How to understand the social problem in younger cancer patients

—Developing QODL as a visual assessment tool to patient’s social risks—

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Presentation Agenda

Ⅰ Motivation

Ⅱ Research problem
   1. Background
   2. The problems patients face

Ⅲ Method
   1. Fact Finding Interview
   2. Literature review
   3. Visual Assessment tool Development

Ⅳ Result

Ⅴ Discussion
I Motivation
Number of Patients with diseases in Japan

Rate per 100,000

- Malignant neoplasms
- Cerebrovascular diseases
- Heart diseases
- Pneumonia
- Tuberculosis
Number of cancer patients in Japan

Per 1000

Total patients

Inpatients

Outpatients

Graph showing the number of cancer patients in Japan over time, with separate lines for total patients, inpatients, and outpatients.
Increase of cancer patients and Reduction of medical costs

Increase of cancer patients at home care!

We have to remain live safely and independently in our community.

We need to find physical and mental as well as a social QOL.
The past

Hospital  ⇔  Home Care

The future

Home Care  ⇔  Community

A paradigm shift
II Research problem
Background

Demographic

- **Cancer**: a leading cause of death in Japan
  
  According to the vital statistics more than 300,000 people died due to cancers in 2009 in Japan.

- In Japan, more than 1.4 million people has been treated for cancer in one year.

- The number of new cancer patients in one year are estimated more than 500,000.
The most popular disease among age group from 15 to 64 is cancer.

National medical expenses in FY2008: 34 trillion yen.

Cancer that accounts for 12% of medical expenses. The cost of cancer treatment takes up the highest percentage in the whole medical expenditure.
II - 2 The problems faced by patients

The problems faced by patients

Cancer → Treatment → Treatment to be continued → Home Care → Hospital

Terminal phase

Clinical Support

The past
Trends in mortality in Japan

(1958y~2009y)

Rate per 100,000
Political Assistance

15y~64y
Medical insurance
Medical insurance for Elderly
Long-term care insurance
Pension insurance
Pediatric special insurance

65y~69y
70y~75y
75y

Retired
Pensioner

Child-rearing,
Subsistence
Worker,
Care of parent

<Feature of daily life>
Treatment to be continued

Hospital

Home Care

Terminal phase

Recovery

The future

Cancer

Treatment
Clinical Assistance

- The shortening of hospital stay period
- Encouraging home care

Political Assistance

Cancer patients of younger generation take a large social role.

BUT

political support is small.

Cancer patient of younger generation have
Risk of decreased QOL ⇒ QOL decline
Ⅲ Method
Results of interview survey

- Three categories were extracted

1️⃣ Livelihood
2️⃣ Relationship with family
3️⃣ Role in the society
What is QOL for Cancer patients of younger generation?

A lot of cancer patients of younger generation are receiving home care.

QOL is the spirit of independence in daily life ⇒ daily life

and

a risk factor of QOL decline

「Livelihood」「Relationship with family」「Roles in the society」
Ⅲ－2 Literature review in Japan

Results of Literature review

- QOL scale’s types used by physicians
  - Evaluation of treatment effect: 68%
  - Psychology: 16%
  - Pain control: 9%
  - Side effect: 5%
  - Other: 2%

Evaluation of treatment effect: 68%

Literature review in Japan
Evaluation of care 56%
- Factor survey 11%
- System evaluation 11%
- Depression research 11%

Other 11%

Drug assessment 57%
- Side effect 15%
- Evaluation of care 14%
- System evaluation 14%
Commonly used QOL scales

- European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ)
- MOS-Short from 36 (SF-36)
- Functional Assessment of Cancer Therapy scale (FACT)
- Performance Status (PS)
- QOL Questionnaire for Patients treated with Anticancer Drugs (QOL-ACD)

etc
These scales show us

<Treatment effect • Side effect • Psychological state>

But,

QOL factors of younger cancer patients are

「Livelihood」「Relationship with family」「Roles in the society」

And

we named the spirit of independency “Quality of Daily Life” [QODL]

So,

Cancer patients of younger generation have
Risk of QODL decline
Ⅲ — 3  Visual Assessment tool Development

- Concept of QODL

Level of RISK about the risk factors

Mismatch of

Subjective Perceptions (wants) and Objective Health Status (needs)

QODL: Good status of balance on Subjective Perceptions and Objective Health Status
How to evaluate?

Risk level: Mismatch of Subjective Perceptions and Objective Health Status

Evaluation by patients or patients’ families and evaluators

Patients or patients’ families: Subjective Perceptions

Evaluators: Objective Health Status

<For example: Livelihood>

<Evaluation index>

1. Have supporters
2. Know support systems
3. Know needs
4. Have consultants
IV Result
Risk assessment

Evaluation of QODL about livelihood

Objective Health Status

- All apply
- Three of four
- Two of the four
- One of the four

Subjective Perceptions

- Dissatisfaction
- Less satisfactory
- A little satisfactory
- Satisfactory

Risk

Ideal QODL

Actual QODL

positive

negative
Evaluation of QODL about livelihood

Objective Health Status

- Positive
- Negative

Subjective Perceptions

- Dissatisfaction
- Less satisfactory
- A little satisfactory
- Satisfactory

Risk

Ideal QODL

Actual QODL

One of the four
Two of the four
Three of four
All apply
Visualization of risk about three factors

Objective Health Status

positive

negative

All apply

Three of four

Two of the four

One of the four

Support ①

Support ②

Support ③

Dissatisfaction

a little satisfactory

less satisfactory

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Actual QODL

Subjective Perceptions

Objective Health Status

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Two of the four

Three of four

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V Discussion
We may be able to grasp the priority of support by Visualization of RISK

Patients and their families will be able to prevent new disease by early detection of RISK

We require experts of evaluation
WHO?

Certified Nurse Specialist about cancer nursing

They have professional knowledge and ability of assessment. They understand problems faced by patients at home care.

WHEN?

At discharge
Two weeks after discharge
When the disease becomes worse
When the patient wishes for support

HOW to use?

Use Visual Assessment tool each other And, evaluate RISK level
Trial

We have a plan to evaluate using the assessment tools by home care nurses for home care cancer patients in Kumamoto city.

Thank you for your attention.