

Applying a Shared Decision Making Platform to Improve I-131 Patients Medical Care Quality

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Abstract—This paper provides post-operative thyroid cancer patients with assessment and health education about the radioactive iodine (I-131) treatment and proposes a platform where information technologies are applied to facilitate effective physician-patient communication to ensure optimal treatment for patients. A questionnaire survey was conducted in the Department of Nuclear Medicine of Chang Gung Memorial Hospital, Taiwan, from September 2017 to May 2018. Before implementation of Shared Decision Making (SDM), the 1 to 7 questions mean score was 1.3; after the implementation of SDM, the 1 to 7 questions mean score increased to 4.89. We conclude that applying SDM establishes a standardized and effective communication process for physicians and patients, and offers each patient a personalized and most appropriate treatment method.

Keywords—Shared Decision Making (SDM); patient safety; medical quality; nuclear medicine.

I. INTRODUCTION

Patient safety is the foundation of medical quality and also the common goal of care providers and patients. The Ministry of Health and Welfare's Taiwan Patient Safety Goals for Hospitals for 2018-2019 outlines eight goals. These goals are meant to build consensus on patient safety among medical institutions and serve as a guideline for Taiwan's medical institutions and personnel. The underlying purpose of these goals is to drive a simultaneous improvement of all institutions rather than to audit them. The eight goals are as follows: (1) Improve communication among health care personnel; (2) Reinforce management of patient safety events; (3) Improve surgical safety; (4) Prevent falls and reduce the degree of injuries in patients; (5) Improve medication safety; (6) Ensure effective control of infections; (7) Improve tubing safety; (8) Encourage patients and patient families to participate in patient safety tasks. As to the goal of encouraging patients and patient families to participate in patient safety tasks, the strategy has been modified from its 2017 predecessor as follows: provide multiple channels for participation in patient safety practices, increase awareness of patient safety, implement Shared Decision Making (SDM), and improve the care knowledge among primary caregivers in hospitalization and post-hospitalization settings [1][2]. The 2016 annual report of Taiwan Patient-safety Reporting System (TPR) provides an analysis of communication-related causes of safety events among 10,749 cases that occurred in 2016 [3]. The analysis shows that 41 out of 100 cases were related to “poor

communication between the care team and patients or patient families”, making this factor the primary cause. The second cause was “poor communication within the care team”, accounting for 29.8 cases per 100 cases. As shown in Figure 1, these statistics highlight the importance of communication.

The term “shared decision making” was first mentioned in a U.S. patient-centered care program in 1982 to promote mutual respect and communication between physicians and patients[4]. In 1997, Cathy Charles proposed an operational definition of SDM, suggesting that SDM is where at least two participants, namely physician and patient, are involved; the physician provides evidence of various treatment options available to the patient; both parties share and discuss information; an agreement is reached on the treatment to implement [5]-[7]. SDM is a patient-centered clinical process characterized by three elements, namely knowledge, communication, and respect. As shown in Figure 2, the objective of SDM is to allow clinicians and the patient to share evidence on treatment outcomes, consider the patient’s preferences and values, provide treatment options to the patient, involve both parties in the care process, create a consensus over the care decision, and support the patient’s choice of treatment based on personal preference. Evidence-Based Medicine (EBM) is an attempt to confirm the medical outcome of a treatment based on scientifically obtained evidence [8]. EBM is also defined as the conscientious, explicit, and judicious use of best available evidence in making decisions about the care of individual patients [9]. The underlying principles of EBM include: (1) the clinical decision should be made based on the most up-to-date and best available scientific evidence; (2) from which domain to seek scientific evidence depends on the clinical problem; (3) the best available evidence is determined based on epidemiology and biostatistics; (4) the conclusion derived from EBM needs to be implemented in the clinical decision (i.e., it should be able to influence the physician’s treatment of the patient); and (5) how it is implemented should be continuously evaluated [10].

In Section 2.1 Patient’s and Family’s Rights and Responsibilities of 2017 Hospital Accreditation Standards and Evaluation Criteria (for Medical Centers), Article 2.1.2 describes that it is necessary for hospitals to communicate with patients and explain the medical condition, suggested treatment, and therapy to the patients. Hospitals should also have a code of practice and require patients to sign a letter of consent when an invasive examination or treatment is needed. Developing characteristic and effective

communication and explanation methods suitable for patients with diverse needs is considered of great importance [11][12]. Article 2.1.3 indicates that hospitals should explain to hospitalized patients and their families about the necessity of hospitalization and the physician’s treatment plan, and also have measures to assist and encourage their engagement in the medical process and decision making. The requirements for compliance include providing adequate assistance to patients and allowing their families to access care information and participate in decision making. Developing policies and guidelines, promoting active participation in decision making among patients and patients’ families, and building consensuses between physicians and patients are indicators of high performance [13][14]. Article 2.8.15 indicates that all inspection and examination procedures shall be effectively and safely carried out. The requirement for compliance is that each inspection and examination shall be conducted following a standardized operating procedure that applies, and if necessary, before the inspection or examination is due to begin, hospitals should arrange for a patient assessment and explain to the patient or the patient’s family about the procedure [15].

Mayo Clinic is a healthcare system focused on integrated clinical practice, education and research [16]. The Mayo Clinic Shared Decision Making National Resource Center aims to advance patient-centered medical care by promoting shared decision making through the implementation and assessment of patient decision aids and share decision making techniques. The philosophy of the center is “the best

interest of the patient is the only interest to be considered”. Patients and physicians have different expertise when it comes to making consequential clinical decisions. While physicians know information about the disease and how to treat it, patients know information about their physical conditions, goals for life, and healthcare. Only collaboration in decision making ensures that the ideal of EBM can come true [17].

On Shared Decision Making platform, patients and their families are guided to express their concerns following a structured procedure. Through discussion, physicians and patients can minimize their cognitive gap. Meanwhile, attending physicians can also demonstrate to resident physicians and medical interns how to interact with patients based on a learning by doing approach. This allows resident physicians to learn from the most comprehensive and practical SDM. The rest of the paper is structured as follows. In Section 2, we present the SDM system analysis and design. In Section 3, we have the results and evaluation. Section 4 discusses the process improvement and limitations. We conclude the work in Section 5.

II. METHOD

A. SDM Resources Platform for Nuclear Medicine I-131 Treatment

In this study, we used the nuclear medicine I-131 treatment provided in Kaohsiung Chang Gung Memorial Hospital as an example. Based on EMB and SDM, we

Details on communication-related problems	Within care team					Between care team and patient			Between patient and family/other patients		Other factors	Number of communication-related events
	Insufficient communication	Ineffective handover tasks	Unclear order	Inconsistent interpretation of abbreviations	Hastily written words/unclear marks	Between care team and patient or patient’s family	Insufficient or improper health education	Insufficient information on the patient	Lack of communication between patient and family	Poor communication between patients		
Event type	N	N	N	N	N	N	N	N	N	N	N	N
Medication	744	282	57	13	6	237	58	83	--	--	57	1,204
Surgery	75	--	--	--	--	997	827	134	--	--	77	1,633
Blood transfusion	580	--	--	--	7	205	149	318	43	--	2	833
Medical care	107	--	--	--	--	5	2	1	--	--	5	111
Public accident	609	--	--	--	--	270	116	82	18	--	3	861
Public safety incident	26	--	--	--	--	27	7	4	--	--	3	63
Injurious behavior	82	--	--	--	--	662	406	80	--	--	45	1,081
Tubing incident	34	--	--	--	--	257	24	12	207	781	29	1,237
Sudden cardiac arrest	356	--	--	--	--	1,551	994	184	766	--	78	2,948
Anesthesia	10	8	--	--	--	39	4	13	--	--	1	65
Inspection and examination	21	2	1	--	--	3	4	4	--	--	0	28
Medication	561	--	--	--	--	152	15	53	--	--	2	685
Total	3,205	292	58	13	13	4,405	2,606	968	1,034	781	302	10,749

Figure 1. The 2016 report of the Taiwan Patient-safety Reporting System

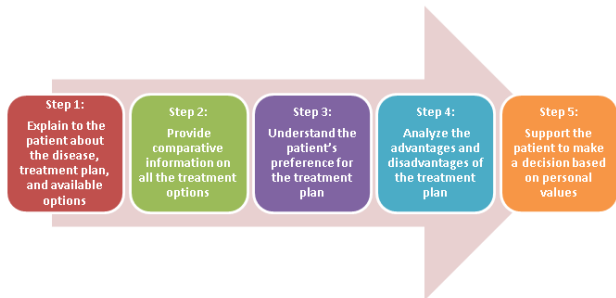


Figure 2. The steps for shared decision making proposed by National Health Service Source: Newsletter – June, 2016, Joint Commission of Taiwan

developed an SDM resources platform for nuclear medicine I-131 treatment. This platform consists of five components, including Patient Search System (PSS), Shared Decision Making System (SDMS), Health Education System (HES), Evidence-based Medicine Agent (EBMA), and Data Repository System (DRS). We input physician's explanations about thyroid cancer related diagnoses, goals and effects of the treatment, implementation methods, potential complications, and their occurrence rate and coping methods, success rate and risks from non-treatment, alternative treatments, post treatment reminders, and patients' basic data and health conditions that we had collected into the repository. With this database, the proposed system can directly display information related to the examination result as the physician explains the diagnosis to a patient. The system also takes into account the concerns and questions that patients are likely to have to assist them with making the best decision. The tools used for developing this system include JSP, JSP server Tomcat, MySQL database system, and ontology editor Protégé, all of which are freeware. The system structure is as illustrated in Figure 3. The decision tree is shown in Figure 4 [18]-[20].

B. EBM analysis of I-131 treatment

Figure 5 shows the characteristics according to the American Thyroid Association (ATA) and American Joint Committee on Cancer (AJCC) staging system that may impact post-operative I-131 decision making. The general suggested dose of I-131 is 30~150mCi. Administration of 30mCi I-131 is called a low-dose remnant ablation therapy, while administration of a dose greater than 30mCi is called a high-dose remnant ablation therapy. According to Atomic Energy Council, Executive Yuan, an oral dosage of I-131 greater than 30mCi should be administered only in a hospitalization setting [21][22].

In the current practice, when a patient is not at ATA low risk or not at ATA intermediate risk, but exhibits low risk characteristics or is classified as intermediate risk, the I-131 dose for the patient will be directly determined by the physician. In this study, we integrated patient's data, physical conditions and considerations, examination related information, and points to note in the system analysis to make the decision making mechanism more conscientious

and careful, facilitate consensus building over medical decisions, and support the patient to make a decision based on personal preferences. We continuously collected articles addressing the impact of pharmaceutical characteristics on I-131 treatment from various sources, including the hospital's electronic journal systems, the journals and magazines available in the hospital's library, out-of-hospital electronic journal systems, and out-of-hospital journals and magazines. We invited Director Shu-Hua Huang and Dr. Yen-Hsiang Chang of Department of Nuclear Medicine to analyze these articles based on their professional knowledge and expertise. Their analysis results were manually inserted into the database by the research assistant.

C. The principles for I-131 treatment

Because the accuracy and integrity of treatment principles affect the SDM result for the patient, the principles should be established by a domain experts. Thus, we invited Director Shu-Hua Huang and Dr. Yen-Hsiang Chang of Department of Nuclear Medicine to be the co-directors of this study, providing domain knowledge and assisting in analyzing the rules of keywords. For example, for patients who are at ATA low risk or who are at intermediate risk but exhibits low risk characteristics (e.g., metastasis of small-sized central lymph nodes, no residual disease or other abnormal characteristics visible to the naked eye), a low-dose I-131 remnant ablation therapy (approximately 30mCi) is more commonly accepted after they undergo a total thyro-

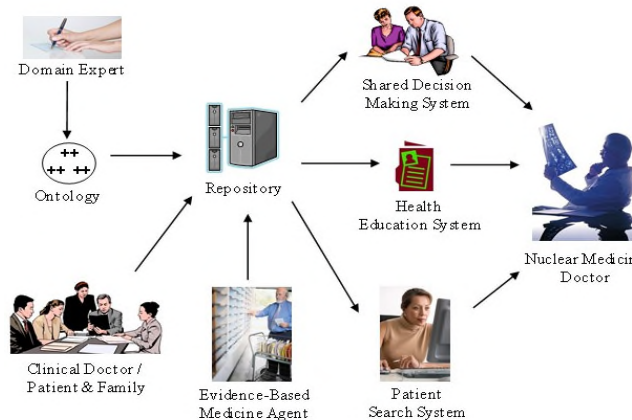


Figure 3. The system structure

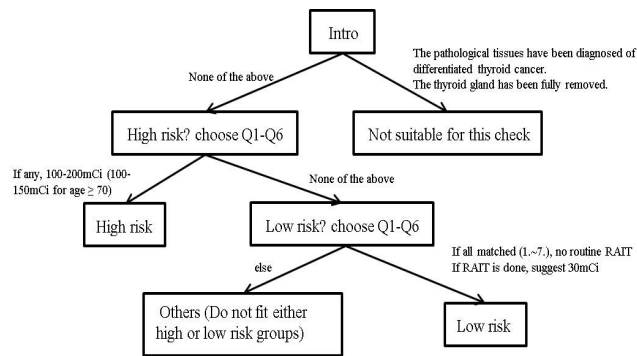


Figure 4. The decision tree

idectomy. Finally, based on the analysis results, we used the ontology editor Protégé to develop I-131 treatment principles, is shown in Figure 6.

III. EASE OF USE

This study was intended to use an information system to assist patients in understanding the examination items involved in the I-131 therapy. The proposed SDM resources platform for I-131 treatment provide a standardized and effective communication procedure for physicians and patients, allowing each patient to receive a personalized and appropriate type of treatment. Besides, through the standardized procedure of this system, attending physicians can also step-by-step guide their resident physicians through

interactions with their patients based on the concept of learning by doing. This allows resident physicians to learn from the most comprehensive and practical SDM. The original procedure was that the patient had completed thyroidectomy in the general surgery to the metabolic department to receive radioactive iodine 131 treatment. But in the outpatient clinic, if you encounter health education or hospitalization related questions, you need to answer the nuclear medicine department. After the implementation of SDM, it will be changed to SDM for the first time to complete the understanding of the iodine 131 treatment process, and then to the metabolic department; the patient does not need to go back and forth between two subjects. This is shown in Figure 7.

<i>ATA risk Staging (TNM)</i>	<i>Description</i>	<i>Body of evidence suggests RAI improves disease-specific survival?</i>	<i>Body of evidence suggests RAI improves disease-free survival?</i>	<i>Postsurgical RAI indicated?</i>
ATA low risk T1a N0,Nx M0,Mx	Tumor size ≤1 cm (uni-or multi-focal)	No	No	No
ATA low risk T1b,T2 N0, Nx M0,Mx	Tumor size >1-4 cm	No	Conflicting observational data	Not routine ^b —May be considered for patients with aggressive histology or vascular invasion (ATA intermediate risk).
ATA low to intermediate risk T3 N0,Nx M0,Mx	Tumor size >4 cm	Conflicting data	Conflicting observational data	Consider ^b —Need to consider presence of other adverse features. Advancing age may favor RAI use in some cases, but specific age and tumor size cutoffs subject to some uncertainty. ^a
ATA low to intermediate risk T3 N0,Nx M0,Mx	Microscopic ETE, any tumor size	No	Conflicting observational data	Consider ^b —Generally favored based on risk of recurrent disease. Smaller tumors with microscopic ETE may not require RAI.
ATA low to intermediate risk T1-3 N1a M0,Mx	Central compartment neck lymph node metastases	No, except possibly in subgroup of patients ≥45 years of age (NTCTCSG Stage III)	Conflicting observational data	Consider ^b —Generally favored, due to somewhat higher risk of persistent or recurrent disease, especially with increasing number of large (>2-3 cm) or clinically evident lymph nodes or presence of extranodal extension. Advancing age may also favor RAI use. ^a However, there is insufficient data to mandate RAI use in patients with few (<5) microscopic nodal metastases in central compartment in absence of other adverse features.
ATA low to intermediate risk T1-3 N1b M0,Mx	Lateral neck or mediastinal lymph node metastases	No, except possibly in subgroup of patients ≥45 years of age	Conflicting observational data	Consider ^b —Generally favored, due to higher risk of persistent or recurrent disease, especially with increasing number of macroscopic or clinically evident lymph nodes or presence of extranodal extension. Advancing age may also favor RAI use. ^a
ATA high risk T4 Any N Any M	Any size, gross ETE	Yes, observational data	Yes, observational data	Yes
ATA high risk M1 Any T Any N	Distant metastases	Yes, observational data	Yes, observational data	Yes

^aRecent data from the NTCTCSG (National Thyroid Cancer Treatment Cooperative Study Group) have suggested that a more appropriate prognostic age cutoff for their and other classification systems could be 55 years, rather than 45 years, particularly for women.
^bIn addition to standard clinicopathologic features, local factors such as the quality of preoperative and postoperative US evaluations, availability and quality of Tg measurements, experience of the operating surgeon, and clinical concerns of the local disease management team may also be considerations in postoperative RAI decision-making.

Figure 5. The characteristics that may impact post-operative I-131 decision-making
 Source: 2015 American Thyroid Association Management Guidelines

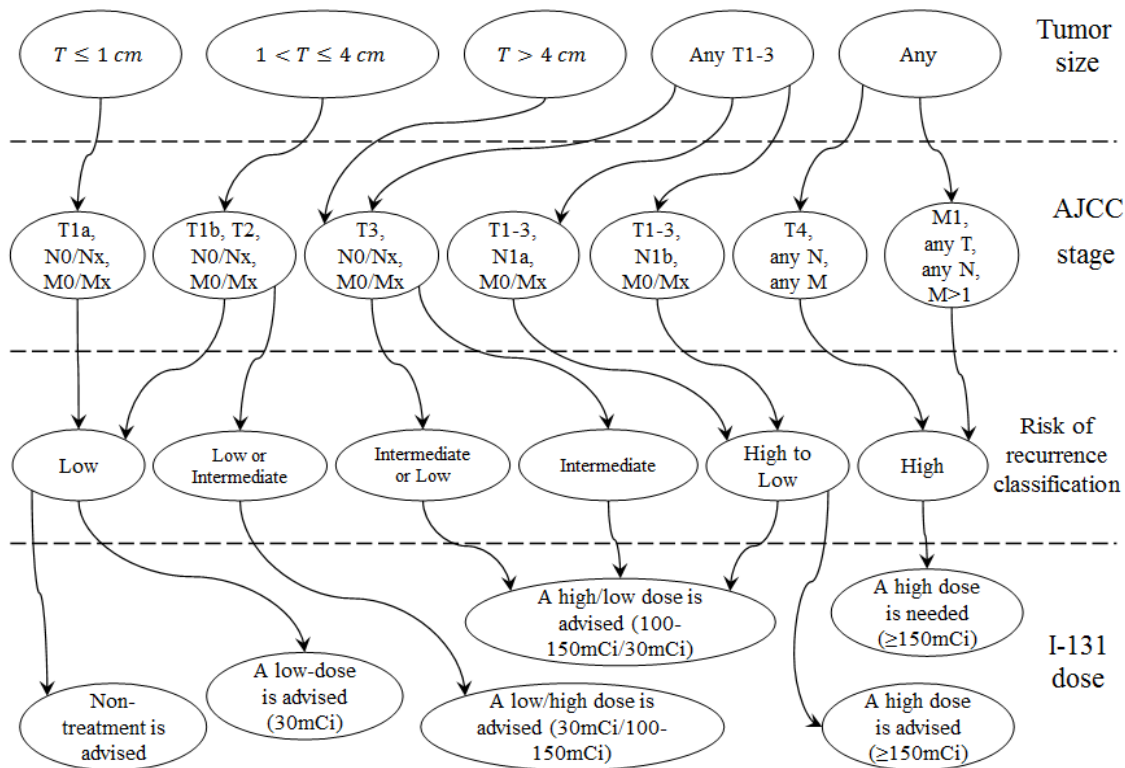


Figure 6. The principals for I-131 treatment

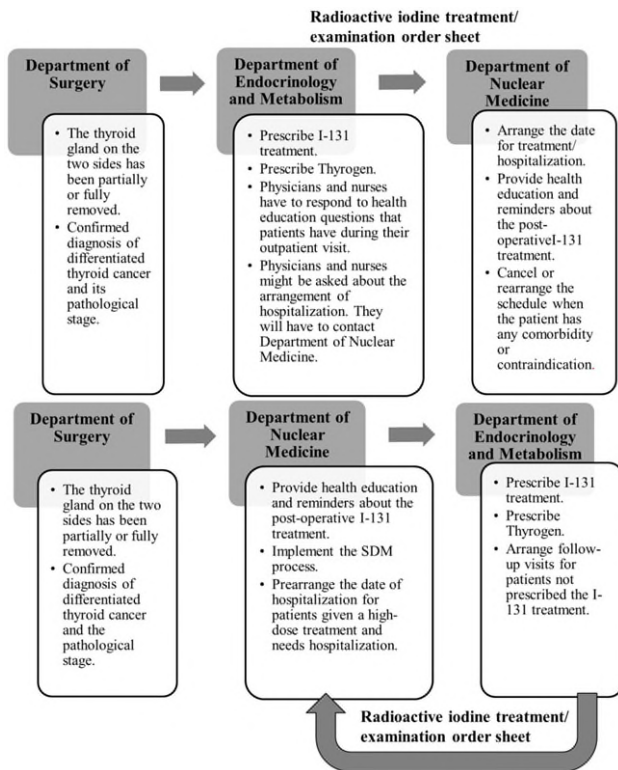


Figure 7. Analysis of the SDM procedure

A. Analysis of the SDM procedure

Since 2016, SDM has been listed by the Joint Commission of Taiwan (JCT) as one of the strategies for “encouraging patients and patient families to participate in patient safety tasks”. To comply with JCT’s policy, our hospital has also set SDM as a focus of our medical quality and patient safety activities for 2017. In collaboration with the Department of Endocrinology and Metabolism, our department analyzed the procedure for implementing SDM for thyroid cancer patients who are suggested to receive the I-131 treatment after a thyroidectomy. In the original procedure, patients would undergo the thyroidectomy in the Department of Surgery first and then be transferred to the Department of Endocrinology and Metabolism for the I-131 treatment. The physicians of the Department of Endocrinology and Metabolism would directly prescribe a low-dose or a high-dose I-131 treatment for the patients. Later, the patients would have to visit our department for an arrangement of the dates of hospitalization and treatment. However, the clinical efficiency in our department might be affected when our outpatients need health education or have questions about hospitalization. Besides, cancellation or rearrangement of hospitalization or treatment date due to comorbidity or contraindication is also common in our hospital. Changes of this kind would cause trouble to both patients and physicians. With the implementation of SDM, the procedure has been modified as follows: patients visit

our department first to understand the full procedure of the I-131 treatment, and then make a treatment decision that best suits their preferences and conditions through shared decision making. Afterwards, they visit the Department of Endocrinology and Metabolism for the prescription. This procedure can save patients time and the hassle of visiting two departments more than once.

B. Design of the SDM system

Patient privacy is highly respected in our department. Hence, patients are kept anonymous when using the system. Based on the design concepts for decision-making support tools introduced by Mayo Clinic Shared Decision Making National Resource Center, we adopted a streamlined and simple layout for our system interface. This system has been designed to provide messages in a clear and straightforward manner and guide patients through the questionnaire question by question, based on their post-operative status. This is shown in Figure 8. By applying the principles for I-131 treatment, the system would carry out a decision-tree analysis to infer the risk type (high, intermediate, and low) for treatment and non-treatment, overall mortality, the treatment’s potential side effects and impact on daily life, and alternative treatment options for each patient. As most patients who need the I-131 treatment are elderly people, we considered the relatively higher difficulty of text reading in elders in the design of our system interface. We adopted a colorful layout and larger fonts for text messages. Moreover, we also designed the system to visualize percentage data using pictogram charts, which pop up only when the mouse moves over them to keep the display simple and clear. If patients still have difficulty reading the text on the screen, they can click the “Show in a new window” button. The content will then be enlarged in a new window, as shown in Figure 9.

C. Integrated health education and consultation services

Health education is an indispensable step in the SDM process. Without appropriate health education aids or a pre-established health education process, patients may not have sufficient understanding of the side effects of the treatment, necessary care at home, and low-iodine diet. In the present, our department uses health education leaflets to provide health information to patients. Although the leaflets contain rich information, including an introduction to the I-131 treatment, indications, points to note, side effects, care at home, and low-iodine diet, physicians or nurses have to use highlights or add notes to remind patients of important information. After implementation of the SDM platform’s integrated health education and consultation services, physicians or nurses can simply rely on the standardized health education procedure and the hierarchically structured webpages to explain the instructional materials to patients page after page. As all the important messages are presented in larger fonts and different colors, patients gain sufficient understanding of the treatment after the health education

and are able to directly enter the SDM process, where they will have effective communications with their physicians and determine the treatment method that best suits them. The integrated health education and consultation services are as shown in Figure 10.

D. Effectiveness evaluation

During September 2017~May 2018, we conducted a questionnaire survey on the proposed SDM platform among post-operative patients who underwent the I-131 treatment.

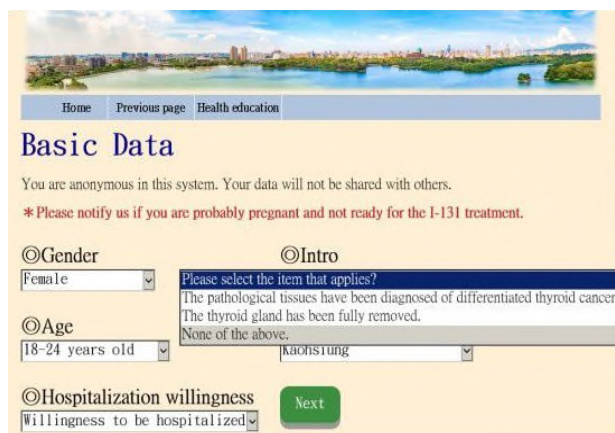


Figure 8. The anonymous user interface

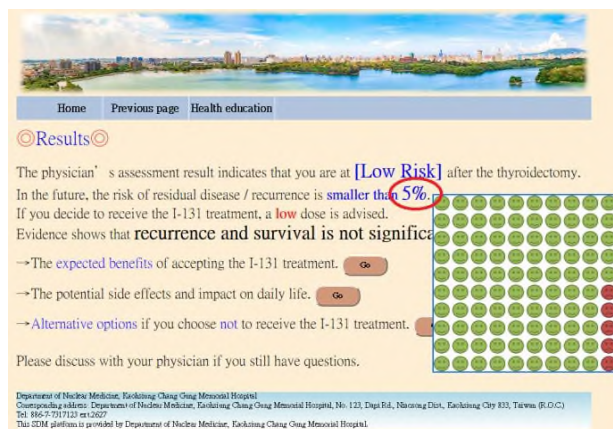


Figure 9. Using a pictogram chart to visualize percentage data

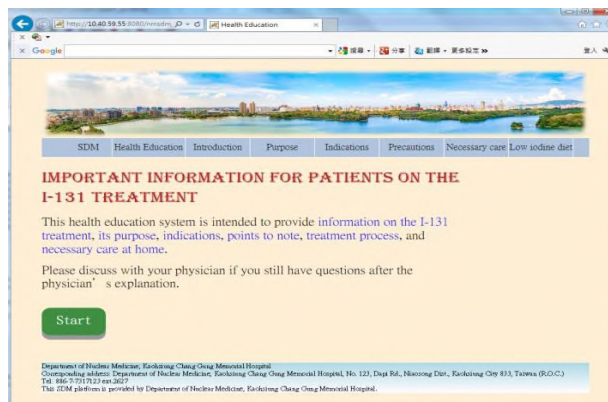


Figure 10. Integrated health education and consultation service

A total of 64 copies of the questionnaire were distributed, and 64 responses were returned (100% response rate). Participants were classified by whether they have used the SDM platform, and the questions were intended to measure patients' understanding of SDM on a Likert scale ranging from 1 to 5. The questionnaire of SDM for the I-131 treatment consisted of 8 questions. The analysis of the responses showed that the average score among non-SDM users was 1.3 and that among users reached as high as 4.89. The increased understanding of the treatment suggests that the proposed platform has helped reduce the extent of worry and fear about the I-131 treatment in patients. Because of better understanding, certain concerns would still reside in patients. Therefore, these concerns were excluded in the calculation of mean score. To assess patients' conditions after using the platform, we added two questions in the post-test questionnaire: satisfaction with the I-131 treatment decision and trust for the physician. The mean was 4.97, suggesting that SDM has helped improved physician-patient relationship. The survey results are shown in Figure 11.

IV. DISCUSSION

A. Implementing SDM to improve the I-131 treatment procedure

In recent years, JCT has been very active in promoting SDM. No matter in annual goals of hospital medical quality and patient safety or in hospital accreditation standards and evaluation criteria, SDM is considered an important strategy. According to Taiwan Patient-safety Reporting System, communication problems between care team and patients and patients' families have always constituted a high percentage. The main causes of these problems include: insufficient information is given to the patient during the diagnostic process; the physician has many patients to take care of but limited time for communication; there is a wide knowledge gap between the physician and the patient; and the use of medical terminologies has made it hard to understand the physician's explanation, resulting in misunderstanding and even dispute. The existing journal and

research articles on application of SDM have focused mainly on application of SDM in invasive examinations, treatments of high-risk diseases or paper work operation. Research integrating nuclear medicine radioactive examinations into a SDM platform is rare. In our survey, the mean scores for all the questions were higher in the post-test, confirming the effectiveness of the proposed SDM platform for patients and information systems to assist the less.

B. SDM implementation strategy

Under the department director's support, we implemented the proposed system as a research project. The engineers of the department worked in collaboration with the attending physicians. After several meetings, we finally submitted our project in March 2017 to Department of Medical Research for review. The project was approved in June 2017. For physicians, the time they have to spend on SDM is greater than the time they used to spend on health education, but the SDM platform has alleviated much of their effort. Besides, physicians' communication skills and attitude also affect the success of SDM. If given training on communication skills, physicians might be more able to lead Asian patients to express their opinions during SDM.

V. CONCLUSION

In this study, we used computer programming to develop a SDM platform that guides patients and their families to express their main concerns following a structured procedure and facilitates discussion between physicians and patients to reduce the cognitive gap between the two parties.

The proposed system conforms to the three elements advocated by JCT, namely knowledge, communication, and respect. Results confirmed that it can drastically improve the medical quality, patient safety, and satisfaction of thyroid cancer patients. Besides, the system provides a standardized communication procedure, allowing attending physicians to guide their resident physicians through interactions with patients based on the approach of learning by doing. Their resident physicians thus have an opportunity to learn from the most comprehensive and practical SDM procedure.

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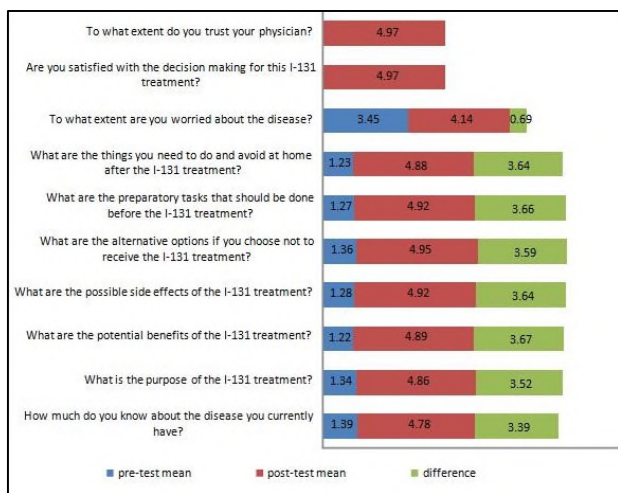


Figure 11. Patients' understanding of the I-131 treatment

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