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Views and Experience on Patient Engagement in Healthcare Professionals and Patients—How Are They Different?

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Abstract

A patient-centered approach is used to build a therapeutic alliance between patients and the healthcare professionals in care process which should be supported by a good engagement of both parties. The study aimed to explore the gap between healthcare professionals and patients on patient engagement in hospital. It was a cross-sectional survey. 2774 doctors and nurses from Department of Medicine of public hospitals completed the self-administered questionnaire and 1042 patients discharged from corresponding wards completed the telephone interviews. Participants were interviewed using structural questionnaires. The Mann-Whitney test or Pearson's chi-square test was used to analyze the agreement between health-care professionals and patients on the views and experiences of patient engagement. A difference was considered to be statistically significant when the p-value was <0.05. Although both groups valued the importance of patient engagement, there was a discrepancy on understanding, views and experiences. More healthcare professionals particularly in nursing were concerned about the possible negative impact of the engagement. The majority of healthcare professionals reported that they engaged well with patients, and perceived more difficulties than patients did. The findings highlighted the mutual understanding of patient engagement, involvement and challenges encountered by both groups in Department of Medicine, which was crucial in efforts to provide meaningful patient engagement in regards to jurisdictions, health system, specialty, discipline and background of patients. It provided insight that a collaborative strategy involving both healthcare professional and patients might be an alternative approach to improving patient engagement.

Keywords

Patient Engagement, Patient Satisfaction, Patient Experience, Patient Centered Care

1. Introduction

Patient engagement in healthcare has been a concern of a series of societal movements and civil rights groups since the 1960s, including the Black/African American Civil Rights Movement for autonomy [1], the Women's Health Movement, with its a primary goal of improving health care for all women [2], the Physical Disabilities Movement, which demands equal treatment and access to health care for people with disabilities [3] [4], and the AIDS Movement, which promotes equitable access to treatment, care and prevention services and has launched anti-stigma and education campaigns [5]. The common concern shared by such movements is the importance of consumerism, and the need for a transition from patients as passive recipients of health care to their more active collaboration and taking control of their own health. A considerable amount of evidence has indicated the benefits of patient engagement for health outcomes, and the importance of improving resources and staff morale to enhance the sharing of decision-making, thereby decreasing decisional conflict, increasing adherence to treatment and lifestyle modification and building more trust [6] [7] [8]. In 1984, the World Health Organization highlighted the importance of patient engagement "to reinforce the values of solidarity, equity and human rights, while recognizing the rights of individuals to freedom of choice, participation and dignity" [9]. The Institute of Medicine has further emphasized the value of patient engagement whereby individuals have the opportunity to access appropriate medical information and clinical knowledge, enabling them to be the "source of control" in making health-care decisions [6]. Recent issues of the British Medical Journal and Health Affairs dedicated to patient engagement stressed "putting patients at the centre of health care" as a principle of care [10]-[15]. Although the benefits of engaging patients for both patients and the health system have been proven and are considered to be a cornerstone of patient-centered care, the concept of patient engagement has not been defined explicitly, and is often associated with terms such as "collaboration", "involvement", "participation", "partnership", "empowerment" and "shared decision-making" [16]. Engagement is a dynamic interpersonal process set in the context of humanistic values, in which there is mutual respect and a sharing of power [17].

Several studies have drawn attention to different components of patient engagement, but much of the research has focused on a single aspect, such as shared decision-making [18], different forms of communication [19] [20], the applications for self-management [21] [22], the use of virtual reality in rehabilitation [23] and patient education [24] [25] [26]. Furthermore, current evidence indicates that health-care staffs often have a poor understanding of their patients' perspec-

tives with respect to their involvement in decision-making [27], desire for information [28], beliefs in the effectiveness of treatment and prognosis [29], level of health literacy [30] and emotional state [31] [32]. Patient engagement formally emerged in the 2001 Institute of Medicine report "Crossing the Quality Chasm: A New Health System for the 21st Century", which called for reforms to achieve a "patient-centered" health-care system. The understanding and experiences of patient engagement have not been evaluated systematically in the past 20 years.

To address this oversight, we explored: 1) attitudes towards patient engagement; 2) the understanding of the components of patient engagement; 3) the experiences of patient engagement during care; 4) the difficulties of involvement in the suggested components of patient engagement during routine care; 5) the major challenges to incorporating patient engagement; and 6) suggested improvements to the actions of both health-care staff and patients to enhance patient engagement. These areas represent a critical gap in the current knowledge, particularly because an understanding of the challenges and difficulties of incorporating and fostering patient engagement in a broader context is important.

2. Methods

2.1. Study Design

A cross-sectional questionnaire survey of both healthcare professionals and patients from the Departments of Medicine of all 25 public hospitals under the Hong Kong Hospital Authority was conducted between May and August 2013. The contents of questionnaires for the staff and patient survey were developed based on the literature review as well as findings of focus group discussions with healthcare professionals and patients respectively. The Department of Medicine was chosen as the study setting because it contributes a major portion (30%) of the discharges from public hospitals, which cover about 90% of secondary and tertiary health-care services in Hong Kong provided by the Hong Kong Hospital Authority.

For the survey of healthcare professionals, all department heads of the 25 public hospitals were invited to approve the distribution of questionnaires to their staff, which totaled 6886 doctors and nurses, during the study period. A paper-based, self-administered, anonymous questionnaire was used to survey healthcare professionals, and comprised seven sections with 17 items on: 1) their attitude towards patient engagement; 2) their understanding of the components of patient engagement; 3) their experience of patient engagement during their care; 4) the difficulties of involvement in the suggested components of patient engagement during routine care; 5) the major challenges of incorporating patient engagement; 6) suggested improvements to actions to enhance patient engagement; and 7) demographics and personal details. The section on the components of patient engagement was derived from the literature and was divided into three main aspects: communication and information sharing; involvement in decision-making; and self-care and safety [33] [34] [35]. To ensure confidentiality and anonymity, healthcare professionals were requested to send the com-

pleted questionnaires with sealed envelope to the on-site collection box or mail to the research site.

For the telephone-based patient survey, the patients were interviewed using the same structured, anonymous questionnaire which was used in the healthcare professional survey. They were enrolled from a patient discharge list from the Departments of Medicine of the corresponding consenting public hospitals provided by the Hong Kong Hospital Authority between May and August 2013. The inclusion criteria for the patient population were: Hong Kong citizens with a Hong Kong Identity Card, aged 18 years or above, Cantonese-speaking, with at least one overnight stay in one of the 17 hospitals, inpatients discharged from one of 17 hospitals within 48 hours to 1 month before interview, and able to give consent to participate in the study. According to sample size calculation, a total of 1000 successful patient cases were targeted as minimum sample size with 3% margin of error at 95% confidence interval for the survey.

2.2. Statistical Analysis

Data management and analysis were performed using STATA version 10. Descriptive statistics were used to analyze the attitudes to and experience of patient engagement of both the health-care professionals and patients. The Mann-Whitney test or Pearson's chi-square test with linear-by-linear association was used to analyze the agreement between health-care staff and patients on each element of patient engagement, experience of patient engagement, difficulties and challenges, and suggested directions to enhance patient engagement during hospital care. For all of the analyses, a difference was considered as statistically significant when the p-value was <0.05.

2.3. Ethical Approval

This study was approved by Clinical Research Ethics Committees of the Hospital Authority. All participants were informed about their rights, and given information about the purpose of the study and details of the research procedures prior to interview. Participants were allowed to withdraw from the study at any point. For patients, initial screening for eligible patients was conducted and their consents to participate in the study were obtained by hospital staff. Implied consents from staff were adopted for the healthcare professional survey when they returned the filled questionnaire to us and informed verbal consent over phone from patients was further verified prior to the interview by research team. All data were kept confidential and anonymous.

3. Results

A total of 17 of the 25 public hospitals agreed to participate in the study; the 4531 doctors and nurses working at the Departments of Medicine of these hospitals represented 65.8% of all doctors and nurses (6886) in the 25 public hospitals with Departments of Medicine. Of the 4531 questionnaires distributed to the doctors and nurses, 2774 were completed, giving a response rate of 61.2%.

Nurses accounted for 62.3% (2351/3776) of the nursing population and doctors accounted for 54.3% (410/755) of the doctoral population. Nearly half of respondents (48%) had more than 10 years of working experience and half of the respondents worked in acute settings (51%) (Table 1). For the patient survey, a

Table 1. Demographics of healthcare and patient respondents.

Healthcare Respondents N(%) [n = 2774]		Patient Respondents N(%) [n = 1042]	
Profession		Gender	
Physician	410(14.8)	Male	579(55.6)
Nurse	2351(84.8)	Age	
Not willing to answer/Don't know	13(0.5)	Mean ± standard deviation	64.9(16.7)
Gender		Living in old-age home	
Male	620(22.4)	Yes	39(3.7)
Female	2122(76.5)	Education level	
Not willing to answer/Don't know	32(1.2)	No formal education or kindergarten	198(19.0)
Age		Primary	346(33.2)
18 - 29	737(26.6)	Secondary (F.1-F.5)	354(34.0)
30 - 39	968(34.9)	Matriculation (F.6-F.7)	24(2.3)
40 - 49	686(24.7)	Post-secondary	33(3.2)
50 - 59	311(11.2)	Tertiary or above	86(8.3)
60 and above	13(0.5)	Not willing to answer/Don't know	1(0.1)
Not willing to answer/Don't know	59(2.1)	Marital status	
Job Title		Single	118(11.3)
Doctor		Married	788(75.6)
Interns	9(2.2)	Divorced/Separated	26(2.5)
Resident	129(31.5)	Widow	106(10.2)
Specialist	63(15.4)	Not willing to answer/Don't know	4(0.4)
Senior Medical Officer/Assistant Consultant	135(32.9)	Working status	
Consultant/Chief of Service	68(16.6)	Retired	629(60.4)
Not willing to answer/Don't know	6(1.5)	Unemployed	47(4.5)
Nurse		Full-time student	11(1.1)
Enrolled Nurse	363(15.4)	Home-maker	90(8.6)
Registered Nurse (had < 5 years experiences)	595(25.3)	Full-time worker/Part-time worker	261(25.0)
Registered Nurse (had ≥ 5 years experiences)	896(38.1)	Not willing to answer/Don't know	4(0.4)
Advanced Practice Nurse/Nursing Officer	329(14.0)	Receiving any government allowance[a]	
Ward Manager/Department Operations Manager	113(4.8)	Yes	546(52.4)
Not willing to answer/Don't know	55(2.3)	Self-perceived general health condition in past 4 weeks	
Working experience in profession		Very good	13(1.3)
Less than 1 year	75(2.7)	Good	183(17.6)
1 - 10 years	891(32.1)	Fair	646(62.0)
11 - 20 years	894(32.2)	Poor	177(17.0)
21 - 30 years	344(12.4)	Very Poor	23(2.2)
More than 30 years	89(3.2)	Having any longstanding condition[b]	
Not willing to answer/Don't know	481(17.3)	Yes	712(68.3)

[a]Types of the government allowance included 1) Comprehensive Social Security Assistant, 2) disability allowance and 3) old-age allowance. [b]Types of long-standing conditions included 1) deafness or server hearing impairment, 2) blindness or partially sighted, 3) a long-standing physical condition; 4) a learning disability; 5) a mental health condition, or 6) a long-standing illness such as heart disease, hypertension, diabetes or cancer etc.

total of 1042 of the 2192 patients approached completed the interview, giving a response rate of 64%. All of the interviews were carried out within 2 weeks of the eligible patients being discharged from the hospitals of Hong Kong Hospital Authority. The majority of the respondents were male (56%), had a primary level of education or below (52%), were married (76%), were retired (60%), received a government allowance (52%) and had a chronic disease (68%); their mean age was 65 years. Compared with the discharge population from medicine, it was similar except there were significantly higher proportion of male among the respondents (52%) and significantly younger (mean age of 69 years). The demographics of the health-care and patient respondents are shown in Table 1.

3.1. Attitudes toward Patient Engagement

Figure 1 shows that both the healthcare professionals and patients agreed that patient engagement was important (95% of healthcare professionals versus 98% of patients) and a benefit to healthcare (92% of healthcare professionals versus 98% of patients). However, a significantly lower proportion of patients (65%) than healthcare professionals (90%) agreed that patient engagement was necessary ($P < 0.001$). A significantly higher proportion of healthcare professionals (40%) than patients (7%) were concerned about the possible negative impact of patient engagement on health care ($P < 0.001$) and more nurses (43%) than doctors (19%) were concerned with this problem ($P < 0.001$).

3.2. Understanding the Elements of Patient Engagement

Among the 12 stated elements of patient engagement in three main aspects in Figure 2, significant discrepancies were found between the patients' understanding and the healthcare professionals' perception of the operation of patient engagement: Communication and Information Sharing: "sharing information on

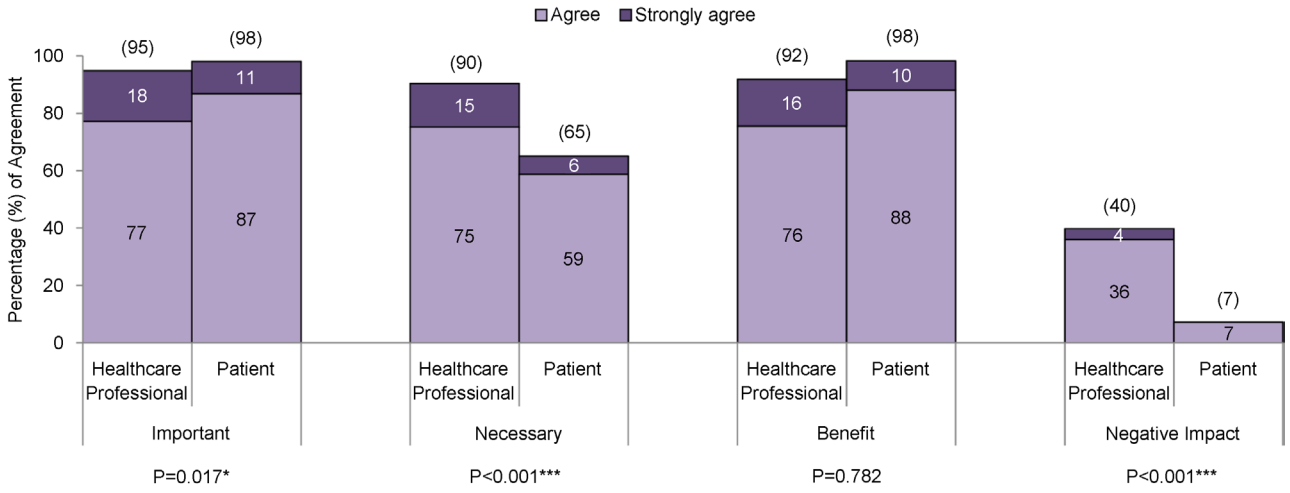

Figure 1. Agreement on importance and benefit of incorporation patient engagement into routine practice. (Mann-Whitney test was performed and a difference was considered to be statistically if P-value was < 0.05. *P-value < 0.05; **P-value < 0.01; ***P-value < 0.001, which means the difference is significant at the 0.05, 0.01 and 0.001 level. Important: It is important to incorporate patient engagement. Necessary: It is necessary to incorporate patient engagement. Benefit: Incorporating patient engagement will benefit health care. Negative Impact: Incorporating patient engagement will cause negative impact on health care.)

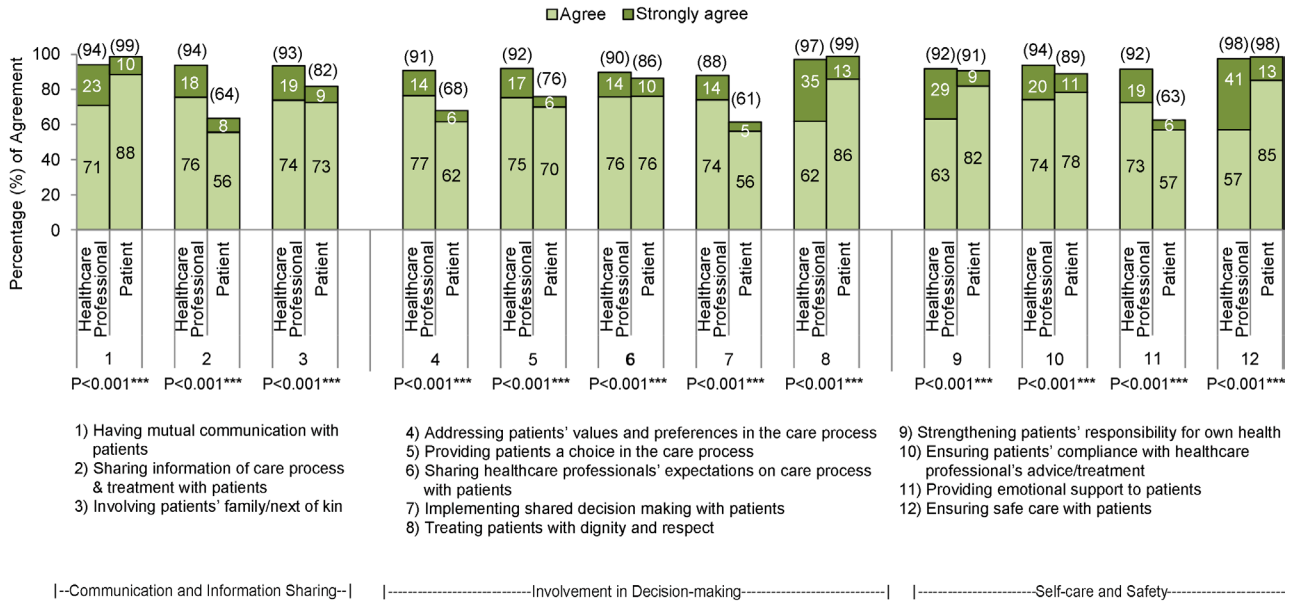

Figure 2. Agreement on 12 stated elements of patient engagement. (Chi-square tests were performed and a difference was considered to be statistically if p-value was < 0.05. *P-value < 0.05; **P-value < 0.01; ***P-value < 0.001, which means the correlation is significant at the 0.05, 0.01 and 0.001 level.)

the care process and treatment" (P < 0.001); Involvement in Decision-making: "addressing the patients' values and preferences in the care process" (P < 0.001) and "implementing shared decision-making" (P < 0.001); and Self-care and Safety: "providing emotional support" (P < 0.001).

3.3. Experience of Patient Engagement

The healthcare professionals consistently perceived that they engaged patients (sometimes/always/often) in the 12 stated elements of patient engagement in Figure 3; however, the patients perceived being engaged to a significantly lower degree than that stated by the health-care staff (P < 0.001) in *Communication and Information Sharing*: "sharing information on the care process and treatment with patients" (98% of healthcare professionals versus 68% of patients); *Involvement in Decision-making*: "addressing the patients' values and preferences in the care process" (95% of healthcare professionals versus 65% of patients), "providing patients with a choice in the care process" (96% of healthcare professionals versus 64% of patients) and "implementing shared decision-making with patients" (94% of healthcare professionals versus 49% of patients); and *Self-care and Safety*: "providing emotional support to patients" (97% of healthcare professionals versus 60% of patients). In addition, a large discrepancy was found in the degree of involvement. More than half of the healthcare professionals stated that they either "often" or "always" engaged patients in "involving patients' family/next of kin" (69%) and "sharing health-care professionals' expectations of the care process" (52%); however, the opposite was reported by patients, less than half of whom felt that they were "often" or "always" engaged (29% and 31%, respectively).

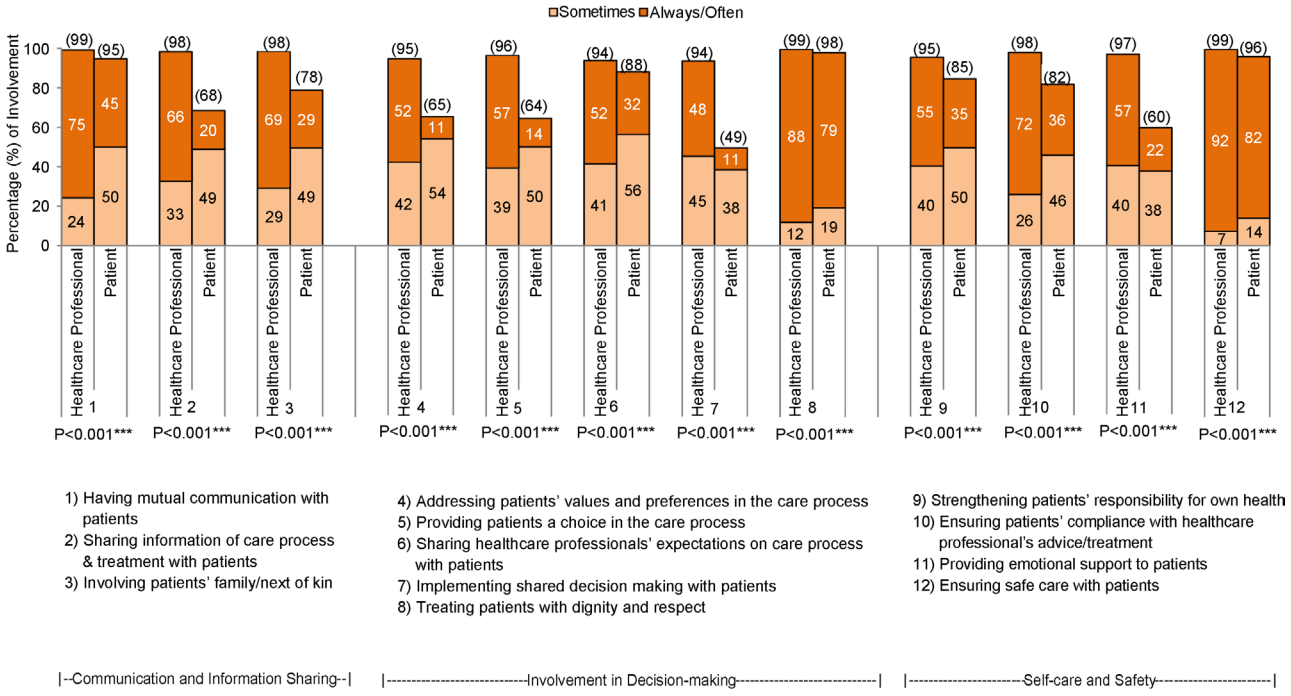

Figure 3. Perceived involvements of 12 stated elements of patient engagement. (Mann-Whitney test was performed and a difference was considered to be statistically if P-value was < 0.05. *P-value < 0.05; **P-value < 0.01; ***P-value < 0.001, which means the correlation is significant at the 0.05, 0.01 and 0.001 level.)

3.4. Difficulties of Involvement in the Suggested Elements of Patient Engagement

In general, significantly more healthcare professionals than patients perceived difficulties with patient engagement, as shown in Figure 4 (P < 0.001). The eight components identified by the majority of healthcare staff were "involving patients' family/next of kin" (62%), "addressing the patients' values and preferences in the care process" (59%), "providing patients with a choice in the care process" (53%), "sharing health-care professionals' expectations of the care process with patients" (53%), "implementing shared decision-making with patients" (60%), "strengthening patients' responsibility for their own health" (69%), "ensuring patients' compliance with healthcare professional's advice/treatment" (66%) and "providing emotional support to patients" (59%).

3.5. Major Challenges in Incorporating Patient Engagement

Heavy workloads, time constraints and patients with cognitive difficulties were expressed as the major challenges by both healthcare professionals (67% and 37%, respectively) and patients (65% and 25%, respectively). The healthcare professionals further highlighted the patients' attitude (47%), the gap between the expectations of patients and healthcare staff (26%) and patients with poor family support (23%) as challenges, whereas the patients expressed their poor health condition (30%), the physical setting of the hospital environment (25%) and not knowing when or how to discuss with/ask questions of health-care staff (23%) as barriers to engaging in the care process.

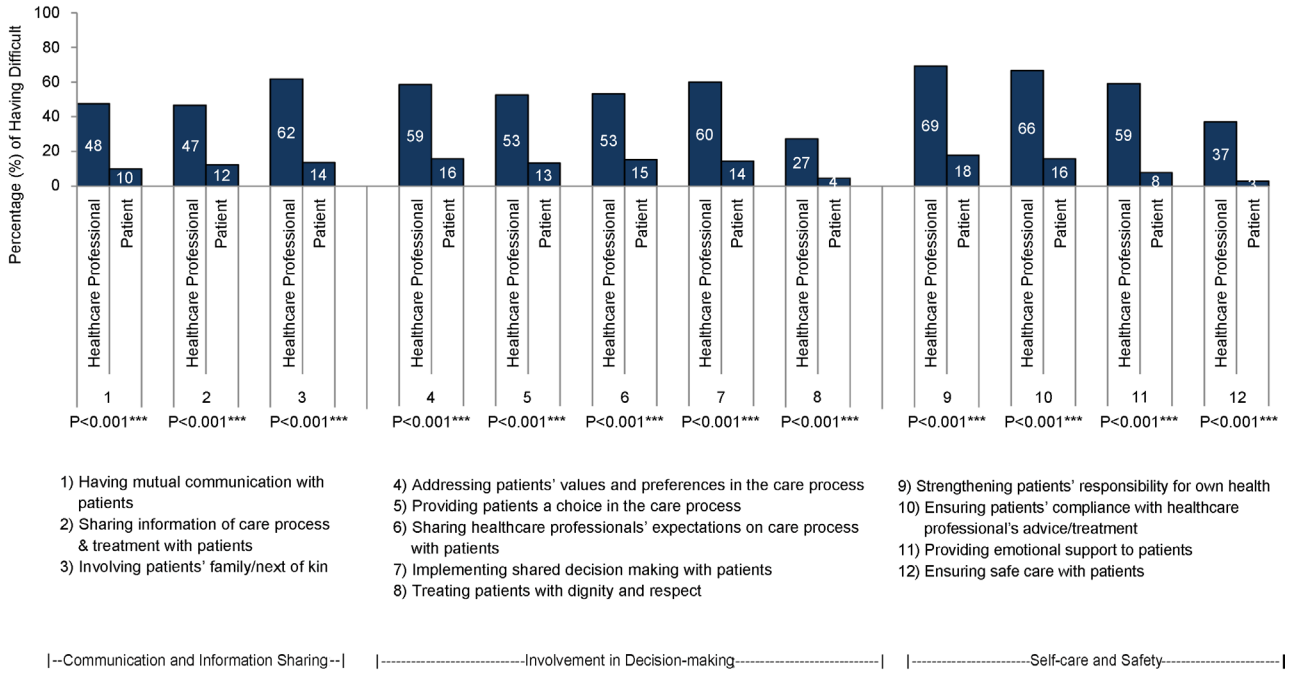

Figure 4. Perceived having difficulties of involvement in 12 stated elements of patient engagement. (Chi-square test was performed and a difference was considered to be statistically if P-value was < 0.05. *P-value < 0.05; **P-value < 0.01; ***P-value < 0.001, which means the correlation is significant at the 0.05, 0.01 and 0.001 level.)

3.6. Suggested Improvements to Actions to Enhance Patient Engagement

To enhance patient engagement, both healthcare professionals and patients suggested reducing the workload of healthcare staff (95% and 78%, respectively) as an important measure and the need to improve communication skills between staff and patients (97% and 52%, respectively) and change the style in term of atmosphere and physical setting of hospital of management to foster patient engagement (93% and 49%, respectively). In addition, patients highlighted improving patients' health literacy (50%) and their communication skills with health-care staff (47%), whereas healthcare staff emphasized improving ways to disseminate to and discuss information with patients (94%) and encouraging patient participation in self-care (94%).

4. Discussion

This is a first study to explore and compare the understanding and experience of patient engagement in both healthcare professionals and patients. It therefore provides comprehensive information on the views and experiences of patient engagement from both of them in Hong Kong. The findings show that both the healthcare professionals, particularly in nursing and patient participants were aware of the importance and benefits of patient engagement. However, the healthcare professionals were concerned about the negative impact of patient engagement, which might possibly relate to their fear of the impact of patient engagement on the workload of healthcare staff, time commitments and costs [36]. Patient engagement is important in service planning and delivery to

achieve good health outcomes and positive illness experience, and focuses on the humanitarian aspects of care, such as being treated with dignity [13]. The concern might reflect the misalignment between the healthcare professionals' knowledge and skills and the advances of movements advocating patients' rights. Nurses play a pivotal role in all phases of patient care; surprisingly, the concern about the negative impact of patient engagement was expressed by more nurses than doctors, and may be an invisible barrier to the collaborative approach to the development of a care plan and a hindrance to patient-provider communication and emotional disclosure. The patients believed that patient engagement was important and beneficial but not completely necessary. This counterintuitive finding implies that the patients' self-abasement or inability to express themselves given the unbalanced power relations with health-care staff and low health literacy. Patient engagement is conceptualized as patients' self-awareness and ability to express their physical and emotional needs, thus resulting in better orientated professional interventions [37]. Discussing preferences and views or disagreeing with a recommendation are communication skills used in everyday life, but for many patients these may be novel in the context of a medical consultation [38] [39], which could impede the development of effective self-coping strategies for disease management [37].

In terms of the understanding and logistics of patient engagement, the healthcare professionals agreed that all of the 12 stated components were important in patient engagement. In contrast, the patients emphasized the importance of the areas of Communication and Information Sharing and Self-care and Safety and put less focus on Involvement in Decision-making, which reflects with their fear of being categorized as a "difficult or unwelcome patient" by participating to a greater extent in their own health care, as expressed in the focus group and echoed by the study of Dominick *et al*. [40].

A large discrepancy was found in the experiences of patient engagement among the healthcare professionals and patients. The majority of the healthcare professionals believed that they had engaged patients across the 12 components of patient engagement; however, the majority of patients did not feel that they were being engaged in the care process. Besides "ensuring safe care with patients" and "treating and receiving patients with dignity and respect", which were well aligned between health-care staff and patients, the health-care staff had a poor understanding of patient engagement from the patients' perspective, in particular with regard to the aspects of communication and information sharing and involvement in decision-making, a finding also reflected in previous studies [27]-[32] [41] [42] [43]. Similar to two previous reviews, we found that the provider's knowledge of and attitude towards patient engagement were a barrier to implementation [44] [45].

In addition to the heavy workloads/time constraints and communication skills of healthcare professionals, our study uncovered another barrier to patient engagement: a lack of certain physical and cognitive abilities and communication skills among patients and the physical setting of the hospital. This finding pro-

vides valuable input for strategies to help patients to engage in the caring process, which previously have only focused on healthcare staff, such as their training in communication skills and the development of decision tools. Implementation models are unlikely to succeed if patient engagement relies solely on healthcare staff to initiate communication with patients and distribute decision aids. Strategies that encourage patients and improve facilities, such as improving health literacy and the physical environment, are promising alternatives.

A successful implementation may also depend on the development of clinical information systems that can track each patient's progress throughout the entire process of patient engagement and identify the most difficult steps in this process. Our findings also have implications for suggesting measures to improve patient engagement, which might include a system to disseminate information to patients effectively, a training workshop in communication skills for healthcare staff and patients, and health literacy education for patients. Management fostering of patient engagement, in terms of both staff and the physical setting of the hospital, and creating an atmosphere to encourage patients to participate in self-care could help to ensure meaningful engagement. Incentives that target areas other than the volume of visits and greater care coordination may be necessary for patient engagement to take hold.

The study has some limitations. As the recruitment of the study was from the department of medicine in the selected public acute and rehabilitation hospitals only, the voices and experiences of patient engagement in other departments in the hospitals are not clear.

The participants who were recruited for the patient survey were significantly younger and less likely to live in an old age home than the general discharge population. The findings of the study may not be generalized to some of the patients. In addition, our study used a cross-sectional design; longitudinal studies are needed to establish its sensitivity to change.

5. Conclusion and Policy Implications

Patient engagement is a cornerstone of patient-centered care and is beneficial to patient health outcomes, staff morale and health system performance. An understanding of patient engagement and the involvement of and challenges encountered by both healthcare professionals and patients are crucial in efforts to provide meaningful patient engagement in different contexts in term of jurisdictions, health system, specialty, discipline, background of patients and time period. Most of the commentary assumes patients are homogenous and healthcare staff is likewise homogenous. Our findings show the differences between healthcare professionals and patients in their understanding, views and experiences of patient engagement in Hong Kong public health sector and it could be used as a lesson to be shared and reference to be compared. According to the framework of the Continuum of Patient and Representative Group Engagement of NHS Trusts developed from "A Ladder of Citizen Participation" [46], there are three phases of citizen engagement across six ladders: the Passive Phase (approach,

inform); the Active Phase (consult, involve); and the Committed Phase (partner, devolve). Patient engagement in Hong Kong is in the "Active" phase of two-way communication [47]. The first step towards the Committed Phase of partnering with patients is to establish a mutual understanding and to align expectations. Development of a collaborative strategy involving the different stakeholders, including health-care staff, managers, policy makers and patients, should then be developed to transform participation in health care. Further study is required to explore understanding and experience in different health systems, disciplines and groups of patients.

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Conflict of Interest

The authors of this manuscript have no conflict of interest to report.

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