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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 \pm 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)
<u>Doctor</u>		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)
<u>Nurse</u>		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 \geq 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)

^aTypes of the government allowance included 1) Comprehensive Social Security Assistant, 2) disability allowance and 3) old-age allowance. ^bTypes of longstanding 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

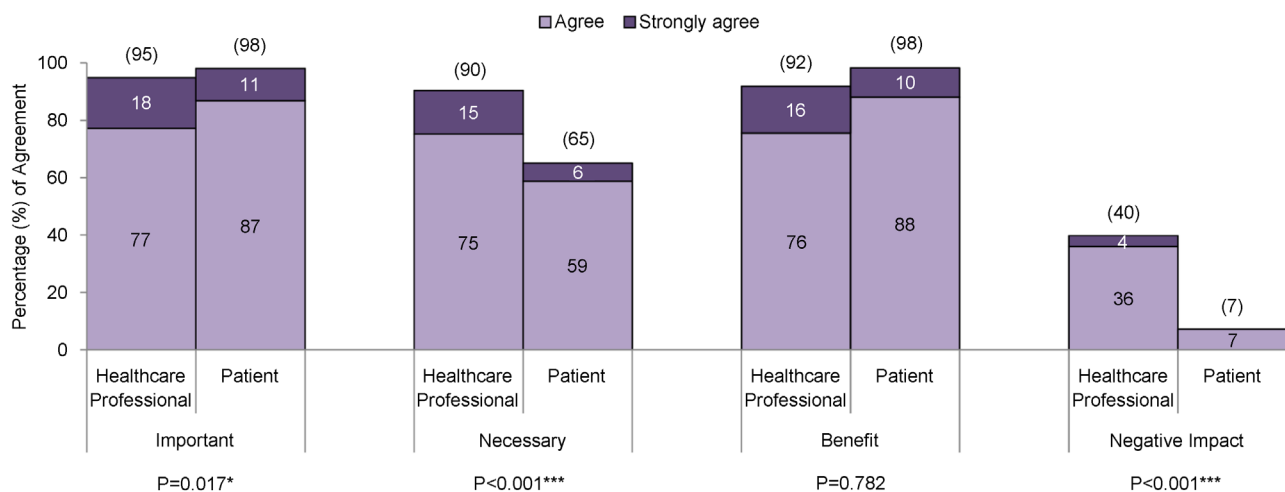


Figure 1. Agreement on importance and benefit of incorporation patient engagement into routine practice. (Mann-Whitney test was performed and a difference was considered to be statistically if P-value was < 0.05 . *P-value < 0.05 ; **P-value < 0.01 ; ***P-value < 0.001 , which means the difference is 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.)

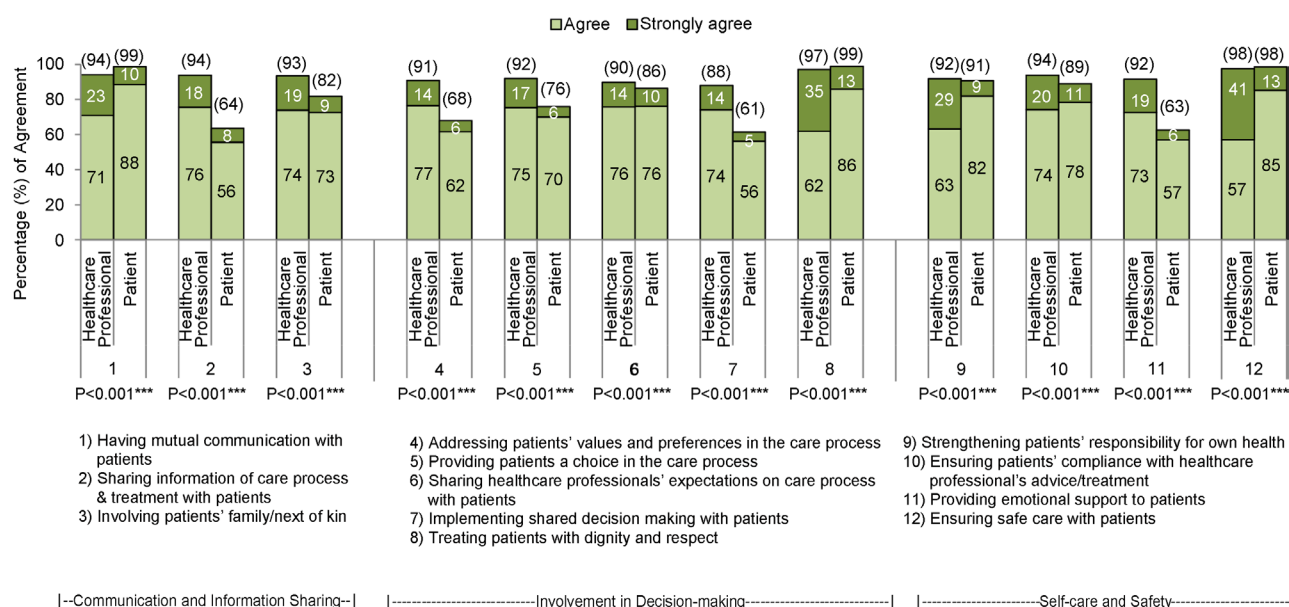


Figure 2. Agreement on 12 stated elements of patient engagement. (Chi-square tests were performed and a difference was considered to be statistically significant if p-value was < 0.05. *P-value < 0.05; **P-value < 0.01; ***P-value < 0.001, which means the correlation is significant at the 0.05, 0.01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

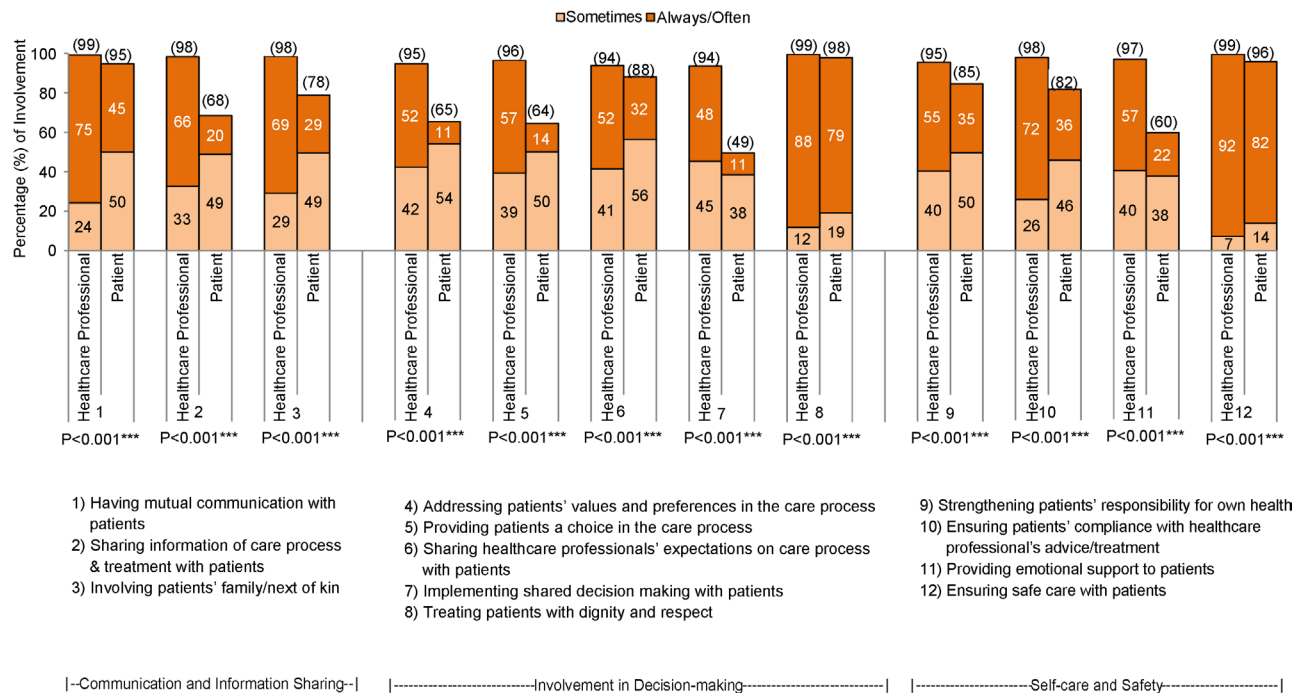


Figure 3. Perceived involvements of 12 stated elements of patient engagement. (Mann-Whitney test was performed and a difference was considered to be statistically if P-value was < 0.05. *P-value < 0.05; **P-value < 0.01; ***P-value < 0.001, which means the correlation is significant at the 0.05, 0.01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

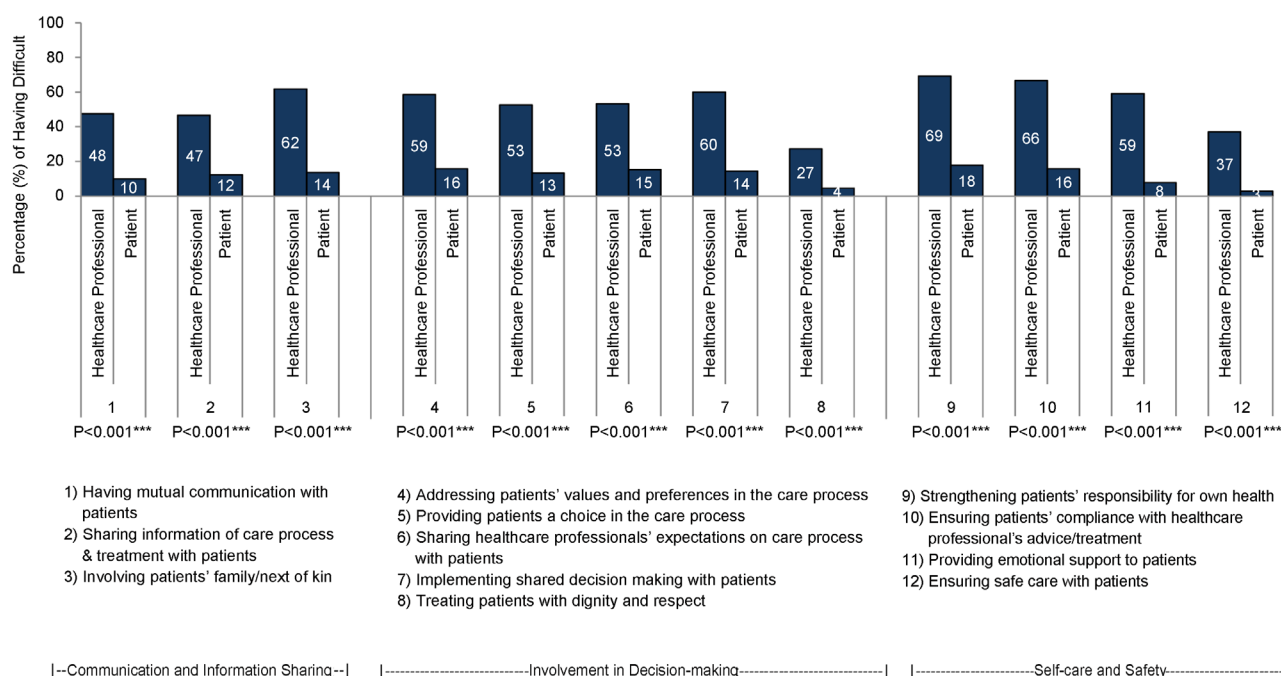


Figure 4. Perceived having difficulties of involvement in 12 stated elements of patient engagement. (Chi-square test was performed and a difference was considered to be statistically if P-value was < 0.05. *P-value < 0.05; **P-value < 0.01; ***P-value < 0.001, which means the correlation is significant 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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Citation Classics in Patient Engagement Research: An Analysis of the 50 Most Cited Articles

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Abstract

Background: Patient engagement offers a promising pathway toward improved population health, better-quality care, and greater cost efficiency. The objective of the current study is to identify and analyze the characteristics of the 50 most frequently cited articles in patient engagement journals. **Methods:** The ISI Journal Citation Reports: Science Edition 2014 database was used to determine the most frequently cited published articles in Dec 2016. The most cited 50 articles were selected and assessed according to the published journal, origin of institutions, publication year, impact factor, topic, and type of study. **Results:** The 50 selected articles were published in 19 journals, the majority of which originated from the UK. The most common study design was quantitative study and reviews. The improvement of health care services quality and the construction of engagement model were the top two topics. And 2013 is the most published year receiving the most citations. **Conclusions:** Our findings provide a historical perspective on the scientific progress of patient engagement and allow for recognition of important developments and limitations in this field.

Keywords

Citation Analysis, Patient Engagement, Publication, Systematic Evaluation

1. Introduction

Given the governments around the world struggling to meet the health needs of their citizens in the face of rising costs, aging populations, and massive variations in health care during the last 20 years [1], patient engagement as a powerful and potentially beneficial force has been strongly introduced into our daily health care services. However, how can we evaluate the progress and contribu-

tions of this “blockbuster drug of the century” from a series of researches and studies [2]? Citation analysis is a commonly used bibliometric method, which could be used to explore the impact of the field, the impact of a number of researchers and the impact of some particular articles [3].

Citation classics for the most cited articles as a new research method were firstly introduced by Garfield in 1977 [4]. For now, a variety of journals and research fields have published their citation classics. It always offers a distinctive insight into the history and development of the research for the reader.

Meanwhile, it is also very useful to use citation classics to identify the authors who have published the significant findings on any particular topics, as well as the short or long term impact of their works from the literary perspective [5]. Extensively cited articles from patient service journals also serve as an important role to inspire the medical staffs, researchers, or policymakers to reflect and improve the current plans and policies.

Identification of citation classics has been conducted in various medical fields, but very few in the domain of patient care. According to our literature searching, until now, none of the previous citation studies had focused on the patient engagement. Therefore the aim of the present study is to identify and examine the characteristics of the 50 most frequently cited articles in patient engagement.

2. Method

In the light of no category is named “Patient Engagement” of ISI Journal Citation Report: Science Edition 2014 (Web of Knowledge), Twenty-five journals dedicated to patient related service and care and its subspecialties were selected from the Journal Citation Report 2014 under the subject category “Health Care Science and Services”, “Health Policies and Services”, “Nursing” and “Public, Environment & Occupational Health”. All searches were chosen peer-reviewed literature, confined to publish between January 1995 and December 2016, including e-publications ahead of print. The 50 most frequently cited articles in the journals dedicated to patient engagement were identified using the database of the ISI web of science (Web of Knowledge), with the Science Citation Index Expanded (1965-) and Social Sciences Citation Index (1956-). Only English article had been considered for reviewing.

As we know, there is not a unified and standard definition of patient engagement. In addition, a lot of other conceptions, like patient involvement, patient activations, or customer engagement under the umbrella of the patient-centered care, had some kinds of similarities and overlaps to each other. Therefore, in order to ensure our conclusions’ consistency and accuracy, we only included the articles discussing the concept of patient engagement through two independent reviewers, but not include or discuss the other parallel concepts like, patient activation, patient adherence, patient involvement, patient participation or patient empowerment.

All articles were collected initially through the database of electronic copies. For those the electronic copies were unavailable, hardcopies were sought out

through CUHK library from local or oversea sources as an alternative. Search results were stored in a Mendeley database (ver. 1.15.2, Elsevier, New York, NY) and duplicate records were removed. Two reviewers (RX and EW), together screened all the titles and abstracts to evaluate and decide which articles to be selected based on the inclusion and exclusion criteria. Using a data extraction form, all full text of eligible articles which were identified would be gone through and evaluated independently by two reviewers (RX and EW). All articles which neither met the inclusion criteria nor met the exclusion criteria were listed in a table independently by two reviewers and verified together. If there were any disagreements of article selection, the disputed articles would be retrieved and reviewed by two authors again, or appointed to a third researcher to evaluate it. The whole process of consistency and accuracy of article selection based on the pre-set criteria would not be completed until a consensus had been made among the authors. The selected articles were collected and analyzed according to various characteristics, including 1) year of publication; 2) journal name; 3) Impact factor of journal; 4) number of citation; 5) authorship; 6) number of publications per year; 7) institution; 8) country; and 9) study design.

The study design was further divided into the following categories: 1) prospective trials, including randomized controlled, non-randomized controlled, and uncontrolled experimental trials; 2) qualitative studies, including interview and focus group study; 3) surveys, including questionnaire and validation studies; 4) reviews, including literature reviews, systematic reviews and meta-analysis; and 5) other designs that do not belong to any of the above four categories.

3. Results

Of the 25 journals included in our bibliometric analysis, only 19 provided articles in our top 50 list (**Table 1**). The earliest journal, as we know, is the “Medical Care” from the US, which published its first volume in 1963. The youngest journal is the “BMC Implementation Science” from UK, which published its first volume in 2006. In general, the journals related to patient engagement are relatively new, among which the oldest one reported the results of patient engagement has only been published for about 50 years. The analysis of impact factor shows that the 5-year impact factor for all 19 journals ranged from 1.47 to 5.25. And all of them were published in English. According to the searching results from JCR: Science Edition 2014, during the whole study period from 1956 to 2016, there were totally 463 records found related to patient engagement. 244 of them had been cited at least once, which account for 52.8%. The top article received 210 citations, and only three articles had been cited over 100 times in our fixed search categories.

Table 1 also indicated the breakdown of the 19 journals included in this study. Health Affairs (9 articles), [1] [6]-[13] Journal of Medical Internet Research (6 articles) [14]-[19] and BMC Health Service Research (6 articles) [20]-[25] had occupied the top three of the list, which covered nearly 40% of all the included articles. Besides, no correlation between number of citations and impact factor has been confirmed in our study.

Table 1. Summary of included journals.

No.	Title	Abbreviation	Volume 1 at	Impact factor	# of top 50 cited articles
1	Health Affairs	HEALTH AFFAIR	1981	4.96	9
2	Journal of Medical Internet Research	J MED INTERNET RES	1999	5.25	6
3	BMC Health Service Research	BMC HEALTH SERV RES	2001	1.71	6
4	Patient Education and Counseling	PATIENT EDUC COUNS	1983	2.89	5
5	Journal of Advanced Nursing	J ADV NURS	1976	1.91	4
6	Health Expectations	HEALTH EXPECT	1998	3.75	3
7	AIDS Patient Care and STDs	AIDS PATIENT CARE ST	1987	3.49	3
8	BMJ Quality & Safety (Quality & safety in Health Care)	BMJ QUAL SAF	1992	4.99	2
9	Medical Care	MED CARE	1963	3.48	2
10	BMC Family Practice	BMC FAM PRACT	2000	1.67	1
11	BMC Implementation Science	IMPLEMENT SCI	2006	4.10	1
12	International Journal of Nursing Studies	INT J NURS STUD	1964	3.64	1
13	Social Science & Medicine	SOC SCI MED	1982	3.59	1
14	Quality of Life Research	QUAL LIFE RES	1992	3.08	1
15	Journal of Patient Safety	J PATIENT SAF	2005	2.44	1
16	Nursing Outlook	NURS OUTLOOK	1994	2.43	1
17	Health	HEALTH	1997	1.96	1
18	Health Communication	HEALTH COMMUN	1989	1.93	1
19	Journal of Nursing Administration	J NURS ADMIN	1971	1.47	1

Table 2 summarized the 50 top-cited articles related to patient engagement in descending order, according to the cited numbers by each article [1] [6]-[54]. The most frequently cited article “The impact of nursing work environments on patient safety outcomes – The mediating role of burnout/engagement” received 198 citations [41]. Furthermore, 44 articles were originated from universities [1] [7] [8] [10] [12] [14]-[30] [32] [33] [34] [36]-[54]. Six of them were accomplished by research institutes [6] [9] [11] [13] [31] [35]. The total cited frequency is 1387.

Type of article was most frequently survey design with 25 contributions [1] [6] [8] [9] [12] [15] [20] [21] [26] [28] [29] [30] [31] [32] [34] [39] [40] [41] [42] [43] [45] [47] [48] [49] [52]; 10 were systematic review or meta-analysis [10] [16] [22] [23] [27] [33] [36] [37] [46] [51]; 7 were trial design [14] [17] [18] [19] [24] [35] [54]; 2 were qualitative studies [25] [50]; and the other six articles deal with other designs [7] [11] [13] [38] [44] [53] (**Table 3**).

Our study also showed that the US dominates the list of the 50 most cited articles with nearly 60% of contributions (**Table 4**) [6]-[13] [16] [17] [18] [19] [22] [24] [27] [29] [30] [31] [32] [35] [36] [37] [38] [39] [42] [43] [44] [45] [49] [51]. UK was the second one, possessing 11 articles (22%) [1] [14] [21] [25] [28] [33] [34] [41] [46] [52] [53], followed by Australia [20] [40] [47] [54] and Canada, Finland, New Zealand, Netherlands, and Israel contributed to the rest five articles [15] [23] [26] [48] [50].

Table 2. Description of top 50 cited articles in descending order according to the number of citations each received.

No.	Author (Year) (Country)	Title	Cited	Organization
1	Laschinger, <i>et al.</i> (2006) (UK)	The impact of nursing work environments on patient safety outcomes—The mediating role of burnout/engagement	210	University
2	Davis, <i>et al.</i> (2007) (UK)	Patient involvement in patient safety: what factors influence patient participation and engagement?	113	Research Org.
3	Carman, <i>et al.</i> (2013) (US)	Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies	113	Research Org.
4	Franklin, <i>et al.</i> (2008) (UK)	Patients' Engagement With "Sweet Talk"—A Text Messaging Support System for Young People With Diabetes	68	University
5	Gruman, <i>et al.</i> (2010) (US)	From patient education to patient engagement: Implications for the field of patient education	59	Research Org.
6	Ruusuvuori (2001) (FIN)	Looking means listening: coordinating displays of engagement in doctor-patient interaction	54	University
7	Koh, <i>et al.</i> (2013) (US)	A Proposed "Health Literate Care Model" Would Constitute A Systems Approach To Improving Patients' Engagement In Care	43	Research Org.
8	Furukawa, <i>et al.</i> (2014) (US)	Despite Substantial Progress In EHR Adoption, Health Information Exchange And Patient Engagement Remain Low In Office Settings	42	Research Org.
9	Domecq, <i>et al.</i> (2014) (US)	Patient engagement in research: a systematic review	40	Research Org.
10	Cabral, <i>et al.</i> (2007) (US)	Outreach program contacts: Do they increase the likelihood of engagement and retention in HIV primary care for hard-to-reach patients?	34	University
11	Staniszewska, <i>et al.</i> (2004) (UK)	Patients' evaluations of the quality of care: influencing factors and the importance of engagement	33	Research Org.
12	Couper, <i>et al.</i> (2010) (US)	Engagement and Retention: Measuring Breadth and Depth of Participant Use of an Online Intervention	33	University
13	Broom, <i>et al.</i> (2008) (UK)	The role of the internet in cancer patients' engagement with complementary and alternative treatments	33	University
14	Martinez, <i>et al.</i> (2009) (US)	Patient-clinician information engagement increases treatment decision satisfaction among cancer patients through feeling of being informed	27	University
15	Irizarry, <i>et al.</i> (2015) (US)	Patient Portals and Patient Engagement: A State of the Science Review	25	University
16	Thomson, <i>et al.</i> (2005) (UK)	Tensions in public health policy: patient engagement, evidence-based public health and health inequalities	24	University
17	Kralik, <i>et al.</i> (1997) (AU)	Engagement and detachment: Understanding patients' experiences with nursing	23	Research Org.
18	Knowlton, <i>et al.</i> (2010) (US)	Antiretroviral Use Among Active Injection-Drug Users: The Role of Patient-Provider Engagement and Structural Factors	23	University
19	Cosgrove, <i>et al.</i> (2013) (US)	Ten Strategies To Lower Costs, Improve Quality, And Engage Patients: The View From Leading Health System CEOs	22	Research Org.
20	Tripathi, <i>et al.</i> (2009) (US)	Engaging Patients For Health Information Exchange	22	Research Org.
21	Lewis, <i>et al.</i> (2009) (US)	Examining Cross-Source Engagement With Cancer-Related Information and Its Impact on Doctor-Patient Relations	21	University
22	Young, <i>et al.</i> (2007) (AUS)	Patient Engagement and Coaching for Health: The PEACH study a cluster randomised controlled trial using the telephone to coach people with type 2 diabetes to engage with their GPs to improve diabetes care: a study protocol	21	University
23	Piette, <i>et al.</i> (2013) (US)	Engagement With Automated Patient Monitoring and Self-Management Support Calls Experience With a Thousand Chronically Ill Patients	21	University
24	Protheroe, <i>et al.</i> (2008) (UK)	Promoting patient engagement with self-management support information: a qualitative meta-synthesis of processes influencing uptake	20	University
25	Mirzaei, <i>et al.</i> (2013) (AUS)	A patient-centred approach to health service delivery: improving health outcomes for people with chronic illness	19	University
26	Christopoulos, <i>et al.</i> (2013) (US)	"Taking a Half Day at a Time": Patient Perspectives and the HIV Engagement in Care Continuum	18	Research Org.

Continued

27	Cornelia, <i>et al.</i> (2011) (NLD)	Determinants of Engagement in Face-to-Face and Online Patient Support Groups	16	University
28	Abdelhadi, <i>et al.</i> (2011) (ISR)	Promoting patient care: work engagement as a mediator between ward service climate and patient-centred care	16	University
29	Han, <i>et al.</i> (2013) (US)	Survey Shows That Fewer Than A Third Of Patient-Centered Medical Home Practices Engage Patients In Quality Improvement	16	University
30	Forbat, <i>et al.</i> (2009) (UK)	Engaging patients in health care: An empirical study of the role of engagement on attitudes and action	15	University
31	Grande, <i>et al.</i> (2014) (US)	A classification model of patient engagement methods and assessment of their feasibility in real-world settings	15	University
32	Berger, <i>et al.</i> (2013) (US)	Promoting engagement by patients and families to reduce adverse events in acute care settings: a systematic review	13	University
33	Pelletier, <i>et al.</i> (2013) (US)	Action brief: Patient engagement and activation: A health reform imperative and improvement opportunity for nursing	12	University
34	Schaefer, <i>et al.</i> (2005) (US)	Continuity of care practices and substance use disorder patients' engagement in continuing care	11	University
35	Sadasivam, <i>et al.</i> (2011) (US)	Development of an Interactive, Web-Delivered System to Increase Provider-Patient Engagement in Smoking Cessation	10	University
36	Cox, <i>et al.</i> (2012) (US)	Influence of race and socioeconomic status on engagement in pediatric primary care	10	University
37	Laurance, <i>et al.</i> (2014) (UK)	Patient Engagement: Four Case Studies That Highlight The Potential For Improved Health Outcomes And Reduced Costs	10	University
38	Frank, <i>et al.</i> (2015) (US)	Conceptual and practical foundations of patient engagement in research at the patient-centered outcomes research institute	9	Academy
39	Coventry, <i>et al.</i> (2014) (UK)	Capacity, responsibility, and motivation: a critical qualitative evaluation of patient and practitioner views about barriers to self-management in people with multimorbidity	9	University
40	Tancredi, <i>et al.</i> (2013) (US)	Targeted versus tailored multimedia patient engagement to enhance depression recognition and treatment in primary care: randomized controlled trial protocol for the AMEP2 study	8	University
41	Pryor, <i>et al.</i> (2010) (AUS)	Enhancing inpatient rehabilitation through the engagement of patients and nurses	8	University
42	Shippee, <i>et al.</i> (2013) (US)	Patient and service user engagement in research: a systematic review and synthesized framework	8	University
43	Christopher, <i>et al.</i> (2015) (US)	Patterns and predictors of patient and caregiver engagement in heart failure care: A multi-level dyadic study	7	University
44	Burns, <i>et al.</i> (2014) (CAN)	"Practical" resources to support patient and family engagement in healthcare decisions: a scoping review	7	University
45	Sandy, <i>et al.</i> (2013) (US)	United Healthcare Experience Illustrates How Payers Can Enable Patient Engagement	6	Research Org.
46	Danis, <i>et al.</i> (2012) (US)	Providers, Payers, The Community, And Patients Are All Obligated To Get Patient Activation And Engagement Ethically Right	5	Research Org.
47	Sheridan, <i>et al.</i> (2012) (NZL)	Patients' engagement in primary care: powerlessness and compounding jeopardy. A qualitative study	5	University
48	Holzmueller, <i>et al.</i> (2012) (US)	A Framework for Encouraging Patient Engagement in Medical Decision Making	4	University
49	Ingersoll & Berger (2015) (US)	Parent Engagement With a Tele health-Based Parent-Mediated Intervention Program for Children With Autism Spectrum Disorders: Predictors of Program Use and Parent Outcomes	4	University
50	Oostendorp, <i>et al.</i> (2015) (UK)	Measuring organisational readiness for patient engagement (MORE): an international online Delphi consensus study	2	University

The "deliberation and intervention of improving service quality" (17 articles) [8] [9] [11] [12] [14] [18] [20] [24] [28] [29] [35] [43] [45] [47] [49] [52] [54] is the main topic covered by these highly cited articles. Considerable focuses were

also given to the topics of “development of model and framework” (15 articles) [1] [7] [10] [16] [17] [25] [30] [32] [36] [38] [44] [46] [51] [53] [55]. Followed by “professional-patient communication” (11 articles) [6] [15] [23] [26] [31] [34] [39] [40] [42] [48] [50], “patient safety” (3 articles) [27] [33] [41], and “scale development” (2 articles) [19] [21]. Other topics include “patient education” [37] and “the barriers to effective engagement” [22] (Table 5).

As shown in Table 6, articles were published from 1997 to 2015. The most published year is 2013 (12 articles). Nearly 70% of articles cited by top 50 were published after 2010 (34 articles). Compared to other years, 2013 is also the year that publications were most frequently cited (299 times).

4. Discussion

It is well recognized that a closer look at the number of citations could be very helpful to confirm the impact of the journals and the contributions by individual

Table 3. Study types of origin of the 50 most cited articles.

Type of articles	No. of articles
Survey study	25
Systematic or meta-analysis	10
Trial design	7
Qualitative study	2
Others	6

Table 4. Countries of origin of the 50 most cited articles.

Country	No. of articles
The United Kingdom	11
The United States	30
Canada	1
Netherlands	1
Australia	4
Finland	1
Israel	1
New Zealand	1

Table 5. Main topics covered in the 50 most cited articles.

Domain	No. of articles
The improvement of service quality	17
Model and framework development	15
Professional-patient communication	11
Patient safety	3
Scale development	2
Patient education	1
Barriers to effective engagement	1

Table 6. Years of origin of the 50 most cited articles.

Domain	No. of articles
1997	1
2001	1
2004	1
2005	2
2006	1
2007	3
2008	3
2009	4
2010	4
2011	3
2012	4
2013	12
2014	6
2015	5

authors [56]. Our work is the first one to evaluate the 50 top-cited articles in the literature of patient engagement, though this very important and valuable conception has been introduced into the area of health care service for nearly 20 years.

Firstly, we found all the 50 most cited articles were published by the authors or institutes from western countries. Amongst them, 62% from North America (CAN 2 articles & US 29 articles), 30% from Europe. These figures indicated that there is a big gap, as well as opportunities, in studying patient engagement in Asia. Especially, countries and areas like Japan, China, and Hong Kong have been facing greater challenges of aging population than ever, which require them to transform its traditional provider-centered health care pattern to a modern patient-centered health care pattern as soon as possible.

Secondly, the range of cited articles related to patient engagement from top 50 articles is from 2 to 198, which is considerably lower than other areas related to health care services. For example, the range for citation of patient safety is 100 to 584, and patient satisfaction, the range is 156 - 875. It may be explained by two reasons. The first one is that the conception of “patient engagement” is relatively new. Although it has been existed for nearly 20 years, according to our study, the real peak of studying this topic started from 2010. The second reason is that, as we know, there are some partially similar and potentially overlapped conceptions had existed, for example, patient involvement, patient activation or customer engagement, which had attracted some scholars’ attentions and published their research findings use other titles already. Therefore, it may be hard to identify all the articles or articles using the keyword as patient engagement.

Other observations are not surprising. Trends in the number of publications of patient engagement have been promising in recent 20 years. It reveals that

more resources and attentions from governments and research institutes have been transferred to this more effective and efficient patient-centered health care pattern. This is consistent with the results of other previous studies that awareness of involving the patient in their own health care in order to promote the health outcomes was increasing for both professionals and patients [57]. And this condition may encourage and inspire more researchers to focus on the study of patient engagement in the future.

Another finding is the impact factor of the journals in patient engagement is not high. The journal with the highest impact factor, 5.25, is the “Journal of Medical Internet Research (JMIR)”. However, there is an obvious limitation of the articles published in JMIR, that is most of them are assessing the patient engagement only based on the internet-related studies. By contrast, the topics are more pluralistic of the second top journal “Health Affairs” (The IF is 4.96). We hope more mainstream journals with higher impact factor could share more attentions on the topics of patient engagement.

Finally, the list of the top-cited articles identifies topics that reflect major tendency and development in patient engagement over the last 20 years. Nearly 70% of articles focused on the improvement of health care service quality and the construction of patient engagement model. These results indicate that the studies of patient engagement are still at an early and exploratory stage. Likewise, the main purpose of such kind of studies is establishing the relationship between patient engagement interventions and high quality of health care services. In terms of study types, the majority of the studies followed the quasi-experimental design, using interviews or surveys to evaluate the efficiency of interventions, among which only six studies employed the randomized design. This finding demonstrates that the quality of interventions in this area is still under-developed, and could benefit from further, stricter analysis.

Our study provides important information into how knowledge in the field of patient engagement has been introduced and developed in the last few decades. The current study shows the impressive advances in this field. Patient engagement is growing in studying patients’ experience, health utility use and service efficiency. Our findings encourage that in the field of patient engagement, future influential studies and articles could be conducted and published, and further explore the role of patient play in the patient-centered care.

There are some limitations of our study. Firstly, we did not count the number of citations from articles published in books, which may lead to the missing of some very important articles during the review. The second one is that we only checked the articles written in English, which may lead to the selection bias that some good articles written in other languages being omitted. Thirdly, since there is not a recognized category called patient engagement through the search, we chose other four most related categories as our target source of journals, hence, some articles related to this area in other clinical, medical or social science categories might not be included. The last limitation is that patient engagement is a relatively new conception, which means the older articles are more likely to be

cited than the newer ones, simply due to their longer existence. This means some more solid, rigorous, or even seminal works could not be listed in our search.

5. Conclusion

Although limitations exist, the review of the 50 top cited articles in patient engagement may be worthwhile on a few accounts. The data we provided imply how much knowledge and how many developments in the field of patient engagement have been disseminated and made during the last 20 years. Most studies reported the positive relationship between patient engagement and health outcomes makes us optimistic and convincing that the input of resources and capacities to make meaningful progress on this new field is worthwhile. These findings encourage more excellent researchers and influential journals to participate in the exploration of the role in patient engagement to improve health outcomes.

6. Authors' Contributions

RX conducted the literature review, statistical analysis and prepared the manuscript. EW conceived the study and gave careful advice and revised the manuscript. Both authors read and approved the final manuscript.

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Maternal Uncertainty about Infants' Hospitalization for Acute Childhood Illness: A Qualitative Study

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Abstract

Mothers often express intense stress and uncertainty when their children develop acute childhood illnesses and it is important for healthcare professionals to consider maternal uncertainty when providing support for mothers. This study aimed to examine maternal uncertainty about children's hospitalization due to acute childhood illnesses. We recruited 15 Japanese mothers of children aged 1 - 12 months who had been hospitalized for the first time due to acute childhood illnesses, and conducted unstructured interviews with the participants at the time of discharge. Content analysis was used to examine uncertainty in their expression of their psychological state. Mothers' uncertainty was classified into five categories: ambiguity about the severity of the illness, unpredictability of the course of the illness, discrepancy of the judgment with healthcare professionals, lack of information about the causes of the illness, and ambiguous appropriateness of management. The former three categories were reported as uncertainty of mothers of children with chronic diseases, while the latter two categories were particularly characteristic of mothers of children with acute childhood illnesses. It is, therefore, important to explore the causes of children's illnesses and help mothers build confidence in their ability to manage their children's illness before discharge.

Keywords

Acute Childhood Illness, Mothers, Pediatric Nursing, Qualitative Study, Uncertainty

1. Introduction

The first year of a child's life involves several new experiences and uncertainties,

and mothers perceive an overwhelming responsibility for their child, leading to various kinds of stress [1]. That is, the contraction of acute illnesses in children has the greatest impact on mothers' stress levels [2] [3]. A significant source of maternal psychological stress is uncertainty about a child's illness [4].

Mishel defined maternal uncertainty as a cognitive situation wherein a parent is unable to accurately understand the meaning of the events related to the child's illness due to insufficient information about those events [5]. Based on this theory, some studies have focused on parents' uncertainty regarding a child with acute illness [6]. This review explored whether parents who waited for results of the diagnostic testing and whose children had serious symptoms had high uncertainty. Furthermore, situations such as lack of helpful information from health care providers and changes in the family system also lead to uncertainty in parents. In this review, children's acute illnesses refer to severe illnesses, an exacerbation on chronic illness, or illnesses requiring major lifesaving treatment. In other reviews published thereafter, parents' uncertainty was focused on situations wherein children required intensive care; children had cancer relapses; parents waited for hereditary disease screening test results; or the child had chronic pain [4] [7] [8]. Thus, no studies have focused on maternal uncertainty when a child has an acute childhood illness (ACI).

ACIs (e.g., respiratory infectious diseases and infectious gastroenteritis) have a sudden onset and acute recovery. ACIs often occur in children less than two years of age. Although most children with an ACI get better without an aftereffect, mothers who are uncertain sometimes find it difficult to assess the severity of their child's illness [9] and tend to use medical services [10]. However, this practice is sometimes unnecessary from the standpoint of health care professionals, whereas it is common in Japan. The Fire and Disaster Management Agency in Japan [11] has reported that only 1.1% of the ambulance events for children with ACIs were serious cases. Japanese society has a significantly declining birthrate, which means that many first-time parents have little experience in contact with children and a lack of basic knowledge in childrearing [12]. Therefore, it is difficult for most parents to interpret the severity of signs of childhood illness and use medical services appropriately. This situation might also result in delayed consultation and aggravation of the illness [13] [14] [15]. This decision of help-seeking behavior influenced the perception of uncertainty [16] [17].

We hypothesize that the main causes of this problem in Japan as mentioned above might be due to the uncertainty of mothers regarding their children with ACI, and therefore, exploring mothers' uncertainty could help decrease this problem. Therefore, the purpose of this study was to examine the uncertainty of mothers with children aged between 1 and 12 months who had an ACI for the first time.

2. Methods

2.1. Study Design

The present study used a qualitative descriptive design according to the consoli-

dated criteria for reporting qualitative research (COREQ) checklist [18] for this qualitative study, and collected data through open-ended interviews.

2.2. Participants

Purposive sampling was used to recruit Japanese mothers accompanying children with ACIs who were hospitalized at a certified pediatric emergency unit in a children's hospital (primary care facility) in urban Japan. In this area, almost everyone receives more than a high school education. This hospital annually hospitalizes approximately 3000 children mainly due to ACIs. In general, mothers are the primary childcare provider, especially during infancy [19] [20] and most Japanese fathers tends to leave childcare to mothers and concentrate on work compared to fathers in other countries [21]; therefore, only mothers who have had enough information about their child's condition—during both good health and illness—were included as study participants. Inclusion criteria were as follows: 1) the first hospitalization of the child, 2) the child was the first born and 3) less than one year old, and 4) an approximate one-week hospital stay. The one-week period was shorter than the average length of hospital stay for infants in Japan (9.0 days [22]) since ACIs generally have a short course [23]. ACIs include upper respiratory tract infections, childhood infectious diseases, gastroenteritis, and other febrile diseases [23]. We excluded the cases of chronic or genetic diseases. The chief nurse initially approached the mothers of children who met the inclusion criteria within three days after admission. The first author met the mothers following the chief nurse's introduction and provided them with written information about the study. Participants agreed to participate in the study and completed an informed consent form.

2.3. Data Collection

Data were collected between November and December 2014 with open-ended interviews conducted on either the day of discharge or the day before discharge. The first author interviewed the participants alone and recorded the data from all cases in an isolated sound-proofed family visiting room outside the ward. The first author referred to the guidelines of interview method [24]. Following the explanation of the study purpose and the meaning of uncertainty, the first author asked the mother to explain her psychological state regarding her child's illness and also asked in-depth questions about her uncertainty. When at least two consecutive participants provided no new information to add to the previous responses, we considered it as data saturation. We predicted that approximately 15 participants were needed for the sample size to achieve data saturation based on previous similar studies [25] [26].

2.4. Ethical Considerations

This study was approved by the Ethics Committee of Health Sciences, Osaka University (No. 300) and the Institutional Review Board of the research hospital (No. 21). Ethical considerations were as follows: 1) voluntary participation; 2)

privacy protected; 3) able to withdraw from the study at any time, even after providing written consent; 4) additional questions; and 5) all collected data would be anonymous and confidential.

2.5. Data Analysis

We transcribed the interviews verbatim using the arrangement function of qualitative data management software (NVivo ver. 10, QSR International, Japan). We reviewed and read the transcripts repeatedly to achieve immersion. The arranged verbatim record was divided into meaning units by coding. This coding process was conducted by the first author. We did a content analysis using these codes. Content analysis is a systematic and objective means of describing phenomena so that it was possible to distil words into fewer content-related categories [27]. Each code was sorted into subcategories, and each subcategory was integrated into the categories. These coding processes were recorded using an audit trail. We re-examined the raw data in each category to confirm whether the categories were supported by the raw data. This analysis was carried out by two authors and we discussed the validity of coding name.

In order to examine the reliability and consistency of the analysis, the two authors repeatedly confirmed the relevance and coherence of each step of the analysis until consensus was achieved [28]. The second author analyzed the data independently. In order to examine the credibility, the first author consulted the co-authors and participants about the meaning of the terms and its significance [29]. We referred to the literature for the definition of Mishel's uncertainty [5] and discussed to confirm whether our findings adhered to the requirement for uncertainty. After analyzing the data, we sent each participant their verbatim report and a summary of their interview to determine the need for revisions. Finally, we discussed the reliability to identify a wider range of concepts in the data and agreed on the interpretation of the data.

3. Findings

Twenty-four mothers were recruited. Four of them complained about their poor psychological or physical condition at the time of recruitment and therefore, did not participate in the study. Twenty mothers agreed to participate in the study but five of them withdrew due to their poor physical condition or sudden discharge of their children. Ultimately, 15 participants participated in an interview. Their background data are shown in **Table 1**. The major characteristics of the participants were as follows: residing in cities (100%) and married (93.3%). The average duration of the interviews was 28.1 minutes (range 16 - 51).

Content analysis yielded five categories: 1) ambiguity about the severity of the illness, 2) unpredictability about the course of the illness, 3) discrepancy of judgement with health care professionals, 4) lack of information about preventives against the illness, and 5) ambiguous appropriateness about coping.

3.1. Ambiguity about the Severity of the Illness

This category indicated that mothers were unable to accurately assess their

Table 1. Participants' demographic data (n = 15).

Items	Average (Range)	Number (%)
Mothers' age (years)	29.1 (19 - 40)	
Children's age (months)	7.2 (1 - 12)	
Period between the hospitalization and interview (days)	6.8 (4 - 9)	
Mothers who were married		14 (93.3%)
Mothers who were employed		4 (25.0%)
Mothers who resided in cities		15 (100.0%)
Children who attended a nursery school		1 (6.3%)
Hospitalized child's disease		
Respiratory infectious disease		9 (60.0%)
Infectious gastroenteritis		5 (33.3%)
Febrile convulsion (isolated seizure)		1 (6.7%)

child's condition due to the child's immature verbal communication. If a mother became aware of their child having an unusual condition, she could not assess the severity of her child's symptoms. One mother said, "*I have to say, I realized that my child suddenly showed some strange symptoms. Before visiting the hospital, I thought that my child had a touch of the flu, and I could only think about how something was wrong with my child*" (Participant 4). Another mother said, "*There weren't any cues about the illness, as I would usually expect. I could not understand why my child was crying. I wondered where my child was hurting*" (Participant 9).

A mother explained her difficulty in communicating the child's condition to the medical staff and said, "*Perhaps because this is my first child, I did not know how to inform the doctor about my child's condition. My child was too young to explain his condition, so I had to explain it to the doctor, but...*" (Participant 14).

3.2. Unpredictability about the Course of the Illness

This category indicated that mothers were unable to predict or imagine the course of their child's illness. This uncertainty appeared especially when the actual diagnosis was more serious than expected one. Anxiety resulting from this unpredictability caused panic and crying in the mothers. Some mothers hesitated to be hospitalized with their children due to this uncertainty. A mother said, "*My daughter will get a painful treatment, such as an infusion and I have a scary image of her hospitalization. I cannot imagine how to spend time at the hospital as an attendant. A doctor told me a little while ago that he did not know when my child would be discharged. I absolutely dislike my child being hospitalized*" (Participant 4).

This uncertainty decreased with adequate and plausible explanations for the illness from the healthcare professionals, however, it reappeared at the time of discharge. Some mothers often care for their children at home excessively. A

mother said, *“After all, I absolutely don’t want my child to be infected with the RS virus from now. I will stop meeting my friends and their children for a while because I don’t know how long the virus can be infectious”* (Participant 15).

3.3. Discrepancy of Judgement with Health Care Professionals

This type of uncertainty appeared at mothers’ first contact with a doctor. Most mothers could not determine the appropriateness of treatment because they did not understand how the healthcare professional had derived at their judgment or therapeutic strategy from the child’s condition. In the acute phase, mothers think the treatment was not effective because their child’s condition seemed to worsen despite the ongoing treatment. A mother said, *“A doctor said that my child would be well within a few days. I am not a doctor, so I do not know if it is true or not. When he was ill, my child sweated, and even if his fever temporarily abated, it soon returned. Because of this, I doubted whether my child would really be well”* (Participant 6).

In the recovery phase, mothers did not feel the need to continue the current treatment because their child seemed to be better. Another mother said, *“My child’s illness seemed to get better after three days of hospitalization. I told my husband that maybe our child could be discharged. But the doctor said that my child had to stay because there were still symptoms”* (Participant 2).

3.4. Lack of Information about the Causes of the Illness

This type of uncertainty indicated that mothers could not explain why and how their child became ill, and appeared when they were calm enough to think of these things. The child had fallen ill despite their mothers’ efforts to prevent the illnesses. The mothers, therefore, considered various possible causes. A mother said, *“Well, I just don’t know how my child got norovirus. My child was playing at the nursery for about one hour before he became sick. He might have fallen ill there. Or [it might have been when] I took him to the child play corner the day before, he fell ill there. My child was licking toys because he is very young. If that was the reason, honestly, I am afraid to go out with him during this winter”* (Participant 7).

3.5. Ambiguous Appropriateness of Management

This category outlined situations in which mothers hesitated or became unsure about managing their child’s illness due to their lack of experience. Mothers did not know how to administer medication to the child or respond to the child’s behavior during treatment via an intravenous drip. A mother said, *“This is the first time to give my child medicine. I have not taken my child to the hospital and have no experience of hospitalization. I really don’t know anything. Well, now there are communities on the Internet, so I am able to search for answers. But I’m not sure that the internet information is correct. I think that every parent is probably raising his or her child through trial and error. However, I was helpless”* (Participant 11).

Although mothers often knew some possible management strategies, they could not choose the appropriate one. For example, they could not decide whether to call the ambulance, walk to the hospital, or observe the child's condition at home. During hospitalization, they were unsure of whether they should call a nurse. A mother said, *"When I noticed my child's symptoms, I called the ambulance even though I was alone and unsure. The ambulance arrived, and the paramedics said that my child smiled and did not look so bad. Though they said that my child wasn't crying, I didn't know whether I should have called the ambulance. Should I only call when my child cries? I feared that it would be too late if my child cried and then lost consciousness"* (Participant 11).

Mothers also expressed their uncertainty about the need for management strategies due to ambiguous explanations from healthcare professionals. For example, although a healthcare professional explained to a mother why bed rest, nutrition, and attention to the child's behavior during the infusion were necessary, she did not receive specific instructions (e.g., how much milk she could give the child). She also did not know how much she should limit her child's activities at discharge. A mother said, *"After my child is discharged, I don't know if I can take my child to the supermarket. I have to go the supermarket, but I don't want to take my child out because I'm afraid his condition will worsen"* (Participant 7).

4. Discussion

There have been comprehensive reviews that have explored the antecedents, consequences, management of the uncertainty of parents of children with severely acute illness, life threatening illness, or acute period of chronic illness [6] [7]. However, no studies have examined the perception of parents' uncertainty when their child had an ACI. In this study, we showed the uncertainty experienced by mothers whose children were hospitalized due to an ACI. Maternal uncertainty was categorized into five categories: ambiguity about the severity of the illness, unpredictability about the course of the illness, discrepancy of judgement with health care professionals, lack of information about causes of the illness, and ambiguous appropriateness of management.

The parents' uncertainty during a child's chronic illness can be measured by Mishel's PPUS [5], which includes 34 items. Items in the PPUS, such as "I don't know what is wrong with my child" or "The seriousness of my child's illness has been determined (reverse scoring)", are similar to our first category "ambiguity about the severity of the illness". Francis *et al.* reported that mothers required specific information to assess the severity of their child's symptoms [13] [30]. Our findings that mothers of children with ACI may be uncertain about whether the child is serious or not, are consistent with these studies.

The categories of "unpredictability of the course of the illness" and "discrepancy of judgement with health care professionals" in the study were consistent with items in the PPUS. The former had a similar meaning as the literatures' findings including the PPUS: trajectory uncertainty [6] [7] [31]. The uncertainty

with unpredictability varied with the pattern of child's symptoms or the parents' experience in caring for an ill child [5] and children with ACIs often show significant changes in symptoms [19] [23]. Moreover, the latter category involved items of "the effectiveness of the treatments are undetermined" or "the results of my child's tests are inconsistent" in the PPUS. Mishel reviewed that health care professionals were not helpful in sharing information [6]. Another study reported that there was a discrepancy between the parents' and health care professionals' judgments about the child's illness [32]. This study also discussed that the discrepancy could lead to mistrust in medical services [32]. Therefore, health care professionals should clearly explain the bases of their judgements regarding the severity of a child's illness and the meaning of treatment. In conclusion, the first three uncertainties were similar to those of mothers who have children with chronic diseases.

The two categories, "lack of information about causes of the illness" and "ambiguous appropriateness of management", were not included in any of the items of the PPUS, although the other papers had already found similar meanings. Regarding a similar meaning of the former category, one study reported that mothers were unable to receive information on what caused the child's symptoms [25]. Langer *et al.* reported that mothers' concern was closely linked to the cause of fever when their children had fever [33]. Ingram *et al.* also reported that all mothers of children who had cough referred to multiple causes before deciding on what to do [34]. Therefore, a lack of information about the causes of the illness is particularly important when we consider the uncertainty of mothers of children with ACI. Health care professionals tend to be interested in how to treat the illness during hospitalization and mothers often felt uncertainty about the lack of information about causes of the illness at the time of discharge. As a result, mothers took excess preventive measures at home; e.g., mother did not want to take her child out (participant 7). Healthcare professionals should explain possible preventive methods to avoid reoccurrence, e.g., hand hygiene and/or facemasks; however, evidence for the effectiveness of any preventive methods is limited [35] [36]. Therefore, they should also explain that excess preventives are not needed because it is impossible for mothers to prevent ACIs entirely and most children will suffer from ACIs again.

Mothers experienced ambiguous appropriateness of management of their child with an ACI. Previous studies have reported similar findings that mothers felt ambiguity about their appropriateness of management [34] [37]. Neill *et al.* also reported that parents' uncertainty was evident in defining the illness and the legitimacy of seeking medical help [38] [39]. This decision of help-seeking behavior was affected by an informal social role. In our findings, the participant could not decide whether to call the ambulance or not. Although mothers felt the need to do something, they hesitated to take action because they felt ambiguous appropriateness about management or had low confidence in their skills. Such hesitation might be induced by a flood of information received by the mothers. Mothers can find various kinds of information through the Internet

quickly and easily; however, this information is sometimes inconsistent and inaccurate. The website of the Japan Pediatric Society includes guidelines for parents using ambulances when children suddenly become ill and this authoritative guideline should be shared with families with children [40], but it does not explain how to manage children with ACIs. It is important for a mother with little knowledge and experience of childrearing to explain how to manage in this situation. When mothers become more confident and self-assured about management with their child's ACI, it may lead a shorter hospital stay and more appropriate use of medical resources (e.g., use of ambulances, emergency outpatient visits), resulting in reduced medical expenses. We consider that understanding maternal uncertainty based on all five categories is useful for health care professionals who deal with mothers of children with ACI in a clinical setting.

This study had some limitations. First, the findings might be specific to Japanese mothers, who tend to be reserved [32]. Social factors may have affected our results because there were few supporters with experience of child-rearing surrounding the mothers due to the declining birthrate and widespread nuclear family situation in Japan. It is therefore necessary to additionally investigate maternal uncertainty across various cultures to standardize our results. Second, the degree of each category was not determined and may vary with individual background and the child's condition. We need to make more accurate and individual assessments of maternal uncertainty at each stage in the course of a child's illness. Based on our results, it may be necessary to develop a scale that measures maternal uncertainty for acute childhood illnesses to investigate the actual levels of these categories of uncertainty.

5. Conclusion

When their children had ACIs, mothers experienced uncertainty about the severity, cause and course of the illness, judgement of health care professionals, and management. Uncertainties due to "lack of information about causes of the illness" and "ambiguous appropriateness about management" were characteristic of perceptions among mothers with children who had ACIs. Uncertainty should be explored further in relation to individual background and stages of the child's illness to ensure that mothers can be given appropriate support. Prior to discharge, it is particularly important for healthcare professionals to help mothers build confidence in childrearing while understanding these uncertainties.

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Experiences of Occupational Stress among Emergency Nurses at Private Hospitals in Bangkok, Thailand

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Abstract

Introduction: Occupational stress has negative effects on employee's health and organizational productivity. Nurses in emergency department are more exposed to stress than nurses in other departments. **Aim:** To explore nurses' experiences of occupational stress in emergency departments in private hospitals in Bangkok, Thailand. **Design:** A descriptive qualitative design, with a deductive approach based on the Job Demand-Control-Support model was used. **Methods:** Fifteen emergency department nurses at two different hospitals were interviewed and the data were analyzed using a manifest content analysis. **Results:** Three main categories: "work context is an issue", "consequences of reactions to stress", and "coping with work stress", including seven sub-categories emerged from the data analysis. **Conclusion:** The patients' and their relatives' behaviors were experienced as the primary stressor at the private hospital, in addition to excessive work tasks. Other important stressors were misunderstanding and conflicts between emergency department nurses and the other health care professionals, presumably related to hierarchy and power relations between health care professions. Creating a better working environment and a balance between the number of patients and nurses would reduce workload and stress, encourage ED nurses to stay in the profession and ultimately maintain patient safety.

Keywords

Emergency Department, Emergency Room Nursing, Occupational Stress, Private Hospitals

1. Introduction

Nursing is considered a stressful occupation, particularly in emergency depart-

ments (ED), where nurses encounter unpredictable events and specific stressors, such as trauma, violence, acute life-threatening conditions, sudden death and overcrowding [1]. Furthermore, they report more time pressure, higher job demands, lower decision-making authority, fewer adequate work procedures and fewer rewards compared to general hospital nurses [2]. ED nurses in public hospitals in Thailand have reported problems with heavy workloads, stressing situations involving patients and their relatives, violence in the ED, lack of skill improvement, low income, and difficult relationships within the nursing team. These problems affected the ED nurses' physical and mental health, family relationships, job satisfaction, and the quality of their nursing care [3]. Emergency care is also provided in the private care sector, but less is known if the experience of stress among ED nurses is the same as in public care sector. Therefore, the current study focuses on ED nurses' experiences of occupational stress in private hospitals in Thailand.

2. Background

Karasek and Theorell [4] defined occupational stress using the Job Demand-Control-Support (JDCS) model, which describes interactions between demands, control and support at work. Job demand refers to any psychological demand at work such as workload or time pressure. Job control dimension is divided into two aspects including skill discretion, which refers to the opportunity of skill used by the employee in his or her workplace, and decision authority refers to the autonomy of an employee to make a task-related decision by themselves at work. The support dimension refers to the overall support at work that is available for a worker [4]. According to the model, employees who experience high psychological demands with low level of job control and low social support are likely to have a greater risk of stress and to suffer from poor health [4]. Occupational stress occurs when job requirements mismatch workers' capabilities, resources, or needs. It can cause a variety of psychophysiological health-related problems and may have important consequences for the organization [5].

Previous studies have shown that occupational stress leads to negative consequences for ED nurses, such as stress-related psychophysiological illnesses, increased arousal and feeling of uneasiness [1] [3] [6] [7]. Due to this, ED nurses have higher rates of absenteeism and sick leave, decreased work performance [2] [8], more work-home conflicts and more intentions to leave the profession compared with nurses who work in other environments [2]. These effects relate to both ED nurses' considerable psychological job demands and to a perceived lack of supervisor support [8]. Ultimately, the consequence may be impaired patient care [2].

The current study focuses on ED nurses working in private care in Thailand. The majority (89.5%) of the registered nurses (RN) in Thailand work in the public sector [9], where the care is funded by the government. In contrast, private hospitals require patient payment, usually through self-pay, private health insurance or employer-provided health insurance, but occasionally also through

the Social Security System [10]. Differences in patient populations between public and private hospitals have been described; people with low-income use public and people with middle- to high-income tend to use private hospitals [11]. Due to economic expansion, globalization, international trade, and medical hub policies in Thailand [12] the number of private hospitals have increased [10] [13]. They host primary, secondary and tertiary care under the same roof and provide specialized care and treatment, including high-technology surgery. The services aim to meet all the patients' needs and expectations, but the payment system favors patients with high incomes [14]. Public and private hospitals should provide the same standard of nursing care for all patients [15]. Nursing practice in Thailand is also influenced by Thai culture and beliefs, especially from Buddhist perspectives [16]. In relation to nursing, the "kreng jai" concept implies that junior nurses have to pay respect to both senior nurses and physicians [16]. This can, for example result in that junior nurses may have to carry out tasks that senior nurse or physicians require them to do, even if they do not feel comfortable with it, which may influence their decisions regarding nursing care.

Tyson and Pongruengphant [17] studied stress in nurses in both the public and the private sector. They found that high workload, involvement in circumstances concerning life and death, interruptions of nurses' work by management, and performing tasks considered physicians' duty, caused stress among nurses in private hospitals. Raungsrijan and Suppakitiporn [18] showed that 63% of the nurses in a private hospital had high levels of stress, which was associated with disrespect from patients, colleagues and supervisors. Most studies in this area are quantitative and few qualitative studies have specific focus on ED nurses' experiences of stress in private hospital. Therefore, the aim of the current study is to get a deeper understanding of nurses' experiences of occupational stress in EDs in private hospitals in Bangkok, Thailand.

3. Methods

3.1. Study Design

A descriptive qualitative design, with a deductive approach based on the JDCS model was used.

3.2. Setting and Participants

Semi-structured interviews were conducted between May and August 2013. Twenty-eight ED nurses from two large private hospitals were recruited. The hospitals have more than 200 inpatient beds each and provide a variety of treatments and health care services. Therefore, the participants were likely to have relevant experience in emergency care and a broad perspective of stressful situations. The inclusion criteria were RNs of either gender who worked full-time and had at least one year of experience in emergency care. RNs with less than one year of experience in emergency care or were working part-time were excluded. All ED nurses working at the two hospitals ($n = 28$) were invited to participate; 11 were excluded because they had less than one year of experience in

emergency care, and two ED nurses were not willing to participate. All had a bachelor degree in nursing science and worked at a nurse practitioner level. The demographic information of the participants is shown in **Table 1**.

3.3. Data Collection

The interview guide (**Table 2**) was based on previous studies [1] [3] [19]. Some interview guide questions were inspired by the JDACS model [4], for example “Could you tell me about your job description and your responsibility in your position?”, related to job demand, and “Do you think you have control over your work tasks? Work situation? Working hours?”, related to job control. During the interview (performed by the first author), follow-up questions were used to obtain a better understanding of the participants’ experiences. The interviews were performed during the nurse’s work hours (morning, evening, or night shift). Each participant was interviewed in a private room in the ED or in a private location of his or her choice. The interviews lasted until data saturation was obtained, between 25 and 80 minutes.

3.4. Data Analysis

The audio-recorded interviews were transcribed verbatim by the first author (NY) and translated into English. The transcriptions were reviewed by a professional linguist to confirm their accuracy, consistency and to determine conceptual equivalence. A content analysis [20] with a deductive approach based on the

Table 1. Description of the participants demographics (age, gender, job experience and marital status).

Demographic information	(n = 15)
Age; Md (range)	27 (20 - 39) years
Gender; f/m	12/3
Emergency care experience; range	1 - 10 years
Marital status; single/married	12/3

f = female, m = male, Md = median, n = number.

Table 2. Interview guide, including 7 questions and examples of follow-up questions that could be asked to get a better understanding of the respondents’ answers.

1. Could you tell me about your job description and your responsibility in your position?
2. Do you think you have control over your work tasks? Work situation? Working hours?
3. Can you choose your work tasks? How?
4. Could you tell me what is stressful in your workplace according to your perception?
5. Would you please describe why these factors cause stress in your workplace?
6. Does the stress in your workplace influence your health? In what way does it affect your health?
7. Does your workplace offer you resources/possibilities/facilities to cope with work stress? If yes, what? If no, why?

Follow-up questions:

Could you describe that experience?

How do you feel about this situation?

How does this situation makes you feel stress?

JDCS model was used to conceptually describe the nurses' experiences of occupational stress. The analysis procedure is depicted in **Figure 1**.

3.5. Ethical Approval

The study was approved by the Regional Ethical Review Board in Uppsala, Sweden (Dnr. 2013/087) and the research ethics committees of the included hospitals in Thailand. The study was conducted in accordance with the Helsinki Declaration. Written consent was obtained before the interviews began.

4. Results

Three main categories, including seven sub-categories, emerged from the data analysis and are shown in **Figure 2**.

4.1. Work Context Is an Issue

This category described what the participants experienced as causes of stress in the EDs in private hospitals. The main causes were related to the participants' workplace context, and described by three sub-categories.

4.1.1. Encountering the Excessive Work Tasks and the Nature of ED Work Characteristics

The work characteristics of the ED were sources of stress. Providing urgent nursing care to critically ill patients implies working under pressure and in unpredictable situations. Multiple work tasks and excessive work hours, and in particular, tasks beyond the nursing role made them experience a high level of

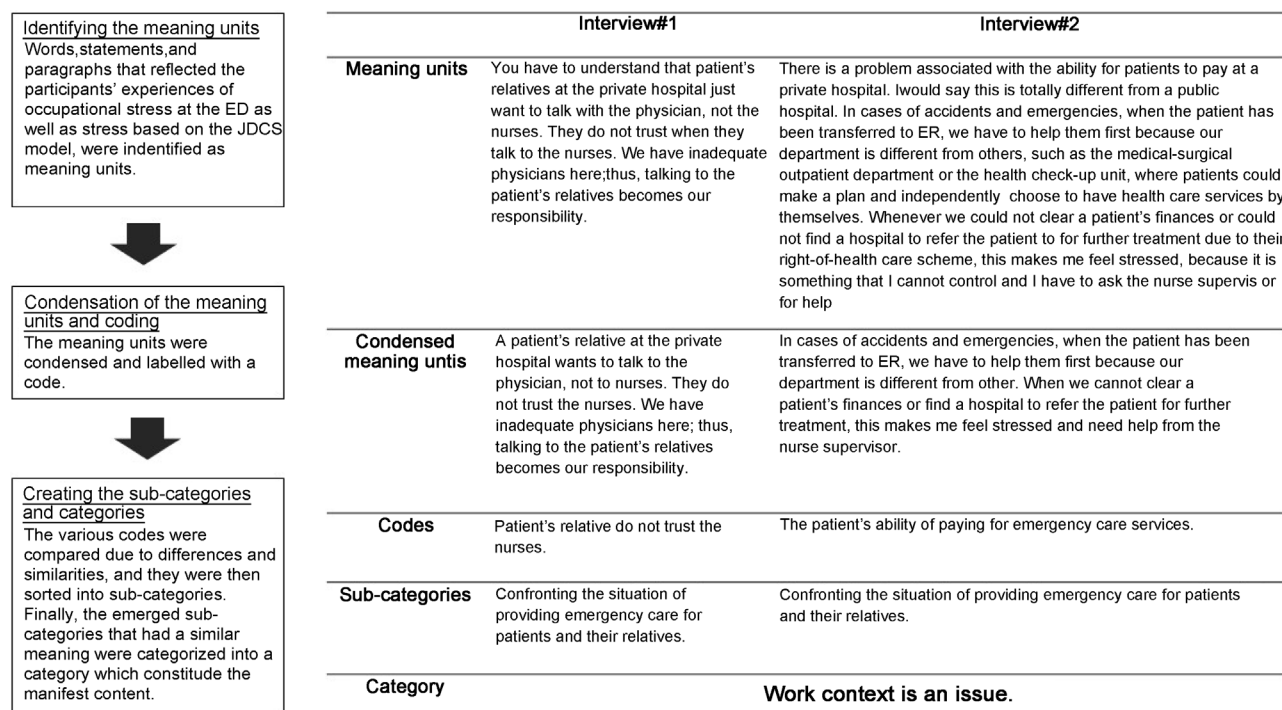


Figure 1. Example of the analysis process from identifying to condensation of meaning units to finally creating sub-categories and categories.

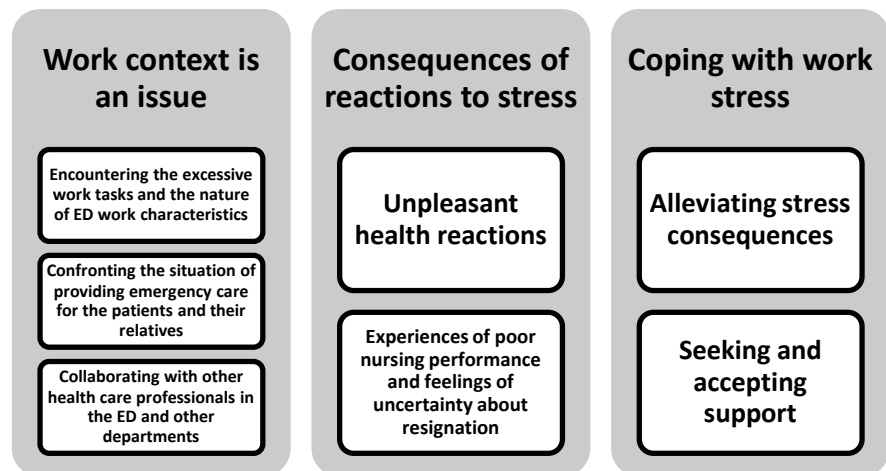


Figure 2. The result showing the three categories and seven sub-categories that emerged from the analysis.

stress. They described having to perform physicians' tasks while waiting for the physician to arrive at the ED and perceived these circumstances as uncontrollable situations at work: "If we keep waiting for them (physicians), the patient might get worse. We are on the front line; we must do something, inevitably" [RN5]. The senior ED nurses had to concurrently perform several tasks; simultaneously caring for patients assigned to junior nurses and their own patients. One senior ED nurse stated:

I have to take care of them (newly graduated nurses), as a mentor ... It is like double tasks at the same time because I have to take care of my assigned patient, the newly graduated nurses, and their assigned patients! This make me stressed because of too many tasks at the same time [RN5].

Lack of work experience was also associated with stress. The participants who had only worked 1 - 2 years in the ED experienced problems with work management and decision-making. When they were in charge, they felt that they could not manage both their work tasks and their colleagues, particularly the senior nurses. A high number of patients and a shortage of nursing staff also increased workload and stress: "They (hospital directors) reduced hiring of new staff. This leads to shortage of nursing staff, and sometime there is a high workload, too many patients and not enough nursing staff. This makes us stressed" [RN7].

4.1.2. Confronting the Situation of Providing Emergency Care for the Patients and Their Relatives

The participants described the situations of providing emergency care for patients and their relatives as the most common stressor including unpredictable patient conditions, waiting time for treatment, and the patient/relatives misunderstanding of the triage system. The medical service at an ED relies on the priority of patients with more severe conditions; however, the participants described that some patients and their relatives did not understand that and felt

that they should be treated with the same priority as patients with severe conditions:

A patient came to the ED with a common cold, but another patient came with a severe cut. The one who had the common cold did not understand and demanded to be treated first. He/she did not listen to us and perceived that he/she had the right to be treated the same as the patient with the severe condition [RN7].

Private hospital patients and their relatives also had high demands and expectations because they paid a high fee for medical and nursing services. Sometimes they behaved disrespectfully, which had a detrimental effect on the participants. Moreover, the participants explained that in Thai culture, people value physician more highly than nurses and feel like nurses are not health care professionals:

They (patients and their relatives) just want to talk to the physician, not with the nurse because they do not believe and respect us as a health care professional. As you know, in Thai culture, the people give a high value to a physician, not a nurse like us [RN3].

The participants described that the ED differs from other healthcare facilities, such as the medical-surgical outpatient department, where patients can book an appointment with the physician when they are in need of care and treatment. In contrast, when someone has an accident and arrives at the ED, hospital policy requires the ED staff to provide health care whether the patient can pay or not. The participants indicated that this situation was a cause of stress:

In cases of accidents and emergencies, when the patient has been transferred to ED, we have to help them first because our department is different from others... When we cannot manage a patient's finances issue or find a hospital to refer the patient for further treatment... this makes me feel stressed [RN9].

4.1.3. Collaborating with Other Health Care Professionals in the ED and Other Departments

Working with other health care professionals in the ED and other departments was expressed as a stressor and contributed to conflicts among ED nurses, nurses in other departments and other health care professionals, such as pharmacists and particularly physicians. Some physicians rarely provided treatment according to the hospital treatment guidelines, which led to conflicts between the ED nurses and the physicians: "They (physicians) do not follow the treatment flow or guideline of the hospital's treatment standard. In this case, I have no power to address them because I am just a nurse in a practitioner level" [RN9]. Such conflicts created misunderstandings and miscommunication among ED nurses and other health care professionals. They also depended on the hierarchy and the differences in power relations among health care professions. One junior ED nurse described her experience: "It is like a colleague who is older than me, such as nurse aid or practical nurse sometimes, I ask them to

do something, but they do not listen and do not do what I ask them for” [RN2].

The ward nurses, especially the intensive care unit (ICU) nurses, often refused to receive patients from the ED or demanded the ED nurses to perform all of the nursing procedures for patients before the ICU accepted them. This resulted in conflicts between ward nurses and ED nurses: “They (ICU nurses) are rather fastidious when we have to transfer patients to them. They ask so many questions, and we have to do everything completely before transferring a patient to them. So this makes me feel stressed” [RN10].

The participants described conflicts among the emergency nursing team, particularly personal conflicts related to people’s particular behaviors. These conflicts led to an inability for the nurses to work together: “It is like I am in the team that... let’s say it simply: we do not get along well. We cannot work together, just work independently” [RN11].

4.2. Consequences of Reactions to Stress

This category reflected the ED nurses’ reactions to stress consequences, mainly related to ill health and responses to their work at the ED.

4.2.1. Unpleasant Health Reactions

Stress in the ED commonly triggered psychophysiological ill health. One ED nurse described her experiences with poor physical health experiences: “I get headaches when I feel stressed; it is so tense, and I feel very uncomfortable! And also stomachaches, as always ... Yes, when I feel stressed, I get them all the time” [RN14]. Another ED nurse shared her experiences of poor psychological health caused by occupational stress: “Stress makes me feel unhappy at work. I feel frustrated, and then I keep quiet and do not want to talk to anyone” [RN6]. The nurses also reported social problems when they encountered stress at work. This problems mainly affected relationships with their family and partner: “Sometimes I have arguments with some of my family members or my boyfriend” [RN2].

4.2.2. Experiences of Poor Nursing Performance and Feelings of Uncertainty about Resignation

Stress in the ED contributed to feelings of uncertainty about whether to leave or continue working at the current workplace among the ED nurses: “I thought that it would be nicer to work in a private hospital than in a public hospital, but now I want to resign from here and work in a public hospital instead. I have stress here” [RN2]. Furthermore, the ED nurses described their experiences that stress affected the delivery of nursing care. They provided incomplete nursing care, and they worked more slowly because of stress: “Stress affects my nursing care. I may forget to do something to complete the physician’s order... I may forget to send the blood specimen to the laboratory. There are errors sometimes, I would say” [RN4].

4.3. Coping with Work Stress

This category described the ED nurses’ attempts to cope with work stress and

contained two sub-categories: alleviating stress consequences, and seeking and accepting support.

4.3.1. Alleviating Stress Consequences

The ED nurses stated three types of coping behaviors including avoidance, debriefing, and positive reframing. Some described that when they were on duty and experienced stress, they walked away from the situation for a while and returned when they felt better:

If I feel stressed while I am working, I will take a break, walk away, and then I will come back to fix the problem. The reason that I walk away is so I can plan and think about how to solve the problem [RN3].

In the workplace, debriefing by talking with colleagues, especially close and trusted ones, was an effective method of stress release among the emergency nursing team: “I do have a talk with colleagues when I feel stressed, and it helps a lot. Especially the closest one because it is like we feel the same” [RN11].

They also alleviated stress while they were at work by turning stress into a challenge and thinking positively: “I fight it (stress) by smiling (smiles). Sometimes I like it. They (the patients) ask me many questions, and I give them a lot of information as well. It is like a challenge” [RN4]. Additionally, they described several stress-releasing methods in daily life, such as sleeping, exercise, and making merits and meditating according to Buddhist practice. The effectiveness of these coping behaviors depended on the individual’s conception of life.

4.3.2. Seeking and Accepting Support

The organization provided some support for reducing employee stress, for example, by providing sports activities: “There is no stress-relief program or anything like that at this hospital. The hospital director just gives us a stress assessment survey. Whoever gets a high stress score is sent to consult with the psychiatrist” [RN4]. The greatest support described came from colleagues, head nurses, and nurse supervisors. That support consisted primarily of debriefing and discussing the problem at work, which relieved the participants’ stress and enabled them to continue working. Although they described receiving some support from their department and organization, the participants noted that it was inadequate and that they needed additional support at work. Another source of support that they requested from the organization was extra income: “Well, as nurses at a private hospital, we expect to earn more ... The hospital director should support us more in this (extra payment)” [RN5].

5. Discussion

The sources of stress found in the current study were related to the three dimensions in the JDCS model. “Work context is an issue” reflected the nurses’ experiences that involved the psychological demand and limited job control at the ED. The ED work characteristics, such as excessive work tasks, heavy workload, and extended work hours caused stress among the ED nurses, as has previously

been described [1] [2] [6] and could be seen as high psychological demands [4]. Work requirements beyond nursing, e.g. performing physicians' tasks and being a mentor for new junior nurses, also caused stress. Limited decision-making authority (job control) and being in an uncontrollable situation, interfered with their capacity to complete their tasks [3] [17]. The sub-category "seeking and accepting support" reflected the nurses' experiences of inadequate support at work. When there is high demand, low control, and low support at work, a high-strain situation in the workplace can develop and lead to negative health outcomes [4]. This was observed in the category "consequences of reactions to stress" in the current study.

The ED nurses in the current study experienced patients' and their relatives' behavior as the primary stressor, due to their lack of understanding about the ED triage system, in which treatment is provided according to the severity of the patient's medical state [21]. The patients and their relatives have higher expectations and demand more from private hospitals since they pay by themselves for health care services [22]. In contrast, no disrespect from patients and their relatives were reported by the nurses at a public hospital [3], presumably since public hospital patients have different expectations and demands compared with private hospital patients. Providing clear information about waiting times and what to expect at the ED can prevent such a misunderstanding [23].

Administrative tasks regarding the patients' ability to pay also caused patient-related stress, since the medical procedures must be the first priority in emergencies [24]. To simultaneously consider a patient's potentially serious medical condition and pay ability generates a stressing ethical dilemma. This problem does not exist at public hospitals [3]. On the other hand, the violence experienced in public hospitals was not reported at the private hospitals [3].

The ED nurses described that patients and their relatives did not trust them and only valued physicians, reflecting the view of the Thai society. Physicians have higher status [16] and nurses are viewed as simple assistants [25] [26]. This may be one reason for the negative reaction that the nurses experience from patients and their relatives.

The interviews also revealed conflicts among ED nurses, within the emergency nursing team and with other health care professionals, especially with physicians. Various levels of professional hierarchy and an unclear intra-team power distribution can cause a simple disagreement to deteriorate into serious conflict, as described by Janss *et al.* [26].

Occupational stress can lead to poor psychophysiological health and negative social interactions, especially with family members [1] [5]. Work-related stress reactions also contribute to incomplete and delays in nursing care [3], which can lead to impaired patient safety [27]. Some study participants in the current study considered leaving the ED because of occupational stress and job dissatisfaction. This could lead to shortage of ED nurses [28], and the shortage of nurses leads to more stress, causing a vicious circle.

Some participants coped with stressful situations in the ED by taking a break,

making a plan and returning to solve the problem, according to Folkman and Lazarus's theory of emotion-focused and problem-focused coping [29]. In contrast to in the public hospitals [3], the ED nurses also coped with stress by turning it into a challenge, viewing it as an opportunity to demonstrate professional competence. These different reactions to stress can be described as cognitive appraisals [29]. A primary appraisal refers to the determination and assessment of events, which occur in the environment and the secondary appraisal involves an assessment of the person's ability to cope with the event. It can be interpreted as that the person only experiences stress if he or she perceives and judges the event as stressful and feels that he or she is unable to cope with it.

The ED nurses in the current study received support from other ED nurses, nurse supervisors, the ED head nurse, and the nurse manager. This support included debriefing and discussing the handling of stressful situations; the participants experienced this support as an efficient source of stress management, consistent with the findings of Healy and Tyrrell [30]. Some nurses referred to meditation and Buddhist practices as means of personal stress management and reported these methods to be effective. They could represent a difference in coping strategies between Thai and Western populations, as reported by Tyson and Pongruenphant [31]. The hospital managers provided some activities aimed at relieving stress, but the nurses perceived these to be insufficient and stated that higher salaries could be a source of work-related support. Financial rewards, as compensation for stressful work is reported to have beneficial effects, e.g. on workforce stability, occupational satisfaction and the performance of high quality work [32].

The occupational stressors experienced by the ED nurses at both types of hospitals may be related to the nature of the ED, where nurses confront a variety of stressors that inevitably includes a heavy workload, trauma and non-trauma patients with critical conditions and other crisis situations [1] [2] [6] [7]. Consequently, nurses at both types of hospitals report a number of similar sources of stress.

6. Methodological Considerations and Limitation

Despite the small number of participants, the responses and the lively discussion during the interviews generated data saturation. The interviews were performed by a native Thai speaker (the first author), who also translated the transcripts into English. When direct translation was not possible, a conceptual equivalent was used. A professional linguist approved the English translations and the analyzed data in English (from codes to categories). The co-authors reviewed and checked the results by verifying the meaning and confirming the categories. However, some of the phenomena noted in this study related to the Thai culture and may not be completely transferable to a Western context.

7. Conclusions and Implication

The work context and situations are important sources of stress among ED

nurses in private hospitals. In particular, patients' and their relatives' lack of understanding of the triage system led to disrespect, a stressor that is not encountered in public hospital settings. Conflict among ED nurses and other health care professionals, sometimes related to the hierarchy and power relations among health care professions, causes stress. Feelings of uncertainty about continuing working or leaving the profession were also a consequence of occupational stress among ED nurses. Hence, stress may lead to shortage of ED nurses. The working environment for ED nurses needs to be improved by, for example, developing and/or revising the regulations and policies regarding work task assigned for ED nurses, and not forcing them to perform tasks beyond nursing care, as well as creating strategies for counteracting a shortage of nurses. As the nurses in the study suggested, the organization should consider increasing the nursing staff to create a better balance between the number of patients and nurses. A better working environment, and balance between the number of patients and nurses would reduce workload and stress, encourage ED nurses to stay in the profession and ultimately maintain patient safety.

The results of this and other studies could be used to develop an instrument for measuring stress in emergency departments. Such an instrument is useful for measuring the effect of stress-reducing efforts to improve the working environment of emergency departments.

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Perceived Program Components of *Omotenashi Family Experiences Learning Program* in Japan: Qualitative Study of Families of Persons with Mental Disorders

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Abstract

Families need sufficient learning opportunities about mental illness. Therefore, family peer education program has been developed in Japan following the U.S. and Hong Kong. We aimed to identify program components that families recognize which would provide suggestions in modifying the program. We used qualitative and inductive study design. Data were collected through group interviews for six family research participants. We coded the data to focus on relationships between program components, program processes, and impacts. Data Analysis resulted in seven assumptions based on causal relationships and three types of program components: program form, learning style and facilitation skills. The program form is family-led peer group, closed-membership, 5 times per course, and small group. The learning style is combination of textbook and experiential knowledge, family peer learning, and sharing experiences. The facilitation skills are group work focusing on strengths of family members, the acceptance of emotional disclosure, *omotenashi*, and teamwork skills.

Keywords

Mental Disorders, Schizophrenia, Family Support, Family Education, Program Evaluation, Program Component

1. Introduction

Among developed countries, Japan is widely known to have a high psychiatric

bed ratio. Mental health policy in Japan has shifted its emphasis from hospitalization to community-based services. However, 85% of families live with persons with severe mental illness and provide day-to-day care themselves [1]. The education is the most-needed form of support for their families [2] and is often provided by nurses in psychiatric hospitals and community setting; over 20% of families surveyed reported that it took more than three years for them to gain sufficient information about the mental illness of their loved ones in Japan [3]. To promote a national policy of deinstitutionalization, families should have sufficient opportunities to learn about mental illness.

In the US, the National Alliance on Mental Illness (NAMI) developed family peer education programs—the Family-to-Family Education Program (FFEP) in 1991 [4] and Journey of Hope (JOH) in 1993 [5]. These programs have provided by local family groups and have spread throughout the country. Another program, Family Link Education Program has developed in Hong Kong in 2000 [6]. These family peer education program models are one of family education models and are different from family psychoeducation models. Family education models are independent of treatment and focus on improving family own outcomes [7]. A project team of family members and professionals discussed possible solutions and possibilities of the adaptation of existed foreign programs. After the discussion, they developed their own original family peer education program *Omotenashi Family Experiences Learning Program (Omotenashi-FELP)* in 2007. This program takes into account cultural and social differences faced by families in Japan, as opposed to by families from other countries. By the end of March 2015, this program had spread, serving over 1500 families in Japan.

Ninomiya conducted pre- and post-evaluations of the program, and demonstrated the effectiveness of the program in the reduction of anxiety and the empowerment of both family attendees and facilitators [8]. The *Omotenashi-FELP* was developed based not on social-science theories but on the ideas, experiences, and thoughts of family members. We considered that identifying program components from the perspectives of families would provide additional suggestions in terms of modifying to more effective and efficient program. Thus, this study aims to identify program components of the program that families recognize.

2. Methods

2.1. Study Design

We used qualitative and inductive study design. This is a secondary analysis for a qualitative study to describe the process that *Omotenashi-FELP* has impact on family attendees, family facilitators, family groups and other surrounds.

2.2. General Description of the Program

The *Omotenashi-FELP* is a systematic learning program with a peer learning style and small group size. Each course is held on 5 sessions (approximately 3 hours per session). Courses use an 85-page simple mental health psychoeducational textbook, and the material is communicated by a team of family facilitators.

tors. Textbook includes knowledge regarding symptoms and treatment of schizophrenia, rehabilitation for serious mental illnesses, and family coping. All facilitation teams consist of three-six family facilitators who have undergone a one-day training course.

2.3. Research Participants

The research participants were all family members from the project team composed of seven family members and five professionals. They played core roles in developing and disseminating the program for four to five years until 2012. Only one declined, citing illness. Four research participants were women, and two were men. Two of them are in their 50s, 60s, and 70s, respectively. All of them had children who were diagnosed with schizophrenia (duration: ≥ 10 years). They had served as family facilitators in two-four courses, family advisers (who train and advise family facilitators) >10 times, and lecturers in training sessions or lessons 6 - 31 times each.

2.4. Data Collection

Data were collected through semi-structured group interviews lasting approximately 2 hours. Interviews were conducted once at the associations to which each of the six research participants belonged; a total of three group interviews were conducted. The first and second authors who were qualified nurses on the project's team conducted the interviews. The interviews began with the following questions that were answered by each individual: "What were your experiences from the time of your family member's onset of illness?" Next, all of the interviewees were asked the following question to obtain information about the program's implementation: "How was the program conducted?" We also asked each interviewee, "What changes did you notice in yourself or your ill family member and your family's group activities during and after your time as a facilitator?" Interviews were recorded and transcribed with the research participants' permission. In addition to the interview transcripts, we included the following program-related materials in our analysis: program manuals, training materials, articles published in family association newsletters, and published essays.

2.5. Analysis

Weiss [9] suggested that the program evaluation shows the assumptions underlying the program and theories that support the assumptions. To identify causal relationships between program components, program processes and impacts that developed to the assumptions, we first extracted research participants' descriptions regarding program components and the changes caused by them, from all interview transcripts and supplementary materials. Next, according to the causal-consequence model that is one of coding way [10], we coded the data to focus on program components of causal relationships between program components, program processes, and impacts in order to clarify important program components and their impacts rather than to find leading program com-

ponents of targeted impacts. To make valid assumptions of the perceived program theory, we confirmed if the causal relationships can be supported by social-science theories, and research participant-based evidence.

After we created tentative assumptions, research participants were asked to discuss them in a meeting, in which we explained the assumptions, our interpretations of the data, and supportive theories or evidence. We encouraged research participants to discuss and correct the assumptions until all agreed with them. This study was conducted under the supervision of a richly-experienced researcher in qualitative studies.

2.6. Ethical Considerations

The study was approved by Saitama Prefectural University, with which one of the coauthors is affiliated. Research participants were informed of the purpose and methods of the study, that participation was voluntary, and that they could refuse to participate or withdraw from the study at any time. They were also assured of their anonymity, and their written consent was obtained.

3. Results

Analysis of the interview transcripts and supplemental materials resulted in seven assumptions. We discussed the perceived validity of their findings with research participants. After minor modifications, they agreed to the seven assumptions, which are discussed in detail below. The program components, program processes and impacts identified from the seven assumptions are shown in **Table 1**. The words with quotation mark are extracted from families' descriptions.

3.1. Small, Closed Groups Facilitated by Family Members Highlight the Universality of Family and Create High Cohesion; This Leads to a Positive Group Dynamic

The *Omotenashi-FELP* program has the basic structure of a family-led peer group. These groups have closed membership and meet five times each. Research participants appreciate this structure that has “enough time to learn and communicate” which leads to develop rapport with one another. This structure supports recognition of human universality, addressing feelings of being different and alone. The cultivation of feelings of universality helps family attendees to realize that “it was not only me” same as we are all in the same boat by Yalom & Leszcz [11]. This universality is a therapeutic factor of the group format and a powerful source of relief in the early stages of group development [11].

Family facilitators and attendees engage in “open and honest dialogue” characterized by equal interaction without distinctions of status. The efficacy of such a structure is supported by theories on group dynamics and the functioning of self-help groups. Horizontal rather than vertical interaction among members is a structural characteristic that predicts good functionality in self-help groups [12]. This type of interaction is related to cohesiveness and is a key basis for positive group dynamics [11]. The importance of this point is highlighted by quotes

Table 1. Seven assumptions and program components.

Types of program components	Assumptions	Program processes	Impacts
Contents of program components			
Program form			
Family-led peer group	1) Small, closed groups facilitated by family members highlight the universality of family and create high cohesion; this leads to a positive group dynamic.	Universality High cohesion Positive group dynamics	
Closed-membership			
Five times per course			
Small group			
Learning style			
Combination of textbook and experiential knowledge	2) A textbook-based learning style in which experiential knowledge is shared leads to increased knowledge, insight, and self-awareness.	Insight Self-awareness	Embeddedness of knowledge
Family peer learning	3) A family-led peer learning style decreases loneliness and promotes both self-acceptance of disability and embeddedness of knowledge.		Reduced isolation Disability acceptance Embeddedness of knowledge
Sharing experiences	4) Understanding persons with mental illness and learning how to handle difficulties through sharing experiential knowledge improves family relationships.	Self-awareness Hope	Better family relationships
	5) Some families find hope by sharing their experiences with other families and serving as models for other families. They look back on how far they have come to understand the extent of their own recovery.		
Facilitation skills			
Group work focusing on families' strengths	6) Group work focusing on families' strengths and the acceptance of emotional disclosure is linked to reduced self-stigma.	Catharsis	Reduced self-stigma
Acceptance of emotional disclosure			
Omotenashi	7) Group facilitation with Omotenashi and teamwork skills in family facilitators accelerate interaction among group members.	Higher interaction Positive group dynamics	
Group facilitation with teamwork skills			

from a family attendee which were printed in a family association newsletter and a research participant' interview:

"When I found out that other families live with the same thoughts and prayers under the same sky, it was heartening to realize that I am not alone".

"It is important for family facilitators and attendees to be equal, not hierarchical, so that everyone feels safe talking about themselves".

3.2. A Textbook-Based Learning Style in Which Experiential Knowledge Is Shared Leads to Increased Knowledge, Insight, and Self-Awareness

In the *Omotenashi-FELP*, family facilitators and attendees share their own experiences after reading sections of the psychoeducational textbook. They affirm that the process "organizes all of the pieces of my experience into one whole experience", with the textbook serving as "a catalyst to talk about experiences". A simple textbook is more effective than a complex one, as it prompts families to recall their own experiences associated with the information. Speaking about their experiences in conjunction with the textbook leads families to "place and interpret the knowledge personally" or understand the knowledge in light of their own experiences. This is supported by *local understanding* in narrative

therapy. In this context, *local* refers to the language, meaning, and understanding developed during dialogue rather than broadly held cultural sensibilities. One interprets memories, perceptions, and histories through local understanding [13].

Research participants also said, "...speaking about myself makes me organize my own story and helps me to see myself from a third-person perspective", which leads to gains in insight and self-awareness. This is supported by the creation of a narrative through self-reflection and its communication to others [14]. Gergen & Gergen [15] define self-narrative as an individual's account of the relationships between life-relevant events across time; they believe that this process imparts life with meaning and direction. As one research participant stated:

"Through the process of combining knowledge with experiences, I came to understand that this symptom was also present in my family; I realized that what I had been worried about was this illness-related problem. This way of organizing my experiences has been helpful to me".

3.3. A Family-Led Peer Learning Style Decreases Loneliness and Promotes both Self-Acceptance of Disability and Embeddedness of Knowledge

A sense of isolation is fostered when a person does not accept his/her family member's mental illness. A family member of a person with mental illness might investigate what is happening with the person who is ill through independent study. However, when answers cannot be found, isolation ensues; this is the stage of discovery and denial in family recovery [16]. Through family-led peer learning, families can gradually accept the presence of mental illness; such acceptance forms the basis of all other learning. Once families have accepted this knowledge, it is considered to be *embedded*. FFEP attendees also gain knowledge, information, and support together [17]. Although no theory directly supports synergy between knowledge embeddedness and acceptance of disability, the research participants believed that "families cannot absorb knowledge without acceptance of disability". Several research participants emphasized that important point in interviews and an article:

"I was afraid that I would read a book and think, 'My son might change as described in this book'. I knew it was necessary to learn, but I associated knowledge on this topic with what was happening with my son, and it was difficult to accept my son's illness. Learning by myself fueled feelings of isolation".

"Families listen to other families who say they feel the same way and realize that they do not have to deny their feelings. It is hard to accept a family member's mental illness. However, though feelings of acceptance may waver, one can proceed steadily in the program".

3.4. Understanding Persons with Mental Illness and Learning How to Handle Difficulties through Sharing Experiential Knowledge Improves Family Relationships

Experiential knowledge that is truth learned from personal experience with a phenomenon [18]. Through sharing knowledge on textbook and experience

knowledge in this program, families come to understand mental illness and learn to communicate with those who have it. As one family attendee said in the last class, “Now I am the person who understands my son best”. Through the program, families have improved their communication and relationships with mentally ill family members. This assumption is supported by problem-focused theory on stress coping [19]. Through the program, families share their experiential knowledge in order to learn valuable coping skills, which in turn strengthen family relationships. One research participant stated:

“My relationship with my son changed dramatically through this program. I used to ask my son often about his job prospects, but I learned in this program that it is better not to ask about that. After I tried not to ask him, he began to tell me spontaneously about things with which he was struggling. In recent years, he has given me flowers on my birthday”.

3.5. Some Families Find Hope by Sharing Their Experiences with Other Families and Serving as Models for Other Families. They Look Back on How Far They Have Come to Understand the Extent of Their Own Recovery

In the program, families in different stages of caring for persons with mental illness share their experiences with each other. Some families who were still in the early stages became inspired by contact with those who had trod the same path, raising their expectations regarding their own possibilities. Yalom [11] refers to this *instillation of hope* as one of the therapeutic factors of group psychotherapy. When families at later stages watch others follow their example, they see their progress and become aware of the extent of their own recovery. A family attendee and a research participant stated how they were inspired by other families:

“The most impressive thing was the self-introduction by the family facilitators. All of the facilitators enjoy different hobbies and interests, and they all seem to live cheerful, vigorous, hopeful lives. When I saw the facilitators speaking about themselves so vigorously, I became hopeful that I would be able to enjoy my life as well”.

“The stories told by families in the early stages reminded me of how I felt in the beginning—it was tough even to prepare food. Compared with how things used to be, my son and I are now even more cheerful than I had thought possible”.

This assumption was first written as, “Family attendees hope that they may serve as future models, and family facilitators become aware of their own recovery”. However, a research participant suggested that it is not necessary to distinguish between attendees and facilitators, because they all learn from each other. All research participants agreed with this suggestion, leading us to change this assumption to its final form.

3.6. Group Work Focusing on Families’ Strengths and the Acceptance of Emotional Disclosure Is Linked to Reduced Self-Stigma

Families of persons with mental illness suffer from public stigma, prejudice, and

discrimination. Self-stigma occurs when people internalize these negative public attitudes and suffer adverse consequences as a result [20] [21].

The group work skills focused on families' strengths are used in this program. Family facilitators are trained in the skills with the metaphor of the boiled egg [22] [23]: Families must cope with the yolk of worries and difficulties, but the white of coping surrounds the yolk; this arrangement maintains the structure of the egg. Group work focusing on strengths is intended to elucidate family members' intrinsic strengths and lead them to "focus consciously on what families can do (the white of the egg)". This is similar to the strengths-based approach, which focuses on things the families are doing right and envisions life after they have overcome the problem [24].

This strengths-based work is supported by the reduction of self-stigma that results from the empowerment of families to share difficult stories and allow themselves to be accepted by their peers [20]. This approach also has elements of *catharsis*, one of Yalom's therapeutic factors. Discharging suppressed emotions that "could not be told because of shame" is therapeutic only in the context of genuine attempts to understand oneself or others [11]. A family attendee and research participants said the following in a newsletter, an article, and an interview:

"The family facilitators listened to us carefully and never contradicted us; they found things to praise and treated us warmly. It was very comforting to me".

"Family attendees who discharge their suppressed, painful experiences are then accepted by peer families. Through this process, they reaffirm their intrinsic power which they intent to accept objective realities, though they have ever considered reality negatively".

"A family attendee had hidden his son's illness to his relatives. However, during this program, he changed his attitude and decided to disclose the mental illness. I felt that he had relieved some of his self-stigma and taken a load off his mind".

3.7. Group Facilitation with Omotenashi and Teamwork Skills in Family Facilitators Accelerate Positive Group Dynamic and Interaction among Group Members

Family facilitators learn and practice basic group facilitation skills with the mind of *omotenashi*. In this program, a Japanese word *omotenashi* means "thoughtfulness towards family attendees, so that they feel a satisfaction in coming; offering a courteous welcome to other family attendees with hurt feelings and appreciating their painful experiences". Such a skill is necessary for successful group facilitation that leads to positive group dynamic. Japanese culture has long implemented *omotenashi* into its customer service philosophy in order to meet guest expectations [25].

The equal teamwork among family facilitators practice working together as equals while they prepare for and run the program. Good teamwork also accelerates positive group dynamics, which in turn are developed through between-

member interaction; as would be expected, teams with higher levels of cohesion due to active member interaction are expected to have better performance [26], which is supported by theories on teamwork. As one research participant wrote in a journal:

“The family facilitators meet many times during group preparation to discuss how to make family attendees feel satisfied with their participation. The process produces effective teamwork and egalitarian relationships in which the facilitators appreciate each other. As a whole, good teamwork leads to positive group atmosphere”.

4. Discussion

This study describes the seven assumptions underlying the program that families recognize.

4.1. Program Components

As shown in **Table 1**, we identified three types of program components: program form, learning style, facilitation skills. Assumption 1 includes program components regarding program form: family-led peer group, closed-membership, 5 times per course, and small group. Ninomiya [8] showed that higher fidelity on program form leads to decrease isolation of family facilitators. In this study, research participants recognize that such a form relates to program process including universality, high cohesion, effective group dynamics rather than direct outcome.

The program components regarding learning style are also found: combination of textbook and experiential knowledge, family peer learning, and sharing experiences. The research participants considered that such components lead to program process including insight, self-awareness and hope, and that the family attendees and facilitators reached outcomes including embeddedness of knowledge through such program process.

The assumption 6 and 7 include program components regarding facilitation skills: group work focusing on families' strengths, the acceptance of emotional disclosure, *omotenashi*, and teamwork skills. The research participants considered that increased interaction promotes the discharging suppressed emotions leading to the reduction of self-stigma. These results give additional considerations to the previous study that facilitation skills and attitudes of family facilitators were related to increase self-efficacy of family attendees [8].

Based on positive group dynamics caused by program form (Assumption 1) and group facilitation (Assumption 7), knowledge-related experience sharing leads families to couch their knowledge in an intimate and relevant context, which allows them to gain insight and self-awareness (Assumption 2). This family-led peer-learning style produces a synergetic effect by combining knowledge embeddedness and acceptance of disability (Assumption 3). Through sharing their experiences, they also learn how to handle the related issues (Assumption 4) and many families find hope and become aware of the extent of their own re-

covery (Assumption 5). Families recount their own experiences while simultaneously reading the textbook; by accepting themselves openly and being accepted by their peers, they reduce their self-stigma (Assumption 6). We discussed the relationships between seven assumptions and reached a conclusion that all program components are connected with sharing experiences. Therefore, the core component of this program might be sharing experience.

4.2. Significance of Sharing Experiences

When they share their experiences with each other, family members of persons with mental illness are allowed to tell their stories that were too difficult to tell previously. These not-yet-said stories can adversely impact one's identity, since the self is developed through telling one's own story [27]. Telling stories about themselves led families to organize their own stories and see themselves from an outside perspective; through this, they gained insight and self-awareness. People come to know who they are through sharing themselves with others [14]. People live and understand their lives through socially constructed narrative realities, which give meaning and organization to their experiences [13]. In the program, families share and understand their experiences by co-constructing narrative realities with others. As the families realized that "I felt the same as [the others]", their mutual acceptance and empathy was strengthened. This empathy tends to be especially deep and can be perceived as more meaningful than sympathy from those who have not experienced a mental illness in the family.

Self-help groups aim to provide a safe place for people to tell their stories [27]. In this program, no one advises anyone else; the families listen to each other with respect, knowing that all group members are equal, and they understand each other's pain. Through this program, family attendees tell their important not-yet-said stories, which are accepted by other members; in turn, this allows them to accept their own true selves. This is similar to the process undergone by clients and therapists in private therapy, in which not-yet-said stories are co-created mutually [13]. The not-knowing actions and attitudes of therapists express a need to know more about what the client has said [13], similar to the attitudes of group members in this program. In this program, the telling of not-yet-said stories leads to a change in the tone of the narrative from negative to positive. While this program differs from professionally facilitated therapy, it has many features in common with narrative therapy.

4.3. Recommendations and Limitations

This study identified program components that extracted from recognition of families who have developed and disseminated the program. We will revise the fidelity scale in response to the results for a more effective and efficient program. This study showed detailed descriptions of program components that could be useful for future family peer learning programs in other countries.

One of limitations might be discussion environment in the group setting. We asked research participants to discuss until agreement about tentative assump-

tions. Its environment could have led to bias in favor of adopting any proposal mentioned. However, to address the limitation, we tried to encourage their opinions freely not to impose. Another limitation might be that the program components are perceived ones not objective ones. We need to verify their validations by quantitative studies in the future.

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Navigating the Storm of Deteriorating Patients: Seven Scaffolds for Simulation Design

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Abstract

Recent trends in simulation use have necessitated a more considered approach in the use of this teaching/learning tool. The aim of this research is to discover ways to improve simulation as a teaching/learning platform. Action research was used to answer the question, “How can I improve pedagogical practices with undergraduate nurses in simulation?” This study was implemented at a University in Auckland, New Zealand between November 2012 and March 2014. A purposive sample was sought from second and third-year nursing students (n = 161) enrolled in the three-year undergraduate bachelor of nursing program. Methods included focus groups, questionnaires, debriefing sessions, pre- and post-tests, and Lasater clinical judgment rubric analysis. Seven instructional scaffolds emerged which maximized student learning and retention. These scaffolds: 1) helped move students from known into unknown knowledge; 2) provided situated coaching; 3) modeled expected performance; 4) gave opportunity for improvement; 5) reduced confusion; 6) taught effective communication; and 7) promoted new learning through debriefing. These strategies resulted in a simulation experience which improved clinical reasoning in undergraduate nursing students.

Keywords

Simulation, Undergraduate Nursing Education, Scaffold, Deteriorating Patient

1. Introduction

Simulation as a teaching tool has been used in nursing education for over 100 years [1] [2]. However, simulation in its multiple current contexts is a form of inquiry learning which has the potential to assist students in the development of deeper understandings of complex clinical situations [3]. This is an essential requirement in undergraduate nursing education where clinical opportunities

continue to develop in complexity while diminishing in availability.

This research emerged out of a need to understand how educational philosophy impacts simulation design, and how to best apply educational scaffolds to support student learning [4]. Seven pedagogical scaffolds are offered as key insights to guide simulation design in order to prepare students to manage the “storm” of a deteriorating patient situation [5], with the ultimate aim of preparing students to manage the complex clinical settings for which they are destined.

2. Background

2.1. Scaffolding in Simulation Design

Developing a simulation program involves more than purchasing a manikin [6]. The belief that content knowledge and clinical experience alone will produce safe, confident and effective students is likely fiction [7]. Simulation design and implementation requires a knowledge of appropriate philosophical underpinnings [8] along with an ability to communicate effectively and safely with students during simulation [9]. Scaffolding is a learning approach designed to promote deeper understanding [10]. It is the support given during the learning process which is tailored to the needs of the student. The intention of scaffolding is to help students achieve the learning outcomes of the simulation while developing in cognitive and social skills [3].

2.2. Types of Educational Scaffolds

In education, scaffolding refers to a variety of instructional techniques used to move students progressively toward deeper understanding and, ultimately, greater independence in the learning process [11]. Different types of scaffolds are required in order to best support students’ recognition of clinical deterioration [12] [13]. There are several types of scaffolds which can be used to move students forward in their understanding. McLoughlin ([4], p. 128) outlines these below:

- 1) **Conceptual scaffold:** Cues or hints which help students to reach a solution;
- 2) **Coaching scaffold:** Direct teaching strategies or heuristics;
- 3) **Feedback scaffold:** Providing progressive feedback while the task is being undertaken;
- 4) **Reflective scaffold:** Encouraging reflection on tasks by asking the student to self-monitor their approach; and
- 5) **Modeling scaffold:** Providing an example or demonstration of expected performance.

Simulation, as a teaching tool, encourages more active participation and interaction among students because students “do not just watch the simulation, they are the simulation” [14]. This approach enables students to become immersed in an augmented learning environment in which they take an active role in their learning process and construct new understandings of abstract concepts in complex learning situations. Scaffolding is an essential aspect of

this process.

3. Methods

Participant rights in this research were protected and subject to institutional review board approval. Following ethics approval, this study employed action research with the intention of developing a living theory [15] of educational practice. Three investigative cycles were employed to answer the question, “How can pedagogical practices be improved when working with undergraduate students in simulation?” [8]. The aim of this research was to discover ways to improve simulation as a teaching/learning platform used with undergraduate nursing students. After student identification of helpful strategies, interventions were categorized into different scaffold categories [4]. Seven instructional scaffolds [4] emerged from this research which became key elements for improved simulation design [8].

This study was implemented at a university in Auckland, New Zealand between December 2012 and April, 2014. Interpretation of data was informed by the writings of John Dewey [16] [17] [18], whose thoughts on experience and education have been foundational in changing habit formation (acquired ways of using and incorporating the environment) and subsequent integration of habits into how we think and act.

3.1. Action Cycle One

Cycle One involved two focus groups which explored the current context of simulation in undergraduate nursing [8]. A one-hour revised simulation was created embedding themes emerging from focus groups. This revised simulation invited focus group participants to give feedback on changes made. Thematic analysis was completed from the perspective of examining emerging values that informed practice, and then developing criteria and standards of judgment intended for practice improvement [15] [19]. An example of this analysis can be seen in **Table 1**.

Table 1. Example of thematic analysis.

Original sentence examples	Free Node (Code)	Tree Node (Category)	Theme
<i>What I really hate about the simulation is the glass. I d love the educator to be down on the floor with us.</i>	Anxiety-producing	Supportive learning environment	Situated teaching in room by facilitator
<i>Being in the simulation knocked my confidence. When you're running around like headless chickens you think, "When this does happen in the hospital, am I going to know what to do?"</i>	Anxiety producing (decreased confidence)	Supportive learning environment	Facilitator training in debriefing
<i>I do not think we have enough opportunities. We should be doing one a week.</i>	Practice	Simulation opportunities	Scaffolded simulation program
<i>Knowing at the beginning what is expected of us would have been helpful, rather than being chucked as a group into the room. They just start the simulation and we wonder what it is we should be doing.</i>	Lack of orientation	Simulation design	Sound pedagogical underpinnings in design
<i>If we go from the parenting thing, we know the educators can ride a bike. We need to have the training wheels on at first until we can gain the confidence to take the training wheels off.</i>	Practice	Simulation opportunities	Scaffolded simulation program

3.2. Action Cycle Two

Cycle two embedded student suggestions made in cycle one. This cycle involved second year students who participated in the newly designed scenario which employed pre- and post-questionnaires to determine the most valued instructional elements. The following changes were made to the simulation:

- More time was allotted (1.5 hours) for the simulation and debriefing.
- Students were oriented to the simulation room before scenario.
- Pre-briefing to the simulation was given.
- Educator came out from behind the one-way glass and stayed in the room.
- Students were allocated one of four roles.

In Cycle Two, students completed a pre- and post-simulation questionnaire [8]. The responses from these questionnaires were transcribed and thematically coded in the same manner as described in Cycle one [15] [19]. Emerging themes were used to design a simulation suite for Cycle Three.

3.3. Action Cycle Three

Cycle Three involved students moving through a simulation suite of three scenarios (hypovolaemic shock, croup, acute coronary syndrome) [8]. The students proceeded through a specific sequence of instructional events for each scenario, and moved through the scenarios in a specific order (repeated measures design). A 10-question pre-test began the simulation experience and closed the simulation experience for each scenario. The pre- and post-test results were collated and analyzed using SASTM data analysis software.

The students' second performance in each scenario was analyzed by two educators using the Lasater Clinical Judgment Rubric [20]. This data was analyzed using SASTM data analysis software in order to see student changes in clinical judgment as they progressed through the simulation suite.

3.4. Participants

Recruitment methods for this research varied within each cycle. Cycle one recruited participants via student university email and involved students from all three years of an undergraduate nursing program ($n = 15$). Cycle two recruited volunteers via an intermediary in the second year of the nursing program ($n = 125$). Cycle Three employed recruitment via university email to final semester nursing students which quickly expanded to snowballing as students began to recruit through a student-operated FacebookTM page ($n = 21$).

Sample size involved no power calculation and was dependent upon student availability and snowballing (cycle three). Participants were all between the ages of 18 and 32 years at the time of this research. Four participants were male, the remainder female. All participants were enrolled in a three-year bachelor of nursing program in Auckland, New Zealand. Participants were 54% European, 22% Asian, 9% Pasifika, 6% Maori, and 9% undeclared.

Confidentiality was maintained by way of using aggregated data and/or pseudonyms. Informed consent was obtained after reading the prepared information

sheets. Participants consented to being photographed and videoed during all three cycles of this project. Researchers stressed throughout that no judgements of educational or clinical practice were being made and that decisions regarding participation would not affect future education or employment.

3.5. Data Analysis Cycle One: Understanding Nature of the Storm

Themes emerging from thematic analysis [15] [19] in Cycle one included 1) erosion of student confidence in current simulation practice; 2) need for stated learning outcomes before simulation commencement; 3) need for educator training in simulation facilitation; and 4) need for a scaffolded simulation program throughout the undergraduate degree [8]. Students were remarkably clear about erosion of confidence and need for educator training in simulation facilitation:

“I feel sick on the days I have to go into the SIM room—literally sick. No confidence. I feel awkward the whole time. It is too quick, and the situations are complex which isn’t really necessary (Focus Group 1, Cycle One)”.

Students desired to be gently moved through the simulation instead of being exposed to what felt like an out-of-control situation. The need for stated learning outcomes was voiced in the following comment:

“Going over it [the learning outcomes] before the simulation helped us. We could check the BP and make sure we could hear everything, and review how to do the nebulizer. The devil is often in the details in an arrest and it’s those little things that can trip you up (Debriefing, Cycle One)”.

The need for educator training in the facilitation of simulation was voiced by the following student:

“We need to have the training wheels at first until we can gain the confidence to take the training wheels off. It would be better to say, ‘Keep the wheels on until you can go to the end of the driveway by yourself. When I was learning to ride a bike, my dad would run beside me and say, ‘You’re going to fast!’ I need the lecturers to do the same thing (Focus Group, Cycle One)”.

This comment, along with many others, expressed the need for educator training in simulation design and facilitation. We had the equipment, but we now needed the training in order to build an effective undergraduate simulation program.

3.6. Data Analysis Cycle Two: Beginning to Navigate the Storm

Cycle two yielded a prioritization of instructional scaffolds which were valued by students and contributed to their learning. The four most valued educational components of the revised simulation were: 1) educator modeling of expected simulation performance; 2) opportunity to repeat simulation after feedback given; 3) supportive debriefing after simulation; and 4) using the ISBAR tool to obtain support from other professionals.

In regards to modeling of expected performance, one student stated:

“The role play that [the educator] did in the middle was really helpful to show

us all of the roles needed and assessments that needed to be done (Questionnaire, Cycle Two)”.

In regards to repetition, the comment was made:

“[Repetition] helped immensely. It gave me an opportunity to ‘right what was wrong’. Being told what went wrong, and then leaving it at that is not enough for me to know that I have learnt it properly. (Questionnaire, Cycle Two)”.

Supportive debriefing during and after the simulation was voiced as follows:

“In the past, the lecturers needed to have a more positive attitude when giving feedback [debriefing]. Historically we had lecturers who ‘told us off’ for the negative aspects of practice with no emphasis on even a tiny bit of positive aspects of our practice (Questionnaire, Cycle Two)”.

The simulation employed in Cycle Two involved a deteriorating situation in which students were required to recruit assistance of other professionals using the ISBAR tool (Identify, Situation, Behavior, Assessment, Requirement). The use of the ISBAR tool was identified as the fourth most valued educational component in the simulation. One student stated:

“I feel more confident as I now know effective communication skills [through ISBAR]. I mostly appreciated learning that in a live situation we must be fully prepared before calling doctors as being hung up on in reality would be extremely humiliating (Questionnaire, Cycle Two)”.

Communication is key to management of safe patient care. Ultimately, Cycle Two students requested a simulation suite be available in their final semester in order to prepare for entry to professional practice. Thus, Cycle Three emerged.

3.7. Data Analysis Cycle Three: Surviving and Learning from the Storm

Cycle Three provided some insight as to the effect of simulation on content knowledge. As can be seen in **Figure 1**, within each scenario the post-tests improved overall. The focus group comments showed improved student confidence and a feeling that content knowledge was growing as evidenced by the following comment:

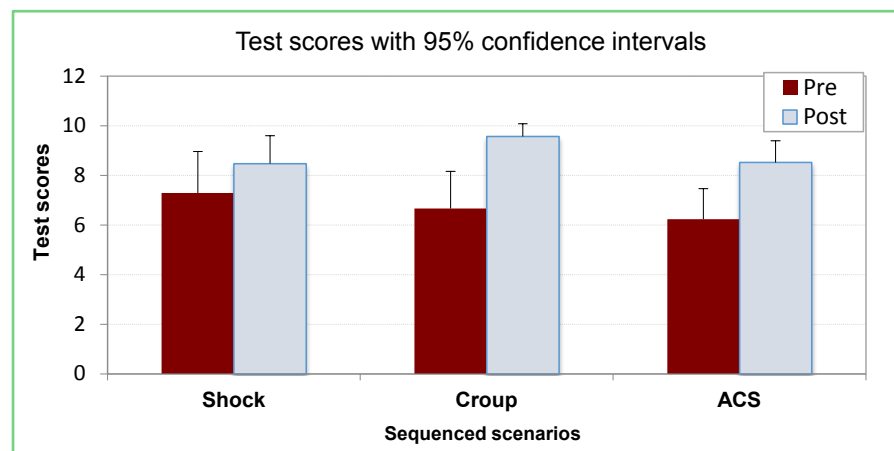


Figure 1. Average pre- and post-simulation scores by scenario.

“I liked the pre- and post-test because I could see my improvement. It makes you aware of what you do not know also (Focus Group, Cycle Three)”.

An interesting aspect from the pre- and post-test data involved a measure of variability called the standard deviation (SD). Standard deviation is a descriptive statistic which indicates the variation from the average [21]. This becomes important in educational research for determining the mastery of subject matter. A smaller standard deviation is desirable indicating a greater degree of mastery over the subject.

The standard deviation for the three scenario test results were 1) hypovolaemic shock SD = 1.94; 2) croup SD = 1.63; and 3) acute coronary syndrome SD = 1.23. The standard deviation decreased as the students progressed through the scenarios. This indicates that the students were showing progression in their ability to master the subject matter. This improvement in content knowledge was echoed in the focus groups:

“Seeing the progress is what is satisfying to us. Seeing ourselves get better really satisfies us personally. Because we know we can improve (Focus Group, Cycle Three)”.

The students also commented on the powerful influence of modeling on their learning:

“With the pediatric simulation I noticed when [my partner] and I did the simulation first time we went for the IM injection first. When we watched the model clip we noticed the educator did the nebulizer first. That made sense as it [the adrenaline nebulizer] acts faster in the lungs than the IM injection. So we changed that order of medications for our second attempt because that made sense (Focus Group, Cycle Three)”.

Figure 1 shows the pre- and post-simulation test scores. As can be seen in **Figure 1**, within each scenario the post-tests improved showing a positive influence of the simulation experience on content knowledge. Secondly, the pre- and post-tests highlighted a marked improvement of students in the second of the three scenarios (*i.e.* croup). The overall improvement in scores of pre- and post-tests across the three scenarios was as follows:

- **Hypovolaemic shock:** Average improvement of 1.2 points between tests
- **Croup:** Average improvement of 2.9 points between tests
- **Acute coronary syndrome:** Average improvement of 2.3 points between tests

Research has shown that it is possible to enhance performance by warming students up to tasks in the educational environment [22]. This is known as the *warm-up effect*. Thus, a possible explanation for the higher scores in the croup scenario might be the *warm up effect* resulting in an increase in the second set of scores by nearly three points. The degree of improvement in the third scenario was not as great as the second, possibly due to the *fatigue effect* [23] influencing student performance after two previous hours of simulation.

By the time the students had completed two scenarios (one hour each), it is possible fatigue began to influence their performance in the final scenario. Re-

search has shown that with progressive multiple choice testing, there is a point where fatigue or boredom can influence test results in the opposite direction, and thus increase the variance and errors in test results [23]. This fatigue effect may have influenced the test scores in the third scenario explaining why the overall improvement in scores dropped from the second to the third scenario. This concept must be taken into consideration in overall simulation design when using multiple scenarios.

Cycle three employed the Lasater rubric [20] which evaluates students in four areas: 1) noticing; 2) interpreting; 3) responding; and 4) reflecting. The Lasater scores showed improvement in clinical judgment as students progressed through the scenarios (Figure 2). This data demonstrates that simulation as a teaching platform, can improve students' ability to notice, interpret, respond and reflection on deteriorating patient conditions. This ability is pivotal to patient safety [24].

When asked about the effects of simulation on her overall performance as a nurse, one student summed it up stating:

"...just being able to hold a space in an emergency situation has improved. Even my knowledge and interventions grew and we learned more as we progressed (Focus Group, Cycle Three)".

This renewed confidence coupled with an improved ability to manage deteriorating situations was keenly felt by students participating in the simulation suite.

4. Discussion

Simulation of real-world settings in which students construct knowledge through active participation in learning increases student engagement [25]. From this research, seven strategies emerged which operated as scaffolds in improving student performance and engagement while managing the "storm" of a deteriorating clinical situation. It is important that designers of simulation become adept at using scaffolds to assist students in constructing effective clinical

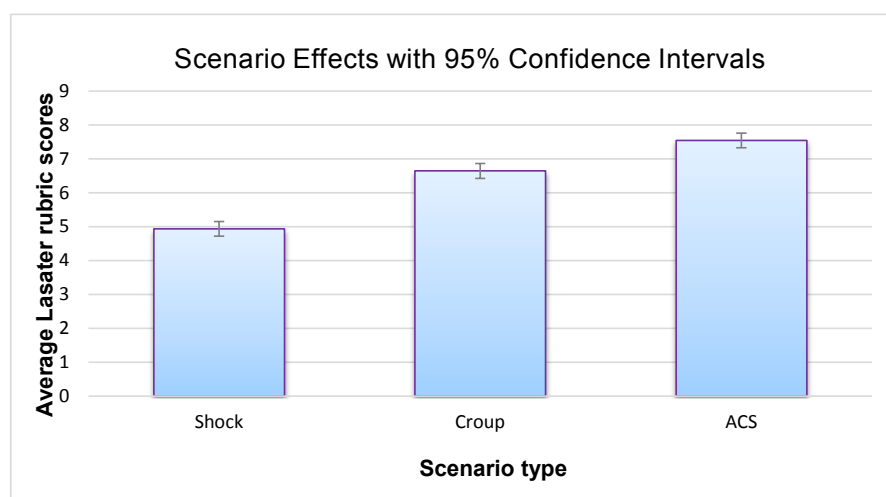


Figure 2. Average Lasater rubric scores by scenario.

management strategies. Seven scaffolds emerged from this research which helped guide students as they constructed their own learning in the management of deteriorating clinical situations.

4.1. Scaffold One: Understand the Basic Causes of the Storm

In order to gently introduce students to the scenario, a pre- and post-simulation test were employed. The test was designed to highlight what the student knew about the causes and contributing factors of the particular deteriorating situation they would encounter in the simulation. The causes of the deterioration were outlined in the pre-briefing (a video podcast of 7 minutes) [8]. Scaffolding as an instructional design technique is often used to bridge learning gaps, highlighting the difference between what students have learned and what they are expected to know [4].

The pre- and post-tests were a form of *conceptual scaffolding* in that they hinted to ways students might reach a solution in managing the “storm”. Because the tests were administered before and after the simulation, they were also a form of feedback given within the simulation learning package (feedback scaffold). In nearly every case, post-tests showed improved scores over pre-tests (Figure 1). The pre- and post-tests gave the students a sense of progress, confidence, and accomplishment as they progressed through the “storm” of caring for a deteriorating patient.

Simulation should engage the student’s activities in a way which is at once both enjoyable, and at the same time inspires future learning. Dewey ([18], p. 27) states, “no experience lives and dies to itself”. Every experience lives on in future experiences. The pre- and post-tests had the effect of “living on”. The students encountered the “storm” first in the pre-test, and again in the post-test. They sensed their improvement in knowledge and clinical reasoning, and wanted to continue to experience this by participating in more simulation. This strategy provided concrete and visible evidence of student progress, which is integral to successful navigation of the simulation storm.

4.2. Scaffold Two: Providing Course Correction in the midst of the Storm

Students in the focus groups in cycle one shared that simulation educators “behind the one-way glass” unnerved them, and created a sense of competition between students and educators which destroyed their sense of a supportive learning environment. This strategy of working alongside students during the simulation provides progressive feedback while the task is being undertaken [4]. It is a form of coaching scaffold providing expected feedback in the midst of the storm.

John Dewey ([17], p. 90) emphasized that, “... the meaning of native activities is not native; it is acquired”. Meaning develops when students interact with a matured social medium. In the context of simulation, the matured social medium is the educator. When the educator is in the simulation with the students, helping them navigate the storm, feedback can result in new understandings

based on a combination of previous knowledge woven together with new ideas.

Some [9] term this form of interaction with students situated teaching. It involves coaching the student through what is salient (most notable and significant) about a specific clinical situation. Ultimately, if this process is occurring regularly and in a safe environment, students will begin to develop clinical imagination and the skills of clinical reasoning [26]. This ability to translate knowledge from pathophysiological, pharmacological, and skills silos, into concerns and actions for a particular patient, is the gold nugget of immersive classrooms [27] [28].

4.3. Scaffold Three: Modeling Best Practice in Managing the Storm

Students in the second action cycle rated modeling by the educator as the most valuable aspect influencing their performance in the simulation. According to McLoughlin [4], modeling is another form of scaffolding which assists students in revising their own performance. Dewey [18] emphasized that a revised performance requires new habit formation. The formation of new habits requires a change in the conditions or context of the learning environment [17]. In this case, modeling provided a changed context which had direct influence on student performance [8].

Dewey [18] explains that modeling expected performance allows for impulse formation. An impulse is a turning point, a point of deviation which begins a new course of response to a problem [17]. Impulses are the starting points for assimilation of new knowledge, which paves the way for the integration of new habits. To the constructivist, learning is a result of the student integrating this new knowledge into current problem-solving processes [29]. The content is not delivered, but constructed in a learner-centric, team-based, collaborative learning environment. Through modeling, new information was “delivered” which the students could use to navigate to safety.

4.4. Scaffold Four: Perfecting New Skills for Navigating the Storm

Students in cycle two stated that the second most valued aspect of the simulation was the allowance of a repeat performance. Allowing for repeat performance, after feedback is given, is a form of conceptual scaffolding [4] which helps students to reach a final solution. Repetition asks students to self-monitor their approach and improve which is also a form of reflective scaffolding [4].

Repetition is a valuable aspect of behaviorist and cognitivist philosophical thought [8]. Repetition combined with reinforcement can assist learners in retaining new knowledge [30]. Cognitivists echo this sentiment stating that repetition ensures that habits are formed which will be embedded into long-term memory [31], thus reducing cognitive load on working memory [32]. Repetition allows for the storing of automated skills ready to be used in the next storm [31] [33]. Repetition as a design scaffold has also been used to allow for refined skill performance and offer a path to skill improvement [34].

4.5. Scaffold Five: Ensuring Every Sailor Has a Role in the Midst of the Storm

Students in all three action cycles stated that creating roles helped them to manage clinical deterioration with greater efficiency and confidence. Designing the simulation so students perform within a role is a conceptual scaffold [4] which assists students to manage the storm of a deteriorating patient while working within a team. They might feel intimidated with managing the entire situation alone, but working within a role is “safer” as no one individual bears the entire weight of the situation.

Additionally, roles help to reduce cognitive load, the amount of processing required to integrate new information by the working memory [32]. Roles assist students to manage the new information more efficiently resulting in renewed confidence and competence. Simulation design should consider the load on working memory (which can only cope with 5 - 7 new pieces of information), while encouraging automated skill formation [33]. This form of conceptual scaffolding helps maximise learning while reducing the sense of being overwhelmed by the simulation storm.

4.6. Scaffold Six: Calling for Help to Ensure Survival of the Storm

The use of the ISBAR (*I*dentify, *S*ituation, *B*ackground, *A*ssessment, *R*equirement) tool was the fourth most valued interventional scaffold identified by students. Teaching the use of this tool is a coaching scaffold [4] which allows students to improve in their ability to elicit assistance. It provides a standardized structure of communication which helps both parties to prioritize information while decreasing the chances of omitting relevant information. It also helps to decrease assumptions by making the reason for the communication obvious at the outset.

These comments are aligned with the importance of clear and concise communication shown in the literature [35]. Failures in communication have been estimated to be the major factor in 60% - 70% of serious incidents [36] in the United States. In a large review of reportable adverse events that led to permanent disability in Australia, 11% were estimated to be attributable to communication issues [37]. It is interesting to note that this is almost double that attributed to inadequate skill levels in practitioners. The students felt that the ISBAR tool kept them focused when stress and other confounding factors were producing anxiety and distraction. In essence, it enabled them to better manage the complexity of the situation, and in educational terms it reduced the load on working memory [32] [38].

4.7. Scaffold Seven: Reflecting on How to Better Manage the next Storm

Debriefing is a reflective scaffold [4] which encourages students to self-monitor and self-assess. It is a means of reflecting with the educator and peers as to ways they might improve in managing the storm when it reoccurs. Debriefing weaves

together the students' prior understandings with new knowledge in a manner which helps clarify confusion [17].

Dewey [17] explains that in order to create educative learning environments, the means (intermediate steps) are as important as the end (the final thought/act). Debriefing is an intermediate step, very close to the end, which allows students to move in a scaffolded manner from knowledge acquisition (pre- and post-tests) to problem solving in the simulation, to reflection on the simulation. The job of a simulation educator is to carefully manage the means by embedding scaffolds to guide students to the desired end. Debriefing, when employed as a reflective scaffold, surfaces new insights and ways of managing the storm.

These instructional events are categorized into scaffold types in **Table 2**. Each instructional event serves a particular purpose in assisting students to navigate the simulation storm of managing a deteriorating patient.

5. Limitations

This study was limited by the number of participants involved. Small numbers in the third action cycle constrained generalizability. In order to make appropriate applications to practice, further research could use a similar design to the third action cycle with approximately 100 students in each scenario (acute coronary syndrome, croup, hypovolemic shock).

Another limitation in the study was a lack of training for raters in the *Lasater Clinical Simulation Rubric*. Due to time constraints, the raters were not upskilled resulting in compromised interrater reliability. This could be amended by training all raters in the use of the Lasater rubric before data collection. Taking this extra step would improve the internal validity of the study.

6. Conclusions: Seven Scaffolds to Manage the Simulation Storm of Deteriorating Patients

In this research, seven scaffolds were employed to help students manage a simulated deteriorating patient situation. Clinical deterioration in patients is similar

Table 2. Scaffolds used for instructional events.

Instructional event	Scaffold used	Purpose of Scaffold
Pre- and post-simulation tests	Conceptual & Feedback Scaffold	To assist students in understanding the basic causes, signs, symptoms, and treatment of a deteriorating patient condition
Work alongside in situated coaching	Coaching & Feedback Scaffolds	To improve problem-solving and enhance critical thinking
Model expected performance	Modeling & Reflective Scaffolds	To provide an example of expected performance while allowing students to reflect and modify their own performance
Give opportunities for improvement	Conceptual & Reflective Scaffolds	To encourage student self-monitoring with a mind to improve overall performance while improving patient outcomes
Allocate roles	Conceptual Scaffold	To assist students to perfect one role while reaching final goal of saving patient and working effectively within a team
Teach effective communication (ISBAR)	Coaching Scaffold	To allow students to call for assistance in a deteriorating patient situation
Debriefing	Reflective and Feedback Scaffolds	To encourage students to self-monitor and self-assess while improving overall performance

to navigating a “storm on the open seas”. As on the seas, the ultimate end of poor patient management could be severe loss or even death. The seven scaffolds highlighted in this research are in actuality seven instructional interventions. In summary, the seven scaffolds are: 1) understanding basic causes of the storm; 2) providing course correction in the midst of the storm; 3) modeling best practice in managing the storm; 4) perfecting new skills for navigating the storm; 5) giving every sailor a role in the midst of the storm; 6) calling for help to ensure survival of the storm; and 7) reflecting on how to better manage the next storm.

None of this is hard. Nevertheless, at the nursing school where this research was conducted, these scaffolds were not being enacted prior to the work done in this research. They are simple strategies that underpin a learning experience that excites, engages and grows the confidence and competence of students.

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A Comparison between Patients' and Residents' Perceptions of Patient Centeredness and Communication Skills among Physicians Working at Jordan University Hospital

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Abstract

Aim: This research aims to evaluate patient-centeredness and communication skills from the patients' point of view and that of the physicians' point of view and compares the two outcomes. **Methods:** This was a cross-sectional study with a convenient sample of 418 patients and 94 residents. Instrument of the study was a structured questionnaire that aimed to evaluate patient centeredness and communication skills of the residents. **Results:** Residents gave themselves a significantly higher score than the score given to them by patients in most studied aspects such as the extent to which the doctor discussed the patient's problem, the extent to which the doctor explained the problem, the doctor introduced himself, the doctor greeted the patient properly and others. The only aspect for which patients gave residents higher score than that residents gave themselves was the extent to which the doctor asked the patient about what is expected to be done (ECG, CT scan, giving antibiotics, ...). **Conclusion:** A transformation from doctor centered approach to patient centered approach is needed.

Keywords

Communication Skills, Patient-Centeredness, Residents

1. Introduction

The Institute of Medicine (IoM) considers patient health care to be patient centered if it is "respectful of and responsive to individual patient preferences,

needs, and values and ensures that patient values guide all clinical decisions” [1].

Patient centered care can have a number of definitions in the literature, and different authors focus on various aspects of this kind of patient care. However, it is common among all references that patient centered care means the kind of care that is individualized to each patient, and takes into account the whole person during the treatment process [2] [3].

Another vital aspect of patient care is the patient-doctor communication. It is well known that good patient-doctor communication has a strong effect on treatment outcomes including symptoms management. This kind of communication can make a consultation either succeed or fail to deliver the expected outcomes [4].

The challenge lies in measuring the levels of patient-centeredness and communication skills among health care providers, as there should be some clear definition of patients’ needs in this regard. It should be taken into consideration that patients have certain image of the “good doctor”, and they build this image based on what they expect from their physicians like perceiving health care provider’s empathy [4] [5].

For the purpose of improving the health services delivered to patients, it is important and of vital role to assess the levels of patient centeredness and communication skills not only from the patients’ perspectives, but also from the perspective of health care providers. This can pin point the gap between the needs of the patients and the perceptions of health care providers [6].

The results of such a study may have their own positive effect on patients, society, and health care systems and may provide baseline data for health care planners and for further research in his field.

Up to the authors’ knowledge, this will be the first research in Jordan that addresses the issue of evaluating patient-centeredness and communication skills of physicians. This research aims to evaluate patient-centeredness and communication skills from the patients’ point of view and that of the physicians’ point of view and compares the two outcomes.

2. Methods

This was a cross sectional study with a convenient sample of 418 patients; and 94 residents working at Jordan University Hospital, Amman, Jordan.

Instrument of the study was a structured questionnaire that aimed to evaluate patient centeredness and communication skills of the residents. Two versions of the questionnaire were used. The first one was directed to the patients and consisted of two parts: the first one about general socio-demographic characteristics of participants, including age, gender, education level and medical insurance. The second consisted of 12 questions evaluating patient centeredness and 13 questions evaluating communication skills. Doctors’ version of the questionnaire consisted also of two parts: the first part comprised general information about the doctor such as level of residency, and the year and country of graduation as

an MD (Medical Doctor). The second part included the same 12 questions evaluating patient centeredness and 13 questions evaluating communication skills. The questions were rephrased to help doctors to self evaluate themselves. Items of the questionnaire were based on Patient Perception of Patient Centeredness questionnaire [7] and on the Membership of the Royal College of Surgeons (MRCS) candidate instructions and guidance notes, MRCS part 3 Communication Skills [8]. Since the tool was already used before in the literature no validity or reliability testing were repeated. Modifications were carried out to enhance content validity of the questionnaires based on the experience of researchers. The questionnaires were tested (pilot study) on 10 doctors and 30 patients before starting the field work. According to this pilot, few changes were taken.

The questionnaires were distributed and collected after filling by a trained research assistant in the following departments of the hospital: Cardiology, Dental clinic, Dermatology, Diabetes clinic, Endocrinology, Ear nose and throat clinic, Emergency clinic, Family Medicine, Gastroenterology, Medicine, Nephrology, Neurology, Neurosurgery, Obstetrics and gynecology, Oncology, Ophthalmology, Orthopedics, Pediatrics, Rehabilitation, Respiratory, Surgery and Urology. Selection criteria of patients included patients visiting the different clinics who were able to read and fill in the questionnaire. Face to face interviews were needed in few patients who were illiterate. Data collection lasted from June to October, 2013. Sample size was predetermined based on consulting an epidemiologist to be 500 for patients and 100 for residents. However, 418 patients and 94 residents successfully completed the questionnaires.

Verbal consent was taken from patients and residents who agreed to participate in the study. The study was approved and funded by the Deanship of Academic Research in the University of Jordan, and approved from the Research Ethical Committee at the University of Jordan and Jordan University Hospital.

SPSS version 17 was used for data entry, cleaning, and analysis. Simple descriptive statistics and independent samples t-test were applied. A p value of less than 0.05 was considered significant at the 0.05 level.

3. Results

Table 1 shows the general characteristics patients included in the study. The highest percentage of participation was from the 20 to 29 years age group (27.5%). Mean age of participants was 41.2 with a standard deviation of 19.4 years. Most participants were females (70.5%). More than one third (37.2%) had a high school education, and around one third (32.9%) had a bachelor degree. The vast majority of patients had a medical insurance (92.3%).

Table 2 presents the general characteristics of residents included in the study. The highest percentage of participants (36%) was in their first year of residency. Around a half (51.9%) graduated as medical doctors between the years 2006 and 2010, and 45.5% graduated between the years 2011 and 2015. The vast majority of residents (81.8%) graduated as medical doctors from Jordanian universities.

Table 1. General characteristics of patients.

Age group (years)	n	%
Less than 20	23	5.6
20 - 29	113	27.5
30 - 39	71	17.3
40 - 49	74	18.0
50 - 59	55	13.4
60 or more	75	18.2
Total	411	100.0
Gender		
Male	123	29.5
Female	294	70.5
Total	417	100.0
Educational level		
Illiterate	19	4.6
High school	154	37.2
Diploma	73	17.6
Bachelor	136	32.9
Post graduate	32	7.7
Total	414	100.0
Medical insurance		
Yes	383	92.3
No	32	7.7
Total	415	100.0

Table 2. General characteristics of residents.

Residency year	n	%
Year one	27	36.0
Year two	14	18.7
Year three	18	24.0
Year four	14	18.7
Year five	2	2.7
Total	75	100.0
Year of graduation		
Before 2000	1	1.3
2001-2005	1	1.3
2006-2010	40	51.9
2011-2015	35	45.5
Total	77	100.0
Country of graduation as MD		
Jordan	63	81.8
Other	14	18.2
Total	77	100.0

Table 3 compares patient centeredness scores between patients and residents (Higher scores indicate better patient centeredness). Residents gave themselves a significantly higher score (3.7) than the score given to them by patients (3.3) regarding the extent to which the doctor discussed the patient's problem ($p = 0.000$). Additionally, residents gave themselves higher scores than the patient gave them for the following aspects: the extent to which the doctor explained the problem (residents' score = 3.5, patients' score = 3.3, $p = 0.004$), the extent to which the doctor explained the treatment (residents' score = 3.5, patients' score = 3.2, $p = 0.005$), the extent to which the doctor listened to what the patient had to say (residents' score = 3.5, patients' score = 3.3, $p = 0.032$), the extent to which the doctor discussed personal, family, work or studying issues that might be affecting the patient's health (residents' score = 2.8, patients' score = 2.4, $p = 0.000$), the extent to which the doctor discussed patient's concerns and anxieties about the complaint (residents' score = 3.2, patients' score = 2.8, $p = 0.000$), and the extent to which the doctor asked about the expectations of the patient about the causes of the complain (residents' score = 2.9, patients' score = 2.5, $p = 0.002$). The only aspect for which patients gave residents higher score than residents gave themselves was the extent to which the doctor asked the patient about what is expected to be done (ECG, CT scan, giving antibiotics, etc.) (residents' score = 2.6, patients' score = 2.9, $p = 0.006$).

Table 4 compares communication skills scores between patients and residents (Higher scores indicate better communication skills). Residents gave themselves significantly higher scores than the scores given to them by patients for the following aspects: the doctor introduced himself (residents' score = 3.1, patients' score = 2.2, $p = 0.000$), the doctor greeted the patient properly (residents' score =

Table 3. Comparison of patient centeredness scores between patients and residents (Higher scores indicate better patient centeredness).

	Patients mean (SD)	Residents mean (SD)	p value
To what extent was your main problem discussed today?	3.3 (0.9)	3.7 (0.5)	0.000
How well do you think your doctor understood you today?	3.4 (0.8)	3.4 (0.5)	0.562
How satisfied were you with the discussion of your problem?	3.2 (0.9)	3.2 (0.6)	0.814
To what extent did the doctor explain this problem to you?	3.3 (0.9)	3.5 (0.6)	0.004
To what extent did the doctor explain treatment?	3.2 (0.9)	3.5 (0.6)	0.005
To what extent did the doctor explore how manageable this treatment would be for you?	3.1 (1)	3.1 (0.7)	0.981
To what extent did you and the doctor discuss your respective roles? (who is responsible for making decisions and who is responsible for what aspects of your care?)	2.8 (1.1)	2.9 (0.8)	0.201
To what extent did the doctor listen to what you had to say?	3.3 (0.9)	3.5 (0.6)	0.032
Regarding today's problem, to what extent did the doctor discuss (personal, family, work or studying) issues that might be affecting your health?	2.4 (1.2)	2.8 (0.8)	0.000
To what extent did your doctor discuss your concerns and anxieties about your complaint?	2.8 (1)	3.2 (0.6)	0.000
To what extent did your doctor ask you about your expectations of the causes of your complaint?	2.5 (1.1)	2.9 (0.8)	0.002
To what extent did your doctor ask you about what you expect him to do for you (ECG, CT scan, giving antibiotics, ...)?	2.9 (1.1)	2.6 (0.8)	0.006

Table 4. Comparison of communication skills scores between patients and residents (Higher scores indicate better communication skills).

	Patients mean (SD)	Residents mean (SD)	p value
The doctor introduced himself to me.	2.2 (1.2)	3.1 (1)	0
The doctor greeted me properly.	3.4 (0.9)	3.6 (0.5)	0.002
The doctor listened to me properly.	3.4 (0.8)	3.6 (0.6)	0.018
The doctor responded to my thoughts, feelings and questions in an appropriate way.	3.2 (0.9)	3.4 (0.7)	0.187
The doctor showed empathy for my situation.	3.1 (1)	3.4 (0.6)	0.001
The doctor presented to me enough facts about my situation.	3.1 (1)	3.3 (0.6)	0.027
The doctor used an easy language that I have understood (not jargon or medical terms).	3.4 (0.8)	3.6 (0.6)	0.003
The doctor let me talk about my complaint as much as I needed to talk.	3.3 (0.9)	3.2 (0.7)	0.513
The doctor checked that I have understood everything he said.	3.2 (0.9)	3.2 (0.6)	0.614
The doctor explained my treatment options, their benefits and risks.	3 (1.1)	3.2 (0.7)	0.011
The doctor offered me support and reassurance.	3.1 (1)	3.2 (0.8)	0.581
The doctor summarized the main points of the interview and ensured that all your questions were answered.	2.9 (1)	2.9 (0.8)	0.551
The interview was organized and logical.	3.2 (0.9)	3.1 (0.6)	0.2

3.6, patients' score = 3.4, $p = 0.002$), the doctor listened to the patient properly (residents' score = 3.6, patients' score = 3.4, $p = 0.018$), the doctor showed empathy for the patient's situation (residents' score = 3.4, patients' score = 3.1, $p = 0.001$), the doctor presented enough facts about the situation (residents' score = 3.3, patients' score = 3.1, $p = 0.027$), the doctor used an easy language (residents' score = 3.6, patients' score = 3.4, $p = 0.003$), and the doctor explained the treatment options, their benefits and risks (residents' score = 3.2, patients' score = 3, $p = 0.011$).

4. Discussion

Up to the authors' knowledge this will be the first paper that evaluates patient centeredness and communication skills of physicians working at a teaching hospital in Jordan. Moreover, it allows the evaluation to be carried out from the perspectives of both patients and physicians.

Mean age of patients participating in the study was 41.2 with a standard deviation of 19.4 years. This is found to be comparable to the mean age of participants, 41.1 with a standard deviation of 11.2 years, in the study by Epstein *et al.* [2]. However, it was less than mean age of participants reported by Clayton *et al.* and Schatrner *et al.* [4] [5]. Participants in the current study were chosen so that they represent six age groups. This heterogeneous mix of several age groups was intended by the researchers to get a more representative and objective evaluation of the targeted aspects of patient centeredness and communication skills.

Most of the residents included in the study were relatively new graduates (not older than 2006 graduates). This is in contrast with the work of Locker *et al.* whose sample included physicians whose median year of graduation was 1980. On the other hand, most physicians in the current study (81.8%) were Jordanian

graduates, while others were international students. This is comparable to the sample of the study by Lockyer *et al.* in that most of their sample (73.2%) were Canadian graduates (graduates of the same country in which the study was conducted) [9].

Several aspects of patient centeredness were rated significantly higher by residents than by patients in the current study. These included the extent to which the patient's problem was discussed, the extent to which the doctor explained the treatment, the extent to which the doctor explored how manageable is the treatment for the patient, the extent to which the doctor listened to what the patient had to say, the extent to which the doctor discussed personal, family, work, or study issues that might be affecting health of the patient, the extent to which the doctor discussed the patient's concerns and anxieties about the complaint, and the extent to which the doctor asked about the patient's expectations about the causes of the disease. In the literature, the researchers did not find published work that have discussed exactly the same aspects of patient centeredness from two perspectives comparable to what has been done in the current study. However, there was an agreement among most of the studies on the importance of delivering patient centered health care [10]. On the other hand, in spite of the debate on whether self assessment (or self rating) is a reliable judgment compared to feedback gained from external resources, it remains an important source of feedback especially for physicians [9] [11]. These findings suggest that there is a need for some exploratory research work to figure out the reasons behind this significant difference in rating of the previously mentioned aspects of patient centeredness. Based on results of such an exploration, interventions can be targeted to improve the service delivered to patients so that it can be more patient centered. Interventions can come in the form of courses for teaching physicians patient centered approach, and such courses have shown positive effects on practice [12]. This can lead to achieving the ultimate goal of gaining patient satisfaction which is found to be highly associated with patient centered behaviors [13].

In contrast, there was only one aspect of patient centeredness that was rated significantly higher by patients than by residents. This was the extent to which the doctor asked the patient what does he/she expect the doctor to do (ECG, CT scan, giving antibiotics ...). This is counted in favor of the residents as they attempt to explore the expectations of their patients. It is well established that meeting patients' expectations can improve patients' satisfaction [14].

As for communication skills, the following items were rated significantly higher by residents than by patients: the doctor introduced himself to the patient properly, the doctor greeted the patient properly, the doctor listened to the patient properly, the doctor showed empathy to the patient's situation, the doctor presented enough facts, the doctor used easy language, and the doctor explained the treatment options.

Differences in the way patients and doctors perceive the medical interview are well established in the literature [6]. However, it should be taken into considera-

tion that the ultimate goal is to provide health service that is tailored to satisfy the patient [4].

A review of doctor patient communication by Ha and Longnecker showed that listening attentively and showing empathy are some examples of skillful communication [15]. Since these two skills were rated significantly lower by patients in the current study, this indicates that doctors need to improve such skills.

With regard to presenting enough facts, when first year medical students were asked to assess their own communication skills in the study by Zick *et al.*, this was their number one observed strength. More than a half (54%) stated that they elicited information and covered important topics [16]. However, this item was rated significantly lower by patients in the current study. A possible reason for this might be the tight schedule of physicians and being responsible to see a large number of patients, which may reduce the chance to provide enough facts. Even though, this should not be an excuse, since it is a right for the patient to have enough facts about his/her condition.

Using language a patient can understand (under the item sharing information) was considered an essential element of patient physician communication by the Kalamazoo Consensus Statement [17]. The statement also focused on checking for understanding and encouraging questions under the item “sharing information”, which includes explaining treatment options.

Using an easy language and explaining treatment options were rated significantly lower by patients in the current study. This again addresses the need to empower the doctors with these skills.

This study was limited by the relatively low response rate of residents. Additionally, the study was conducted in a single teaching hospital so the results may not be generalizable to all teaching hospitals, further research is needed.

5. Conclusions

Several aspects of patient centeredness and communication skills were rated significantly lower by patients than by residents in the current study. This addresses a need for some interventions to improve the patient centered medicine and communication skills. These interventions might come in the form of specialized training courses that are directed towards teaching doctors how to be patient centered and how to acquire the necessary communication skills that can ultimately improve health outcomes and patient satisfaction. A transformation from doctor centered approach to patient centered approached is needed.

Further studies of this issue are needed in other teaching hospitals in Jordan both in the public and private sectors to be able to generalize the results of such studies on a large scale in Jordan.

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The Use and Misuse of Mobile Phones in the Maternity Ward—A Threat to Patient Safety?

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Abstract

An important task for the midwife is following up mother-child interaction to facilitate mother-infant attachment. The aim of this study was to explore midwives' perceptions of parents' use of mobile phones in the maternity ward. The research question was: Is the use of mobile phones in the maternity ward a threat to patient safety? Two focus group interviews exploring midwives' perceptions (n = 10) of parent' use of mobile phones during and after the birth were conducted in January 2016. Systematic text condensation was used to analyse the data, revealing three themes pertaining to safety concerns: Interrupted communication due to parents' excessive use of mobile phones during labour and postnatally, Unsafe care caused by lack of attention to the newborn baby's signals as a result of being disturbed by the mobile phone and Unsafe care because of parents interrupting their conversation with the midwife by answering the mobile, acting in a disrespectful manner and failing to pay attention. The midwives' descriptions of parents' use of mobile phones in the maternity ward included reflections on mobile phone usage as a permanent phenomenon. They were concerned that parents' use of mobile phones in the maternity ward could negatively affect the attachment process and considered that it interrupted their work. In conclusion, there is a need for increased awareness of parents' use of mobile phones in the maternity ward. Further research is required to gain greater insight into the consequences of mobile phone use in order to promote patient safety by ensuring effective communication between parents and midwives. In addition, research is needed to explore the safety discourse, clinical risks and/or health problems involved in the development of infant-parent attachment in newborn babies.

Keywords

Communication, Focus Group Interviews, Infant-Parent Attachment, Midwife, Maternity Care, Mobile Phone, Patient Safety

1. Introduction

The consequences of using mobile phones may or may not influence the professional relationship between midwives and childbearing women and thus the quality of maternity care. The mobile phone (cellular phone) was developed in the 1950s, but became accessible to and popular with the general population in Norway in the 1990s. Today, seven out of every ten persons in Norway possess a Smartphone, thus the Norwegian population is one of the most enthusiastic mobile phone using populations in Europe [1]. Research concerning the use of mobile phones in maternity care involves the use of Smartphone Apps as well as social media platforms. A Cochrane review described that pregnant women who received supportive and informative text messages experienced higher satisfaction, greater confidence and lower anxiety levels in the antenatal period than women who did not receive such messages [2]. An American survey examining new parents' use of Facebook in their transition to parenthood reported that mothers' use of Facebook increased during the transition and that their frequent Facebook visits were associated with higher levels of parenting stress. Fathers, on the other hand, reported better parental adjustment when connecting with their Facebook friends [3]. The use of apps and social media platforms in maternity care appears to have the potential to influence pregnancy, motherhood and parenting practice [4]. Consequently, Tripp *et al.* [5], argue that healthcare professionals should be aware of new information delivered via Smartphones, as these are widely used by women of childbearing age. However, one of the consequences of having access to one's mobile phone is that a vast number of young people check their phones frequently in order not to miss information shared on social media. This exaggerated use is referred to as "fear of missing out" (FoMo) on important and exciting events [6] [7].

The use of mobile phones related to social media in the maternity ward is a relatively new phenomenon and has been frequently discussed in the Norwegian media. Midwives are concerned that the use of mobile phones during and after the birth represents a new challenge to the infant-parent attachment process, raising the question of whether babies have to compete with the Internet and social media to get their parents' attention [8]. They are also concerned about mothers' abilities to read their babies' signals in view of the fact that they focus on their mobile phones rather than on their babies while breastfeeding [9] [10].

Research concerning healthcare professionals' perceptions of mobile phone use in the maternity care context is scarce, despite the fact that communication failure constitutes a threat to patient safety [11]. Conflicts between patients and healthcare professionals due to lack of communication when problems arise have been reported, although pregnant women were found to be insistent and vehement when alerting midwives about safety issues that they believed to be urgent [12]. Five patient risk domains have been reported: organization, communication, patient-related risk factors, clinical management and midwifery care outcomes [13].

Aim

As failure to communicate effectively is the most common cause of medical errors and therefore a threat to patient safety [14], we decided to conduct a study to examine aspects of communication in the maternity ward including midwives' perceptions of parents' use of mobile phones in order to answer the research question: Is the use of mobile phones in the maternity ward a threat to patient safety?

2. Methods

2.1. Design

We employed a qualitative inductive research approach to illuminate midwives' perceptions of the use of mobile phones in the maternity ward [15] [16]. This approach results in a narrative summary that synthesizes participant information, thereby creating a description of human experiences. The "theoretical lens" is based on the World Health Organisation (WHO) patient safety recommendations [17]. The WHO defines patient safety practices as processes or structures that reduce the probability of adverse events caused by exposure to the health-care system across a range of diseases and procedures [18].

2.2. Data Collection and Participants

Participants were recruited from a large hospital in Southeast Norway in 2016. A Professional Development midwife employed at the maternity ward informed all midwives about the study and a detailed information sheet was handed out to potential participants before the interviews took place. We included authorized midwives who were able to understand and speak Norwegian fluently. Twelve midwives who were interested in participating in the study contacted the second author by email, although two later withdrew due to their heavy workload. The remaining ten midwives were divided into two focus groups consisting of four and six members.

The two focus group interviews were conducted in the participants' work place and lasted for 50 and 55 minutes [19]. An interview guide containing the following four questions was employed; 1) Can you describe your experiences of new parents' use of mobile phones in the maternity ward? 2) Can you describe any examples where parents' use of mobile phones may have influenced the infant-parent attachment process? 3) Should midwives draw attention to the importance of infant-parent attachment and 4) How can midwives facilitate the attachment process in a digitalized society? The second author acted as moderator and a colleague as secretary. The midwives were encouraged to narrate freely but were informed before the interviews started that the moderator would interrupt if necessary. The interviews were audiotaped and field notes taken.

2.3. Data Analysis

The interviews were transcribed verbatim and systematic text condensation (STC) was used to analyse the data [20]. STC is a four step strategy for thematic

cross case analysis inspired by Giorgi's phenomenological method. In the first step, the interviews were read to gain an overall impression and preliminary themes were noted. The second step concerned the coding process, during which the transcripts were read line-by-line and meaning units, *i.e.*, parts of the text that could illuminate the research question, were identified, classified and labelled, after which related meaning units were organized into groups and coded.

In the third step, the content of each group was sorted into subgroups and condensed. Finally, an analytical text based on the condensates emerged, including quotations to elucidate the findings.

2.4. Ethical Considerations

The study was conducted in accordance with the Declaration of Helsinki [21]. Before the interview started, the participants received oral information about the study and were asked to sign a declaration of consent. They were informed that participation was voluntary and that they could withdraw from the study at any time without having to give a reason. Approval for the study was granted by the Norwegian Social Science Data Service (NSD; 45,362) and the approval was assessed by the Regional Committee for Medical Research (2015/2064A).

3. Results

Twelve midwives expressed an interest in participating in the study. They worked in different hospital wards, ranged in age from 28 to 50 years, as well as having varying seniority and work experience within maternity care (1 - 20).

The analysis revealed three themes; 1) Interrupted communication due to parents' excessive use of mobile phones during labour and postnatally, 2) Unsafe care caused by lack of attention to the newborn baby's signals as a result of being disturbed by the mobile phone and 3) Unsafe care because of parents interrupting their conversation with the midwife by answering the mobile, acting in a disrespectful manner and failing to pay attention to the midwife.

3.1. Interrupted Communication Due to Parents' Excessive Use of Mobile Phones during Labour and Postnatally

In the first theme, the midwives expressed concern that mobile phone use related to social media reduces parents' ability to focus on the labour and the newborn baby, but patient autonomy prevents them from restricting the use of mobile phones.

3.1.1. Mobile Phones Are Here to Stay

Despite their concerns, the midwives agreed that mobile phones are here to stay. They stated that while some parents did not use the mobile phone during labour, and only employed it to inform their family about the birth several hours after the baby was born, others used it continuously to share information about the ongoing situation and update family and friends. The midwives believed it was essential for young parents to share information on social media. However, one midwife reflected on the amount of time mothers in the post-natal ward seem to

spend checking the number of likes on their Facebook postings, while others were concerned about the loss of control associated with spreading the news by means of social media. Another midwife was puzzled when she found friends accompanying a labouring couple sitting outside the birthing room and watching the ongoing birth via Skype. The midwives believed that young people are more or less “attached” to their mobile phones, and understood that their social lives were dependent upon this device. According to an experienced midwife:

Young people depend on their mobile phone, it seems to be “glued” to their bodies. My generation are able to put it away... we can enjoy that. I don’t think young people enjoy that, it is frustrating for them not to have their mobile phone close at hand and I wonder if the baby will be able to capture the attention that they devote to their mobile. I don’t know. How extreme is their love affair with that gadget? (Focus group 1).

3.1.2. Mobile Phones Use Results in a Change of Focus

All the midwives had personal experience of parents using mobile phones during labour and postnatally. It often started before the baby was born, with parents updating family and friends about the progression of labour, frequently by means of social media such as Facebook, Twitter or Instagram. They perceived this as disturbing, because instead of concentrating on the labour process as a team, the parents were occupied updating family and friends. Although labouring women took an active role in updating family and friends, the prospective fathers seemed even more concerned with information sharing and sometimes handled two mobile phones simultaneously. The midwives perceived fathers’ use of mobile phones as a possibility for them to escape from the situation for a few minutes, which they understood. However, unfortunate situations sometimes occurred, particularly when fathers were so occupied with their mobile phones that they had no time to care for their partners. According to one of the midwives, some situations were difficult to forget:

I entered the birthing room; the woman was eight centimetres dilated. She was lying on her side, totally distressed and groaning. The father was watching a skiing competition on his mobile phone. “Just a moment”, he said, which I found a bit peculiar (Focus group 2).

3.1.3. Mobile Phones Use Concerns Patient Autonomy

Some midwives asked the parents to put their mobile phones away when they entered the birthing room, arguing that it was their job to provide the parents with important information. Others found this difficult and said nothing. Several argued that they gained an overall impression of the parents and interrupted when they considered it necessary to intervene, e.g., if they noticed that the parents spent more time with their mobile phones than with their baby. However, they found it peculiar that they had to inform adults to put away their phones in order to have a conversation. They talked about the “old days” when parents had to ask permission to use the hospital telephone and stated that although they did not wish to interfere with the parents’ private lives, they would like to be able to

communicate to the parents that they should cherish the first days after the birth. However, they sometimes found it difficult to separate patients' autonomy and their professional knowledge. According to one of the midwives:

I believe that sometimes we are a little afraid to let them know that... we are afraid of offending them or barging into their private lives. Maybe we should be more specific, because this is an important time in their lives (Focus group 1).

3.2. Unsafe Care Caused by Lack of Attention to the Newborn Baby's Signals as a Results of Being Disturbed by the Mobile Phone

The second theme concerns the challenges related to parents' ability to understand the newborn baby's signals. Furthermore, midwives feared that use of mobile phones could hinder the initiation of breastfeeding and wondered if mobile phones might have a negative influence on the baby's health.

3.2.1. Mobile Phone Use Reduces Parents' Ability to Notice the Baby's Signals

The midwives agreed that extensive use of mobile phones was likely to disturb the infant - parent attachment process, and felt sad when they entered a room and found the newborn in its cot while the mother was lying in bed with her mobile phone or laptop. They argued that parents who spend a great deal of time using their mobile phones were less attentive to their baby and risked missing her/his natural signals, such as smacking the lips and sticking out the tongue out when hungry. It could also concern signals related to a change in health status, such as low blood sugar or increased temperature. Overall, they considered that parents today are less attentive to their babies and lack knowledge about the attachment process. They argued that it is easy for young parents to get to know their mobile phones, but getting to know a newborn baby is more demanding. According to one midwife:

The baby needs to have its signals reciprocated, to see the mother smile, to have eye contact and see different facial expressions. I do not think that parents know how competent the newborn baby really is. They should look at their baby instead of their mobile phones (Focus group 1).

3.2.2. Mobile Phone Use Disturbs the Breastfeeding Process

The midwives reported that mothers' focus on the mobile phone sometimes disturbed the breastfeeding process. They perceived that mothers lacked understanding about the importance of ensuring a good start to breastfeeding their babies and thought it was sad that they had to request the mothers to put away their mobile phones when breastfeeding. They reflected on the mothers' lack of knowledge and discussed whether it would be a good idea to design breastfeeding and attachment apps because young mothers and families often googled the Internet to find information on various topics. They believed that it might be a good idea to meet the women or families on their own terms and at the same time provide them with correct information.

They discussed what a future postnatal support group would look like:

It would be interesting to be a fly on the wall in future postnatal support groups (using body language to demonstrate how mothers sit looking down at their mobile phones). I think that we have a duty to continue the fight, but we have to find other ways... like an app or something. We are up against a tough crowd (Focus group 1).

3.2.3. Mobile Phone Use May Have a Negative Influence on the Baby's Health

The midwives were concerned that the use of mobile phones could have a negative impact on the baby's health. They were particularly worried about radiation, as they had noticed that parents often put their mobile phones into the baby's cot, close to her/his head. In addition, they believed that light, shrill sounds, and vibration might disturb the baby. While they were aware that this concern was not backed by evidence-based knowledge, they argued that as Norwegian health authorities had recommended that adults should avoid sleeping with their mobile phones in their bed, parents should also avoid putting their mobile phones next to the baby's head. One midwife expressed her concern as follows:

Well, you have radiation, you have vibration and suddenly there is a shrill sound. No... I do not know... it is not evidence-based, but it feels as if it is not good for the newborn baby (Focus group 2).

3.3. Unsafe Care because of Parents Interrupting Their Conversation with the Midwife by Answering the Mobile, Acting in a Disrespectful Manner and failing to Pay Attention

The third theme concerns midwives' experiences of being disturbed in their clinical practice during labour as well as postnatally.

3.3.1. Mobile Phone Use Disturbs Midwives' Work in the Labour Ward

The midwives stated that parents' use of mobile phones during labour hindered their work.

Furthermore, at times they found the use of mobile phones disrespectful and were uncomfortable with photos being taken without their permission. They described the sounds and flashing from the mobile phone as surrounding both the mothers and themselves, adding that the minutes after the baby is delivered are critical and should not be disturbed. The women are often in a lithotomy position with their legs in stirrups, waiting to deliver the placenta while the midwife examines them. At this stage, there is a risk of bleeding, making it essential that midwives are allowed to perform their work without being disturbed.

One of the midwives described feeling overrun by an overeager father taking photos while she was waiting to deliver the placenta:

The parents were on the phone continuously. I had to raise my voice and say "Turn off your phones right now!". Having to ask them to switch off their phones was the most extreme case I have ever encountered. Strictly speaking, it is none of my business at all, but it disturbed the birth (Focus group 1).

3.3.2. Mobile Phone Use Disturbs Midwives' Work in the Postnatal Ward

The midwives also described being obstructed in their work after the birth. They experienced that the parents were too preoccupied with their mobile phones to listen to the information that the midwives provided. They stated that in the course of a conversation the parents would abruptly stop talking in order to answer the telephone, which they considered both frustrating and disrespectful. They argued that parents would miss out on important information as a result. One midwife described that after several attempts to give the parents important information, she ended up documenting in the mother's records that the woman was too busy with the mobile phone to talk to her. Another midwife stated that she had stopped saying she would come back later:

You come in to give them information and they are busy using their mobile phones. It provokes me. Previously I said that I would come back later, but I have stopped saying that. Instead, I say that they have to contact me if they want information (Focus group 2).

4. Discussion

The findings in this study describe challenging situations related to midwives' perceptions of parents' use of mobile phones in the maternity ward. Below, we will discuss the findings from a patient safety perspective, focusing on various aspects of communication.

The importance of good communication in antenatal care is well recognized and found to have a positive effect on patient outcomes such as anxiety, pain control and understanding of information [22]. According to Hunter *et al.* [23], the quality of communication and relationships is interrelated, and effective communication is essential for safe practice. Relationships are therefore important for the "soft side of care" as well as for clinical safety. Accordingly, the authors argue, poor communication between professionals and clients can be regarded as an aspect of sub-standard care. According to Raine *et al.*, [22], a shift towards a partnership model of care will result in greater access to information, while client involvement, such as shared decision-making and self-management, is essential in order to ensure safety and improve the relationship between maternity care staff and clients [24]. In this study, midwives reported that their clients spend a great deal of time on the Internet and on social media both communicating and seeking information, support and advice. They consider that this had led to a "change of focus" during birth, with parents being too occupied with their phones to participate in the here and now. In these situations they find it difficult to establish a good relationship with the parents and to help them to focus on the birthing process. However, according to Currie and Richens [25], midwives may perceive a loss of power and control in the face of having to deal with an increasingly assertive and articulate client population who know about choice. According to Johnson [4], first-time motherhood (and seemingly first time-parenthood) in a digitalized world involves parents' use of a variety of new devices that are likely to influence and change the way we under-

stand and practice maternity care and motherhood. In our study, midwives' stated that they are uncomfortable with the changes taking place, but have to accept them due to patient autonomy.

The midwives were concerned that parents' mobile phone use also resulted in a change of focus after the birth, disturbing the attachment process between the newborn child and her/his parents. They argued that in order to prevent the baby from being under stimulated, the parents must pay attention to her/his. They stated that a newborn baby exhibits a variety of cues, such as lip smacking when hungry, and parents must learn how to interpret them. Thus, if parents look at their mobile phones rather than at the face of their baby, they will miss out on important information enabling them to understand the baby's wellbeing. According to Stern [26] (p. 63), much parent-infant interaction is played out at a microevent level. He states that the "nonverbal behaviours that make up a great part of this relationship are not communications about, nor comments upon, nor interpretations of the relationship; they *are* the relationship". Midwives do not refer to theoretical knowledge of the attachment process when they describing their concern, but argue that it is important for parents to be present and attentive to the baby's signals, as well as questioning whether young parents have sufficient knowledge of the attachment process. Thus, they reflect on the possibility of developing apps to provide young parents with good quality information about breastfeeding and attachment.

Studies have described the relationship between a labouring woman and her caregiver as fundamental to the woman's experience of childbirth [27] [28]. In this regard, trust is essential. According to Rørtveit *et al.* [29], there are four key features of trust: what it is, why it matters, on what it is based, and the danger of trust. However, facilitating and nurturing trust are related to communication, thus communication skills are important for healthcare providers and an integral component of safety culture [30]. Midwives have an opportunity to provide close and tailored care for women by optimizing the normal childbirth process and post-partum period [31]. Thus, when midwives are obstructed and prevented from "working with" the woman and her family to establish a trusting relationship and provide patient-centred care they may find it challenging. There were several situations in the present study where clients' excessive use of mobile phones restricted the midwives' ability to share important information and to build a trusting relationship with them, resulting in frustration about being unable to provide the mothers with essential, knowledge-based information. Furthermore, they described birthing situations where parents' excessive use of mobile phones disturbed their job performance, which they considered both challenging and a threat to patient safety as they risked missing out on important details concerning the health of mother and child. It has been reported that mutuality in the woman-midwife relationship is necessary for good care [32] [33] and that for the midwife, a feeling of being needed can be perceived as a recognition of her role [34] [35]. However, our study also demonstrates that midwives' perceptions of clients' need for support are based on their own ideas

of the purpose of care rather than clients' perceived care needs. Further studies are required to elucidate this discrepancy in order to enhance communication and patient safety in the maternity care context.

Limitations

According to Malterud [36], internal validity concerns whether the study has investigated what it was intended to investigate and whether the methods employed were appropriate. The use of focus groups and an interview guide listing a limited number of fixed questions allowed the midwives in this study to reflect on their experiences, thus providing the authors with sufficient empirical data to broadly elucidate the research question. Two authors conducted the structural analysis and achieved consensus on the interpretation, while the third author validated the themes. However, we are aware that other researchers might have identified different themes or interpreted the findings differently.

To enhance external validity, it is necessary to consider whether it is possible to generalize the findings beyond the setting in which they were generated [36]. Our convenience sample consisted of ten midwives of different ages and seniority employed in various wards, thus although it was small, it was rich. However, the sample was recruited from one institution, which may have influenced the external validity. The study would have benefitted from including participants from Non-Western countries and from several institutions. The authors have different healthcare backgrounds (midwives and a psychiatric nurse) and experience within maternity care, providing varied perspectives and a solid knowledge base. Furthermore, they share a common interest in midwifery and the technological innovations utilized within the maternity care context.

5. Conclusion

Mobile phones have changed our society as well as our way of communicating, and easy access to the Internet and social media has become a part of our daily lives. The present study demonstrates that midwives are concerned about the situation, in particular the way in which parents' use of mobile phone use may affect the infant-parent interaction and pose a threat to patient safety. They argue that there is a need for increased awareness about the use of mobile phones in the maternity ward. Additional research is required to gain further insight into the consequences of mobile phone use in order to promote patient safety and ensure effective communication between parents and midwives.

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Authors Contributions

B.D. and S.Å-C were responsible for study design. S.Å-C was responsible for the

data collection and writing the initial manuscript. S.Å-C and B.D were responsible for data analysis. All authors contributed intellectually, proof read and approved the final manuscript. BD supervised the study.

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