realigned and consolidated categories for the needs for the end-of-life care (No.1)

The elderly person's beliefs about the end-of-life

large category	mid category		breakdown category
1) I want to die peacefully	1. passing away without suffering	1	I want to die quick and painlessly
		2	I want to die quick and painlessly
		3	I want to be healthy until the last moment
		4	I want to die with a smile on my face
		5	I want to die with my family nearby
	2. Believing in the afterworld	6	This world is for the temporary life and the afterworld is for eternal life
		7	Everyone goes to the afterworld
		8	I have no fear about going to the afterworld
		9	I think about the afterworld
	3. Accepting death	10	I want to die naturally, as I get older and weaker
		11	I want to accept death as a destiny
		12	I will accept it when the time comes
		13	I want to get ready to accept death
2) I want to decide how to end my life	4. Having a goal for my life	14	I wish to live a long life
		15	I believe dreams will come true
		16	I want to see how things change in society
		17	I have a strong desire to live
		18	I want to make sure the family blood lines will not cease
	5. Reviewing my life	19	I have my own way of life
		20	I sometimes reminisce about my life
		21	I feel impressed with my own longevity
		22	I am interested in the living will
	6. Thinking how to end my life	23	I want to die at home
		24	I want to choose where I die
		25	I can close my life somewhere other than at my house
		26	I think of the last scene
		27	I think of the last words
3) I want to die with dignity	7. Being myself to the last moment	28	I don't want to burden others with taking care of me
		29	I don't want to be a burden to my children or family
		30	I want to die with the feeling of appreciation
		31	I want to be myself
	8. Maintaining sound mind	32	I want to keep my sanity so I will recognize my friends
		33	I don't want to grow senile
		34	I don't want to become bed-ridden
		35	I want to stay mentally healthy so I can talk to others
		36	I want to continue to be able to take care of myself
	9. Living with dignity	37	I don't want to feel miserable
		38	I won't prolong the dying process
		39	I keep in mind the thoughts and wishes of those who perished during the war
		40	I should be responsible to maintain health

Table8. Realigned and consolidated categories for the needs for the end-of-life care (No.2)

The elderly person's actions for the needs for the end-of-life

large category	mid category		breakdown category
1) Taking responsibility for my health	1. Having established habits to promote health	1	I eat a lot of vegetables
		2	I perform daily routines and activities
		3	I control stress
		4	I am staying social
	2. Taking responsibility for my health	5	I take responsibility for maintaining my health
		6	Maintaining health is No.1 priority
		7	I pay attention to my own health
	3. Taking care of ourselves	8	I am better at taking care of myself after suffering illness
		9	There are many ways to take care of ourselves
		10	Various ways to take care of ourselves represent wisdoms born from every day life
2) Value the relationship	4. Trusting family	11	I want my family to be there when I die
		12	I believe my children will take care of me when I am dying
		13	I trust my family
	5. Sharing thoughts	14	I want to say what I need to say just before I die
		15	I have something to say before I die
	6. Support system in community	16	The yuimaru tradition still remains
		17	We help each other
		18	We listen to each other
	7. Confidence in experts	19	I want an expert to be with me
		20	I want an expert to help me when I need
3) Enjoying *yuntaku* (chatting)	8. Having friends to have yuntaku (chatting)	21	I enjoy *yuntaku* (chatting)
		22	I do *yuntaku* with others
	9. Participating events	23	I join community/family events and have *yuntaku*
		24	I am busy with community/family events
	10. Environment for yuntaku (chatting)	25	I have a place to enjoy *yuntaku*
		26	I have time to enjoy *yuntaku*
		27	I enjoy living with others
		28	I enjoy the company of my friends

care was given to two elderly people who were unable to spend their dying moments in their own homes. These results suggest problems in providing people with terminal health care at home.

V. Conclusion

In order to maintain a healthy life and approach the end of their lives in a way which reflects their wishes, elderly people take part in *Yuntaku* and are integrated within their communities. *Nujifa*, the ceremony which looks after the spirit of the dead, is also very important to them. It is believed that there are other traditional ways of existence which support elderly people in their approach to an active life and a peaceful death. In order to help individuals put into practice how they want to live and die, we should provide community care which reflects traditional methods as mentioned above. It is therefore important to establish support systems such as '*Yuntaku Net*', a network based on *Takuro-sho* (small-sized multifunctional group homes) and also to encourge *yuntaku*.

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