JMIR Nursing

Virtualizing care from hospital to community: Mobile health, telehealth, and digital patient care
Volume 2 (2019), Issue 1   ISSN 2562-7600   Editor in Chief: Elizabeth Borycki, RN, PhD, FIAHIS, FACMI, FCAHS, Social Dimensions of Health Program Director, Health and Society Program Director, Office of Interdisciplinary Studies; Professor, School of Health Information Science, University of Victoria, Canada

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Original Paper

Understanding Nursing Workflow for Inpatient Education Delivery: Time and Motion Study

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Abstract

Background: Diabetes self-management education and support improves diabetes-related outcomes, but many persons living with diabetes do not receive this. Adults with diabetes have high hospitalization rates, so hospital stays may present an opportunity for diabetes education. Nurses, supported by patient care technicians, are typically responsible for delivering patient education but often do not have time. Using technology to support education delivery in the hospital is one potentially important solution.

Objective: The aim of this study was to evaluate nurse and patient care technician workflow to identify opportunities for providing education. The results informed implementation of a diabetes education program on a tablet computer in the hospital setting within existing nursing workflow with existing staff.

Methods: We conducted a time and motion study of nurses and patient care technicians on three medical-surgical units of a large urban tertiary care hospital. Five trained observers conducted observations in 2-hour blocks. During each observation, a single observer observed a single nurse or patient care technician and recorded the tasks, locations, and their durations using a Web-based time and motion data collection tool. Percentage of time spent on a task and in a location and mean duration of task and location sessions were calculated. In addition, the number of tasks and locations per hour, number of patient rooms visited per hour, and mean time between visits to a given patient room were determined.

Results: Nurses spent approximately one-third of their time in direct patient care and much of their time (60%) on the unit but not in a patient room. Compared with nurses, patient care technicians spent a significantly greater percentage of time in direct patient care (42%; *P*=.001). Nurses averaged 16.2 tasks per hour, while patient care technicians averaged 18.2. The mean length of a direct patient care session was 3:42 minutes for nurses and 3:02 minutes for patient care technicians. For nurses, 56% of task durations were 2 minutes or less, and 38% were one minute or less. For patient care technicians, 62% were 2 minutes or less, and 44% were 1 minute or less. Nurses visited 5.3 and patient care technicians 9.4 patient rooms per hour. The mean time between visits to a given room was 37:15 minutes for nurses and 33:28 minutes for patient care technicians.

Conclusions: The workflow of nurses and patient care technicians, constantly in and out of patient rooms, suggests an opportunity for delivering a tablet to the patient bedside. The average time between visits to a given room is consistent with bringing the tablet to a patient in one visit and retrieving it at the next. However, the relatively short duration of direct patient care sessions could potentially limit the ability of nurses and patient care technicians to spend much time with each patient on instruction in the technology platform or the content.

(JMIR Nursing 2019;2(1):e15658) doi:10.2196/15658

KEYWORDS

nursing; workflow; time and motion studies; patient education; type 2 diabetes mellitus

Introduction

Persons living with chronic, complex medical conditions, including diabetes mellitus, must learn to self-manage their condition to enable optimal outcomes. Diabetes self-management education and support (DSMES) improves diabetes-related outcomes including glycemic control, risk of complications, and use of hospital and emergency room services [1-8]. Despite demonstrated efficacy of DSMES, as recently as 2015 almost half of people diagnosed with diabetes had never received diabetes self-management education [9]. In addition, less than 7% of patients with private insurance receive DSMES during the first year after diagnosis [10].

Strategies are needed to expand the reach of DSMES among the over 30 million persons living with diabetes in the United States [11]. DSMES is typically provided in the ambulatory practice setting in classes or via individual visits with a diabetes educator or nutritionist [12]. Adults with diabetes have high hospitalization rates for both diabetes-related and nonrelated diagnoses and high rates of 30-day readmissions when compared with persons without diabetes [13]. Therefore, hospital admissions present a critical opportunity not only for appropriate diagnosis and medical treatment but also for providing education to persons with diabetes.

Nurses, supported by patient care technicians (PCTs), provide much of inpatient care and are typically responsible for delivering patient education, including diabetes self-management education, at the bedside prior to discharge. Often diabetes specialty teams are not available, or such teams cannot meet the demand to teach all persons with diabetes. Integrating education into nursing unit workflow can present challenges. In the current health care environment, ever-increasing nursing staff workload and shortening lengths of stay impact the amount of time nurses and unit staff have available for patient care activities, including providing education [14-15]. In a survey of almost 3000 nurses on general medical-surgical units, 52% reported not having time to provide needed patient education on their last shift [16]. The use of technology to support education delivery in the hospital is one potential solution to these challenges. There is evidence that patients are willing to use tablet-based education programs and these programs can be effective for inpatient education [17-20].

Diabetes to Go is a diabetes education program that can be delivered to patients on a tablet computer via Web access [21]. The program provides diabetes survival skills education and consists of a 15-question validated knowledge test and short videos (most less than 3 minutes). It was designed to be used independently by the patient, and the full program takes 20 to 30 minutes to complete. The aim of this study was to evaluate nurse and PCT workflow, where workflow is defined as the frequency, duration, and pattern of activities, to identify opportunities for providing education. The results of this study were used to inform the design of implementing the Diabetes to Go intervention pragmatically in the hospital setting within existing nursing workflow with existing unit staff and minimal impact on workload.

Methods

Study Design

We conducted a time and motion study of nurses and PCTs on medical-surgical units of a large urban tertiary care hospital. A time and motion study is a quantitative data collection method where an observer continuously records the actions of a subject and, more specifically, the time and movements required to complete those actions [22]. Time and motion studies are often used to understand workflow to identify process efficiencies and improvements [22].

From May to July 2017, five trained observers conducted time and motion observations in 2-hour time blocks. The observers were all members of the research team; one observer was a medical assistant, while the others were bachelors- or masters-trained research assistants or coordinators without any clinical experience. During each 2-hour observation block, one observer shadowed a nurse and one observer shadowed a PCT, and each recorded the tasks, locations, and their durations. The 2-hour observation blocks were distributed across Monday through Saturday, from 10 am to 7 pm, which were considered by nursing to be the days and times most likely for education to be provided. Observations were scheduled for a specific date, time block, unit, and role (nurse or PCT). Two observers reported to the assigned unit at the assigned date and time and worked with the unit manager to find staff participants (one nurse and one PCT) who were willing to be observed by the study team. After the observers identified whom they would observe, they continuously recorded the nurse or PCT tasks and locations for 2 hours. The observers took a 1-hour break and then returned to the unit for an additional 2-hour observation period. Participants were not observed off the unit, as it was not relevant to the study and usually represented a personal break for the participant.

Setting and Participants

The research was conducted on three medical-surgical units within a 912-bed tertiary care medical center in Washington, DC. Two of the units are standard medical-surgical units. The third unit is a cardiac care unit, where most patients are recovering from cardiac surgery. We selected the units based on their high census numbers for adult patients with type 2 diabetes. Participants were nurses and PCTs who provided verbal consent to be observed as they performed their typical duties. To assure employee privacy and confidentiality, we did not collect descriptive information from the participants being observed, and the observation data could not be directly linked back to any individual. The MedStar Health Research Institute institutional review board approved the research.

Data Collection

Initial task and location categorizations were developed based on the Omaha System nursing taxonomy [23] and a time and motion study of nurses by Schenk et al [24]. The task categories included teaching and guidance, treatment and procedures, case management, surveillance, electronic health record interaction, reading, communicating, and walking between locations. Location categories included patient room, hallway, team area at a computer, team area but not at a computer, medication room, supply room, nutrition room, and off unit. Early pilot testing demonstrated that it was difficult for observers, particularly nonclinical observers, to reliably discern the more specific task categorizations without disrupting the participants to ask what they were doing. In addition, when nurses are performing direct patient care, they frequently multitask (for example, educating the patient about a medication while administering the medication) and task switch, with blurred lines between when one task ends and another begins. Because the purpose of this study was to identify opportunities to provide education, we determined that it was important to know when the nurse or PCT entered a patient room, how long he or she engaged in direct patient care before leaving the room, and when he or she returned to the room, as these would affect the ability to provide education. The specific tasks of direct patient care and specific locations when staff were not in the patient room were deemed not important for the study. Therefore, task and location categories were simplified, and four task categories and three location categories were defined for use during the observations (Textbox 1).

To record observations, observers used a tablet computer to access a Web-based time and motion data collection tool, TimeCaT [25]. The TimeCaT interface allows the user to specify co-occurring task, location, and communication (Figure 1). Note that the TimeCaT communication domain was not used in this study. Instead, communication was classified as other activities in the task domain. When the user selects a new task or location, TimeCaT timestamps the data entry. The user can also enter notes attached to each data entry. The study team used this feature to record the patient's room number when in a patient room was selected as the location.

Prior to the start of data collection, the observers attended a 2-hour training to ensure common understanding of the study and observation procedures. The training included instruction on the purpose of the study, observation procedures, definition of each task and location category, and use of the TimeCaT data collection tool. After the classroom training, multiple paired observations were conducted to confirm interobserver reliability. TimeCaT includes a feature to calculate the kappa coefficient for paired observers. Through the commutative property, all observers were confirmed to be interreliable. Kappa values for consistency in naming each task and location ranged from 0.77 to 1.00, and kappa values for consistency in the proportion of time within each task and location ranged from 0.90 to 0.99, which indicated excellent agreement [26].

Textbox 1. Study task and location category definitions.

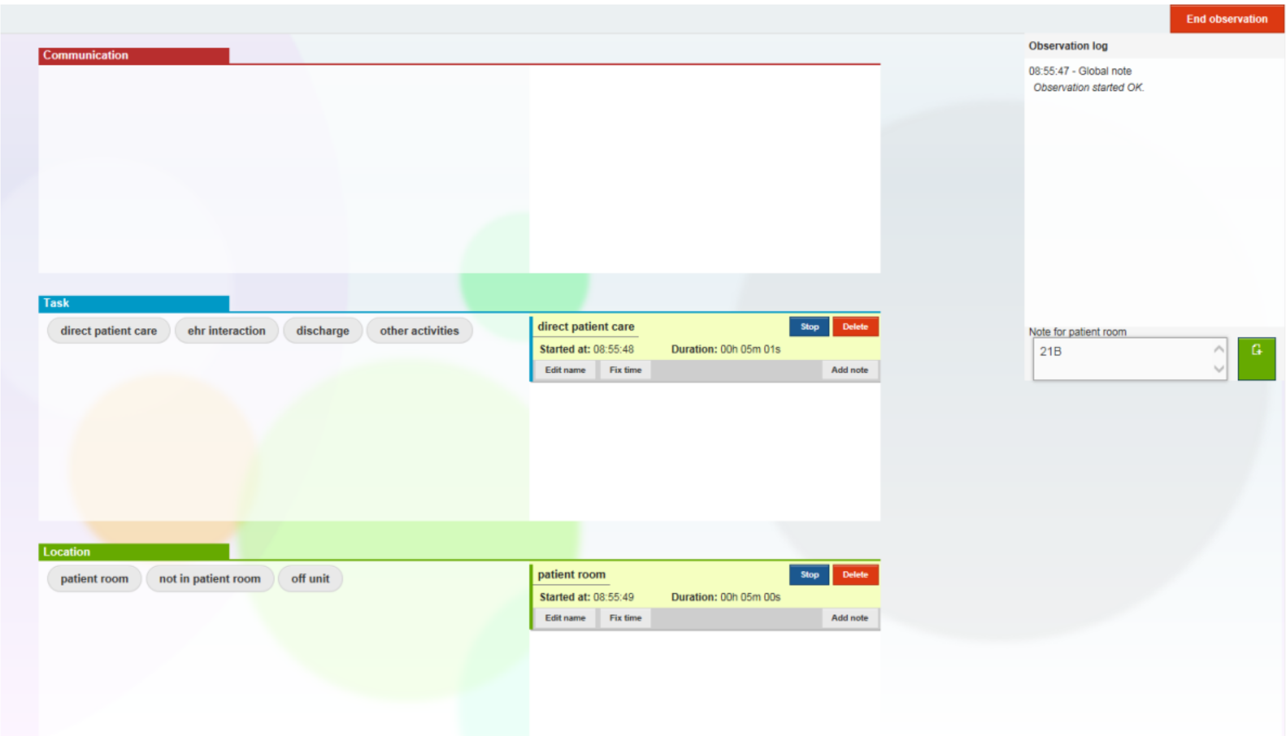
Task domain:

- Direct patient care: any in-person interaction with the patient
- Discharge activities: a specific type of direct patient care; any in-person interaction with the patient where discharge was specifically discussed
- Charting: interaction with the electronic health record
- Other activities: any task that did not fit one of the three previous categories, including, for example, retrieval of medications or supplies, communication with other health care team members, and travel between patients

Location domain:

- In a patient room: in a room occupied by a patient
- Not in a patient room: outside of a patient room but on the unit, including, for example, medication room, supply room, nurses' station, and hallway outside the patient rooms
- Off unit: not on the unit

Figure 1. TimeCaT interface for study.



Observation log

08:55:47 - Global note
Observation started OK.

direct patient care
Started at: 08:55:48 Duration: 00h 05m 01s

patient room
Started at: 08:55:49 Duration: 00h 05m 00s

Note for patient room: 21B

Data Analysis

Data collected in TimeCat was exported to an Excel (Microsoft Office 365 ProPlus, Microsoft Corp) spreadsheet for manipulation, and statistical analyses were conducted using the statistics program SPSS Statistics version 19 (IBM Corp). Percentage of time spent on a task and in a location and mean duration of task and location sessions were calculated and compared across roles (nurse vs PCT), day of the week, time of day, and unit. Analysis of variance was used to test for significance. In addition, the number of sessions per hour on a given task or in a given location, number of patient rooms visited per hour, and mean time between visits to a given patient room were determined.

Results

Observation Summary

The study team conducted 92 2-hour observation sessions, resulting in 182.4 hours of observations. There were 46 sessions for 91.4 hours with nurses and 46 sessions for 91 hours with PCTs. The observations were conducted Monday through Saturday, between 10 am and 7 pm, on three units, including two general medical-surgical units and one cardiac care unit (Table 1).

In many cases, the same participant was observed for two consecutive 2-hour blocks. It is possible the same participant was observed on multiple days, but we did not collect identifying information from the participants, and thus cannot confirm that possibility.

Percentage of Time on Task and in Location

Nurses spent on average approximately one-third (32%) of their time in direct patient care, including discharge-related activities completed with a patient. One-quarter (25%) of nurses’ time on average was spent charting, and the remainder was spent on other activities such as retrieval of medications or supplies, communication with other health care team members, and travel between patients (Table 2). Nurses spent the bulk of their time (60%) on the unit but not in a patient room (Table 3); this included the nurses’ station, hallway outside the patient room where nurses do much of their electronic health record charting on a computer workstation on wheels, medication room, and supply room. Compared with nurses, PCTs spent, on average, a significantly greater percentage of their time in direct patient care (42%; *P*=.001) and on other activities (54%, vs 43%; *P*=.003), while nurses spent more time charting (Table 2). Compared with nurses, PCTs spent, on average, a significantly greater percentage of their time in a patient room (47% vs 33%; *P*<.001; Table 3).

Table 1. Study participants by role and unit.

Task	Nurses observed	PCTs[a] observed
Medical-surgical unit 1	14	14
Medical-surgical unit 2	15	15
Cardiac care unit	17	17

[a] PCT: patient care technician.

Table 2. Percentage of time spent by task.

Task	Nurses, mean (SD)	PCTs[a], mean (SD)	*P* value
Charting	25 (14.3)	4 (7.1)	<.001
Direct patient care	31 (16.6)	42 (14.8)	.001
Discharge activities	1 (2.5)	—[b]	.14
Other activities	43 (18.3)	54 (15.2)	.003

[a] PCT: patient care technician.

[b] Not applicable.

Table 3. Percentage of time spent by location.

Location	Nurses, mean (SD)	PCTs[a], mean (SD)	*P* value
In patient room	33 (15.7)	47 (16.8)	<.001
Not in patient room	60 (16.8)	42 (16.1)	<.001
Off unit	8 (12.9)	11 (14.5)	.24

[a] PCT: patient care technician.

Task and Location Sessions

Nurses averaged 16.2 tasks per hour, which included 5.1 direct patient care tasks per hour. The mean length of a direct patient care session was 3:42 minutes, while charting sessions and discharge activities were slightly longer at 4:57 minutes and 4:28 minutes, respectively (Table 4). PCTs averaged 18.2 tasks per hour, of which 8.2 were direct patient care tasks. PCTs' mean session length was 3:02 minutes for direct patient care, 3:22 minutes for charting, and 3:27 minutes for other activities (Table 4). It is important to note that these averages are the result of many short sessions and fewer, longer sessions. For nurses, 56.37% (836/1483) of task durations were 2 minutes or less, and 38.23% (567/1483) were 1 minute or less. An even greater percentage of PCT task durations were short, with 61.99% (1039/1676) being 2 minutes or less and 44.27% (742/1676) being 1 minute or less; 9.10% (135/1483) of nurse tasks and 6.68% (112/1676) of PCT tasks were longer than 10 minutes.

Nurses averaged 13.7 locations per hour, and PCTs averaged 19.6 locations per hour. Nurses spent an average of 3:41 minutes in a patient room whereas PCTs spent an average of 2:57 minutes in a patient room (*P*=.03; Table 5). Again, the location duration averages are the result of many short sessions and fewer, longer sessions. For nurses, 52.99% (683/1289) of location durations were 2 minutes or less, and 36.85% (475/1289) were 1 minute or less. For PCTs, 63.97% (1131/1768) of location durations were 2 minutes or less and 48.02% (849/1768) were 1 minute or less. For nurses, 11.64% (150/1289) of location durations were longer than 10 minutes, while for PCTs, 6.39% (113/1768) were longer than 10 minutes.

Table 4. Session duration on task.

Task	Nurses, mean[a] (SD)	PCTs[b], mean (SD)	*P* value
Charting	4:57 (6:44)	3:22 (5:24)	.06
Direct patient care	3:42 (5:05)	3:02 (4:12)	.07
Discharge activities	4:28 (6:59)	—[c]	.50
Other activities	3:12 (5:54)	3:27 (7:59)	.42

[a] Mean session durations reported in minutes and seconds.

[b] PCT: patient care technician.

[c] Not applicable.

Table 5. Session duration by location.

Task	Nurses, mean[a] (SD)	PCTs[b], mean (SD)	*P* value
In patient room	3:41 (4:58)	2:57 (4:12)	.03
Not in patient room	4:22 (7:12)	2:31 (5:37)	<.001
Off unit	15:20 (13:48)	17:42 (16:40)	.12

[a] Mean session durations reported in minutes and seconds.

[b] PCT: patient care technician.

Room Visits

Nurses visited 5.3 (SD 2.2) and PCTs 9.4 (SD 4.0) patient rooms per hour. The mean time between nurse visits to a given room was 37:15 minutes and between PCT visits to a given room 33:28 minutes. In the 2-hour observation blocks, 36.7% (66/180) of rooms visited by a nurse being observed were only visited once by that nurse, and 42.6% (162/380) of rooms visited by a PCT being observed were only visited once by that PCT.

Day of Week, Time of Day, and Unit Comparisons

Comparisons of measures across day of the week were conducted to determine if there were differences that might make one day better or worse than another for providing education. There were no significant differences across day of the week for nurses or PCTs for percentage of time spent on a task category or in a given location. In addition, there were no significant differences in the mean number of task or location sessions per hour. For nurses only, there was a statistically significant difference in session duration for other activities, with a high on Saturday of 5:20 minutes and a low on Tuesday of 2:23 minutes. This trend was not observed in PCTs.

We also compared measures across time of day to determine if there were differences that might indicate that a given time of day would be better or worse for providing education. To make this comparison, we grouped observations that started from 10 am to 12 pm as morning, observations that started from 1 pm to 3 pm as midday, and observations that started from 4 pm to 5 pm as late afternoon. Nurses spent a significantly greater percentage of their time off the unit during midday (observation blocks that started at 1 pm, 2 pm, or 3 pm). Off unit session duration was also significantly longer in this time block. In addition, nurses spent significantly more time charting in the midday time block. There were no other significant differences across time of day for nurses. For PCTs, the percentage of time spent charting and the mean session length for charting were significantly greater during the late afternoon observation blocks (starting at 4 pm or 5 pm). There were no other significant differences by time of day for PCTs.

Across the three study units, there were no significant differences in study metrics for nurses. PCTs on the cardiac care unit generally had more and shorter sessions than the PCTs on the two medical-surgical units.

Discussion

Principal Findings

This time and motion study of nurses and PCTs on medical-surgical units revealed important findings about staff workflow in an urban tertiary care hospital, specifically about the potential to support tablet-delivered bedside diabetes education. While providing patient education is a nursing responsibility, our prior research showed that PCTs were interested in contributing to patient education activities [27], so we also considered the workflow of PCTs. Nurses visited an average of 5.3 patient rooms per hour, while PCTs visited 9.4 patient rooms per hour. The workflow of nurses and PCTs, constantly in and out of patient rooms, suggests an opportunity for either a nurse or PCT to deliver a tablet to the patient bedside. In addition, the average time between visits to a given room is consistent with bringing the tablet to a patient in one visit and retrieving it at the next visit. The average time between nurse visits to the same patient room was 37:15 minutes and between PCT visits was 33:28 minutes. This time span would allow the patient sufficient time to engage with the education. To our knowledge, there are no other studies in the literature reporting a room visit analysis similar to that reported here (ie, time between visits to the same room). These findings add to the body of knowledge on nursing workflow on inpatient medical-surgical units and demonstrate the feasibility of a nurse or PCT completing an activity that requires them to visit a patient room initially and then return to the same patient room within a timeframe that is neither immediate nor as long as an hour.

It is possible then, within existing workflow, to drop off and pick up a tablet computer for diabetes education delivery. However, the relatively short duration of direct patient care sessions, at an average of 3:42 minutes for nurses and 3:02 minutes for PCTs, could potentially limit the ability of the nurses and PCTs to spend much time with each patient on instruction in use of the technology platform or in answering questions about the content. This suggests that it would be important for the patient to be able to engage with the education independently. We also found that some rooms were visited only once by the nurse or PCT being observed, but we believe that this may be an artifact of the 2-hour observation periods and the observation of a single care team member. When a room is initially visited late in a given observation period, a return visit would not necessarily be expected until after that observation period had ended. In addition, other care team members may have visited those rooms.

The finding that nurses spent approximately one-third of their time in a patient room in direct patient care is consistent with other studies in the literature, where time and motion studies report that nurses average 22% to 37% of their time in direct care activities [28-30] and 31% to 34% of their time in a patient room [24]. The average is somewhat higher for nurses on intensive care units at 41% to 50% [31-32].

Of perhaps greater relevance to capacity to deliver education is the length of time spent on individual tasks. We found that fully 38% of nursing tasks and 44% of PCT tasks were accomplished in less than one minute. The high percentage of short duration tasks indicates significant task switching and highlights the challenge of providing patients with effective in-person education or instruction in the use of the tablet computer within the current workflow. It is difficult to make comparisons between this study and other similar studies on duration of individual tasks and number of tasks per hour due to inconsistency in task definitions. In this study, we used four task categories, while other similar studies used, for example, 10 [28], 10 and 11 [33], 29 [34], and 41 [32] task categories, as dictated by the goals of the research. It is not surprising that a study with more specifically defined tasks would find more tasks per hour and tasks of shorter duration. In a study with more task categories, a participant might complete multiple individual tasks that would be classified as a single task of direct patient care in our study. For example, Cornell et al [33] reported more than 50% of tasks were completed in 30 seconds or less in an observation study of nurses on medical-surgical and pediatric oncology units that used 10 (medical-surgical) and 11 (pediatric oncology) task categories, and Douglas et al [32] found that nurses switched tasks an average of every 29 seconds in their study of adult and pediatric intensive care unit nurses where they used 41 task categories. Despite the differences in the number of task categories, these similar studies all conclude that nurses experience high levels of task switching and fragmented workflow [28,32-34].

Within the days and times of the study, there was no day of the week or time of day where nurses spend a greater percentage of their time in a patient room in direct patient care or have longer sessions in a patient room in direct patient care. Not surprisingly, nurses spent a significantly greater percentage of their time off the unit during midday, likely due to their lunch break. We conclude that, with the possible exception of midday, the data do not indicate that any day of the week or time of day, within the days and times observed, provides a better or worse opportunity for nurses and PCTs to deliver education.

There were several significant differences in nursing workflow compared to PCT workflow. These differences are due to the differences in responsibilities and patient load for the two groups. PCTs have little or no charting and discharge responsibilities. It is not surprising then that PCTs spend significantly more of their time in direct patient care; nurses spend a quarter of their time charting which leaves less time for direct patient care. In addition, on the study units, the PCTs are typically responsible for approximately twice as many patients as the nurses. It follows that PCTs would have more locations per hour and more tasks per hour as they divide their time among more patients. And while PCTs spend a greater portion of their time in direct patient care, the average duration of a direct patient care session is lower than a nursing direct patient care session. Overall, these results are consistent with either a nurse or PCT dropping off and picking up a tablet computer within their existing workflow.

Limitations

There were several limitations to this study. First, although the units in the study are typical medical-surgical and cardiac care units, the study was conducted in a single hospital. While this served our study purpose of designing a process to implement a diabetes education intervention in that hospital, it potentially limits generalizability of the study outcomes. Second, participants were chosen based on their willingness to be observed, which may have introduced selection bias, and they were aware that they were being observed, which may have influenced their decisions on how and where to spend their time. Observers attempted to mitigate this by explaining that they were objectively recording what the participants were actually doing and not making subjective judgments about what participants should be doing. In addition, we did not attempt to assess how the nurses prioritized their time. We assumed that if a nurse was not in a patient room, he or she had a higher priority task outside the patient room and was not available to provide education. We also did not attempt to characterize the specific tasks done with the patient. We assumed that any visit to a patient room could potentially be used to deliver the education program but did not gather data to support this assumption.

Conclusions

DSMES has been widely shown to be beneficial for persons with diabetes. In the hospital, nursing staff are responsible for providing patient education, but time and resource constraints often limit education delivery. This study generated data showing that nurses and PCTs make frequent short trips into patient rooms and constantly task switch. The data suggest that, within current workflow on hospital general medical-surgical nursing units, it would be feasible for nurses or PCTs to provide a technology-delivered diabetes education program to the bedside for patients to complete independently between staff visits to the room. Future research should pursue pragmatic implementation of delivering tablet-based patient education.

Acknowledgments

The National Institutes of Health National Institute of Diabetes and Digestive and Kidney Diseases funded this work (R34 DK-109503). The authors would also like to thank the nurses and PCTs who participated in the study and the research associates who collected the observation data (Clayton Bourges, Jamie Brown, Kimberly Burke, Kimberly Cockey, and Kelly Rosendall).

Conflicts of Interest

None declared.

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Abbreviations

DSMES: diabetes self-management education and support
PCT: patient care technician

Edited by E Borycki; submitted 29.07.19; peer-reviewed by K Monsen, PY Yen, D Chrimes; comments to author 14.09.19; revised version received 25.09.19; accepted 09.10.19; published 01.11.19.

Please cite as:
Baker KM, Magee MF, Smith KM
Understanding Nursing Workflow for Inpatient Education Delivery: Time and Motion Study
JMIR Nursing 2019;2(1):e15658
URL: https://nursing.jmir.org/2019/1/e15658/
doi:10.2196/15658
PMID:34345775

Original Paper

Design of a Consumer Mobile Health App for Heart Failure: Findings From the Nurse-Led Co-Design of Care4myHeart

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Abstract

Background: Consumer health care technology shows potential to improve outcomes for community-dwelling persons with chronic conditions, yet health app quality varies considerably. In partnership with patients and family caregivers, hospital clinicians developed Care4myHeart, a mobile health (mHealth) app for heart failure (HF) self-management.

Objective: The aim of this paper was to report the outcomes of the nurse-led design process in the form of the features and functions of the developed app, Care4myHeart.

Methods: Seven patients, four family caregivers, and seven multidisciplinary hospital clinicians collaborated in a design thinking process of innovation. The co-design process, involving interviews, design workshops, and prototype feedback sessions, incorporated the lived experience of stakeholders and evidence-based literature in a design that would be relevant and developed with rigor.

Results: The home screen displays the priority HF self-management components with a reminder summary, general information on the condition, and a settings tab. The health management section allows patients to list health care team member’s contact details, schedule medical appointments, and store documents. The My Plan section contains nine important self-management components with a combination of information and advice pages, graphical representation of patient data, feedback, and more. The greatest strength of the co-design process to achieve the design outcomes was the involvement of local patients, family caregivers, and clinicians. Moreover, incorporating the literature, guidelines, and current practices into the design strengthened the relevance of the app to the health care context. However, the strength of context specificity is also a limitation to portability, and the final design is limited to the stakeholders involved in its development.

Conclusions: We recommend health app development teams strategically incorporate relevant stakeholders and literature to design mHealth solutions that are rigorously designed from a solid evidence base and are relevant to those who will use or recommend their use.

(JMIR Nursing 2019;2(1):e14633) doi:10.2196/14633

KEYWORDS

heart failure; mobile health (mHealth); mobile apps; self-management; mobile phone; patient involvement

Introduction

The management of chronic conditions is an important public health challenge [1]. Globally, 26 million people live with heart failure (HF) [2], a chronic condition with considerable economic burden [3] that places great stress on patients, caregivers, and health care services [2]. Supporting patients and caregivers in long-term HF care is essential [2] with self-management linked to better quality of life, lower mortality, and readmission rates [4]. For these reasons, self-management is supported by health care policy [5,6] and is the mainstay for disease management in HF [4,7]. However, as with many chronic conditions, patients with HF find it difficult to follow self-care advice because it can be complex and challenging to sustain behavior change over the long term [4].

In an era of rapid technological advancement, there is a growing interest in consumer digital health to help with improving health. Out of the 318,000 plus mobile health (mHealth) applications (apps) available to consumers across the world [8], an abundance of health apps are available for self-monitoring [5] with condition management apps now accounting for 40% of apps [8]. The widespread interest among patients with chronic conditions to use health technologies stretches across health status, age, and other sociodemographic variables [9]. The quantity and variety of mHealth apps available present an overwhelming choice for consumers [8,10], often without guidance from their health care provider [10].

From the health provider perspective, the lack of evidence regarding the effectiveness of mHealth apps to improve health care outcomes limits their addition to treatment protocols [10]. Particular concerns are around the evidence of consumer apps regarding accuracy, efficacy, and security [10], and the inconsistent impact on disease control and health care utilization [11]. Most apps are developed outside health care systems [10], the average app quality is often low [8], and some may even threaten patient safety and privacy [12]. mHealth apps are neither yet established for widespread and sustained use nor embedded in the Australian health policy [5]. More locally, our health service's HF team does not currently recommend a HF self-management app to patients. However, the body of evidence regarding the health impacts of mHealth apps is expanding [5,8], exampled by the growing number of clinical trials in recent years [10], and the value of mHealth to improve health care delivery is high among providers [10].

If we are to embrace consumer digital health care for its potential to address the burden of chronic conditions, interventions need to be well designed, evidence-based, and fit-for-purpose for health care providers and health care consumers alike. With this in mind, the aim of this research was to use co-design processes to develop a consumer mHealth intervention for HF self-management that is both relevant to stakeholders and developed with rigor. This paper reports the outcomes of the nurse-led design process in the form of the features and functions of the developed app, *Care4myHeart*.

Methods

Methodology

This research was informed by the Design Science Research Cycles proposed by Hevner [13] and refined by the research team [14]. Hevner's framework consists of 3 cycles: design, relevance, and rigor. The relevance cycle consists of context-specific inputs from the environment, and the rigor cycle incorporates theories and methods from the existing knowledge base [13]. Data from both cycles were incorporated into the design cycle where the innovation was developed and iteratively refined [13].

Design Process

The systematic design and development followed the Stanford University's Design Thinking Process of innovation [15]. The 5-stage process enlisted incorporated empathizing with stakeholders, defining the health care challenge, ideating possible solutions, creating a rapid prototype, and testing with end users [15]. Embedded in the research is co-design. Co-design is a design-led process incorporating creative and participative principles and tools to actively involve a diverse group of stakeholders to explore, develop, and test solutions to shared challenges [16]. Clinicians, patients, and family caregivers were recruited from our health service, a large metropolitan tertiary hospital campus specializing in cardiac care in metropolitan Sydney, Australia. Clinicians included 2 nurse practitioners, 1 nurse consultant, a dietitian, a physiotherapist, a pharmacist, and a cardiologist. Design activities were led by a cardiac clinical nurse specialist and occurred on the hospital campus or via email as required. Ethical approval was granted from the University of Tasmania and St Vincent's Private Hospital Sydney. First, we present the design processes enlisted in the empathize and define phase, followed by creative, dynamic processes within the ideate and prototype phase.

Empathize and Define

Interviews were conducted with 7 patients, 4 family caregivers, and 7 clinicians to identify experiences, challenges, and opportunities regarding the lived experience of the main stakeholders. The following design artefacts—material objects that can be viewed by others, used to challenge perceptions, and inspire new ideas [17]—were created by the research team from analysis of the data:

1. Journey map: a list of daily self-care activities and associated emotional responses.
2. Stakeholder map: personal and professional persons involved in self-care.
3. Personas: 4 diverse characters representing patient needs and insights [18].
4. Current care summary: health professional's critique of self-care support [19].
5. Clinical relevance information: considerations for the effective implementation of the mHealth app [19].

The design brief was developed by the research team (authors 1, 2, 4, and 5) from analyzing the design artefacts. It is a result of the composite of the design artefacts as interpreted by the research team. The design priorities within the brief were to (1) address medication and symptom management challenges, (2) involve some form of self-care plan, and (3) manage all stakeholders in care, as well as being evidence-based, useful, simple, and easy to use [19].

Ideate and Prototype

A subset of 11 participants representing each of the three stakeholder groups (seven clinicians, three patients, one family caregiver) participated in two workshops and 4 months of iterative prototype development in 2017 [20]. This subset of participants will hereafter be referred to as *co-design team members*. Firstly, design artefacts were actively used in timed and focused group activities within the workshops resulting in a storyboard of the initial design on a whiteboard. Thereafter, individual co-design team members met with the design lead to refine the prototype referring to the design artefacts and other resources as required. A recurrent analysis of the academic literature, local policies, national guidelines, standards, online resources, and self-management tools ensured consistency with the evidence base. Co-design team members identified these resources as needed and referred to them intermittently throughout the development. The skills, knowledge, and experience of each co-design team member was incorporated in version updates which involved an ongoing and collaborative negotiation between co-design team members to decide on the content. The final software version reported in this paper represents the outcomes of the design cycle as the team's collective decisions regarding the features and functions of the app.

Results

The findings elicited throughout the co-design process are reported alongside each app component in a justification of the final app design. First, we present an overview of the app and thereafter describe the app's 3 main sections.

Design Overview

Care4myHeart is an evidence-based, modular, patient-facing consumer mHealth app for Android and iOS. The app interface consists of 3 main sections: (1) the *home screen*, (2) the *health management* section, and (3) the *My Plan* section. The home screen is the initial contact with the app's interface and contains the priority and daily components of HF self-management, reminder summary, general information on the condition and a settings tab (see Figure 1). As much of the self-management work for patients with long-term conditions is associated with management of medical documentation, medical appointments, and health care team interactions, health management tools are included in the app's design and are reported under the heading *health management* (see boxed sections, Figure 1). The *My Plan* section includes nine components of HF self-management and the favorites option (see Figure 2).

The three main sections of the app are described further with a description of the rationale behind the design.

Figure 1. The Care4myHeart home screen including the health management section (boxed in orange).

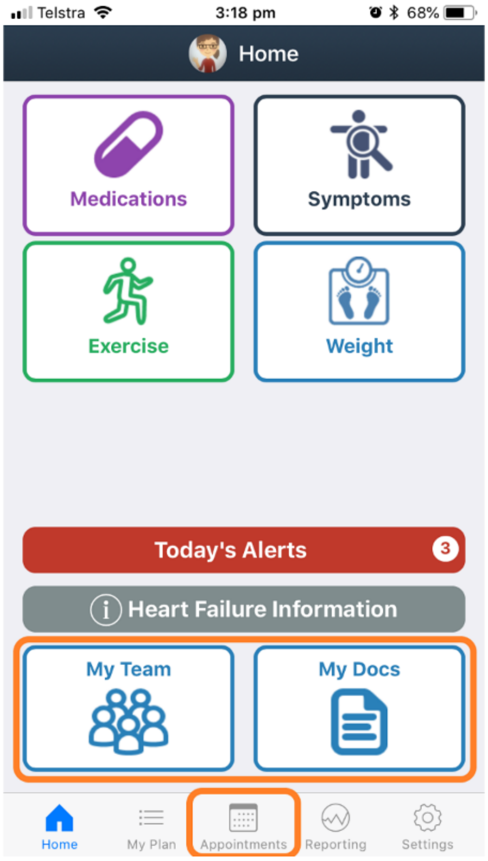
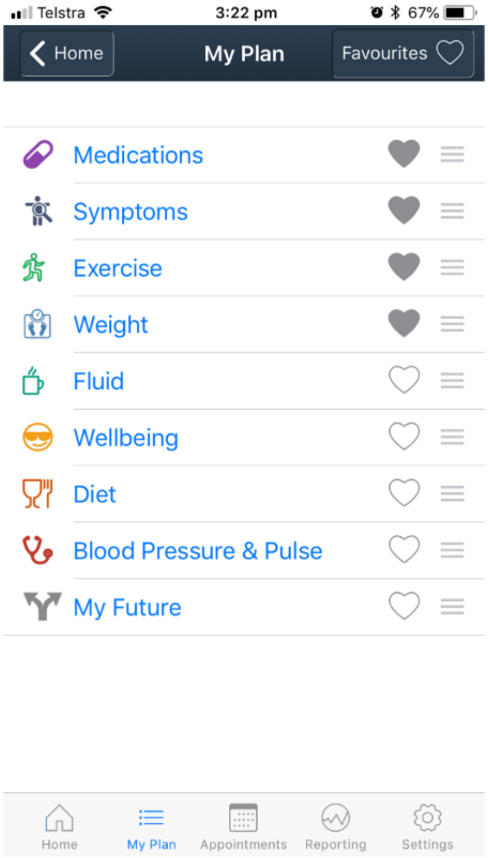


Figure 2. The Care4myHeart app "My Plan" section.



Section 1: Home Screen

Table 1 presents the home screen design which comprises the *My Plan* subsection, HF information, today's alerts, and settings.

Table 1. Care4myHeart's home screen design and rationale.

Subsection	Item	Rationale
My Plan icons	Nine self-management components; *favorites* appear on home screen	Design priority to involve some kind of self-care plan; clinicians wanted individualized care plan which involves the patient and family; standards [21] and recommendations [7] for the ongoing management of HF[a].
Heart failure information	Information pages: overview, symptoms, and treatments	Design priority to have an evidence-based resource that would be useful, simple, and easy to use; clinicians wanted early, regular, clear, appropriate, basic, and needs-based educational material; health literacy considerations; the credible source for the information was the St Vincent's Heart Health website [22].
Today's alerts	List of tasks to be completed	The literature highlights the key measures to track in HF and the importance of setting self-care goals [23-25].
Settings	Enter baseline data and set goals	The team referred to the key measures to track in HF and recommendations to set self-care goals [23-25].

[a] HF: heart failure.

My Plan

This subsection is based on the principles within the Australian standards [21] and recommendations [7] for the ongoing management of HF which emphasize the need for self-care education and support [7]. The core requirements of these standards are the provision of clear and reliable information on symptoms, exacerbating factors, and both medical and lifestyle management [7]. The benefit of *My Plan* subsection is the modular approach providing an option as to which subsections are pertinent, in appreciation that individually tailored management plans are recommended as a tool to support care coordination [21] and optimize wellness. For relevance to the health care context, clinicians believed individualized care planning could be improved in current practice with a key design priority to involve a self-care plan. The favorites function—allowing users to select their individual priority *My Plan* components—displays important self-management subsections on the home screen. Having favorites displayed on the home screen was especially relevant as it actively facilitates the involvement of patients and family in individualized care planning during the set-up process, through choice of components from the *My Plan* list *and* number of components based on their preferences and goals.

Heart Failure Information

HF information, written in plain English including an overview of the condition, common symptoms, and treatments, is found via a button on the home screen accessible by patients and their family. The information was sourced from the St Vincent's Heart Health website [22] and deemed an appropriate inclusion by clinicians and patients alike. The HF information section provides an opportunity to communicate educational material in *patient-friendly* language as a useful, clearly displayed repository of evidence-based information, as prioritized by clinicians and noted in the design brief. Clinicians recognized that educational material for patients with HF should be given early, regularly and should be clear, appropriate, basic, and needs-based. Previous work with health writers for the website content was discussed in the design workshops, and thus, paragraph sizes were limited to 4 to 5 lines, and large text sizes were used to improve readability for patients. Providing a HF information summary clearly visible on the home page was deemed important by the co-design team who often encounters family members asking for details about the condition and its treatments.

Today's Alerts

A summary list of self-management tasks for the user to complete for the day (today's alerts) was a priority design inclusion. Local clinicians believed that follow-up with patients should be improved in current care to aid memory. The co-design team members considered reminders and scheduling important functions of the app to be addressed and are, therefore, included features in the alerts summary.

Settings

Baseline self-management data and patient goals are personalized in the app's settings. The co-design team members prioritized patient ownership, interactivity, and tracking as important for the user experience. In the app settings, the key measures to track [23-25] or goals to be set relate to weight, fluid restriction volume, blood pressure (BP), pulse, daily steps, and number of exercise videos to be viewed daily.

Section 2: Health Management

The *health management* section of the app provides the opportunity for users to enter medical appointments into a calendar, digitally store medical documents, and list contact details for all personnel involved in their care. The design and rationale are summarized in Table 2.

Table 2. The health management section design and rationale.

Subsection	Item	Rationale
Appointments	Add medical appointments including detail	Patients experienced challenges managing multiple appointments with family caregivers often assisting; clinicians believed follow-up and connected care is not done well in the health service; scheduling and reminders were a priority; reviewed current tools for documenting clinic and doctor visits [23,25].
My Docs	Store, review, and share test results, letters, and referrals	Some patients wanted test results but may misplace documentation; clinicians wanted to include or track data, facilitate team communication, and maximize and join care; reviewed tools to document health records [23,25]; hospital's discharge checklist contains echocardiogram results [21].
My Team	Contact details of emergency contact person and health professionals	Patients frequently liaise with their health care team but experience poor information sharing between health care providers; a design priority was to manage all stakeholders in care well and facilitate team communication; referred to the recommendations [7] and standards [21] for multidisciplinary care in HF[a]; the literature highlights the importance of team communication [24] and provides tools to document their contact details [23-25]; the hospital's HF discharge checklist contains postdischarge care and follow-up details [21]

[a] HF: heart failure

Appointments

The appointments tab contains a calendar to add, review, and set reminders for medical appointments with the ability to add detail needed for the appointment. The HF self-management literature lists the importance of keeping track of clinic and doctor visits [23,25]. Locally, clinician's critique of current self-management support is that follow-up care and connected care is not done well, and the co-design team prioritized *scheduling and reminders* as design priorities. From the patients' perspective, there were reported challenges managing multiple medical appointments as some choose to take notes immediately after appointments to summarize the conversation to capture the complexity of care. Especially, necessary for those living in rural areas who need to travel for specialized medical care, careful coordination of appointments effectively could improve time away from loved ones, avoid early wake-ups, and missing meals or medication doses. Furthermore, some family caregivers reported feeling like project managers, regularly assisting with scheduling, and attending medical appointments causing feelings of being overwhelmed with caregiver responsibilities. These important patient- and family-centered considerations were incorporated in design improvements of the appointments section.

My Docs

The My Docs (documents) section provides an opportunity to store, review, and share test results, letters, and referrals. Documenting health records [23,25] is important in managing one's health, and the health service's HF discharge checklist contains echocardiogram results (Appendix F [21]) for effective communication when moving between care settings. During workshops, the co-design team determined that it was relevant to the patient persona who want to know echocardiogram and pathology results but may periodically misplace this documentation. From the perspective of clinicians, a design priority was to include or track patient data for the purposes of reviewing this data later. The My Docs section was seen as a way for the patient to facilitate communication between the health care team, to better maximize and join care between health care providers and settings.

My Team

My Team lists the contact details of the user's emergency contact person and the health professionals relevant to their care. The recommendations [7] and standards [21] for multidisciplinary care demonstrate the importance of patients engaging effectively with their care providers through, for example, communication with health professionals [24] and documenting their contact details [23-25]. The hospital's discharge checklist contains specific details regarding the person(s) responsible for postdischarge care and follow-up in the community (Appendix F [21]). This section was considered relevant by all stakeholders throughout the app's design. Patients may have an available and approachable multidisciplinary team, foster relationships with respect and trust with doctors and nurses in their health care team and seek care regularly. However, participants also reported poor information sharing between health care providers and may be unsure who else is providing care for them commonly relying on memory. The stakeholder map identified that the patient's spouse and general practitioner are the most likely personal and professional involved in HF self-management. Other members of the family and the pharmacist were also frequently involved, followed by a person's employer or friends and specialist. In terms of the relevance of the My Team section to health care providers, clinicians wanted a tailored care plan that includes the multidisciplinary care team to ensure that care was holistic, and the design brief emphasizes the importance of managing all stakeholders in care well. Clinicians communicated their concerns of health inequality as some patients have poor access to specific multidisciplinary team members. Finally, during design workshops, the co-design team prioritized team communication as a priority function. These factors resulted in a group decision to include a list of names and details of all persons involved in the care of a person with HF.

Section 3: My Plan

This section includes nine subsections of HF self-management, and the favorites option and is summarized in Table 3. Each of the nine self-management subsections (listed in no particular order) were included because they are considered as the key in the ongoing management in HF and a relevant, useful, and helpful inclusion by patients, family caregivers, and clinicians. This is based on the local clinical service framework which supports that all patients with HF *should have access to individually tailored, disease management*, and rehabilitation services offered on an outpatient or community basis (p. 29 [21]).

Table 3. The My Plan section design and rationale.

Subsection	Item	Rationale
Symptoms	Infographic of common signs and symptoms; help seeking information; understanding deterioration information	Patients reported frequent, varied symptoms. Some were frustrated by multiple, interacting, and complex symptoms or lacked understanding of the treatment rationale in lessening symptom burden; the design brief highlighted the importance of addressing symptom management challenges; the co-design team wanted information and self-help which is visual and simple; source of the infographic was the St Vincent's Heart Health website [22]; when deciding on the content for the information and advice pages, HF[a] patient information booklets [23,24], the St Vincent's Heart Health website [22] and the chronic HF action plan [24] were referred to.
Medications	Medication, previous medications, and allergy list; medicine information; diuretic plan	Clinicians believed medication management should be better supported; patients reported challenges with managing their medications with caregivers often involved; medication information was an important design feature, with specific insights and expertise provided by the pharmacist; the team referred to HF medicine information in patient education booklets [23-25] which includes a medication list template [23], reviewed information on the National Prescriber Scheme Medicine Wise website [26] and the flexible diuretic regime in the hospital's HF discharge checklist [21].
Fluid	Visual representation of jug at volume of fluid restriction; user enters oral fluid intake throughout the day	Patients experienced challenges with maintaining fluid restrictions; the co-design team wanted tracking with feedback and an interactive interface; fluid-related HF information and advice [24,25,27], local guidelines [22,27], tools and guidelines for documenting fluid intake [23,25,27] and previous qualitative research on fluid restriction adherence [28] were referred to when deciding on content.
Diet	Healthy eating; low salt (sodium) eating including label reading and foods to avoid	Patients wanted general information only; caregivers often prepare meals; specific insights and expertise were provided from the clinical dietitian on the co-design team; information and advice on healthy eating including reducing salt [23-25,29], the *healthy eating* section of the Heart Foundation website [30] were referred to during the design.
Weight	Record daily weight with 7-day graph; interactive, color-coded feedback and pop up alerts	Patients may not be accurate or remember their daily weight; clinicians wanted to include or track HF-related data in an interactive, visual, and tailored format; the cardiac nurse consultant mainly designed the feedback system; information on fluid retention including documenting daily weight and guidelines for help seeking were referred to [23-25,27].
Blood pressure (BP) and Pulse	Record and store BP and pulse measurements	A patient suggested this subsection and the cardiologist supported its inclusion; patient booklets supported intermittent documentation of BP [23,25] and a recent BP and pulse is included in the hospital's HF discharge checklist [21].
My Future	Information and prompts to *decide* on a plan, *discuss* this with others, speak to your *doctor*, and plan what happens to your *defibrillator*	Clinicians suggested the inclusion of information on advance care planning; the team referred to the local advance care planning website [31] and palliative care recommendations [7].
Well-being	Interactive depression screening tool; *at risk* or *low risk* results screen	This subsection was suggested by a patient; patients frequently reported anxiety and worry; emotional support was a priority function; the team reviewed the local depression screen tool (Patient Health Questionnaire-2, PHQ-2 score) in use at the hospital [32,33] and reviewed psychological care recommendations for HF [7].
Exercise	Step counter with 7-day graph; 3× exercise videos demonstrated by physiotherapist (balance, upper limb, and lower limb) with 7-day graph	Patients reported using their smartphone's step counter, appreciated supervised physical exercise, and set their own exercise goals; clinicians wanted to include or track data; the physiotherapist designed the exercise program, using the Otago exercise program [34] as a guide.

[a] HF: Heart failure.

Symptoms

This subsection includes an infographic containing the common signs and symptoms of HF, information to assist in appropriate help seeking, and information about worsening HF. This subsection was an important inclusion in the app because patients frequently reported symptoms such as breathlessness, urinary frequency, sleep disturbance, fatigue, exhaustion and nighttime breathlessness, anxiety, and agitation. Patients said they were frustrated by multiple, interacting, and complex symptoms. Other patients lacked understanding of the treatment rationale in lessening symptom burden. During workshop activities, the co-design team decided it was a design priority to include information and self-help in a visual and simple format. The infographic representing common HF symptoms was sourced, with approval, from the St Vincent's Heart Health website [22]. Hyperlinks to further information and advice pages are accessed through this infographic, and it was collated from patient information booklets [23,24], the St Vincent's Heart Health website [22], the chronic HF action plan [24] as well as the multidisciplinary team members themselves based on their clinical experience and expertise.

Medication

The medication component includes a list of current medications, previous medications, an allergy list, medicine information, and the patient's own diuretic plan. Clinicians thought it appropriate to facilitate improved medication management as a component that should be improved in current care. The pharmacist on the co-design team provided specific insight into the design of this subsection. Patients reported the disruption to their routine when medication prescriptions were changed and the inconsistent documenting of medication lists with some writing changes on scrap paper or even forgetting important changes in the reality of daily life. Family caregivers are sometimes involved in reminders, and patients reported taking tablets with them during outings; so, these realities of the daily management of medications were incorporated into the design of this subsection. During workshop activities where the subsection was further refined, the co-design team members prioritized medication information as an important design feature. The cardiac nurse consultant regularly caring for indigenous Australians saw value in including the color of the medication as a visual reminder. In regard to the literature, medication is a reported important component of HF self-management as per the information contained within the patient education booklets [23-25] which provides a written medication list template [23] and by the hospital literature with the flexible diuretic regime listed in the hospital's HF discharge checklist (Appendix F [21]). The National Prescriber Scheme Medicine Wise website [26] was also reviewed for general medicine information.

Fluid

This subsection comprises of the important fluid restriction guideline for HF. The page displays a visual representation of a measuring jug at the volume of fluid restriction tailored to the patient's restriction volume in the settings (commonly 1200 mL or 1500 mL per day). The jug gradually fills as users enter oral fluid intake throughout the day. Restricting fluid intake is likely the most important method to prevent fluid congestion alongside taking diuretic medications; however, patients commonly reported challenges with maintaining fluid restrictions in daily life, especially with thirst. Clinicians wanted to include or track data, and during design workshops, the co-design team emphasized that user feedback and an interactive interface were important. Information and advice [24,25,27], local guidelines [22,27], and tools and guidelines regarding documenting fluid intake [23,25,27] were local and national literature sources considered during the design. Previous qualitative research conducted in the same clinical setting regarding fluid restriction adherence was also referred to [28].

Diet

The diet component includes information for healthy eating, low salt (sodium) eating, label reading, and foods to avoid. Patients reported that they were not necessarily interested in calorie counting, so general information and advice on healthy eating including reducing salt [23-25,29], recipe suggestions and the *healthy eating* section of Heart Foundation website [30] were consulted. These resources were deemed relevant to family caregivers who commonly prepare and/or assist with meal planning and cooking. Recommendations, advice, and insight regarding nutritional education were provided by the clinical dietitian on the co-design team.

Weight

Daily weight management in this subsection of the app gives the user the ability to record daily weight, view a 7-day weight trend on a bar graph, receive color-coded feedback based on this data and pop up alerts depending on stability of that day's weight in comparison to the dry weight set in the settings tab. Information on fluid retention including documenting daily weight and guidelines for help seeking [23-25,27] throughout the literature was consulted, alongside specialist input from the 2 nurse practitioners on the co-design team who regularly assisted in managing the variations in weight due to fluid congestion in worsening HF. The patients interviewed had variable understandings regarding fluid management, reporting what they knew about dry weight and the concern about going 2 kg over their dry weight. Clinicians thought that the weight section was highly important to include in the apps design, specifically around tracking weight data over the longer term. The co-design team believed having an interactive and visual interface that was tailored to patient parameters improved its utility. The nurse consultant was particularly involved in the colorful design of the feedback alert system when weights varied from the dry weight.

Blood Pressure and Pulse

For some, self-monitoring of BP and pulse is important in HF. This *My Plan* subsection provides the option to record and store BP and pulse measurements. Clinicians generally supported the inclusion of patient data to track them; however, the inclusion of recording BP and pulse specifically, was inconsistent. One patient initially suggested the inclusion and the cardiologist agreed to it; however, the other clinicians believed it was not important enough to include especially comparative to other daily measures to track in HF. A second patient who does not self-monitor this data did not see it necessary to include in the app. Through ongoing discussions, it was decided this subsection would be included in the final design as the literature supports the intermittent documentation of BP [23,25]. Furthermore, the hospital's discharge checklist specifies recording a postural BP (measurements taken while sitting and standing) and nature of the pulse as either regular, irregular, or paced (Appendix F [21]).

My Future

This subsection relates to the long-term planning required for patients with HF. This section contains information and prompts to decide on a plan, discuss this with others, speak to their doctor, and plan what happens to their defibrillator (an implantable medical device) if they have one. The inclusion of this section was deemed relevant by clinicians, and patients on the co-design team agreed to its inclusion without providing specific input into its content. The team reviewed the local advance care planning website [31] and palliative care recommendations for the multidisciplinary care of people with HF [7] as key literature sources.

Well-Being

The well-being component represents the psychological aspect of self-management. It contains an interactive depression screening tool, *at risk* or *low risk* results screens and information and advice pages. This section was suggested by a patient on the co-design team during the second design workshop as they felt it necessary to address the emotional support needed for people living with HF. In the interviews, patients reported the frequency of anxiety and worry. Patient needs included family, nature, mindfulness, and happiness demonstrated in 1 patient persona who balances quality of life with safety in HF in her pursuit to maintain well-being. The co-design team then conducted a literature review of the psychological care recommendations for HF [7], and clinicians communicated their use of the depression screen tool (Patient Health Questionnaire-2, PHQ-2 score) [32,33] routinely used in current practice. The PHQ-2 store is a 2-item validated questionnaire designed for the initial assessment of depression and anxiety in the primary care setting [32,33] and precedes referral for specialized care in the local hospital setting.

Exercise

The exercise component has a step counter with 7-day graphical representation of daily steps. There was an inclusion of 3 exercise videos demonstrated by the physiotherapist—balance, upper limb, and lower limb—with a 7-day graph. Patient interviews uncovered that patients were using their smartphone's step counter, appreciate supervised physical exercise and set exercise goals, for example one patient setting a 2 km daily walk. Clinicians valued ability to track patient data in considering the relevance to the patient group, and physiotherapist on the co-design team designed the exercise program to the specific context. The Otago exercise program to prevent falls in older adults [34], a resource commonly referred to for this patient population, formed the basis of the content of the balance and lower-limb exercises.

Discussion

Principal Findings

We have presented the final design of the *Care4myHeart* app which includes the home screen, a health management section, and a My Plan section. With the goal to support local patients with HF self-management and representing the opinions and perspectives of those who would use or recommend the novel app, we enlisted a co-design methodology. The strength of the context-specific co-design process to elicit the final design was the access to, and ongoing involvement of, key stakeholders and the relevant literature. However, the strength of context specificity is also a limitation to portability, and the final design is limited to the stakeholders involved in its development. These key strengths and limitations are explained further.

Strengths of the Co-Design Process to Achieve the Final Design

The greatest strength of the co-design process to achieve the design outcomes was the involvement of clinicians, patients, and family caregivers. Drawing on best practice, the literature supports using collaborative, team-based processes to develop mHealth interventions [35]. The benefit of the approach to design was strategically coordinating stakeholder involvement within each development stage. As we progressed from the empathize and define phase to the ideate and prototype phase, we were able to achieve the intermediate design goals to input into the subsequent phases, ensuring efficiency of development to achieve the final design.

First, in the empathize and define phase, stakeholders were individually interviewed to understand their experiences, ensuring perspectives and opinions were appropriately defined. Appreciating the various interests of different stakeholders [35] by interviewing patients, caregivers and clinicians separately ensured a good understanding of health care challenge to be addressed in the design from many different standpoints. However, it was the careful emphasis on the *define* phase—where these experiences were visually represented in poster format—which facilitated cross-stakeholder empathy. Referred to as a mutual learning [36], knowledge transfer between different stakeholders was maximized [35] in this process. Patient personas were a way to represent the important health care consumer voice, as patients are often passive in health care improvement activities [37] and traditionally excluded from design efforts [17]. It has previously been shown that the benefit of documenting patient narratives on preferences, beliefs, and values is that it legitimizes their preferences [38]. Equally, it was important to interview caregivers in HF, who in other settings have expressed distrust towards the health system due to feelings of role strain [39]. As a vessel for positive change in health care, the empathize and define phase in co-design presents a method of inclusion and mutual respect, ensuring that for caregivers (and indeed all stakeholders) are *more explicitly involved in the design of disease-management interventions* as recommended by Burke and colleagues (p. 736 [39]). The benefit of representing stakeholder experiences separately gives relevance to their specific needs and insights to be considered in the subsequent design stage.

Second, bringing stakeholders together was beneficial in the ideation phase for a fit-for-purpose design. Collaborative practices support design features that would be accepted by potential users and are technically feasible [35]. As suggested by Skeels and Pratt [36], the role of team members as *partners* in the design process was emphasized in our design process, allowing for the creation of a collaborative group dynamic where participants addressed each other directly [36] in design workshops. However, in this research, we were limited by the small number of patients who chose to attend the workshops. To account for this, design activities included the use of the design artefacts, commonly used in design workshops as a design strategy to provoke an alternate way of thinking, challenge perceptions or raise questions about conventions and assumptions [17]. Design artefacts were considered a practical tool for co-design, spurring creativity, and supporting meaningful participation [16] through discussion and collaborative decision making to achieve the conceptual design of the app by the end of the second workshop.

Finally, in the prototype phase, all stakeholders provided feedback independently to refine the wireframes. The overarching principal was that the design reflected the ideas generated by the group [36] even though stakeholder involvement was done individually. Content was written by clinicians with the relevant expertise, checked by patients for clarity, and iteratively refined until consensus was achieved. One-to-one feedback sessions facilitated a hands-on assessment of the digital prototype version for review. To maximize honest feedback and in appreciation of their voluntary participation, the nurse-lead offered a safe, respectful, and relaxed environment. Updating the prototype quickly meant they were engaged and valued in the creation of the innovation.

Another noteworthy contribution of this research was incorporating the literature, guidelines, and current practices into the design which strengthened the relevance of the app to the health care context. Clinicians aspired to develop this app as a self-management tool to be an adjunct offering in addition to existing HF care. To support clinicians in providing the expert care they aspired to provide, they were unanimous, it needed to include the locally relevant evidence-based information and be consistent with the self-management support literature they provide. The app aimed to supplement (not replace) other traditional formats of patient education (eg, patient information booklets [23-25]) as interventions that emphasize and reinforce the complexity of HF have been considered particularly valuable [4]. Anderson and Emmerton [5] suggest pairing app interventions with health care professional input, advising against *leaving consumers to their mobile devices without periodic check-ups* (p. 594 [5]). The purposeful integration of the app to the health care setting is undoubtedly more likely to be achieved if it is developed within an existing health care environment, with only 2% of existing consumer mHealth apps connecting and communicating with provider health systems [10]. Embedded practices and policies were, therefore, incorporated from early in the app's design to ensure consistency with the local execution of evidence-based care.

Limitations of the Co-Design Process

The outcomes of the design are limited by the stakeholders involved in the project. Each person had a role to play to positively impact the final design but also the potential to limit the design. For example, the nurse lead who facilitated the design activities had limited design experience and, thus, learned co-design processes as the project developed. A skilled facilitator in co-design chooses the right tools and provides the right environment to engage and inspire [16]. In addition, study participants were drawn from local clinicians, patients, and family caregivers who were a self-selecting group of volunteers. Therefore, the design outcomes are based perspectives from this limited, context-specific group of stakeholders, which would have biased the findings. From an organizational point of view, the hospital or university venture needed to be formalized as a research project which had implications on recruitment. In this case, ethical approval was required to obtain patient and family caregiver participation which means that not all target end users could be involved. Recruited participants were those with adequate literacy to understand the information sheet and consent form, and confidence to collaboratively engage with various stakeholders, many of whom are in positions of power in the health care setting. Future co-design projects should incorporate more diverse patient and family caregiver perspectives to ensure the health technology is relevant to as many consumers as possible and not limited in relevance to a homogenous patient population.

The strength of context specificity is also a limitation of the portability of the design. The Australian policy and current practices and procedures were included to address the needs of the local health care environment. Therefore, extra work in the design will be required to make the app relevant outside of the community in which it was designed, to be aligned with other health care environments and consumer needs.

Future Directions

The first step is assessing patients' acceptance of such a tool to their current lifestyle. This research team has undertaken a usability study aimed to understand the experience of using the app with new subset of patients not involved in the design phase. Findings from the usability study will determine other features for inclusion in the next version and provide implications of consumer mHealth apps to self-management practices.

Co-design processes for context-specific digital health, particularly with the involvement of multiple stakeholders, should be evaluated for effectiveness. Currently, researchers are interrogating the process from the perspective of co-design participants and the nurse lead.

Conclusions

In this paper, the final, modular design of the consumer mHealth app for HF, *Care4myHeart*, was presented with the rationale associated with each app section and subsection. The design outcomes were elicited from a co-design process incorporating the active involvement of patients, family caregivers, and clinicians together with the local literature. In planning for utility and acceptability, health app development teams should strategically incorporate relevant stakeholders and the literature to design mHealth solutions which are rigorously designed from a solid evidence base and relevant to those who will use and recommend their use.

Acknowledgments

The authors would like to thank the patients, family members, and clinicians for contributing their time and feedback in the development process. This research is supported by a St Vincent's Clinic Foundation grant and a scholarship from the District Nurses, Hobart.

Conflicts of Interest

None declared.

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Abbreviations

BP: blood pressure
HF: heart failure
mHealth: mobile health
PHQ-2: Patient Health Questionnaire-2

Edited by E Borycki; submitted 07.05.19; peer-reviewed by J Cameron, Å Revenäs, P Athilingam, P Vandekerckhove, B McKinstry, C Magnusson; accepted 25.07.19; published 23.09.19.

Please cite as:
Woods L, Duff J, Roehrer E, Walker K, Cummings E
Design of a Consumer Mobile Health App for Heart Failure: Findings From the Nurse-Led Co-Design of Care4myHeart
JMIR Nursing 2019;2(1):e14633
URL: https://nursing.jmir.org/2019/1/e14633
doi:10.2196/14633
PMID:34345774

Original Paper

Four Dissemination Pathways for a Social Media–Based Breastfeeding Campaign: Evaluation of the Impact on Key Performance Indicators

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Abstract

Background: Social media utilization is on the rise globally, and the potential of social media for health behavior campaigns is widely recognized. However, as the landscape of social media evolves, so do techniques used to optimize campaign dissemination.

Objective: The primary aim of this study was to evaluate the impact of 4 material dissemination paths for a breastfeeding social media marketing campaign in Ghana on exposure and engagement with campaign material.

Methods: Campaign materials (n=60) were posted to a Facebook and Twitter campaign page over 12 weeks (ie, baseline). The top 40 performing materials were randomized to 1 of 4 redissemination arms (control simply posted on each platform, key influencers, random influencers, and paid advertisements). Key performance indicator data (ie, exposure and engagement) were extracted from both Facebook and Twitter 2 days after the material was posted. A difference-in-difference model was used to examine the impact of the dissemination paths on performance.

Results: At baseline, campaign materials received an average (SD) exposure of 1178 (670) on Facebook and 1071 (905) on Twitter (n=60). On Facebook, materials posted with paid advertisements had significantly higher exposure and engagement compared with the control arm (P<.001), and performance of materials shared by either type of influencer did not differ significantly from the control arm. No differences in Twitter performance were detected across arms.

Conclusions: Paid advertisements are an effective mechanism to increase exposure and engagement of campaign posts on Facebook, which was achieved at a low cost.

(JMIR Nursing 2019;2(1):e14589) doi:10.2196/14589

KEYWORDS

social media; health communication; breastfeeding; dissemination; Ghana

Introduction

During social media's early days in 2005, a mere 5% of Americans utilized it, while more recently in 2018, it was used by 67% and 49% of adults in advanced and emerging economies, respectively [1]. Over the past 14 years, the social media options have expanded to include a variety of platforms for a variety of purposes, ranging from Facebook's focus on networking and relationships, to YouTube's emphasis on information sharing, to Twitter's emphasis on conversation [2]. Collectively, social media represents online platforms in the era of Web 2.0, on which user-generated content can be created or exchanged [3]. These platforms are heavily trafficked by their users. A survey conducted in the United States found that 74% of Facebook users visit the platform at least daily and 51% visited the platform multiple times a day [4]. Among teens, social media is a ubiquitous part of life, with 89% of teens participating in a Pew Research Survey reporting that they were online *almost constantly* (45%) or several times a day (44%) [5]. Given the time spent on social media and the abundance of information users are exposed to, social marketers need to utilize approaches to compete for user attention against messages that promote unhealthy behaviors from diverse product marketers [6].

As social media has evolved, so have the marketing techniques used by businesses to push their products and ideas on the population. Social marketing of public health goods is also finding its place on this environment, with social media becoming widely recognized as “an unprecedented opportunity...to deliver socially influential online behavior change interventions” [7]. Social marketers have adapted commercial marketing techniques to promote the adoption and maintenance of health behaviors (eg, identify objectives of targeted behavior changes and tailor messages for target audiences) [6,8]. Furthermore, there is a growing body of literature that such online health interventions can increase knowledge and understanding of health topics, including smoking cessation, diet, and exercise [7,9-11].

Specifically, social media has been identified as an opportunity for a potentially cost-effective approach to improve breastfeeding outcomes relative to traditional social marketing, yet research for social marketing for breastfeeding promotion is needed to identify best practices and approaches [8,12,13]. To date, there are no published studies on efficient and effective approaches to disseminate breastfeeding information via social media. Given the significance of social support as a determinant of breastfeeding [13], a social media–based breastfeeding campaign that taps into social networks and connections to disseminate the campaign messages may improve the success and acceptability of a campaign among the target population.

In social media marketing, consumer-to-consumer interaction and word-of-mouth dissemination of information is widely used in the form of influencers [14]. Social network targeting, an application of social network analysis, has been tested in Honduras to evaluate impacts on adoption of chlorine tablets and multivitamins use [15]. Through this approach, social network analysis indicators are used to identify socially influential individuals to spread an intervention, idea, or product. This approach has the potential to optimize the dissemination of breastfeeding information in a social media–based campaign through the social connections and interactions between socially influential individuals and individuals previously unreached and uninterested by the campaign messages.

Alternatively, social media platforms have established mechanisms for businesses to pay for advertisements to appear on the news feed of targeted consumer groups. These paid advertisements have been effective for business, especially when paired with creative marketing, and as a result are considered essential in business social media marketing plans [16]. This is due in part to the social media platform’s algorithms that limit the amount of posts from business pages that appear on consumer’s feeds, unless the business pays. This can be achieved through advertising specific posts or advertising the full business page or account. Overall, numerous strategies have been considered and published with regard to effective social media marketing, which generally position social media within the context of broader business or product marketing strategies, such as brand awareness [17-19].

Between 2008 and 2014, the rate of children under 6 months of age who were exclusively breastfed in Ghana declined from 63% to 52% [20,21]. In response, Ghana’s Becoming Breastfeeding Friendly (BBF) Initiative committee (led by the University of Ghana) identified key gaps in the national breastfeeding environment and recommended social media as a platform on which specific gaps could be filled [22]. Social media penetration has rapidly risen in Ghana in recent years to reach 32% among adults in 2017 and 43% among 18- to 36-year-old, with 2 of the most popular platforms in the country being Facebook and Twitter [23]. On the basis of the BBF Initiative recommendations and rising popularity of social media, the Breastfeed4Ghana social media–based campaign was designed and implemented with the aim of disseminating messages on breastfeeding protection, promotion, and support on Facebook and Twitter [24]. The campaign targeted the broad population of Ghanaian adults, given that campaign messages included supporting women to breastfeeding and protecting maternity leave legislation, which are relevant to the general public.

Therefore, the primary aim of this study is to evaluate the impact of different dissemination paths on exposure and engagement with campaign material and to examine the relationship of acceptability of campaign material with material performance.

Methods

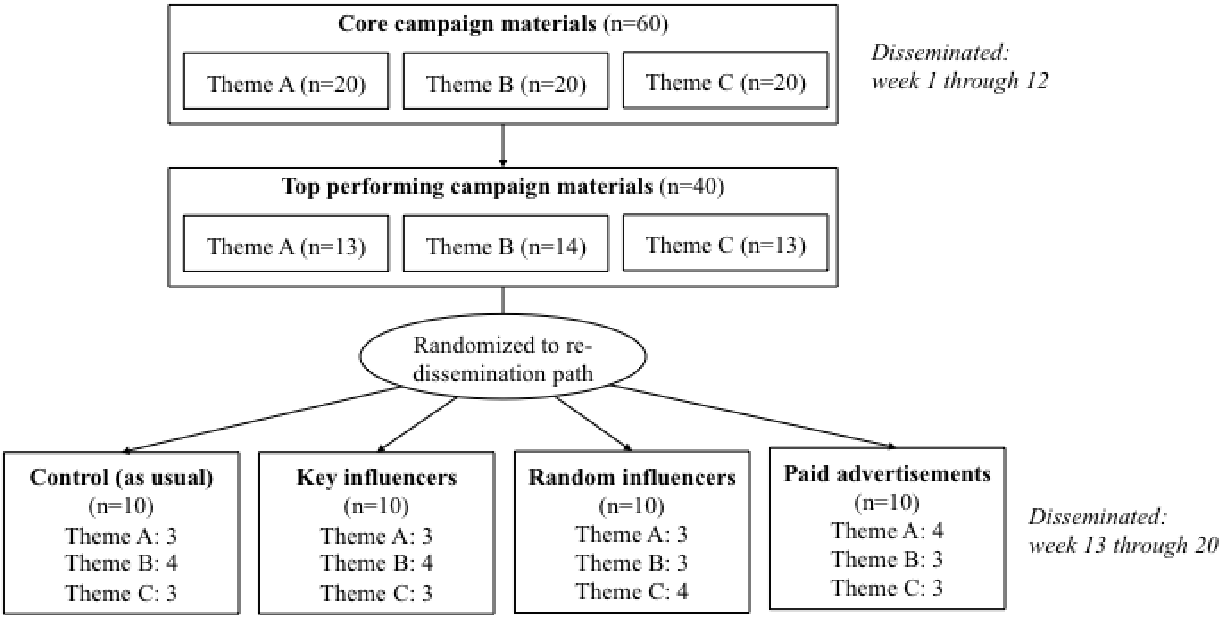
Design

We implemented a 6-month long Facebook (Menlo Park, CA, US) and Twitter (San Francisco, CA, US) campaign that targeted the protection, promotion, and support of breastfeeding in Ghana, on the basis of evidence from recommendations from the BBF Initiative in Ghana [22]. The methods of the campaign design have been previously published [24]. In brief, a total of 60 core campaign materials, each consisting of a brief message and a corresponding photograph, were iteratively developed via 6 focus group discussions among Ghanaian mothers to gain input on message and image acceptability, understandability, and alignment of the message and image. Materials were also reviewed by various content and technical experts in infant and young child feeding and were approved by Ghana’s Food and Drug Authority. Materials represented 3 campaign themes: (1) promote correct and complete information about breastfeeding; (2) support women to breastfeed anytime and anywhere; and (3) protect working women’s right to breastfeed. These materials were disseminated initially on Facebook and Twitter over a 12-week period, during which 5 materials were posted simultaneously on both platforms at the same date and time each week; 40 of these core campaign materials were chosen on the basis of their engagement performance (ie, materials that performed better, as described below) for redissemination during a subsequent 8-week period. Similar to the 12-week initial dissemination period, 5 materials were posted on both platforms at the same date and time each week. In addition to a Facebook page and Twitter page, a Facebook profile for the campaign coordinator was established before the campaign was launched to engage with those interested in the campaign further.

Campaign performance for platforms (ie, Facebook and Twitter pages) and individual material performance (ie, Facebook posts and tweets) were monitored using data extracted from Facebook Insights and Twitter Analytics and entered into a Microsoft Access database (Microsoft Corp, Redmond, WA, US). Platform data were collected weekly and included the number of followers and likes on both Facebook and Twitter; and reach, engagements, views, and follower and engagement demographics by age, sex, and country on Facebook. Data on the campaign posts, such as the core campaign materials, were extracted at 3 timepoints: 1 day, 1 week, and 2 weeks after the material was posted. These data included material impressions or reach, likes, share or retweets, and comments or replies. Materials were selected for redissemination in the test phase based on a composite indicator of the amplification and applause rates per 100 followers for each Facebook and Twitter at the 1 day time point. Thus, materials were ranked from highest to lowest performance, by theme, and the top performing 40 campaign materials (13 or 14 per theme) were selected for redissemination across an 8-week period.

Stratified by theme, materials were randomized to 1 of 4 redissemination paths: (1) posted as usual (ie, control group); (2) shared by 6 key influencers on Facebook and 6 key influencers on Twitter after being posted; (3) shared by 6 random influencers on Facebook and 6 random influencers on Twitter after being posted; or (4) paid advertisement with US $6 on each Facebook and Twitter after being posted (Figure 1). Each dissemination pathway was assigned a corresponding number (1 through 4), and using a random number generator without replacement, each theme was randomly assigned 1 dissemination pathway (themes A and C) or 2 dissemination pathways (theme B) that would be assigned 4 materials, while the other pathways would be assigned 3 materials, to achieve balance across dissemination pathways by theme. Within each theme, materials were listed in descending order by performance score, and using a random number generator (1 through 4), each material was randomly assigned to a dissemination pathway. Once a pathway reached the number of materials to be assigned (ie, 3 or 4 materials), no more materials were assigned to that pathway.

Figure 1. Study design for testing dissemination paths via Facebook and Tweeter. Theme A: Promote correct and complete information about breastfeeding; Theme B: Support women to breastfeeding anytime, anywhere; Theme C: Protect working women’s right to breastfeed.



Influencer Selection

To select the influencers, publicly available details (ie, number of friends or followers, number of friends or followers in common with the campaign, recent activity, and country of residence) from Facebook and Twitter user profiles were extracted from the respective platform among *friends* from the Breastfeed4Ghana campaign coordinator’s Facebook profile and followers from the Twitter page. The sampling frame for the influencers was the Breastfeed4Ghana Facebook *friends* and Twitter followers, excluding individuals who did not reside in Ghana. The size of an individual’s reach was calculated based on the size of their network that did not overlap with the campaign’s network based on the number of friend or follower that the individual had that were *not* in common with the campaign (ie, number of followers or friends *minus* the number of follower or friends in common with the campaign). This indicator of reach was used as an approximation of the significance of each individual in these social networks [25,26].

The selection of key influencers focused on influencer reach and network ties, and therefore, the previous level of involvement with the campaign was not a selection criterion, although all influencers were at least following the campaign. Those with the highest reach were vetted by the campaign coordinator to make sure that they did not have inappropriate content (eg, pornography, violence, extremist behavior, or other offensive content) on their social media page and were then invited to be a key influencer for the campaign. It was explained to potential influencers that as an influencer they would be asked to share or retweet 1 to 2 campaign posts per week for 8 weeks and would receive a small incentive for their time of 80 Ghana cedis (~ US $20 or US $2.50 per week) for sharing the posts. This was repeated until a total of 6 key influencers on each of Facebook and Twitter were selected. To achieve this sample of 6 key influencers per platform, a total of 19 individuals were approached on Facebook and 9 on Twitter. To select random influencer, the remaining individuals in the sampling frame *after* the key influencers had been selected were numbered. We randomly selected individuals from this list using a random number generator. Selected individuals were vetted by the campaign coordinator to ensure they did not have inappropriate content on their page and invited to be a campaign influencer. This was repeated until 6 *randomly* selected influencers were confirmed for each Facebook and Twitter. To reach 6 randomly selected influencers on each platform, we invited 13 individuals on Facebook and 14 individuals on Twitter. Influencers were sent weekly instructions to share or retweet specific posts on Facebook and Twitter, respectively.

Paid Advertisements

Scheduled, targeted advertisements for the selected campaign materials were achieved through business accounts on both Facebook and Twitter, equating to US $6 per platform for each material randomly assigned to the paid advertisement dissemination arm. On Facebook, advertisements targeted 18 to 49 years old women residing in Ghana and were conducted in the form of a post *boost*. The objective of the advertisement was set to *post engagement*, which aims to gain more views and engagement, such as *likes* and *shares*, for the post [27].

For Twitter, acquiring a business account in Ghana required going through a third-party company, which required meeting a minimum quarterly advertising budget. Similar to Facebook, advertisements targeted individuals 18 to 49 years old residing in Ghana. For both Facebook and Twitter, the paid advertisement was schedule along with the posts being scheduled, which were generally scheduled at least 1 week before the post date.

Campaign Material Acceptability Survey

Campaign material acceptability was assessed via an online survey conducted over 3 timepoints. Each survey timepoint corresponded with the completion of the initial dissemination of campaign materials from 1 of the 3 campaign themes (ie, dissemination during the initial 12-week campaign period) and asked about the core campaign materials from that particular theme. Survey participants were a convenient sample of women ≥ 18 years of age residing in Ghana. The survey was promoted through an advertisement post on the campaign's Facebook and Twitter pages and completed through Qualtrics (Provo, UT, USA). Materials presented in the surveys were chosen on the basis of material performance to represent the bottom, median, and top performance within the respective campaign theme, with performance on the basis of the number of *likes* and *share* on Facebook and *likes* and *retweets* on Twitter. For each material, participants were asked questions regarding their understanding and acceptability of the image, the message, and the overall material; 10 questions were asked, based on a 5-point Likert scale ranging from *strongly disagree* to *strongly agree* (5 questions regarding the image and 5 regarding the message); 3 questions asked about the overall rating on a 5-point Likert scale (from *very bad* to *very good*) of each of the image, message, and material, respectively. Performance was calculated as a composite indicator of the amplification and applause rates per 100 followers for each Facebook and Twitter at the 1-day time point. A total of 9 campaign materials were evaluated (Multimedia Appendix 1).

Variable Generation

All data were imported into Stata 14.1 (Stata Corp, College Station, TX, USA) for cleaning and analysis.

Key performance indicators (KPIs) for platform and material exposure and engagement were developed from available data and based on Neiger et al 2012 definition of KPIs [28].

Platform Engagement was defined as the number of followers on each Facebook and Twitter. For this analysis, this KPI was used to adjust material KPIs by follower based at the time the material was posted, to make them comparable across time and platform. As reported elsewhere, the campaign started with 3061 Facebook followers and 27 Twitter followers and ended with 4096 Facebook followers and 736 Twitter followers [24].

Material Exposure was defined as reach on Facebook, which is the number of unique people who saw the material; and as impressions on Twitter, which is the number of times the material appeared on a Twitter timeline. These values were converted into rates per 100 followers on the respective platform at the time of the material posting to make them comparable across time and platform. These rates were used at the primary KPI for material exposure on each Facebook and Twitter.

Material Engagement comprises 3 subindicators: applause, amplification, and conversation. Applause was defined as the number of likes on each Facebook and Twitter; amplification was defined as the number of shares on Facebook and retweets on Twitter; and conversation was the number of comments on Facebook and replies on Twitter. Each of these subindicators by platform were converted to a rate per 100 followers on the respective platform at the time of the material posting (ie, (subindicator ÷ number of follower) × 100). Applause and amplification rates per 100 followers from all material posts and timepoints (n=300) for each Facebook and Twitter were standardized (μ=0; σ=1), and summed by platform and collectively to generate 3 material engagement scores for each material: total engagement score, Facebook engagement score, and Twitter engagement score.

In the content analysis survey, 13 statements examined the material image, message, and overall acceptability. The 5-point-Likert response options were collapsed to emphasize *positive* response options, thus agreement included *extremely agree* and *agree*, and not in agreement included *neutral*, *disagree*, and *extremely disagree* for analysis. For negative statements, such as *the picture is confusing*, the responses were collapsed to emphasize disagreement (*extremely disagree* and *disagree*); and for the overall rating questions, responses were collapsed to good (*very good* and *good*) and not good (*neutral*, *bad*, and *very bad*).

Statistical Analysis

To determine the impact of dissemination path on material performance, a series of difference-in-difference models that accounted for material performance at baseline were run for each of the following material KPI: Facebook exposure, Twitter exposure, total engagement score; Facebook engagement score, and Twitter engagement score. Given the difference in the indicator for exposure on Facebook versus Twitter, a total engagement score was not tested.

To determine characteristics of campaign materials that related to higher material performance, content survey data was pooled across the 3 timepoints, and material performance (low, middle, and high) was examined in relation to material acceptability defined as agreement with each of 6 acceptability statements, disagreement with 4 negative statements, and rating the image, message, and material as *good* in the respective 3 questions. Logistic regression models, controlling for the survey taken (1, 2, or 3), and the respondent examined the odds of binary material acceptability across low, middle, and high material performance.

Ethical Approval

This study was approved by the Yale University Institutional review board and the review board for Ghana University hosted by the Noguchi Institute. Influencers and content survey participants provided their electronic consent to participate in the study before their respective participation.

Results

Overall Performance

During the 12-week long baseline period, the 60 core campaign materials received an average (SD) exposure of 1178 (670) on Facebook and 1071 (905) on Twitter (Table 1). On both Facebook and Twitter, the majority of engagement was seen in applause, followed by amplification. On both platforms, minimal conversation was observed. All measures of material exposure and engagement were larger in absolute values on Facebook compared with Twitter, and larger in rates per 100 followers on Twitter than on Facebook, with the exception of conversation.

Dissemination Paths

The top 40 performing core campaign materials were selected for the dissemination test period, with baseline characteristics summarized in Table 1. Among these 40 materials, there were no statistically significant differences across the 4 arms in baseline exposure, applause, amplification, and conversation per 100 followers at *P*<.05.

KPI for exposure on Facebook and all engagement indicators tending to increase from baseline to the test period, though these increases were only significant in the paid advertisement arm (Table 2). When these differences were examined across arms, paid advertisements yielded significantly higher exposure and engagement on Facebook, compared with the control group (Figure 2). Specifically, Facebook exposure increased by 124% in the paid advertisement group (from 39.76 impressions per 100 followers to 88.88), compared with a decrease of 1% in the control arm (36.20 impressions per 100 followers to 35.96; *P*<.01). Similarly, the Facebook engagement score in the paid advertisement group increased by 953% (0.40 engagement per 100 followers to 4.21), compared with an increase of 147% in the control arm (0.19 engagement per 100 followers to 0.47; *P*<.01). There were no statistically significant differences between the 2 influencer arms and the control arm.

All 40 posts were disseminated via scheduled posts on both Facebook and Twitter at baseline and during the test period. Among the 10 materials randomly assigned to the paid advertisement arm, all had the paid advertisements directed at adults (18-49 years) in Ghana scheduled alongside the post schedule, as planned. Among the 20 materials that were randomized to the key influencers (n=10 materials) and random influencer (n=10 materials) arms, influencers were requested to share the material within 48 hours; 2 of the 6 key influencers on Facebook did not share all 10 materials that were requested and 1 of the 6 key influencers on Twitter did not share all the materials requested. All of the random influencers on Facebook (n=6) and Twitter (n=6) shared all 10 materials requested.

Table 1. Definitions and summary of baseline performance indicators for core campaign materials on Facebook and Twitter, representing all 60 core campaign materials and the subsample of 40. Table is based on data collected 2 weeks after the material was posted.

Performance indicator and platform	Definition	Baseline (n=60)		Baseline (n=40)[a]	
		Mean (SD)	Mean (SD) per 100 followers	Mean (SD)	Mean (SD) per 100 followers
Exposure					
Facebook	Reach[b]	1178 (670)	33.12 (19.12)	1425 (655)	40.12 (18.84)
Twitter	Impressions[c]	1071 (905)	375.98 (396.34)	1345 (951)	494.13 (433.08)
Engagement					
Applause					
Facebook	Likes	56.03 (34.01)	1.59 (0.99)	67.13 (36.08)	1.90 (1.06)
Twitter	Likes	4.28 (2.99)	1.63 (2.14)	5.23 (2.97)	2.12 (2.46)
Amplification					
Facebook	Shares	9.37 (5.11)	0.26 (0.15)	11.45 (4.77)	0.32 (0.14)
Twitter	Retweets	2.23 (2.07)	0.81 (1.14)	2.83 (2.07)	1.07 (1.29)
Conversation					
Facebook	Comments	1.33 (2.66)	0.038 (0.076)	1.9 (3.08)	0.054 (0.088)
Twitter	Replies	0.02 (0.13)	0.004 (0.033)	0.03 (0.16)	0.006 (0.041)

[a] Top and middle performing material based on engagement (sum of applause, amplification, and conversation).

[b] Reach is unique people saw content on Facebook.

[c] Impressions refers to times it appeared on a Twitter timeline.

Table 2. Material performance at baseline and repost (test period) by dissemination path arms.

Key performance indicators	Control, mean (SD)	Key influencers, mean (SD)		Random influencers, mean (SD)		Paid advertisements, mean (SD)		*P* value[a]
	RP[b]	BL[c]	RP	BL	RP	BL	RP	
Exposure[d]								
Facebook	35.96 (8.64)	46.51 (31.43)	50.61 (26.87)	38.01 (13.36)	57.19 (35.41)	39.76 (13.87)	88.88 (11.79)[e]	<.001
Twitter	393.57 (312.14)	446.43 (300.58)	686.34 (358.34)	533.02 (444.02)	502.49 (278.32)	738.3 (577.61)	666.85 (548.28)	.58
Engagement[f]								
Combined	−0.67 (0.59)	−0.05 (1.32)	0.48 (1.13)	−0.09 (1.62)	0.63 (1.43)	1.23 (2.49)	7.14 (4.18)[e]	<.001
Facebook	−0.47 (0.51)	0.27 (1.43)	0.13 (1.02)	−0.19 (0.81)	0.44 (1.57)	0.40 (1.11)	4.21 (1.81)[e]	<.001
Twitter	−0.20 (0.44)	−0.32 (0.41)	0.35 (0.51)	0.10 (1.34)	0.18 (0.40)	0.83 (2.54)	2.93 (5.10)	.36

[a] P value for dissemination arm by repost interaction in the difference-in-difference model.

[b] RP: repost time point.

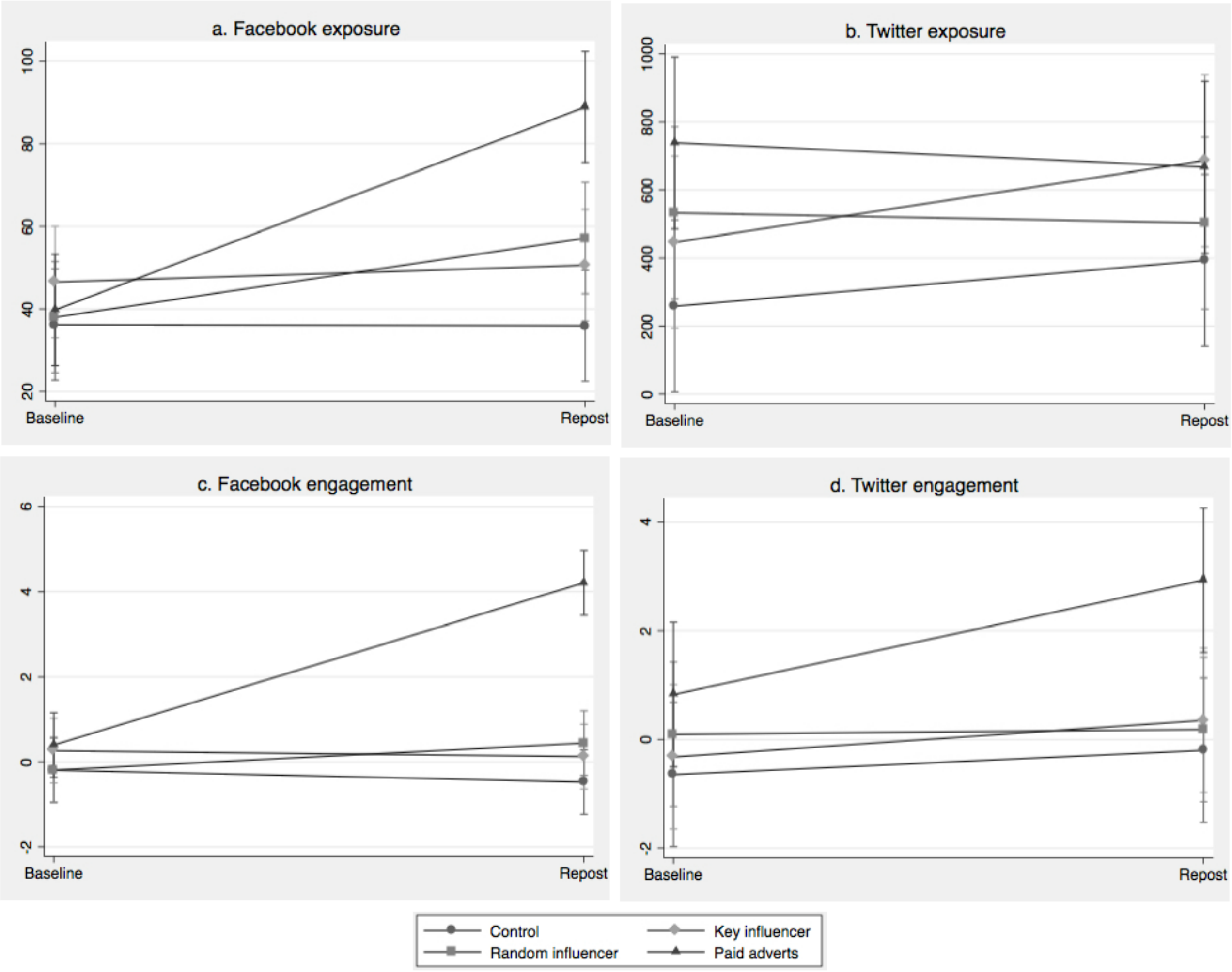
[c] BL: baseline.

[d] Defined as reach per 100 followers on Facebook and impressions per 100 followers on Twitter.

[e] *P*<.01 for key performance indicator between baseline and repost.

[f] Defined as the sum of the standardized applause and amplifications rates per 100 followers for both platforms combined, and individually.

Figure 2. Difference-in-difference models for material exposure on Facebook (a) and Twitter (b), and material engagement on Facebook (c) and Twitter (d) across dissemination path arms (95% CIs).



Performance and Acceptability

A total of 44 female participants completed the content survey (Table 3). The majority of participants were based in Greater Accra (68%, 30/44), married (43%, 19/44), employed (77%, 34/44), and highly educated (86%, 38/44). All participants had access to their own smartphone and 73% (32/44) and 32% (14/44) daily accessed Facebook and Twitter, respectively.

Respondents reported the campaign materials to be acceptable, with over 75% agreement (or disagreement to negative statements) for 12 out of 13 acceptability statements across all materials (Table 4). Agreement ranged from 64% with the statement *I like this picture* to 91% with the statement *this message is informative*. The odds of acceptability of the material image were significantly greater among the high-performance material compared with the low-performance materials, based on 3 out of the 5 acceptability statements at *P*<.05 (Table 4). Similarly, the odds of acceptability of the material message was significantly greater among the middle-performance material compared with the low-performance materials, based on 2 out of the 5 acceptability statements. The odds of overall acceptability, based on rating the image and material as *good*, was significantly greater among both the middle- and high-performance material compared with the low-performance material; and the odds of rating the message as *good* was significantly greater among the middle-performance material compared with the low-performance material.

Table 3. Survey participant characteristics (N=44).

Characteristics	Value
Age (years), mean (SD)	28.61 (4.20)
Based in Greater Accra, n (%)	30 (68)
Married, n (%)	19 (43)
Employed, n (%)	34 (77)
Education: bachelor’s or higher, n (%)	38 (86)
Had children, n (%)	18 (41)
Daily access in the past week to:	
Internet, data, and Wi-Fi, n (%)	37 (84)
Facebook, n (%)	32 (73)
Twitter, n (%)	14 (32)
Access to own smartphone, n (%)	44 (100)

Table 4. Material acceptability across material performance levels.

Statements and rating	Prevalence (SE) of *agreement* with statement overall, and by material performance (N=44)				Odds ratio (SE): measure of material acceptability by material performance[a]		
	All	Low	Middle	High	Low	Middle	High
Image							
This picture promotes breastfeeding	79.55 (3.51)	70.45 (6.88)	79.55 (6.08)	88.64 (4.78)	Reference	1.69 (0.90)	3.52 (2.08)[b]
The picture is informative	78.03 (3.60)	68.18 (7.02)	77.27 (6.32)	88.64 (4.78)	Reference	1.69 (0.95)	4.13 (2.31)[b]
This picture is confusing[c]	81.06 (3.41)	75.00 (6.53)	75.00 (6.53)	93.18 (3.80)	Reference	1	4.59 (2.85)[b]
I like this picture	64.39 (4.17)	59.09 (7.41)	61.36 (7.34)	72.73 (6.71)	Reference	1.10 (0.41)	1.86 (0.72)
This picture is misleading/dishonest[c]	87.88 (2.84)	86.36 (5.17)	88.64 (4.78)	88.64 (4.78)	Reference	1.23 (0.78)	1.23 (0.69)
Message							
This message promotes breastfeeding	87.12 (2.92)	79.55 (6.08)	95.45 (3.14)	86.36 (5.17)	Reference	5.50 (4.79)[b]	1.64 (0.92)
The message is informative	90.91 (2.50)	81.82 (5.81)	100.00 (0.0)	90.91 (4.33)	Reference	__[d]	2.28 (1.32)
This message is confusing[c]	86.36 (2.99)	86.36 (5.17)	88.64 (4.78)	84.09 (5.51)	Reference	1.23 (0.87)	0.83 (0.46)
I like this message	80.30 (3.46)	72.73 (6.71)	88.64 (4.78)	79.55 (6.08)	Reference	2.99 (1.54)[b]	1.47 (0.50)
This message is misleading/dishonest[c]	87.79 (2.86)	84.09 (5.51)	90.91 (4.33)	88.37 (4.89)	Reference	1.90 (1.09)	1.44 (0.69)
Overall rating as good[e]							
Image	76.52 (3.69)	61.36 (7.34)	79.55 (6.08)	88.64 (4.78)	Reference	2.50 (1.23)[b]	5.07 (2.91)[f]
Message	87.88 (2.84)	79.55 (6.08)	95.45 (3.14)	88.64 (4.78)	Reference	5.54 (4.32)[b]	2.03 (1.00)
Material	78.03 (3.60)	61.36 (7.34)	86.36 (5.17)	86.36 (5.17)	Reference	4.15 (1.84)[f]	4.15 (2.05)[f]

[a] Odds ratio for logistic regression models adjusted for content survey and respondent.

[b] *P*<.05.

[c] Prevalence represents disagreement with statement.

[d] Could not calculate Odds ratio because prevalence in middle performing group was 100%.

[e] Prevalence represents rating as *good*.

[f] *P*<.01.

Discussion

Principal Findings

Breastfeed4Ghana core campaign materials achieved higher exposure and engagement on Facebook than on Twitter, and higher exposure and engagement rates per 100 followers on Twitter than on Facebook, because of the relatively small number of followers on Twitter. In this study, paid advertisements significantly increased material exposure and engagement on Facebook. Although neither influencer type had a significant impact on material performance on Facebook, there was a trend in higher engagement and exposure as a result of random influencers, compared with baseline. Conversely, there were no significant differences across the 4 dissemination paths on Twitter (ie, control, key influencers, random influencers, and paid advertisements), and it is important to consider the variations in purposes of different social media platforms and how they are used and how to consider this variation as part of the *social media ecosystem* [2,17].

A total of US $6 per material per platform was allocated to advertisement for each material in the paid advertisement arm. Accounting for the airtime incentives provided to influencers across the test period, each material in the influencer arm *cost* US $12 per platform for promotion. Furthermore, there was more personnel time required to share the materials with the influencers, follow-up with influencers, and provide the incentives to influencers. Influencer management accounted for approximately 90 min per week of the campaign coordinators times, compared with approximately 10 min/week to manage the advertisements. Thus, the findings from this study indicate that paid post advertisements, through Facebook's business account, was not only most effective in increasing material performance but also at a lower cost than our model for either key or random influencers.

Word-of-mouth is a recognized marketing approach for the expansion of a product or idea [29], and the use of influencers is a way to amplify the word-of-mouth on social media. We employed a technique of microinfluencers, who are individuals with typically more than 10,000 followers. Microinfluencers are contrasted with macroinfluencers, who are individuals with much larger followings and include well recognized celebrities [30]. Both types of influencers have been used across different social media platform to promote products or ideas and microinfluencers have been touted as able to achieve more engagement than the macroinfluencers and at a lower cost [31].

There is no prescribed way to recruit, select, and manage influencers, as Keller and Fay describe various case studies in their business marketing report, and influencers generally can impact various outcomes such as message amplification and product sales [14]. In this study, it was surprising that neither type of influencer yielded higher engagement or exposure with the campaign posts. It is possible that a greater number of influencers would be required to achieve such impacts on performance. It is also possible that the target population of Ghanaian adults was too broad, and a more focused target population of new mothers in Ghana would have been more effective.

Our key influencers were selected with consideration for social network targeting, and also aimed to examine the difference in selecting key influencers (ie, social network targeting) as is done often with micro- and macroinfluencers versus randomly selected influencers. Similar to findings within a community health program in Honduras, between social network targeting and randomly selecting influencers, there were not significantly different outcomes; however, in Honduras, both social network targeting (akin to macroinfluencers) and random selection yielded significantly higher adoption of the intervention than the control group [15]. The lack of a difference on both Facebook and Twitter found between targeted and randomly selected influencers suggest that it is not necessary to expend resources to select *highly influential* individuals. As well, in this study, the randomly selected influencers were more adherent to sharing posts compared with the key influencers. Customer-to-customer interactions, such as those prescribed to influencers, has further been modeled in the marketing literature to be able to start a chain effect among consumers, with lasting impacts [32], which may make it superior to a paid advertisement approach in some context. Such superiority of influencers to paid advertising was achieved in a Twitter-based skin cancer prevention campaign [33]. Yet, findings from this study are discordant with the Ireland skin cancer prevention campaign, in that the influencer promotion did not impact post performance, which may be the result of contextual differences in topic and target audience.

In our examination of domains of material acceptability and material performance, overall acceptability of the image, message, and material were associated with performance in terms of engagement. Most notable was that highest performing materials were those that had images viewed as (1) promoting breastfeeding; (2) informative; and (3) *not* confusing. Research which aims to shed light on social media consumer behavior and interaction with content provides insights into findings from this study. Indeed, Berger postulated a framework for the drivers of viral content: social currency, triggers, emotion, public, practical information, and stories [34]. Yuki expanded on this work by evaluating the 2000 most and least shared Facebook posts by various brands between 2013 and 2014 using an online survey among 10,083 individuals in the United States [35]. Findings from this study suggest that higher performing posts were viewed as informative, which aligns with the viral posts surveyed in Yuki's study and with Berger's framework. High-performing materials were also those with images viewed as promoting breastfeeding, which may provide social currency—in an environment where breastfeeding is typically viewed positively and promoting breastfeeding could be viewed as looking good or intelligent.

While this campaign generated 60 core campaign materials that were disseminated 1 to 2 times during the active campaign period, and as a result varied the images so as not to be too repetitive (a feedback from our formative material development work). Despite the variety of images presented in the campaign materials, the highest performing material for each theme was that of a woman breastfeeding. This may suggest that such variety (ie, 60 unique materials) was not necessary, and generating images most aligned with the campaign focus and message will yield the greatest engagement and acceptability among the target population. As such, other social marketing campaigns have generated a small number of messages and materials that are widely and repeatedly disseminated [36].

This study also reports on KPIs of campaign materials. In public health, return on investment is not always a useful indicator, and Neiger et al summarized KPIs and evaluation metrics for health promotion on social media [28]. Although their work provides an important list of possible KPIs and corresponding metrics, adoption and reporting of such indicators in the health promotion field is not widespread. This is an important *data gap*, both in terms of reporting and consideration for consistency in metrics. Although different campaigns and studies will have different goals that should drive indicators of performance or success, work by Neiger and metrics reported in this study can provide a guide for other campaigns.

Limitations

To our knowledge, similar studies have not been published. However, paid advertisements, as well as paid influencers, are widespread social marketing techniques used across businesses and industry. It is important to recognize the limitation in lack of comparable studies and results for us to consider. These results also reflect a short-term study and small number of influencers. Therefore, it is possible that in a study of longer duration with a higher number of influencers could yield different results. The lack of differences across dissemination path arms on Twitter could be the result of a small follower based on that platform, as well as a significant increase in follower (approximately doubled) right before the test period of the study. Finally, we would like to acknowledge that these results come from a breastfeeding social media–based campaign that targeted the population of Ghana. There are variations in how social media is used in different contexts across geographic space, demographics, and time, and therefore, generalizability of these results beyond the context should be done with caution. Similarly, for context, it is important to note the dates of from this campaign (March to September 2018). Social media platforms are continually updating their business platforms, advertising option, and algorithms for what is viewed on user’s news feeds, and therefore, comparability of the findings from this study may be limited based on how the landscape of social media changed and evolves with time.

Conclusions

Paid advertisements are an effective mechanism to increase exposure and engagement of campaign posts on Facebook, achieved at a low cost. Although influencers are used in marketing and are generally considered effective at increasing consumer engagement or sales, microinfluencers were not effective at increasing exposure and engagement in this study. Furthermore, the use of influencers to promote materials required a greater financial cost compared with paid advertisements in our study.

For social marketing, there are challenges with how to compete against product advertisers with bigger budgets and more ways to reach consumers (eg, infant formula companies) [6]. As social media marketing campaigns continue to rise in popularity for health behavior research, common metrics for evaluating campaign performance, such as platform and material performance, and how campaign outcomes and impacts are reported should be used. This study contributes to a small, but growing, body of literature on KPIs in social media health behavior and promotion campaigns.

Acknowledgments

The authors would like to acknowledge Gabriela Buccini for her invaluable advice throughout the campaign on breastfeeding and lactation questions from followers, Amber Hromi-Fiedler for her guidance throughout the campaign, Katherine Doucet and Cara Safron for their input during the campaign development, Katherine Doucet and Abena Engmann for essential logistical support, the survey participants for their time and feedback, and all the Breastfeed4Ghana campaign “friends” and “followers” for their participation in the campaign. The research was funded through the International Society for Research in Human Milk and Lactation Trainee Bridge Fund.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Materials tested in the content survey.
[PDF File (Adobe PDF File), 306KB - nursing_v2i1e14589_app1.pdf]

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Abbreviations

BBF: becoming breastfeeding friendly
KPI: key performance indicator

Edited by E Borycki; submitted 04.05.19; peer-reviewed by A Gough, S Segura-Perez; comments to author 27.06.19; revised version received 14.07.19; accepted 30.07.19; published 26.09.19.

Please cite as:
Harding K, Pérez-Escamilla R, Carroll G, Aryeetey R, Lasisi O
Four Dissemination Pathways for a Social Media–Based Breastfeeding Campaign: Evaluation of the Impact on Key Performance Indicators
JMIR Nursing 2019;2(1):e14589
URL: https://nursing.jmir.org/2019/1/e14589/
doi:10.2196/14589
PMID:34345773

Original Paper

Nurses as Stakeholders in the Adoption of Mobile Technology in Australian Health Care Environments: Interview Study

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Abstract

Background: The 2017 Australian Digital Health Agency (ADHA) Strategy is based on the underlying assumption that digital technology in health care environments is ubiquitous. The ADHA Strategy views health professionals, especially nurses, as grappling with the complexity of installing and using digital technologies to facilitate personalized and sustainable person-centered care. Yet, ironically, the 2018 debate over how to enroll Australians into the national electronic health record system and its alteration from an opt-in to an opt-out model heightened public and professional concern over what constituted a “safe, seamless and secure” health information system. What can be termed a digital technology paradox has emerged where, although it is widely acknowledged that there are benefits from deploying and using digital technology in the workplace, the perception of risk renders it unavailable or inaccessible at point of care. The inability of nurses to legitimately access and use mobile technology is impeding the diffusion of digital technology in Australian health care environments and undermining the 2017 ADHA Strategy.

Objective: This study explored the nature and scope of usability of mobile technology at point of care, in order to understand how current governance structures impacted on access and use of digital technology from an organizational perspective.

Methods: Individual semistructured interviews were conducted with 6 representatives from professional nursing organizations. A total of 10 interview questions focused on factors that impacted the use of mobile technology for learning at point of care. Seven national organizations and 52 members from the Coalition of National Nursing and Midwifery Organisations were invited to participate. Interviews were recorded and transcribed verbatim. Data analysis was systematic and organized, consisting of trial coding; member checking was undertaken to ensure rigor. A codebook was developed to provide a framework for analysis to identify the themes latent in the transcribed data. Nurses as stakeholders emerged as a key theme.

Results: Out of 6 participants, 4 female (67%) and 2 male (33%) senior members of the nursing profession were interviewed. Each interview lasted between 17 and 54 minutes, which reflected the knowledge of participants regarding the topic of interest and their availability. Two subthemes, coded as *ways of thinking* and *ways of acting*, emerged from the open codes. Participants provided examples of the factors that impacted the capacity of nurses to adopt digital technology from an emic perspective. There were contributing factors that related to actions, including work-arounds, attentiveness, and experiences. Nurses also indicated that there were attitudes and influences that impacted thinking regarding access and use of mobile technology at point of care.

Conclusions: Nurses are inadequately prepared for the digital future that has now arrived in health care environments. Nurses do not perceive that they are leaders in decision making regarding digital technology adoption, nor are they able to facilitate digital literacy or model digital professionalism.

(JMIR Nursing 2019;2(1):e14279) doi:10.2196/14279

KEYWORDS

digital; health policy; digital professionalism; nursing education

Introduction

The rapid evolution of health technology and informatics has significantly altered health care delivery and impacted the health care workforce in Australia and internationally [1-4]. In Australia, nurses are the largest group of registered health professionals [5]; however, as digital technology has been introduced into health care environments, nurses have struggled to be included in decision-making processes [6]. A failure to provide clear direction to nurses about access to, and use of, digital technology at systems, organizational, and individual levels has been found to be a contributing factor to disempowering nurses [7]. Additionally, lack of empowerment can also be attributed to the cost of preparing nurses to become digitally literate and capable of enabling other stakeholders, such as consumers, to become proficient end users of digital technology [8]. Fear of inappropriate use [9,10] and resistance to changing workflow routines [11] also play a role in the lack of agency that nurses exhibit in advocating for the adoption of digital technology to advance nursing practice.

Increasing awareness of the need for change is evident in a number of initiatives. The release of the Australian Digital Health Agency (ADHA) Strategy [12] outlined seven strategic priorities, with the sixth one highlighting the importance of workforce education and training of health professionals. The ADHA Strategy underpins changes being implemented by the Australian Nursing and Midwifery Accreditation Council (ANMAC) in its review of standards for accrediting undergraduate nursing education programs. Previously, an explanatory note [13] was published to clarify the expectation of health technology and health informatics to be included at a technical, contextual, and emancipatory level into new nursing curricula. More recently, ANMAC has proposed that the integration of health technology and health informatics be articulated more prescriptively in the revised standards [14,15]. Clear direction regarding the required minimum standard of capability of undergraduate students to be work ready at registration will create pressure on organizations and higher education institutions to initiate or further promote preparation of the nursing workforce to be digitally literate and digitally professional [7,16]. There will be a need to accommodate the impending changes within curricula that will impact work-integrated learning.

Other recent initiatives include the development of national nursing informatics competency standards to provide guidance to nurses about the expected level of understanding of computer and information literacy and management [17]. Another includes the release of the combined Australian nursing and health informatics organizations' Health Informatics Position Statement [18] outlining professional expectations of all stakeholders of health technology and health informatics implementation in health care settings. Outputs prioritized by the ADHA Strategy [12] include the following, in order to support health professionals currently employed within health care settings: "resources and curricula will be developed to ensure healthcare practitioners are exposed and trained in digital technologies and their use during training and upskilling." Furthermore, the employment of clinical informatics champions as outlined in the strategy will drive cultural change and awareness at a local level. Concurrently with the release of the ADHA Strategy [12] was a change to the rollout of the national electronic health record—My Health Record—from an opt-in to an opt-out system for all Australian citizens. This process was precipitated by a range of factors, including reluctant voluntary uptake due to numerous data privacy and security breaches [19,20]. Currently, less than 25% of all Australian citizens have an electronic health record [21], although this is now expected to expand dramatically. However, given that there had been inadequate training for frontline health professionals, including nurses, to improve their digital literacy or educational preparation, they will continue to struggle to explain to consumers the merit of having their own digital health record [22].

The release of the Nursing Informatics Position Statement [18] demonstrates that nurses within the health technology and health informatics field recognized the pivotal role of nurses to successfully implement digital technologies within health care environments. The position statement articulated seven elements that outlined the need for a strong nursing presence in governance and decision making at systems, organizational, and individual levels to "safeguard adoption and optimization of clinical information systems" [18]. It was in this broad context of structural change within the Australian health technology and health informatics field that this research examined the use of mobile technology for informal learning and continuing professional development (CPD) of nurses at point of care. The research aimed to understand the factors influencing mobile technology policy development from the perspective of nursing profession organizations. The purpose of this study is to inform the profession about the current status of using digital technology at point of care so that the nursing profession can advocate its perspective at a national level and become more included in policy decisions affecting the nursing profession.

Methods

Recruitment

Individual semistructured interviews were undertaken with 6 representatives from professional nursing organizations. Purposive sampling was used to recruit participants who were able to represent organizations from a policy or guideline perspective and who had expertise in nursing practice. Seven national organizations were identified and a further 52 members from the Coalition of National Nursing and Midwifery Organisations (CoNNMO), who had email addresses available on their website, were invited to participate. Follow-up emails 2 weeks after the initial invitation and a reminder email were sent 1 month after the first invitation. Those organizations that listed telephone details were also contacted via telephone. An information sheet was provided with the invitation to participate, and consent was recorded using Skype for Business prior to the beginning of each participant interview. Participants chose the venue and time for the interview. The University of Tasmania Social Sciences Human Research Ethics Committee granted approval (approval number: H0016097) prior to initiating this study.

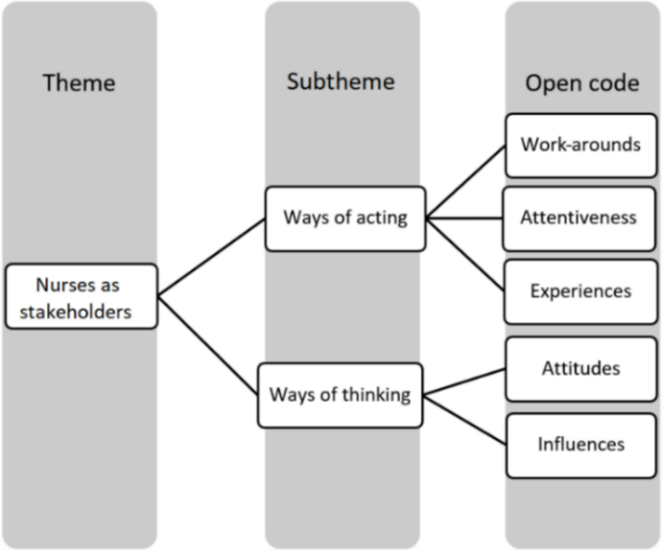
Interview Schedule

A total of 10 interview questions were developed (see Multimedia Appendix 1) from the findings of previous research [23] and focused on whether the nursing profession organizations had a policy position on mobile technology for informal learning and CPD. Questions then explored factors impacting the use of mobile technology for learning at point of care. Interviews were undertaken by the first author (CM) during December 2016 and January 2017 and transcribed verbatim.

Data Analysis

Data analysis was a systematic and organized process consisting of trial coding; constant member checking was undertaken to ensure rigor. A codebook was developed to provide a framework of codes. Fidelity of application of labels across interviews to ensure consistency was undertaken during coding. Microsoft Excel 2016 was used to tabulate *meaning units* [24]. Reducing the phrases by coding enabled further refinement, and the subthemes of *ways of acting* and *ways of thinking* were emergent from the data. From the analysis, *nurses as stakeholders* was identified as a theme (see Figure 1).

Figure 1. Coding process.



Results

Overview

Six interviews were conducted during the data collection period. Of the 6 participants, 4 were female (67%) and 2 were male (33%). All participants identified themselves as senior members of the nursing profession with extensive clinical, educational, research, or administrative experience in a range of health care environments (see Table 1).

These nurses were paid employees or were associated with CoNNMO as volunteers within Australian nursing specialty professional bodies. Each interview lasted between 17 and 54 minutes. The length of each interview was related to each participant's available time and knowledge regarding the topic of interest. Two subthemes coded as *ways of acting* and *ways of thinking* emerged from the open codes (see Figure 1).

Table 1. Participant demographics.

Interview #	Gender	Source of recruitment	Nursing organization	Nurse role
1	Female	Direct email to organization	National representative (executive)	Administration
2	Male	Email from CoNNMO[a] secretariat	Specialty nursing executive position (volunteer organization)	University academic and clinician
3	Female	Direct email to organization	National representative (executive)	University academic
4	Female	Email from CoNNMO secretariat	Specialty nursing executive position (volunteer organization)	Clinician
5	Male	Email from CoNNMO secretariat	Specialty nursing executive position (volunteer organization)	Administration and clinician
6	Female	Direct email	National representative (executive)	Administration

[a] CoNNMO: Coalition of National Nursing and Midwifery Organisations.

Ways of Acting

Overview

Participants provided examples of how nurses behaved in relation to accessing and using digital technology in the workplace. These nurses highlighted the risks, challenges, barriers, and benefits of accessing and using digital technology in health care service provision and for learning and teaching. Participants indicated that the capacity for digital technology adoption by nurses was affected by contributing factors related to actions linked to work-arounds, attentiveness, and experiences. Each is explained in detail below.

Work-arounds

When listening to and coding their conversations, it became apparent that participants often perceived that they did not have a voice in decision making regarding access and use of digital technology. The lack of inclusion resulted in unintended consequences. Nurses developed work-arounds to accommodate perceived workflow issues [25]. For example, one participant indicated that nurses used their personal mobile devices to seek and retrieve information:

> *I did a survey of about 10 [city] hospitals, [specialty] departments, and less than half the staff had Internet access and when you take out the senior staff in that survey, there was, you know, most of the staff, the direct care nurses didn't have Internet access. So, people are using their mobile phones for Internet access and to find evidence and to source, you know, information, which is just terrible.* [Participant #2]

Another participant stated that due to funding constraints, using a mobile device enabled improved efficiency of health care service delivery by facilitating access to information:

> *You know, they're taking away massive amounts of funding and things are very privatized, so these facilities are kind of left to their own devices as far as how many RNs [registered nurses], if they have RNs at all now. So, I think that one way—and I don't know how to combat that—but one way to ensure better patient care is by allowing staff to have that kind of information where they can look at a patient and put symptoms or use education that's right there and then on their phones and that will probably lead to better patient care and identification of deterioration or issues. I think that's an area that could be incredibly useful.* [Participant #4]

Attentiveness

There were divergent views about accessing digital technology in relation to attentiveness. Participants provided examples of how mobile devices can be used in real time for improving efficiency of health care delivery. For example, one participant outlined a benefit of integrating digital technology into nursing practice:

> *But if you're actually learning in real time as you've got an actual issue happening, it's great. I think there's also potential to use downtime better. I was going to say like everything that's mobile, it just becomes integrated more into people's lifestyle.* [Participant #6]

However, there was also the view that there needed to be a minimum standard of capability of nurses rather than relying on digital technology when there was the potential to negatively impact safe health care delivery:

> *...you know, you're not going to be sitting there in the middle of a [cardiac] arrest going, "Okay, wow, the doctor's just asked for adrenalin, hold on let me just quickly Google adrenalin and find out how fast I should push it and is the actual correct dose and, oh, what's its indication, oh, what's its mode of action?"* [Participant #5]

Another participant indicated that there were perceived risks associated with distraction when using mobile technology:

> *People will get enamored or caught up on what's going on in their phone and not be paying attention to what's going on with their patient.* [Participant #1]

Experiences

Nurses provided examples of how digital technology could change behavior to enhance nursing practice and support learning by students while undertaking work-integrated learning:

> *Particularly, I worked in rural and remote-type areas so where you didn't have someone else that you could ask for help, and just for the students I've found that if they can look something up then and there, that they learn it because it makes sense to them, that they need to know it.* [Participant #3]

Additionally, participants were aware that the digital revolution was imminent. They could foresee the benefits of enabling personalized learning that could contribute to supporting person-centered care. One participant stated the following:

> *I think it's got huge potential for really looking at being able to adapt to different learning styles and being able to bring that, the ideal situation where you've got theory with experience at the same time, and you can look at what you've assessed and then put that into mobile learning technology and find out what you've missed or how that measured up against the theory on the information.* [Participant #4]

Participants acknowledged that the role of nurses included experiences that promoted engagement and improvement in health literacy, digital literacy, and health education of consumers. One participant indicated the following:

> *I think too that a lot more consumers are going to the Internet for information these days; to be able to show them what is a useful site or is a safe site for them to go to so they're not getting false information about things would be quite useful as well. So, I think there's significant benefits there.* [Participant #3]

Ways of Thinking

Overview

The second subtheme that emerged was *ways of thinking*. Nurses in this study provided their perceptions of what nurses thought from an emic perspective and how this impacted the use of digital technology in health care settings. Participants provided rich descriptions about the attitudes and influences—the two open codes associated with this subtheme that they encountered—in relation to digital technology and the nursing profession.

Attitudes

Nurses raised the issue of balancing person-centered health care delivery, learning, and integrating digital technology within nursing practice. One participant stated the following:

> *I think there's an issue on duty in that the staff will say they've got enough to do without having to sit down at the computer...if they are allocated time in their workday to do it, well then that's probably okay. But if they're just expected to fit it on around everything else, I'm not sure how much focus they'll give it.* [Participant #1]

However, participants also acknowledged there was a range of attitudes about nurses using digital technology in health care environments. An example quotation about nurses being viewed negatively by other stakeholders is shown below:

> *...all the nurses seem to do is pay attention to the computer even where they've got electronic health records and order entry systems and all that they have now. And you do hear at times members of the community see that the nurses are tied more to the computers than they are tied to the people.* [Participant #1]

In stark contrast, a participant whose attitude was positive regarding implementation of digital technology into nursing practice stated the following:

> *We're just burying our head in the sand saying, you know, let's just say no phones, well that's not happening. Anyway, it's actually detrimental because it's a really useful tool, these mobile devices, for our staff. We can just train people better in how to use their phone.* [Participant #2]

Influences

Implementation of digital technology will require support at systems and organizational levels before stakeholders will be influenced to adopt it to advance nursing practice. One participant indicated the following:

> *So, I think there's a lot going on but there's not—as far as I'm aware—there's not a really big push from the government to use technology, or funding from the government to use technology well. And there's lots of, I guess, private and smaller initiatives taking off, but I think the drive has to be from the health district as well, but there has to be government funding and incentives to be implementing technology and, particularly, mobile technology.* [Participant #4]

At an individual level, one participant indicated that nurses have the capacity to change their views when exposed to the benefits of using digital technology. However, others are also influenced, which impacts on nurses' capacity to use digital technology within their workplace. The following quotation illustrates this view:

> *I've certainly had clinical facilitators in the past make comments that, you know, it has been changing and that they'd seen students with mobile technology and gone to them with the idea of criticizing them for using it and then discovered that they were using it for very relevant purposes. And their attitudes were changing due to that type of thing, so I'd been supportive of that type of learning and the success they were having. But now it's very different, we've got an edict from above and we're not allowed to do it [use digital technology].* [Participant #3]

Discussion

Principal Findings

Findings from this research indicate that nurses within the profession's organizations do not perceive that they are leaders in decision making regarding digital technology. Participants believed that nurses' access to, and use of, the Internet within health care environments is decided by others. This perception shapes their ways of acting and thinking, which impacts on their capacity to advocate for being included as stakeholders regarding health technology and health informatics at systems, organizational, and individual levels.

Participants realize that there is a mobile learning paradox where, although it is acknowledged that there are benefits to using digital technology, they are unable to access it [26]. This paradox extends beyond using mobile technology at point of care. Participants acknowledged that work-arounds have occurred to accommodate the lack of access to the Internet by individual nurses providing direct care to patients. Additionally, nurses deployed digital technology within their nursing practice to improve efficiency due to funding constraints. Some participants lamented the lack of capacity to harness the benefits of digital technology, while others understood the risks of digital technology being used inappropriately. These views are congruent and support the efforts being made by ANMAC to ensure that undergraduate nurses become digitally professional and work ready at graduation [14,15]. Furthermore, the ADHA Strategy will provide support for CPD of nurses currently working within health care environments and will underpin the foundational knowledge of undergraduate students [16]. A period of overlap will be required as registered and student nurses learn from each other and develop a mutual understanding [27] of the knowledge and skills required to meet the National Informatics Standards [17]. There is potential for the development of agency by nurses when they share their experiences in this way and, as demonstrated by the findings, nurses are capable of adapting their behavior based on their experiences.

When undergraduate nurses are educationally prepared to use health technology and health informatics, and to undertake work-integrated learning, they will be better able to challenge the status quo arrangements that marginalize them and to request inclusion in accessing and using digital technology. For example, registered nurses are permitted password access, whereas in the future, supervising nurses and undergraduate students conversant with policy and guideline documents [12,17] will be able to lobby health care organizations for password access to health information systems for documentation purposes. Students will also be keen to translate their learning about patient information flows within a simulated environment by documenting nursing activities in an operational electronic health record while in practice. Additionally, students indicated that they prefer to access learning resources in real time at point of care [28]. Personalized learning and the development of digital literacy by students early in their studies will benefit all stakeholders, including consumers, who can be influenced by nurses to participate in their own care when the nurses are confident and capable in using digital technology.

This research supports the need for a digital health strategy as proposed by the ADHA [12]. However, to enable adoption, there is a need for nurses to become leaders by ensuring that they are involved in decision making regarding implementation of health technology and informatics in health care environments.

Fixsen and colleagues [29] identified six stages of implementation (see Figure 2) that can be applied to the evolution of digital technology within the Australian health care context. Exploration and adoption of digital technology has been followed by trial installations and initial implementation of various applications and health information systems. The publication of the ADHA Strategy's strategic priorities [12] demonstrates that the Australian health care sector is now positioned for full implementation of health technology and informatics (see Figure 2). However, there have been delays in deploying health information systems within some Australian states. Western Australia and Queensland health care providers have experienced data systems failures that have reduced citizen trust and delayed implementation of electronic record systems [19,30]. Such mistrust could be partially remediated by nurses being more included in organizational decision making [31], given that nurses are the largest group of stakeholders within the health care sector [5]. This research highlights the urgent need for this group of health professionals to be fully engaged in the digital future of health care environments.

Figure 2. Stages of implementation (modified from Fixsen et al, 2005).

Limitations

Limitations of this study include the timing of the interview period, which spanned the traditional end-of-year Christmas and summer holiday period; this may have contributed to the low participation rate. Interviews ceased with the publication of the Nursing Informatics Position Statement [18], as the researchers considered that this statement had the potential to influence the nursing profession organizations' views about health informatics. The low participation rate reduces generalizability of the findings.

Future Directions

A larger international comparative study could be undertaken to replicate this research. Findings may determine whether registered nurses in other countries experience similar perceptions or whether the Australian context is unique.

Conclusions

There is still much work to be undertaken to engage all stakeholders, including nurses, in embracing the digital future in health care. This research demonstrates that nurses from professional organizations understand their health workforce but lack the agency to demand inclusion in decision making that impacts nurses at organizational and individual levels. To enable implementation of health technology and informatics in health care environments more effectively, it is crucial for nurses to become stakeholders at every level. Doing so will not only mitigate the risk of implementation failure, but engagement of nurses as frontline health professionals will assist the Australian Government in achieving its goal of a "safe, seamless and secure" digital health system for all.

Acknowledgments

We would like to acknowledge the representatives from the nursing profession organizations who agreed to be interviewed and contribute to this research.

Authors' Contributions

CM was involved in all aspects of this research, including study design, the ethics application, recruitment, data collection, analysis, preparation, and review of the manuscript. EC was involved with study design, ethics, analysis, and review and editing of the manuscript. FG was involved with analysis and with review and editing of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Nursing profession organization interview schedule.
[DOCX File, 14KB - nursing_v2i1e14279_app1.docx]

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Abbreviations

ADHA: Australian Digital Health Agency
ANMAC: Australian Nursing and Midwifery Accreditation Council
CoNNMO: Coalition of National Nursing and Midwifery Organisations
CPD: continuing professional development
RN: registered nurse

Edited by E Borycki; submitted 05.04.19; peer-reviewed by H Pratomo, A Arbabisarjou, P Klein, T Martin, T Hebda; comments to author 05.06.19; revised version received 22.06.19; accepted 23.06.19; published 09.08.19.

Please cite as:
Mather C, Cummings E, Gale F
Nurses as Stakeholders in the Adoption of Mobile Technology in Australian Health Care Environments: Interview Study
JMIR Nursing 2019;2(1):e14279
URL: https://nursing.jmir.org/2019/1/e14279/
doi:10.2196/14279
PMID:34345771

Original Paper

Advancing the Science of Recruitment for Family Caregivers: Focus Group and Delphi Methods

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Abstract

Background: Successful recruitment of participants is imperative to a rigorous study, and recruitment challenges are not new to researchers. Many researchers have used social media successfully to recruit study participants. However, challenges remain for effective online social media recruitment for some populations.

Objective: Using a multistep approach that included a focus group and Delphi method, researchers performed this study to gain expert advice regarding material development for social media recruitment and to test the recruitment material with the target population.

Methods: In the first phase, we conducted a focus group with 5 social media experts to identify critical elements for effective social media recruitment material. Utilizing the Delphi method with 5 family caregivers, we conducted the second phase to reach consensus regarding effective recruitment videos.

Results: Phase I utilized a focus group that resulted in identification of three barriers related to social media recruitment, including lack of staff and resources, issues with restrictive algorithms, and not standing out in the crowd. Phase II used the Delphi method. At the completion of Delphi Round 1, 5 Delphi participants received a summary of the analysis for feedback and agreement with our summary. Using data and recommendations from Round 1, researchers created two new recruitment videos with additions to improve trustworthiness and transparency, such as the university's logo. In Round 2 of the Delphi method, consensus regarding the quality and trustworthiness of the recruitment videos reached 100%.

Conclusions: One of the primary challenges for family caregiver research is recruitment. Despite the broad adoption of social media marketing approaches, the effectiveness of online recruitment strategies needs further investigation.

(JMIR Nursing 2019;2(1):e13862) doi:10.2196/13862

KEYWORDS
family caregivers; recruitment; social media; illness stories

Introduction

Overview

Social media use is widespread across generations, with 68% of Americans using Facebook and 73% accessing YouTube. Twitter is gaining popularity with adult Americans (14%) compared with already-engaged younger adults (45%) utilizing this social media platform [1]. Social media promotes communication, interaction, collaboration, and sharing [2]. The flexibility of communication inherent to social media platforms has led to their increased use in health and health care, including family caregivers caring for ill loved ones [3,4].

The social media illness story is a modern form of interaction that encourages relationship development and encapsulates a rich narrative that holds untapped resources for understanding the psychological, physical, spiritual, and social impact of the patient's illness journey [5]. Some ill people write an illness blog using a blog platform; others use Facebook or a microblog format like Twitter to tell their illness stories. This form of online journaling has been found to be beneficial for patients and their family caregivers [3,6,7]. For example, online journaling is known to bring meaning of the illness to both the patient and family caregiver. Social media is also becoming a successful and popular venue for recruitment [2,5]. However, in previous research, the authors found recruiting family caregivers whose loved ones tell their illness stories on social media challenging since this small subset of family caregivers is difficult to define and identify. Although family caregivers are included in many illness stories on social media, they are not easy to identify.

Understanding and contributing to the science of social media recruitment for family caregivers with a loved one who tells their illness story on social media is paramount to advancing family caregiver recruitment. To explore challenges to successful recruitment of family caregivers through social media, we used two companion approaches. In the first phase of the study, we conducted a focus group with social media experts to identify critical elements of effective social media recruitment material. Utilizing the Delphi method, the second phase of the study confirmed that the product created aligned with focus group feedback.

Background

Successful recruitment of participants is imperative to a rigorous study, but recruitment challenges are not new to researchers. In fact, failed recruitment efforts result in underpowered studies and nonsignificant findings [8]. Theoretical development surrounding response behavior in research found that poor response rates were associated with socioeconomic demographics for underrepresented participants, such as women [9]. However, efforts to evaluate study participation recruitment methods through varied questionnaire distribution choices, such as Internet distribution, have shown promise [10].

Many researchers have successfully recruited study participants through social media, such as a Facebook advertisement feature that utilizes a targeted format (eg, researchers select specific demographics and keywords) [11]. Even researchers with targeted and small populations [8], such as our study population of family caregivers with loved ones who tell their illness stories on social media, have had success with social media recruitment [12-14]. Furthermore, several studies have concluded that online recruitment is more cost-effective than traditional strategies [15-17]. However, challenges remain with recruitment for family caregivers who read or interact with their seriously ill loved ones online through patient illness stories.

Previous Work

In our previous work, we found that a patient's illness blog assisted the family caregiver with communication, creation of meaning, and identification of their role as caregiver [3]; however, we encountered several recruitment challenges for this population when using a Facebook campaign [11]. While serious illness affects many Americans, issues confronted by family caregivers during serious illness comprise a sensitive topic that may not be of interest to social media users. Therefore, we did not obtain a high-enough click-through rate by potential study participants to maintain a successful Facebook recruitment campaign [11]. Additionally, the population recruited was a narrow subgroup of family caregivers (ie, those who read their loved one's illness story online) who were difficult to locate. Finally, technical skills involved with social media recruitment are not typically taught to nurse researchers, which means collaboration outside of nursing is required.

In this study, we sought to develop our understanding of the science of recruitment of family caregivers through social media. Using a data-based, multistep approach, we gained a more complete understanding of the science of recruitment for our population, improving the likelihood of reaching our target population and ensuring their engagement. The purpose for the focus group was to gain meaningful insight, opinions, suggestions, and feedback to develop social media-based recruitment methods for future research studies. For the Delphi method, the purpose was to test the developed material to gather insights, opinions, and suggestions from our target population: family caregivers of people who tell their illness stories on social media.

Methods

Overview

Institutional Review Board approval was obtained through Kent State University, Kent, OH, prior to conducting all aspects of the study (approval number: 16-226). All participants were provided with project information and gave consent to participate in this two-phase study. In the focus group (Phase I), social media experts provided expert opinions for both development of social media recruitment materials and barriers to recruiting family caregivers with loved ones who tell their illness stories on social media [18]. In Phase II, the Delphi method containing quantitative and open-ended questions was used to obtain feedback on the quality, trustworthiness, and clarity of the newly developed recruitment material [19,20].

Focus Group: Phase I

Sampling

Researchers used purposive sampling methods to recruit 5 social media experts through email messages sent to department heads of a major Northeast Ohio public university, including Journalism and Mass Communications, Web and Social Media Services, the Marketing Department of the College of Business, and other departments with researchers engaged with social media in research. Email messages explained the purpose of the focus group and time commitment, with a request to nominate potential faculty members that met the following inclusion criteria: (1) expertise in social media (ie, able to contact targeted populations using social media recruitment) and (2) representation by both male and female members.

The 5 peer-nominated expert faculty—3 female (60%) and 2 male (40%) participants—comprising the focus group have a record of accomplishment in social media, including capturing and analyzing social data metrics. The group's expertise included a faculty member from the Alumni Association Department with knowledge of online marketing and engagement strategies, a researcher from the Department of Sociology with experience recruiting men with gynecomastia, two faculty members in the Public Relations Department taught social media usage, and one faculty member contributed expertise in education and instructional design.

Setting

The focus group ran for 2 hours in a seminar room at the university. To engage participants in a natural conversation, we began the focus group with introductions, presented Facebook advertisement material used in our prior research, and described the purpose of our research and need for effective recruitment materials.

Interview

Serving as moderator, one of the experienced qualitative researchers (BLD) initiated the audio-recorded, semistructured discussion by asking specific questions about methods used for our previous study (eg, "What do you think about those methods and do you have suggestions for improvement?"). We also asked broad questions about social media (eg, "Tell us about your experiences with social media and social media recruitment.") and facilitated interaction among the group with prompts and redirection. Specific questions about social media recruitment dealt with characteristics that make for high-quality social media recruitment materials, best options for recruitment strategies, and barriers to effective social media recruitment.

Analysis

Researchers conducted focus group analysis following descriptive qualitative methods [21], and the principal investigator (DH) verified and transcribed the recorded focus group session verbatim. Four researchers from the university's College of Nursing, two with expertise in focus groups and Delphi methods and two with expertise in caregiver research, individually analyzed the focus group data utilizing descriptive qualitative methods. Each researcher categorized the themes, and researchers met twice to discuss the findings. Researchers modified the thematic structure throughout the analysis until reaching consensus [22]. To ensure trustworthiness, we conducted a member check; the findings were sent to each focus group participant for verification, and each focus group participant agreed that the analysis represented his or her views. Therefore, final themes represent the authentic view of the participants' discussion.

Delphi Method: Phase II

Overview

Using the online Delphi method, we accessed expert stakeholders—family caregivers with seriously ill loved ones who tell their illness stories on social media—from a large geographic area for differing perspectives. The Delphi method—a group facilitation technique featuring an iterative, multistage process—is frequently used to reach consensus. The Delphi method allows for multiple rounds of questions to a group of experts, providing an opportunity to improve the product, in this case recruitment videos, while building consensus among participants regarding important characteristics of the recruitment material. Although there is no universal agreement for what constitutes consensus, the typical range of percent agreement (ie, the standard for Delphi methods) is from 51% to 80% or more [23].

Sampling

The Delphi technique utilizes purposive sampling to identify experts, defined as informed individuals specializing in the field or who have knowledge about the subject [24]. For the Delphi phase of this study, experts were identified as family caregivers with loved ones who use social media to tell their illness stories. This subset of family caregivers was narrowly defined and therefore difficult to recruit. In previous research, we found that women tended to tell their illness stories publicly more often than men, making men the more common caregivers for our study sample, although not typical of the general caregiver population [3,11]. Therefore, our study sample is representative of this subset of family caregivers whose loved ones tell their illness stories on social media. There is no universal agreement on the proper size of the expert panel for Delphi methods; however, panels have ranged in size from 4 to more than 3000 participants [25,26]. Regardless of the large range of sample sizes in research studies, 5-10 experts are suggested [26].

Family caregivers from our previous studies who elected to be contacted regarding future research opportunities were asked if they would like to participate in the Delphi portion of our study. A total of 3 out of 9 family caregivers consented to participate. In addition, 2 more participants were recruited through snowball sampling, a nonprobability sampling technique in which an existing participant recruits other participants because of their acquaintance, resulting in 5 family caregiver participants. All 5 participants were 18 years old or older, with loved ones with a serious illness who use social media to communicate about their illness. Trustworthiness was established with a member check of our analysis of each round [27]. Researchers conducted a member check by sending a summary of the results from each round and asking family caregivers to confirm the summary or add any necessary clarifications.

Qualtrics Survey

The Round I Qualtrics survey began with a consent form explaining the study; those who agreed to participate were taken to the online survey. The first part of the survey requested demographic information and then introduced six open-ended questions: (1) What kind of recruitment practices interest you the most?; (2) What drew your interest to participate in this research study?; (3) What is important in recruiting family caregivers to participate in a research study?; (4) In your opinion, what qualities make you trust an online advertisement?; (5) What recommendations do you have for improving study recruitment materials?; and (6) What social media sites do you visit most frequently? In other words, to which social media sites should we post recruitment videos?

To ascertain what motivates family caregivers to participate in research studies, we asked respondents to rate the following statements on a 5-point Likert scale, from 1 (not at all agree) to 5 (strongly agree):

1. What is the likelihood of participating in a research study that uses online recruitment strategies?
2. I participated in this research study because I believe in advancing science through participation in studies.
3. I participated in this research study because I received compensation.

Participants were then asked to watch recruitment video 1 and answer questions about video quality, trustworthiness, whether the viewer was encouraged to visit the website, and whether the viewer would answer the call to action by clicking on the landing page (ie, the website that explains the research). Participants were asked the same questions about video 2. The final question of the survey asked about the time of day participants typically use social media and are therefore more likely to see recruitment ads.

Following Round 1, researchers sent a summary of Round 1 analysis to the 5 Delphi participants, who then provided feedback as to whether they agreed with our summary and were given the opportunity to offer clarification. Using data and recommendations from Round 1, we sought the assistance of a professional graphic designer to develop two new recruitment videos related to recruiting family caregivers to participate in research. Following completion of the videos, we conducted Round 2 of the Delphi method by sending a new Qualtrics survey with links to the new recruitment videos to Delphi participants and encouraged them to provide feedback for those videos.

Validity and Delphi Analysis

Content validity in Delphi methods is achieved utilizing expert panel members, and successive rounds increase concurrent validity [23]. To ensure the accuracy of Delphi results, we confirmed that the questions and instructions were clear. After Round I, we discovered that participants may have misunderstood one of the questions, so we reworded the question and provided further clarification to ensure understanding. We followed up with one nonrespondent, accurately coded the survey data, recorded all qualitative and quantitative data, and verified the data with a member check after each round.

The same four researchers who analyzed focus group data individually analyzed quantitative and qualitative data from Round I of the Delphi method. A research assistant generated a report from Qualtrics yielding descriptive data for quantitative questions and created a Word document listing the open-ended questions and answers from all participants.

Results

Focus Group: Phase I

Overview

Opening discussion with focus group panelists was rich and offered opportunities to clarify the purpose of the research and the intended audience for recruitment material. Nonetheless, panelists did express some confusion regarding the study. For example, one participant asked,

> *What is the relationship between the caregiver and their experiences as a caregiver and then the loved one's blog?*

Another participant inquired,

> *So we're focusing primarily on the person that's sick who's blogging, not necessarily the family caregiver that's blogging?*

Researchers clarified that although patients are telling their stories, recruitment centers on family caregivers of those patients who are interacting with or reading their loved one's blog. Another participant acknowledged the difficulty inherent to recruiting this subset of family caregivers, acknowledging,

> *So, that's what makes this complicated; you are depending on the ill person to relay the information to the caregiver and it's a very focused target group. So, that's the challenge.*

The results of the analysis fell into three overarching categories: barriers, effective social media material, and need for a landing page.

Barriers

During analysis of focus group data, three barriers to effective family caregiver recruitment were identified, including lack of staff and resources, issues with restrictive algorithms, and not standing out in the crowd.

Lack of Staff and Resources

Lack of staff and resources was identified as a barrier due to the time required to manage the social media accounts. Without infrastructure to support resources and the necessary research staff, in terms of skill level, it is difficult to maintain active social media accounts that include frequent postings and identification of appropriate algorithms for recruitment. This scarcity was supported by the focus group participant comment,

> *The resources are barriers in terms of staff time and folks that are nurturing these accounts.*

Another participant stated that an inactive social media account is a "red flag" to potential participants, adding, "...ideally, the account is active [has postings] one-to-three times per week." One participant expressed his concerns regarding inactive accounts, asking,

> *So is it [the Facebook page used in previous research] inactive? Because that raises a red flag for me if this page is only running advertisements and you might post once every three months—that's technically like*

> *an inactive page and your user does not want to see that.*

Another resource identified as a barrier was the budget. A participant with a background in recruiting alumni to events stated,

> *Budget—that was a big one and then actually converting clicks into action...We get a lot of clicks on our ads, but if we have 300 clicks on one of our ads, we might get one or two RSVPs from that. So, the ads are usually good because they're working, they're getting lots of clicks, and the cost per click is low, but then how do we get them to RSVP to an event, take the action that we want them to do.*

Another participant noted,

> *So, that's even why it's more important to pay to play with these [ads] because you can gradually get right in front of people. So, the fact that you guys are already started with advertising is a good strategy.*

Algorithms

Algorithms were identified as barriers to family caregiver recruitment because the researcher is limited to allowable criteria determined by the social media venue. For example, on Facebook, one can target a recruitment advertisement to a certain age or even certain words, such as cancer or illness. Since we are targeting a very specific group of family caregivers (ie, those who have loved ones who tell their illness stories on social media), it was difficult to find accurate identifiers. This complexity was voiced by one participant who stated,

> *There's a fine line because you don't want to post too much on social media because then you start to turn people away and they'll tune you out. Targeting is a huge barrier, like you said; to get down to exactly who you need to be in front of takes a lot of fine tuning—there's age, demographics, interest, there's all that.*

Another participant noted, "Another barrier is the algorithms because that dictates who sees your content."

Not Standing Out in the Crowd

Focus group participants identified not standing out in the crowd as another potential barrier to successful recruitment. Despite the necessity of drawing potential study participants to the social media account, focus group participants recognized that the topic of death and dying might not draw a large audience. One participant explained,

> *We approach it more from the perspective of the person in terms of why this would be valuable to them to participate. For example, you'll have the opportunity to share your voice and how this impacts your life or something along those lines because I'm sure that they are impacted by this.*

However, having a unique message helps to be recognized and stand out in a crowd. Another participant noted that,

> *The content of the ad is a really critical part of the social media strategy in terms of creating content that's valuable, and if you can showcase the value here [in the recruitment ad], then that's when it brings others, too.*

Another participant validated this comment by stating,

> *Something else that I noticed [about recruitment material previously used] was all of these headlines say we want to interview you. Whereas this headline [the one that drew the most attention] was 'Is your loved one seriously ill?' I think that's a better catch.*

Effective Social Media Material

Creating effective social media material was another theme discussed by participants. Three supporting subthemes for effective social media material included the need to connect on a personal level with the target audience, the need to use real photos instead of stock photos, and the need to create a crystal-clear message. Focus group participants strongly stressed the need for a personal connection with potential study participants to encourage more robust online recruitment. One focus group member stated that the audience must believe researchers are addressing them individually, suggesting that researchers ask questions that elicit the response, "Yeah, that's me, yeah that's me, yeah that's me. We want you to click here!" According to the focus group, another critical part of the social media strategy in terms of creating content is to "showcase the value—that is what brings others to it [the social media advertisement]." One participant with experience in public relations stated,

> *Provide value and what's in it for you, that's the mantra in public relations. So, I wonder if we approach it more from the perspective of the person in terms of why this would be valuable to them to participate in the study versus we want to interview you, maybe you'll have the opportunity to share your voice and how this impacts your life or something along those lines because I'm sure that they are impacted by this [caregiving experience].*

Another focus group participant noted,

> *You pointed out defining a caregiver, I think that's important so, if there would be a way to work that in somehow, I think that would be good.*

Focus group participants also identified the importance of using real photos instead of stock photos. Real photos elicit a more personal connection, and stock photos are considered a red flag to the potential participants. One focus group member noted that,

> *When they [potential study participants] see stock images—they [potential study participants] know that's an ad. So, they'll scroll right past it...I think that you need more compelling images that are going to catch somebody's attention.*

Participants expressed the need for a crystal-clear message to engage the audience with a call to action. The call to action motivates the audience to click on the link that takes them to the study's landing page. Potential study participants must feel compelled to click on the link. One method identified by focus group participants to deliver a clear message containing a call to action is through a video message. Video messages do not have word limits as do Facebook advertisements, allowing researchers to explain the research in more depth and create a more personal message. Focus group participants offered various strategies for using video messaging to improve family caregiver recruitment, including the following guidance:

> *...take your iPhone, record something and post it in these forums and then steer them to the landing page.*
>
> *Facebook is really rewarding people who use video advertisements right now and you get more bang for your buck.*
>
> *Use organic posting for Facebook and Twitter, not just advertisements—if you create a 30-second video, you can upload that directly to Twitter and you will see a lot of engagement because it autoplays just like it would on Facebook.*

Landing Page

Finally, focus group participants suggested creating a study landing page for potential research participants that is user friendly, expands on the clear message, and presents a call to action as a way to connect all recruitment material. One participant highlighted the need for "making it simple and making that call to action very clear so it takes them to the landing page." Another participant agreed with the necessity of a study landing page, stating,

> *...once you get them to that page where they are actually converting, that has to be simple, too. So, that landing page is another critical piece.*

Participants also suggested creating a hashtag that goes out with every recruitment effort to connect the recruitment material, explaining that "The hashtag will take them back to the landing page." This landing page can be an active social media account, such as Facebook, or an active webpage.

After compiling focus group recommendations, work began to create new social media recruitment material. We decided to create recruitment videos that would take potential participants to our study landing page, which provides information about current studies and how to become part of our caregiver registry. The principal investigator created two videos using a program called Biteable [28]. These two videos included no audible words but displayed pictures of people representing the target population. Words describing the purpose of the video and how to contact the researcher were displayed on the screen, and music played in the background.

Delphi Method: Phase II

Overview

Using the Delphi method, the updated recruitment videos were tested with a sample of 5 family caregivers who have a loved one who tells their illness story on social media. Delphi participants ranged in age from 57 to 70 years with a mean age of 58 (SD 7). Caregivers were predominantly male (4/5, 80%) with an average of 3 years of caregiving experience (see Table 1). Participants' responses to reasons for participating in the study and the importance of recruiting family caregivers in research were varied (see Textbox 1).

Table 1. Demographics of participants for the Delphi method.

Demographics	Value
Age (years), mean (SD)	58 (7)
Gender (n=5), n (%)	
Male	4 (80)
Female	1 (20)
Years of caregiving, mean[a]	3

[a] SD is not provided for years of caregiving because responses were ranked options (eg, 0-2 or 3-5 years).

Textbox 1. Participants' open-ended responses from round 1 of the Delphi method.

Participants' reasons for participating in this study:

- Participants' awareness of positive results that come from research
- Son uses Facebook and Caring Bridge to talk about his illness journey
- Was asked by a friend
- Experience as caregiver
- Happy to contribute our experiences to others

Importance of recruiting family caregivers to participate in research:

- So that caregivers know what kind of help is available and to help others
- We would not be where we are today in the medical field if studies were not conducted
- Explaining the goals of the research
- Caregivers are frontline workers and need support, including emotional support
- Diversity—it's best when a study covers a wide range of circumstances

Delphi Round 1

For each video, Delphi participants were asked to rate specific characteristics, including the overall quality, trustworthiness, the extent to which the video encourages or discourages participants to seek more information, and, finally, the likelihood that participants would act on the video's request (ie, to "click here"). Participants rated each characteristic as *poor*, *fair*, *medium*, *high*, or *highest*.

The first round of videos yielded encouraging results that offered opportunities for improvement. Both videos did not have lower than *medium* rating scores, although the overall quality was slightly higher in video 1. Video 2 had a slightly higher score for trustworthiness compared to video 1, and both videos had one rating of *poor* for trustworthiness. Neither video was ranked well in encouraging participants to seek more information; however, video 2 performed worse than video 1 in this category. For both videos, more participants said that they would not "click here."

We also asked several open-ended questions. In terms of when family caregiver participants would be most likely to see a recruitment video on social media, 3 out of 5 participants (60%) reported 5:00-8:00 am as the most likely time, another participant (1/5, 20%) chose 1:00-3:00 pm, and one other participant (1/5, 20%) was more likely to see a recruitment video from 8:00-10:00 pm. Participants identified newspaper ads, social media posts, fliers in physicians' offices and waiting rooms, and email messages as the most appealing recruitment practices.

In their responses to the question, "What is important in recruiting family caregivers to participate in a research study?" participants identified three factors that facilitate trust for recruitment videos on social media. These factors focused on the family caregiver's ability to trust the organization and for the organization to do the following: (1) ensure the source of the recruitment material is clear and visible on the recruitment material, which includes a recognizable logo; (2) improve the clarity of the research purpose presented on the recruitment material; and (3) use known social media sites such as Facebook, Twitter, and Instagram. Participants stated that they participate in research studies because they believed in advancing science through research and suggested posting on disease-specific sites, such as the National Multiple Sclerosis Society website or the Stem Cell Transplant Group Facebook page.

Prior to moving forward with Round 2, we consulted with a researcher with expertise in recruiting participants at the end-of-life stage and conducting research with social media illness stories. She reviewed the videos from Round 1 and the newly developed Round 2 videos, along with the scripts for each video. Her feedback was incorporated into the final production of Round 2 videos.

Delphi Round 2

In Round 2, participants were asked the same questions about characteristics of the videos to allow us to analyze issues identified with the videos in Round 1. Ratings improved to above a *medium* score for each video in all characteristics, with video 2 achieving slightly higher overall ratings.

Overall, recommendations provided to improve Round 2 recruitment videos were successful, as 100% consensus was achieved. For example, one participant commented, "These ads were a big improvement, very clear and to the point." We summarized Round 2 feedback and sent that summary to Delphi participants, who confirmed consensus. Comments from this group included the following statements:

> *All good points on the feedback.* [Participant #1]
>
> *With the new videos and new feedback, your videos should work well.* [Participant #1]
>
> *Thank you for letting me participate.* [Participant #1]
>
> *I would agree with the summation.* [Participant #2]
>
> *Good summary and you did capture my feedback.* [Participant #3]
>
> *I think you have correctly captured my comments; thank you.* [Participant #4]

Some suggestions mentioned the addition of closed captioning, which has been completed.

Discussion

Principal Findings

Family caregivers at the end-of-life stage provide important support for the dying patient; they also need vital support to better help their loved ones. However, recruitment for this population is complex, especially for a subset of family caregivers whose loved ones tell their illness stories on social media. This study offers insights on recruitment for this subset of caregivers. Focus group participants and Delphi participants validated that social media is an important venue for participant recruitment and offered critical suggestions for effective social media recruitment material for family caregivers. These recommendations include identification of barriers, creation of effective recruitment material, and the need for a landing page prior to recruitment efforts. Development of effective recruitment material includes ensuring the identity of the organization, improving trustworthiness and transparency, and ensuring that the purpose of recruitment is clear.

Social media algorithms determine which advertisements align with users' interests based on their onsite activity, listed interests, and interactions. Creating a video with a focused and targeted audience is required to take full advantage of social media advertising. For example, using real photos instead of stock images builds a connection with the target audience, which leads to greater trust [29]. Our findings revealed that algorithms were identified as barriers to social media recruitment for our study population of interest, as researchers are limited to criteria of interest for a specific group of family caregivers (ie, those who have loved ones who tell their illness stories on social media). These findings remain consistent with a systematic review reporting similar limitations in other study populations, because using ads on social media websites requires targeting specific age groups and locations based only on the information an individual provides on his or her profile [30]. Therefore, there is no guarantee that awareness of the study reached all potential participants, which introduces bias into the results.

Focus group participants acknowledged that maintaining active accounts and updated valuable ad content are critical components of social media to draw a large audience. Our findings validate Pang and colleagues' findings that unless researchers utilize transparent and relevant information for health care consumers, online and social media platforms used in recruitment will not command traffic [29]. In our study, we found an emphasis on the need to make a personal connection with potential study participants so they may receive the "call for action" and the necessity for a clear message to engage participants and maintain account activity. Our focus group participants (Phase I) discussed the importance of delivering a clear message so that potential participants could easily identify with the research. Akers and Gordon also emphasized the importance of linking the study recruitment advertisement to the study URL (ie, the place where participants are directed when they click on the ad containing details of the study) and the Facebook landing page [31].

Howcutt and colleagues propose a marketing framework to improve recruitment [32]. Combined perspectives of marketing science and behavioral science focus on persuasion and decision making. Success with marketing employs strategies to connect the researcher to the participant, understanding that both receive a benefit from the relationship. However, successful recruitment occurs when there is an emphasis on the "consumer" or on the potential participant's needs, decreasing barriers to research participation and improving participant motivation to engage [32,33]. In the Delphi phase, we found that the caregivers were not motivated by compensation but, rather, were motivated by the idea of making a difference for others. Similar to our findings, it is suggested that emphasis be placed on the commonalities of the population (eg, caregivers' desire to share experiences) instead of manipulating behavior to fulfill researcher goals [33].

Howcutt's framework includes attending to perceptions and attitudes of participants, which may influence family caregiver recruitment [32]. As an example, some people base decisions on consideration of the facts and reflection on the benefits and burdens of participation. We know that our target population of family caregivers does not have an abundance of free time. However, perceptions and attitudes affect how individuals consider participation in an activity, which may include identifying time constraints of caregiving as burdensome, thus increasing that burden. However, if caregivers perceive the benefit of research participation to help others as more important than time constraints, caregivers may be more likely to engage in research. Family caregivers who participated in the Delphi method perceived research participation as important to helping others. Therefore, another layer of complexity is added when researchers must also consider the variety of perceptions and attitudes held by their target population.

Integration is a concept in Howcutt and colleagues' discussion that is likened to what our participants labeled a "call to action." The call to action is influenced by what Ajzen [34], in his seminal work, referred to as a person's intent to adopt a new behavior. By understanding and removing barriers as uncovered in our focus group of social media experts, we can turn interest or intent by potential study participants into action.

In addition to extending a new perspective to examine the importance of social media relationships, social network sites offer researchers from a variety of disciplines a unique venue for recruitment [35]. Challenges with participant recruitment are often the primary reason for study delays [36]. Using social media for recruitment improves the capacity of sampling while minimizing the cost of obtaining large sample sizes, thereby increasing access to hard-to-reach populations, such as caregivers of patients with serious illness.

Limitations

While the purposive sampling method allowed for participation of peer-nominated participants with expertise in social media recruitment and advertisement as well as expert stakeholders in the Delphi method, the findings are not generalizable. In addition, the focus group method presents challenges associated with collecting data. These challenges may arise from the nature of questions posed by the moderator, or a more gregarious participant may drive the direction of the discussion. However, the member check allowed us to assess if these issues existed in our study. All participants agreed with our data analysis and did not offer additional insight.

With Delphi methods, there is no evidence of reliability. For example, we do not know whether study results would be the same if identical information was given to another panel of family caregivers. However, validity is also an issue when using the Delphi method and arises from pressures put on panel members to change their opinions according to the group response [23]. Our participants did not change their responses after the summary was provided; therefore, we are confident in the validity of our findings in this sample. Typically, there are at least three rounds in a Delphi method to reach consensus. However, we believe we were able to reach consensus after two rounds because of the initial focus group data that was used to develop recruitment material presented to Delphi participants.

Conclusions

One of the primary challenges to conducting research with family caregivers is recruitment. Recruitment through social media is a promising means of engaging family caregivers in research and may be a cost-effective alternative in recruiting hard-to-reach populations [36]. Furthermore, because of widespread use of social media, there are fewer geographical boundaries for Internet recruiting, which may improve generalizability of research studies. This study contributes a unique view of the science for building effective videos to recruit family caregivers. Videos offer a short and clear message about the research, and the visual aid assists consumers with learning and understanding the content [29]. The initial focus group comprised of social media experts helped us develop targeted recruitment materials to overcome barriers to social media recruitment with family caregivers. The Delphi portion of this study allowed us to gain valuable feedback on the new recruitment material and then adapt that material based on participant feedback.

Despite the broad adoption of social media marketing approaches, the effectiveness of different online recruitment strategies needs further investigation. Future research should focus on the utility of various social media sites for recruitment purposes

Acknowledgments

Funding for this research was provided by a New Investigator Seed Grant from the Midwest Nursing Research Society. The authors wish to thank participants from the focus group and Delphi study for their participation and insights. We would also like to thank Emily Yates for her expertise in graphic design that resulted in two quality recruitment videos, Dr Cathy Heilferty for her expert review of the videos during the Delphi phase, and Denise Karshner for her editing expertise.

Conflicts of Interest

None declared.

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Edited by E Borycki; submitted 28.02.19; peer-reviewed by K Kim, J Appalasamy; comments to author 01.04.19; revised version received 16.05.19; accepted 08.06.19; published 22.07.19.

Please cite as:
Hansen D, Petrinec A, Hebeshy M, Sheehan D, Drew BL
Advancing the Science of Recruitment for Family Caregivers: Focus Group and Delphi Methods
JMIR Nursing 2019;2(1):e13862
URL: https://nursing.jmir.org/2019/1/e13862/
doi:10.2196/13862
PMID:34345769

Original Paper

The Needs and Barriers of Medication-Taking Self-Efficacy Among Poststroke Patients: Qualitative Study

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Abstract

Background: Stroke is one of the top 10 leading diseases worldwide, with high mortality and morbidity rates. There is an incomplete understanding of the various types of self-efficacy involved in the prevention of recurrent stroke, and one of them is medication-taking self-efficacy.

Objective: This study aimed to explore the fundamental needs and barriers of medication-taking self-efficacy in poststroke patients in Malaysia.

Methods: We performed in-depth individual interviews with poststroke patients (N=10) from the Outpatient Neurology Clinic, Hospital Kuala Lumpur. All interviews were transcribed verbatim, and an inductive thematic analysis was performed on the data collected from the interviews.

Results: Two key themes were identified: (1) self-efficacy in taking the effort to understand stroke and its preventative treatment for recurrent stroke and (2) self-efficacy in taking prescribed medication to prevent stroke. Patients needed to be proactive in seeking reliable information about stroke and the perceived benefits of preventative treatment for stroke. The discussion was focused on eliciting the needs and barriers related to medication-taking self-efficacy. Patients needed to develop independence and self-reliance to overcome barriers such as dependency and low motivation. External factors such as limited information resources, low perceived severity, poor social environment, and poor communication add to the challenges of poststroke patients to improve their self-efficacy of managing their medications.

Conclusions: The study identified potential key findings related to the needs of patients in a localized setting, which are also related to several health behavioral concepts and constructs, indicating the importance of overcoming barriers to improve the quality of life in poststroke patients. We anticipate that the results will be taken into consideration for future personalized patient education interventions.

(JMIR Nursing 2019;2(1):e14399) doi:10.2196/14399

KEYWORDS

poststroke; medication taking self-efficacy; medication adherence

Introduction

Surviving a stroke can be an enduring challenge that affects many facets of a person’s life. Stroke was the second leading cause of noncommunicable disease death globally in 2016 [1]. In fact, stroke has been known to be a cause of substantial disability and debility, and its prevalence is estimated to double by 2035 [1,2]. Research on stroke preventative medication such as antiplatelets and anticoagulants by pharmaceutical industries and treatment by health care providers has resulted in outstanding improvements in the morbidity and mortality of poststroke patients [3-5]. Hence, adherence to lifesaving therapies needs to be sustained in order to achieve optimal treatment outcomes. Otherwise, medication nonadherence would result in deficiency of treatment optimization, increasing the risk of stroke and leading to a possibility of stroke recurrence [6-8]. A review paper suggested that poor medication adherence is associated with modifiable patient factors that are related to a lack of understanding caused by low health literacy. The paper also highlighted variances in belief, attitude, and motivation caused by behavioral factors. Poor adherence is also associated with an increase in medication-related problems [6,9]. In other studies, poor adherence of stroke preventative medications among poststroke patients was also associated with a higher prevalence of cognitive disability, depression, low motivation, less social support, and low self-efficacy [10,11]. Interestingly, similar studies have shown a lack of self-efficacy among stroke survivors despite patient education and counseling effort, regardless of various health care settings [12,13]. Patient empowerment was suggested to be a significant facilitator of enhanced medication adherence [6]. Therefore, exploring the effect of self-efficacy on medication-taking behavior was considered to be important.

Self-efficacy is defined as the belief in one’s ability to execute a specific task or actions in order to achieve a goal [14]. This type of faith in oneself leads to high confidence and better control, which translates the intention to perform into carrying out the planned action. Self-efficacy is an important component in various behavioral models such as self-efficacy theory, social cognitive theory, and the health belief model (HBM) and is associated with better medication adherence among poststroke patients [15-17]. However, exploratory research examining the types of self-efficacy underpinning medication-taking behavior among poststroke patients is limited. Identification of the needs and barriers of specific medication-taking self-efficacy is of utmost importance for the development of potential interventions to improve medication adherence. Hence, it is crucial to understand the view and impact of those needs and barriers on poststroke patients. Therefore, the research question of this study is as follows: What are poststroke patients’ needs and barriers to sustain medication-taking self-efficacy? The current qualitative study described findings from individual in-depth interviews of poststroke patients.

Methods

Ethics Approval

The design and conduct of the study were approved by the Malaysian Medical Research and Ethics Committee (NMRR ID-15-851-24737) in July 2015.

Study Setting

The study recruited patients followed up at the Outpatient Neurology facility at Hospital Kuala Lumpur (HKL), who were informed about the study and provided consent. HKL is the principle tertiary facility in Malaysia and receives a high number of patients with stroke from different territories in the Klang Valley and throughout Malaysia, with approximately 1000-1200 acute and recurrent stroke cases every year. The Neurology Department is a pioneer in setting up an acute stroke center in Malaysia, which is overseen by a group of neurologists, doctors, and other health services supporting staff.

Recruiting Participants

For the interview, patients were randomly selected via a simple random sampling method, from a list of 89 patients with potential drug-related problems (DRP) [18], who were identified by a clinical pharmacist. DRP is a set of categories of medication issues used by medical personnel to conduct a strategic medication review in order to ensure optimization of the prescribed medication. The issues could be related to medication interactions, dosage appropriateness, adverse events, or adherence. Thus, a patient with DRP would be the best candidate to analyze medication-taking behavior [9]. The inclusion criteria were diagnosis with first stroke in the last 6 months from the initial date of screening and interview (January 1, 2016, until March 30, 2016); taking stroke-prevention medications such as statins, antiplatelets, or anticoagulants; and no memory problems and ability to converse, read, and write in Malay or English. We selected patients who had potential treatment issues such as a subtherapeutic effect with causes related to medication use process (eg, medication not taken). In-depth interviews were deemed most appropriate to build a trustful rapport between the researcher and patients and obtain more comprehensive views. This method also ensures that patients are comfortable and that their thoughts are not suppressed due to the presence of other patients. It was not possible to conduct a focus group discussion due to schedule and venue problems, as these patients had physical immobility or transportation issues. One researcher approached all patients and explained the purpose of the interview and study. The research team agreed to recruit more patients until data saturation [19]. However, of the 32 patients who showed interest, only 10 patients (31.2%) agreed and signed the consent form to volunteer for a personal interview for a maximum of 30 minutes. We completed full semistructured interviews with a total of 10 patients (5 women, 5 men; age range: 44-78 years; Table 1).

Table 1. Characteristics of the poststroke participants (N=10).

Characteristics	Value
Age (years), mean (SD)	57 (10.01)
Sex, n (%)	
Male	5 (50)
Female	5 (50)
Ethnicity, n (%)	
Malay	7 (70)
Indian	2 (20)
Chinese	1 (10)
Type of stroke, n (%)	
Ischemic	8 (80)
Hemorrhagic	2 (20)
Number of prescribed medications, mean (SD)	3.7 (0.94)
Medication nonadherence, mean (SD)	2.8 (0.63)
Employment status, n (%)	
Employed	6 (60)
Unemployed	4 (40)
Education level, n (%)	
Primary	2 (20)
Secondary	6 (60)
Tertiary	2 (20)

Data Collection

In-depth interviews were conducted on the basis of a qualitative open-ended interview guide developed by a nurse educationist, two pharmacist educationists, and a neurologist. This group represented views from different health care professionals involved in stroke treatment and care. The interview guide was pretested on nine poststroke patients for their relevance and suitability in the Outpatient Neurology clinic setting. Although short, the guide was precise in order to prevent burdening patients with many questions while giving them enough time to recall meaningful events (Multimedia Appendix 1). Each patient was given an appointment for the interview. One researcher (JA) led each scheduled participant to a quiet room at the Outpatient Neurology clinic, started the interview after a friendly chat, and continued to brief them about the study. The interviews focused on patient's experiences of stroke and medication management. The interview was conducted at a relaxed pace, whereby the patient was allowed to pause or have a short break. The researcher (JA) posed prompts whenever necessary or when the conversation was mixed. After 15 minutes of interview, two online video vignettes were shown to the patients. The video vignettes of 2 minutes each were in an animated form, conveying messages on the importance of understanding the disease and its preventative medication and how people perceived their medications (Multimedia Appendix 2). The researchers (JA and SR) developed the video vignettes in English and Malay language to prompt patients to elicit a deeper thought of self-reflection, and in doing so, the video allowed the researchers to obtain a better understanding of the patients' needs or barriers to improve their health conditions. Vignettes were suitable, as they empowered accumulation of delicate subjective information and are a successful device for inspiring judgments and discernments [20]. The videos that lasted less than 2 minutes had satisfactory face validity and content validity, as confirmed by three poststroke patients, a clinical nurse, two neurologists, and two pharmacists. Patients were asked to describe their experiences of adhering to prescribed medications after viewing the video. All responses were audio recorded, and the researchers ensured the confidentiality of the recordings.

Data Analysis

All interviews were transcribed verbatim, checked by another researcher, and then documented for data analysis. All transcripts were manually coded and classified using the inductive thematic analysis methodology [21]. The methodology were as follows: (1) understanding the transcripts, (2) diagramming key points into codes, and (3) summarizing the mapped codes into subthemes and emergence of major themes. Six scripts in the Malay language were translated by an independent translator. Two researchers (JA and SR) reviewed the transcripts and met intermittently to discuss the themes, outlines, and issues established in the data. Once the themes were generalized, they were verified by two other reviewers (PW and CS) to ensure uniformity, precision, and quality [22].

Results

Study Themes

Two major themes related to medication-taking self-efficacy were identified: self-efficacy in taking the effort to understand stroke and its preventative treatment for recurrent stroke and self-efficacy in taking prescribed medications to prevent stroke. A majority of the subthemes discussed by the patients referred to the individuals' necessity, needs to attain the specific self-efficacy, and the challenges considered to be barriers to attaining those needs. Thus, the results section is organized into two sections that discuss the needs and barriers of both main themes. The first portion of each section discusses the needs and the second portion discusses the barriers. The themes emphasized on individual well-being, communication, and independence, which were elicited in response to specific probing of the elements related to medication-taking self-efficacy.

Self-Efficacy in Taking the Effort to Understand Stroke and its Preventative Treatment for Recurrent Stroke

The Needs: Proactive in Acquiring Information

Self-efficacy is a necessity that determines how one approaches challenges and accomplishes tasks. It is a belief in oneself to be able to achieve planned goals. The needs of poststroke patients in this study related to medication-taking self-efficacy were concluded based on deduction from specific cues, quotes, and observed expressions. The poststroke patients in this study recognized that they required the confidence to be "independent and active learners" in order to gain knowledge about stroke recurrence and rationalize how the stroke occurred and why they must adhere to preventative medications. In other words, patients would need to be responsible for taking their own decisions and their own efforts to seek more information about their illness and treatment rather than accepting any passive information. One patient stated:

> *Once you have a stroke, you need to read a lot to know more about it…we don't know when we can get it again.* [ID3]

By doing so, the patients were able to justify the importance of taking prescribed medications and improving their adherence to treatment:

> *We need to take the medicine, if not it can worsen our condition; that's what I've learnt from the internet.* [ID8]

The Needs: Perceived Benefit of Stroke and its Prevention Therapy

We assumed that a minority of patients lacked the trust and belief in information, which was crucial to guide their actions toward understanding the purpose of adhering to prescribed medications, as exemplified by the following statement:

> *I don't know why the doctor gave me so much medicine...I take the doctor's medicine alternately because I can control my blood pressure with my own herb mixture.* [ID2]

This statement reflects a current situation wherein patients had the tendency of negative belief, which gave them an impression that their medication-taking actions were more beneficial than the advised information. Hence, there is a need to increase patients' awareness to appraise any information about their illness and its treatment regardless of the source of information or belief.

The Barriers: Limitation on Reliable Information Resources

The patients also expressed some disappointment in not receiving vital information about stroke on time before the actual event occurred.

> *I only learned more about stroke when I got one.* [ID7]

The information about stroke and its prevention could have been delivered in various media formats or oral communication. One patient's statement strongly indicated the existence of the barriers:

> *I didn't know I was having stroke, until my daughter explained to me.* [ID3]

Participants acknowledged that health care clinics' efforts to educate patients are important, but they were also concerned about the limited resources or health care facilities for obtaining information, particularly on optimizing treatment for personal benefit.

> *I know they (the doctors) are very busy. So they don't have time to explain.* [ID9]
>
> *I can't remember everything…I think they should give us free medicine box.* [ID10]

The Barriers: Poor Communication

There were possibilities of poor communication or language barriers between the prescriber and patient. This issue was potentially related to the lack of self-efficacy in taking the effort to understand the purpose of stroke preventative medication:

> *Sometimes, I don't understand what the doctor or pharmacist told me.* [ID5]

The Barriers: Lack of Perceived Severity

A diversity of perception was identified from spontaneous remarks by the patients. Low perceived severity occurs when there is a low inclination toward acceptance of illness, that is, belief that a stroke is not a serious disease. One patient lamented:

> *I know I was having some symptoms…but I felt it was ok so I kept on driving because it went away after a while.* [ID2]

Poststroke patients showed negative perception of the value of stroke-prevention medication, particularly antiplatelets, anticoagulants, and antihypertensive agents. Patients perceived a lack of benefit of these prescribed medications and misconceptions of their mechanism of action:

> *The medicine will definitely cause more side effect…it is toxic especially to your kidneys...you just need to*

> *relax to bring down the blood pressure, sometimes I control it myself.* [ID4]

The Barriers: Environmental Influence on Medication-Taking Behavior

Patients' environment and experiences acted as barricades (excellent influence) for perceived illness and medication-taking self-efficacy of prescribed medications. Family, friends, and common health practice in a community influenced these patients' attitude and action of responsibility toward their illness, which affected their medication-taking behavior:

> *My friend bought me this tea, it thins your blood…if I tell my doctor, he will definitely disagree...but I know it works.* [ID1]

> *My children and neighbor asked me to try some herbs. You know that expensive one for blood circulation...but I don't want to...* [ID7]

There was also influence from electronic media, which acted as a stimulus of behavior changes and action:

> *I learn a lot using the internet, this person advises you can take certain herb, so I tried it out.* [ID8]

These phenomena challenge the patient education efforts made by public agencies and hinder their efforts for instilling positive medication-taking behavior among poststroke patients.

Self-Efficacy in Taking Prescribed Medication to Prevent Stroke

The Needs: Independence and Self-Reliance

One of the underlying reasons for not being adherent is the lack of independence in medication taking and self-management. Poststroke patients realized that independence and self-reliance have a positive effect on managing prescribed medications, and this is one-step toward success in improving their stroke conditions.

> *I googled more...you need to know what and how you take your medicine. I asked the doctor about my medicine if I don't understand.* [ID3]

Nevertheless, poststroke patients need to have confidence and trust that their prescribed medications will benefit them, albeit the acceptable risks:

> *We should not be afraid of side effect, you have no choice but to take it...because the medicine benefits you.* [ID8]

The Barriers: Dependency in Medication Management

Success in managing one's own medication requires ample skills and perseverance to overcome obstacles. However, this "mastery experience" could also undermine self-efficacy belief if failures were not overcome, which in turn become a norm and increased dependency. A few patients provided testimonials on reflecting on a potential failed experience and increasing dependency on managing medications:

> *I have limited moving ability to manage my medicine, so, my wife takes care of them.* [ID6]

> *I don't know much about the medicine...you have to ask my daughter.* [ID5]

> *I was not informed how to store my medicine...they didn't teach me, but just briefly told me at the counter.* [ID2]

The Barriers: Low Motivation

Despite the need for self-efficacy for taking medications, a lack of motivation has been a challenge for those who wanted to change; hence, this factor is the foremost barrier against self-efficacy toward medication taking and management. Patients expressed feelings of not being understood and suffering alone, and there were high chances that they were getting frustrated and depressed.

> *Those who didn't experience stroke, don't understand how I feel.* [ID1]

Physical disability is also a huge barrier that complements low motivation.

> *I tried going for rehab for six months…no improvement, everyone kept advising me the same thing, what is the use?* [ID4]

Apart from low motivation affecting self-efficacy toward medication adherence, it was evident that there was a transit effect on the patients' quality of life.

Discussion

Principal Findings

Normally, confidence is thought to be adequate to carry out a task, and it is simple to adhere to medications. Confidence has a positive effect on self-efficacy; however, this may not be the case vice-versa. The ability to understand, think, plan, and use prescribed medications to sustain medication adherence and ensure treatment effectiveness depends on the individual's self-efficacy levels [15,16,23]. Hence, self-efficacy in understanding and taking medication appropriately found its specific niche in nonadherence and has been studied for more than a decade [24]. This qualitative study managed to obtain an overview of poststroke patients' needs and barriers toward sustainable medication-taking self-efficacy.

Patients expressed a lack of the understanding that every stroke event portrays different symptoms, and inability to control stroke risk factors increases the risk of a recurring stroke event. This finding was consistent with a previous qualitative study of stroke patients' perception, which highlighted the difficulty of identifying various atypical stroke symptoms [25]. It was clear that the patients were not proactive. About 5 of the 10 patients (50%) knew that relevant knowledge was important, but they were laid-back even though they were experiencing a stroke. Moreover, the lack of knowledge and awareness was limited to not only illness but also its preventative treatment. A trend of negative responses from those with a lower health literacy level was observed: 2 of the 10 patients (20%) had poor literacy levels. To achieve self-efficacy in order to gain an understanding of stroke and its preventative medication purpose, patients were faced with barriers such as inadequate or unreliable sources of information and poor communication with prescribers, which dampen their knowledge search. Importantly, unassessed low health literacy complements the knowledge attainment barriers [25].

Other than being proactive, perception and belief are essential in the patients' decision making process in medication-taking behavior. Perception is subjective of what an individual thinks about an issue and how one is influenced by one's beliefs. Thus, the intensity of medication-taking self-efficacy depends on the level of patients' perception of their disease and its treatment [17,26]. Therefore, we could summarize that patients with similar underlying stroke risk factors or severity may not have the same perception of illness and belief about their medications even if they were assumed to have the same knowledge about stroke and its treatment. It is possible that varying physical and emotional experiences with stroke cause differences in perception and beliefs. Therefore, actions of poststroke patients' toward adherence are steered by their perceived susceptibility and severity of stroke and led by their perceived benefits or barriers of medication taking, which are influenced by their beliefs [27,28]. Nevertheless, diverse populations and cultures have a strong influence on these beliefs too [29,30]. Hence, the success of a behavioral intervention depends on these factors as well.

Self-efficacious patients tend to develop or learn skills on their own in an effort to overcome worsening of the disease condition. They choose self-empowerment and a high responsibility of medication management to ensure optimal therapy effect. Some self-care examples are monitoring blood parameter, scheduling medication intake using the pill reminder, preparing appropriate medicine storage, and being aware of any allergy symptoms [31-33]. In the same way, self-efficacy is highly influenced by parallel changes in self-motivation and quality of life, and these changes vary between individuals according to the effect of personal experiences (mastery experience) and the perspectives of stroke and belief in the preventive treatment [12,34,35]. In other words, self-efficacious patients living with long-term illnesses tend to put effort into attaining an in-depth knowledge about their disease and treatment, creatively solving problems, and increasing their expertise of improving their own health [36]. Thus, in order to sustain medication-taking self-efficacy for optimizing treatment effectiveness, health professionals should ensure that their intervention fulfils patients' needs of self-efficacy to understand and use medication appropriately and that it addresses their barriers toward the intended self-efficacy.

Study Limitation and Strength

This study was based on the viewpoints of 10 poststroke patients. We experienced a high drop-out rate, as we were unable to secure appropriate funding when patients requested for their financial reimbursement. Therefore, generalizability of the study findings was limited by the small sample size. There were also challenges in distinguishing the needs and barriers of language or health literacy level. Hence, more in-depth interviews with validated tools are required to categorize varying health literacy levels among poststroke patients. This sample may not have captured the full range of the needs and barriers of poststroke patients. However, this did not detract from the clear importance of the two main needs of medication-taking self-efficacy: self-efficacy in gaining an understanding of stroke and managing the intake of preventative medications for stroke.

The strength of this study is that it revealed emotional experiences of poststroke patients under an unconstrained technique with the help of focused prompts and video vignettes to elicit deeper thoughts compared to close-ended questionnaires. The themes were discussed in specific probes of self-efficacy related to medication adherence dimensions. Hence, this study indirectly proposed the usefulness of video in modifying focused or planned behavior [37,38].

Conclusions

Our findings were exploratory, and hence, the outcomes on verifying the association between the needs and barriers and medication-taking self-efficacy should be confirmed using quantitative measures with adequate sample size. Nevertheless, the results provided a subjective perspective of poststroke patients based on their experiences, and thus, it is crucial to consider these viewpoints as a groundwork for future interventions related to understanding medication taking and its self-efficacy.

Acknowledgments

We would like acknowledge the contributions of the patients from the Outpatient Neurology Clinic, Hospital Kuala Lumpur.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Patient interview guide.
[DOCX File, 12KB - nursing_v2i1e14399_app1.docx]

Multimedia Appendix 2
Video 1.
[MP4 File (MP4 Video), 2MB - nursing_v2i1e14399_app2.mp4]

Multimedia Appendix 3
Video 2.
[MP4 File (MP4 Video), 1MB - nursing_v2i1e14399_app3.mp4]

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Abbreviations

DRP: drug-related problems
HBM: Health Belief Model
HKL: Hospital Kuala Lumpur

Edited by E Borycki; submitted 15.04.19; peer-reviewed by A Bukhsh, M Johansson, H McCarron; comments to author 05.06.19; revised version received 09.06.19; accepted 23.06.19; published 22.07.19.

Please cite as:
Appalasamy JR, Subramanian P, Tan KM, Seeta Ramaiah S, Joseph JP, Chua SS
The Needs and Barriers of Medication-Taking Self-Efficacy Among Poststroke Patients: Qualitative Study
JMIR Nursing 2019;2(1):e14399
URL: https://nursing.jmir.org/2019/1/e14399/
doi:10.2196/14399
PMID:34345772

Original Paper

Primary Health Care Nurses' Experiences of Consultations With Internet-Informed Patients: Qualitative Study

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Abstract

Background: Most people in modern societies now use the Internet to obtain health-related information. By giving patients knowledge, digital health information is considered to increase patient involvement and patient-centered interactions in health care. However, concerns are raised about the varying quality of health-related websites and low health literacy in the population. There is a gap in the current knowledge of nurses' experiences with Internet-informed patients.

Objective: The objective of this study was to explore primary health care nurses' experiences of consultations with patients who present health-related information from the Internet.

Methods: This is a qualitative study based on interviews with 9 primary health care nurses. Data were analyzed using qualitative content analysis. Results are reported according to the consolidated criteria for reporting qualitative research guidelines.

Results: The phenomenon of Internet-informed patients was considered to change the usual rules in health care, affecting attributes and actions of patients, patterns of interactions in consultations, and roles of nurses and patients. Three categories were identified: (1) Facing the downsides of Googling, (2) Patients as main actors, and (3) Nurse role challenged. Although the benefits of health-related Internet information were described, its negative consequences were emphasized overall. The problems were mainly ascribed to inaccurate Internet information and patients' inability to effectively manage the information.

Conclusions: Our study suggests ambivalent attitudes among nurses toward health-related Internet information. In order to promote equitable care in the digital era, increased awareness in health care about useful strategies for overcoming the difficulties and embracing the benefits of conferring with Internet-informed patients seems to be a legitimate goal.

(JMIR Nursing 2019;2(1):e14194) doi:10.2196/14194

KEYWORDS

eHealth; Internet; consumer health information; health literacy; patient-centered care; qualitative research; primary health care

Introduction

In the ongoing digitalization of modern societies, health care has also been affected. The widely used term *eHealth* refers to the use of information and communications technology (ICT) in health care. The World Health Organization has acknowledged the potential of ICT to play a major role in improving public health and it urges member states to prioritize the development of eHealth technology [1]. The vision of the Swedish government is that by 2025, Sweden will be the best country in the world at using eHealth to make it easier for people to achieve good and equal health and to increase patients' participation [2]. Digital services currently delivered by Swedish health care include electronic health records, electronic prescriptions, and online communications with health care professionals (HCPs) [3]. To provide health-related Internet information (HRII) as a part of eHealth, the Swedish county councils and regions provide its citizens with a national website, 1177, that contains health-related information and advice that is quality assured by medical experts [4]. However, nearly 80% of the population choose Google and only 8% use the national website to search for information about medical conditions [5]. Google, or similar search engines, is also the primary choice, internationally, for people who search for HRII [6,7].

About 85% of the Swedish population use the Internet to various degrees to obtain health-related information [8] and studies show similar numbers in the rest of Europe and the United States [6,7]. Patients' reasons for their HRII searches include learning about a medical condition, deciding whether a health care visit is needed, preparing for a consultation, or validating information received during a health care consultation [9,10].

HRII has been described as accelerating a shift among patients, from passive recipients to active consumers of health information [11], and among patient-HCP relationships, from hierarchical to more reciprocal [12]. By equipping patients with knowledge about health, HRII may increase their involvement in care and ability to make informed decisions, which could increase person-centered interactions between patients and HCPs [11,13-15]. The World Health Organization and policy makers across the world have emphasized a need for health care to become more person-centered [16-18].

However, concerns have been raised about the general quality of HRII; several studies have shown significant variation in the accuracy and readability of HRII and only a minority of health-related websites has been assessed as offering high-quality information [19-21]. Concerns also include the fact that a disquieting proportion of European and US populations have limited health literacy skills [22,23], which means they are not likely able to accurately interpret and use relevant health information and resources to achieve their health goals [24]. The consequences of inaccurate HRII and patients' various abilities to evaluate that information include increased worries, inadequate self-care, postponements of clinical encounters, and tensions in the patient-HCP relationship [25,26]. The ability to manage health knowledge acquired from digital sources (ie, eHealth literacy) requires additional skills, including the appropriate use of digital tools [27].

Previous research on HCPs' views of Internet-informed patients has mainly focused on physicians, showing mostly positive or neutral attitudes [28,29] but some negative attitudes as well [25]. Previous studies exploring nurses' views of patients that bring up HRII in clinical encounters have used quantitative approaches and reported generally positive attitudes [30,31].

The dedication of HCPs seems a fundamental prerequisite to the success of policy makers' and health care providers' efforts toward eHealth. The attitudes of HCPs toward HRII and increased patient involvement are also central to person-centered care. However, there is a lack of research on nurses' views of their consultations with Internet-informed patients. Swedish primary health care nurses (PHNs), who most often work independently of general practitioners, usually represent the first contact for patients in need of care or health advice [32]. Central work tasks of Swedish PHNs include counseling patients over the telephone, guiding them to the right HCP or level in the health system, preventing illness, and treating patients in their catchment areas [33]. The aim of this study was, therefore, to explore PHNs' experiences of consulting with Internet-informed patients.

Methods

Study Design

A qualitative inductive approach was used. According to the Enhancing the QUAlity and Transparency Of health Research (EQUATOR) guidelines, the consolidated criteria for reporting qualitative research checklist for qualitative studies was followed during the study process [34].

Participants and Setting

A total of 9 PHNs working at three primary health care centers participated in the study. Two of the health care centers were in a midsized city in Northern Sweden and one was in a rural area in Northern Sweden. Head managers of the health care centers were asked to assist in recruiting participants, preferably varying in age and years of working experience, for an interview about eHealth. PHNs were informed in person or at staff meetings and 9 PHNs volunteered to participate. Inclusion criteria were being a registered nurse with a specialist graduate nursing diploma in primary health care nursing. The 9 participating PHNs ranged in age from 27 to 64 years (median 42) with work experience of 4-39 years (median 18) as registered nurses and 1-23 years (median 5) as PHNs.

Data Collection

Semistructured interviews were conducted by two of the authors (AES and AE) in 2016. An interview guide consisted of open-ended questions about the nurses' experiences of meeting patients who present HRII during consultations. Questions from the guide included "How do you, in your everyday work, perceive patients searching for HRII?"; "What problems do you perceive?"; "What benefits do you perceive?"; and "How do patients' presentations of HRII affect you in your everyday work?" With the interview guide as a skeleton, follow-up questions were asked and participants were encouraged to give several examples of their experiences. The recorded interviews, which were rich in data, lasted from 30 to 60 minutes (median 50) and were transcribed verbatim.

Data Analysis

The interviews were analyzed using qualitative content analysis as described by Graneheim and Lundman [35]. Initially, the data were read thoroughly to acquire a basic understanding of the content. Text that corresponded to the aim was divided into meaning units and condensed (ie, shortened, but with the core message kept). The condensed meaning units were interpreted and labeled with codes. All authors discussed the codes and, based on similarities and differences, three categories and nine subcategories were identified. The authors continuously discussed the coding and categorization until consensus was achieved, which strengthens the study's trustworthiness [36].

Ethical Considerations

The study was conducted according to the ethical principles described in the Helsinki declaration [37]. Participants were provided with information about the study, both verbally and in a written letter. Participation in the study was voluntary, and the participants were informed that they could withdraw at any time without stating any reason. Informed consent was obtained from both participants and managers of the primary health care centers. Data material and personal information have been handled confidentially. The Regional Ethical Review Board at Umeå University approved the study (approval number: 2014-179-31M).

Results

Overview

The PHNs unanimously described consultations with Internet-informed patients as common in their everyday work. Internet-informed patients were described to be of all ages, although mainly of working age. The analysis of the interviews resulted in three categories: (1) Facing the downsides of *Googling*, (2) Patients as main actors, and (3) Nurse role challenged. Each category consisted of three subcategories. The theme that emerged and encapsulated the essence of experiences related by the PHNs was *Internet-informed patients change the rules of the game* (see Table 1). Each subcategory in the following sections is illustrated with a quotation.

Table 1. Categories and subcategories of the theme, *Internet-informed patients change the rules of the game*, emergent in the analysis.

Category	Subcategories
Facing the downsides of *Googling*	Confusion due to contradictions; Disputes related to differing opinions; Unfounded anxiety among patients
Patients as main actors	Patients as lay experts; Self-care initiatives facilitated; Patients as equal partners
Nurse role challenged	Being considered unnecessary; Importance of keeping up-to-date; Coaching instead of controlling

Internet-Informed Patients Change the Rules of the Game

The overarching theme, *Internet-informed patients change the rules of the game*, summarizes the interpreted essence of the PHNs’ experiences of the considerable influence of HRII and knowledgeable patients on health care consultations. This influence was described to generate changes in patients’ behaviors, patterns of interaction during consultations, and the roles of patients and PHNs. The overall experiences and attitudes toward these changes were marked by ambivalence, although the problems were made very explicit.

Facing the Downsides of Googling

Overview

Inadequate and contradictive HRII, often as a result of patients’ free Googling for symptoms and illness, was described to frequently generate confusion, anxiety, and conflict. These downsides were described not only as unfavorable for patients, but also as challenging and time-consuming for the PHNs in their everyday work.

Confusion Due to Contradictions

The nurses reported that during consultations, patients often expressed confusion and uncertainty about what information to trust, due to the contradictory nature of information on different websites. Inaccurate HRII and search methods were emphasized as important factors in confusing the patients. Free Googling was highlighted as a significantly critical activity, since many patients were described as unable to distinguish reliable from unreliable HRII when sorting through search results.

> *People tend to over-seek for symptoms and illness on the Internet. They use Google and end up on the wrong websites. Because it is not like the most credible websites will be on top of the search results list. I wish they could go directly to 1177. They would then receive the correct information at once, without having to get so confused...*

Parents of toddlers stood out to the nurses as a group particularly inclined to becoming confused by HRII. This was ascribed mainly to their frequent visits to different parenting forums and groups, where the false belief flourished that parents’ experiences around their children were automatically transferable to other parents’ children. Inaccurate methods of obtaining and critically analyzing HRII were described as occasionally causing parents to reject important recommendations, such as the necessity of immunizations.

Disputes Related to Differing Opinions

The PHNs described patients’ presentations of HRII to be a frequent generator of conflicts. Such disagreements arose when patients presented HRII or interpretations of HRII that went against the PHNs’ knowledge or, from a professional point of view, were even completely false. In cases of differing opinions about, for example, diagnoses or desired treatments, patients with firm ideas were described as challenging, frustrating, and stressful. The nurses considered themselves obliged to respect the patient’s opinion but also to be clear about their view on the matter and to refer patients to reliable websites. The nurses emphasized that mutual and respectful dialogue was essential for patients to be satisfied with their care despite conflicting opinions.

A recurrent conflict of opinions occurred when the PHN advised self-care or a change of lifestyle as a primary treatment strategy to patients who preferred *quick-fix* options they had read about online.

> *When there are several steps to treat a disease, well, then they immediately wish to go to step three. Instead of trying the first two steps. When they have an eye infection, we can say, “Wash your eyes for a week and come back if it doesn’t get better.” Well, then*

> *they instead want you to prescribe antibiotics at once so they can go to work or send their kids to school...It seems tough to endure.*

Unfounded Anxiety Among Patients

Unfounded anxiety among patients was unanimously experienced as a common consequence of HRII. Due to online searches, many patients were reported to interpret minor symptoms as the "worst imaginable disease," not infrequently cancer. Searching indiscriminately for HRII was felt to be particularly destructive for people who already suffered from health anxiety, since it was regarded to increase anxiety considerably.

> *...or when they call about a headache. Well, then they imagine it is a brain tumour. Since they read on the Internet that for some people it started with a headache, well, then it has to be a brain tumour...*

A group described as particularly disposed to become anxious from obtaining HRII was parents of toddlers. Their anxiety was mainly ascribed to unreliable websites and forums where they read other parents' shared experiences of severe symptoms and diseases and interpreted their own child's banal symptom to signal a life-threatening disease. The PHNs described frequently being contacted by anxious patients and parents, who after obtaining HRII wanted to be reassured and to rule out dangerous conditions that could purportedly be causing their symptoms. Dealing with patients or parents who were anxious after obtaining HRII was often perceived as problematic, since these patients tended to seem obstinate, take up more time, and show more dissatisfaction with health care than other patients.

Patients as Main Actors

Overview

Knowledge acquisition through HRII was considered to enable patients to adopt a more active and confident role in their care. Benefits of such an active patient role included the patients' increased ability to manage self-care activities at home, which was considered to relieve the health care system. However, the PHNs also described the increased patient involvement as partly problematic, since many patients were perceived to adopt a lay expert role that they lacked the competence to manage.

Patients as Lay Experts

The PHNs described how easily accessible HRII made several patients seem to consider themselves medical experts. These patients were characterized by their use of advanced medical terminology and clear conceptions of diagnoses and treatment requirements. Patients who were perceived as self-declared experts and who had already formed their opinion prior to contact were reported to be generally less receptive than others to information given by the PHNs and more likely to question the competence and knowledge of the PHNs.

The perceived development of ever more *lay experts* was described as problematic, since many of these patients were considered to have difficulty properly interpreting the HRII they found. These problems were explained by a lack of medical experience among patients, an attribute that was considered important in making certain medical decisions.

> *Most often, patients start by saying what diagnosis they believe they have, instead of saying, "Hi! I would like counselling. I have these problems..." That almost never happens, but rather they [claim to] have a clear diagnosis.*

Self-Care Initiatives Facilitated

The PHNs stated that the Internet was a useful source of health information, but only if the HRII was obtained from reliable websites. Reliable websites were described as scientific or governmental sources providing evidence-based information. These reliable websites were considered to play an important role in giving patients advice on self-care activities. The Swedish national website, 1177, was highlighted as a particularly valuable resource, since it allowed patients to assess whether they needed professional help right away or if they could try self-care as the first step of treatment. Since advice on self-care is a central part of the PHNs' everyday work, they regarded reliable HRII from sources such as 1177 to facilitate their work and thereby reduce their workload.

All the nurses stated that they frequently referred patients to the 1177 website for advice on specific medical conditions and self-care. This website was considered to promote safe and equal care, as the self-care advice was based on evidence and not on a specific carer's personal experience.

> *The benefit [of HRII] is that patients sometimes can avoid seeking healthcare. That must be said to be the absolute benefit. That a lot can be handled at home.*

Patients as Equal Partners

Nurses with many years of experience in the profession reported that patients are more involved in their own care today than they were 15 or 20 years ago. The increased involvement was believed to be linked to, and supported by, patients' increased knowledge about health, which was ascribed to their use of the Internet.

The patients were generally described as well-prepared prior to meetings in person or over the telephone, which was considered favorable for both patients and PHNs, but only if patients had accessed accurate HRII. Well-prepared patients were considered better equipped to ask relevant questions and to contribute to more well-structured conversations. When patients were prepared with adequate information prior to a consultation, the nurses felt able to move quickly past basic information toward mutual reasoning about the patient's specific problem. The ability of patients to visit reliable websites to have a consultation to control the correctness of the information accessed was mentioned as a beneficial aspect of HRII. The development of more competent, involved, and well-prepared patients was considered to contribute to an approach in which the patient and the nurses were equal partners.

> *I also have the opinion that we must work together with the patients to find the diagnosis, as they are the experts on themselves and how they feel. And we are able to handle the part with...well, the function of the human body and diseases and stuff...And well...then we together can figure out what it can be about.*

Nurse Role Challenged

Overview

The PHNs described that increasingly active and knowledgeable patients, enabled by HRII, had brought a development in which their professional role was challenged and somewhat changed. Challenges of this role change included managing feelings of being marginalized and questioned, adapting to a more coaching role, and keeping updated with the latest evidence-based knowledge.

Being Considered Unnecessary

Consultations with patients who had a clear perception of a diagnosis and treatment from HRII often generated feelings in the PHNs of marginalization and being considered unnecessary. Many patients were perceived to want the consultation only to have their medicines prescribed or be referred to another HCP. In these situations, the nurses felt their advice was unwanted and that the patients considered a conversation needless. Thus, the traditional gatekeeper PHN role of assessing patients' symptoms and deciding on proper treatment or guidance was considered endangered and somewhat diminished.

> *It's like...they are focused on only one solution, there are no alternatives. "I must meet a doctor! Because I have this and this." And "I have tonsillitis, I'm sure!" Okay...And then you ask some questions and take a look at them. So...they are so sure they would rather not meet a nurse, because they just want medicine and to see a doctor.*

Keeping Updated Is Essential

The progress of easily accessible HRII and increasingly knowledgeable patients was described to place higher demands on the professional skills of the nurses. Being well-prepared with the latest evidence-based facts and ensuring patients were provided with correct information were considered crucial to conducting credible consultations. Higher knowledge demands were considered beneficial to the quality of the PHNs' professional role as well as for health care in general. The nurses highlighted the importance of continually visiting and keeping updated on the information on the websites that they recommended to their patients to visit for patient facts and self-care advice.

Patients were described to frequently present HRII on topics that the nurses had less knowledge about. These situations were stressful, since lacking certain knowledge was associated with feeling unprofessional. However, the nurses emphasized that being credible included being able to admit a lack of knowledge about a specific topic.

> *The patients having more knowledge requires more of me as a nurse. I often have to motivate and argue [with them] for them to buy what I say. Before, it was more like I could say, "this is the way it is," and they immediately bought it.*

Coaching Instead of Controlling

The shift in role from compliant and passive patient to more expert and active participants in care was described as having necessitated a complementary change in the role and approach of the PHN. With the massive supply of HRII, it was felt necessary for PHNs to accept reduced control over their patients. A cooperative approach, in which patients are considered the experts on their own well-being and the HCPs contribute the medical perspective, was considered optimal, although challenging. Coaching skills and respectful communications were highlighted as important in helping patients to obtain reliable information from the Internet and thereby take an active role in their own care.

Supporting patients who had become anxious or confused from searching for HRII was also described as a central and important part of the everyday work of PHNs. The significance of making a reliable impression and promoting positive consultations with such patients was emphasized. Strategies used by the PHNs in these situations included calming, supporting, arguing, normalizing, informing, and dedramatizing. Supporting patients in their evaluation of HRII, which could mean either confirming or denying the veracity of the information and guiding patients to credible websites, was considered to be a main function of PHNs in the current digital era.

> *One has to be very clear and informative. It is about supporting, calming, arguing...I have to argue and motivate them to understand, "you don't have to worry, I do not suspect any serious disease." I have to normalise [their situation].*

Discussion

Principal Findings

The PHNs in our study thought that Internet-informed patients had changed the usual rules of health care. These changes were seen in patient attributes, patterns of interaction during consultations, and the roles of patients and PHNs. The benefits of HRII were described, but its negative consequences and difficulties were emphasized overall. Our results, therefore, show more negative attitudes among nurses to the phenomenon of Internet-informed patients than previous research with the same focus [30,31].This is in line with a study by Öberg et al, who found ambivalent perceptions among PHNs of the digitalization of health care [38].

The PHNs in our study distinguished clearly between different qualities of HRII, considering reliable HRII favorable and unreliable HRII unfavorable. Previous studies have shown that the accuracy and quality of patient-presented HRII is relevant to HCPs' attitudes [28,30]. Like HCPs in previous studies [12,29], the PHNs in our study considered evidence-based HRII beneficial for its contribution to well-prepared patients and, therefore, more structured and fruitful consultations.

One finding in our study was that having HRII, patients challenged the nurse's role. HRII has been described as transforming patients from passive recipients to active consumers of health information [11] and the patient-HCP relationship to more of a partnership [12,29]. This transformation is in line with the efforts of policy makers and health care systems toward increasingly person-centered care [17]. The PHNs in our study were unanimously positive toward increased patient involvement and the person-centered approach, although there seemed to be a fine line between patients being moderately involved and being overly involved. Humble expressions of involvement were described as favorable for both patients and health care systems; however, expressions of *lay expertise* and overinvolvement coupled with a lack of medical competence were perceived as problematic. Disagreements arising from patients' presentations of false or inaccurately interpreted HRII were highlighted as challenging by the PHNs of this study, as similarly described in previous research [29,39,40]. The PHNs in our study emphasized the importance of supporting positive encounters by showing respect for patients' opinions. This approach is in line with previous research, which suggests the importance both of acknowledging patients' efforts to acquire knowledge and of clearly explaining the reason for divergent opinions in order to give patients a positive experience and increase the chances of patients accepting the HCPs' advice [41,42].

The Internet has been described as a catalyst for shifting power in HCP-patient interactions, which can be regarded as a threat toward HCPs' medical authority [11,43]. HCPs' negative feelings about conferring with patients equipped with HRII knowledge, previously reserved for HCPs, have been attributed to perceptions of being undervalued, perceived as incompetent, or losing control of the consultation [44]. Similarly, the PHNs in our study described the lay expert role of Internet-informed patients as challenging, as it caused them to feel that their professional knowledge was being questioned, which was especially stressful when they lacked full knowledge of a specific topic. This confirms a study by Öberg et al, in which PHNs also described negative feelings about being questioned and feeling insecure when meeting well-informed patients [38]. The PHNs in our study emphasized the importance of admitting when they lacked knowledge, an attribute of HCPs that Internet-informed patients value and consider to strengthen the patient-HCP relationship [12]. HCPs who act in patriarchal ways and are unwilling to admit a lack of knowledge, on the other hand, have been shown to negatively affect patient experiences [41].

The PHNs in our study were also concerned about HRII as a potential source of negative effects on patients. Free Googling, a well-documented and dominant first strategy for patients who search for HRII [26,45,46], was emphasized as a common generator of confusion and anxiety among patients. Symptom inquiries in search engines like Google often return high rates of statistically unlikely results (eg, a headache signaling a brain tumor) [47], according to the nurses in our study, and caused notable unfounded patient anxiety. Increased anxiety after searching for HRII, especially in health-anxious people, has been reported in several studies as *cyberchondria* [48-50]. HCPs have been advised to either counsel health-anxious patients to avoid HRII [48,51] or to actively guide them to credible websites [47,52]. The PHNs' perception that parents of toddlers are high consumers of HRII, particularly inclined to insecurity and anxiety, is in line with a study by van der Gugten et al [53]. The PHNs' concerns about the negative effects of HRII searches on patients are confirmed by research and appear legitimate.

The PHNs suggested equality in care as a benefit of reliable HRII, as it offers everyone access to the same information. However, considering the PHNs' experiences of patients having problems with HRII and other research that shows low levels of health literacy [22,23], it is probably pertinent to ask how to achieve equitable care. In consultations with Internet-informed patients, promoting equitable care would mean enabling patients with varying predispositions to partake in the general information supply. The PHNs' described shift in roles and tasks, moving from controlling to coaching increasingly knowledgeable patients, seems to be a step in this direction. Dickerson et al also described how the Internet had changed nurses from educators to knowledge consultants [54]. Previous research has suggested different approaches for coaching patients' HRII use. Since misconceptions easily arise from inaccurate HRII and poor levels of eHealth literacy, previous studies have emphasized the importance of HCPs in facilitating and encouraging open discussions about HRII [26,39,55]. Active assessment of patients' use of HRII has been recommended as valuable [13]. Guiding patients to credible websites is also important to ensure that they obtain reliable information and to minimize confusion, anxiety, or poor health decisions based on contradictory information or misunderstood medical jargon [11,31,45]. Research into patients' views has shown a desire for such navigational help from HCPs [26,56,57]. Since HRII is broad and general, HCPs could play an important role in contextualizing the HRII to the patient's personal situation [26,53]. It has been suggested that nurses occasionally visit the most popular parenting forums for updates on current health questions, since parents often leave these sites confused by conflicting information [58]. It is also important for HCPs to be aware that even though most patients obtain and are influenced by HRII, far from all of them mention this information to their HCP. Such reluctance may be due to fear of being perceived as challenging, previous bad experiences of presenting HRII, fear of embarrassment, or the perception that the HRII is not important enough [28,39]. Patients with navigational needs have been shown to be less likely to discuss their Internet findings [59], a fact that supports the importance of HCPs actively encouraging discussions about HRII.

Strengths and Limitations

This study offers both strengths and limitations. The participating PHNs were varied in age and years of professional experience, which strengthens the trustworthiness and transferability of our results [36]. All the participating PHNs were women, which could be considered a limitation. However, most Swedish PHNs are women [60], which should make the results transferable in this context. There is a possibility that PHNs with stronger views on the subject of eHealth were more likely to volunteer for the study, which could represent a bias.

Because they are in accord with previous research, some aspects of our results are also considered transferable to other health care professions. The interviews offered rich data, and saturation was considered reached by the last interviews.

Because four of the study authors are PHNs, like the participants, reflexivity was considered throughout the research process. Familiarity with the attributes of participants can contribute to a better in-depth understanding of the participants' experiences, but we were alert to avoiding our own projections during the process. In order to consider different perspectives, continuous discussions were held within the research group [61]. All authors were involved in the analytical process, which is considered to strengthen the trustworthiness of the study.

Implications for Future Research and Practice

PHNs and other HCPs are encouraged to actively raise discussions about patients' perceptions of HRII, help patients to evaluate and contextualize their Internet findings, and guide patients to credible and evidence-based websites.

This study implies that the phenomenon of Internet-informed patients affects the everyday work and professional role of PHNs. Further research is needed to make a profound analysis of the mechanisms behind ambivalent attitudes, for example, regarding concepts like *power* and *professional identity*, and how attitudes are linked to perceptions of patients' eHealth literacy levels. Future studies will also explore PHNs' Internet use and eHealth literacy and how these factors affect attitudes toward Internet-informed patients.

Conclusions

This study suggests that PHNs are ambivalent about working with Internet-informed patients. While they expressed fundamentally positive attitudes toward increased patient involvement and patient-centered interactions, these attitudes were somewhat overshadowed by reported negative perceptions of the effects and consequences of HRII. Accurate and correctly managed HRII has been shown to offer many possible advantages for patients and health care systems. However, the negative attitudes and apprehensions of HCPs about Internet-informed patients could obstruct the development of increased patient involvement. To promote equitable care in the digital era, increased awareness in health care about useful strategies for overcoming difficulties and embracing benefits of HRII seems to be a legitimate goal.

Acknowledgments

The authors would like to thank the Swedish Diabetes Association and Strategic Research Area Health Care Science (SFO-V) for providing funding for this study. The authors would also like to thank the participating PHNs who shared their experiences.

Authors' Contributions

ÅH, AE, and AES were responsible for the study concept, study design, and recruitment of subjects. AES, AE, ÅH, SH, and UI analyzed the data and prepared the manuscript. All authors critically revised, contributed comments on, and approved the final version of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

EQUATOR: Enhancing the QUAlity and Transparency of Health Research
HCP: health care professional
HRII: health-related Internet information
ICT: information and communications technology
PHN: primary health care nurse
SFO-V: Strategic Research Area Health Care Science

Edited by E Borycki; submitted 29.03.19; peer-reviewed by A Willis, E Neter, F Webster; comments to author 15.05.19; revised version received 21.05.19; accepted 19.06.19; published 30.07.19.

Please cite as:
Sjöström AE, Hörnsten Å, Hajdarevic S, Emmoth A, Isaksson U
Primary Health Care Nurses' Experiences of Consultations With Internet-Informed Patients: Qualitative Study
JMIR Nursing 2019;2(1):e14194
URL: https://nursing.jmir.org/2019/1/e14194/
doi:10.2196/14194
PMID:34345770

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
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Email: support@jmir.org