

Improving cancer care through patient experience

A facilitated networks perspective

Cancer is currently regarded as one of the major illnesses worldwide. Advancements in new drugs, treatment, and technology improve the survival probabilities and life expectancies of people with many types of cancers. A report from the Institute of Medicine (2013) concludes that the rapid increase in the number of cancer survivors has produced a potential problem for cancer care delivery. Since many modern cancer treatments result in psychosocial and physical sequelae and side effects that must be taken care of beyond treatment completion, cancer should be reconceptualized and managed as a chronic disease (*Stanton et al.*, 2015). As a consequence, cancer care should be extended into long-term survivorship, in which more instructions from medical professionals and more interactions with other patients are needed.

This series of studies aims to propose a set of design guidelines for innovative healthcare services to improve the effectiveness and lower the costs of cancer care delivery, especially for head and neck cancer (HNC). To achieve this goal, the patients' unmet needs and pain points in the current cancer care continuum must be identified through deep learning from patient experience. In-depth interviews are conducted extensively with cancer patients and medical professionals. Through content analysis, the information-seeking behavior and information needs of cancer patients are clarified and categorized into three main

themes. Interview transcripts are further coded using grounded theory, and, with reference to self-determination theory, the psychosocial needs of cancer patients are revealed. Based on these findings, a causal model for behavioral and procedural structures behind pain points is proposed.

To refine and verify this model, a series of text mining approaches, including latent Dirichlet allocation (LDA), are applied to analyze thousands of posts and comments in a number of major online cancer patient groups. From the summarized patient journey map, the issues affecting patients' information and basic psychosocial needs are fully understood. The timely and appropriate information and psychosocial support during different stages of the cancer care continuum will help patients experience improved and balanced quality cancer care.

The research results of this series of three studies are briefly summarized as follows.

Information-seeking behavior and information needs of head and neck cancer patients

Oxana (2016) discovered that information-seeking behavior significantly differs among patients with HNC depending on their age, gender, educational attainment, and coping attitudes towards cancer. A linkage between information and anxiety is identified: some patients actively seek

various types of cancer-related information to ease their anxiety, while others avoid learning too much information due to anxiety. One of the major findings is that patients interviewed refer to online information as one of the main information sources, but the degree of trust is low. Instead, they have more faith in the experience of other patients and caregivers, particularly information learned through face-to-face interactions.

Regarding the information needs of patients with HNC, nutrition and rehabilitation are the two most emphasized categories. It is discovered that the timing and the channel through which such information is delivered are unrecognized and ill-designed in the current cancer care practice. Furthermore, this needed information is infrequently obtained in full and in a timely manner from the medical professionals, making the patients rely more on online communities and patient support groups.

The findings summarized above imply a good number of breakthrough points for cancer care service innovation.

Pain points, psychosocial needs, and self-determination theory

Yu (2017) applies grounded theory to further analyze the interview transcripts collected by Oxana (2016) and discusses the pain points of patients with HNC from the perspective psychoso-

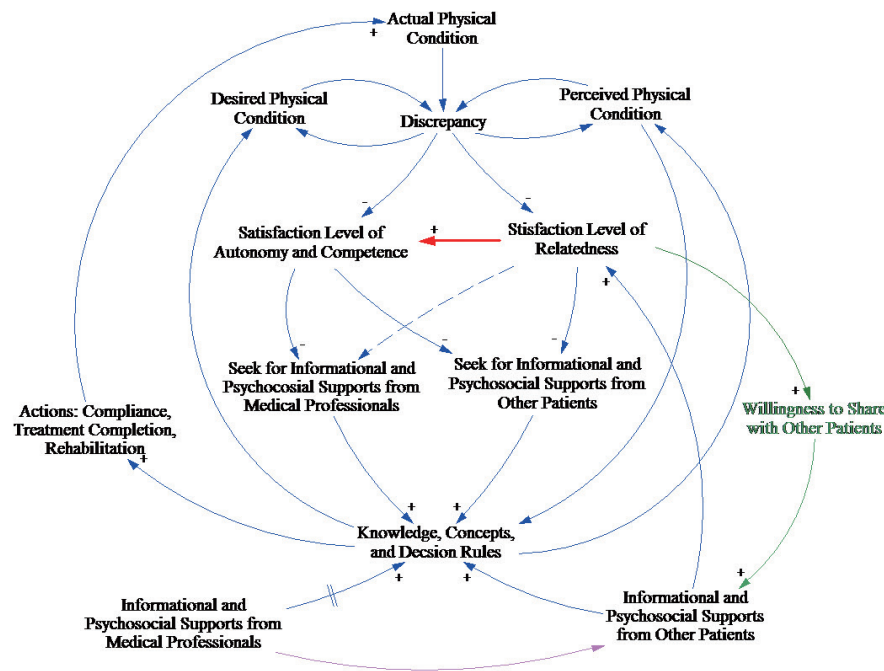


Figure 1. Behavioral and procedural structures behind pain points.

cial needs. After the coding and theory constructing processes, Yu discovered that the three basic psychosocial needs of autonomy, competency, and relatedness (ACR) in self-determination theory (SDT) provide a good reference construct to explain the observed patient behaviors. The causal structures driving the behaviors are thus developed from SDT, as shown in Figure 1.

The 'Actual', 'Desired', and 'Perceived Physical Conditions' on the top of the diagram jointly create the 'Discrepancy' that negatively impacts the level of ACR satisfaction. The lowered satisfaction levels urge patients to seek informational and psychosocial support from medical professionals and other patients. As the support from the former is usually delayed and insufficient, the decisions made and the subsequent actions taken by the patients mostly relied on the knowledge and concepts learned from other patients' experience.

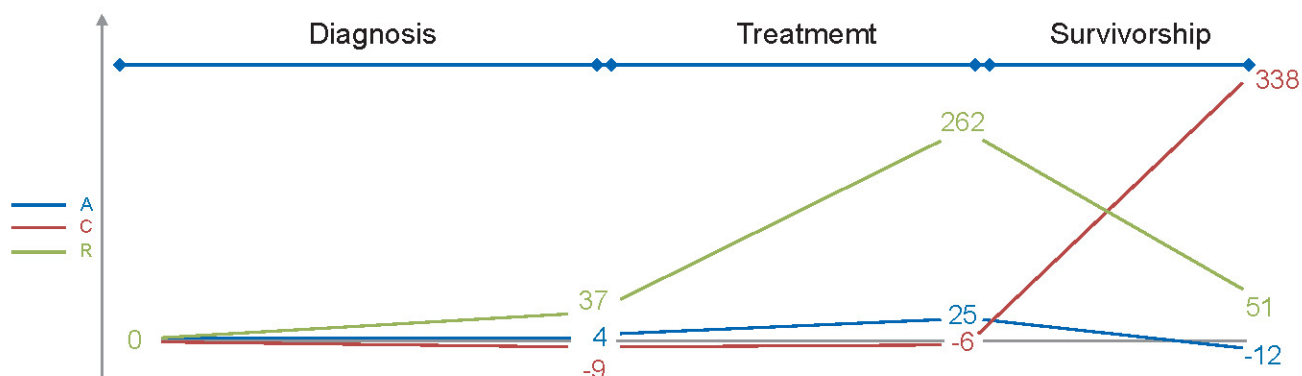
One of the insightful findings of this study is that improving the level of satisfaction with relatedness leads to an increased level of satisfaction concerning autonomy and competence, as illustrated by the red arrow in Figure 1. Detailed discussions on the model and the related findings can be found in Yu (2017).

The major design guidelines integrated from this study are illustrated in Table 1, which is dimensioned by cancer phases and types of patient needs. These design guidelines are now leading to some prototypes for cancer care service innovation.

Online patient social networks and text mining topic modeling analysis

To generalize the aforementioned results, Li (2018) integrates SDT with text mining techniques to analyze the posts and comments collected from a

Facebook-based cancer patient support group, "Cancer Information Web: Nasopharyngeal Carcinoma (NPC) Interactive Networks", a Traditional Chinese font-based group whose participants are mostly NPC patients and caregivers from Hong Kong and Taiwan. These unstructured and unlabeled textual data consist of 1,276 posts by 417 members and 11,746 comments by 845 members within 1,131 days and are categorized into three cancer care continuum phases using indicative words suggested by medical professionals. A set of ACR indicators is purposefully developed to evaluate the dynamics of patients' psychosocial needs throughout the three phases, and some significant changes are observed. The topic modeling technique in text mining, LDA, is then applied to identify the key topics and issues discussed among these NPC patients. The research results of this study are summarized in Figure 2.



Patient experience	Sub-healthy	First visit	Pathology exam	Exam report	Confirmation	Medical explanation from doctors	Treatment selection	Patient instruction before treatment	Early stage	During treatment	Side effects reduction	Final stage	Treatment complete	Treatment report	Follow up	Stabilized stage
Main issues and touch points	Symptom of illness	First contact with medical team	Exam procedures	Discrepancy between actual and perceived physical condition	Uncertainty and uncontrollability	Understand treatments to be administered and potential side effects	Pros and cons of different treatments	teeth exam and treatment	Feeling of discomfort and powerlessness	Onset of side effects Doubts about doctors and treatment selected	Effective ways to reduce side effects	Persistence	Lasting side effects and sequela	Discrepancy between actual and desired physical condition	Transfer prevention Nutrition Rehabilitation	Maintain cancer-free life style
Changes in ACR indicator	C↓	A↓	A↓↑ C↓	A↓ A↓	A↓ R↑	C↓ C↓	A↑	A↓	AC↓	C↓ R↑↑	C↑ R↑	A↑ C↑ R↑	A↑ C↓ R↓	A↓	A↓	C↑
Information needs	-	Early treatment often leads to better survivorship	Details of the exam procedures	Belief in the medical team Supports from family and friends	Experiences about this stage shared by other survived patients	Treatment efficacy and ways to reduce the potential side effects	Successful stories of different treatments	Chinese medicine Nutrition Expenses, especially items uninsured	Experiences about this stage shared by other survived patients	Food and drinks Alternative treatments Drugs or exercises	Belief in the medical team Supports from family and friends		Rehabilitation Timing and duration Probability to recover	Belief in the medical team Supports from family and friends	Rehabilitation instruction Patient group Successful stories	Share experiences Support other new patients
Direction for improvement	-	C↑	C↑	CR↑	C↑	C↑	A↑	AC↑	C↑	C↑	CR↑		CR↑	CR↑	CR↑	CR↑

Figure 2. Integrated NPC Patient Journey, showing changes in ACR indicators, main issues and touch points, information needs, and direction for improvement.

Conclusion and discussion

Zuboff and Maxmin (2002) propose that a system of “deep support” for cancer survivors over their life spans is urgently needed. This would be a system congruent with the “chronic care model” to meet the needs of a

highly activated and empowered patient base with the responsiveness of a prepared and patient-centered care environment. The trilogy presented here is an attempt to respond to this call from a management study. Academics in service design and operations management are po-

sitioned to reduce much of cancer patients’ avoidable pain and suffering and are well situated to contribute to the next generation of research and evidence-based practice to promote the health and well-being of the millions living beyond a cancer diagnosis.

Table 1. “How might we” questions as design guidelines

	Informational needs	Psychosocial needs	
		Autonomy & Competence	Relatedness
Diagnosis Phase	<ul style="list-style-type: none">• How to let patients and caregivers more completely understand the information delivered by the medical professionals?	<ul style="list-style-type: none">• How to let caregivers know what can be done to help their patients?	<ul style="list-style-type: none">• How to let patients and caregivers feel supported when they learn the bad news?
	<ul style="list-style-type: none">• How to help patients and caregivers start their double-loop learning as soon as possible?• How to do all these with the help of healthcare-facilitated networks?		
Treatment Phase	<ul style="list-style-type: none">• How to let patients and caregivers know clearly what to expect/do next?• How to proactively provide patients and caregivers with right information at the right time via appropriate/effective channels?	<ul style="list-style-type: none">• How to know the exact problems that patients and caregivers are facing by service contacts?	<ul style="list-style-type: none">• How to help patients learn from the experience of side effects from other patients?
	<ul style="list-style-type: none">• How to do all these with the help of healthcare-facilitated networks?		
Survivorship Phase	<ul style="list-style-type: none">• How to let patients and caregivers obtain clear and complete diet and nutrition information?	<ul style="list-style-type: none">• How to encourage patients to do rehabilitation exercises persistently?	<ul style="list-style-type: none">• How to facilitate the communication of thoughts and sharing of feelings between patients and caregivers?
	<ul style="list-style-type: none">• How to improve patients' compliance concerning rehabilitation exercise?	<ul style="list-style-type: none">• How to make patients and caregivers feel that their hard work is leading them to a better future by improving their satisfaction levels of autonomy, competence, and relatedness?	
	<ul style="list-style-type: none">• How to design some activities/services to incorporate the help from healthcare-facilitated networks?		

References

1. Institute of Medicine, Committee on Improving the Quality of Cancer Care: Addressing the Challenges of an Aging Population. (2013). *De-*

livering High Quality Cancer Care: Charting a New Course for a System in Crisis. The National Academies Press, Washington, DC.

2. Li, Y.-T. (2018). An Exploration on Cancer Patients Needs in Self-De-

termination Theory Perspective by LDA Topic Modeling Analysis. Master thesis. Department of Business Administration, National Taiwan University.

3. Oxana S. (2016). Investigation on Information Seeking Behavior and Information Needs of Head and Neck Cancer Patients. Master thesis. Department of Business Administration, National Taiwan University.

4. Stanton, A.L., Rowland, J.H., Ganz, P.A. (2015). Life after diagnosis and treatment of cancer in adulthood: contributions from psychoso-

cial oncology research. *American Psychologist*. 70(2), 159–174.

5. Yu, J.-Y. (2017) Improving Care with Learning through Patients Experiences: A Perspective of Facilitated Networks for Cancer, working paper.

6. Zuboff, S., Maxmin, J. (2002). *The support economy: Why corporations are failing individuals and the next*

episode of capitalism. New York, NY: Viking Penguin.

Jiun-Yu Yu

Assistant Professor, Department of Business Administration, College of Management

Smart Health Technology Research and Development Center

jyyu@ntu.edu.tw

Telehealth management program for patient care in NTUH

– A 10-year experience



The Telehealth Center of National Taiwan University Hospital was established in 2009 (Figure 1). Our center provides the fourth generation of a synchronized, integrated, remote management program for patients with multiple chronic diseases. The goal of our telehealth management program is to reduce the number of unplanned hospitalizations and improve overall health outcomes with the assistance of advanced monitoring and communication technologies. This telehealth management program provides the following services: (1) Re-

mote monitoring of biological data, including single-lead electrocardiography, blood pressure, heart rate, and pulse oximetry, which are transferred from the patients' homes to our center on a daily basis and on-demand; (2) comprehensive case management, for which purpose nurse case managers communicate with patients daily and on-demand by telephone to improve patient adherence to medication regimens and to provide personalized medical instruction; (3) continuous support from the medical team, which includes full-

time nurse case managers and cardiologists who are in charge of the telehealth management program 24 hours a day; and (4) integrated long-term care, with discussions conducted regarding long-term medications and management with the patients' primary-care physicians if acute conditions occur. Our telehealth program emphasizes the prevention and early detection of clinical deterioration as well as continuous, evidence-based medical care.