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Development of Conceptual Framework from the View of Patients and Professionals on Patient Engagement: A Qualitative Study in Hong Kong SAR, China

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Abstract

Objective: To investigate patient engagement to gain understandings of professional and patient's views and inform the development of a patient engagement conceptual framework for further development of a valid and reliable evaluated measure. Method: 17 selected hospitals from Hong Kong East Cluster, Hong Kong West Cluster, Kowloon Central Cluster, Kowloon East Cluster and New Territory East Cluster of Hospital Authority Hong Kong involved in the study. Focus groups were conducted with 37 medical staffs, which included 15 doctors and 22 nurses, and 33 patients. Semi-structured qualitative interview study, with purposive sampling and constant comparative analysis. Results: Data were analyzed using a qualitative approach of latent content analysis. Patient engagement is a multi-dimensional concept. Five hierarchical themes separately from the patient and medical staff's perspectives containing different conceptions and attitudes related to patient engagement have been identified and summarized. Through analyzing both professional and patients' perspectives, a hierarchical framework incorporating patients-professional dynamically fluctuating relationship was built. The framework divides engagement into five levels and five stages. Conclusions: Patient engagement is recognized by more patients and professionals as a means and a cornerstone to build the foundation of patient-centered-care. Our framework encourages that patient engagement related to not only an individual patient's behavior but a reciprocal, dynamic and pluralistic relationship with their professionals and healthcare systems. Understand this relationship can help us better conceptualizing, evaluating, and implementing interventions to improve the population's health.

Keywords

Patient Engagement, Qualitative Study, The Framework

1. Introduction

Deal with the growing number of people lives with long-term conditions, multi-morbidity, and frailty that required a radical reform of current healthcare system [1]. Traditionally, neither patients nor the public has had the powerful voice to affect and shape the healthcare service they pay for or use [2]. As a result, the system could not deliver an effective and high-quality care for the consumers. Carman hinted that "We are in the midst of an important transformative shift related to patients' roles in healthcare" [3]. Fortunately, patient-engagement is increasingly become the newest salvo over the several past decades to move the healthcare system forward [4] [5] [6] [7].

Although there are a lot of previous studies confirmed that patient engagement could potentially lead to fewer adverse events, less use of diagnostic tests, and healthcare facilitates, shorter lengths of stay in hospitals, and better self-care management [8]-[15], the healthcare field has yet to coalesce around a specific definition of patient engagement. Angela Coulter's well-known definition refer to promote and support active patient and public involvement in health and healthcare and to strengthen their influence on healthcare decisions, at both the individual and collective levels [16]. However, what indicators could reflect the engaged level, and how to evaluate or improve patient engagement are yet concurred [5] [17]. Lack of gold standard to measure patient engagement, a multi-faceted conceptualization, has been verified in a lot of previous studies [4] [5] [18].

Measuring patient engagement is the essential step for improving patient's care experience and outcomes, the amount of valid and reliable instruments for greater evaluation of the engagement process, however, is scarce [3]. Carman implied that evaluating the progress of patient engagement requires the use of parsimonious and robust measures to assess what factors affect patient engagement; what dividends of engagement, and how to evaluate these effects [5]. At this stage, therefore, the basic building block should prepare the valid framework for designing robust measures and interventions.

Since 2010, Hong Kong Hospital Authority (HA) conducted a series of patient experience studies and provided a lot of important insights to healthcare professionals on their care to patients in the public health care system and identified areas for improvement. The results were encouraging that patient engagement is an important area for further investigation. Conducting patient engagement study would help the government to in-depth understand and identify factors and barriers which would further inform us the strategy/action for quality improvement. However, how professionals and patients view the various indicators

related to patient engagement is as yet unclear. In this article we propose a framework of patient engagement that presents the level of patient engagement can take, from search the information to partnership at different phases of health care from both patients and professionals' perspective.

2. Method

2.1. Sampling

The medical staffs working in 17 departments of medicine from five clusters of Hong Kong Hospital Authority (HA) were agreed and determined to participate in our study. Patients who were discharged from the department of medicine in selected hospitals during the study period and interested in sharing his/her views on patient engagement were approached for the study. A convenience sample of consenting patients and professionals meeting inclusion criteria was recruited over three months. The inclusion criteria for patient participants consisted of: 1) Hong Kong citizens, 2) aged 18 years old or above, 3) Cantonese-speaking, 4) had at least one overnight stay in one of the selected hospitals, 5) inpatient being discharged from HA hospitals within 48 hours to 1 month prior to the interview; and 6) able to give consent to participate the study. However, potential participants who were day cases and psychiatric and mentally handicapped patients were excluded from the study. The inclusion criteria for professionals included, 1) being a doctor or nurse working in the target hospitals, 2) understand Cantonese, and 3) able to provide informed written consent. Demographic data were collected for both medical staff and patient participants and displayed in Table 1 and Table 2.

2.2. Data Collection

A series of questions from the literature review and expert panel discussion were selected. A total of ten focus groups were held. Five with doctors and nurses working in the medical department and five focus groups with patients who were discharged from the medical department. Each group consisted of participants from the same HA geographical cluster in order to ensure coherent discussion. The whole process lasted for three months. All the focus groups were held in a private setting. A list of semi-structured guiding questions was devised by the research team based on their clinical knowledge and experience and a review of the literature. In the professional discussions, the participants were invited to express their perceptions of patient engagement, including their perceived concept, benefits, experience in routine practice, barriers, and suggested improvements on the issue. In the patient focus group, the participants were asked to express their perceptions of patient engagement, including perceived meaning, experienced benefits and barriers, and suggested strategies to improve patient engagement. All the focus groups were conducted by an experienced interviewer and discussed in Cantonese so that the participants could express their idea clearly in any areas related to patient engagement. Each group interview

Table 1. Characteristics of staff focus group participants.

	Doctor		Nurse	
	n	%	n	%
Gender				
Male	12	80.00	3	13.64
Female	3	20.00	19	86.36
Age				
25 - 35	3	20.00	1	4.55
35 - 45	10	66.67	11	50.00
>46	2	13.33	10	45.45
Educational attainment				
Bachelor	11	73.33	5	22.73
Master	2	13.33	17	77.27
PhD	2	13.33	0	0.00
Working experience(year)				
<10	4	26.67	2	9.09
11 - 20	7	46.67	12	54.55
21 - 30	2	13.33	6	27.27
31 - 40	1	6.67	1	4.55
>41	1	6.67	1	4.55
Department				
Hematology	1		1	
Rheumatology	1		0	
Renal	1		2	
Endocrinology	1		0	
Internal Medicine	1		0	
Endocrinology & Diabetes	1		0	
Respiratory	1		2	
Medicine	2		1	
Herpetology	1		0	
Gastroenterology & herpetology	1		1	
Respiratory Medicine	1		2	
Endocrine	1		0	
Other	1		3	
Neurology	1		1	
Stroke			1	
Cardiac			3	
Hospice Palliative Care	0		1	
Gerontology	0		1	
Geriatric	0		1	
Oncology	0		1	
General Rehabilitation	0		1	

Table 2. Characteristics of patient focus group participants.

	Patient		
Gender	n	%	
Male	17	51.52	
Female	16	48.48	
Age			
18 - 40	8	24.24	
41 - 60	12	36.36	
>61	13	39.39	
Educational attainment			
Primary or under	8	24.24	
Secondary	22	66.67	
College or above	3	9.09	
Working status			
Retired	10	30.30	
Full-time worker	11	33.33	
Part-time	7	21.21	
Unemployed	5	15.15	
Living status			
Live alone	4	12.12	
With family/others	29	87.88	
Chronic disease			
Yes	14	42.42	
No	8	24.24	

lasted approximately one to two hours. Field notes were recorded by two members of the research team during each focus group to capture contextual and non-verbal information. Interviews were audio recorded and transcribed verbatim using pseudonyms to protect participant anonymity (patients/professionals A-G). Data integrity between audio files and transcripts was assured through line-by-line verification by the transcriptionist as well as the members of the research team. Written consent and personal information were obtained at the beginning of each interview. All comments, however, were anonymous and personal details were removed from the transcripts.

2.3. Analysis

When finished all ten focus groups, data analysis began. All the data includes transcripts and field notes, were analyzed within principles of constant comparisons [19]. The data from professional and patients were separately analyzed. The analyzing process divided into three stages. The first is open coding. All the

information of interviews was deconstructing to identify primary domains and categories. These domains were used to compare with other findings from all the transcripts. We also compare them to the domains and categories we found from the previous literature review [20]. Then we combine and filter the existing domains and categories. The next stage is axial coding, which we mutually connect all the concepts and domains to summarize and derive new meanings and proposed concepts [21]. In turn, the last stage is assembling and reviewing all the concepts and generate our list of key themes (selective coding process). Data explanation and analysis procedure used iterative manner over several weeks among authors lead to consensus on key themes. Two members of our study team coded every single transcript and field note line-by-line independently according to our open coding approach. The other two meetings were held to ensure the robustness of proposed themes and continuously compared and discussed until consensus was reached by all the researchers [22]. Finally, the research team concluded all the themes and subthemes from both professional and patient focus groups.

2.4. Ethical Consideration

Ethical approvals were obtained from the Clinical Research Ethics Committees of the Hospital Authority Hong Kong.

3. Results

37 medical staffs (15 doctors and 22 nurses) and 33 patients were successfully interviewed. Following thematic analysis, a framework of five hierarchical themes containing different conceptions and attitudes emerged from the data, which produces a fulsome and holistic picture of the area of interest (Figure 1). All of these themes are explained below and illustrated using quoted passages from the interviews.

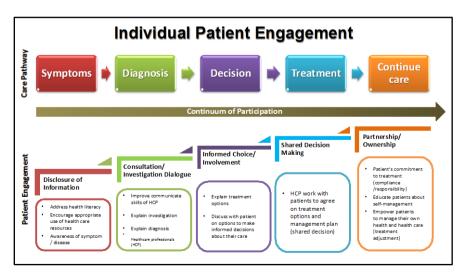


Figure 1. The conceptual framework of patient engagement.

3.1. Disclosure of Information

Providing information/obtaining information.

Patient engagement could be characterized by how much information flows between patient and provider [3]. Both professionals and patients offered their perspective on information flow should be optimally addressed over the patient engagement journey. While both participants identify achieving the objectives of information flow is important, professionals felt they should predominate this process to addressing engagement issues. Patients stressed the salient and necessity of information flow is critical to keep a healthy lifestyle in daily routines and activities.

Doctor G3G: Explain clearly the pros and cons of the processes and some invasive tests, how necessary are they. Sometimes we have to discuss with the patients, and make final decisions.

Doctor G3B: (patient engagement) also include telling them what happened, and they know what happened to them. And then they understand what they should do in the future that's best for their conditions.

Patient P1D: I found the price list of the drugs a bit different, as the drugs prescribed by public hospitals were usually cheaper... I think the doctor could have provided a list of drugs for you to choose from, and explained their effects, rather than giving you the drug directly...

Patient P4A: ...usually we know our own conditions, but if the doctors could discuss with you after the diagnosis, we could know more in daily life.

3.2. Consultation/Investigation Dialogue

Follow the order

While strictly or blindly follow doctor's order may violate patients' values and preferences. But critically and positively follow professional's order may lead to more trust and better outcomes of care incorporating the patient's values and preferences in the health service. It also enriched patients' experience and knowledge to understand their disease and reduce the risks and avoid unnecessary re-admissions.

Patient P1B: It means you (doctor) prescribe medications to the patient according to his conditions, the patient must take the drugs. Give them good drugs.... Then disease will be cured when the therapy is proper to follow...

Patient P2G: The doctors have professional knowledge, we must listen to what he said... The patient should follow the instructions of the professionals....

Patient P4D: Follow the doctor's order is a win for all.

3.3. Informed Choice/Involvement

Mutual communication

Communication is the foundation for effective engagement. This is an important theme for both professionals and patients. With regard to barriers specific to professionals, some doctors reported that they have limited communicated

skills in encouraging their patients to be more active. Likewise, patients also describe that lack of skill is a big confusion for effectively interacting with doctors. But in retrospect, they also identified professional's inactive attitude and willingness to communicate during the clinical encounter having a largely negative impact on their aspiration to engage.

Doctor G5C: For all that we've talked about, one of the great barriers is you don't know how to communicate...

Nurse G5F: Engagement is very simple. It means communication, really, just communication.

Nurse G2H: Skills are important, I mean communication skills. They only listen to you when they trusted in you.

Nurse G2A: ...if we're talking about engaging the patients, we'll do everything based on them, and they have to communicate (with us), to express their expectations and their views on what they want from the treatment plan.

Patient P5C: There should be good communication between doctors and patients. Don't give them too much pressure... If you give them too much pressure, they will have no confidence to perform the operation, and it will (mess up).

Patient P2E: Sometimes I would have many questions in mind, I'd ask, but sometimes you have to trust the doctors ...Actually I...I don't understand, but I don't know how to ask.

3.4. Shared Decision Making

1) Shared responsibility

Partly due to the complexity of patient conditions, professionals often lack the ability to ground the investment of time and resources for ensuring the quality of care. Extensive responsibilities and efforts from patients are required to improve health and well-being. Therefore, professionals are willing to share responsibilities to advocate for a better outcome. Patients must understand their health conditions and take great ownership of keeping a healthy lifestyle and report potential risks timely and accurately for both within and without the context of a specific care encounter.

Doctor G2E: ...if the patient can engage and does have some knowledge in it, he'd share some risk...or responsibilities...I mean if you really want to take the risk, we can work together to sort things out...Simply put, ... we don't need to bear all responsibilities.

Doctor G2C: ...this is part of the engagement, they (patients) have the responsibilities to help me to help them... I don't know what they think, but engagement means the patients have the responsibilities to make sure they will help us complete the treatment plans.

2) Shared decision making

Both professionals and patients believed sharing decision-making is essential for improving patient engagement. It seeks to focus on clinical consideration of the patient's needs and concerns instead of the doctor's. A majority of professionals addressed shared decision-making as the main locus of patient engagement. Shared decision-making can unburden professionals from the drudgery of assembly-line services and reduce the confusion and hesitation that makes medical care anything but patient-centered. Patients also recognized that no matter how active they are prepared in health care, their preferences and professionals' decisions are sometimes conflicting and intertwined, it needs healthcare system to delineate clear criteria and provide tailored information for permitting meaningful deliberation and shared an understanding to promote patient engagement.

Nurse G5D: I believe for Chinese, engagement is superficial, like ...whether to insert feeding tube or not...I mean the engagement we're talking about should be amount to decisions ...

Doctor G4E: ...there is a series of things for them (patient) to, sometimes decide, sometimes cooperate, so it can be rather broad in patient engagement.

Doctor G2D: ...if you choose not to control your diet, or you're going to smoke or not, they're all more or less a kind of choice. Up till now I can't think of a kind of engagement without decision making.

Patient P5C: Patients have the responsibility to make decisions!

Patient P2B: Patients should be informed about how the system works, participate in decision making, and ... interested in giving feedback to foster improvement.

3.5. Partnership/Ownership

1) Patient autonomy

Patient autonomy was identified as the heart of patient engagement. For professional's perspective, to reach the partnership, patients should play a more active role in understanding how the health care they want to receive, what healthcare services meet their needs, and how could receive an inner peace when they feel uncertainty. From patient's perspective, they want to be fully expressing their wants, values, and preferences in making decision when collaborate with professionals. However, to ensure patients have the autonomy, an effort needs to come from both professional and patient side.

Doctor G1A: I think the spirit should be patient autonomy. I guess as health professionals, we're always providing some information for them to exercise autonomy to decide whether they'd accept certain treatments or not.

Doctor G3B: ... Based on the patients' condition, I may pick two or three treatment plans for them ... After that the decision is in their hands... Of course, if in the end the patient says "how about you pick one for me?", then I'll just pick a reasonable one, but I still need his agreement, right? ...so finally it's still up to him.

Doctor G5C: Patients should be allowed to make autonomous decisions about their health care.

2) Have the choice

Patients believe they could do more during the self-care management. Professional's subjective judgments are not always corresponding to patient's needs. Make decision based on fully understanding patients' wants could contribute to stronger adherence and self-care. Most patients state that lack of opportunity to make choice let them feel hard to understand the efficacy of treatment or drug use. And another conundrum affect patients to make choice is lack of enough knowledge and skills, which make them feel less confidence to manage their health. Furthermore, some patients even indicate that have the choice is their right and should be respected by healthcare providers.

Patient G1D: Right, and I want to know where to find evidence to support choices.

Patient P2D: We've just mentioned choices and engagement... if the doctor said, "now you can choose to have a pill or swallow the tube, which will you prefer?" that's having choices, if he said so... as you want to know what happens to your body.

Patient P5C: Patients have the right to make choices!

4. Discussion

Hong Kong has a paternalistic healthcare system, while doctors providing knowledge and expertise, and the patients being fairly passive to receive in the diagnosis or treatment. This study is the first time in Hong Kong, provides an in-depth qualitative investigation and multi-perspective insight into understanding and addressing issues related to patient engagement in public health care system. While previous studies indicated the focus of patient engagement is the redefinition of the patient as a key player in the healthcare [23], we believe the redefinition of patient-doctor relationship is equally essential. A hierarchical framework covers five levels of engagement over five stages of disease management was envisioned from the findings of previous literature review and qualitative study.

Our findings suggested that patient engagement should be a process, which is reciprocal, dynamic and pluralistic, rather than an invariable status, among patients and doctors. We can observe a prominent focalization on the previous patient engagement context implies patients' cognition or behavior as a key factor in promoting treatment effectiveness, but the leeway and responsibility given to the patient for engaging can vary widely by doctors' interaction [18] [24]. We suppose the framework that presents the levels of patient engagement can be manifested from the simply improve health literacy to the final partnership with each other. Furthermore, given the fluctuation of psychological, physical and socioeconomic conditions, patients must show different attitudes or behaviors at the different time point of communicating with health care services. Therefore, our framework also suggests dividing the whole disease process into five-time points to consider the patient engagement separately. They are symptoms, diagnosis, decision, treatment, and continue care.

Patient engagement framework presents two main implications for policy making and intervention evaluation. The first is patient engagement is a changing process. It is a patient-professional relationship that keeps moving and developing. Both patients and professionals might show different intentions and motivations to involve in the decision making at different stages of treatment or disease management. Previous studies have mainly explained the patient engagement from their physical or psychological conditions on interacting with healthcare system [18]. Our framework, however, considers measuring patient engagement should not only considering and observing patients' willingness on participating in the healthcare services, but also whether professionals or the healthcare system effectively and sufficiently responsive to the patients' needs, priorities, and preferences. Therefore, our patient engagement framework developed on the understanding of a patient-professional engaged relationship. It does not matter who played the more active role in initiating a conversation or building partnership but focusing on whether an engaged relationship established or not. Without the efforts of both patients and professionals, no engagement could be reached. Likewise, our framework also hypothesizes that patient-professional engaged relationship is not always developing unidirectionally. It means engaged relationship could move forward to "partnership", but also could move back to "follow the order". It depends on the patients' physical and psychological conditions, the professional he or she contact with, and even the variations of local or regional health policies [6]. This guess has not been confirmed by any empirical study, but our framework provides an important principle that when designing an intervention to improve patient engagement, we need to provide a flexible plan that the interventions must both respect patients' preference and professionals' judgement whatever the final results of the intervention could build the partnership or not.

Another implication is patient engagement is changing at the different time point of disease management. With the epidemic of chronic diseases, there are two trends occurred, the first is people live with long-term conditions need to communicate with healthcare system more frequently, they need to make more decision about their health than ever before [25]. Secondly, nowadays, patients have more ways to capture the information and knowledge to know their health conditions, it means they have more experience to make the decisions about their health [26]. Therefore, our framework focus on dividing the evaluation of engagement into more detailed phases of health care, which including symptoms, diagnosis (self-diagnosis or clinical diagnosis), decision (pre-disease, after-disease), treatment, and even extend to continue care (in-hospital, out-of-hospital). Previous studies agreed that studying patient engagement in treatment is very important, but our framework believes people's willingness to engage in process of the health might be varied greatly. Our framework suggested a more detailed consideration and comparison of patients' engagement at the different time point of communicating with health care system. Moreover, engaging patients and professionals in continue care at home or at the hospital could also yield great benefits to create a balance between "demand" and "supply" of healthcare services. Our framework provides different, but adequate explanations, understandings to explain and assess the variations of patient engagement.

Several empirical previous studies underlined promoting the active role of the patient in health management is a pathway toward patient-centered care [5]. Coulter indicated that patient engagement can achieve the goals of better care quality, greater cost efficiency and improve the population health [17]. Berwick, et al. also demonstrated patient engagement can contribute to a more economical and sustainable system [4] [6] [15]. But a wide debate still exists on how to translate theories into frontline professional's real practice, how to evaluate engagement level to improve the healthcare outcome, and how to make the most available resources to support interventions? The previous tools, such as Patient Activation Measurement (PAM) that only focus on patients' behaviors or motivations, but without addressing the engagement status is a kind of patient-professional relationship [24]. Not only patients' willingness or doctor's or even other medical professional's attitude can change engagement level, but advancing technology, cultural diversity and social awareness also constitute the fundamental resources to affect patient engagement [5]. Our framework has oriented a revision of patients and professionals' attitude to health and wellness promotion. It offers to understand in designing instruments or interventions must give patients a proper role and take them on board for a high-quality process in the different phases of care delivery.

Our study is not without limitations. First, for patients' selection, we did not consider of their demographic and socioeconomic diversity, for medical staffs, all the participants only come from public hospitals, no private sector or general clinics included, which may limit the representatives of some findings. Second, several patients declined to participate due to lack of time. Some of them may have had different levels of engagement.

5. Conclusion

Our framework outlines that patient engagement is not only related to an individual patient's behavior, but a reciprocal, dynamic and pluralistic relationship connect patients, professionals and healthcare systems. Understand this relationship can help us better conceptualizing, evaluating, and implementing interventions to improve the population's health.

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