

Quality of life for family caregivers is impacted by satisfaction with care

Cancer has an emotional and physical impact on caregivers as well as patients. If relatives are not happy with the care they are able to provide for the patient, this can impair their quality of life. Dr Miki Morishita-Kawahara at the Tokyo Women's Medical University aims to understand better the factors that influence the quality of life of family caregivers who look after relatives with digestive cancer. Once these factors are better understood, they can be used to inform best-practice approaches to improve quality of life for carers and patients alike.

In 2012, around 30% of total deaths in Japan were due to cancer, equating to approximately 360,000 deaths. Of these, just over half (55%) were due to digestive cancers, such as liver, colon or stomach cancer. Cancer has been a leading cause of death for more than 30 years.

However, cancer does not just affect the patient; it also impacts upon their friends, family and carers. In particular, family members are often responsible for providing care to their relative. The added responsibilities of caring for someone with digestive cancer can be challenging as caregivers not only have to manage their own lives but provide mental, physical, social and sometimes financial support to the patient. It is already known that these additional responsibilities can take a toll on caregivers, including sleep deprivation and an increased incidence of depression and other mental illnesses.

Care experience may also be influenced by the stage of cancer; those caring for someone with curative cancer will have a different experience than those caring for a family member with recurrent disease, cancer which returns after treatment, or metastasised disease, in which cancer has spread to other tissues of the body. Both latter forms of disease generally have a poor prognosis. Therefore, palliative care plays a vital role in ensuring optimum mental and physical well-being of the patient during disease progression.

Cancer has a significant impact on the quality of life (QOL) for both patients and their caregivers, and satisfaction with care is thought to be essential for the QOL of family caregivers. It is this that Dr Miki Morishita-Kawahara, at Tokyo Women's Medical University, aims to explore in her work on caregivers' QOL status, and factors associated with their QOL.

STUDY METHODS

The cross-sectional study involved 111 caregivers who provided care for a family member with recurrent or metastasised digestive cancer. These caregivers were recruited while the patients were seen in a hospital ward at a university hospital in Tokyo and were asked to complete a number of questionnaires. The participants were perceived by the patient or family to be their primary caregiver.

The dependent variable, caregivers' QOL, was measured using a validated questionnaire, the 'Short-Form 36'. The Short-Form 36 includes questions on both mental and physical health.

These questions can be combined to give an overall QOL score or be considered individually.

Independent variables, the factors that may influence the dependent variable, were also measured using validated questionnaires. The first set of questions covered topics relating to both caregiver and patient, such as demographic data, perceived health status of the caregiver and economical status.

In addition, Dr Morishita-Kawahara used a well-established method to assess satisfaction with care. The Care Evaluation Scale (CES) is frequently used to quantify to what extent the family think that palliative care provision needs to be improved. A further tool was used to determine the burden that providing care placed on the caregiver, for example in terms of time and financial costs.

SATISFACTION WITH CARE AND QOL

The ages of caregivers participating in the study ranged from 29-87 years, with 76% of participants being female. Dr Morishita-Kawahara found that there was a significant correlation between evaluation of care and satisfaction with care. On the other hand, she found some contents that were highly evaluated were not related to the satisfaction with care. For example, the correlation between satisfaction with family burden care and evaluation of family burden care was low (Correlation coefficient was 0.3).

There were several factors which contributed to the physical health

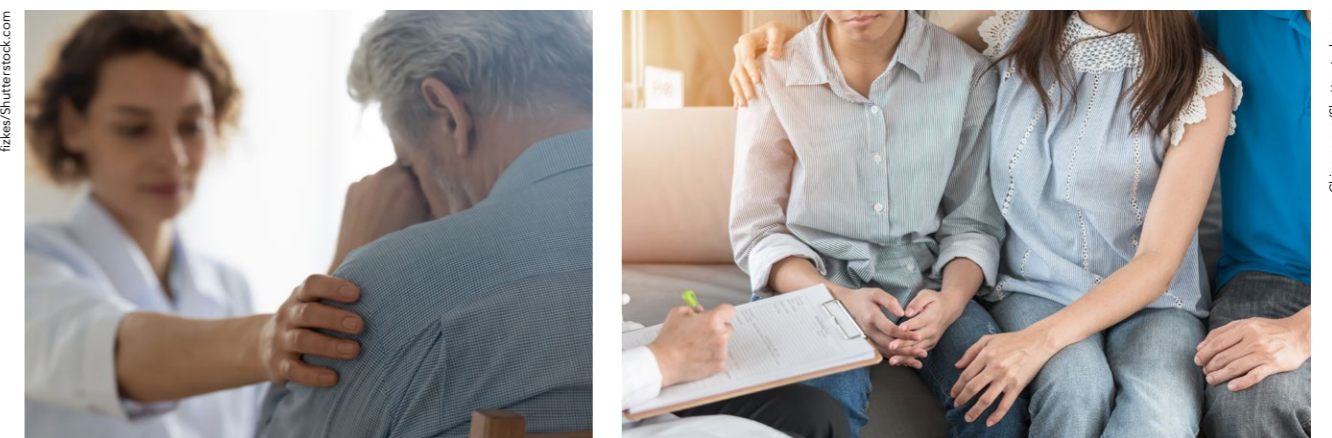


The satisfaction factor with care seems to be an important factor for the mental health of caregivers.

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of caregivers, including the carer and patient being younger, and the caregiver perceiving their own health as good. However, satisfaction with care was not related to physical health but seemed to be more important for the mental health of caregivers.

In contrast, satisfaction with care did impact on the mental health of the family caregiver. This was in addition to other factors, including the caregiver being older or having worse perceived health. This was also the case when the caregiver was not a spouse, the patient



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did not undergo surgical intervention or when the patient was being treated not only for their symptoms.

The researchers found that people who were caregivers for family members had lower QOL scores than the national average. Overall, family caregivers of patients with recurrent or metastasised digestive cancer requiring palliative care had lower QOL, both physically and mentally, than the national average. This relationship has also been seen in a South Korean study.

The results of Dr Morishita-Kawahara's study suggest that family caregivers of patients who have been admitted to hospital have an increased need for mental and physical support from the initial treatment stage through to the terminal stages of cancer.

The results suggest that measures to improve satisfaction with care (whether actual or perceived) may contribute to improved QOL and in turn, this may correlate with improved satisfaction with care. Obtaining quality care may be one way to improve satisfaction with care, as family caregivers want

their relative to be comfortable and to feel as though they are providing the best possible care for the patient. This subsequently provides relief for the caregiver: if they are satisfied with care, they are able to meet their wish to maximise QOL for their relative.

INFORMING CLINICAL PRACTICE
Ultimately, this study provides evidence that improving satisfaction with care

Satisfaction with care is thought to be important for the QOL of family caregivers.

may improve the mental health and well-being of family caregivers of palliative cancer patients.

While there has been some work done into the experiences of family caregivers, there are only a few that explore digestive cancers, as done by Dr Morishita-Kawahara. Furthermore, studies often focus on patient satisfaction with care, rather than the family member.

It is important to remember that other factors can influence QOL for caregivers, such as age, gender, relationship to patient, and economic

status. While the study found no relationship between physical health and burden of care or satisfaction with care, other studies have suggested that the mental burden can often manifest in physical health problems. Dr Morishita-Kawahara suggests that further work could be done in this area to more closely examine the impacts of caregiving on physical health.

Future studies are still needed to investigate whether the same correlations between satisfaction with care and

caregiver QOL are also seen with other types of cancers.

The information derived from these studies can be used to identify the most significant influences of caregiver QOL. Once identified, these data can inform future practice and help provide the most effective and appropriate support for family caregivers of patients with digestive cancers. For example, if it is known that help with decision-making increases satisfaction with care, and thus caregiver satisfaction, palliative support services should include measures to address and enforce this.



Behind the Research

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Research Objectives

Dr Morishita-Kawahara studies the quality of life of family caregivers that care for patients with digestive cancer.

Detail

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Bio

Miki Morishita-Kawahara received a PhD in Health Sciences from the University of Tokyo. She conducts research focusing on the well-being of family caregivers of cancer patients. She is selected as a member of the survivorship, patient, and bereaved family support group of the Japanese Association of Supportive Care in Cancer.

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Collaborators

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References

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Personal Response

What steps can be taken to help improve family caregiver satisfaction with care, and thus their quality of life?

“ The medical staff should communicate with patients and families sufficiently and understand the superficial reaction of patients and families and their thoughts that were not expressed verbally. For families, understanding and being able to weigh the advantages and disadvantages of patients' care and treatment are essential. I believe these steps, for both medical staff and family caregivers, will reduce the regret that bereaved families tend to have, improve their quality of life, and reduce the incidence of psychological distress among them. Further investigation is needed, such as pre- and post-death study, and I am currently working on it. ”

