

Original

Deciding the place of care for the terminally-ill : Pilot Study with UK medical social workers' (MSW) attitude and practice

Etsuko KAMISHIRAKI¹

Megumi BABA^{2,4}

Shoichi MAEDA^{3,4}

Abstract

Background and aims:

When deciding the place of care for the terminal cancer patients, there may be a difference in the opinion between the patient, their family and the doctor as to the most appropriate place. It may be complicated when the patient lacks capacity to decide and there has been no prior expression of the preference by the patient. We are currently investigating the views and practice among the Japanese and the UK MSWs, who are involved with the decision making on place of care for these patients, by carrying out a national survey. We report our pilot survey with four MSWs who belongs to the Marie Curie Hospice in the UK. We plan to report the results of the national survey in Japan and UK subsequently.

Methods:

Anonymised questionnaire survey during the month of November 2013.

Subject:

Four MSWs who work for the Marie Curie Hospices in UK (There are total of 9 Marie Curie Hospices in the UK, each may have a several MSWs) .

Results and Conclusion:

This pilot study showed that the MSWs respected the wishes of the patient first in deciding the place of care when they had the capacity to make decisions and when there had been an expression of wishes by them before they lost the capacity regardless of the age of the patient. Otherwise the family's wishes were respected, so long as it was considered to be in the best interest of the patient.

1 Yamaguchi Prefectural University

2 Department of Pediatric Palliative Care, Children's Hospital for Wales, Cardiff and Vale University Health Board

3 Keio University, Graduate School of Health Management

4 Medical Ethics & Patient Safety Laboratory, Keio Research Institute at SFC

(The names are arranged alphabetically. All authors made an equal contribution.)

Further research to compare the UK and Japanese MSWs may highlight the cultural differences and scope for education and development in this area of social work.

Keywords: terminally-ill, decision making, place of care, the best interest, UK medical social worker

1. Background and aims

When deciding the place of care for the terminal cancer patients, there may be a difference in the opinion between the patient, their family and the doctor as to the most appropriate place. It may be complicated when the patient lacks capacity to decide and there has been no prior expression of the preference by the patient. How should the place of care be decided in such a situation? While respecting patient's autonomy is important, it may result in a significant burden (financially and emotionally) on the family. There are also situations where the patient's preference cannot be determined. The views on the medical social workers, who are involved in discharge planning of the terminal cancer patients, on these issues has not been examined previously. We are currently investigating their views and practice among the Japanese and the UK MSWs by carrying out a national survey. We report our pilot survey with four MSWs who belongs to the Marie Curie Hospice in the UK. We plan to report the results of the national survey in Japan and UK subsequently.

2. Methods

2.1 Methods

Anonymised questionnaire survey during the month of November 2013.

2.2 Subject

Four MSWs who work for the Marie Curie Hospices in UK (There are total of 9 Marie Curie Hospices in the UK, each may have a several MSWs) .

2.3 The questionnaire

The questionnaire was anonymised and consisted of four parts. The first part asked about the current practice by the MSWs with their client with terminal cancer and their family in making decisions about the place of care. The second part asked about the general views of the MSWs on the place of care for the terminal cancer patients who has completed the curative treatment. The third part asked about the views of the MSW's on place of care in more specific case scenario with adult clients and the fourth part was the same except the client was a child. The results from the part two (general situation) , three (specific situation with adult patient) and four (specific situation with paediatric patient) are used for the purpose of this study report.

3. Results

3.1 Respondent demographics (Table 1)

Table 1: Respondent demographics

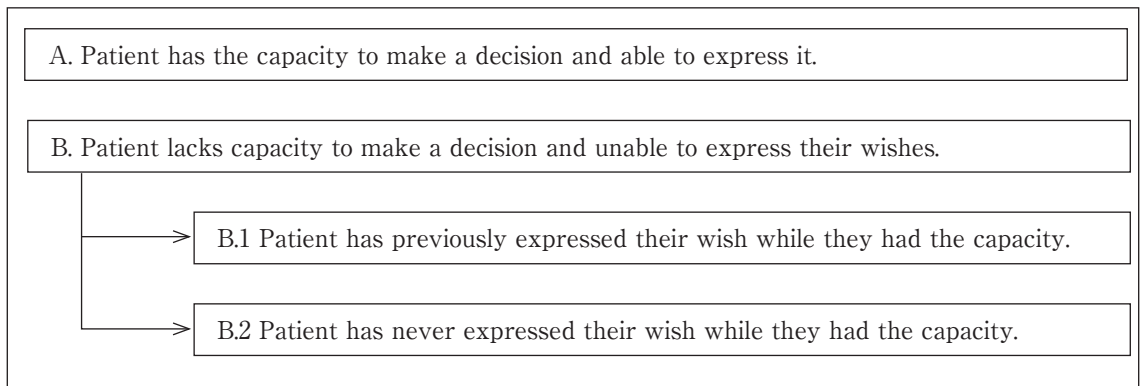
	Gender	Age	Experience	Education	Medical institution you work in	Number of beds in your hospital
A	Female	55	15	University (postgraduate)	Charity	30
B	Female	47	15	College	Charity	30
C	Female	55	2	University (postgraduate)	Charity	16
D	Female	49	16	University (undergraduate)	Charity	30

3.2 Place of care for terminally ill cancer patients

When deciding on place for palliative care,

depending on the patient’s capacity to decide and presence or absence of advance will the following situations are possible (Figure1) .

Figure1: Situation categories by the capacity and prior expression of wishes



3.3 The general views of the MSWs

3.3.1 In the situation A how do you think the decision on place of care should be made?

1. Based on patient’s wishes
2. Based on the wishes of patient’s family or someone close to the patient

3. Based on medical/care team’s judgement
4. Based on doctor’s judgement
5. Based on nurses’ judgement
6. Based on MSW’s judgement
7. Other_____

Answer for 3.3.1

	1	2	3	4	5	6	7
Respondent A	<input type="radio"/>						
Respondent B	<input type="radio"/>						
Respondent C	<input type="radio"/>						
Respondent D	<input type="radio"/>						

Respondent	Comments
A	Patient has capacity should be the patient's decision. Team should not adapt a paternalistic perspective.
B	If the patient has capacity to make the decision they are classed as being the decision maker under the Mental Capacity Act, even if that decision is unwise.
C	The patient has the right to choose.
D	-

3.3.2 In the **situation B1** how do you think the decision on place of care should be made?

1. Based on patient's wishes
2. Based on the wishes of patient's family or someone close to the patient
3. Based on medical/care team's judgement
4. Based on doctor's judgement
5. Based on nurses' judgement
6. Based on MSW's judgement
7. Other_____

Answer for 3.3.2

	1	2	3	4	5	6	7
Respondent A	<input type="radio"/>						
Respondent B		<input type="radio"/>					
Respondent C	<input type="radio"/>						
Respondent D	<input type="radio"/>						

Respondent	Comments
A	-
B	We would attempt to work with family & patient in consensus. The assessments made by the medical care team would need to be considered to enable the family to decide an appropriate care.
C	When they had capacity they made a clear choice. But circumstances must be the same as when the decision was taken.
D	-

3.3.3 In the **situation B2** how do you think the decision on place of care should be made?

1. Based on patient's wishes
2. Based on the wishes of patient's family or someone close to the patient
3. Based on medical/care team's judgement
4. Based on doctor's judgement
5. Based on nurses' judgement
6. Based on MSW's judgement
7. Other_____

Answer for 3.3.3

	1	2	3	4	5	6	7
Respondent A			<input type="radio"/>				
Respondent B	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
Respondent C							<input type="radio"/>
Respondent D		<input type="radio"/>	<input type="radio"/>				

Respondent	Comments
A	Based on best interest decision by the medical team. Mental capacity legislation should inform medical team decision.
B	A best interest decision should be made taking into account all opinions- family, patient, MDT. If a family member has losing power of attorney for welfare decisions – they would be the decision maker.
C	Best interest decision making; MDT including patient’s family + advocator’s appropriate.
D	Family and best interest decision.

further discussion with the patient and his wife.

3.4 Specific scenarios – Adult patient

An 80 year-old man has been given a **prognosis of 3 months** with his cancer. Currently he is in a **central hospital** and receiving opioids for pain control and oxygen for breathlessness. He is in bed most of the time.

He lives with a 75 year-old wife and they have no children. She is healthy and get on well with her husband. Their only source of income is their pension but they have no issues with housing environment. Their relatives live far away. The community has enough resources to support medical and nursing care for the patient.

The doctor explained to them that no further cancer directed treatment will be given and a discussion was held to decide where he should be cared for from now on. However, patient and his wife were unable to decide and MSW was going to have

3.4.1 The patient has the capacity to decide and he is able to express his wishes.

The patient is requesting to go home and be cared for **at home** but wife is requesting for a care in a **palliative care unit about 1 hour away from home**. His doctor thinks it is best for him to be cared for on a **medical ward in the hospital near the patient’s home**.

Where do you feel is the most ideal place of care for this patient?

1. Home
2. Palliative care unit 1h away from home
3. Medical ward in a local hospital.

Answer for 3.4.1

	1	2	3
Respondent	A	○	
	B	○	
	C		○
	D	○	○

Respondent	Comments
A	Provided adequate care is provided, then home is the most natural place to be – familiar surroundings.
B	The patient has capacity to choose. The community can support with medical care at home. I would want to explore why the wife had chosen the unit as opposed to their home & see if support could be offered to her.
C	It won't work at home as his wife is not on board with that decision. Local hospital would facilitate visiting but is generally not a good place to die. Hospice the best choice so long as wife can travel or stay.
D	Ideal place is where patient wishes to be – And where care can safely be managed.

3.4.2 The patient lacks capacity to decide but has previously expressed his wish to be care for at home. His wife is requesting for a care in a **palliative care unit about 1 hour away from home**. His doctor thinks it is best for him to be cared for on a **medical ward in the hospital near the patient's home**.

Where do you feel is the most ideal place of care for this patient?

1. Home
2. Palliative care unit 1h away from home
3. Medical ward in a local hospital.

Answer for 3.4.2

	1	2	3
Respondent	A	<input type="radio"/>	
	B	<input type="radio"/>	
	C		<input type="radio"/>
	D		

Respondent	Comments
A	If the patient have expressed a wish to be cared for at home previously – this should be honored providing adequate care for both husband & wife can be provided.
B	I believe the starting point should still be his wishes. It would be important to explore the risks of being home. Is the wife saying she will not care for him at home?
C	It won't work at home as his wife is not on board with that decision. Local hospital would facilitate visiting but is generally not a good place to die. Hospice the best choice so long as wife can travel or stay.
D	Doctors advice should be taken into account if patient needs acute admission on medical grounds. But patient wishes should be considered first.

3.4.3 The patient lacks the capacity to decide and never expressed his wish on place of care previously.

His wife is requesting for a care in a **palliative care unit about 1 hour away from home**. His doctor thinks it is best for him to be cared for

on a medical ward in the hospital near the patient's home.

Where do you feel is the most ideal place of care for this patient?

1. Palliative care unit 1h away from home
2. Medical ward in a local hospital.

Answer for 3.4.3

	1	2	3
Respondent	A	<input type="radio"/>	
	B	<input type="radio"/>	
	C	<input type="radio"/>	
	D	<input type="radio"/>	<input type="radio"/>

Respondent	Comments
A	Staff on a palliative have more skills & knowledge & time, specialist medical knowledge.
B	I would think that the palliative care unit would be best placed to offer appropriate end of life care & give support to the wife. More than the medical ward - that can be very busy, noisy- be too medicalized.
C	It won't work at home as his wife is not on board with that decision. Local hospital would facilitate visiting but is generally not a good place to die. Hospice the best choice so long as wife can travel or stay.
D	If patient needs acute intervention - Doctors advice should be listened to. If NOT then wife's wishes should be considered.

3.5 Specific scenarios - Paediatric patient

A 15 year-old boy has been given a prognosis of 3 months with his cancer.

Currently he is in a central hospital and receiving opioids for pain control and oxygen for breathlessness. He is in bed most of the time.

He was living with his parents (both 40 years old) before the admission to the hospital. His parents are both healthy and the family get on well with each other. They both work as civil servants. There are no issues with housing environment. Their relatives live far away. The community has enough resources to support medical and nursing care for the patient.

The doctor explained to the family that no further cancer directed treatment will be given and a discussion was held to decide where he should be cared for from now on. However, patient and his parents were unable to decide and MSW was going to have further discussion with the patient and his parents .

3.5.1 The patient has the capacity to decide and he is able to express his wishes.

The patient is requesting to go home and be cared for at home but parents are requesting for a care in a palliative care unit about 1 hour away from home. His doctor thinks it is best for him to be cared for on a medical ward in the hospital near the patient's home.

Where do you feel is the most ideal place of care for this patient?

Deciding the place of care for the terminally-ill

1. Home
2. Palliative care unit 1h away from home
3. Medical ward in a local hospital.

Answer for 3.5.1

	1	2	3
Respondent A	<input type="radio"/>		
Respondent B	<input type="radio"/>		
Respondent C	<input type="radio"/>		
Respondent D	<input type="radio"/>		

Respondent	Comments
A	Has capacity - legally Gillick competency able to decide where he wishes to be.
B	It is the patient wishes & he has capacity to decide. I would want to discuss with the family & they were reluctant to have him home, but advocate for his right to be home.
C	To enable the boy to have quality time in his home environment. Unlikely to happen, parents will probably make the decision.
D	Work with family regarding support, practical + emotional to carry out son's wishes if possible.

3.5.2 The patient lacks capacity to decide but has previously expressed his wish to be care for at home.

His parents requesting for a care in a **palliative care unit about 1 hour away from home**. His doctor thinks it is best for him to be cared for on a **medical ward in the hospital near the patient's home**.

Where do you feel is the most ideal place of care for this patient?

1. Home
2. Palliative care unit 1h away from home
3. Medical ward in a local hospital.

Answer for 3.5.2

	1	2	3
Respondent A	<input type="radio"/>		
Respondent B	<input type="radio"/>		
Respondent C	<input type="radio"/>		
Respondent D	<input type="radio"/>	<input type="radio"/>	

Respondent	Comments
A	Made his wishes when he was competency had mental capacity.
B	I believe the starting point should still be his wishes. It would be important to explore the risks of being home. Is the wife saying she will not care for him at home?
C	To enable the boy to have quality time in his home environment. Unlikely to happen, parents will probably make the decision.
D	If possible carry out patient's wishes - also need to consider how parents are coping - May be best interest decision would need to be made for hospice if parents unable to cope.

3.5.3 The patient lacks the capacity to decide and never expressed his wish on place of care previously.

His parents are requesting for a care in a

palliative care unit about 1 hour away from home. His doctor thinks it is best for him to be cared for on a medical ward in the hospital near the patient's home.

Where do you feel is the most ideal place of care for this patient?

1. Palliative care unit 1h away from home
2. Medical ward in a local hospital.

Answer for 3.5.3

	1	2
Respondent A	<input type="radio"/>	<input type="radio"/>
Respondent B	<input type="radio"/>	<input type="radio"/>
Respondent C	<input type="radio"/>	<input type="radio"/>
Respondent D	<input type="radio"/>	<input type="radio"/>

Respondent	Comments
A	More cut all to meet the needs of someone who has palliative needs.
B	As reasons for the adult patient as believe specialist palliative care would be most suitable rather than a medical word. However, would the palliative unit have offer young people there? I would want to try to ensure he was somewhere with similar ages.
C	I do not believe a medical word would be a good place for this young man to die.
D	If palliative care unit can manage situation best placed there. If doctor believes acute intervention needed - would need to consider doctor advice.

4. Discussion

All respondents had the view that the patient's wishes should be respected when they had the capacity to decide and when they had expressed specific wishes before losing the capacity. This is in keeping with the principle of informed consent.

For the patients who lack capacity some respondents said the decision should be made in the patient's best interest while others said they would base their decision on family's wishes. The question would be who should decide the patient's best interest. Those who said they would decide in the best interest of the patient mentioned that all parties concerned including the medical and social team, family and the patient should be consulted. It was however not made clear who ultimately decide what the best interest of the patient is. Within the Japanese medical and social cultures the family would be considered as the best judge of the patient's best interest. This may not be the case in the UK and this point is worth exploring in the further study.

Safety was mentioned frequently by the respondents. Two respondents said that the wishes of patient and family should be respected so long as the care can be provided safely. One respondent said the doctor's advice should be taken into account in the scenarios given if an acute intervention was required, otherwise the patient's wishes would be considered first. This respondent was probably also concerned about the patient safety. Patient safety seems to play a significant part in the UK MSWs decision making in the place of care.

For the paediatric patient, the MSWs view

was that his wishes and decisions should be respected so long as he was competent. In Japan, whether the patient is an adult or a child would probably impact hugely on the MSWs response to the situation. A larger study to explore and compare the views of the Japanese and the UK MSWs on young persons' care would also be interesting.

5. Conclusion

This pilot study showed that the MSWs respected the wishes of the patient first in deciding the place of care when they had the capacity to make decisions and when there had been an expression of wishes by them before they lost the capacity regardless of the age of the patient. Otherwise the family's wishes were respected, so long as it was considered to be in the best interest of the patient. Further research to compare the UK and Japanese MSWs may highlight the cultural differences and scope for education and development in this area of social work.

6. Authors' Contributions

All authors made an equal contribution. EK and SM produced the study protocol. EK and SM developed the questionnaire. EK, MB, and SM contributed to the manuscript. All authors read and approved the final manuscript.

References

Bomba, P.A., Morrissey, M.B., Leven, D.C. 2011 Key role of social work in effective communication and conflict resolution process: Medical Orders for Life-Sustaining Treatment (MOLST) Program in New York and shared medical decision making at the end of life.

Journal of Social Work in End-of-Life & Palliative Care, 7 (1) , 56-82. doi: 10.1080/15524256.2011.548047

Fried, T.R., Redding, C.A., Robbins, M.L., Paiva, A., O'Leary, J.R. et al. 2010 Stages of change for the component behaviors of advance care planning. Journal of American Geriatrics Society, 58 (12) , 2329-2336

Gillick, M.R. 2010 Reversing the code status of advance directives? The New England Journal of Medicine, 362 (13) , 1239-1240

Hope, T., Savulescu, J., Hendrick, J. 2008 Medical Ethics and Law: The Core Curriculum 2nd ed. Churchill Livingstone, UA: Elsevier.

Leflar, Robert B. 2002 The Japanese healthcare and the law, 131-134, Tokyo: Keiso-shobo. (Japanese)

Maeda, S. 2005 Informed Consent. Tokyo: Igaku-Shoin. (Japanese)

Mizuno, T. 2005 Informed Consent 2. In: Akabayashi, A. Eds., Medical Ethics: An introduction, 159-169, Tokyo: Keiso-Shobo. (Japanese)