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Perceptions of Rural Emergency Department Providers regarding Telehealth-Based Care: Perceived Competency, Satisfaction with Care and Tele-ED Patient Disposition

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Abstract

Introduction: This study assesses rural providers' perceptions of their ability to deliver high quality care via telehealth compared to usual care, and whether attending providers perceive that emergency department (ED) telehealth visits influence clinical reasoning in regard to patient disposition, specifically in tele-behavioral and tele-neurological cases. **Methods:** A cross-sectional survey was conducted of 134 ED providers (nurses [$n = 126$] and physicians [$n = 8$]) who were working in five Midwestern critical access hospitals (response rate 83%). Descriptive, correlational and stepwise regression analyses were employed to evaluate provider perceptions of 1) competency level in telehealth delivery, 2) patient health outcomes, 3) access to continuing education in telehealth, and 4) clinical influence of telehealth visit. Evaluation of preliminary set of $N = 100$ telehealth cases were assessed for influence of telehealth on clinical reasoning of attending physicians regarding patient disposition. **Results:** The majority (67%; $n = 90$) of participants had at least minimal experience with telehealth care delivery, with an average of 1 - 2 visits in teleneurology, and 3 - 4 visits in telebehavioral cases. Providers rated their overall mean competency level in telehealth care delivery as 3.01/5.00 based on a 5 point "novice (1) to expert" (5) scale. Mean scores for providers perceived competency level in 7 evidence-based sub-categories for telehealth care delivery were self-reported as relatively low to mid-range values, ranging from 2.64 - 3.57/5.00. Stepwise linear regression analysis of whether all providers "would recommend telehealth to their family and friends" revealed two predictors for model of best fit ($n = 81$; $p < 0.000$; $R^2 = 0.598$): 1) their percep-

tions of telehealth experience compared to usual care; and 2) perceptions of patient health outcomes with telehealth compared to usual care. Providers rated “neutral” to “very unlikely” that they “would recommend telehealth to family and friends” (2.75/5.00; $n = 122$; 91%). Attending physicians reported that for a majority of cases, telehealth visits influenced patient disposition and transfer decision-making (58.4%), and the influence of telehealth visits on patient disposition was statistically significantly higher for behavioral health cases ($p < 0.018$). **Discussion:** This study will be followed on to inform administrators/policy makers about 1) perceived level of competency of providers who implement tele-emergency care, 2) potential importance of telehealth equipment used and teamwork between rural providers and distant specialist, and 3) how use of telehealth may enhance ability of rural ED providers to improve quality of care. Perceived influence of telehealth on patient disposition is reported to be highest for telebehavioral patients. Healthcare educators need to place a priority on addressing provider competencies in telehealth through health professions degree programs and continuing education. Further research is needed to promote application and testing of evidence-based provider competencies in telehealth, and potentially relevant health communication models, to increase providers’ perceived efficacy and competency in telehealth care delivery, thus supporting high quality patient health outcomes.

Keywords

Telehealth, Telemedicine, Rural Emergency Department, Critical Access Hospital, Provider Competency, Attending Physician, Patient Disposition, Telebehavioral, Teleneurological

1. Introduction

The use and applications of telehealth services have expanded over the past twenty years, along with the role of technology in improving access to, and delivering healthcare. Telehealth has improved a healthcare organization’s capacity to increase access to specialty care, reduce or eliminate patient’s travel time to tertiary facilities, and improve quality of care through targeted provider support. [1] The traditional model of telehealth is of primary consideration for the current study, and involved care delivered “virtually” via a secure, online internet-based audio/video connection to emergency department patients at a series of originating sites, from appropriately licensed specialists working at distant sites.

Public and private payers currently reimburse providers for certain services delivered through telehealth, and the shift from a fee-for-service system to accountable quality of care systems in the United States has the potential to increase utilization of telehealth. [1] In the U.S., reimbursement programs discouraging hospital readmissions and high numbers of preventable emergency department (ED) visits are examples of how shifting incentives away from providing a high volume of services can encourage use of telehealth to improve patient

outcomes, while potentially reducing costs. [1] Although telehealth services utilization has grown, there remains a need for robust, replicable telehealth studies in rural and/or medically underserved areas that can inform provider preparation and care delivery, especially as the emphasis on quality of care and cost effectiveness continues to increase [1] [2].

1.1. Current Applications of Telehealth: Emergency Departments

Ekeland and colleagues [2] recently concluded that telemedicine (telehealth) has been demonstrated to be effective in behavioral health counseling and management of chronic diseases. However, there is a need for more evidence regarding the effectiveness of telehealth to support delivery of emergent care in behavioral health (e.g., suicide attempt, overdose), neurology (e.g., stroke, seizure), and trauma (injury) care in rural emergency departments (EDs). [2] A recent analysis of telehealth applications in the U.S. showed that 32% of the 4727 reporting hospitals are using at least one type of telehealth service, and services are currently being utilized in approximately 8% of emergency departments. [3] While utilization of telehealth is on the rise, a systematic review of telemedicine studies revealed that “high-quality evidence to inform policy decisions on how best to use [telehealth/telemedicine] in health care is still lacking”. [2] In addition, although most hospitals participating in telehealth-based programs are in rural settings, [4] [5] many studies reporting on telehealth-based programs often focus on larger urban healthcare systems due to larger patient volumes, and thus, enhanced capacities for statistical analysis [5].

One recent U.S. rural hospital survey wherein 63,193 ED cases were examined for frequency counts revealed that the most common diagnoses treated using telehealth were mental health, trauma, circulatory issues and presentation of complex signs or symptoms ($n = 1512$ telehealth cases). [6] This descriptive assessment involved 21 rural critical access hospitals, and also highlighted thematic interview data that a sample of rural providers ($n = 85$) believed that telehealth helped support rapid patient transfers. [6] No quantitative analysis was included regarding patient disposition decision-making, perceptions of telehealth-based outcomes compared to usual care, nor perceptions of provider-level competencies in telehealth care delivery in the clinical setting.

1.2. Telehealth and Provider Perceptions of Competency of Care

While tele-emergent care has been identified as an ideal use of telehealth for rapid consultation with care specialists, there is a need for more in-depth evaluation of the major implications regarding implementation and outcomes of the utilization of tele-emergency care. [6] Medicare has also suggested tele-emergency care as ideal for quick consultation with rural sites; [5] however, provider perceptions of their competency level in regard to their continuing education needs in telehealth, and the potential influence of the telehealth visit on different types of patient cases, have not been thoroughly investigated, including perceptions of the ability to deliver high quality care via telehealth

compared to usual care [1] [2] [3].

1.3. Purpose of the Study

The purpose of this study was to inform rural emergency care providers, administrators and policy makers about the perceived competency level of providers who implement emergency care via telehealth for behavioral health and neurological patients, as well as the attending providers' perceptions of the influence of the telehealth visit on clinical reasoning in relation to patient disposition and patient health outcomes. As part of a multi-phase, longitudinal study, these efforts should allow healthcare leaders and policy makers to begin to more strategically support evidence-based national and regional policies and procedures in healthcare provider telehealth education and practice that may positively influence the ability of rural providers to improve the quality and efficiency of care that patients receive in U.S. critical access hospitals (CAHs).

2. Methods

This cross-sectional study examined perceptions of educational preparation in telehealth and telehealth care delivery for ED providers working in five Midwest U.S. CAH EDs during October-December, 2015, to determine baseline perceptions of: 1) Competency level in utilization of telehealth applications; 2) educational preparation and access to continuing education in telehealth; 3) number of clinical experiences with telehealth; 4) patient health outcomes compared to usual care; 5) the telehealth visit's influence on the attending provider (physician) in regard to their clinical decision-making related to patient disposition for the two primary types of cases (telebehavioral and teleneurological); 6) and request for healthcare provider comments to help reveal additional information surrounding the overall context for the optimal delivery of telehealth-based care. Ethical institutional review board approval for the study was obtained prior to the onset of study.

2.1. Study Participants

Emergency department provider role characteristics are presented in **Figure 1** for those participating in the study in five Midwestern CAH EDs. All providers were engaged in the majority of their work time in the rural EDs, and were comprised of nurses ($n = 109$), physicians ($n = 8$) and other ancillary ED providers, such as respiratory therapy and nursing assistants. Participants were 84% female ($n = 112$) and 16% male ($n = 22$). Participation in the study was voluntary, and all interested ED personnel completed an informational webinar describing the purpose of the study, and those volunteering to participate provided written informed consent prior to the launch of study activities.

2.2. Equipment

A traditional model of telehealth care delivery was utilized for the current study, and involved care delivered "virtually" via secure, online internet-based Tandberg/

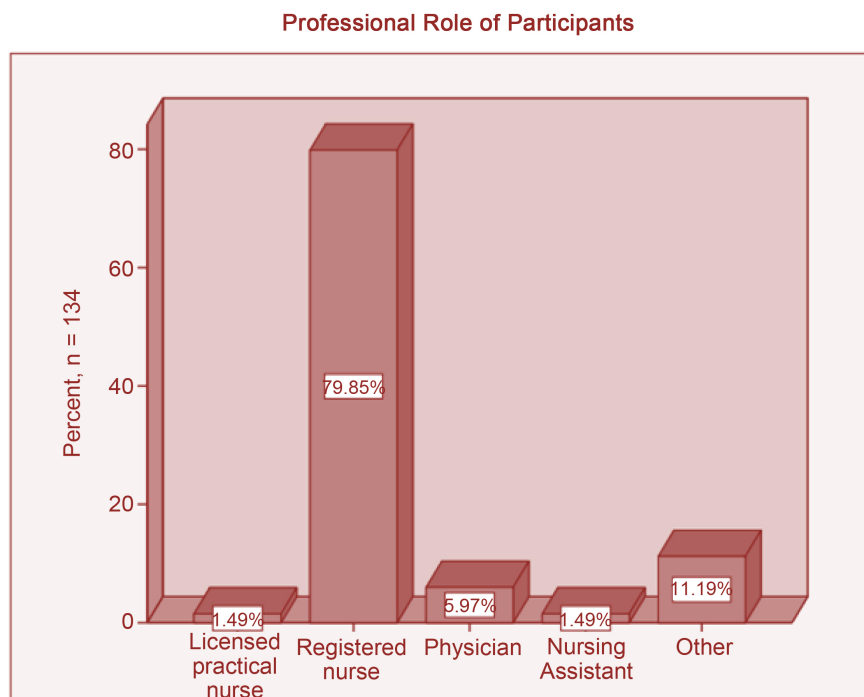


Figure 1. Professional role distribution of participants.

Cisco videoconferencing infrastructure, sometimes called “computers on wheels” (COWs), with bandwidth ranging from 364 Kbs-720 Kb/s utilizing point-to-point fiber optic connections and Ethernet service to connect the patient and health care team at each rural hospital’s originating site to an appropriately licensed specialist working at a distant site. Rather than a “store and forward” approach to telehealth care delivery, all participating rural hospitals utilized “live video interaction” in “real time” to activate a telehealth visit with the desired specialist for the patient, as determined by the attending provider (rural ED physician).

2.3. Provider Survey

A 30-item, 5-point Likert-type password-protected online survey, the “Inventory for Tele-Emergent Care (ITEC)” [7], which had been refined by the authors in a series of CAH pilot studies during 2012-2014, was implemented during Fall, 2015, to evaluate rural ED provider perceptions of: 1) competency level in telebehavioral and teleneurological applications (5 point scale, “novice” to “expert” in 7 sub-categories); 2) presence of telehealth education in their health professions degree program (5 point scale, “strongly agree” to “strongly disagree”; 3) access to continuing education in telehealth from one or more sources (5 point scale, “strongly agree” to “strongly disagree”); 4) degree of clinical experience with the 2 different telehealth care categories (5 point scale, “0 visits” to “12+ visits” performed); and 5) patient health outcomes utilizing telehealth were comparable to usual care (5 point scale, “strongly agree” to “strongly disagree”). Internal consistency reliability was 0.93 for the ITEC survey instrument.

Attending physicians were also asked to rate the following probability statements on a 5-point Likert-type scale for each of the initial telehealth patient cases ($n = 100$) treated during the first 6 months of the study: 1) Prior to the telehealth visit, their intention was to transfer the patient; and 2) How much the telehealth visit influenced their clinical decision-making in relation to patient disposition. An open-ended question asking participants if there was any additional information they wanted to share was also included at the end of the provider survey.

Of a total of 162 providers polled who completed written informed consent to voluntarily participate in the survey and the telehealth case evaluations, 144 accessed and 134 completed survey, including registered nurses ($n = 107$), physicians ($n = 8$) and other ED providers ($n = 19$) engaged in telehealth delivery, demonstrating a response rate of 83%. With a 4% margin of error, the 134 valid samples reflects statistical power greater than 90%.

2.4. Data Analysis

The Statistical Package for the Social Sciences (SPSS) version 22.0 was utilized to evaluate for differences, similarities and statistically significant relationships between and among the study variables. Interrelationships explored included the ED provider's educational preparation in telehealth care delivery and access to continuing education in telehealth, perceptions of telehealth-based care compared to usual care, and the potential influence of the telehealth visit on the attending provider's decision-making based on type of case being treated in the ED. Null hypotheses were stated for all variable relationships before analyses were conducted, with statistical significance set at $p < 0.05$. Any additional information or comments that participants shared at the end of the quantitative survey were also analyzed for content and major themes, to help provide context for the quantitative survey results.

3. Results

3.1. Educational Preparation

A majority of participants had not participated in continuing education (CE) in telehealth during the past year ($n = 81$; 62.3%), nor was their educational preparation likely to have included telehealth practice experiences ($n = 88$; 69.3%). Providers' reported that their comfort level with telehealth care delivery was associated with engagement in continuing education (CE) ($p < 0.004$). Overall, providers' self-reported experience with telehealth care delivery varied widely, and ranged from 0 visits performed to more than 12 visits performed based on survey results.

3.2. Provider Perceptions of Telehealth Care Delivery

The majority (67%; $n = 90$) of participants had at least minimal experience with telehealth care delivery, with an average of 1 - 2 visits in teleneurology, and 3 - 4 visits in telebehavioral cases. Providers rated their overall mean competency lev-

el in telehealth care delivery as 3.01/5.00 based on a 5 point “novice (1) to expert” (5) scale. In addition, mean scores for providers perceived competency level in 7 evidence-based sub-categories [1] [2] for telehealth care delivery, including communications (patient-provider and provider-provider), understanding use of the equipment/technology, critical thinking skills needed, clinical judgment skills needed, quality of care delivery, and privacy/confidentiality, were self-reported as relatively low to mid-range values, ranging from 2.64 - 3.57/5.00 (Table 1).

In regard to the potential predictors for providers’ perceived tendency to recommend telehealth-based care, stepwise regression analysis revealed the following: For telebehavioral patients, ED providers’ perceptions of 1) their level of

Table 1. Summary of providers’ perceived competency for telehealth care delivery.

Items	Provider Competencies	Likert Scale Items (% Respondents)					Statistics		
		1	2	3	4	5	Mean	α (t test 1)*	α (t test 2)**
1	Communication skills with patient during the telehealth visit	22.1	11.5	39.7	22.1	4.6	2.76 ± 1.16	0.003*	0.000**
2	Communication skills with other provider(s) during the telehealth visit	20.6	12.2	37.4	25.2	4.6	2.81 ± 1.16	0.016*	0.000**
3	Understanding any limitations of the equipment/technology in order to make a sound care decision	22.9	16.8	38.2	17.6	4.6	2.64 ± 1.15	0.001*	0.000**
4	Critical thinking skills	6.9	4.6	38.2	38.2	12.2	3.44 ± 1.00	0.008*	0.010**
5	Clinical judgment regarding decisions about when a patient may require an in-person evaluation	6.9	4.6	44.6	36.9	6.9	3.32 ± 0.93	0.015*	0.002**
6	Adhering to the same quality of care standards as for an in-person visit	5.3	5.3	48.9	34.4	6.1	3.31 ± 0.88	0.127	0.007**
7	Adhering to the same standards of patient privacy and confidentiality	4.6	4.6	38.5	33.8	18.5	3.57 ± 1.00	0.418	0.123

*t test 1: Significant difference between providers answering “Yes” for Q: “Did your educational preparation address competencies for quality of telehealth care delivery in any of your degree programs?” and providers answering “No”. Statistical significance level is 0.05. **t test 2: Significant difference between providers answering “Yes” for Q: “Have you had any continuing education to address competencies for quality of telehealth care delivery in any facilities where you have worked?” and providers answering “No”. Statistical significance level is 0.05.

experience in telehealth care delivery, and 2) patient health outcomes compared to usual care, were statistically significant predictors for the statement “would recommend telehealth to family and friends” ($n = 81$; $p < 0.001$; $R^2 = 0.598$). For teleneurological patients, ED providers’ level of experience in telehealth care delivery experiences was the only predictor ($n = 39$; $p < 0.001$; $R^2 = 0.642$) for the statement “would recommend telehealth to family and friends”. Overall, from a descriptive standpoint, providers rated “neutral” to “very unlikely” that they “would recommend telehealth to family and friends” ($\mu = 2.75/5.00$; $n = 122$; 91%).

In additional stepwise regression analysis for care of telebehavioral patients, ED providers’ perceptions of their 1) competency level in telehealth and 2) following the evidence-based protocol for the telehealth visit, were significant predictors for “overall comfort level with telehealth care delivery” ($n = 81$; $p < 0.001$; $R^2 = 0.598$). For teleneurological patients, ED providers’ perceptions of their level of experience in telehealth care delivery was a statistically significant predictor ($n = 39$; $p < 0.001$; $R^2 = 0.642$) for their “overall comfort level with telehealth care delivery”.

3.3. Influence of Telehealth Visit: Attending Provider Decision-Making

Attending physicians were also asked to rate the probability that the telehealth visit influenced their clinical decision-making in relation to patient disposition for this initial phase of the study ($N = 100$ patient cases; $n = 61$ telebehavioral, $n = 39$ teleneurological). Attending physicians reported that for these cases, a majority of the telehealth visits influenced patient disposition and transfer decision-making (58%; $n = 58$). In addition, it is important to note that the reported influence of telehealth visits on patient disposition was statistically significantly higher for behavioral health cases ($p < 0.018$). The most common diagnoses for which a telehealth visit was activated by the rural ED attending provider were 1) Behavioral health diagnoses: overdose, either accidental or intentional; suicidal ideation or suicide attempt; substance abuse; depression; anxiety; and 2) Neurological diagnoses: stroke (CVA) and transient ischemic attack (TIA).

3.4. Contextual Comments by Participating Providers

A content analysis of the free-form comments provided by the participating providers at the end of the survey was performed to determine major themes surrounding providers’ perceptions of telehealth-based care. Three major themes were revealed by the providers, which supplied important context for future modifications of the mode of telehealth care delivery for this longitudinal study. Example narratives supporting the themes are provided below.

3.4.1. Technical/Equipment Issues

Several of the healthcare provider participants complained about the cumbersome nature of, and the time and effort involved in, utilizing and manipulating all the technical features needed on the “COWs” to deliver the telehealth visits.

In addition, numerous audio and/or video internet connection issues were described, to such an extent that providers would become discouraged at times and were reluctant to actually attempt to utilize and conduct a telehealth-based visit, because they felt it sometimes negatively impacted patient care. One nurse expressed the following frustrations: “It needs to work well. You can not [sic] expect to meet pt needs using telemedicine if it doesn’t work right most of the time. Telebehavioral works best but teleneurology rarely works and unlike telehealth I think neurology consults should be done in person.” Another provider shared that “Telebehavior needs to be quicker-after we fax our information there is still a wait time of several hours for the pt-many pt’s [sic] make comments about not being important enough or get angry enough they demand to leave-this opens up all kinds of problems-having to call security or the police etc. The end result is that the pt [sic] is feeling worse than when they came in. And admission could have happened hours before.”

3.4.2. Lack of Responsiveness/Collegiality: Distant site Specialist(s)

Several providers also reported that specialists may not initially respond to phone calls when a telehealth visit was initiated, and that when the specialist did finally call in, 30 minutes were typically required for a call-back to deliver the care, especially if the visit was requested during the night shift. Moreover, when some of the specialists called in, the providers perceived that the specialist was annoyed and/or was not behaving in a collegial manner with the distant rural team, especially when they had questions and/or requested more information from the specialist on call. Some providers stated that, “it’s a lack of availability of teleneuro, long delays in response or sometimes no response at all”, and “it’s the timeliness of consults. Sometimes it takes a while for a consult to begin, they do not respond very quickly. When we have technical issues, this does not set well and they [specialists] get upset”.

3.4.3. Need for Continuing Education/Technical Education

Several providers also asked for and/or expressed a need for continuing education in regard to implementation of telehealth-based visits in regard to best practices, and also in regard to being able to use the equipment and the various features available on the “COWs” telemedicine cart. A physician and a nurse commented, respectively, “We need sufficient education for staff to increase comfort level for usage and advantages of tele-health”, and “Too much time is spent trying to identify and troubleshoot problems with the equipment which can be detrimental to the patient.”

4. Discussion

In this study, a majority of ED providers self-reported an average to low level of comfort with telehealth care delivery, and the majority are unlikely to recommend telehealth to family and friends. However, based on the contextual comments by several providers, ED healthcare staff may be more likely to recommend and successfully implement telehealth-based care with equipment that is

easier to utilize, with improved and upgraded audio/video connectivity capabilities, and/or when self-reported need for continuing education is provided to support best practices in technical applications of the equipment, and, ultimately, evidence-based implementation of telehealth care delivery.

4.1. Equipment and Technical Difficulties

While participants in one large project in tele-emergent care implementation reported few technical issues in telehealth-based care delivery, [8] the author reported surveying only hospital administrators rather than the ED staff who are responsible for actually using telehealth equipment and implementing visits (end-users). A more recent study revealed that technical difficulties in telehealth care delivery can result from inadequate bandwidth for the internet connection, [9] thus underscoring the potential need to bolster this aspect of the rural hospital-based and community-based infrastructures supporting the technology when implementing a telehealth program.

While Ward and colleagues [10] recently reported positive findings for a systematic review of telehealth studies relating to technical quality and end-user satisfaction, some U.S. rural hospitals may not have the financial resources to keep up with technological improvements in equipment and/or internet platforms currently available for seamless implementation of telehealth care delivery. Based on these initial outcomes and provider concerns in relation to technical issues for delivery of telehealth-based care in the participating rural hospitals, alternatives to the current COW set-ups, and current internet platform capabilities that are being utilized in the rural hospital EDs, will be considered by the Midwest rural telehealth network and research team.

4.2. Continuing Education for Healthcare Providers

With the advent of technologically-driven healthcare, continuing education in telehealth care delivery methodologies and equipment for providers is not only practical, it is a professional imperative. [8] [9] [11] Duchesne and colleagues [9] described a significant learning curve in regard to the utilization of telehealth-based equipment, and observed that in addition, the all-too-familiar calls for excellence in teamwork and communication between rural providers and the distant site specialist were essential to the success of their rural telemedicine program in the U.S. state of Mississippi.

Henry and colleagues [11] recently systematically evaluated a set of 45 studies worldwide relating to healthcare provider behaviors, perceptions and concerns in regard to telehealth care delivery from a qualitative perspective. While the authors believed they could not yet present a set of best practices for clinician behaviors in regard to telehealth care delivery, they emphasized the following emerging themes as important considerations to improving provider education, as well as the quality of care, to support optimal utilization of telehealth, including: "Perceptions of the utility of telehealth; differences in communication patterns such as pace and type of discourse; reliance on visual cues by both provider

and patient especially in communicating empathy and building rapport; and confidentiality and privacy in telehealth care delivery” [11].

While an emphasis seems to have been placed on continuing education for telehealth team end-users to promote excellence in telehealth care delivery, further research is needed to determine an evidence-based set of best practices to support healthcare professionals’ initial exposure to, and continuing education in, the implementation of telehealth-based care. Moreover, some experts suggest that beyond technical training and education to promote development of best practices, and to maximize the impact of end-user uptake of telehealth, digitized modes of care such as telehealth must actually be integrated into the culture of an organization [12].

The study team therefore recommends the consideration and testing of different health behavior communication models with telehealth provider teams in particular. Further research in this realm would help providers move beyond simply implementing basic algorithms of care in telehealth for various health conditions, to testing relevant health behavior communication models to promote high quality, virtual telehealth-based care for patients and families. This approach should help inter professional healthcare teams collectively implement and evaluate an evidence-based communications model as a best practice in telehealth for providers and distant site specialists, promoting excellence in patient health outcomes, as well as in professional telehealth practice in a variety of healthcare settings. As Wade and colleagues’ [13] recent qualitative study reminds us, “clinician acceptance” is key to fostering sustainability in telehealth care delivery.

4.3. Limitations of the Study

This study was limited to participation of a majority of ED providers in five U.S. critical access hospitals, and as such the results are not necessarily generalizable to ED providers working in all U.S. critical access hospitals. Further study is needed to help discern the important educational needs of rural and urban providers who deliver patient care via telehealth. In addition, the ITEC survey tool is available from the researchers and needs further testing to bolster support for its validity and reliability in regard to the 7 sub-categories of factors tentatively proposed to influence provider perceptions of telehealth care delivery. However, the authors believe that these initial results may help lay the foundation for future research in regard to development of tools that are useful in telehealth program evaluation in regard to providers’ educational needs, as well as provider perceptions of different types of telehealth care delivery compared to usual (face-to-face) care.

4.4. Conclusion

Continuing education in telehealth is an educational imperative, with the current emphasis on health information technologies to enhance efforts to improve patient health outcomes in rural CAH EDs. While technical difficulties may be

addressed with improvements in telehealth platforms and equipment in future planning with rural CAHs, important work also lies ahead in regard to enhancing rural site-distant site teamwork in rural settings, promoting engagement in telehealth-based continuing education, and in testing and adopting health communication models for astute telehealth practice. Communication (verbal and nonverbal) is key to successful telehealth care delivery, as it underscores and drives cultural and behavioral health understanding in professional care delivery settings. Working on our collective communication from a practical standpoint represents an entrée into the organization's ability to achieve an optimal level of cultural integration of telehealth care delivery.

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Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Autonomic Nervous Activity in Multiparous Women during Early Postpartum Period: A Descriptive Study

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Abstract

Background: The purpose of the present study is to analyze the autonomic nervous activity in multiparas while resting, nursing, and rooming-in/rooming-out during days 1 to 3 of early postpartum period. **Methods:** Subjects were asked to record the actions they performed while wearing a heart rate monitor. Changes in autonomic nervous activity from 9 am to 12 pm and relaxation based on the relaxation (RE) scale were surveyed in multiparous women experiencing a normal postpartum period, on postpartum days 1 to 3. **Results:** Thirteen subjects were enrolled but heart rate data for all 3 days were available for only 5 of them. In these patients, the autonomic nervous activity (heart rate, high frequency [HF], or low frequency [LF]/HF) showed no significant differences between the days during any of the time periods. However, of the 3 days, day 2 demonstrated a lower HF and higher LF/HF. Subjective sense of relaxation was higher on postpartum day 3 compared to days 1 and 2, but there was no significant difference observed in the 3-day total score. Though no significant differences in HF and LF/HF at rest and during nursing were observed for any of the 3 days, there was a tendency for HF to be lower and LF/HF to be higher during nursing than at rest. **Conclusions:** Autonomic nervous activity demonstrated no significant major changes between the 3 days of postpartum (day 1 to 3). However, the lower HF and higher LF/HF during nursing and rooming-in suggest that even multiparas, who are supposedly accustomed to nursing and child-rearing, can be tense. Results suggest that multiparas require monitoring, personal care, and attention so that they can be relaxed and less tense while nursing and caring for their children.

Keywords

Autonomic Nervous Activity, Early Postpartum, Multiparous Women, Rooming-In, Nursing

1. Introduction

Immediately after delivery, a woman undergoes significant physical and mental changes, with changes in sex hormones and autonomic nervous activity, leaving her prone to, both, physical and mental crises. Nakakita [1] noted that autonomic nervous activity in women who have recently delivered puts them potentially at risk of entering an unstable state, especially on postpartum day 1. Hasegawa [2] has also reported that many women who have recently undergone childbirth have non-specific complaints, and these complaints that arise in this period are due to changes in their autonomic nervous activity.

Previous research in women in the early postpartum period has shown that their sense of relaxation and age are related to changes in autonomic nervous activity [3], and that women who have recently delivered and have high levels of stress have higher sympathetic nervous activity on postpartum day 1 [4]. Primiparas are at high risk of post-partum blues, and due to the first experience with childbirth, they require nursing care as well as guidance while in the hospital. In contrast, multiparas, having experienced childbirth, receive lesser nursing care or guidance while in the hospital after giving birth. Nonetheless, clinically, it is not uncommon even for multiparas to complain of anxiety or tension, and require care that will produce a sense of relaxation. Mental and physiological imbalances in multiparas have been hypothesized to be possibly related to autonomic nervous activity, influencing factors different from those observed in primiparas, and factors other than pregnancy and delivery [3]. However, existing data is insufficient to investigate such theories. Therefore, there is a need to study the features of autonomic nervous activity in multiparas, and develop nursing care based on the results.

The purpose of the present study is to study the autonomic nervous activity of multiparas while resting, nursing, and rooming-in/rooming-out during the early postpartum period.

2. Material and Methods

2.1. Study Design

The present study used a survey with experimental techniques.

2.2. Study Participants and Data Collection Period

The study was conducted at an obstetrics and gynecology facility in Japan's Kanagawa Prefecture. The participating facility implements rooming-in only during the day (11 am to 9 pm); at night, neonates are cared for in the nursery, allowing their mothers to have ample sleep. On the morning of postpartum day 2, they receive guidance on nursing and infant bathing.

The subjects were women going through postpartum days 1 - 3. Inclusion criteria included multiparity, birth weight of the neonate of at least 2500 g, a favorable state of health after delivery in both mother and child, and rooming-in care for the neonate during the day. Exclusion criteria included a prior history

that would affect the autonomic nervous activity, cesarean section, loss of 500 g or more of blood during delivery, diseases such as jaundice that requires phototherapy or birth defects in the child. The study period was from September to November 2015.

The purpose of the study was explained and an informed consent was obtained from the participating patients. The study design was approved by the Toho University Faculty of Nursing research ethics review committee (approval no.: 26016).

2.3. Measurement Apparatuses

Subjects were asked to fill out a questionnaire with basic information such as age, number of deliveries, age of previous child/children (≥ 3 years or < 3 years), and family structure, as well as information on the delivery (duration of labor, child's birth weight, loss of blood during delivery, and whether an episiotomy was performed). They were also asked to respond to questions regarding their current state (extent of physical symptoms and state of relaxation). Subjects were asked to keep a simple log of actions performed while wearing a heart rate monitor.

A miniature heart rate recording device, ActiHR4 (CamNtech Ltd and CamNtechInc, England), was used to record the heart rate, which was then analyzed through frequency analysis on a personal computer.

For autonomic nervous activity, I measured high frequency (HF) and low frequency (LF)/HF. HF is representative of parasympathetic nervous activity, and the LF/HF ratio is an indicator of sympathetic nervous activity [5] [6] [7]. HF was analyzed after logarithmic conversion (\log_{10}), because of considerable individual differences and variations in the distribution of frequency domains.

Emotional state and relaxation were scored on a RE scale using the questionnaire. The RE scale is a self-administered questionnaire developed by Netate and Uesato [8]. I used the modified version from Takahashi *et al.* [9], which uses a 10-point rating scale. Respondents use 10 points to rate the following four items: "I was feeling high-strung/I was feeling relaxed", "I had strength in my body/My body had lost strength", "I was anxious/I had peace of mind", and "I felt confined/I felt open and free". The higher the score, the stronger is the sense of relaxation.

2.4. Data Collection Method

The subjects wore the heart rate monitor for 3 hours—from 9 am to 12 pm—from postpartum day 1 to day 3. The heart rate measurements were analyzed through frequency analysis to calculate autonomic nervous activity (sympathetic nervous activity and parasympathetic nervous activity).

2.5. Statistical Analysis

The statistical analysis was performed with SPSS Statistics 22 (IBM, USA). The subjective attributes were analyzed with descriptive statistics. The three-day

changes in heart rate, HF, and LF/HF were analyzed by repeated-measures one-way analysis of variance and paired t-test. The level of significance was set at 5%, with two-sided tests in all instances.

3. Results

3.1. Participant Attributes

Of the 13 subjects, data of all 3 days was obtained from 5 and their attributes are shown in **Table 1**. The mean age was 32.6 ± 3.84 years. Four women had previously experienced one childbirth while one woman experienced two childbirths. The mean neonatal birth weight was 3039 ± 284.4 g, duration of labor was 346.8 ± 128.8 min, and blood loss was 232.6 ± 78.1 g. All 5 women were from nuclear families. Three women had children under 3 years of age. Child-care during hospitalization was provided by the husbands alone in 3 women and by the woman's parents in 2 women.

3.2. Three-Day Changes in Autonomic Nervous Activity and RE Scale

None of the items—heart rate, HF, or LF/HF, showed any significant differences for the 3 days after childbirth (**Table 2**). However, of the 3 days, day 2 had the lowest HF values, and highest LF/HF. On the RE scale, the mean RE score was 25.6 ± 5.4 points for day 1, 25.4 ± 6.3 points for day 2, and 29.2 ± 4.1 for day 3. Compared with postpartum day 1 and day 2, a rise in scores was observed on day 3, but there was no significant difference observed in the total RE scores between the 3 days after birth ($F = 2.378$, $p = 0.195$).

Table 1. Subject characteristics.

Number of subjects	5
Mean age (years)	32.6 ± 3.84
Duration of labor (min)	346.8 ± 128.8
Child's birth weight (g)	3039 ± 284.4
Average blood loss (g)	232.6 ± 78.1
Prior childbirth experience:	
One prior pregnancy	4 (80.0%)
Two prior pregnancies	1 (20.0%)

Table 2. Three-day changes in autonomic nervous activity.

	Days after birth			<i>F</i> -value	<i>p</i> -value
	Day 1	Day 2	Day 3		
Mean Heart rate (beats/min)	77.3 ± 8.6	81.0 ± 9.1	77.9 ± 7.2	0.801	0.482
Parasympathetic nervous activity indicator HF (msec ²)	2.80 ± 0.64	2.29 ± 0.25	2.60 ± 0.71	0.730	0.511
Sympathetic nervous activity indicator LF/HF (msec ²)	2.54 ± 0.63	3.11 ± 1.65	3.01 ± 1.23	0.649	0.548

3.3. Actions Affecting Autonomic Nervous Activity Units

Of the 3 hours when the heart rate monitor was worn, rest was defined as the time when the activity log showed “Slumber”, “Time spent in bed”, and “Leisurely resting”, and the mean autonomic nervous activity during this period was calculated. The total resting time spent by each subject was 1 to 1.5 hours/3 hours. HF at rest was $2.54 \pm 0.43 \text{ msec}^2$ on day 1, $2.61 \pm 0.42 \text{ msec}^2$ on day 2, and $2.70 \pm 0.34 \text{ msec}^2$ on day 3. LF/HF was $2.24 \pm 1.12 \text{ msec}^2$ for day 1, $2.18 \pm 1.93 \text{ msec}^2$ for day 2, and $2.20 \pm 1.60 \text{ msec}^2$ for day 3.

Time that was logged as nursing was counted as nursing, and the mean autonomic nervous activity during this period were calculated. HF during nursing was $2.26 \pm 0.36 \text{ msec}^2$ on day 1, $2.09 \pm 0.38 \text{ msec}^2$ on day 2, and $2.05 \pm 0.54 \text{ msec}^2$ on day 3. LF/HF was $2.72 \pm 1.06 \text{ msec}^2$ for day 1, $3.77 \pm 2.39 \text{ msec}^2$ for day 2, and $3.02 \pm 1.24 \text{ msec}^2$ for day 3 (**Table 3**).

HF and LF/HF at rest and during nursing did not show a significant difference on any of the days. However, compared with nursing, HF and LF/HF at rest were lower and higher, respectively. Furthermore, compared with the 3-hour mean, HF and LF/HF at rest were also lower and higher, respectively.

We compared HF and LF/HF during rooming-in and rooming-out, which began at 11 am. HF during rooming-out was $2.54 \pm 0.28 \text{ msec}^2$ on day 1, $2.35 \pm 0.27 \text{ msec}^2$ on day 2, and $2.51 \pm 0.35 \text{ msec}^2$ on day 3. During rooming-in, it was $2.27 \pm 0.33 \text{ msec}^2$ on day 1, $2.18 \pm 0.35 \text{ msec}^2$ on day 2, and $2.10 \pm 0.50 \text{ msec}^2$ on day 3. LF/HF during rooming-out was $2.28 \pm 0.92 \text{ msec}^2$ on day 1, $2.84 \pm 1.87 \text{ msec}^2$ on day 2, and $2.58 \pm 1.26 \text{ msec}^2$ on day 3; during rooming-in, it was $3.12 \pm 0.55 \text{ msec}^2$ on day 1, $3.69 \pm 1.61 \text{ msec}^2$ on day 2, and $3.91 \pm 1.57 \text{ msec}^2$ on day 3. HF and LF/HF during rooming-in and rooming-out did not show a significant difference for any of postpartum days 1 to 3, but compared with rooming-out, rooming-in HF was lower and rooming-in LF/HF was higher (**Table 4**).

Table 3. Comparison of autonomic nervous activity at rest and during nursing over 3 days.

	HF (msec ²)		LF/HF (msec ²)	
	At Rest	During Nursing	At Rest	During Nursing
Postpartum Day 1				
Mean \pm SD	2.54 ± 0.43	2.26 ± 0.36	2.24 ± 1.12	2.72 ± 1.06
t-value		-1.015		0.549
p-value		0.368		0.612
Postpartum Day 2				
Mean \pm SD	2.61 ± 0.42	2.09 ± 0.38	2.18 ± 1.93	3.77 ± 2.39
t-value		-2.107		2.007
p-value		0.103		0.115
Postpartum Day 3				
Mean \pm SD	2.70 ± 0.34	2.05 ± 0.54	2.20 ± 1.60	3.02 ± 1.24
t-value		-2.625		1.282
p-value		0.059		0.269

Table 4. Comparison of autonomic nervous activity during rooming-out and rooming-in over 3 days.

	Parasympathetic nervous activity indicator HF (msec ²)		Sympathetic nervous activity indicator LF/HF (msec ²)	
	Rooming-out	Rooming-in	Rooming-out	Rooming-in
Postpartum Day 1				
Mean ± SD	2.54 ± 0.28	2.27 ± 0.32	2.28 ± 0.92	3.12 ± 0.55
<i>t</i> -value	1.241		−1.754	
<i>p</i> -value	0.283		0.154	
Postpartum Day 2				
Mean ± SD	2.35 ± 0.27	2.18 ± 0.35	2.84 ± 1.87	3.69 ± 1.61
<i>t</i> -value	1.166		−1.373	
<i>p</i> -value	0.308		0.242	
Postpartum Day 3				
Mean ± SD	2.51 ± 0.35	2.10 ± 0.50	2.58 ± 1.26	3.91 ± 1.57
<i>t</i> -value	1.683		−2.376	
<i>p</i> -value	0.168		0.076	

4. Discussion

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4.1. Autonomic Nervous Activity and Sense of Relaxation during the Early Postpartum Period

The results of the present study do not show significant fluctuations in autonomic nervous activity or subjective sense of relaxation over the immediate post-partum 3 days. Mizuno *et al.* [4] has suggested that women who present with psychological stress during the perinatal period have elevated sympathetic nervous activity along with diminished parasympathetic nervous activity in the early postpartum period when compared with women who do not develop psychological stress. However, because none of the results of the present study demonstrated a significant difference and the small sample size, the present study has failed to show a modulation of autonomic nervous activity in the early postpartum period in multiparas.

Hayashi [6] stated that HF is higher in the morning than afternoon and circadian variations in cardiac parasympathetic nervous activity are endogenous. Nevertheless, it may be possible that the lower parasympathetic nervous activity observed during nursing and rooming-in when compared with rest and rooming-out are due to tension/excitation brought on by the child's presence. Further investigation to study if this is truly a physiological response is needed.

In previously reported research on autonomic nervous activity in women who have recently given birth [1] [2] [4] [10], the measurement time was 5 to 15 minutes, and measurement at rest was based on an experimentally prepared environment. Therefore, the measurement of heart rate and its variability over 3 hours, as done in the present study, is a better representation of the reality of autonomic nervous activity in these women. Despite the longer period of observation, it is difficult to determine if these findings were disorders of autonomic nervous activity or were attenuated results due to measuring at certain time of the day only. Thus, further studies investigating the autonomic nervous activity over 24 hours are required for better quality of data.

Izumi *et al.* [11] suggested the possibility that assessing autonomic nervous activity by heart rate variability could help detect women who have recently given birth and are at risk of anxiety or depression. The results in the present study demonstrate that careful analysis of changes in autonomic nervous activity during the immediate post-partum period for each individual mother along with subjective indicators, may lead to quicker identification of disruptions in the autonomic nervous activity and early detection of maternity blues, and postpartum depression.

4.2. In-Hospital Care for Multiparas

Postpartum women reportedly experience relaxation, decreased anxiety, and happier mood when oxytocin is secreted from the posterior pituitary in response to nursing, and reportedly experience its long-term stress-reducing effects [12]. However, in the present study, autonomic nervous activity did not differ significantly between rest and nursing, and though not a major deviation from the norm, the parasympathetic nervous activity was lower and the sympathetic nervous activity was higher during nursing than at rest. Morimoto *et al.* [13] also reported that though prior experience with childbirth alleviated the basic fears associated with it, it did not provide total relief from childbirth and raising children. Therefore though multiparas may not be in acute need of follow-up care such as techniques of raising children, it is necessary to understand the neonate's individuality and characteristics and the differences from the older child (ren), and acclimatization to the child requires some time and support. In a study by Ono and Manabe [14] in primiparas, mothers with a strong stress response in the week after birth had continued to maintain their stress response 4 weeks later, and their sense of efficacy as a parent was also reduced; they reportedly had a strong sense of constraint due to childcare, and around 90% of mothers recognized nighttime or post-nursing crying by the child as a source of stress. Thus, during the early postpartum period, some mothers potentially experience stress while nursing, even though they may have prior experience with nursing. Therefore, in the early postpartum period in the hospital, not only primiparas but also multiparas require care that reduces stress or keeps it under control, so that their stress remains within the physiological range. Doing so may require mental and physical care, personal care and attention, and monitoring that in-

duces relaxation during child-care.

The results of the present study are from a small sample size and a single facility; further clarification of autonomic nervous activity in multiparas will require further studies with a greater number of subjects. If child-care, including nursing, and time spent in rooming-in together with the child are regarded stressful by the mothers in the early postpartum period, then mothers going through complete rooming-in and nursing at night, as well, can be expected to be more prone to disruptions in their autonomic nervous activity. Enhanced care for mothers caring for their children may require detailed assessments of their daily autonomic nervous activity in the hospital and data that is better reflective of reality.

5. Conclusions

The present study clarifies the following matters.

- 1) Changes in autonomic nervous activity and a sense of relaxation on postpartum days 1 to 3 are not significantly different.
- 2) Although significant differences were not observed in autonomic nervous activity between rest and nursing, or rooming-out and rooming-in, HF and LF/HF values were lower and higher, respectively, during nursing and rest. HR and LF/HF values were also lower and higher, respectively, during rooming-in than rooming-out.

In the early postpartum period immediately after childbirth, even multiparas with prior experience with nursing and child-care were found to be in a state of stress. Results suggest that even multiparas require ample care, monitoring, and personal attention until they understand the child's characteristics and a bond between the mother and child can be established.

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Conflict of Interest

There is no conflict of interest that could be perceived as prejudicing the impartiality of the research reported.

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Collaborating with Young Adults Diagnosed with Schizophrenia: A Participatory Design Study to Shape the Healthcare System

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Abstract

Introduction: Disengagement from mental health services in young adults with schizophrenia has been associated with dissatisfaction and unmet needs. Striving to improve engagement, we invited service users recently diagnosed with schizophrenia to be co-designers of a smartphone technology that will be responsive to their needs. **Aim:** This paper reports the first phase of a three-phased participatory design process. The objective was to identify needs of support in young adults recently diagnosed with schizophrenia and to generate ideas of how the needs could be accommodated using smartphone technology. **Methods:** Participatory design guided the research process and a qualitative approach was used to generate and analyse the data. Data were generated by means of participant observations ($n = 45$ hours) and interviews ($n = 6$) with young adults from a first episode psychosis program in Denmark. **Findings:** Low levels of knowledge and high levels of uncertainties are characteristic of young adults recently diagnosed with schizophrenia, bringing about a vast need of support in order for them to gain power over their new life situation. Our study suggests that the smartphone may be used to foster empowerment by guiding the young adult's actions in situ, providing comprehensive and easily understood information on the go, allowing for recovery tracking, and notification of mental health changes, providing medication overview and giving easy access to healthcare providers. **Conclusion:** Young adults recently diagnosed with schizophrenia require comprehensive support in order to become empowered to confidently manage their new life situation. The smartphone holds this potential by offering flexible collaboration and timely access to self-management resources.

Keywords

Empowerment, Mobile Health, Participatory Design, Schizophrenia, Young adults

1. Introduction

The early phases of schizophrenia have gained increased attention over the past decade, and today it is well established that when a young adult suffers from a psychotic illness, intensive care is required to control symptoms, prevent psychotic relapse and improve quality of life [1] [2] [3]. Encouraging and promoting service engagement among young adult in the early phases of schizophrenia, however, is a challenge despite intensive and specialized care being routinely offered [4] [5] [6]. This is a serious treat to mental health recovery, as disengagement, when a service is still needed, can lead to devastating consequences [7], including exacerbations of psychotic symptoms [8] [9] social isolation and suicidal behaviour [3].

It is hypothesized that the first five years of schizophrenia care is optimal to change the long-term course of the illness [3]. Fostering service engagement in the early phases of schizophrenia therefore is of particular importance to improve the mental health recovery.

Research has been established that disengagement from mental health services is associated with dissatisfaction [5] and unmet needs [6] in persons with schizophrenia. This provides a strong basis for shaping services around input from service users, which would then foster mental health recovery through healthcare that they themselves perceive to be meaningful and relevant.

Shaping services with mental health users, however, is not common practice [10]. This is true regardless of user-involvement being at the heart of the recommendations for a more modern and sustainable mental healthcare system [10] [11] [12] [13] [14], and irrespective of research designating that service user involvement offers a promising pathway towards better quality healthcare, more efficient care and improved population health [15] [16] [17].

As a result, we set out to shape an early intervention service in collaboration with young adults recently diagnosed with schizophrenia. We wanted to design a service that was “engaging”, by grounding the innovation in user needs and by drawing on the power of smartphone technology to extend services beyond the confines of the physical clinic [18] [19] [20]. Smartphone ownership is particularly high in younger people with schizophrenia [21] making the smartphone highly relevant as a tool to respond to service user needs at all times.

This article reports the first phase of a three-phased participatory design process. The objective of the first phase was to identify the needs of support in young adults recently diagnosed with schizophrenia, and to generate ideas of how the needs could be accommodated using smartphone technology. The objective of phase two and three were to design and develop the technology and to

test it in a clinical setting, respectively.

Figure 1 provides an overview of the different phases and activities in the participatory process of shaping, designing and testing a service with young adults recently diagnosed with schizophrenia.

2. Methods

2.1. Research Design

The overall research was conducted within a methodological framework of participatory design (PD) [22]. PD has roots in action research [23], and is preoccupied with finding and developing solutions to practical problems in close collaboration with service users [24] [25] [26] [27]. Therefore, PD supports the practice of making service users co-designers of services responsive to their needs.

A qualitative approach was used to generate and analyse the data. In the first phase of the PD process, data were collected through participant observations and interviews with service users from a specialized first episode psychosis program in Denmark (OPUS). OPUS is a two-year program that provides intensive care for young adults between the ages of 18 - 34 years old, recently diagnosed with schizophrenia. Participant observations were carried out to generate a contextual understanding of the young adults' problems and needs, in order to get a grasp of what mattered most to them. Observations were primarily used to identify themes for a semi structured interview guide [28], thus, the findings in this article solely focus on the interviews.

2.2. Participants and Data Collection

Firstly, the first author carried out passive participant observations (45 hours) to construct the interview guide. The observations were obtained in the primary contexts of the OPUS program. This included an outpatient clinic in which home consultations were provided as well as an in-patient clinic for young adults only. Observations and field notes were taken concurrently in accordance with Spradleys recommendations [29]. Nine observations of home visits, with two nurses and an occupational therapist, were obtained. The rest of the time was spent in the car or the clinic talking to healthcare professionals (HCPs) about the problems of living with schizophrenia and the needs to be accommo-

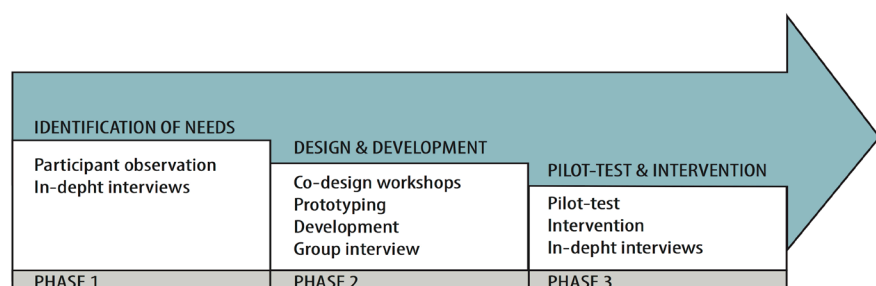


Figure 1. An overview of the different phases and activities in the participatory design process.

dated. The managers of both settings gave their consent to be observed, and patients were asked permission for the first-author to sit in on conversations between them and their HCP.

Secondly, the first author conducted individual interviews with ($n = 6$) young adults from the OPUS program, using the interview guide. In order to encourage the participants to speak freely, interview questions were open ended and not established in a fixed sequence, rather as prompts [30]. A Venn diagram [31] was used as a tangible artefact to address the supportive network, in an attempt to get an idea of how the technology should be “wired” to accommodate the needs of the young adults in a real life setting. To secure depth of data, each interview was continued until saturation had been reached [32], therefore, the interviews stopped when the narrative became repetitive and no new data were revealed. Interviews lasted between 55 minutes to 1 hour and 18 minutes. They were conducted either at the participants’ home (5 interviews) or at the research unit at the hospital (1 interview) depending on participant’s preference. Interviews were digitally recorded and transcribed verbatim. The interviews were conducted in Danish; therefore the quotes in the findings section were translated into English, omitting any corrections in phrasing.

Criteria for inclusion in the study were willingness and ability to share information and ideas by virtue of knowledge and experience. However, since it has been argued that individuals who are not “stuck” with too much experience make excellent innovators [33] [34], we were interested in recruiting participants that had been diagnosed within the past year. Criteria for exclusion were inability to speak or understand Danish and unwillingness to provide written consent. Recruitment was conducted in close collaboration with HCPs from OPUS, who singled out relevant participants, gave them an information letter and asked them to consider participation. The first-author contacted them either by phone or email, to make further arrangements, when consent had been obtained.

2.3. Data Analysis

A hermeneutical approach to data analysis was chosen. Within this frame of reference, interpretation of meaning is an iterative and circular process [35], which fits the methodology of PD [36]. In the tradition of Gadamer it is rejected, that hermeneutics is a step-by-step method, rather it is an explication of general principles [28]. Guided by canon principles of hermeneutical interpretation, interpretation of meaning was constructed through an incessant back-and forth process between parts and the whole of the interview text, which follows from the hermeneutical circle. The process of hermeneutical questioning continued until an inner unity of a text free of logical contradictions had been reached.

2.4. Ethical Considerations

The study was submitted to the North Denmark Region Committee on Health Research Ethics. In accordance with Danish law, the committee found that a formal ethics approval of the study was not required. In line with the Helsinki

Declaration [37], all participants were fully informed about the purpose of the study and informed consent was obtained both verbally and in writing before enrolment. The participants retained the right to withdraw from the study at any given point, and they were carefully informed, that withdrawal would not influence their course of care. Authorization by the Danish Data Protection Agency was obtained (2008-58-0028).

3. Findings

Six participants in the OPUS program were eligible for interviews (four women, two men). All accepted the invitation to participate. At inclusion, the age of the participants ranged between 19 - 27 years. All had been diagnosed within the past year, received social benefits and lived independently. All owned a mobile phone and used it on a daily basis.

The hermeneutical inspired process of analysis governing the findings is outlined in **Figure 2**. Based on the young adults descriptions of living with schizophrenia, we identified a need of support to gain power, to be able to control the new life-situation confidently. The need was related to low levels of knowledge and high levels of uncertainties, making the new and changed life situation somewhat impossible to cope with independently. Six ideas for resources to accommodate the need using smartphone technology were identified. The findings are outlined in the next section.

Interview text Quotations	Immediate answers: What is said in relation to needs?	De-contextualisation through interpretation	Result: Needs of support arise from the coding process	Ideas to accommodate the needs of support
"...would be really nice to get suggestions for how to help myself [...] and to have the suggestions handy"	Suggestions for how to help myself Have the suggestions handy	Request for power to self-manage illness on side	Support to take actions in-situ	In-situ guidance
"I often forget, how I was yesterday [...] it feels as though the good days calmly passes by"	Often forget Good days passes by	Impaired memory makes progress hard to recall	Support to recall own process of recovery	Recovery tracking
"Often I do not understand what is going on [...] really stressful not knowing what to expect from the illness"	Do not understand Stressful not knowing what to expect	Powerless in 'reading' the illness	Support to identify deterioration	Notifications of illness exacerbation
"Its really difficult to remember all the different drugs I have tried the past year [...] a whole lot easier if I had some sort of chart at hand that I could show them"	Difficult to remember Easier if I had some sort of chart at hand that I could show them	Request for help to keep overview of medication	Support to recall past and present drugs at all times	Wired list of medication
"I searched the Internet for facts about the illness, just to know what I should expect"	Search the Internet for facts What I should expect	Internet as source to get timely information	Comprehensive info around the clock	On demand information
"I'm so happy that she [the nurse] has a mobile phone. She is always within reach. That is really comforting to know"	Mobile phone Always within reach Comforting	Availability increase sense of certainty	Boundless and 'out of hours' communication with health care providers	Online lifeline

Figure 2. Outline of the hermeneutical process of analysis governing the study findings.

3.1. A Need of Support to Gain Power in Order to Control the New Life Situation Confidently

3.1.1. In-Situ Guidance

The participants emphasized how they sometimes felt powerless and helpless in managing the illness and their new life situation. All had received psychoeducation, either only individually or individually followed by 10 weeks of group sessions with other service users in the OPUS program. The participants were explicit that education about the nature of the illness, recovery rates, medication, relapse prevention and symptom management was truly helpful, and key to becoming in charge of the illness, rather than a victim of it:

“What has helped me the most has been to learn about the illness. When I began to know the signs [of illness] and know when I was extra vulnerable, I got power. Then I was smarter than my own head. There could be just as many questions and concerns, but because I had seen through it [illness], then I could do something in advance-I could act instead of just being a victim.”

However, despite their contentment with the psychoeducation, in specific situations they felt incapable of translating the knowledge obtained in the “classroom” into action. Lack of “translation” and “adoption” skills made them reliant on help from their HCPs. Nevertheless, dependency was something the participants strived to extricate themselves from, and they stressed the need of having access to resources, that could guide them “in situ” to self-manage the illness appropriately and pro-actively:

“It would be really nice to get suggestions for how to help myself... and to have the suggestions handy. Then it would be a whole lot easier to manage this in the long run.”

Thus, it appeared that extending psychoeducation outside the physical walls of the classroom was crucial for making the young adults more independent and increasing their confidence in their ability to navigate their new life situation. This became especially visible in regard to the time restriction of the OPUS program. Since the program was within a two-year timescale, they were under the pressure of time, learning what to do and how to act unassisted. As such, in-situ guidance emerged as a resource to assist young adults on the go in the process of managing the illness more independently over the course of time.

3.1.2. Recovery Tracking

The participants stressed how cognitive impairments were a central feature of their illness. In particular, they emphasised how severe impairment of memory and attention made it hard to recall their own progress, which vastly impacted the hope of recovery. Since experiences were no longer stored in the memory, the good days often faded or even disappeared:

“I often forget, how I was yesterday. It’s difficult to remember, what I have been doing, and whether it was a good day or a bad day. It feels as if the good days calmly passes day by day.”

The pass of the good days was evident among the participants even though they stressed how the OPUS program had bettered their mental state signifi-

cantly. Particular on “the bad days”, the loss of memory impacted the hope of recovery, as it was difficult to believe that things would actually change for the better:

“Will this ever be better? On the bad days, I really doubt it.”

Thus, impaired memory left the participants in doubt of recovery, and maintained a strong presence of the bad days in the memory.

Several of the participants explained how their HCPs had encouraged them to monitor their health in an attempt to call to mind their own progress. Some had taken the word of advice using a diary to record the day; others had discovered that using the camera in their smartphone was a useful strategy to keep a sense of perspective, therefore keeping track of their progress over time. Yet others did not monitor their progress and had discovered how the “bad days” had the strongest presence in their memory.

A participant proposed that systematic tracking of the mental state could help to recall and tell apart the good days and bad days respectively, and emphasised how a display would be an important resource for believing in progress:

“I think that getting things in black and white could help to convince me that I am getting better.”

As such, it appeared that recovery tracking could help provide a more accurate and realistic picture of the process of recovery, particularly if the tracking were presented visually. Thus, recovery tracking emerged as an important feature to keep up the hope of recovery and to escape the mental captivity of illness.

3.1.3. Notifications of Illness Exacerbation

Fear of illness exacerbation was widely recognized by the participants. They emphasised how the OPUS program had improved their mental state significantly, yet, still they persistently wondered whether and when the illness would “strike” again. They were highly alert of early warning signs of impending psychotic relapse, as were their relatives. In fact, their mind was almost programmed to think that even small changes in the mental state could be deterioration:

“What is this... a relapse? Honestly, that is always the first thing I think of. The thought of relapse and hospitalization really freaks me out.”

The thoughts of relapse and hospitalization were dominant, and it appeared that the participants had difficulty “reading” the illness. Since they did not know what to pay attention to and what to let pass unattended, they identified all information from the senses as potential signs of impending psychotic relapse:

“Is it the illness speaking now, or is it just me being young?”

As such, lack of knowledge and insight into their relapse signature and drill left them in an incessant potential danger, not knowing for certain whether to be worried or not. The uncertainty was evident over the course of time. A participant explained how, still after one year in the OPUS program, he found it difficult to interpret fatigue, for example. This could be interpreted as a negative symptom (something normal for people suffering from schizophrenia), an early sign of illness exacerbation (a potential danger that should be acted upon) but

also, a healthy reaction to living an irregular and “normal” youth life, occasionally having too little sleep.

The sustained problem of reading the illness prevented the participants from knowing whether to be worried or not, thus preventing them from “*becoming the captain of one’s own life*” as one of the participants framed it. This restricted their ability to be proactive. Further, this left them watchful 24/7-worried and controlled by their illness, rather than certain and in control of it:

“Sometimes it feels as if I’m at work nonstop. It would be so helpful, if I could get some kind of warning telling me when to be alert. Then I could focus less on my illness and more on just living my life.”

Thus, notifications of illness exacerbation appeared to be a resource of paramount importance to promote a sense of confidence and control in their life with their illness, but also in “taking time off” from the illness, and focusing on being young rather than being ill.

3.1.4. Wired List of Medications

The participants stressed how the severe impairment of memory and attention, did not only impact their hope of recovery, but also their ability to keep track of their medications. Most stressed how they had control of taking their daily medication through different routines, but found it difficult to remember the names, types and doses of different psychotropic drugs, particularly ones used in the past. This left them powerless, particularly in stressful situations, where they had to account for it:

“It’s really difficult to remember all the different drugs I have tried the past year. If they ask me at the General practitioner or the Emergency room, I can’t really report it, to be quite honest.”

Having a sense of perspective of prescribed medication, both present and past, was greatly stressed as a means to be in control, and several stressed how a list of wired medications would be a helpful resource to recall this:

“It would be a whole lot easier if I had some sort of list at hand that I could show them.”

The emphasis of having a list at hand pointed towards the importance of ubiquity in order to support the memory. Thus, a wired list of medications emerged as an important resource to keep a sense of perspective and feel in control.

3.1.5. On-Demand Information

The need for widespread and timely information was evident among the participants. All turned to websites looking for information about the nature of illness, treatment options, rates of recovery, medication, as well as tips and tools to fight and manage the illness and their new life situation. This was particularly true when they had just been diagnosed:

*“At first, I really needed information. I searched the Internet for facts about the illness, just to know what I should expect the first couple of months... Because, F*** they were hard.”*

As such, the Internet was used as a tool to seek answers and self-educate. However, the information on the Internet, did not necessarily empower them:

“It [information] can be really hard to understand, but also to relate to, since they use so many trade terms.”

Thus, it appeared, that easily comprehensible information was key in order to keep a sense of perspective in the process of preparing for the time to come. As such, the participants pointed towards the importance of an on-demand information resource that was simple and enlightening, thus workable and applicable in the early phases of schizophrenia where the level of knowledge was low and the level of uncertainties high.

A participant shared the idea that the application could provide an encyclopaedia consisting of a knowledgebase with a search option similar to Google, and an interactive part where all the patients enrolled in the OPUS program could share their tips and tools, therefore providing each other with useful information through websites and articles. Thus, the active role in sharing and disseminating meaningful information was mentioned as an important aspect to take into account in the re-design of standard formats of information and learning aids.

3.1.6. Online Lifeline

The participants stressed the importance of easy access to their HCP. In this respect, they highlighted how their mobile phone was the platform commonly used to reach out for guidance and directions. This mode of contact was really reassuring:

“I’m so happy that she [the HCP] has a mobile phone. She is always within reach. That is really comforting to know.”

As such, the mobile phone served as an online lifeline ensuring that qualified advices was within reach regardless of time and place.

Reaching out for guidance and directions appeared to be equally important day and night. In fact, nights were often the time of day where the participants felt the biggest need for help and guidance:

“After dark, I often feel anxious. That is the time of day where I feel most vulnerable.”

The OPUS program, however, was only available during office hours. Consequently, it was not possible to communicate with the HCPs after 4 pm. Yet, several of the participants sent texts to the HCPs after hours, knowing that their messages would not be seen or answered until the next day. They had experienced how just getting things off their chest made them calm down and relax:

“It’s really nice that you can always write down things and send it off straight away, even in the middle of the night. Then [name of the HCP] can look at it when she has got the time: read through it, analyse it and send it back.”

An important feature of the lifeline was customized guidance and directions. To this end, written communication was highly emphasised. The participants explained how their impaired memory and short attention span made it not only hard to focus, but also to remember the verbal advice received by phone. This

made written guidance somewhat more supportive in controlling their new life situation:

“It is really hard for me to communicate [verbally], since I have to think fast and remember what has been said afterwards. It is much easier and convenient to have things in writing.”

As a result, it appeared that the mobile phone served the means of an online lifeline, making help and guidance feel accessible. Yet, the mobile phone emerged as a key feature in establishing a secure and empowering environment that enabled the participants to take time off from the illness, even in their most vulnerable hours where many questions and doubts arose.

Summing up, six ideas for supportive resources of power for the participant's to control their new life situation were identified. The findings are synthesised in **Figure 3**.

4. Discussion

The findings presented here provide new insights into the users' perspectives on the needs of support when being young and recently diagnosed with schizophrenia, including potential features that should be considered in designing a smartphone technology to accommodate these needs. Our study highlights that a smartphone technology should be designed to promote empowerment while responding to the needs required to confidently navigate this new life situation.



Figure 3. Synthesis of findings.

There is growing evidence that the perception of personal control plays a critical role in health and wellbeing [38], and finding ways to increase this power is important as a means to this end [39]. We identified six ways to increase this power in the early phases of schizophrenia, where the levels of knowledge are low and uncertainties high.

The analysis revealed that knowledge is a source of power, which is of great importance to control the new life situation independently. In-situ guidance, on-demand information and on-line lifeline were all different means to this end. The power of knowledge is highly recognized in psychoeducation literature [40], where evidence has been established that education helps individuals with schizophrenia gain basic knowledge on their illness [41]. Our study signifies that young adults with schizophrenia want to be educated in order to self-manage their illness, but they are unable to use the knowledge obtained outside the classroom to do this effectively. These findings are concurrent with previous studies claiming that knowledge gained through psychoeducation does not appear to help individuals with schizophrenia to manage their illness better or engage actively in the recovery process [41] [42]. Considered together, this substantiates the relevance of ubiquity to be able to assist young adults on the go, in the process of resuming the management of their lives independently.

The analysis revealed that memory is another important source of power to feel certain and in control of the new life situation. In this respect, recovery tracking and a wired list of medications came up as resources to help memorizing and keeping a sense of perspective. Cognitive impairments are a distinct dimension of schizophrenia and are highly evident in persons with this illness [43], as was widely evident in our sample. Cognitive deficits have emerged as an important new target in schizophrenia care, due to evidence suggesting that they are critically related to difficulties of functioning in everyday life [44]. Our study indicates that the smartphone may play an important role in compensating for cognitive deficits, therefore providing improved functioning in everyday life for those with schizophrenia. More importantly, our findings suggest that memory support may help keep the good days present, when the hope of recovery is hard to obtain. Thus, recovery tracking appears vital to sustain hope in the young adults on their journey towards mental health recovery.

Also, the analysis revealed how warnings are an important source of power to assert control. To this end, notifications of illness exacerbation came up as an idea to provide a sense of certainty and control in managing their new life situation. Birchwood proposes that persons with schizophrenia have a strong interest in learning to recognize and prevent impending psychotic relapse [45], and stresses the importance of promoting a sense of control through knowledge and insight into their relapse signature and drill [46]. This is in line with our findings, which eventually suggests that reading the illness and recognizing early signs of change is somewhat impossible in the early phases of schizophrenia, which makes notification of undesirable changes crucial to assert control. Notifications of illness exacerbations may be provided using smartphone technology.

The persuasive personal monitoring system, MONARCA, developed for the treatment of persons with bipolar disorder, is an example of this. This system uses an automatic trigger mechanism to detect early changes in the mental state through electronic self-assessments provided by the patients [47].

Summing up, our study advocates that control in the management of the early phases of schizophrenia may be achieved if support is extended into the everyday lives and homes of the young adults, where powerlessness, helplessness and worries develop. The smartphone, which enables digital engagement with patients in real time and real environments [48], may facilitate this process through easy and timely access to support. Firth and Torous [49] have documented high rates of engagement and satisfaction with apps in the care of people with schizophrenia. This further encourages the nascent potential of the mode of service delivery to accommodate the needs of young adults with schizophrenia at all times.

Study Limitations

The study was conducted with rigorous qualitative methodology, but there are some limitations.

The majority of the sample population were women. Since first episode schizophrenia incident rates are approximately two times higher in males than women [21] [50] our sample is gender biased. This might indicate that our findings are in favour of women, however, we did not see any distinct differences in relation to the needs of support in the two genders.

The sample was small and the study only included ethnic Danes from one outpatient clinic. Thereby, it reflects the culture, norms and values of young ethnic Danes, in a specific clinic at a specific time. It might be argued that a variation in ethnicity might have broadened the perspective of needs and ideas for their accommodation, particular since needs may vary over the course of an illness and depend on a patient's health status, demographics and culture [39]. This could affect the transferability of our results. Thus, it would be interesting to replicate the study in other contexts, countries and within different ethnic groups.

There were no distinct differences in experiences and statements from the participants; thus, the sample size appears to be adequate for the subject studied. However, the cognitive difficulties addressed in the findings, and widely documented in the literature [43], questions whether data saturation was actually reached. Even though the interviewer experienced saturation during each interview, there is a risk that some complexities did not unfold.

5. Conclusion

This study demonstrates that young adults with first episode schizophrenia need comprehensive support to become empowered to manage and feel certain in their new and changed life situation. Our study suggests that the smartphone may be used to foster empowerment by guiding the young adult's actions in situ,

providing comprehensive and easily understood information on the go, allowing for recovery tracking, and notification of mental health changes, providing medication overview and giving easy access to HCPs. The high rates of engagement and satisfaction with apps in the care of people with schizophrenia encourage the nascent potential of the mode of smartphone service delivery to accommodate the needs of support at all times.

Clinical Implications

Our study advocates that smartphone technology holds the promise of empowering young adults newly diagnosed with schizophrenia to manage their new life situation confidently through easy and timely access to flexible collaboration and self-management resources. One thing to be aware of, however is, that patient empowerment may lead to over-involvement in own care [39]. Generally, over-involvement has gained less attention than under-involvement, although evidence has been provided that both types of mismatches affect patient satisfaction [51]. Since dissatisfaction is associated with disengagement from mental health services in young adults with schizophrenia [5], it appears crucial that HCPs continually assess with the patient whether the technology has become a burden. Otherwise, the technology may foster service disengagement rather than encourage and promote engagement. This strongly indicates the need for further research on the topic, and highlights that future studies could benefit from not exclusively addressing how the smartphone may promote empowerment, but also when and how such a technology may defeat its own purpose.

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The Effectiveness of Treatment Training for Children with Acute Respiratory Tract Infection to Mothers of Toddlers in Bandung Indonesian

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Abstract

Acute Respiratory Tract Infection (ARTI) remains a health problem for toddlers in Indonesia and the leading cause of death for toddlers. In addition to causing health problems, ARTI can also cause death. Indonesia, as one of the countries signing of the Millennium Development Goals (MDGs), is required to be able to reduce toddler mortality rate. The research intends to find the effectiveness of treatment training for children with ARTI in increasing the knowledge, attitude, and skill of mothers of toddlers in the working area of Community Health Centre Sukajadi, Bandung. It employed a quasiexperimental method with the pre-posttest two group designs. The sample, taken with the random sampling technique, consisted of 26 mothers of toddlers for the control and intervention groups, respectively. For the intervention group, the treatment training for children with ARTI was given for 4 - 5 hours in one day, and the control group was only given a conventional extension program for 15 minutes. The knowledge, attitudes, and skills before and after intervention were measured three days after the training using the same instrument used during the pretest. The results of this research show that in terms of the effectiveness of the training using modules, there were differences in the average scores for knowledge with p value ($0.030 \leq \alpha$ (0.05), for the aspect of attitudes with p value ($0.046 \leq \alpha$ (0.05), and for the sub-variable of skills as proven by the p value of ($0.046 \leq \alpha$ (0.05). Based on these results, the intervention of ARTI treatment training at home had significant effect on the knowledge, attitudes, and skills of the toddlers' mothers. With this inference, it is recommended that the research results can be made a topic of study for the development of a training model or standardized training guidelines that will be used by health officers at Community Health Centre Sukajadi, Bandung City Indonesian.

Keywords

Training, ARTI, Knowledge, Attitude, Skill

1. Introduction

Acute respiratory tract infection (ARTI) covers three main elements, namely infection, respiratory tract, and acuteness. Infection is the invasion of germs or microorganisms into human body in which they reproduce themselves, thereby causing disease symptoms. Respiratory tract is a set of body organs, starting from the nose to alveoli along with the adnexal organs. Meanwhile, acute infection is infection that lasts for 14 days or more. Acute respiratory tract infection (ARTI) remains to be one of the health problems faced by toddlers in Indonesia and the number one cause of death in toddlers. In addition to causing health problems, ARTI may cause death as one of the countries signing the Millennium Development Goals (MDGs) was required to be able to reduce maternal mortality rate for up to 3/4 of the rate in 1990, so that by 2015 it was expected that the rate would decrease to 102/100,000 live births [1]. Another target to meet was to reduce toddler mortality rate for up to 1/3 of the rate in 1990, or 32/1000 live births by 2015.

One of the efforts made by the Ministry of Health to reduce maternal mortality rate and toddler mortality rate as well as to improve the health of mother and children is the implementation of Mother and Child Health Book. The book has been developed since 2004, and in 2007 the book was made a national policy. Unfortunately, although the Ministry of Health has implemented Mother and Child Health Book, toddler mortality rate remained high, namely 43% of the total number of toddlers in West Java [2]. West Java Department of Health has also conducted education-based training for health officers, particularly nurses, in an attempt of reducing toddler mortality and morbidity rate; however, the morbidity rate of ARTI in West Java was reported to remain high.

Another effort of reducing toddler mortality rate lies in the role of mothers of toddlers who are one of the caregivers in a family environment. Caregiver is an individual who gives both formal and informal support and assistance through various activities to people with disabilities or with long-term illness or elderly [3]. The caregiver can provide emotional or financial support and is also ready to give assistance in various tasks. In the treatment of children with ARTI, it is important to recognize various signs and symptoms of the disease and treat the children temporarily at home and immediately take the children to receive professional treatment, when the disease cannot be treated at home only. The knowledge, attitudes, and skills of mothers become the main focus in treating sick toddlers at home because mothers play the primary role in the decision making and care of children. Thus, in order to support the reduction of morbidity and mortality rates among toddlers caused by ARTI, sustainability of intensive, structured, and continuous training program is needed. The implication is

that training should give more emphasis on the elements of knowledge, attitudes, and skills in the treatment of children with ARTI to mothers at toddlers at home.

The research then aims to find the effectiveness of the treatment training for children with ARTI in the aspects of increased knowledge, attitudes, and skills of mothers of toddlers in the working area of Puskesmas (Community Health Center) Sukajadi, Bandung.

2. Method

This is quasi-experimental research with pretest and posttest with control group design [4]. It involved two groups, namely the treatment group with intervention and the control group without any intervention. For each group, measurements were conducted before (pretest) and after (posttest) the intervention. In this research, the results of intervention with treatment training for children with ARTI using a module of treatment for children with ARTI at home to mothers of toddlers were compared. The control group was not given a structured training; instead, it was provided with a conventional or direct extension program. The research took place in the working area of Puskesmas Sukajadi, Bandung City, in August 2015. The population included all mothers of toddlers in the working area of the Puskesmas. The sample was taken using the equation for numerical research with paired samples, namely:

$$n^1 = n^2 = n^1 = n^2 = \left(\frac{(Z\alpha + Z\beta)}{x^1 - x^2} \right)^2$$

If $z\alpha = 5\%$ (1.96), $z\beta = 10\%$ (1.28), then the previous research's standard deviation is 35, and the difference that is considered significant = 20, so the equation will be:

$$n^1 = n^2 = n^1 = n^2 = \left(\frac{(1.96 + 0.84)}{20} \right)^2 = 24$$

Hence, the number of sample is 24. With an addition of 10% to anticipate drop out using the correction formula of $N = n(1 - f)$ a number of 26 people were taken as sample, both for the intervention group and control group (52 in total) [5]. The sample for the intervention group of mothers of toddlers was determined by randomly selecting three out of the 10 Posyandu (integrated service pos) in Cipedes Village Administrative Unit, and the Posyandu from RW* 01, 03, and 04 were selected. Meanwhile, the sample for control group was randomly selected from the 11 integrated service posts in Sukabungah Village Administrative Unit, and the posts from RW 01, 07, and 09 were selected. Subsequently, the stratified random sampling was done to each of the RWs in the intervention group from Cipedes and control group from Sukabungah Village Administrative Units to finally get 26 respondents as the sample for each group. Before the collection of data, the 26 mothers of toddlers of each group were given explanations about the aim of the research and signed informed consent forms. Before the

intervention (pretest), the toddlers' mothers from both the intervention and control groups filled in a questionnaire of knowledge and attitudes for 30 minutes, while the pretest of skill was conducted by the researchers with the assistance of three cadres, in which the toddlers mothers were divided into five groups. Afterwards, each of the toddlers' mothers was given a pretest on skill for around 15 minutes. Hence, in total, each toddler's mother spent 45 minutes for the pretest of knowledge, attitudes, and skills. The questionnaire and observation sheet of the mothers' skills had been through validity and reliability tests with $r > 0.762$ and $r > 0.8$, for the validity and reliability, respectively.

The researchers trained the intervention group with ARTI module for mothers of toddlers for 4 - 5 hours in one day. The materials of the module that were delivered during training were: Chapter I (Introduction), consisting of background, aims, goals, objectives, and scope of the module; Chapter II (Treatment of Children with ARTI): definition, signs and symptoms, and skills on treating children with ARTI; and Chapter III (Closing). After explanations of the module, the researchers gave opportunities to the mothers of toddlers to ask if there were things that needed clarification. This was followed by the researchers demonstrating the skills on treating children with ARTI, and the mothers of toddlers were given the opportunity to re-demonstrate their skills of treating children with ARTI. The module was then brought home by the mothers of toddlers for further reading and understanding, and the mothers could practice their skills in the treatment of children with ARTI at home. Three days after the training, the researchers conducted a posttest or evaluation of training in the intervention group with the same instrument at the time of pretest. In the control group only given conventional counseling at the time of visit to Pos Yandu (Integrated Service Pos) also conducted pretest and posttest using the same instrument. For fairness, upon the completion of research, the control group was also given the module and trained on how to treat children with ARTI.

Bivariate analysis was carried out to test the mean difference of the two groups' data before and after training for each of the variables of knowledge, attitudes, and skills. The statistical tests used were the paired (dependent) and independent *t*-tests for two means with the decision rule stating that if $p\text{-value} < \alpha$ (0.05), then statistically there was significant effect, and if $p\text{-value} > \alpha$ (0.05), then then there was no significant effect.

3. Results

The results of the analysis of the effectiveness of treatment training for children with ARTI in improving mothers of toddlers' knowledge, attitudes, and skills are elaborated as follows:

3.1. Univariate Analysis

Table 1 shows that the majority of the respondents, both from intervention group (88.5%) and control group (76.9%), were at the category of young adults. Meanwhile, in terms of academic background, the majority respondents

Table 1. Distribution of respondents' characteristics based on age, academic background, and occupation.

NO	CHARACTERISTICS	INTERVENTION		CONTROL		Sig
		F	%	f	%	
1	Age					
	• 17 - 40 y.o. (young adults)	23	88.5	20	76.9	0.16
	• 41 - 60 y.o. (middle-aged adults)	3	11.5	6	23.1	
	• >60 y.o. (elder)	0	0	0	0	
	Total	26	100	26	100	
2	Academic Background					
	• Primary (elementary and junior high schools)	8	30.8	12	46.2	0.04
	• Secondary (senior high schools)	12	46.2	9	34.6	
	• Higher education	6	23.1	4	19.2	
	Total	26	100	26	100	
3	Occupation					
	• Employed	15	57.7	20	76.9	0.072
	• Unemployed	11	42.3	6	23.1	
	Total	26	100	26	100	

in the intervention group (46.2%) finished secondary education level, while the majority of the control group (46.2%) completed primary education. Finally, most of the respondents in both the intervention (57.7%) and control groups (76.9%) were employed. Statistic analysis shows that demographic respondent are homogen for age and occupation.

From **Table 2**, it can be seen that there was an increase in the mean score of knowledge before and after intervention for the intervention group, namely from 7.73 to 9.30. The same was also true for the control group, with an increase from 7.07 to 8.50.

Table 3 indicates that there was an increase in the mean scores of attitudes before and after intervention for the intervention and control groups, namely from 53.50 to 56.26, and from 49.53 to 52.76, respectively.

From **Table 4**, it can be seen that there was an increase in the mean scores of skills before and after intervention for both the intervention and control groups, namely from 51.53 to 56.19, and 51.84 to 54.38, respectively.

3.2. Bivariate Analysis

Based on **Table 5**, it is clear that the difference in the mean scores of the effect of training on the knowledge of the mothers of toddler in the intervention group before and after the intervention was 1.57, with a standard deviation of 1.17, and *p*-value 0.000. Meanwhile, in the control group, the difference in the mean scores of the effect of training on mothers of toddlers' knowledge before and after intervention was 1.42, with a standard deviation of 1.20, and *p*-value 0.000.

Table 6 indicates that the mean difference of the effect of training on the mothers of toddlers' attitudes in the intervention group before and after intervention was 2.23, with a standard deviation of 2.80, and *p*-value 0.020. On the

Table 2. Description of mothers of toddlers' knowledge before and after training intervention.

ELEMENT	INTERVENTION				CONTROL			
	Pre		3 rd days post training		Pre		3 rd days post conventional education	
	Mean	SD	Mean	SD	mean	SD	Mean	SD
KNOWLEDGE	7.73	1.53	9.30	0.83	7.07	1.52	8.50	1.02

Table 3. Description of mothers of toddlers' attitudes before and after training intervention.

ELEMENT	INTERVENTION				CONTROL			
	Pre		3 rd days post training		Pre		3 rd days post conventional education	
	Mean	SD	Mean	SD	mean	SD	Mean	SD
ATTITUDE	53.50	4.07	56.26	4.65	49.53	3.34	52.76	3.54

Table 4. Description of mothers of toddlers' skills before and after training intervention.

ELEMENT	INTERVENTION				CONTROL			
	Pre		3 rd days post training		Pre		3 rd days post conventional education	
	mean	SD	mean	SD	mean	SD	Mean	SD
ATTITUDE	51.53	4.65	56.19	4.76	51.84	4.32	54.38	5.20

Table 5. The effect of the treatment training for children with ARTI at home on the knowledge of mothers of toddlers.

GROUP	N	Difference between Pre and posttest means	sd	Sig
INTERVENTION	26	1.57	1.17	0.000
CONTROL	26	1.42	1.20	0.000

Table 6. The effect of the treatment training for children with ARTI at home on the attitudes of mothers of toddlers.

GROUP	N	Difference between pre posttest means	sd	p-value
INTERVENTION	26	3.23	2.80	0.020
CONTROL	26	2.96	3.26	0.050

other hand, the mean difference of the effect of training on the attitudes of the mothers of toddlers before and after intervention was 2.96, with a standard deviation of 3.26 and *p*-value 0.050.

Table 7 illustrates that the mean difference of the effect of the training on the

skills of the mothers of toddlers before and after intervention for the intervention group was 4.88, with a standard deviation of 3.06 and p -value 0.030. Meanwhile, in the control group, the mean difference of the effect of the training on the mothers of toddlers' skills before and after intervention was 2.53, with a standard deviation of 3.11 and p -value 0.010.

From **Table 8**, it can be observed that the mean scores of the intervention group and control group were 0.22 and 0.28, respectively, and $t = 1.63$ with p -value 0.030. This result proves that the training intervention had significant effect and was effective in improving the knowledge of the mothers of toddlers. This inference is made after comparing the mean scores between the intervention group and control group.

Table 9 indicates that the mean scores of the intervention group and control group were 0.77 and 0.74, respectively, and $t = 1.28$ with p -value 0.046. This result proves that the training intervention had significant effect on and was effective in improving the attitudes of the mothers of toddlers. This inference is drawn after comparing the mean scores of attitudes for the intervention group and control group.

Table 10 demonstrates that the mean scores of the intervention group and control group were 0.16 and 0.19, respectively with $t = 1.15$ and p -value 0.042.

Table 7. The effect of the treatment training for children with ARTI at home on the skills of mothers of toddlers.

GROUP	N	Difference between pre posttest means	sd	p -value
INTERVENTION	26	4.88	3.06	0.030
CONTROL	26	2.53	3.11	0.010

Table 8. The effectiveness of the treatment training for children with ARTI at home in improving the knowledge of mothers of toddlers.

GROUP	N	mean	t	p -value
INTERVENTION	26	0.22	1.63	0.030
CONTROL	26	0.28		

Table 9. The effectiveness of the treatment training for children with ARTI at home on the attitudes of mothers of toddlers.

GROUP	N	mean	t	p -value
INTERVENTION	26	0.77	1.28	0.046
CONTROL	26	0.74		

Table 10. The effectiveness of the treatment training for children with ARTI at home on the skills of mothers of toddlers.

GROUP	N	mean	t	p -value
INTERVENTION	26	0.16	1.15	0.042
CONTROL	26	0.19		

The scores proved that the training intervention had significant effect and was effective in improving the skills of the mothers of toddlers. This inference is drawn after comparing the mean scores of skills for the intervention group and control group.

4. Discussion

The research results presented in **Table 1** support the claim of the effectiveness of treatment training for children with ARTI to mothers of toddlers. Meanwhile, **Tables 2-4** show that the training intervention of the treatment of children with ARTI using the medium of training module significantly affected the improvement in the knowledge, attitudes, and skills of the mothers of toddlers. Meanwhile, the research results in **Tables 5-7** demonstrate that there was a difference in the mean scores of knowledge of the intervention group between pre and posttests with $p\text{-value} = 0.000$. There was also a difference in the mean scores of attitudes with $p\text{-value} = 0.020$. Similarly, a difference in the mean scores of skills was also obtained, with $p\text{-value} = 0.030$. The mean differences indicate that the training using learning module had effect on the knowledge, attitudes, and skills of the mothers of toddlers. The findings show that almost half of the mothers (48.6%) as respondents in her research had very limited knowledge about ARTI disease which might be due to their level of education, in which almost half of them were graduates of primary school (45.7%) [6]. Therefore, teaching and learning through training with the medium of a module is really necessary in order to increase knowledge. Learning theory as a theory that offers explicit guidelines on how to help people learn and develop better [7]. The types of learning and development include the cognitive, emotional, social, physical, and spiritual aspects. It means that experience-based learning has several characteristics, namely: 1) design-oriented, which means it is focused on the attempt of meeting learning goals; 2) identifying learning methods (ways to support and facilitate learning) and the situations during which the method can/cannot be used; and 3) the learning method can be elaborated into lesson plan.

Knowledge can be gained from the medium of learning module because basically learning using a module provides students with an opportunity to learn autonomously [8]. Attitudes are always linked to the behaviors that are still within limits and considered normal, which are responses or reactions to a certain stimulus, although attitude is essentially only the predisposition or tendency to behave in a certain way, so that it cannot be said as an action or activity [9]. In this regard, a nurse as an educator, a caregiver, a facilitator, and an advocator plays an important role in an attempt of empowering and enabling mothers/families of toddlers [10]. Attitude is affected by the information given by others who have acquired or formed a certain attitude towards a certain object based on their direct experience. An individual who obtains accurate information by him/herself will gain a direct experience of the object. Changes in attitude can be in the form of an addition to, a shift, or modification of one or more components, which means that one or more components of attitude may

change, but the other components remain unchanged. The factors of experience and maturity are highly influential in an individual's attitude changes.

Tables 8-10 indicate that the mean scores of knowledge for the intervention group and control group were 0.22 and 0.28, respectively, with $t = 1.63$ and p -value 0.030. The mean scores for attitude of the intervention group and control group were 0.77 and 0.74, with $t = 1.28$ and p -value 0.046. Meanwhile, the mean scores of skills for the intervention group and control group were 0.16 and 0.19, respectively, with $t = 1.15$ and p -value 0.042. The results proved that the treatment training for children with ARTI at home using the medium of learning module was effective. Training using a module as guidelines has been implemented in various efforts of improving knowledge [11]. Module is one of good and effective learning media to assist students in planned and continuous teaching and learning processes. Module is also an effective individual learning system with the main goal of increasing learning effectiveness and efficiency. A module can be used at home, so that the module can be studied anywhere. In addition, the duration of learning using a module can last from several minutes to hours and can be done by oneself or combined with other methods. The treatment training for children with ARTI using learning module was effective, for the module can be studied and applied at home [12].

The sub-variable of skills showed the greatest increase or improvement compared to the two other subvariables. The results indicated that the treatment training for children with ARTI using learning module at home had significant effect on changes in the skills of the mothers of toddlers, as proven by p -value $0.03 < 0.05$, which means the training had effect on the skills of the mothers of toddler, and the increase was statistically significant, as can also be seen by the scores displayed in **Table 7**. The effectiveness of the training is also proven by the results presented in **Table 10**. Bloom's theory explain that there are three domains of human behavior [13]. The classification is made for the interest of education goals, namely knowledge, attitude, and its prediction for behavior. The cognitive component contains perception, belief, and stereotype possessed by an individual regarding something and behavior/skill has one or more measurable dimensions, namely frequency, duration, and intensity [14]. Behavior/skill can be observed, explained, and recorded by others or the people involved in the behavior [15]. An individual's behavior in performing a certain skill is also situational, meaning that each individual will behave differently in different situations.

Based on the above explanations, it can be concluded that the training of mothers of toddlers using a module of treatment for children with ARTI at home was effective.

5. Limitations of the Study

The limitations in this study are difficulties in controlling the respondent's variables. 1) Academic background are heterogent between intervention group and control group. 2) There are difficulty to control biased during training such as:

concentration, motivation and barriers of the environment during the training/intervention.

6. Conclusion

The results of this research show more significant increases in the mean scores of knowledge, attitudes, and skills of the mothers of toddlers who were given intervention than the scores of those who were not given any training, which means that the treatment training for children with ARTI at home was proven to be effective and had significant effect on the increased knowledge, attitudes, and skills of the mothers of toddlers.

7. Suggestions

Based on the research results, the following recommendations are formulated: 1) The results of this research can be made a topic of study for developing a model or standardized training guidelines; 2) The results can be made the basis for community service programs to improve people's health in an attempt of reducing toddler morbidity and mortality rates caused by ARTI.

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Changes in Japanese Nurses' Awareness of Patient Interactions Following a Japanese Tea Ceremony

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Abstract

This study provided foundational data for use in nursing interventional methods for improving nurse-patient relationships. This was a descriptive study on the effectiveness of a Japanese tea ceremony (in Japanese: *chado*) intervention for improving nurse-patient relationships. I conducted a Japanese tea ceremony and examined changes in nurses' awareness regarding interactions with patients after this intervention. The tea ceremonies were conducted with the cooperation of an *Urasenke* tea ceremony lecturer. A quiet environment with chairs and tables was provided for all participants while they provided written answers to a descriptive survey, which was administered before and after the intervention; they required approximately 20 min to complete the survey. The mean length of each nurse's description was 800 characters. The tea ceremony was effective in bringing about definite changes in nurses' awareness concerning interactions with patients. This study is useful in that it suggests how nurses can maintain good interpersonal relationships with patients.

Keywords

Interventional Methods, Japanese Tea Ceremony, Nurse-Patient Relationships

1. Introduction

In recent years, the clinical practice, education, and research capabilities of nurses have increased; however, there remain complaints from patients and their family members concerning their interactions with nurses. To promote a sense of patient satisfaction during medical treatment, nurses should be aware of sub-services that provide insight into the feelings of patients and that facilitate appropriate nurse-patient interactions [1]. Although the goals of nursing include

consideration, compassion, and empathy toward patients, there is no concrete method of engendering these in a nurse.

Henderson (1964) noted that in the nurse-patient relationship, “getting under his/her skin” is a way to understand a patient [2]. Erikson (1997a) considered empathy to be “feeling concern for suffering,” and showed that a nurse must acknowledge a patient’s suffering to make the patient feel they are respected as a person [3]. To alleviate a patient’s suffering, a nurse should discover the patient’s desires, and the patient’s feelings of trust, hope, powerlessness, guilt, and shame [4]. A nurse needs to understand each patient’s unique experience of his or her disease, knowledge, and feelings [3] [5]. Such a nurse-patient relationship is considered the foundation of a therapeutic relationship.

Keenan (1996) reported that the Japanese tea ceremony is useful for stress management in nurses [6], and Donnelly (2007) reported that by placing participants within a natural setting [7], the tea ceremony allows participants to enjoy the life that is universally shared by humans and to maintain harmony with others. Uno (2015) reported on the importance of hospitality (in Japanese: *omotenashi*) in the Japanese culture as a characteristic of the nursing interactions that were desired by patients [8]. Although the Japanese tea ceremony is a part of the traditional Japanese culture, few Japanese individuals practice the art daily, and reports concerning the role of the tea ceremony in the field of nursing are rare. Thus, in this study, nurses who worked in a clinical practice participated in the Japanese tea ceremony to evaluate changes in their awareness with respect to their interactions with patients. I focused on the Japanese tea ceremony as a method to form peaceful interpersonal relationships during patient interactions.

This study provided basic data to explore interventional methods for nurses to improve nurse-patient relationships. I examined the manner in which awareness of the nurses regarding their patient interactions changed after participating in the Japanese tea ceremony.

2. Methods

This study was a descriptive survey of a Japanese tea ceremony intervention. In 2014, I conducted a similar intervention involving three participants and descriptive surveys, similar to those used in the present study. I confirmed that there were no mental or physical burdens on the participants and that there was a change in nurses’ awareness.

2.1. Participants

I initially mailed 100 regional medical care support hospitals in the Kinki region of Japan to explain the purpose and methods of the study and to request their cooperation. Four hospitals agreed to cooperate. A total of 14 nurses expressed an interest in participating in the present study; however, only 12 nurses were included for analysis because two dropped out during the study. Twelve was the maximum number of individuals who agreed to cooperate. However, the 800 words provided in total by these individuals was sufficient for qualitative sum-

marization.

2.2. Data Collection

The study period was from March to May 2015. Interventions were performed once per week over a 4-week period (*i.e.*, a total of four times). Interventions were performed in a tea ceremony room located in a temple in the Osaka Prefecture, Japan.

2.3. Ethical Considerations

The participants received an explanation that data obtained from the study would not be used to identify any individual or for purposes other than research, would be strictly managed, and would be destroyed following the conclusion of the study. Cooperation was voluntary, and participants were assured that they would not be at a disadvantage if they decided not to participate. Furthermore, they were told that the program had no connection with evaluations at their affiliated hospital. The study was approved by the ethics review committee of participating hospitals in Osaka.

2.4. Operational Definitions of the Terminology

The “Japanese tea ceremony” (in Japanese: *chado*) is a traditional Japanese art that has been referred to as a “composite art form”. “Tactfulness in silence” refers to the insight of sensing the thoughts and feelings of others that are not expressed in words.

2.5. Study Design

I administered a pre-intervention survey to assess the individual characteristics of the nurses (age, years of experience as a nurse, affiliated hospital wards, and experience participating in tea ceremonies) and the following items:

- A. Interactions with nurses believed to be desired by patients,
- B. Awareness of daily interactions with patients,
- C. Interactions believed to improve the quality of nursing, and
- D. Image of the tea ceremony.

A quiet environment with chairs and tables was provided for the participants while they provided written answers to the survey.

The tea ceremonies were conducted with the cooperation of an *Urasenketea* ceremony lecturer. The tea ceremony lecturer acted as the tea master during the ceremonies.

The guests were the participants, who were divided into groups of six individuals; each experienced the same program content for approximately 1 h in each session. To ease the tension of the participants who were participating in the tea ceremony for the first time, the researchers, who had participated in a tea ceremony before, presented a partial example of a ceremony. However, to avoid influencing the study results, the participants were allowed to act naturally during the tea ceremony (**Figure 1** and **Figure 2**). The tea ceremony steps are listed



Figure 1. The manner of entering the tea ceremony room.



Figure 2. Method used by visitors.

below.

First, participants walked on paving stones in the tea ceremony garden and washed their hands in a stone washbasin in that garden (**Figure 3**). Then, they moved through a small door (in Japanese: *nijiriguchi*), by bending at the knee, to enter the tea ceremony room.

Second, the participants walked to the teahouse, sat quietly in the tea ceremony room, and read both the Zen Buddhist phrase on the hanging scroll in the room and on the teacups (**Figure 4**) while the tea master explained the tea ceremony process to them.

Third, they observed the water brazier and jar, which were to be used in the tea ceremony (**Figure 5**).



Figure 3. Approach to the tea ceremony room.



Figure 4. The hanging scroll featuring a Zen phrase, with flowers in the tea ceremony room.



Figure 5. Water brazier and jar for the ceremony.

Fourth, they then smelled the incense (in Japanese: *kiku*), ate the Japanese confectioneries, and drank a cup of green tea (in Japanese: *maccha*).

Finally, the participants handled the tea ceremony utensils, incense, and tea-cups and received an explanation regarding the utensils to be used.

Each time, different Zen Buddhist phrases, flowers, Japanese confectioneries, and teacups were used to provide variety to the ceremonies. I administered a descriptive survey to the participants after the intervention, using methods similar to those used for the pre-intervention survey.

Data analysis compared the responses to A, B, C, and D, before and after the

tea ceremony intervention.

3. Results

3.1. Individual Characteristics

The mean age of the 12 participants, all of whom were female, was 48 years (SD = 6.6). The mean years of nursing experience was 23 (SD = 5.8). The nurses worked in the Department of Internal Medicine (chronic disease ward), and no participants had previous experience of participating in a tea ceremony (**Table 1**). Four of the nurses qualified at a university and eight were qualified as nurses at a vocational school.

3.2. Nurse's Consciousness of Interactions with Patients before and after Intervention

The participants required approximately 20 min to write their descriptions. The mean length of each nurse's description was 800 characters. The descriptions of items A through D were qualitatively analyzed and compared before and after the intervention (**Table 2**).

4. Discussion

Results of the pre-intervention awareness analysis revealed an awareness of appropriate professional interactions, such as “interacting gently and kindly”, “interacting safely”, “explanations and skills with a scientific basis”, and “empathetic attitude”. The Japanese tea ceremony involves silent communication between the host and guests, as the guests “sensitively feel the intentions of the tea master, who takes great pains to provide an atmosphere of hospitality”. The post-intervention comments were related to peaceful interactions, such as “interacting without pressure”, “interacting while maintaining an appropriate distance”, “interacting with a sincere attitude”, and “insight in sensing feelings that are not expressed in words”. These categories were based on an awareness of the interactions with patients that were not limited to their status as a professional nurse.

Considering three aspects, I assessed how participant's awareness changed regarding interactions with patients after the tea ceremony. The first aspect was related to changes in feelings because of being in a teahouse and the formal interpersonal relationships that were created. After the intervention, categories related to calmness of mind were suggested by the nurses. For the nurses who were busy with daily nursing tasks, the Japanese tea ceremony was a place where they

Table 1. Demographic characteristics of nurses ($n = 12$).

Age (years)	
Mean \pm SD	48 \pm 6.6
Working experience as a nurse (years)	
Mean \pm SD	23 \pm 5.8

Table 2. Change in nurses' awareness following tea ceremony.

	A	B	C	D
	Interactions with nurses believed to be desired by patients	Awareness of daily interactions with patients	Interactions believed to improve the quality of nursing	Image of tea ceremony
Before	Smile	Interact gently and kindly	Keep learning	Stiff
	Kindness	Interact safely	Learn and practice ways of communicating regarding disease	Difficult
	Communication	Explanations and skills provided with a scientific basis	Always think about the patient's feelings	Unfamiliar
	Explanation	Empathetic attitude	Do not make medical mistakes, etc.	Only some rich people learn
After	Not superficial gentleness; treat patient as a person Understand what the patient wants, by understanding his/her nonverbal communication	Interact without pressure	Provide a good recuperative environment Always remind yourself how casual and caring you are Catch precisely as soon as possible Touch according to the patient's desire	Can be incorporated into daily life
	I deeply feel what you want	Interact while maintaining an appropriate distance	As a professional, it is better to avoid using technical terms as much as possible	The spirit of the tea ceremony adapts to the Japanese people
	Treat the individual as a someone who is a part of nature	Interact with a sincere attitude	Try to use the senses, such as in the manner of touching Empathic understanding	Become the starting point of how to contact people
	As a nurse, explain what is expected of the patient	Insight in sensing feelings that are not expressed by words	Even just going to a room and talking is part of the nurse's job	My own heart calms down

could relax and find peace of mind. The second aspect was that the participants (nurses) received polite hospitality and were cared for. People tend to be rude to others when they are treated rudely themselves. The work of nurses constitutes emotional labor, that is, the management of emotions in the workplace [9]. After

the intervention, the categories “interacting with a sincere attitude” and “insight in sensing feelings that are not expressed in words” were observed. Therefore, the tea ceremony is useful for controlling emotions through polite hospitality and caring for guests.

The third aspect was the way in which the five senses were utilized. Nurses should have a high degree of sensitivity while working in a hectic and highly stressful environment. However, here the participants were given a chance to return to nature by appreciating seasonal flowers. That is, the participants were able to relax in a beautiful environment that could be experienced through the five senses. These findings are important for managing the working environment of nurses, who are likely busy with numerous other daily tasks when interacting with patients.

The program used in this study exceeded the limits of the field of nursing, but it appeared useful for creating favorable nurse-patient relationships. Specifically, this method effectively relaxed the nurses, which suggests that relaxation is one way to improve interpersonal relationships. In summary, the intervention method used in this study is useful for nurses to maintain good interpersonal relationships with patients.

5. Conclusion

Changes in nurses’ awareness related to interactions with patients were noted after the tea ceremony intervention. I observed changes related to increased functional beauty and spirituality, as exemplified by the categories “interacting without pressure”, “interacting while maintaining an appropriate distance”, “interacting with a sincere attitude”, and “insight in sensing feelings that are not expressed in words”. Thus, participating in the tea ceremony was effective in bringing about definite changes in nurses’ awareness concerning interactions with patients. However, a future study with an increased sample size is needed to verify the present study’s results, and a survey of patients who received nursing care from the participants is also necessary.

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Conflict of Interest

The author declares that no conflict of interest exists.

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Simulation Is Not a Pedagogy

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Abstract

Simulation as a teaching/learning tool has evolved at an unprecedented pace which some believe has occurred despite a lack of research into pedagogies appropriate to guide this technology-based learning tool. There seems to be some confusion as to what simulation actually is. Some have called simulation a pedagogy, which is incorrect. Simulation is not a pedagogy, but an immersive teaching/learning platform which is a representation of a functioning system or process. Simulation has been used in undergraduate nursing education in a focused manner for nearly 20 years. Its effectiveness in improving clinical reasoning and critical thinking is not certain if overall instructional design principles do not reflect suitable philosophical paradigms. Simulation as a teaching/learning platform is maximized when instructional design includes the inspiration of behaviorism, cognitivism, and constructivism. **Behaviorist design principles** include rote learning, repetition, modular learning, stimulus-response, and conditioning. **Cognitivist design principles** include observational techniques, bootstrapping, and equilibration in the form of assimilation and accommodation. **Constructivist design principles** include new habit formation through experience and interaction with a “mature social medium” in the form of a simulation facilitator. All of these philosophical underpinnings have the potential to maximize simulation when used as underpinnings in the overall design.

Keywords

Simulation, Undergraduate Nursing Education, Behaviorist, Cognitivist, Constructivist

1. Introduction

There has been some confusion as to the definition and potential uses of simulation in the training of undergraduate nurses. Upon researching simulation extensively, it has become apparent that there is some confusion around the definition of simulation. Some educators believed simulation to be a pedagogy [1].

Simulation is not a pedagogy, but an immersive teaching/learning platform which is a representation of a functioning system or process [2]. The aim of this article is to “unpick” some of these language traps in order to better understand how a sound pedagogical approach that includes the use of simulation can maximize learning for undergraduate nurses.

2. What Is Pedagogy?

Pedagogy is rarely made explicit in curricula, and is often assumed or taken for granted. Pedagogy deals with the theory and practice of teaching. The Merriam Webster online dictionary [3] defines pedagogy as the art, science, or profession of teaching. A comprehensive use of pedagogy includes considerations around the nature of knowledge; what is taught; how it is taught; and how learning occurs [4]. It is an educator’s pedagogical knowledge which most profoundly influences the teaching/learning environments he or she creates [5]. Designing effective simulation involves a comprehensive understanding of the pedagogical underpinnings which can enhance simulation as a teaching/learning tool. Simulation is not a pedagogy in itself; but rather a tool or method used to implement various pedagogies [6].

There are at least three philosophical perspectives which underpin sound simulation design: 1) behaviorism [7] [8] [9]; 2) cognitivism [10] [11] [12]; and 3) constructivism [13] [14] [15] [16]. These can be seen in **Figure 1**.

Each of these theoretical frameworks involves, to some degree, repetitive practice, feedback, personal and group reflection, and a safe learning environment. Cognitivism and constructivism involve movement from dependent to independent learning. All of these theoretical frameworks have contributions to make to a pedagogical approach that includes the use of simulation [6].

2.1. Behaviorism

Behaviorism as an educational philosophy is the earliest theoretical underpinning

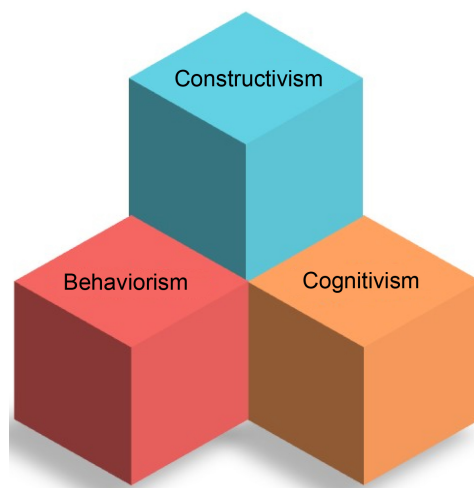


Figure 1. Building blocks of sound simulation design.

identified in educational research [8] [17] [18]. In behaviorism learning is confirmed by behavioral responses to specific stimuli [17] [19]. John B. Watson (1878-1958) is generally considered to be the founder and champion of modern behaviorism. Watson believed that behavior was the proper material for study, not methods that dealt with the mind [9]. Internal thought processes are not considered as the focus is on external response to stimuli. The human mind is considered a memory bank for knowledge, with the teacher being responsible for transmission of knowledge, and the learner a passive recipient [20]. Behaviorists espouse that environment shapes behavior and that external factors can be manipulated to produce desirable actions [6] [21].

Behaviorist methods employed in simulation include rote learning, repetition of skills, pre-briefing, and modular learning [21]. While basic and often assumed, rote learning forms the foundations of any professional healthcare career by providing students with a body of facts (e.g. lab values, physiology, and clinical protocols) [19] [22]. Application of factual knowledge to clinical problems is the beginning of bridging the theory-practice gap so often noted as an issue in undergraduate nursing education [6].

Conditioning theories of learning, arising from behaviorism, are also helpful in maximizing simulation design [6]. Skinner [7] developed the best-known conditioning theory termed operant conditioning. If a behavior is positively reinforced through conditioning, a response is more likely to occur. Students can therefore be conditioned to respond to certain stimuli (e.g. loss of consciousness, rapid pulse,) with appropriate responses (e.g. BP check) in simulation. Quickened conditioned responses can improve patient outcomes. Thorndike (1874-1949) extended Skinner's work by making deliberate associations between experiences and responses in what was called connectionism [8] [23].

Connectionism espouses that the most fundamental type of learning involves the forming of associations (connections) between sensory experiences (stimuli or events) and neural impulses (responses) that manifest themselves behaviorally [24]. Thorndike [8] proposed the law of exercise, which suggests that practice strengthens the connection between the stimulus and the response, while disuse weakens it. Skill development employing repetition strengthened with the law of exercise can result in modified and improved competence [25] [26] [27].

The positive aspects of behavioral theory include the development of skills in response to certain stimuli, and an assurance that learners will respond in similar ways when in similar circumstances. While this has its place in nursing education, it does involve a mechanistic stimulus-response approach which cannot account for all behavior [28]. Behaviorism is not concerned with creativity or autonomy of learners, nor with their internal mental states [6]. Behaviorism is less concerned with solving the problem and more concerned with how the right outcome can be conditioned and repeated. This lack of focus on judgment, critical thinking, and analysis has become part of the criticism of behaviorism [6] [28]. It could be said that behaviorism has a reductionist approach which limits its usefulness in developing thinking at higher levels required for professional

practice. This weakness has highlighted a need to seek out other educational philosophies more focused on the student's ability to problem-solve and critically evaluate clinical situations [6]. Therefore, the influence of cognitivist and constructivist philosophies has proved valuable in simulation design.

2.2. Cognitivism

While behaviorists believe that learning occurs as a response to stimuli, cognitivism carries the notion that learning involves the reorganization of experiences [6] [29]. Behaviorists stress the role of the environment and the effect on learning, while cognitivists stress what students do with the information. Cognitivists want to know how students attend to, rehearse, transform, code, store, and retrieve information given [24]. The leading, and most influential, cognitive theorist in the West is Piaget [30], while Vygotsky's work [12] is more influential in Eastern Europe [6] [31]. Learning to the cognitivist involves a move away from stimulus-response modes of learning to a focus on students' beliefs and thought processes, perceptions and insights [5] [6] [24].

One of the major challenges to behaviorism came from the studies on observational learning conducted by Albert Bandura [10]. Bandura found that people could learn new actions merely by observing others perform. More importantly, observers did not have to perform the actions at the time of learning. This cognitivist notion impacts simulation design in the area of pre-briefing material and model simulation clips used to showcase professionals caring for clients in deteriorating clinical situations. Students can learn by simply observing model clips [6]. They are able to build this learning into cognitive schema before attending simulation sessions. Piaget's [11] work inspired thoughts on how to maximise the development of such cognitive schema.

According to Piaget [11], equilibration, the drive to produce an optimal state of equilibrium (or adaptation) between cognitive structures and the environment, is the primary motivating force behind cognitive development. To resolve internal conflict in thought, an individual can use one of two component processes of equilibration: assimilation or accommodation. Assimilation refers to fitting external reality into existing cognitive structures. Accommodation refers to changing internal structures to provide consistency with external reality [24]. Both of these processes inspire learning in simulation as students strive to achieve equilibrium.

An example of accommodation occurred when students were shown a model clip of lecturers caring for a croup baby in crisis. The model clip showed the administration of nebulized medication before the intra-muscular injection [6]. Students had previously performed the simulation giving the injection first followed by the nebulizer. Upon noticing the opposite order in the model clip, they amended their own performance to provide consistency with this external reality. They were even able to give rationale for why this change was correct, "The nebulized medication is absorbed more quickly than the injection so should be given first". This accommodation and explanation gave the students added con-

fidence they were competent to care for such a patient safely [27].

Ironically, one weakness of cognitivism arises from its strength. Whereas schemata can make learning more meaningful, a learner is at a marked disadvantage when relevant schemata or pre-requisite knowledge do not exist [6] [29]. In this instance, the learner may enter into a process called bootstrapping which involves the creation of new representational resources which are more powerful than those present at the outset [32]. In order for bootstrapping to occur, three processes must arise: 1) the facilitator must specify the innate representations that provide the building blocks of the target concepts of interest; 2) the facilitator must describe how the target concepts differ from those innate representations currently available and: 3) the facilitator must characterize the learning mechanisms that enable the construction of new concepts out of the prior representations [32]. Facilitator input in the form of situated teaching is essential for bootstrapping to occur [27].

It is the job of the instructional designer to choose tasks which will assist students to retrieve and work with knowledge as they reorganize experiences in cognitive schemata [6]. Cognitive theory underpins simulation in the area of developing clinical reasoning and problem solving [6] [33]. Without consideration of cognitive architectural features, instructional design is likely to be suboptimal [34]. Constructivist philosophy moves simulation design in a different direction.

2.3. Constructivism

Constructivist thought draws from a variety of disciplines including education and psychology. John Dewey [14], Jerome Bruner [13], Ernst von Glasersfeld [35], John Mezirow [16], and Malcolm Knowles [15] represent some profound thinkers whose work contributes to contemporary constructivist thought. Constructivist knowledge develops by a process of active construction and reconstruction of theory and practice [6] [36]. Von Glasersfeld [35] postulates that knowledge is the collection of conceptual structures that are adapted or viable within the subject's range of experience.

Constructivism holds that learners have some prior knowledge and experience, and are capable of building their own content in order to solve a particular problem [37] [39]. Constructivism is a learner-centric educational paradigm where the learner constructs meaning in a team-based, collaborative learning environment. The needed knowledge is not delivered by the educator, but constructed in the mind of the learner [38]. The learner moves from a passive stance in behaviorism, to an active participant in the learning process in constructivism [6] [19].

Constructivism impacts simulation design in the area changing outdated habits in favor of more effective ones [14]. Dewey [39] contributed to constructivist thought when he emphasized the construction of meaning in learning environments through experiences and interactions with others. According to Dewey [14], telling students what to do will not embed new ways of thinking/acting

(i.e. new habits). Learners must be allowed the freedom to consciously search for new ways of responding, while being given the freedom to find their own solutions [6]. These solutions are further refined when students interact with a “matured social medium” [[14] p. 90]. This combination of student search intermingled with facilitator input allows for knowledge construction in a manner which situates the learner firmly in the driver’s seat, a concept at the heart of constructivist thought [6] [27].

An example of new habit formation encouraged by the presence of a matured social medium occurred when a student forgot to wear her watch and was forced to view another student’s watch. When the other student shifted position, the count was lost. The facilitator pointed out the clock on the wall and the new habit of using the wall clock was formed [6]. The problem was solved and the student commented:

I did not realize there was a clock on the wall, so I could not effectively measure respiratory rate. It was very supportive that [the educator] told me the location of the clock. It was good that the educator was with me (Focus Group, Cycle One).

This kind of facilitation becomes essential for students when they are attempting to form new habits. They appreciate the interaction with a matured social medium in the form of a simulation facilitator, who can give them feedback during and after the simulation in the form of debriefing [6].

One of the challenges posed with constructivism is that learners may inadvertently build knowledge that is inaccurate or not the best “fit” for the problem posed [40]. Some pre-existing ideas may be ad hoc or unstable [41]. If the facilitator is not aware of what a particular student is “thinking”, incorrect solutions may result. This problem can be mitigated by training simulation facilitators to monitor and guide student thinking in the debriefing session [6]. This is one reason why debriefing, to ensure refinement of new knowledge, is an essential component when using simulation as a teaching/learning platform [6] [42].

3. Conclusions

The past 15 years have borne witness to a paradigm shift in the delivery of undergraduate nursing programs from transmission-based delivery models to immersive learning environments involving simulation of practice experiences [6] [43]. Simulation is not a pedagogy, but a teaching/learning platform used to facilitate training for undergraduate nurses [6]. In order to maximize simulation’s impact on learning, at least three pedagogical underpinnings must be considered: 1) behaviorism; 2) cognitivism; and 3) constructivism. Simulation design elements which move students progressively through rote memory, to acquiring cognitive schema, and finally capturing learning moments through application of memorized and stored information to clinical practice; are the golden nuggets of simulation design. Simulation facilitators must be trained in the implementation of these pedagogical underpinnings in order to ensure a safe and effective student journey through this immersive learning environment. The final result of

this process will be students “fit for purpose” and ready to engage with complex clinical environments for which they are destined.

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Doctor, Ease My Mind! Associations between Cancer Patients' Emotional Distress and Their Perception of Patient-Centeredness during Oncology Consultations

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Abstract

Objective: To investigate whether perceived patient-centered communication during oncology consultations relates to patient satisfaction and degree of emotional distress following the medical encounter. **Methods:** 226 cancer patients attending an oncology outpatient clinic completed questionnaires before and after a consultation including the Physician-Patient Relationship Inventory, the brief Profile of Mood States, and the Information satisfaction questionnaire. **Results:** Patients who perceived the communication during the consultations to be highly patient-centered were more likely to be maximally satisfied with information provided by the oncologist. Additionally, adjusting for pre-consultation distress, as well as sociodemographic, clinical, and consultation-related variables, patients who perceived the oncologist to communicate in a highly patient-centered manner, experienced lower levels of emotional distress after the consultation. **Conclusion:** Patient-centered communication may be an important quality in oncology as an approach to positively influence patient outcomes, including emotional distress. However, the findings in the present study of an effect of PCC on patient satisfaction and emotional distress are modest, and no firm conclusions can thus be drawn. **Practice Implications:** Oncology settings may benefit from the positive effects of patient-centered care and physicians should acknowledge the potential of their own relational competence in order to facilitate patient-centered communication.

Keywords

Patient-Centered Communication, Cancer Patients, Emotional Distress, Satisfaction

1. Introduction

A growing body of research has shown patient-physician communication to be important for the delivery of high-quality patient-centered care, and as an indicator of a successful consultation [1]. A reliable and trusting patient-physician relationship is particularly important for cancer patients due to the emotional distress associated with a life-threatening disease and the fear that it evokes. Guarantees are rarely given with respect to treatment outcome, and many patients therefore find themselves in a vulnerable state [2].

Patient-centered communication (PCC) involves developing physicians' abilities to deal with emotional and psychosocial aspects in relation to the patient, e.g. coping with distress and facing fear [3]. However, PCC also involves information giving and sharing. Patients make subjective sense of the information, and their interpretations are influenced by past experiences as well as their own understanding and beliefs about their illness [4]. PCC skills may help physicians to meet the individual needs of the patients by asking for their preferred level of information, to encourage them to ask questions, and to engage in active listening. PCC has been defined by Epstein and Street (2007) in terms of processes and outcomes of the patient-physician interaction, and conceptualized into six core interactive functions including 1) fostering healing relationships, 2) exchanging information, 3) responding to emotions, 4) making decisions, 5) managing uncertainty, and 6) enabling patient self-management. These core functions are not to be understood independent nor hierarchical. Instead, they interrelate and interact to produce communication that has the potential to positively affect patient outcomes, including satisfaction and emotional states [4].

Empirical research in PCC has demonstrated a positive relationship between the quality of patient-physician communication and patient satisfaction [5] [6] [7] [8]. However, although the results of a meta-analysis by Venetis *et al.* (2009) provide some evidence for the effect of PCC on patient satisfaction, only few of the included studies recognize variables that may play a moderating role on the effects of PCC (e.g. patient demographics and disease-related characteristics) [2]. For example, Rademakers *et al.* (2012) found that according to their preferences, patients with a lower educational level received "too much" in the patient-centered domains related to information and shared decision [9]. Identifying influencing variables may therefore increase our understanding of PCC and explain possible variability in patient outcomes.

PCC may also influence the patients' level of emotional distress; however, the evidence is rather small and inconclusive. Whereas physicians' empathy have been associated with less patient distress in some studies [10] [11] [12], other studies have found that empathy was associated with increased patient distress after their visit [13]. Moreover, other studies found no associations [14] [15]. A diagnosis of cancer often disrupts important aspects of daily living, and many treatments are associated with considerable side effects. In conjunction with the complexity of the medical information, this adds a significant emotional dimension to the patient-oncologist interaction [16] [17]. Cancer patients may not di-

rectly express feelings of distress and the physicians' ability to elicit and subsequent respond to patients' emotions may therefore influence patient outcomes [18]. In a study of cancer patients' preferences for information, involvement and support, it was shown that although most patients wanted their oncologist to ask them if they wanted emotional support, a fourth of cancer patients were dissatisfied with the emotional support received [19]. Healthcare professionals might not have the necessary communication skills to identify patients' individual concerns and problems [20]. The information provided may therefore be insufficiently tailored to the patients' information and communication needs, which could have a negative impact on the patient's perception of PCC. Moreover, providing high-quality patient-physician interactions can be difficult due to time constraints. It has been argued that time pressure may result in a more inflexible and disease-oriented consultation with less attention given to the psychosocial aspects of the patient's illness. As a result, the patient's perspective may be neglected and fewer psychological issues identified [21]. However, the results of an experimental study has shown that it took less than 40 seconds for a physician to be perceived as compassionate by the patient and thereby reduce the patient's anxiety levels [22].

Taken together, due to a lack of conceptual clarity as well as methodological variations between the existing studies of the effect of PCC on patient outcomes it continues to be difficult to draw any firm conclusions. Additionally, studies often fail to control for important confounders, e.g. patient demographics or disease status. The aim of the present study was therefore to investigate whether the degree of perceived PCC during oncology consultations relates to patient satisfaction and emotional distress following the encounter while controlling for pre-consultation distress and potential sociodemographic and clinical confounders. Based on previous findings, we hypothesized:

H1: Patients who perceive the oncologist to behave in a highly patient-centered manner are more satisfied with the consultation than patients who perceive the oncologist to be less patient-centered.

H2: Adjusting for emotional distress prior to the consultation, patients who perceive the oncologist to behave in a highly patient-centered manner experience lower levels of emotional distress after the consultation, compared with patients who perceive the oncologist to be less patient-centered.

2. Method

2.1. Participants

We conducted the study as part of a research project investigating cancer patients' information needs and patient-oncologist communication in an oncology outpatient clinic [23]. All patients, regardless of cancer type and treatment status, scheduled for a consultation with an oncologist at the outpatient clinic from September 20th to 25th 2010 were considered eligible if they were: 1) over the age of 18, 2) able to read and write Danish, and 3) without any severe cognitive impairments.

2.2. Procedures

One week prior to their consultation, eligible patients received written information about the study, a questionnaire-package (*Questionnaire 1*), and a closed envelope. Questionnaire 1 was to be completed before the consultation, while the closed envelope holding a second questionnaire-package (*Questionnaire 2*) was to be opened and completed immediately after the consultation. Participating patients gave their informed consent, and on the day of the consultation, they returned Questionnaire 1 prior to and Questionnaire 2 following the consultation to a research assistant who was present in the waiting room.

2.3. Questionnaires

Questionnaire 1 included questions about demographic and disease-related factors and the following instruments and single items:

1) Preferred content of information in relation to the consultation was assessed by asking patients to estimate how detailed they would want their oncologist to inform them during the consultation. Response options ranged from very detailed “*thorough information on the subject*”, “*general information on the subject*”, to “*practical information on the subject*” relevant for activities of daily living.

2) Current level of emotional distress was assessed with the 11-item brief version of The Profile of Mood States (POMS), which has been used in previous studies [24] [25] [26]. POMS is a well-validated measure often used to measure changes in emotional state after interventions for cancer patients [27] [28] [29]. The POMS-11 measures general distress, rather than its specific dimensions (e.g. anxiety or depression), and has been found to correlate highly with the total distress score of the longer version ($r = 0.93$) [24]. POMS-11 was used before and after the consultation to evaluate the immediate impact of the encounter on the patients’ levels of distress. A higher score indicates more severe distress. POMS-11 internal consistency (Cronbach’s alpha) was 0.9 before and after the consultation.

Questionnaire 2 consisted of POMS-11 and the following single items and instruments:

1) Consultation characteristics were assessed with single items concerning previous encounters with the same oncologist, the duration of the consultation, and whether a relative was present at the consultation.

2) Consultation-specific satisfaction with information was assessed with a single item from the Information Satisfaction Questionnaire (ISQ) measuring overall satisfaction with the information provided by the oncologist during the consultation [30]. Responses were given on a five-point Likert scale ranging from “very dissatisfied” (“1”) to “very satisfied” (“5”). Consistent with previous studies, the satisfaction scores revealed a ceiling effect [31] [32]. We therefore chose to dichotomize the variable into *less than maximally satisfied* and *maximally satisfied*. Although this dichotomization may lead to loss of information and statistical power, it is likely to be more valid in multiple regressions than highly

skewed continuous data.

3) Perceived patient-centered communication was assessed with a revised version of the Physician-Patient Relationship Inventory (PPRI) [6] [10] [23]. This questionnaire, consisting of 12 items and two single items, measures the patient's perception of the degree to which the oncologist exhibits PCC. The items cover several of the core functions of PCC, including exchanging information; e.g. "*the physician explained things to me so I can now understand what may be wrong with me*", "*the physicians way of responding was open and flexible, and I felt I got through to him*" fostering healing relationships; e.g. "*the physician treated me respectfully and politely*", responding to emotions; e.g. "*the physician usually sensed how I felt*", and making decisions; e.g. "*the physician gave me the opportunity to express my thoughts and feelings concerning the tests and treatments I am having*". Additionally, patients were asked to rate their satisfaction with the personal contact with the physician and the ability of the physician to handle the medical aspects of the patient's situation. The response format was a 7-point Likert scale ranging from "strongly disagree" to "strongly agree", and a higher score (range: 12 - 84) indicates higher perceived PCC. Although not validated, the PPRI has previously been reported to have adequate psychometric properties [6] [23] [33], and in the present sample, internal consistency was 0.9.

4) Severity of the patient's cancer disease was given by the oncologist based medical records and the current treatment goal (*curative intention, not curative*). Unfortunately, in 61 (27%) cases the oncologist did not report disease severity. To maintain statistical power, missing cases were coded as "*unknown*" and included in the analyses.

Data concerning the cancer type, age, and gender of the eligible non-responding patients were obtained from medical records.

2.4. Statistics

For all scales, the proportion of missing values was computed, and missings were substituted with the mean values for the remaining scale items for each patient. For cases with more than 50% of items in the respective scale, the case was omitted from the analysis [34].

An independent samples t-test was used to test hypothesis 1 (a positive association between perceived PCC and satisfaction with consultation-specific information). Hypothesis 2 (the association between perceived PCC and post-consultation emotional distress) was tested with multivariate hierarchal regressions, determining the association between perceived PCC and distress following the consultation, while adjusting for pre-consultation distress, socio-demographic, clinical, and consultation-related variables. Prior to testing a final model, in order to prevent over-fitting, three independent regressions were conducted in order to determine which variables should be included in the final hierarchical regression. The first model consisted of socio-demographic variables: age, sex, marital status, and education, the second model tested the clinical variables: cancer type, time since diagnosis, and disease severity, and the

third model tested the consultation specific variables: duration of consultation, information satisfaction, and perceived PCC. To prevent under-fitting, the significance level in the first 3 independent regression models was set at $p < 0.10$, and variables that were statistically significant at this level were carried forward to the next model. In the final model, pre-consultation distress was included together with all variables that were significant at level $p < 0.10$ in the previous three independent models. The level of significance for the final model was set at $p < 0.05$.

3. Results

A total of 226 (46%) patients gave their informed consent and completed all questionnaires (Table 1). Participants did not differ in age or gender, but were

Table 1. Patient characteristics.

	N	(%)	Mean age
Eligible patients	494	(100.0)	-
Participating patients	226	(45.7)	60.6
<i>Gender</i>			
Male	91	(40.3)	62.4
Female	135	(59.7)	59.4
<i>Age</i>			
20 - 40 years	16	(7.1)	-
41 - 50 years	28	(12.4)	-
51 - 65 years	97	(42.9)	-
>65 years	85	(37.6)	-
<i>Marital status</i>			
Married/Living with a partner	172	(76.1)	62.6
Living alone	49	(21.7)	59.9
Unknown	5	(2.2)	65.6
<i>Education</i>			
7 - 12 years of school	146	(64.6)	60.9
More than 12 years of school	73	(32.3)	59.1
Unknown	7	(3.1)	68.6
<i>Cancer type</i>			
Breast cancer	70	(31.0)	56.9
Lung cancer	33	(14.6)	64.7
Gastrointestinal cancer	26	(11.5)	67.2
Urogenital cancer	34	(15.0)	61.2
Head or neck cancer	19	(8.4)	63.8
Other cancer type	44	(19.5)	58.0
<i>Disease severity</i>			
Curative intention	99	(43.8)	59.4
Not curative (life-prolonging/palliative)	66	(29.2)	64.2
Unknown ^a	61	(27.0)	58.6
<i>Years since diagnosis</i>			
<1 year	109	(48.2)	58.9
≥1 year	114	(50.4)	62.2
Unknown	3	(1.3)	65.6

^aDisease severity was not reported by the oncologist in 61 cases (27%).

less likely to have lung cancer compared to eligible non-participants ($\chi^2(5, 443) = 11.76, p < 0.05, \phi = 0.2$).

3.1. Consultation Characteristics

Data were obtained from 226 consultations. As shown in **Table 2**, most patients came for a routine follow-up. Only few patients stated that they always saw the same oncologist, and for more than half of the patients it was their first meeting with the actual oncologist. Of those who have had previous consultations with the same oncologist, 89.7% indicated that they had been either satisfied or very satisfied with the previous consultations. More than half of the patients were accompanied by a relative. Patients with more severe disease status (not curative) were more likely to bring a relative than patients who had been treated with curative intentions or had unknown disease status ($\chi^2(2, 209) = 8.65, p < 0.05, \phi = 0.2$).

Of the sociodemographic, clinical, and psychological characteristics, only time since diagnosis was associated with preferred content of information. Patients who were diagnosed more than one year previous to participating in the study were more likely to prefer practical information compared with patients diagnosed less than one year prior to the study ($\chi^2(2, n = 211) = 10.8, p = 0.04, \phi = 0.2$).

More than two thirds of the consultations lasted 20 minutes or less. Longer duration was associated with longer education ($\chi^2(1, n = 203) = 4.1, p = 0.04, \phi = 0.2$) and the presence of a relative during the consultation ($\chi^2(1, n = 208) = 10.5, p = 0.001, \phi = 0.2$). There were no associations with age, gender, marital status, and disease severity. Patients who spent more than 20 minutes with the oncologist also reported higher levels of distress (POMS-11 Mean = 12.9, SD = 8.1) than patients who spent 20 minutes or less with the oncologist (Mean = 8.6, SD = 7.8) ($t(198) = -3.3, p = 0.001$). Additionally, more distressed patients were generally less satisfied with the duration of the consultation than patients feeling less distressed ($r = -0.2, p < 0.01$).

3.2. Satisfaction with Patient-Centered Communication (H1)

No significant associations between patients' age and gender and their perceived level of PCC. Having a partner was associated with higher levels of perceived PCC (Mean = 75.1; SD = 7.5) compared to patients who were single (Mean = 70.6; SD = 13.4), $F(2, 204) = -2.2; p = 0.03$). Although not statistically significant, there was a trend for an association between perceived PCC and the presence of a relative, indicating that patient who had a relative present at the consultation perceived the physician to communicate in a more patient-centered way (Mean = 75.1; SD = 6.7) compared with patients who attended the consultation without a relative (Mean = 72.1; SD = 12.5), $F(2, 195) = -3.1; p = 0.056$. While we found no associations between preferred content of and satisfaction with information provided at the consultation ($p > 0.05$), patients who preferred information with a practical relevance perceived the oncologist as more patient-

Table 2. Consultation characteristics.

	N	(%)	
<i>Referrals</i>			
Newly referred	6	(2.7)	
Chemotherapy	46	(20.4)	
Specific problems	37	(16.4)	
Routine follow-up	99	(43.8)	
Acute patient	1	(0.4)	
Unknown ^a	37	(16.4)	
<i>Preferred content of information detail</i>			
Thorough and detailed information	91	(40.3)	
Overall information	45	(19.9)	
Practical information	78	(34.5)	
Unknown	12	(5.3)	
<i>Previous consultations with the oncologist</i>			
This is the first time	116	(51.3)	
3 times or less	61	(27.0)	
More than 3 times	19	(8.4)	
I always see this oncologist	11	(4.9)	
Unknown	19	(8.4)	
<i>Duration of consultation</i>			
Less than 10 min	84	(37.2)	
10 - 20 min	72	(31.9)	
20 - 30 min	41	(18.1)	
More than 30 min	11	(4.9)	
Unknown	18	(8.0)	
<i>Relative present at the consultation</i>			
Yes	132	(58.4)	
No	77	(34.1)	
Unknown	17	(7.5)	
<i>Current emotional distress</i>			
	Mean (%)	SD	(Range)
Before consultation (POMS-11)	9.8	8.2	(0 - 44)
After consultation (POMS-11)	6.7	6.9	(0 - 44)
<i>Perceived patient-centered communication</i>			
Perceived patient-centeredness (PPRI)	74.2	9.3	(12 - 84)
Perceived importance of patient-centeredness (PPRI-I)	54.1	5.6	(12 - 60)
<i>Satisfaction</i>			
Maximally satisfied with information (ISQ)	(46.5)		
Less than maximally satisfied with information (ISQ)	(44.7)		
The oncologists handling of medical aspects	6.5	0.9	(1 - 7)
Personal contact with the oncologist	6.4	0.9	(1 - 7)

^aReferrals were not reported by the oncologist for 16.4% of the patients. *Note:* POMS = Profile of Mood States, PPRI = Patient Physician Relationship Inventory, ISQ = Information Satisfaction Questionnaire.

centered (Mean = 76.0, SD = 7.2) than patients who wanted to receive information on a more general level (Mean = 71.8, SD = 12.5), $F(2, 199) = 3.0$, $p = 0.05$). Patients wanting thorough and detailed information from the oncologist did not differ from either of the two remaining categories with respect to their evaluation of PCC. Following the consultation, patients who were maximally satisfied with information provided by the oncologist perceived the communication as being more patient-centered (Mean = 77.8, SD = 8.0) than patients who were less satisfied (Mean = 70.0, SD = 9.1), $t(194) = -6.4$, $p < 0.01$. Furthermore, the degree to which the oncologist exhibited PCC during the consultation was positively correlated the oncologists handling of medical aspects ($r = 0.8$, $p < 0.01$), and the personal contact with the oncologist ($r = 0.8$, $p < 0.01$).

3.3. Emotional Distress before and after the Consultation (H2)

On average, patients' experienced significantly less emotional distress after the consultation (Mean = 6.6, SE = 6.8) than prior to the consultation (Mean = 9.7, SE = 8.1), $t(198) = 7.1$, $p < 0.01$. **Table 3** presents the results of the bivariate unadjusted and the adjusted multivariate hierarchical regressions. The final model adjusted for distress prior to the consultation and included all variables statistically significant at $p < 0.10$ in the previous adjusted regressions. The significance level in the final model was set at $p < 0.05$. Four variables reached statistical significance, with emotional distress prior to the consultation being the strongest predictor of emotional distress after the consultation. Longer consultation time and having more severe disease status were associated with higher levels of post-consultation distress, whereas higher levels of perceived PCC was associated with lower levels of post-consultation distress. The final model explained 49.8% of the variance, and 6% was accounted for by the consultation characteristics, *i.e.* consultation time and PCC, corresponding to a medium Effect Size Correlation (ESR) of 0.25. Perceived PCC independently accounted for 2% of the variance corresponding to a small Effect Size Correlation (ESR) of 0.10.

4. Discussion

In the present study of cancer patients attending an oncology outpatient clinic, we examined the association between perceived PCC, patient satisfaction, and emotional distress following a consultation. Based on previous findings [5] [8] [35] [36] [37], we hypothesized that when oncologist exhibited PCC, patients would experience higher levels of satisfaction and lower levels of emotional distress. The results confirmed our hypotheses. When patients perceived the oncologist as communicating in a patient-centered way, patients were more satisfied with information received, the oncologist's handling of the medical aspects, and the personal contact with the oncologist. Moreover, while adjusting for potential confounders, including disease severity and the patients' pre-consultation levels of emotional distress, patients who perceived the oncologist's communication to be more patient-centered were also more likely to experience lower levels of emotional post-consultation distress.

Table 3. Hierarchical multivariate regression model for predicting emotional distress after the consultation.

Independent variables	Bivariate analyses		Adjusted analyses	
	β	p	β	p
Model 1: Socio-demographic characteristics				
1. Age	0.17	0.81	-0.03	0.72
2. Sex	0.09	0.20	0.09	0.24
3. Marital status (Single/living with a partner)	-0.03	0.71	0.001	0.99
4. Educational level (<12/≥12 years)	0.08	0.28	0.10	0.18
$R^2 = -0.005$, ns				
Model 2: Clinical characteristics				
5. Cancer type (Breast = reference)	-0.10	0.18	0.01	0.88
6. Years since diagnosis (<1/≥1 year)	-0.16	0.03	-0.17	0.01
7. Disease severity (Not curative intention = reference)	-0.22	0.001	-0.22	0.003
$R^2 = 0.059$, $p = 0.002$				
Model 3: Consultation characteristics		Adjusted for 6 and 7 in model 2 ($p < 0.1$)		
8. Preferred content of information (Thorough = reference)	-0.05	0.47	0.01	0.84
9. Consultation time (<20/≥20 minutes)	0.27	<0.01	0.29	<0.01
10. Information satisfaction (Less than max/max)	-0.31	<0.01	-0.19	0.01
11. Perceived patient-centered communication	-0.16	0.02	-0.17	0.02
$R^2 = 0.194$, $p = 0.002$				
$\Delta R^2 = 0.155$, $p < 0.0001$				
Final model		All variables at $p < 0.1$ in model 2 and 3		
Step 1: Pre-consultation emotional distress			0.57	<0.01
Step 2: Years since diagnosis (<1/≥1 year)			0.01	0.79
Disease severity (Not curative intention = reference)			-0.11	0.04
Step 3: Consultation time (<20/≥20 minutes)			0.20	<0.01
Information satisfaction (Less than max/max)			-0.10	0.11
Perceived patient-centered communication			-0.12	0.04
$R^2 = 0.498$, $p < 0.001$				
ΔR^2 step 2 = 0.017, ns				
ΔR^2 step 3 = 0.06, $p < 0.001$				
($R^2 = 0.03$ for consultation time; $R^2 = 0.007$ for information satisfaction, ns; $R^2 = 0.024$ for perceived PCC)				

Note: In the first three models, a significance level of 10% was chosen for adding variables in the subsequent model. In the final adjusted model, emotional distress before the consultation was entered in the first step and the significance level was set at 5%.

Although we assessed the patients prior to the consultation with respect to preferred content of information, this variable did not exceed the significance threshold ($p < 0.1$). Thus, contrary to previous findings, we found no clear indication of an association between preference for information and post-consultation distress [37] [38]. One explanation for the null-finding could be that pa-

tients may not be consistent in their information preferences before and after the consultation, as their needs may be influenced by specific events during the consultation, which may influence their current information needs, which in turn may have an effect on post-consultation emotions [38]. This is consistent with the findings of Robinson *et al.* (2012), who found that patient satisfaction appeared to be more closely linked to the actual participation in decision-making than it did to mere opportunities to participate [32]. On the other hand, we found a borderline-significant association between patients' information preferences and post-consultation satisfaction with information ($p = 0.09$), which could indicate that while tailoring of information may influence patient satisfaction, emotional aspects are more likely to be influenced by the relational aspects of PCC. Furthermore, in the bivariate and multivariate analyses conducted prior to adjusting for pre-consultation distress (Table 3, model 3), satisfaction with information was significantly associated with post-consultation distress, which could be seen as providing some support for the findings by Robinson *et al.* (2012) suggesting an indirect pathway between perceived PCC, satisfaction, and psychosocial health [32].

Our results also indicated that patients who were more distressed prior to the consultation spent longer time with the oncologist than patients reporting less distress. Moreover, when entered into the regression model, consultation time emerged as a statistically significant predictor of distress, showing that patients who spent more than 20 minutes with the oncologist were more distressed after the consultation compared to patients spending less than 20 minutes with the oncologist. Despite spending more time with the oncologist, patients who were more distressed were also less satisfied with the amount of time available at the consultation. A recent study of more than 2,500 cancer patients showed that depression was associated with feelings of insufficient consultation time [39]. General distress has shown to correlate moderately with depression [40], and one could argue that patients who are either depressed or emotionally distressed may find it harder to process information, and therefore perceive the available consultation time as insufficient. Another study found that patients being dissatisfied with consultation time were also less satisfied with the extent to which their emotional needs were met [41]. The patients in our study, who were more distressed, perceived the oncologist as being less patient-centered compared with patients, who were less distressed, and according to the findings by Ogden *et al.* (2004) they may have lacked the feeling of being seen and understood emotionally, which could explain higher level of post-consultation distress. Although disease severity was not independently associated with duration of consultation, more severe disease was associated with higher levels of post-consultation distress. However, we did not record the consultation, and since it was a medical consultation, we do not know whether some patients may have been told that their disease had progressed, hence feeling more emotionally distressed.

Given the relative large sample of patients included in the present study, we were able to adjust for a number of demographic-, disease-, and consultation

specific variables in the multivariate analyses, which is a considerable strength in our study. However, the current study also has a number of limitations that need to be acknowledged. First, our study is based on a single visit per patient-oncologist interaction and may not give a comprehensive understanding of the perception of PCC [42]. Therefore, the long-term impact of PCC on distress is unknown. Second, we only have the patients' perspectives on the oncologists' PCC, and recent critiques claim that patient-centeredness must also include the physicians' perspective on the patient's way of communicating, since physician's communicative behavior may be related to the communicative style of the patient. Hence, a comprehensive measure of PCC would involve everyone taking part in the consultation (e.g. physician, patient, relative), as the quality of the interaction itself depends on the joint involvement [43] [44]. Third, in the present study we were only given information on the physicians' age and genders. Not being able to identify the individual physician hindered multilevel modeling, which may have revealed between-physician variation in PCC. Future studies should take into account the possible variation of physicians regarding their PCC skills and including an individual identification number of participating physicians should be attempted. Fourth, the literature includes both observational and perceptual assessments of patient-physician interactions. In our study we used the perceptual approach, which has both strengths and limitations. Unlike observational approaches based on more objective measures, the perceptual approach is based on subjective, self-reported statements from the patients, and may not wholly reflect the reality of the consultation [42]. However, post-consultation outcomes often depend upon how patients perceive and interpret the events of the encounter, and patient perceptions may therefore have a greater impact on patient outcomes than the actual behavior of the physician [42]. For example, Blanchard *et al.* (1990) have shown that compared to observer-coded physician behaviors, patient perceptions explained a larger amount of the variance in overall satisfaction [45]. Nevertheless, although patients may be considered the best subjects to evaluate PCC exhibited by physicians, their responses may also be influenced by recall bias. When patients experienced lower levels of emotional distress after the consultation, they may, in retrospection, have perceived the encounter with their oncologist as more (or less) supportive than they did during the encounter. Therefore, it is not possible to establish a cause and where the effect is to be located.

Some critiques of patient satisfaction as an outcome measure has been concerned with the issue that some patients may be satisfied with inadequate health care, and that effective patient-physician communication should lead to improved patient health [46]. Research has shown that although patients and physicians may both believe they had a high-quality consultation and patients reported being very satisfied, audits still suggested inadequate care [4]. However, in the study by Robinson *et al.* (2012), they established an indirect effect by showing that increased PCC was associated with increased patient satisfaction, which in turn was associated with decreased hopelessness [32]. Therefore patient

satisfaction will continue to be a valuable and informative measure in regard to patient outcomes, such as emotional distress.

5. Conclusion

The results in the present study generally confirmed that patient-centeredness may be an important quality goal in oncology settings as an approach to positively influence patient outcomes, including emotional distress. However, the findings in the present study of an effect of PCC on patient satisfaction and emotional distress are modest and conclusions are limited to the present sample, and thus we are not able to draw any firm conclusions.

6. Practice Implications

Patient-centered communication is reliant on both the physician's ability to identify and respond to the patient's needs, as well as communicating at times rather complex information. Oncology settings may therefore benefit from the positive effects of patient-centered care and physicians should acknowledge the potential of their own relational messages in order to facilitate patient-centered communication.

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Relationship between Level of Knowledge on Anger Control and Occurrence of Real Assaultive Behaviour in Patients (20 - 45 Years) Admitted at a National Referral Psychiatric Hospital in Zimbabwe

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Abstract

Background: Aggressive tendencies from psychiatric inpatients are increasingly becoming problematic at a national referral psychiatric hospital in Zimbabwe. No research has been done in this context to determine the dynamics around this disturbing phenomenon. **Objectives:** To determine the level of knowledge on anger control, to determine the occurrence of real assaultive behaviour and to examine the relationship between level of knowledge on anger control and occurrence of real assaultive behaviour in patients aged 20 - 45 years admitted at a national referral psychiatric hospital in Zimbabwe. **Method:** A descriptive correlational design was used. Seventy-six respondents aged between 20 and 45 years were selected using simple random sampling. A structured interview was used to collect data. The occurrence of real assaultive behaviour was adapted from the Staff Observation and Aggression Scale completed by observing patients during the assaultive behaviour occurrence. Patient observation was done by the psychiatric trained nurses who were specifically trained for this study to fill the part of the data collection instrument that needed observation. Data were analysed using descriptive statistics, Pearson Correlation Coefficient test and simple regression analysis. **Results:** Results showed a Pearson coefficient test of ($r = -3.47$, $p < 0.01$). R-Squared indicated that levels of knowledge on anger control accounts for 12% variance in the occurrence of real assaultive behaviour. **Conclusions:** Results call for collaboration of mental health practitioners to empower patients with anger control skills.

Keywords

Assaultive Behaviour, Anger Control, National Referral Psychiatric Hospital,

Risk, Psychiatric Nurses, Staff Observation and Aggression Scale-Revised

1. Introduction

Assaults pose as an increasing problem for mental health service employees. In a study conducted over three years in just one hospital, results showed that there was a total of 41,631 hospital treated assaultive injuries, 13,698 admissions and 27,933 emergency cases in patients whose age was 15 years and over [1]. One incident of assaultive behaviour constitutes a psychiatric emergency because it implies injury or death to staff, other patients and the assaultive patient himself [2] [3]. Evidence has shown that destruction of property, injury and death can result from aggression [4]. In a study conducted to determine annual rates of assaults to psychiatrists, 42% of respondents were assaulted more than once. 61% of the assaults were committed by patients from general psychiatry and half occurred during urgent assessments. 58% of assailants were known to have previously assaulted a member of staff and 88% of the assailants had been drinking alcohol prior to the assault [5].

Anger appears to be an important emotion linked to assaultive behaviour [6]. Anger and occurrence of assaultive behaviour have been studied widely and outcomes of these studies show that the majority of subjects have poor anger control [7]. As a result, anger management control programs have been developed to give alternative strategies to control and express anger impulses.

Assaultive behaviour was a major problem in cases admitted at the national psychiatric hospital in Zimbabwe at the time of the study. Assaultive behaviour was observed to be directed at family members, friends, acquaintances and health care professionals. This study therefore sets out to find out the correlation between level of knowledge on anger control and occurrence of real assaultive behaviour in patients (20 - 45 years) admitted at the national psychiatric hospital in Zimbabwe.

In the study, real assaultive behaviour was conceptualised as an event of any verbal or physical behaviour that was threatening to others, self or property. It was operationalized through the occurrence of real assaultive behaviour data sheet/scale modified from the Staff Observation Aggression Scale-Revised (SOAS-R) [8]. Level of knowledge on anger control was conceptualised as having awareness of information, insights and skills on how to control patient's own anger.

2. Methods

A descriptive correlational design was used. The variables under study were knowledge on anger control as the independent variable and occurrence of real assaultive behaviour as the dependent variable. A sampling frame was developed for inpatients that met the inclusion criteria. Simple random sampling was used in the study. The method was chosen to increase representativeness, decrease

systematic bias and decrease sampling error [9]. Respondents were chosen from the national referral psychiatric hospital. It was therefore perceived to be representative of the target population and generalisations could be made from the population from this type of setting [10].

2.1. Inclusion Criteria

The patients who were included were those who:

- Had been admitted with a history of violent behaviour at the national referral psychiatric hospital;
- Were between the ages of 20 - 45 years;
- Were confirmed to have a psychiatric disorder;
- Were able to communicate verbally in English, isiNdebele and Shona.

2.2. Sample Size

The sample size was calculated following consideration of amount of variance in the phenomenon, statistical analysis assumption, significance level, power, effect size and potential attrition rate. The medium effect size of 0.5 was utilised as recommended for nursing studies [11]. Power calculations were based on the Lipsey (1990) tables for estimating sample size [12]. In combination with other indicators for sample size, an effect size of 0.5, level of significance of 0.05 and a power of 0.80, the study had an adjusted sample of 80 patients who met the criteria for the study.

2.3. Instrumentation and Data Collection

The instrument had three parts: the demographic data, occurrence of real assaultive behaviour (modified Staff Observation Aggression Scale) and the level of knowledge on anger control part. Face to face interviews were done for the demographic data and for level of knowledge on anger control.

Demographic variables were operationalized as those attributes of the respondents that described them. These included but were not limited to age, gender, marital status, religion, employment level of education and residence. Level of knowledge on anger control was conceptualised as awareness of information, insights and skills on how to control patient's own anger. This had a minimum score and a maximum score. The score attained by the respondent indicated their level of knowledge on anger control. The minimum score represented limited knowledge on anger control while the maximum score represented adequate knowledge on anger control by the respondent.

Occurrence of real assaultive behaviour data was collected using the modified Staff Observation Aggression Scale [8]. The instrument measured frequency, severity and determinants of inpatient aggression. The researcher trained the psychiatric trained nurses to correctly record any incidents/episodes of verbal and physical abuse (incident data) as they occurred to inpatients in the study. The member of staff recording the incident indicated the target of assault, source of provocation, means used to assault, consequences for victims/results and meas-

ures taken to stop the assault. Staff recording the incidents behaved normally in their stations of clinical practice.

2.4. Ethics

Permission to conduct the study was obtained from the Medical Research Council of Zimbabwe, study site (the national referral psychiatric hospital) and from respondents who participated in this study.

2.5. Data Analysis

Data was analysed using the Statistical Package of Social Sciences (SPSS). Research questions were analysed using descriptive and inferential statistics. Descriptive statistics were used to describe demographic information, level of knowledge on anger control and occurrence of real assaultive behaviour among in patients with a history of violent behaviour (20 - 45 years) admitted at a national referral psychiatric hospital in Zimbabwe. The second stage of analysis involved examining the relationship between level of knowledge on anger control and occurrence of real assaultive behaviour among in patients with a history of violent behaviour (20 - 45 years) admitted at a national referral psychiatric hospital in Zimbabwe. A Pearson product moment correlation was calculated between knowledge on anger control and occurrence of real assaultive behaviour. Statistical significance was set at the 5% level or at $\alpha < 0.05$. Simple linear regression was used to examine the strength of the relationship between knowledge on anger control and occurrence of real assaultive behaviour.

3. Results

The following research questions were answered:

- 1) What is the level of knowledge on anger control in patients with a history of violent behaviour (20 - 45 years) admitted at the national referral psychiatric hospital in Zimbabwe?
- 2) What is the occurrence of real assaultive behaviour in patients with a history of violent behaviour (20 - 45 years) admitted at the national referral psychiatric hospital in Zimbabwe?
- 3) What is the relationship between level of knowledge on anger control and occurrence of real assaultive behaviour in patients with a history of violent behaviour (20 - 45 years) admitted at the national referral psychiatric hospital in Zimbabwe?

3.1. Sample Demographics

The discussion of sample demographics will dwell only on major findings for each variable. The study consisted of seventy six respondents and were all admitted at a national referral psychiatric hospital in Zimbabwe at the time of the study. The demographic characteristics of the respondents generally reflected their inherent predisposition to assaultive behaviours or tendencies.

Respondents were aged between twenty and forty five years. Results showed a

mean age of 33.64 years with a standard deviation of 7.25. Studies on assaultive behaviour and age generally support that assaultive behaviour peak in the twenties [13]. All the 76 (100%) respondents who met the inclusion criteria were male. This supports available evidence that the violent patient is typically male under the age of forty five years [14]. The majority, 88.2% were Christians. Empirical evidence has extensively demonstrated that there is a significant relationship between religion and aggression especially where the target of aggression threatens the values of the aggressor [15]. This could have been the case with assaultive Christian inpatients admitted at the national referral psychiatric hospital.

Marital status of 55% of respondents were single, 23% were divorced and only 22% were married. Studies have underscored the reality of physical and psychological aggression within marriages [16]. It is therefore possible that this could have contributed to either the singleness or divorce statuses among the respondents in the study. They probably can't cope with marriage because of their inherent vulnerability of being mentally ill. 57.9% of the respondents stayed in urban high density areas while the rest were spread between mining towns and rural areas. It has been established that aggression and violence is common among public housing residents highlighting the influence of the crowded, noisy environments on assaultive dispositions [17]. It is therefore conceivable that while psychiatric patients were admitted at the national referral psychiatric hospital, they already had the propensity for aggression owing to their preadmission environments of origin. 63.2% were unemployed and only 52.6% had attained secondary education. In a separate study, a similar conclusion was reached that lower education and unemployment are risk factors for assaultive tendencies [18].

3.2. Level of Knowledge on Anger Control

Knowledge on anger control is essential in reducing occurrence of real assaultive behaviour. On level of knowledge on anger control, the minimum score was 0 and the maximum possible score was 12. 46% of respondents scored above the mean. Results revealed a generally low level of knowledge on anger control. Scores of below 50% are a cause for concern because it shows that the respondents' level of knowledge on anger control was not adequate. The results are contra directional to the position of a study that underscored the importance of an individual knowing their anger style, learning to monitor their anger and learning to deescalate their anger [19]. That way, they would be more likely to utilise that knowledge for anger catharsis.

3.3. Occurrence of Real Assaultive Behaviour

Assaultive behaviour is of major concern in psychiatric settings. Given the high and increasing rate of assaults on other patients as revealed in this study, it would be beneficial if the psychiatric nursing staff were able to predict, anticipate and possibly identify potentially assaultive patients. Assaultive behaviour

was categorised into: how many times the patient had been assaultive during a four week period, what provoked the patient, means used for assaulting, target of assault, consequences of the assault and measures taken to stop the aggression.

In this study, during the 4 weeks of observation, the episodic frequencies were as follows:

34.2% had one episode of either physical or verbal assault closely followed by 31.6% who had more than four episodes. Related studies are clear to say that one incident of assaultive behaviour constitutes a psychiatric emergency as it implies injury or death to staff, other patients and the assaultive patient himself [2] [3]. According to literature sources, aggression in psychiatric patients can result in destruction of property injury or even death. In view of these findings, the results are a reflection of a crisis [20]. The study had 25% of patients requiring treatment and 5.3% requiring specialist treatment. It is important to note that with the crisis of this magnitude, the priority measure to stop the aggression was talking to the patient. Use of both injectable and oral medication was minimal. One wonders if the medicines were available for use.

On target of aggression, other patients were the most frequent target for violence accounting for more than half of the episodes. It is also interesting to note that the majority 46.1% of cases, the patients were provoked by other patients in the psychiatric unit while in 22% of cases the patients were provoked by being denied something. Studies have consistently indicated that assaults often take place during times of high activities and interactions such as meal times, during visiting hours and patient transportation [21].

On means used, results indicated that majority of assaults were verbal, accounting for 64% of assaults. A significant correlation between hostile verbalisation and physically assaultive behaviour was found to actually exist [22]. This means that patients who are verbally abusive are likely to be physically assaultive as well. This implies that all verbal assaults are not to be ignored but to be reported as these can escalate to physical assaults.

Measures to stop aggression included talking to the patient by staff in 44.7% of cases. It was found that there was limited medication at the institution at the time of the study. The staff therefore had limited options with which to stop the aggressive tendencies of patients. This resource constrain translated to potential for harm to staff, other patients and property.

3.4. Relationship between Level of Knowledge on Anger Control and Occurrence of Real Assaultive Behaviour

Pearson correlation analysis was used to examine the relationship between level of knowledge on anger control and occurrence of assaultive behaviour. The correlation coefficient is an index that measures the strength or magnitude and direction of a linear relationship [23]. After computing the Pearson correlation coefficient it was found to be -0.347 . The negative sign (-3.47) on the correlation coefficient indicates that there is a negative linear relationship between level of knowledge on anger control and occurrence of real assaultive behaviour. It

means that as the independent variable increases, the dependent variable decreases. The results therefore support that as level of knowledge increases, there is reduction of occurrence of assaultive behaviour. It is also important to note that the level of knowledge on anger control was negatively correlated with the occurrence of assaultive behaviour ($r = -0.347$, $p < 0.01$). This signifies a weak association between the independent variable and the dependent variable [24].

Regression analysis was used to examine the strength of the relationship between anger control and occurrence of real assaultive behaviour. The effect of the level of knowledge on anger control (independent variable) was indicated by $R\text{-Squared} = 0.120$. This means that the effect of level of knowledge on anger control accounts for 12% of the variance in occurrence of assaultive behaviour. Unstandardised beta (0.235) represented a change in the occurrence of real assaultive behaviour for every unit change in the level of knowledge on anger control. The significant Beta indicated the relative importance of the level of knowledge and occurrence of real assaultive behaviour. For the study, that importance was 34.7% in terms of contribution to the occurrence of real assaultive behaviour. The level of knowledge on anger control therefore has a negative influence on occurrence of real assaultive behaviour.

4. Discussion

Research has consistently shown that anger is an appropriate and normal response to any stimuli perceived as threatening. An individual's interests are protected and preserved because the individual would have been motivated by anger to take action. Anger and aggression also avail important set of circumstances for socialisation and establishment of willpower, self-mastery or the ability to control oneself.

Having a patient in a clinical setting translates to the fact that they would have failed to express their anger in a socially acceptable manner needing to be put in a setting where others can control him/her. Health care providers tasked with this opportunity will then need to conduct a focused patient assessment that picks those triggers that put the patient at risk of exhibiting assaultive tendencies. The assessment should include history of impulsive and aggressive behaviour, abuse of substances and their support system. In the management of the patients with assaultive behaviour, use of standardised policies and procedures should be given high priority. All these strategies become complete when the patient himself has some semblance of control on what happens to him. This translates to the notion of developing and supporting anger control skills at individual level. Empowerment of the psychiatric patient assists them to be conscious of what works for them when they are coping with stressful life events or threatening stimuli. In the process, this reduces the tendency of aggression as a default system for a psychiatric patient under pressure.

5. Implications to Practice

The following is an inference and indication of the direction nursing practice

should take in view of the study results:

- There is need to train psychiatric patients in cognitive skills of coping with and expressing anger in adaptive ways. This will prevent assaultive tendencies both in and out of custody/hospital. To target males in their thirties as they are more prone to real assaultive behaviour.
- Periodic training of staff to deal with violence in the workplace. Although there are varied ways of dealing with assaultive behaviour, preventive training of staff in risk assessment should take priority especially in the study setting where there are limited options of medications that would be needed for a violent patient.

5.1. Implications to Research

Mental health research should take cognisance of the following:

- Mental health and psychiatry should be influenced by research and be evidence based. This calls for focus of future research which should be inclined towards development of a psychological profile of patients most likely to be assaultive. Some variables that might be considered in developing such a profile include personality factors such as level of paranoia, anxiety, familial violence, childhood discipline, intellectual ability and history of assaultive behaviour.
- The findings indicate that there is need for further study on impact of verbal threats/assaults to other patients and staff.
- Further research is needed to find out more information about other variables that seem to have an effect on occurrence of real assaultive behaviour since this study revealed that level of knowledge on anger control accounts for only 12% of variance in occurrence of real assaultive behaviour.

5.2. Limitations of the Study

- Part of data was collected through observations which means those forms were filled by staff other than the researcher. This could lead to interrater unreliability. To contain this problem, observers were trained and were requested to observe and record the same events independently using developed protocol. Comparison of data was done and differences were ironed out.
- Data collected through use of the Staff Observation Aggression Scale-Revised (SOAS-R) was limited to the extent that staff observing an aggressive behaviour were able to provide an accurate account of it. This was contained by training the staff on how to correctly observe and document the observed behaviour.
- The study targeted only hospitalised patients exhibiting assaultive tendencies and excluded other patients receiving care in the community. Results cannot be generalised beyond hospitalised patient populations.
- Three languages were used in collecting data. Some respondents communicated in English while others responded in isiNdebele and Shona. It is possi-

ble that respondents might have understood questions differently.

6. Conclusion

Results call for collaboration of mental health practitioners, researchers and policy makers to empower patients with anger control skills. This will reduce occurrence of assaultive behaviour among inpatients in psychiatric units and hospitals. Preventive efforts that include identifying triggers and providing appropriate medications should be of high priority in inpatient treatment settings for psychiatric patients in Zimbabwe.

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Shared Decision Making in Residential Aged Care: A Framework Synthesis

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Abstract

Very little is known about shared decision making (SDM) in residential aged care, despite world-wide policy and imperatives that encourage resident choice and autonomy. This paper provides a framework synthesis of SDM in residential aged care (RAC) and potential barriers and enablers to implement SDM utilising a theoretical framework of implementation. A review of the literature on SDM in RAC from 2005 to 2016 was undertaken, using MEDLINE (Ovid), CINAHL, PsychINFO and Scopus. The articles were synthesised by utilising an implementation theory framework to better understand what may facilitate or hinder the introduction of SDM. Eighteen studies were identified and analysed to determine barriers and enablers to SDM in RAC from the perspectives of staff, residents and relatives. A workplace culture of person-centred care and judicious use of research evidence are enablers of SDM. There is a potential need for additional resources, such as education for staff and families to enable implementation of SDM. Implementation of any health care intervention, including SDM, relies on many complex factors but these are predominantly related to capacity. Determining current uptake and readiness of RAC organisations, residents and their families to adopt SDM is an essential starting point.

Keywords

Narrative Synthesis, Shared Decision Making, Residential Aged Care, Implementation

1. Introduction

Shared decision making (SDM) brings clinicians and patients together about making shared decisions on patient's care, as opposed to clinicians making decisions on behalf of the patient [1]. SDM is considered the pinnacle of Person

Centred Care (PCC) [2]. SDM integrates patient values, goals and concerns with the best available evidence about benefits, risks and uncertainties of treatment to achieve an option which is acceptable to both the patient and the clinician [3]. SDM is based on important moral, ethical and legal principles, and is recognised as important in developing a genuinely patient-centred health system [4]. The core of SDM is that individual self-determination and autonomy are desirable goals for patients [2].

There are no existing definitions of SDM specific to differing health care settings. In general, Coulter and Collins [5] describe three essential components of SDM:

- The patient is provided with current, unbiased evidence based information about potential treatment, care or support clarifying outcomes or uncertainties
- There is decision support counselling with a clinician to clarify options and patient preferences
- There is a robust system to record patient preferences, to communicate them to others and to execute the preferred choice.

SDM is poorly understood by clinicians [6] who, in addition, may not have a sufficient level of research literacy to fully understand evidence based findings from the literature [7], let alone translate those findings in a meaningful way in a patient encounter. Current research in SDM has been limited to measuring processes used by clinicians in patient/clinician dyads as well as focusing on patient perspectives of their involvement and satisfaction with the decision making process, or clinicians' opinions on SDM effectiveness [8].

Very little is known about SDM in residential aged care (RAC) settings, despite increasing emphasis on resident choice and autonomy in aged care reforms internationally [9] [10] [11]. Likewise knowledge specific to the implementation steps required successfully achieving SDM in the context of RAC is unknown. This is problematic given that the World Health Organization (WHO) advocates for a human rights approach for health and ageing including the right of a person to actively participate in decision making about their health care, as a basis for quality of care [12]. SDM is increasingly advocated in clinical guidelines and health care policy [3] [13] [14]-an imperative that health care providers cannot achieve without a greater understanding of the enablers and barriers to implementation.

2. Design

We synthesised the literature for current practices and processes for potential implementation of SDM in RAC from the perspective of staff, residents and resident's families. A narrative synthesis approach was utilised as opposed to a rigid systematic review. A systematic review uses strict criteria to summarize the evidence of studies and focuses on the effectiveness of an intervention. On the other hand, a narrative synthesis employs a textual approach to examine the heterogeneity of studies and population groups, while incorporating principles of a

systematic review. Application of the strict criteria of a systematic review would have excluded relevant studies concerned with implementation of the phenomena under review. Hence, a narrative synthesis was better suited to describe the scope of the existing SDM concepts to describe implementation in practice.

Narrative synthesis enabled the interpretation of isolated research findings which used different research approaches. We used framework synthesis, described by Richie and Spencer [15], based on existing conceptual framework to identify *a priori* themes [16].

2.1. Conceptual Framework

Two frameworks were utilised for this review. Previously identified terms and the taxonomy and mapping of concepts [17] was utilised for the search strategy. The studies are described using this conceptual framework to show the relationship to SDM. The findings from this search are then synthesized using May's theory of implementation [18], to explain how the findings relate to clinical practice.

Embedding SDM as a new healthcare intervention within the usual clinical practice may be challenging. May [18] proposes implementation of a new intervention as a social process of collective action as it never refers to a single 'thing' that is to be implemented but rather a complex bundle of material and cognitive practices to be introduced into a social system. It follows that a process as complex as SDM needs substantial support and planning before and during widespread implementation into clinical areas to enable its success [19]. A theoretical framework of implementation characterises the elements of context and agency within a social system, that enable capacity to implement change [18]. May's [18] framework provides a template to understand health care contexts and the elements involved which act as barriers or enablers to implementation of new interventions. The key components of May's framework include potential, capacity, capability and contribution to implementation in practice.

A conceptual framework is an essential component for undertaking framework synthesis [20]. A framework guides decisions regarding analysis and assists in the interpretation of findings [21].

2.2. Search Strategy

The first author extensively reviewed the literature from August to December in 2015 and updated the search in November 2016. An anticipated complexity of the literature search was the multiple terms used independently and interchangeably for SDM. The heterogeneity of the concepts, definitions and terms used in relation to SDM has been described by other authors [22]. Makoul and Clayman [23], found in a review of 418 papers devoted to SDM that the terms "patient preference" and "options" were terms used in more than half. Policy documents frequently refer to "patient choices" [24] and "consumer participation" [25]. Cooper [26] supports incorporating the broadest conceptual definitions possible.

Subsequently the search strategy was based on previously identified terms and concepts developed in a taxonomy and mapping of SDM [17]. Additional terms used to describe RAC internationally and traditionally were added (such as long term care and nursing homes). Because the focus was clinical practice, clinicians were defined by terms used internationally in the literature (care staff, nurses, allied health and medical staff). The search was adapted to each bibliographic database and Medical Subject Headings (MeSH) used where possible.

Search terms used for SDM and related concepts were;

“Shared decision making” OR “decision-making” OR “patient preference” OR “patient option” OR “patient choices” OR “consumer participation” OR “Consent” OR “guardianship” OR “advocacy” OR “proxy” OR “next of kin” OR “advance care plans” OR “patient centred care” OR “patient autonomy” OR “evidence based practice” OR “variations in care” OR “training” OR “education” OR “health literacy” OR “decision aids”.

To capture the relevant literature in residential aged care settings, SDM search terms were combined with AND for: “residential aged care” OR “nursing home” OR “long term care” OR “care staff” OR “medical staff” OR “allied health” OR “nurses”.

Bibliographic data bases searched included MEDLINE (Ovid), CINAHL, PsychINFO and Scopus.

2.3. Inclusion/Exclusion Criteria

Articles related to governance and occupational health and safety were excluded since the aim was to explore practice and processes relevant to SDM implementation in RAC. Studies conducted in settings other than RAC, such as community or transitional care, were excluded. Studies prior to 2005 were excluded to give a contemporary account of existing models and processes. Studies reported in languages other than English were also excluded. Qualitative and quantitative, or mixed methods research approaches were included, plus one case study due to its relevance to the topic under consideration. Systematic reviews were excluded but the reference lists were searched.

2.4. Screening

Quality appraisal of the methodology of the studies and risk of bias was not a central focus. Studies were critically appraised by the first author using the Critical Appraisal Skills Program (CASP) tool [27], to determine validity of the aims and methodological quality.

The search yielded 374 articles, Medline-153, PsychINFO-105, Scopus-47, CINAHL-44, Pubmed-27. Experts in the field of SDM were also contacted to provide other sources of potential studies, which provided three additional articles. The total was reduced to 300 when 76 duplicates were removed. Of the 300 remaining articles, 211 were excluded after reading the abstracts because they were not studies related to the search for models or processes of SDM in

aged care, but focused on tool development or discussion or alternative settings. Eighty nine full text articles were screened and a further 62 excluded for being irrelevant to the research question. Of the 27 remaining articles, nine screened negatively to the two initial screening questions of the CASP and so were eliminated. The final 18 articles are described using the conceptual framework and synthesized using May's theory of implementation. A flow chart shows the selection process in **Figure 1**.

3. Findings from the Literature Search

Seventeen of the articles were published peer reviewed research articles and one a research report. The study designs, year of publication, country or origin, intervention, concept related to SDM and major findings are listed in **Table 1**. In addition, **Table 1** shows the target population, whether the study was conducted with staff, residents or families or a combination. Ten of the studies included

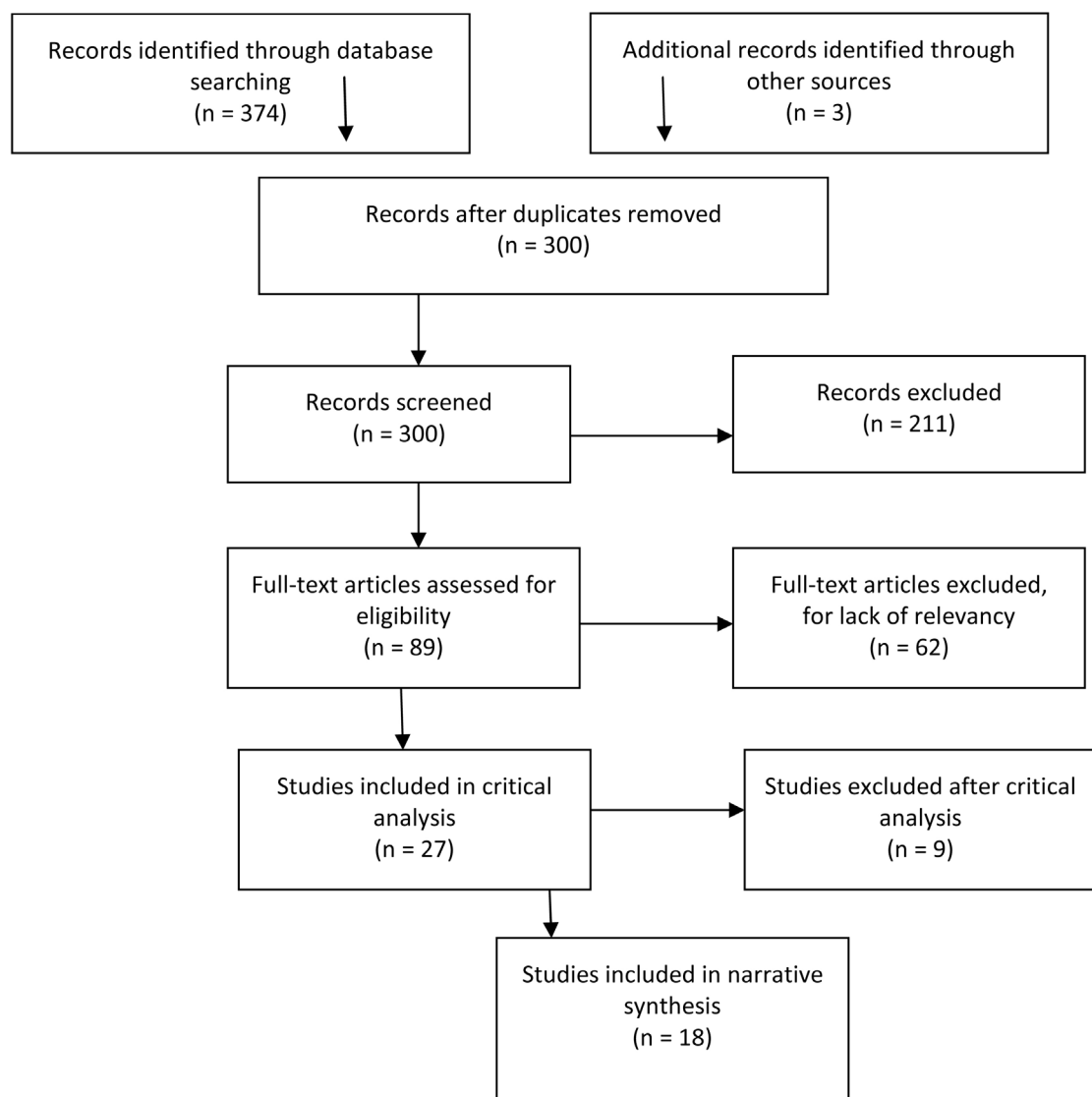


Figure 1. Process of article selection.

Table 1. Summary of included studies related to SDM in residential aged care.

Author-title	Study participants	Study aim	Country	Method	Primary concept/s related to SDM	Finding-potential barriers or enablers to SDM implementation
Qualitative						
Abrahamson, K., Bernard, B., Magnabosco, L., Nazir, A., & Unroe, K. The experiences of family members in the nursing home to hospital transfer decision. (2016) [28]	Relatives	The experiences of family members in the nursing home to hospital transfer decision making process	USA	Interviews	Readiness Evidence based information	Barrier Information on the risks of hospitalisation may assist family members to make decisions. Family roles are variable depending on readiness to make decisions.
Arendts, G., Popescu, A., Howting, D., Quine, S., & Howard, K. “They never talked to me about...” Perspectives on aged care resident transfer to emergency departments. (2013) [29]	Residents, relatives and staff	To explore perspectives concerning decisions to transfer residents to emergency departments	Australia	Interviews	Readiness	Barrier SDM rarely occurred, staff were paternalistic and denied stakeholders choice. Relatives expressed both unpreparedness to make decisions and had conflicting opinions to staff.
Fetherstonhaugh, D., Tarzia, L., Bauer, M., Nay, R. & Beattie, E. “The red dress or the blue?” How do staff perceive that they support decision making for people with dementia living in residential aged care facilities. (2014) [30]	Staff	Staff perceptions of supported decision making for residents with dementia	Australia	Interviews and focus groups	PCC	Enabler Existing culture of PCC. Staff awareness of strategies to support resident decision making. Informed consent apparent in staff ensuring information was understood.

Continued

Gjerberg, E., Lillemoen, L., Forde, R., & Pedersen, R. End-of-life care communications and shared decision making in Norwegian nursing homes-experiences and perspectives of patients and relatives. (2015) [31]	Residents and families	Perceptions of SDM in end of life care	Norway	Interviews and focus groups	Readiness	<p>Enabler</p> <p>Explored readiness for residents and families in SDM for end-of life care.</p> <p>Found that health care professionals should take responsibility for initiating conversations and involve families with consent. SDM should be individualised and iterative.</p> <p>Barrier</p> <p>Some residents and families expressed unpreparedness for SDM. Differences between residents in desire for SDM. Most relatives wanted to be involved in decisions but entrusted staff to make final decisions.</p>
Iden, K., Hjørleifsson, S., & Ruths, S. Treatment decisions on antidepressants in nursing homes: A qualitative study. (2011) [32]	Staff	Explores decision making about treatment with antidepressants	Norway	Interviews and focus groups	Evidence based information	<p>Barrier</p> <p>Lack of EBP and resident/family involvement SDM in antidepressant prescription.</p>
Mann, E., Goff, S., Colon-Cartagena, W., Bellantonio, S., & Rothberg, M. Do-not-hospitalize orders for individuals with advanced dementia: Healthcare proxies perspectives. (2013) [33]	Families	Explores health care proxies understanding of do-not-hospitalize orders and why they may or may not initiate them	USA	Interviews	Evidence based information Readiness	<p>Barrier</p> <p>No collaboration with families to improve capacity to make informed decisions that reflect individual values and wishes.</p>
Norheim, A., & Vinsnes, A. Factors that influence patient involvement in nursing homes: staff experiences. (2012) [34]	Staff	Explores staff experience of factors influencing patient involvement	Norway	Focus groups	PCC Education	<p>Enabler</p> <p>Staff education in PCC. Staff stressed the importance of patient-centred attitudes for resident involvement in decision making.</p> <p>Barrier</p> <p>Time pressure was a key limiting factor to PCC.</p>

Continued

O'Shea, F., Weathers, E., & McCarthy, G. Family care experiences in nursing home facilities. (2014) [35]	Families	Explore relatives involvement in the care of older people admitted to RACF's	Ireland	Interviews	PCC	Barrier Families excluded from participating in decision making. Staff task oriented not PCC. Interventions that engage residents and their families in care required.
Sims-Gould, J., McKay, H., Feldman, F., Scott, V., & Ribonovitch, S. Autonomy, choice, patient-centred care and hip protectors: The experience of residents and staff in long term care. (2013) [36]	Residents and staff	Examine perceptions of staff and residents on the decision to use hip protectors and factors which influence decisions	Canada	Focus group (Part of a larger mixed methods study)	Evidence based information	Barrier Evidence based research took precedence over resident choice. Insistence on EBP even when explicitly declined by the resident.
Tarzia, L., Fetherstonhaugh, D., Bauer, M., Beattie, E & Nay, R. "We have to work within the system!" Staff perceptions of organizational barriers to decision making for older adults with dementia in Australian aged care facilities. (2015) [37]	Staff	The perceptions of staff regarding organizational barriers that prevent facilitating decision making for residents with dementia	Australia	Semi-structured interviews and Focus groups.	PCC	Barrier Staff perceived there was not enough time to facilitate decision making and that education and training is required for the skills as a facilitator. Policies and procedures needed to support practice in facilitated decision making.
Quantitative						
Ampe, S., Sevenants, A., Smets, T., Declercq, A & Van Audenhove, C. Advance care planning for nursing home residents with dementia: policy vs. practice. (2015) [38]	Staff	Evaluate advance care planning policy for people with dementia, and family involvement in advance care planning in practice	Belgium	Audit, self developed ACP questionnaire and OPTION scale	ACP	Barrier Staff failed to discuss the risks and benefits of treatment options with residents or their families. Strategies are required to translate ACP policy into practice. Staff training is required and greater family involvement recommended. Enabler Resident and family readiness for SDM was assessed on admission.

Continued

Eloranta, S., Arve, S., Isoaha, H., Aro, I., Kalam-Saliminen, L. & Routasalo, P. Finnish nurses' perceptions of care of older patients. (2013) [39]	Staff	Explores how far nurses' perceptions of care take into account preferences of older patients and their families	Finland	Questionnaire (25 item purpose-designed from gerontological nursing literature)	PCC	Barrier Staff reluctance and difficulty in practicing SDM, due to perceived expertise of staff. One third of nurses make decisions on patient care themselves. Staff asked the views of patients less frequently than those of family members.
Hanson, L., Carey, T., Caprio, A., Lee, T., Ersek, M., Garrett, J., Jackman, A., Gilliam, R., Wessell, K., & Mitchell, S. Improving decision-making for feeding options in advanced dementia: A randomised, controlled trial. (2011) [40]	Residents and families	Testing quality of decision making about feeding options using a decision aid	USA	RCT-Questionnaire (Decisional conflict scale administered at 1 and 3 months)	Evidence based information Education	Enabler Evidenced based research, utilising decision aids reduced decisional conflict for families and increased knowledge and communication with care providers about feeding options.
Helgesen, A., Athlin, E., & Larsson, M. Relatives' participation in everyday care in special care units for persons with dementia. (2015) [41]	Families	To determine relatives participation in everyday care for persons living in dementia specific facilities and factors which influence it	Norway	Questionnaire (Study specific-derived from 2 previous studies by same researcher)	PCC	Barrier Lack of PCC and SDM. Families seldom participated in decisions about everyday care though half perceived their participation was crucial for PCC.
Werner, P. Perceptions regarding the use of physical restraints with elderly persons: comparison of Israeli health care nurses and social workers. (2005) [42]	Staff	To explore the perceptions of health care workers and social workers on the use of physical restraints with elderly people	Israel	Questionnaire (Perception of restraint use questionnaire)	Evidence based information	Enabler Decision support role for mediation between residents and their families and staff member. Both groups perceived EBP to be important, but decision support role could be strengthened. Barrier Evidence abrogated SDM. Moral dilemmas for staff.

Continued

Mixed methods						
Bauer, M., Nay, R., Bathgate, T., Fetherstonhaugh, D., Winbolt, M., & McAuliffe, L. Constructive staff/family relationships in residential aged care. (2009) [43]	Staff and families	To identify and address barriers to constructive staff-family relationships	Australia	Interview & 2 Questionnaires (34 item adapted version of previously developed British survey tools)	Education	<p>Enabler Staff and family education in PCC, information exchange and communication to facilitate improvements in staff-family relationships.</p> <p>Barrier Differences in staff and family perceptions about information exchange and communication (SDM).</p>
Blackford, J., Strickland, E & Morris, B. Advanced care planning in residential aged care facilities. (2007) [44]	Staff	To describe lessons learned in implementing an advanced care planning program	Australia	Case studies Interviews Questionnaire (unspecified) Informal feedback	ACP Education Documentation, communication and enacting	<p>Enabler Collaborative decision making was facilitated by introduction of advanced care planning.</p> <p>Barrier Sustainability depended on governance structures, educational processes, resident documentation, quality audits and communication. Varying success of sustainability over time. Resources and continued staff education are required over a long time period.</p>
Case study						
Jeong, S., Higgins, I & McMillan, M. Advance care planning (ACP): The nurse as “broker” in residential aged care facilities. (2007) [45]	Residents, families and staff	To describe how advanced care planning is implemented and the role of a clinical nurse consultant	Australia	Case studies in 3 RACF’s.	ACP Enacting	<p>Enabler Decision support and education for staff and families. Additional staff performed roles of mediation, assessment, intervention, coordination, communication and education in advanced care planning.</p>

were published since 2013 and of the remaining eight only four are older than 2009.

Two of the studies retrieved explored SDM in RAC in the context of advance care planning. The other models focused on person-centred care, evidenced based care and models of advance care planning with perceptions of the con-

cepts of decision making or shared decision making within each model, from the perspective of staff, residents and families. One of the studies aimed to measure the process of SDM as a primary outcome. The term “shared decision making” was only found in two of the studies.

The target populations of staff, residents and families was represented across the retrieved articles, providing perspectives of all groups about decision making processes, which helped to reduce bias of the findings collectively.

Eight of the studies are explicitly related to decision making in RAC, though only one described the process of SDM as described by Coulter and Collins [5]. All other studies are implicitly related and concerned with relevant concepts related to SDM, such as person centred care, evidence based practice and knowledge or education. Nine of the studies illustrate potential barriers to SDM implementation, three studies provide examples of potential enablers and the remaining six studies have elements of both barriers and enablers related to SDM implementation in RAC.

4. Application of the Conceptual Framework of SDM

4.1. Person-Centred Care

PCC is a dimension of quality care which is individualised to consider both the patient and their family as integral components of health care decision making and delivery of care [46]. As the essential component, or crux, of SDM [47] models of PCC are an important consideration in RAC. Six of the studies analysed concepts related to PCC [30] [34] [35] [41] [43]. These studies used qualitative [30] [34], quantitative research methods [41] and mixed methods [43] to provide the perspective of residents and families [35] [41] and staff [30] [34] or both groups [43] to illustrate the opinions of all stakeholders. Time pressure and a task oriented focus of care was a key limiting factor in providing PCC. Families were excluded from the decision making process when a PCC workplace culture was absent, though the families viewed their participation as crucial. Staff propose that an existing workplace culture of PCC is an enabler to supported decision making and family involvement [30] [34]. Importantly, the perceptions of staff and families differed about the level of communication and information exchange that was taking place, with staff perceiving higher levels of PCC than families [43].

Additional studies [29] [36] [39] included in the analysis illustrate that non PCC models of care result in a lack of SDM. A consistent finding was that paternalistic, task focused and evidence focused workplace cultures denied residents and families choice, from the perspectives of staff, residents and families [29] [36] [39].

If SDM is to be successfully implemented in RAC it requires a workplace culture of PCC, but evidence suggests that social norms in RAC may not align with PCC, and that residents, families and staff have differing opinions about the workability of PCC.

4.2. Evidenced-Based Practice

Evidence is utilised in SDM to ensure that patients understand all the risks and benefits of associated care and treatment (informed consent) and to help them reach a decision based on their preferences [48] [49]. Like PCC, it is an essential component of the SDM process and utilisation of high quality research evidence demonstrates capacity for the implementation of SDM by workability.

Studies that utilised either qualitative [36] [42] or quantitative [40] designs as an intervention in RAC demonstrated contrasting results about potential SDM implementation. Perspectives of residents and families [40], residents and staff [36] or staff alone [37] [42] are reported in each of these studies. A top down approach to utilising evidence [36] [42], where staff held the knowledge of best practice, denied residents choice and autonomy, while a bottom up approach [40], where families were provided with evidence of treatment risks and benefits increased family members knowledge and facilitated SDM with staff. Staff as reported in Sims-Gould *et al.* study [36] perceived that evidence based practice should take precedence over resident choice, while staff in Werner's study [42] expressed moral and ethical issues about utilising evidence that is known to abrogate resident autonomy. In another study by Hanson *et al.* [40], there is no knowledge of staff opinions of a bottom up approach to utilising evidence. Without staff perspectives of a bottom up approach, understanding of potential implementation is limited.

Four articles focused on advance care planning (ACP) or end-of-life care, two quantitatively measured [38] [44] staff perspectives, one case study [45] described perspectives of all stakeholders and three qualitative methodological approaches [31] [33] focused on residents and families. None of the articles describe utilising evidence to help residents or their families decide on treatment options. Two studies found a lack of provision of information to residents and their families, and reported that staff rarely discussed the risks and benefits of treatment options [28] [38]. Some families indicated that there was a lack of information provided to them to assist in decision making [33]. This suggests that poor knowledge may result in some families deferring decision making to staff, though other families expressed a desire to be part of the decision making process. Staff perceived it was unfair to expect families to make decisions without knowledge of the risks and benefits of the treatment option, and so believed that their expert knowledge justified them as decision makers [29].

4.3. Readiness of Residents, Staff and Organisations

There is evidence that some patients prefer not to be involved and to leave decisions about treatment to clinicians [19] [50]. The reasons for this are multi-factorial, but an important consideration. Additionally, clinician and organisation readiness for the process of SDM is vital to implementation. Readiness to participate in SDM was highlighted in five of the studies regarding ACP and end-of-life care [31] [33] [38] [44] [45], the study methodology and stakeholder perspectives having already been described but which includes a mixture of qua-

litative and quantitative methodologies plus a case study involving all stakeholder perspectives.

There are differences in the level of involvement residents and families wish to have in decision making in ACP and end-of-life care. Resident and family readiness to participate was shown to be a significant factor in the process of collaborative decision making. Perspectives of residents and families willingness to be involved in decision making varied within and across studies. Residents and families often give staff an imprimatur to make decisions on the resident's behalf, rather than being involved [29] [31]. Importantly, some families were stressed and uncertain if expected to make a decision, but postulated that this may be a result of poor knowledge of the consequences of their decision [29]. Alternatively, some family members expressed dissatisfaction with being excluded from the decision making process [29] [31]. The study by Ampe *et al.* [38] demonstrated that readiness of families to be involved in SDM was assessed by inquiring about their preferred approach to receiving information to assist in SDM.

Staff and organisation readiness is paramount to effective SDM [29] [32] [34] [35] [36] [39] [41]. A lack of PCC was the limiting factor in staff and organisation readiness for SDM. Staff unpreparedness for SDM was highlighted in two of the studies [36] [39], while organisational unpreparedness was perceived as a barrier in two [39]. Frequently, the unpreparedness or lack of readiness could be attributed to both staff and organisational factors [29] [32] [35] [41]. Organisational readiness was also identified as having policies to support SDM in practice by two studies [37] [38].

There can be multiple factors contributing to staff and organisation readiness [32] which requires a huge organisation cultural shift [43]. Education was identified as paramount in staff, family and organisational readiness for implementing change.

4.4. Education

Much of the broader literature on SDM, focuses on education for clinicians on how to execute the process of SDM [51] [52], what SDM is [53] [54] and why it is important [6]. Education in SDM was not a focus of any of the articles retrieved, however, many of them utilised education to execute and embed models of care [30] [43] or enact organisational change to adopt new processes [44] [45] and are thus particularly relevant to SDM in RAC if it is to be implemented. Education in SDM was recommended in two studies, [28] [38] particularly about the importance of family involvement. The articles analysed which utilised an educational intervention were predominantly quantitative approaches [40] [43] [44]. Hanson *et al.* [40] differed by providing education to families not staff, while Bauer *et al.* [43] provided education to staff and families concurrently. All of the studies concerned with education excluded the perceptions of residents and focused on staff and families.

Staff and family education in collaborating together is illustrated as the corner

stone for successful implementation of new interventions [43]. It is also important to seek staff opinion on factors which mitigate against collaborating with families [34] [43]. Discussion with family members on treatment options is crucial to SDM [28] [38] [40]. Education can be resource intensive, particularly if it focuses on embedding long term, sustained adoption of change [44] [45].

4.5. Documentation, Communication and Enactment

The third component of Coulter and Collins SDM process [5] is documentation of the decision reached, communication between stakeholders and enactment of the treatment choice. Without this final component, the previous components have no validity in the process of SDM. Documenting and communicating residents preferences so that they can be enacted are the operational phase of SDM.

There were six articles concerned with the components of documentation, communication and execution of care in RAC settings, three articles used a quantitative research design [29] [33] [44], a case study [45], and three used qualitative methodology [29]. Arendts *et al.* [29] provides perspectives of staff, residents and families, while the other articles focus on staff [34] [44] or families [33] alone, or is purely descriptive [45].

A support worker (facilitator or broker) was perceived as the key to implementation of Advance Care Planning (ACP) [44] [45]. The support workers role is to educate staff and families about process and act as a mediator. The support worker initiates discussion with all stakeholders and facilitates the implementation of goals and plans. Involvement of residents and relatives in understanding the process of an intervention is central to successful implementation. The importance of information exchange and communication between stakeholders is emphasized [34]. Barriers to execution of wishes include a lack of documented resident preferences [33], or inadequate planning and communication [29]. Systematic operationalization of an intervention requires regular and ongoing education of all stakeholders [44] as well as auditing of existing processes, policies and strategic planning about organisational changes that may be required for success [28] [37]. High staff turn-over and changes to management of RAC is a threat to sustainability of interventions [44]. Blackford *et al.* [44] describe a system-wide approach to documentation, communication and dissemination of a residents wishes as paramount to success.

5. Narrative Synthesis Procedure Utilising an Implementation Framework

The perceptions of the population groups (stakeholders) regarding the components of SDM (person-centredness, evidence, education and documentation and communication of decisions) are important in illustrating the extent to which each component can serve as a potential barrier or enabler to implementation in practice in a RAC setting. The final part of this synthesis aimed to determine how the components of SDM relate to implementation in practice.

May's theoretical framework of implementation [18] was utilised to under-

stand how the essential components of SDM potentially facilitated or abrogated the process of SDM. An important step in the analysis was to compare and contrast the perceptions of the different populations (staff, residents and families) both within each study and across studies. In light of the predominantly qualitative methodologies of the extant literature, the analysis used a framework synthesis approach to bring together the current evidence [55] and reach conclusions.

Although there are a plethora of implementation frameworks [56] [57], May's framework specifically relates to the complex hierarchical structures of health care settings and potential complex interventions that may be introduced. May's framework recognises that implementation is not simplistic.

How the theoretical framework of implementation [18] was applied to the components of SDM is shown in **Figure 2**. The subject of the "social system" [18] for implementation in this analysis is residential aged care. The "element of context" [18] is the capacity and potential of RAC to implement SDM.

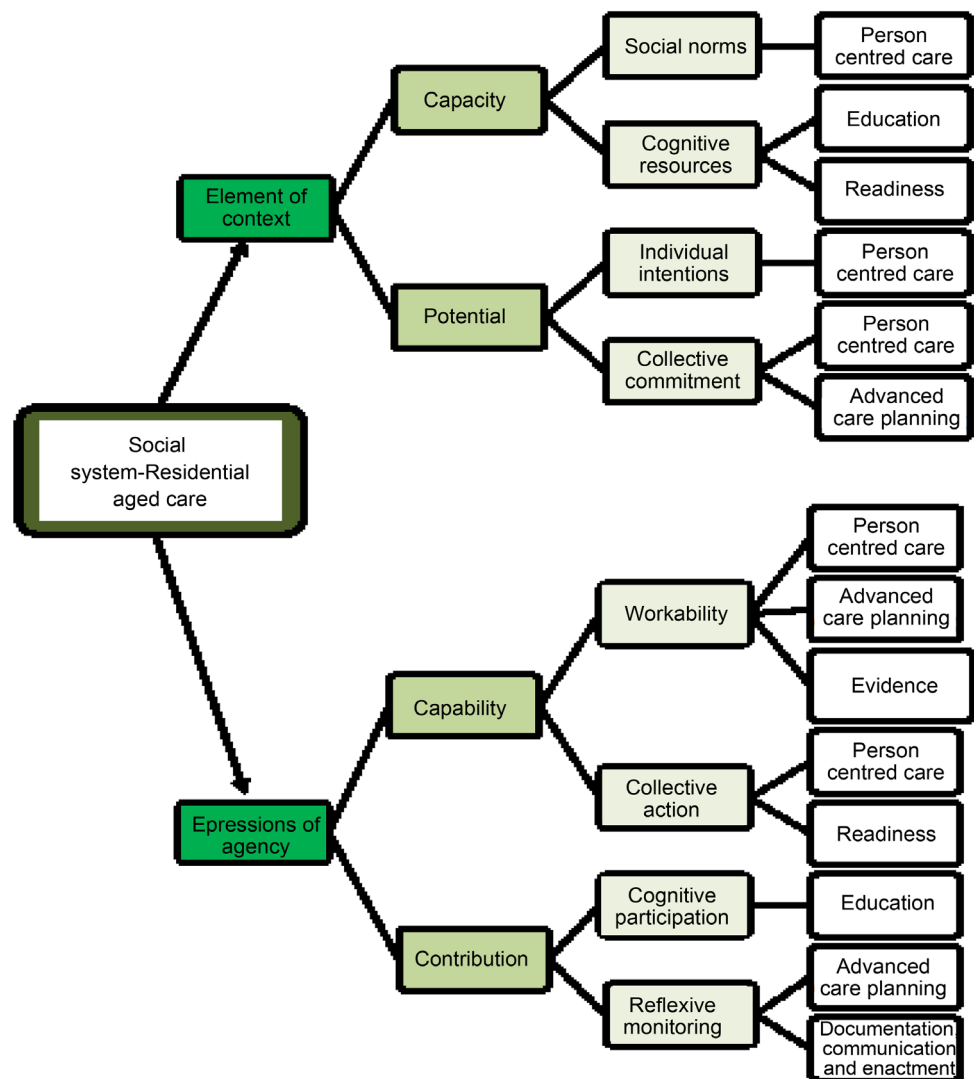


Figure 2. Application of theoretical framework of implementation [18] to the components of SDM.

Potential for implementation relies on organisational readiness, shown through individual intention and shared commitment. Implementation theory describes individual intentions and shared commitment as agents (clinicians, residents and families) motivation to translate beliefs and attitudes into behaviours that align with the social system. Capacity for implementation is dependent on material (access to resources needed for operationalization) and cognitive resources (knowledge, information and evidence) as well as social norms (institutionally sanctioned rules within the social system).

“Expressions of agency” [18] in this analysis are identified by capability and contribution of stakeholders to implement SDM. Capability for implementation relates to workability-social practices the agents perform in enacting or operationalizing an intervention. Contribution in the implementation framework relates to cognitive participation and collective action (how agents enrol themselves or mobilise skills to enact interventions) and reflexive monitoring (appraisal of the intervention).

6. Discussion

The initial literature search aimed to review current practices of SDM concepts in RAC and the synthesis to describe potential implementation of SDM in RAC using implementation theory framework. It is evident that SDM, as described by Coulter and Collins [5] has not been implemented fully in aged care settings. There is also evidence that the full concept of SDM is rarely implemented in any health care settings [52], even when clinicians have been trained in the process. This suggests that clinician training on cognitive resources is only one of the many factors required and that implementation of SDM in practice is complex.

6.1. Capacity

Capacity, in terms of RAC, is bound up in the social norms that govern behaviour within it. Paternalistic attitudes are a common social norm in RAC [29] [36] [39] [58] and the antithesis of SDM-there is an imbalance of power between clinicians and patients created by law and specialist knowledge [59]. Paternalism is frequently driven by clinician’s belief that they know what is best for patients. There is a tension between strong commitment by staff to keeping residents safe and violating their right to choice and autonomy [36] [39]. For SDM to be effective clinicians must relinquish their role as the single, paternalistic authority and train to become more effective coaches or partners [2]. The greatest challenge is turning the rhetoric into reality, changing workplace culture requires a huge shift in the common social norms of many RAC facilities [43]. Respect for a person’s right to make choices and participate in decision making is generally viewed as central to quality of life and well-being [30], however existing social norms in residential aged care potentially prevents SDM implementation [37].

A culture of person centred care is fundamental to SDM, and a recurring theme in the articles reviewed [30] [31] [34] [35] [41] [43]. PCC is a required social norm for implementation of SDM and SDM is viewed as a strategy that in-

corporate PCC principles into standards of care [60]. An audit tool has been developed to measure PCC in RAC settings, which aims to minimise staff bias of their perception of providing PCC [61]. Auditing PCC, as an essential component of SDM, is paramount to determine capacity for implementation. Implementation involves interaction with other agents, processes and contexts [18]. A workplace culture of PCC indicates capacity for SDM implementation, one factor of readiness. As well as organisational readiness, readiness of residents and their families is an essential component of capacity to implement SDM.

Material resources within a social system including their distribution and allocation are also a dimension of capacity. Similarly, shared commitment requires that participants are induced to participate, and Implementation Theory recognises that coercion, rather than motivation may be a strategy used to constrain others. SDM utilises evidence to inform the patient of the risks and benefits of various treatment options, to support their decisions [51] [62], not to coerce patients into practices or treatments that conflict with their preferences and values. Patient preference is a warranted variation to best practice initiatives [63].

Evidence can be utilised through the provision of patient decision aids. Although decision aids do not guarantee that decision making will be shared [64] [65] they offer a structured way to provide detailed information about treatment choices [1]. Decision aids are valuable for patients with low literacy levels [65] and so provide real hope for facilitating SDM with various population groups. Although decision aids have demonstrated effectiveness about increasing patient knowledge and risk perception, SDM is not dependent on them [6]. While increasingly available, a decision aid, or quality evidence may not necessarily exist for the condition under consideration, or the evidence may be rapidly changing. Clinicians must be able to access up-to-date evidence, evaluate quality and ensure that they are appropriate for the patient and their condition [66], skills the clinician may not possess. Utilising decision aids is not straight forward [6]. The implementation theory framework suggests that agent's capacity relies upon cognitive and material resources [18]. Knowledge of how to access, interpret and apply evidence will be crucial to successful implementation of SDM.

The provision of resources to both educate staff and families [34] [42] [43] [44] [45], and promote sustainability increases capacity to implement SDM in RAC. The provision of education in SDM is widely supported [28] [37] [67] [68]. Paradoxically, the resources necessary to implement SDM, such as increased time, support workers and overall governance, may also be a barrier. RAC settings are typically busy, time poor environments [30]. Time constraints are a limiting factor for practicing PCC [34], and also found to be true for SDM [37] [38]. Additional resources and dedicated funding are required to embed SDM practice within RAC facilities.

6.2. Potential

Lack of resident and family readiness for SDM is a barrier to potential implementation [29] [31]. Resident and family readiness relates to individual inten-

tion. Clinicians must first assess the patients preferred level of involvement in decision making [67] [69]. Previous authors of SDM studies [67] emphasize the importance of flexibility and warn that strict adherence to the principles of SDM risks another form of paternalism. Some patients prefer not to be involved and to leave decisions about treatment to clinicians [31]. It is recommended [68] that for SDM to become embedded requires a bottom up approach, where patients have an expectation that decision making will be negotiated together. The current regulatory pressures in many countries [54] to adopt SDM ignores that flexibility must be maintained, and that patient autonomy begins with the preferred level of involvement. Non participation in the decision making process, is in itself SDM, provided that risks and benefits of treatment options are clearly articulated and understood. Individual intention and collective commitment to SDM demonstrate potential to implement it. The object of an implementation process may be a modified way of thinking, where the agent intentionally makes things happen by action.

6.3. Contribution and Capability

Like capacity, much of contribution and capability relate to PCC. SDM includes collaboration (collective action) with families as appropriate and emotional and physical support [70]. Contribution includes cognitive participation and reflexive monitoring. Joint action, such as sharing of information, unites two or more individuals towards a shared end. Documentation and dissemination of resident choices are essential to operationalize SDM [44]. Capability is concerned with the dimension of workability-operationalizing the intervention. Communication between all stakeholders is necessary for dissemination of information but there is evidence that clinicians and residents/families do not communicate well [59]. There is also evidence that enhanced communication can be achieved through a process of education of staff and families on how to collaborate more effectively [43]. To successfully implement and embed SDM will require RAC facilities to undertake reflexive monitoring or appraisal of the effects of SDM to ensure that property is shared, not a single entity. Reflexive monitoring frames how participants collect and utilise information about the effects of the intervention.

7. Conclusion

The most important finding of the synthesis is that the implementation of SDM in RAC, hinges on a person centred culture of care. Paternalistic practices of staff hinder person-centred care and capacity to implement SDM in RAC. Operationalization of SDM practice may be dependent on additional resources in the facilities. As well as a person-centred culture of care, cognitive and material resources such as education of staff and residents/families are important enablers to implementation of SDM. Readiness or preparedness of residents and families to be involved in SDM should be ascertained as part of the process. Importantly this synthesis highlights the caution that must be exercised in introducing research based evidence into practice to ensure that it is utilised to assist in deci-

sion making but balanced with residents' preferences and values. Additionally, evidence needs to be provided in simple, easily understood formats (such as decision aids) to facilitate knowledge and understanding of the information provided and increase workability.

8. Recommendations

Implementation of any health care intervention, including SDM, relies on many complex factors but these are predominantly related to multi-dimensional aspects of capacity. If there is to be effective implementation of SDM, auditing capacity within the system of RAC is required. The synthesis indicates that capacity relies on workplace culture and organisational support for resources such as support workers and education for staff and residents to increase readiness.

To date, little research has been undertaken in RAC to determine staff knowledge, or previous training in SDM. Additionally, little is known about the uptake of SDM in RAC. The absence of studies may not reflect current practice. Aged care quality standards emphasise resident choice, so processes which support this must exist to meet minimum requirements. How regulatory agencies assess this is unclear and not the subject of peer reviewed publications.

As a starting point, rigorous evaluation is required to measure readiness of organisations and residents and families for implementation of SDM processes. This will provide a baseline for future SDM intervention studies.

Ethical Approval

Not applicable, no human research was involved.

Competing Interests

The authors declare they have no competing interests.

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Patient-Provider-Relationship in the Hospital Care of the Elderly—A Qualitative, Multi-Perspective Study

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Abstract

For many years, there has been a growing demand for patient-centered care in inpatient settings, but a lack of clear consensus on how to exactly implement such programs. The main aim of this study was to analyze patient-centered care in the acute-care setting in a multidimensional manner from the perspectives of elderly patients, their relatives, and an independent observer. A multi-method design was used to capture the three perspectives. Passive observations and post-situational interviews with patients were integrated with semi-structured interviews with patients and their relatives. 18 elderly patients and their relatives ($n = 8$) were recruited on wards for internal medicine of six hospitals. The data show significant deficits in patient-centered care in the acute-care setting. Although individual patients have different needs, certain categories of deficits emerge as universally relevant, one being the patient-provider-relationship. Patients express a desire for more frequent contact with the hospital staff. Access to doctors and nurses is particularly limited at night and on weekends. The patients are aware of these limitations and often do not draw attention to their own needs to reduce the workload on the staff. The wishes and needs of patients are not always adequately addressed. However, patients, relatives and the independent observer take positive notice of some employees because of their patient-centered attitude. The results show that there is still a need for improvement of patient-centered care. Participants from all three perspectives described differences between employees within the same institutional setting. This finding suggests that patient-centered care strongly depends on the personality of the individual caregiver.

Keywords

Patient-Provider-Relationship, Patient-Centered Care, Hospital Care, Elderly

1. Introduction

Patient-centered care has been a central aspect in the international health care discussion since the 1990s [1]. Patient-centered care covers a broad range from access to care and coordination to accessible information and physical or emotional help as well as including friends and family in the care process. Patient-centered care also covers the patient-provider-relationship as one main aspect [2].

Research has shown positive effects on the perception of care due to a good patient-provider-relationship. Good communication and empathy reduce fear and stress within patients [3] [4]. There are advantages for the care-givers as well. Misunderstandings are settled faster as they are talked about earlier. And by including patients in the decision making process, doctors take pressure off themselves [5]. Nurses are more satisfied with their work and report better working relationships when a patient-centered approach is followed [6].

Although the relevance of patient-centered care has been documented more and more, patients' field reports show that it is not always abided by. The political framework and financing concepts regulate the workaday life in a hospital. Patient-centered care is thereby pushed aside. Prospectively, this topic will be fundamental because demographic changes affect the health care system. Interestingly, patients are often satisfied with their patient-care, when they rate their satisfaction via questionnaires. This is one reason why the significance of patient satisfaction surveys is discussed controversially, and why respective studies should focus on patients' experience rather than on satisfaction [2] [7] [8]. Therefore, the perspective of elderly patients and their experiences is a main subject of this study. To analyze the discrepancy between high satisfaction mentioned by the patients themselves and low patient-centered care, additional perspectives should be used to describe the care process. One of these perspectives is the view of patients' relatives. They experience the hospital stay as well, yet they are not in the same dependency as the patients. Moreover, the position of a neutral observer can generate further information related to patient-care and the patient-provider-relationship. This perspective gives an insight on possible discrepancies on what happens and what is perceived by the patients.

We explored patient-centered care from the perspective of 1) elderly patients, 2) relatives and; 3) a non-involved observer. Research questions were:

- 1) How do elderly patients experience the hospital care during their stay and afterwards? How do they evaluate the hospital care and which experiences are most important? Where do they see the need for improvement?
- 2) How do relatives experience the hospital care of their loved ones? How do they evaluate the hospital care and which experiences are the most important ones? Where do relatives see the need for improvement?
- 3) How does the observational perspective evaluate the hospital care of elderly patients? Which strengths and weaknesses can be detected? Is there a need for improvement?

2. Method

2.1. Study Design

To collect data to represent the three perspectives, a multi-method-design was chosen. We integrated:

- 1) Theory-based, passive observation;
- 2) Post-situational interviews with patients and;
- 3) Semi-structured interviews with patients and their relatives.

For the data collection an observation guideline and an interview guideline were constructed. The categories for patient-centered-care described by the Institute of Medicine and the Picker Institute were the basis for these guidelines and complemented by further categories found in a literature review [9]-[14].

Passive observation was carried out, meaning the observer was present, but as a non-participant of patient-care. On two half days, patients were observed during specified situations, including: 1) waking up; 2) meals; 3) ward round; 4) interventions or examinations; and 5) medical care. Additionally, there was an hour-long observation that was independent of the situation.

The researcher observed interactions among the healthcare staff, patients and relatives. Categories included: 1) information; 2) coordination; 3) team work; 4) access to care; 5) continuity; 6) patient-provider-relationship; 7) emotional support; 8) physical support; and 9) respect for personal wishes and needs.

During the observations, no tape-recorder was utilized. The observer took notes and wrote the detailed observation summaries directly afterwards.

As part of the observation, post-situational interviews were conducted with the patients during their hospital stay. These interviews were unstructured with the aim of depicting their experiences and perspectives related to the observed process. The short interviews were written down from memory.

One week after discharge, patients and relatives were interviewed to record their retrospective perception of the hospital care experience. There are several reasons why interviews took place after their discharge: patients were able to talk about the whole hospital stay; they were back in their own environment and could talk more comfortably; and patients dependency on the clinic and staff during their hospital stays did not interfere with the data collection because patients may be more cautious in their statements. The interviews were recorded.

2.2. Study Sample

The study was conducted on wards for internal medicine, as the main percentage of elderly patients is cared for in this setting. Six clinics were selected by the following criteria: 1) hospital owner (private, non-profit making, public); and 2) number of inhabitants where the clinic is located (city, rural area).

During the period from 10 March 2015 to 24 August 2015, 18 elderly patients and their relatives ($n = 8$) were recruited on wards for internal medicine in six hospitals. The inclusion criteria for patients were: 1) women and men; 2) age 70 years or older and; 3) unspecific diagnosis on admission. The unspecific diagnosis was chosen to observe the whole treatment process from having examinations

over receiving the results and starting the treatment. The diagnosis itself was of no interest for the study as no major differences were expected. In this context, co-morbidity was not an exclusion criterion, particularly since approximately 75% of elderly patients have more than one disease. The relatives were recruited irrespective of age or gender; however they should have experienced the patient-care of the respective patient.

2.3. Data Analysis

Audio recorded interviews were transcribed in full. All transcribed observations and interviews were managed using MAXQDA software. We performed a qualitative content analysis. For deductive analysis, we used the categories that were the basis for the guidelines. We also searched inductively for new concepts and categories. Within-case and across-case analyses were carried out. To ensure quality of the analysis, the research team constantly discussed and refined the findings as data collection occurred.

2.4. Ethical Approval

The study was approved by the Ethics Committee at the Medical School Hannover (2014). All participants were informed about their rights, and given information about the purpose of the study and details of the research procedures prior to participating. Participants were allowed to withdraw from the study at any point.

Initial screening for eligible patients was conducted by hospital staff. The staff members informed the patients about the study and its goal and asked for permission to be approached by the research team. After permission was granted, the researchers provided further information.

All data were kept confidential and anonymous.

3. Results

3.1. Sociodemographics

Of the 18 patients, the majority were women with only 2 men participating. Since gender has little to no effect on the evaluation of the care, we found this difference not crucial to the results [15]. The average hospital stay was 6.72 days. One patient was transferred into a rehabilitation facility, the others went home ($n = 16$) or to a nursing home ($n = 1$). Five patients needed to be readmitted for either a planned surgery or because of their poor health status.

3.2. Qualitative Findings

Different categories of patient-centered care emerge as overly important for the patients and their relatives. One of these categories is the patient-provider-relationship which will be described in detail.

Findings reveal that the category of patient-provider-relationship can be categorized into seven main themes: 1) contact person; 2) patient as a person; 3) medical staff as a person; 4) comparison of medical staff; 5) professionalism; and

6) own responsibility in the treatment process. Some of these themes, e.g. patient as a person, have further subthemes (**Table 1**).

1) *Contact person*

Continuity and knowing their contact person helps the patients to orientate themselves and remember information. It is adjuvant if the employees introduce themselves. Here, differences between the staff members can be noted. Some employees always introduce themselves and state what they are planning to do; others do not inform the patients at all. In the interviews patients talk more positively about the staff members who introduce themselves. Moreover, they recall the information given by these doctors and nurses better than from others who did not introduce themselves.

During rounds, most of the times there are more than two staff members in the patient's room. One patient reports that she is holding back on questions as she is scared to ask them with so many people present: *"I wanted to, but there was a whole assembled clan. I did not dare to ask"* (17). Introducing the staff members during rounds, might reduce these fears and was observed in other situations.

In the post-situational interviews the patients do not mention this theme directly. Yet, it becomes obvious that a certain continuity plays an important role for them. Doctors wearing different clothes, e.g. other colors, are not perceived as doctors. Later, the patients state that they did not get a chance to talk to a doctor. They do not recall the information those doctors have given them. Patients criticize the changing staff members in the interviews as well: *"And, above all, there were always new doctors. Never the same, always different ones"* (I15). This does not only mean that the patients are unable to build up a relationship, but also that they receive conflicting information from different employees. For the patients this means emotional stress and loss of trust in the treatment.

There are patients on the other hand that experience a close interaction with their treating doctors. Those patients report that responsibilities were transparent and they can depict the conversation with the doctors precisely. This confirms again that contact persons are important for the information brokerage.

Table 1. Main themes and subthemes of patient-provider-relationship.

	Main themes	Subthemes
Patient-provider-relationship	Contact person	
	Patient as a person	Respecting the need for rest respect for the patient change of roles
	Medical staff as a person	
	Comparison of medical staff	
	Professionalism	Competence dealing with complaints image of medical staff
	Own responsibility in the treatment process	

Overall, patients mainly complain about not having a doctor as a steady contact person, nurses are less relevant to them. For the relatives this topic is not as important as for the patients. Still, they confirm the heterogeneous impression. One relative reports that she was supposed to approach the treating doctor without knowing him: *"I did not know his name. I could not call him"* (IR1). One relative reflects the difference in her own and her mother's view: *"I think it was hard for her that there were always different people. Always different doctors. There was no real contact person. That was difficult for her. Nobody had all the information, just notes from the colleagues"* (IR6). In another situation she depicts that this was not a problem for her. (IR6).

2) Patient as a person

This main theme can be further divided into the following subthemes: 1) respecting the need for rest and; 2) respect for the patient.

a) Respecting the need for rest

Some employees respect the patients' need for resting, others persist on their own schedule. Subsequently, there are two observed examples: *"Patient 1 lies in her bed and sleeps. Her blanket is pulled over her head. The arm sticks out from underneath. The nurse takes a blood sample and carries out the blood glucose test. Patient 1 shows no reaction and continues to sleep"* (O1, 105). *"Patient 7 lies in bed and sleeps. The nurse asks the other patients whether patient 7 has slept poorly. The nurse speaks quietly. The other patient answers that patient 7 always says that she sleeps little. The nurse answers that in that case she will come back later and will let her rest"* (O7, 74). In the first example, the nurse invades the privacy of the patient and performs an invasive examination. However, this also reveals the rigid work schedule under which the employees work. In the second excerpt the nurse respects the patient's need for rest.

For patients and their relatives this theme is not very important. If so, they praise the staff members for being considerate. They do not mention any critical situations as they have been observed. The relatives state that the well-being of the patients is very important to them. However, since all have had the feeling that the patients are taken care off, they talk little about this topic.

b) Respect for the patient

Disrespectful behavior can be seen in various situations, it mainly shows non-verbally or by terminating actions hastily. The following situation occurs after the patient's transfer from his wheel-chair into bed: *"The nurse's phone rings. Patient 6 takes his phone and repeats 'hello' over and over again. He seems to be confused that the phone continues to ring. The nurse says softly that it is not the patient's telephone and rolls her eyes. The nurse answers her phone and leaves the room without saying anything to patient 6"* (O6). The nurse shows her annoyance openly but does not clarify the situation for patient 6.

Disrespect also shows when nurses say that they do not want to take care of specific patients as they are too demanding (O6), or think that the hospital stay is unnecessary: *"Outside in the corridor, the nurse says [to the observer] that patient 13 only imagines her illness. She is just lazy, only lies in bed and wants to*

be coddled. In her opinion, the patients in that room can all go home" (O13).

Some employees also talk disrespectfully about patients in their presence. In the following example, two staff members discuss the upcoming move of the station with only one running elevator: "*You cannot lift those patients up and down the stairs (pointing to patient 2 who is strongly adipose)*" (O2). Neither for the patients nor the relatives disrespect is an important topic in the post-situational interviews or interviews.

c) *Change of roles*

In different situation patients and employees break out of the typical interaction patterns. The following sequence has been observed during rounds: "*The patient tells that she is about to move. The chief physician answers: 'That's not possible' and laughs. After that, he says, 'But seriously, moving upsets you too much.' She must keep calm. They talk about how the patient wants to do everything on her own. The chief physician says: 'I know that from my grandpa.' His grandpa is already 93 years old and still wants to do everything himself*" (O10). Both the patient and the physician leave their typical roles here, but still discuss the medical problem. With this break-out, the doctor gets further background information on the patient's life and her compliance, which can have a positive effect on the future treatment. The change of roles also creates familiarity between the patients and the staff members and creates an intimacy that goes beyond the care itself. Here an example that was observed between a nurse and a patient: "*The nurse asks patient 11 if she used to bike. The patient confirms and says that nowadays it is too exhausting, especially with the mountains. Without the hills, she would love to bike. The nurse adds: 'Straight streets and tailwind. Both laugh*" (O11). Patients recall those employees as more empathetic. They do not name the role change explicitly, but describe the same situations as were observed.

3) *Medical staff as person*

The workload is one of the main topics the patients and relatives address. Patients express a desire for more frequent contact with the hospital staff. Particularly at night and on weekends access to doctors and nurses is limited. At the same time they are very understanding and even try to minimize the workload: "*The nurse says to patient 15 that he should ring as soon as the infusion has run through. He replies that they are ringing [him and his bed neighbor] as soon as both infusions have run through. This way she only has to come once*" (O15). The patients and relatives mostly talk about the nurses', rarely about the doctors' workload. The patients take sides with the nurses and defend mistakes they make. They are less forgiving when it comes to doctors and waiting for information or examinations.

4) *Comparison of medical staff*

Between the employees, differences in their interaction with the patient can be identified. These differences concern the communication, the handling of the patient and the care. There are employees who distance themselves from the patients. Those employees do not respond to the patients, turn away during the

conversation, or interrupt the patients verbally or non-verbally: *“The nurse says to patient 14 that she wants to take a blood sample. Patient 14 says: ‘You want blood, but I get nothing to eat.’ Patient 14 laughs. The nurse does not react”* (O14). Other staff members are more attentive.

Patients judge employees as positive who are concerned about their worries, inquire about their welfare and respond to their needs. Positive reviews dominate in the interviews. Even though, critical situations have been observed, the patients hardly mention them: *“One was very loud and the other one was very quiet. [...] But in general, they have been very nice. [...] There is always a black sheep, right?”* (I2). This paragraph also shows that the expectation has a strong influence on the perception and, above all, the evaluation of the hospital stay. Patients forgive negative behaviour to some degree. This phenomenon was confirmed in other interviews.

5) Professionalism

This main theme can be further divided into the following subthemes: 1) competence; 2) dealing with complaints and; 3) image of medical staff.

a) Competence

The fact that nursing assignments are carried out by trainees without supervision, shows deficiencies in professionalism and safety. This leads to stressful situations for both, patients and employees. Whereas the competence of the physicians does not play a role for the patients, the relatives question it in some cases, for example with performed examinations: *“A CT must be done, you cannot see anything on an X-ray image. A CT is the best”* (IR3).

b) Dealing with complaints

Patients' complaints, e.g. about the food, are mostly ignored by the nurses. Patient 7 complains about her lunch after receiving the same meal for several days in a row: *“The nurse shrugs her shoulders and leaves the room”* (O2). In the interviews, patients do not criticize the staff members directly, but rather indicate that some employees are not interested in them.

c) Image of medical staff

Some patients have a clear picture of doctors in general, they call them the *“god in white”* (I7). This picture is accompanied by a certain age of the physicians. Patients think of younger doctors as less competent: *“I also think, although she is as a ward physician, [she is] a bit unsure [...] She was very young, she has a lot to learn”* (I4). Those patients find it hard to trust the doctors' orders. The relatives differentiate between the doctor's image of the younger and the older generation: *“My mother has the picture of the gentlemen with glasses, a lab coat and a stethoscope hanging around his neck. [...] That is, what I believe, her image of a competent doctor. [...] The chief physician who can diagnose his patients from a distance”* (IR6). To the relatives, the age of the doctors is irrelevant, receiving information and having time to talk to them is more important.

6) Own responsibility in the treatment process

Patients often talk about their own responsibility in the treatment process.

They address a number of key issues, such as the way they talk to the medical staff: *“If I ask politely, then I get a decent answer. [...] But above all, ‘please’ and ‘thank you’, you can say that. And not: ‘I want that, I want that.’”* (I9). The relatives agree to this: *“I would say, it depends a lot on the patients, how they address the people who work there”* (IR1). Patients feel responsible for asking actively for information. However, many patients are scared to do so (I4). The relatives confirm this statement (IR5) and rate this as a typical problem of the elderly.

4. Limitations

Most of the limitations of the study are practical or resource-based. Patient caring is a complex process; therefore a multi-methods approach of observation and interviews involved different settings, multiple professions, patients and relatives. Priorities regarding the study design had to be made. The low sample size reduced the data to a manageable extent. Another limitation concerned the observation. Due to potential strain, it was not possible to follow the patients throughout the whole hospital stay. Selecting typical situations produced sufficient data and reduced the stress significantly. To increase rigor and ensure the quality of the data, regular team meetings and supervision took place.

Although, there are limitations, the study design was still quite unique as it addressed more than one view of patient-centered care. The comparison of the three perspectives illustrated a complex picture of patient-centered care.

5. Discussion

This study concentrated on the experience of elderly patients and their relatives. The innovative study design of comparing those two perspectives with the one of a non-involved observer helped depicting the complex picture of the care process and understanding the way patients and relatives evaluate the patient-provider-relationship. Overall, all three perspectives evaluated the patient-provider-relationship similar. Sometimes the patients and relatives were less critical compared to the observer and tended to excuse negative behaviour. In other situations, patients and relatives could not depict their reasoning in detail. In the end however, they mostly reached the same conclusion as the observer. This proves again, that the patient's and relative's opinion is valuable for identifying strengths and weaknesses in the care process.

The patient-provider-relationship is influenced by many different aspects. Contact persons are an important factor, but these are not always recognizable for the patients. To facilitate this, uniform clothing and coloring can make the individual roles and tasks more transparent and thus provide guidance for the patients [16].

Both, in the observations as well as in the interviews, differences between the employees are evident. Patients describe some employees as negative or verbal aggressive, others as caring and thoughtful. Those results can also be found in the literature [17]. These differences exist while working under the same institu-

tional conditions. This confirms that a good patient-provider-relationship depends not only on the institutional situation but also on the attitude of the employees themselves. A reflection of one's own role seems to be critical. Studies show a positive effect on the care process when supervisors set an example and motivate staff members [18]. Therefore, it is also important to implement new concepts on management level and to consider ways of launching them together with practitioners.

The change of perspective is a theme that can be found throughout the data. Patients try to break out of the typical patient role. Hoefert (2010) explains this phenomenon with the fact that older patients perceive the contrast to the healthier nursing staff stronger than younger patients [19]. Elderly patients notice their own physical deficits since these are not present in the nursing staff. This contrast intensifies their dependency. If the patient's resources are not taken into account, this contrast increases further. It is likely that one of the reasons for the frequent role change is to minimize these differences. The role changes also show that patients do not only want to be seen in the patient's role. Breaking-out of the typical hospital roles also has a positive effect on the patient-provider-relationship. It creates familiarity between the patients and the staff members and builds up trust.

Patients are aware that their own behavior has an impact on the patient-provider-relationship. Addressing the staff members in a polite way is one of the ways to build up a positive relationship. Although many elderly patients describe asking actively for information as a further responsibility, a lot of them are scared to do so. Additionally, many patients cut back on their own needs to reduce the workload of the staff. This means that staff member need to anticipate the patient's wishes and pay more attention to possible needs, especially when it comes to the need for information.

Due to demographic changes more patients need assistance. New ways have to be found to help nurses with this additional workload. One way might be the use of electronic assistance systems. It is possible to equip patients with electronic wristbands, which localize the patient or measure both vital signs and thus detect emergencies faster. A close monitoring with electronic assistance systems might reduce the workload for the nursing staff, since they no longer have to carry out the measurements individually. This way, they find more time for the emotional care of patients.

6. Conclusion

The results show that there is still a need for improvement of patient-centered care, especially the patient-provider-relationship. In all three perspectives, differences between employees within the same institutional setting become obvious. This finding suggests that patient-centered care strongly depends on the personality of the individual caregiver. In the future, hospitals need to further adapt to the needs of elderly patients and their relatives. Despite these ideas of designing an advanced hospital, hospitals remain a complex system in which it is

difficult to deviate from the routines. Changes have to be made step by step.

Competing Interests

The authors declare that they have no competing interests.

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Student's Perception of Missed Care: Focus Group Results

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Abstract

Background: With the inflation of economic constraints on health care and demand to increase care quality, there is an increasing need to develop a clear understanding of what actions by health professionals are perceived as threatening quality care. **Objective:** To explore graduate nursing and pastoral care student's perceptions of missed care in Norway. **Research design:** A qualitative study was employed with the formation of six focus groups. Data was analyzed via a thematic content of the discussions. **Participants and research context:** Thirty-one students attending a University College in Oslo participated. **Findings:** Five major themes and thirty subthemes were identified. Major themes included labor constraints, organizational constraints, professional constraints, communication constraints and emotional strain. **Discussion:** Findings of this study resonate with other research as well as with studies on missed nursing care. Findings also lend support to the definition of missed nursing care actions as required care that is omitted, either in part or whole, or delayed. **Conclusion:** The findings from this study extend understanding of what barriers health professionals perceive as inhibiting them from offering quality care. The focus groups provided a valuable flora for discussion regarding what participants perceived as missed.

Keywords

Missed Nursing Care, Suboptimal Care, Noncaring, Focus g Groups, Nursing, Pastoral Counseling

1. Introduction

Society is in a process of constant change in which the past couple of decades have seen unprecedented levels of structural health care reforms in pursuit of efficiency, effectiveness and wider access in most developed nations [1]. As a result, health care providers, administrators, and politicians face competing challenges to con-

trol expenditure, reduce clinical errors, and improve quality of care [2] [3]. Along with health service's new organizational structures, payment systems and performance requirements, the development in medical, technological and political spheres are continuously confronting with new ethical issues. For example, health care services are provided to clients in an environment with complex interactions among many factors such as the disease process itself, clinicians, policies, procedures and resources [4]. In the Western world, today's work environments are further complicated by new medical technologies and a declining average length of hospital stay, that have led to increases in the amount of care required by patients. Patients that traditionally would have been cared for in critical care environments are increasingly located on general wards. This change impacts on the care sector in a number of ways. Patients who are inpatients have more complex problems and a greater number of co-morbidities and are therefore more likely to suffer physiological deterioration [5]. Procedures requiring inpatient stays are often more complex and associated with higher rates of mortality and morbidity [6]. New medical technologies also allow many less serious ill patients who previously would have received inpatient surgical care to receive care in outpatient settings. Also, patients who in the past would have continued the early stages of their recovery in institutions, today are discharged to skilled nursing facilities or to home. Due to these global developments, the need to develop a clear understanding of what actions health professionals perceive as threatening quality care remains paramount [7]. Moreover, health care professionals are increasingly voicing the need to address everyday professional and interdisciplinary tensions and systemic concerns.

1.1. Literature Review

Missed Nursing Care

Missed nursing care is a new concept which is defined as any aspect of required patient care that is omitted (either in part or whole) or delayed and is described as an error of omission. This definition of missed care seemingly has commonalities with other terms used in the literature as suboptimal care, non-caring, uncaring, near misses and futile care [8]-[13].

In exploring aspects of missed nursing care, Kalisch [14] used a qualitative approach to determine whether opportunities for nursing care were regularly overlooked and the reasons for such missed care on medical-surgical units. Using two hospitals and focus group interviews with nurses and nursing assistants, she found nine areas of regularly missed nursing care connected to ambulation, turning, feeding, patient teaching, discharge planning, emotional support, hygiene, intake and output documentation. The reasons for missed care were often related to the nurses themselves. For example, ineffective delegation, "it's not my job syndrome", habit, the amount of time involved and denial were cited as reasons for missed care which in turn had various effects on patient outcomes. This study's results demonstrated that behaviors traditionally associated with good nursing care, were often overlooked and not completed, and nurses failed to follow up on delegated

tasks and used denial as a coping mechanism to deal with missed care.

In another study, Kalisch and Lee [15] explored whether the level of nursing teamwork impacted the extent and nature of missed nursing care. A sample ($n = 2216$) of nursing staff members, on 50 acute care patient care units in 4 hospitals, completed the Nursing Teamwork Survey and the MISSCARE Survey. Controlling for occupation of staff members and staff characteristics (e.g., education, shift worked, experience, etc.), teamwork alone accounted for about 11% of missed nursing care. The results of this study showed that the level of nursing teamwork impacts the nature and extent of missed nursing care.

Kalisch, Landstrom and Williams [16] examined what and why nursing care is missed. A sample of 459 nurses in 3 hospitals completed the Missed Nursing Care (MISSCARE) Survey. Assessment was reported to be missed by 44% of respondents while interventions, basic care, and planning were reported to be missed by >70% of the survey respondents. Reasons for missed care were labor resources (85%), material resources (56%), and communication (38%). The results of this study lead to the conclusion that a large proportion of all hospitalized patients are being placed in jeopardy because of missed nursing care or errors of omission.

In a more recent study, Kalisch, Hyunhwa and Friesse [17] explored the extent and type of nursing care missed and the reasons for missed care. The MISSCARE Survey was administered to nursing staff ($n = 4086$) who provided direct patient care in 10 acute care hospitals. Missed nursing care patterns, as well as reasons for missing care (labor resources, material resources, and communication), were common across all hospitals. Eight variables were significantly associated with missed care: gender, age, job title, shift worked, years of experience, absenteeism, perceived adequacy of staffing, and number of patients they cared for. When nursing staff members were female ($B = 0.84$, robust $S.E. = 0.02$, $p < 0.001$), older ($B = 0.03$, robust $S.E. = 0.01$, $p < 0.001$), RNs (versus NAs) ($B = 0.19$, robust $S.E. = 0.03$, $p < 0.001$), working on a day shift (compared to those on night shifts, $B = 0.05$, robust $S.E. = 0.02$, $p < 0.05$), or experienced more ($B = 0.04$, robust $S.E. = 0.01$, $p < 0.001$), they reported more missed care. Nursing staff who missed more shifts in the past 3 months (compared to those who did not miss any shifts, $B = 0.08$, robust $S.E. = 0.02$, $p < 0.001$), perceived their staffing less adequate ($B = 0.11$, robust $S.E. = 0.01$, $p < 0.001$), or cared for more patients in the previous shift ($B = 0.01$, robust $S.E. = 0.00$, $p < 0.05$), reported significantly more missed care.

Quirke, Coombs and Mceldowney [9] conducted a content analysis on what they termed “suboptimal care” among acutely unwell patients. Delays in diagnosis, treatment or referral, poor assessment and inadequate or inappropriate patient management was found to be related to patient complexity, healthcare workforce, organization and education factors [18]. These authors stated that suboptimal care may have catastrophic consequences for patients such as death, intensive care admission or cardiac arrests.

Miller [19] examined variables that sustained good work among nurses despite the obstacles they encountered. Nurses cited obstacles to good work in nursing as frustration in dealing with market forces which included the growing emphasis on productivity and managed care. Strategies used to overcome ob-

stacles included prioritization, team building, contemplative practices and reflection on the initial reasons for entering the profession.

Atree [20] explored patients' and relatives' perceptions of care and identified key criteria used to evaluate quality care, via descriptions of actual care experiences among 34 acute medical patients and 7 relatives. Care described as 'not so good' were routine, unrelated to need and delivered in an impersonal manner, by distant staff who did not know or involve patients. The nature of the care provided and interpersonal aspects of caring emerged as key quality issues for patients. Lastly, in a Norwegian study, Prang, and Jelsness-Jørgensen [21] explored barriers to incident reporting in nursing homes. Thematic analysis of 13 semi-structured interviews with nurses revealed that unclear outcomes, lack of support and culture, fear of conflicts, unclear routines, technological knowledge and confidence and time and degree of severity were the main drivers of not reporting incidents.

One can summarize from these studies that missed nursing care is related to a complex variety of factors which are related to organizational structures, time, healthcare workforce, professional, material, educational and personal characteristics. What remains clear is that most authors agree that missed nursing care or suboptimal care is either avoidable or preventable [8].

1.2. Purpose

Because it has been reported that attempts to understand students' perspectives on what they perceive as missing care are seldom presented [7] [14], the aim of this qualitative descriptive study was to explore graduate nursing and pastoral care student's perceptions of missed care in Norway.

2. Method

2.1. Design

The study uses an exploratory qualitative design, in which qualitative data are collected, based on real-life experiences brought forth in focus group discussions. Focus groups were selected for enhancing the dynamics of discussions and ensuring that different perspectives would be expressed. The interactions and dynamics among focus groups members can generate important information in a data collection situation [18].

2.2. Focus Group Protocol and Participants

Purposeful sampling included students in post bachelor in cancer nursing, nephrology nursing, pastoral counselling, public health nursing, and Masters' students in community health nursing attending a university college in southeast Norway. Participants were recruited by the researcher (MK) who visited classes at this institution and explained the purpose and procedure of the study at the beginning of their classroom lectures. Six focus groups were conducted and included the following: pastoral students ($n = 4$), two groups of nephrology students ($n = 4$, $n = 5$), a combined group of public health nurses and pastoral students ($n = 8$), and two groups of cancer students ($n = 4$, $n = 6$). Focus groups were conducted in a quiet

room at the same university during April 2016-December 2016. Students were welcomed upon arrival and refreshments were served. The time span of the focus group sessions were between 40 minutes to one hour in length. Two researchers served as moderators where one led the questioning and the other observed verbal and non-verbal interaction. The first part of each session was used to provide ground rule information, remind participants about ethical considerations, and obtain written informed consent and sociodemographic information. Oral consent was also given to tape record the sessions. A short list of standardized questions and prompts were formulated in advance to move the open discussion which included meaning given to professional care. Aspects related to good caring have been published recently [18]. As the focus of this paper is on aspects of missing care, open-ended questions for this theme included: "When you think of the concept of missing care, non-caring, or the opposite of what you envision as good care, what do you think about? Can you give some examples?" "What factors do you believe contribute to not being able to give good care? Can you give some examples?" At the closure of the focus groups, the moderator summarized the main points of the discussion, to verify the accuracy of the information discussed. At this time, participants were also asked to add other comments if needed, as well as express their views regarding the discussion. Field notes were written immediately after each focus group to document impressions, themes, and group interactions. None of the students recruited from classes decided to withdraw from the study after agreeing to participate [18].

2.3. Ethical Considerations

The study was approved by the research committee at the institution where the study took place. Participation was voluntary. Students were told that their refusal to take part in the study would have no consequences for their studies. Written consent to take part in the study was obtained and oral consent was given at the beginning of the focus groups to tape record the sessions and use the results in publications. An agreement was made that the tape recorder would be turned off during parts of the dialogue, if desired. Participants also received the email address and phone number of the researcher (MK) in case there was a need for contact [18].

2.4. Data Analysis

Audio recorded interviews were transcribed in full by a professional transcriber and then translated into English by the researcher (MK). After all the six interviews were conducted, the analyses started with reading the transcribed interviews simultaneously in order to get a feeling of the whole. This holistic approach was taken in order to discern an overall and fundamental meaning of the experiences. Each interview was then condensed by highlighting passages of importance to the investigated phenomenon; by the first author (MK). This started a process of reflection and search for meaning in the text by extracting essential themes. Van Manen (1997) calls thematic analyses [22]. In this analytic

step, a list of preliminary themes was constructed, by highlighting phrases and quotes that seemed to be thematically related to professional caring. This step continued with reflection over the themes by viewing them in light of each interview and the issues of interest as related to the open ended questions. In the process, the preliminary themes were constructed inductively into a hierarchy so that categories were grouped into sub-themes and themes into essential themes. A second researcher then reviewed all steps in this process, also searching for evidence that contradicts and well as conformed to this process [23]. Afterwards, critical discussion ensued until both researchers were in agreement regarding major themes, subthemes and exemplars. This procedure was an interpretative creative process and findings evolved as a result of an intuitive and reflective writing process. This process can be understood as a circular process occurring between reading and re-reading the transcribed interviews, viewing the themes in their own context, and writing and re-writing towards a higher level of abstraction. At the end of this process, the themes were supported by quotations from the interviews to enhance credibility. To enhance the validity of the categorizing method and to guard against bias, a list of themes, subthemes and quotations were then presented to a research group at the institution where the study took place. These colleagues were invited to discuss the naming and classification of the themes and sub-themes, searching for confirmation as well as contradictions to enhance the reliability of the findings [18].

3. Results

3.1. Sociodemographics

Of the 32 students, the majority were women with only 2 men participating. A large proportion were middle aged (40 - 60 years) ($n = 26$, 83.8%) and had worked up to 15 years ($n = 11$, 35.4%) as compared to those working more than 15 years ($n = 4$, 12.9%). Students working full time ($n = 16$, 51%) were approximately as many of those working half time ($n = 15$, 48.3%) and the majority were married with children ($n = 22$, 70.9%). All students were post-graduate students with a minimum of four years university education. Refer to **Table 1** [18].

3.2. Qualitative Findings

Findings revealed that missed care could be categorized into five main themes and thirty sub-themes. The major themes were: 1) labor constraints; 2) organizational constraints; 3) professional constraints; 4) communication constraints; and 5) emotional strain. An overview is presented in **Table 2**.

3.2.1. Labor Constraints

A major theme that consistently emerged throughout the focus groups were factors related to *labor constraints*. This included workloads which featured time restraints, being too busy and not being able to carry out one's duties in a good way as shown by the following comments: 'It is tiring to have so much to do and not being able to carry out your tasks in a good way which gives the patient a

Table 1. Sociodemographic characteristics of the focus groups.

Variable	Number
Number of participants	31
Gender*	
Women	29
Men	2
Age*	
20 - 30	
>30 - 40	4
>40 - 50	7
>50 - 60	10
>60	9
Marital Status*	
Unmarried	0
Married	3
Living together	19
Divorced/separated	6
Widowed	1
Educational Background	
Nursing	27
Counselling	3
Years Working*	
1 - 5	2
>5 - 10	6
>10 - 15	3
>15	4
Working	
Full time	16
Half time	15
Other	1
Children*	
Yes	22
No	4

*Missing answers.

sense of worth. Sometimes, I think to myself, would I have done this if I was a family member? It is especially difficult with senile and nervous clients.” Some participants stated that they knew if they could take more time with specific clients this would be helpful, but due to limited time they were forced to perform acts that they knew were against the client’s best interest as the following comment portrays: “When working night shift and I have a nervous patients, I know if I could just take the time to sit with them, this would have helped, but instead I just say, I know you are nervous, but you need to sleep. I offer medication instead.” In some cases, such acts were against ethical standards as illustrated by

Table 2. Major themes and sub-themes found in focus groups regarding missed care.

Labor Constraints
Workload
Inadequate staffing
Time
Difficult patients
Withdrawal
Technology
Organizational Constraints
Leadership qualities
Time allotment
Rigid system
Lack of caring philosophy and standards
Lack of coordination
Lack of opportunities for self-reflection
Professional Constraints
Professional attitudes
Self-awareness
Personality characteristics
Not genuinely present
Judgmental
Cultural insensitivity
Relationship with colleagues
Communication Constraints
Not acknowledging
Not listening
Not asking questions
Self-interest
Not advocating
Labeling
Emotional Strain
Powerlessness
Loss of professional identity
Fatigue
Self-protective behavior
Irritability

the following: “In the evenings there are so many patients you don’t have time. Instead, I set their medications on their night stands, for them to take themselves, which we aren’t really allowed to do.” Many discussed the aspect of time which was connected to inadequate staffing and moral distress as exemplified by the following: “You go home feeling you haven’t done a good job because there were so few staff. You have had to give priority to other things when you know that the patient needed other things. For example, in the nursing home, it can almost go three years between the times patients are out in the fresh air, because of staff shortage.” Other factors connected to labor constraints which were voiced included complaining colleagues, having too many new clients and the use of technology as illustrated by the following: “There is so much complaining from colleagues, this destroys a lot because we are so busy. We also get too many new patients, and then there is the new data program on top of this. All this

takes our focus away from the patients.” Encounters with “difficult clients” was another factor discussed by many. Such clients were described as those who required more care than others. This resulted in having to set priorities and creating difficult feelings as illustrated by the following: “Non-caring is related to difficult patients who need more than others, which we are not comfortable with, and we think to ourselves is she ringing again?” Another stated: “Some patient’s require a lot of care and this results in less care for others, especially the quiet ones who say little and make little noise.” Others described how these encounters were related to distancing oneself from clients as illustrated by the following statement: “There are difficult clients where you try to create a good relationship and everything is always wrong. They bring up something you have said earlier again and again and accuse you of having labeled them in some way. They are so difficult to work with, I just have to withdraw from them and take deep breaths.” For others, asking colleagues for help when working with difficult clients was a better strategy as verbalized by one: “There are some patients who can be very provocative and I need to signal to my colleagues that I need a break. There are just some patients you don’t share good chemistry with.” Some participants also discussed how technology was related to their workload in relation to calculating time allotted for carrying out specific caring activities. Such strict time allotment resulted in not having time to acknowledge the uniqueness of the other and reduced time for assessing and observing needs as shown by the following comments: “In community nursing we have a technical device that allots how much time we can take with each patient and tells us what our duties are. We do it and don’t observe anything else.” Other issues related to technology were connected to overtreatment and loss of worth as exemplified by the following statement: “For some patients we just try to delay their dying, they are over treated. They just lie on their machines which continue to beep and this isn’t a worthy death. There is so much noise from the machines, no calmness and the patient doesn’t feel of worth.”

3.2.2. Organizational Constraints

Various *organizational constraints* were considered by the majority of participants as creating barriers for good care. This included issues related to leadership qualities. Some described bad leadership as being related to the leader’s need to be liked by staff. One participant stated: “Bad leadership contributes to bad caring in that the leader wants to be friends with everyone. It is the working environment that allows this to happen. It is almost like the staff is more important than the patients.” Poor leadership was also discussed in relation to unethical behaviors which had the possibility to inflict harm as illustrated by the following comments: We had staphylococcus on our floor, and our leader said, “No, this isn’t so dangerous, we can’t use time on developing interventions for this because it would cost too much, even if this patient is affected with this.” Another verbalized: “When we write reports of nursing errors, they don’t get very far in the system, they only land on the leader’s desk.” Time allotted by ad-

ministrative leaders to carry out activities was seen as a major hinder to good care as described by one participant: "I think, as nurses we have to learn new programs, new methods, new techniques all the time. It is almost like our leaders don't expect us to care. We are only required to use our Ipad where we punch in and out, so our leaders can see how much time we have used with our clients. If you happen to use more time than was allotted, you are called on the carpet to find out why. In the end, you have to convince yourself and accept that you can't give the little extra's. In any case, you don't ask the patient how they are feeling because it doesn't go up in the calculations. Instead, you say to your client's, 'here everything is going okay, yes?' It's all about politics and economy." Another participant stated: "In community health, administrators have calculated how much time it takes to put medicine in boxes. There just aren't any minutes calculated to give good care. The word care is out of the system now." A rigid system and lack of a caring philosophy were also described as constraints as shown by these comments: "The system is so rigid, it is difficult to give the little extra to the patients" and "Some institutions have not formulated a caring philosophy, standards or goals for care at all." Lack of coordination, postponement of referrals, not feeling cared for by the system and lack of holistic planning were also discussed. As one participant expressed: "Where I work you can see those who do their job and others who simply postpone things. I have experienced people who have to wait many, many days to come to a dentist when they have extreme pain, because the leader feels a dentist is not necessary or messages get lost in the system. The system gives the person so little worth." Others stated: "Many clients feel we don't have enough time, so they voice only their practical needs and not what they are really concerned about" and "Inter-professional care is missing, and the person isn't followed up. A client gets one treatment from one, and another treatment from another, which lacks any form of holistic planning, because each individual is intervening from their own perspective." Another stated: "Bad care occurs when we as professional are not cared for ourselves by the system. We need space and room to reflect and share."

3.2.3. Professional Constraints

Issues related to *professional constraints* were discussed by many participants. A prevalent issue included professional attitudes such as having ambitions which the client didn't share, not creating opportunities for client decision making, or feeling uncomfortable when advice was not followed as illustrated by following comments: "We can have ambitions for others which they do not have for themselves. Thinking we are right the whole time is a barrier, and this occurs quickly and often." Another theme was related to issues of self-awareness as shown by the following: "It is important not to think, I am here now and I will take care of you, and I completely take over and don't allow the other to participate in making their own decisions" and "It is difficult with those clients who don't follow our advice and make decisions based on their own beliefs. This makes uncomfortable and insecure." Another stated: "We all have our own histories, it is important that that we have reflected over our own weak points and if

one meets the same weaknesses in another, it is important to remember that the other is the most important one.”

Personality characteristics were also discussed by many participants. Issues related to lack of respect and moral sensitivity were also voiced: “I have worked with many people in various institutions and bad care is not only related to staffing, but also to the personalities of those working there.” Others stated: “There are so many things that hang together but some staff simply lack moral sensitivity” and “I had a patient who had just died and I was together with another nurse performing post mortem care. She just talked and talked and talked and of such silly things. I felt so uncomfortable, there was no respect from her side.” Moral insensitivity was also discussed in relation to choice as the following comments illustrate: “Bad care is related to ‘avoidance sins’ as I call them. One simply chooses not to see nor listen to the patient, and one chooses not give good care.” Other’s voiced: “Some people just can’t give good care. For example, I heard a nurse once say to a dying patient, it’s not so dangerous to take more pain medication because you are going to die anyway” and “Bad care is not showing respect for the patient and not doing what you know you ought to do, not doing your job thoroughly.” Many participants discussed not being genuinely present as another feature related to professional constraints. “Missing care is not acknowledging the patient’s needs. Just taking a bit more time is the difference between good and bad care. Being genuinely present. There are so many people who aren’t seen or heard or invited to take part in their own decisions.” Also, factors related to being judgmental were also discussed as illustrated by the following: “I had a nursing model in practice who had such a negative stance towards my patient from the first second she walked through the door. The patient was silent and she was bathed and clothed by her, but this was done in such a hard way. There just wasn’t any understanding. Afterwards, I tried to talk to her about this and she just said; “I am sorry but I have this patient up my throat, we just don’t have a good relationship together.” Issues related to cultural sensitivity were also expressed: “I think we have destroyed a lot with our views of cultural integration, with our kindness attitude, with the idea that we must tolerate everything. We also need to make demands. There is a lot of racism from the other side also” and “I pressed and encouraged a father from another culture to hold his premature daughter, he finally did and I felt that I had supported good caring. Instead, his wife came in and screamed at me and said that her husband felt traumatized having to hold the child. Perhaps this was good care for the baby but not for the father.” Another issue related to professional constraints concerned relationships with colleagues as shown by the following: “There are too many stressed staff, they don’t have control over their own lives. They walk fast, speak fast and it is the patient who suffers. One can observe one’s own colleagues as not being especially caring. However, I don’t think it is necessary to go directly to your leader about this. I mean that it is important to discuss what you are observing with your colleague and ask what is happening.” Another stated: “I feel especially for those who are alone and have

mental problems. But I feel some nurses are only concerned with being rigid, setting boundaries and no one seems to have the capacity to listen to their histories.” Some participants also discussed the need to ask colleagues for help as well. “When caring, one can experience difficult situations and sometimes we just avoid the patient. We need to be more competent in collaborating with each other and asking for help. We need to try to help each other give care instead of trying to forget or say, “I just can’t cope with this” and simply withdrawing.

3.2.4. Communication Constraints

A major theme that consistently emerged were factors related to *communication*. Such factors included not acknowledging the client as a person by not listening and not asking questions as shown by the following statements: “Working in a health station, I have a checklist of so many things I have to ask about, that I concentrate on asking only these questions, and I don’t see the person in front of me.” Another proclaimed: “Suboptimal care is not listening to what the patient is trying to say, it is when you speak over their heads, and you drive them in the corner with your own thoughts.” Other participants described restricting communication by not creating openings for dialogue as illustrated by the following: “It is bad care asking people how they are when you don’t have time to listen to what they say. It’s better just not to ask.” Another participant stated: “My role model in practice says they do not ask the big questions because they don’t have time to meet these problems.” For some participants, not taking time to listen was also described as being connected to one’s own self-interests as exemplified by the following: “I think about those that can’t listen to their clients. They just talk and talk about what they are interested in themselves. We don’t create the openings so the other can really talk about their own concerns.” Other communication issues included not voicing one’s own beliefs and advocating on the patient’s behalf as illustrated by the following: “Bad care is when we don’t take the initiative and dare say our own meanings to the doctors’ regarding our patients. After all, it is we who know the patient best. This is wrong.” Another communication issue was related to labeling clients which was stigmatizing. As illustrated by these comments: “I work with colleagues who label patients and say, this patient is like this and this, and what has happened is his own fault. This has happened because he hasn’t tried to take care of himself” and “Language has power, big power. I work with women who are prostitutes. Why should they be labeled prostitutes? They are women and working with what they do because of necessity.” Another participant described how she herself felt stigmatized: “I had a patient who needed to be more physically active and she told me I was torturing her. Nothing was ever good enough for her and so it is difficult to care because you have only two hands and must plan.”

3.2.5. Emotional Strain

Lastly, many participants also described feelings related to *emotional strain* such as feelings of powerlessness and loss of professional identity. The following comments illustrate these points: “I feel like an industry worker. Also, you con-

nect your patients' to the machines and disconnect them and you don't even have time to talk with them. It's a bad feeling having to go home knowing that you have done only what you had to give priority to" and "I feel that we are just the doctors extended hand. We take blood tests, wash beds, accompany doctors on rounds, make sure they sign their orders, attend meetings, are secretaries, kitchen help, and safety guards. There is very little nursing. I am tired of it." Others described fatigue as connected to self-protective behaviors like avoidance. "One can simply get tired of people generally, you meet so many different people, children and families in just a short span of time. You have kind of reached your own limit." Others stated: "It is important to meet people where they are, but some days you are just too tired, you just say" "do this and this and this and then come back. It is almost a survival strategy so you can keep holding on. You need to protect yourself because you can go over the edge and end up burned." As described by another: "We had a physical therapist who came for consultation at school a couple hours a week. I asked her if she could put a message on her door when she would be available. She said no, because too many people would seek help." However, various participants also observed tiredness as a form of apathy observed in their colleagues as shown by the following: "I think some of the colleagues I work together with have worked too long, they are older and are apathetic but they don't see this themselves. This isn't good for the patients or for themselves." Some participants also described feelings of irritability with colleagues and viewing colleagues as meeting their own needs as shown by the following: "Some days you work together with a colleague you don't share good energy with and both of you end up complaining and blaming each other." Another stated: "I feel sometimes that my colleagues are trying to meet their own needs disguised in professionalism. I work in a prison and I think sometimes the interventions are based on their own interests like hikes in the mountains and rafting with inmates. For example, there are many existential issues which aren't met at all."

4. Discussion

In this study different understandings of the meanings given to missing care were expressed by postgraduate nursing and pastoral students. Five themes and thirty sub-themes emerged from the focus group discussions. The major themes included labor constraints, organizational constraints, professional constraints, communicative constraints and emotional strain.

4.1. Labor Constraints

Many of the descriptions confirmed experiences impacted by workloads, inadequate staffing and limited time as reported by others [16] [17]. Research by Peter and O'Brien [24] found that nurses experienced their work environments as morally uninhabitable with their social positioning leaving them vulnerable to being overburdened by, and uncertain of their responsibilities, as found in the present study. It is well known that client complexity requires a skilled health-

care force with sufficient numbers to deliver the care required together with organizational processes which support timely and appropriate care. Importantly, the negative impact of nurse-patient ratio's hinders health professionals' application of knowledge and skills [25] and is connected with detrimental outcomes [8] [17] [26]. Due to staff shortage, many participants described having to make priorities which affected the care of other patients. Prioritization of which clients to attend to first is an issue which is especially relevant when communication of the client's condition does not convey the urgency required. Moreover, when staffing is minimal this may also result in a delay or absence of communication with other team members [15].

Many participants described not having time to be genuinely present in the situation which was also related to not acknowledging the client as a unique individual and not assessing specific needs. These findings are especially noteworthy. Poor assessment, inadequate exploration, delays in diagnosis, treatment and referral, and lack of recognition of the importance of deterioration have been shown to have detrimental consequences for clients and their families [27]. Further, encounters with difficult clients were described as a major issue by many. Difficult patients have been characterized as those whom health professionals perceive as consuming greater periods of time than their condition suggests. They are described as impeding the work of staff with demands, complaints and lack of cooperation also causing self-doubt among professionals [28]. Difficult patients themselves have also been reported to experience stigmatization and receive inadequate care due to avoidance strategies by health professionals [29] [30] [31] as voiced in the present study. Participants also described feelings of frustration, anger, helplessness when encountering difficult clients, as well as labeling clients in such situations. Similar findings have been reported by others [32]. [28] explored strategies used by 234 clinical nurse specialists when caring for patients involved in "difficult" clinician situations. Unfortunately, the least frequent strategies included changing the nursing staff's assignment to the patient/family, and conducting in-service programs that address behaviors that stigmatize patients. Notably, due to limited time and workloads, some participants even expressed how they felt forced to break standards. For example, they described how they left medications on night stands for patients to administer themselves, even though they knew this was wrong. Importantly, administration errors have been found to be the result of human factors such as fatigue, stress and understaffing [33]. Medication errors have also been shown to be caused by system factors such as leadership, maldistribution of resources, poor organizational climate and lack of standardized operating procedures [34]. Leaving medications on nightstands could have been related to these factors.

4.2. Professional Constraints

Much empirical work report health professional's insensitivity to patients' needs which was also described in the present study. Such insensitivity was grounded in professional attitudes, such as not being genuinely present, lack of self-

awareness, and personality characteristics as found by others [35] [36]. Such insensitivity can be interpreted as threatening the client's sense of dignity. Jacobsen conducted a literature review and found that dignity violations in health care occur through the process of rudeness, indifference, dismissal, disregard, dependence restriction, discrimination, deprivation, assault and objection [37]. Avoidance tendencies, as a form of dismissal, and discrimination in the form of labeling clients, together with various forms of disregard were also found in the present study. In another study, Thorsteinsson [38] explored patient perceptions of bad quality care. Characteristics of nurses included those who were also indifferent, took no initiative, and had a negative attitude. Altree [20] also found "not so good" care was described as being routine, unrelated to need and delivered in an impersonal manner, by distant staff who did not know involve patients. These studies correspond with present findings. Importantly, in a recent landmark report in the United Kingdom, Darbyshire and McKenna [39] found that nurses couldn't care less about the erosion of caring and compassion in nursing. Such findings are extremely important in considering the outcomes of poor quality care.

Various participants also described how their care was related to teamwork and relationships with colleagues as shown in the study by Kalisch and Lee [15]. In the absence of an effective team work culture, others have found that a higher number of problems related to suboptimal care occur [40]. Shift work and staff shortages have also been shown to have detrimental effects on team work as described by many participants [41]. Moreover, lack of professional trust among colleagues has been shown to lead to a lack of clarity of professional roles, lack of team support and professional hierarchies. For instance, when professional hierarchies exist, junior staff were found to be reluctant to call for help when experiencing difficulty for the fear of losing face [9]. In the present study, junior participants working with role models also discussed difficult feelings. Fear of conflicts were also expressed in the Norwegian nursing home study [21]. Thomas, Sexton and Helmreich [42] measured and compared critical care physician's and nurses' attitudes about teamwork ($n = 230$) in eight nonsurgical intensive care units. Only 33% of nurses rated the quality of collaboration and communication with the physicians as high or very high. Nurses reported that it was difficult to speak up as affirmed in our findings. The authors concluded that physicians and nurses have discrepant attitudes about the teamwork which includes suboptimal conflict resolution and interpersonal communication skills. In another study, Johnson [43] described the results of a survey among 33% doctors and 67% nurses in the United Kingdom. Behavior problems were found to be very pervasive where nearly 89% of the respondent's reported witnessing behavior problems between doctors and nurses. A surprising 10 percent said they witnessed problems between doctors and nurses every day.

Various participant's voiced how negative role behavior impacted their care. This was related to behavior observed in colleagues, leaders, and student role models. The influence of role models on student's caring behaviors is well do-

cumented. For example, Fang and colleagues [44] explored baccalaureate nursing student's perspective on learning about caring in Chinese focus groups. Results demonstrated four themes which included learning by positive role models as an ideal way of learning, negative role models as another way of learning, lack of directive substance as a hindrance to learning care, and lack of cultural competence as a barrier to learning about caring also supported by present findings. Traynor and Buus [45] explored professional identity among 49 second and third under graduate students in six focus groups in the United Kingdom. Student's described qualified nurses as either possessing caring characteristics or having "lost" it as described in the present study. In this study participants described strategies for not becoming corrupted in professional practice which included distancing from "bad" qualified nurses. Notably, Byszewski and colleagues [46] reported that over time, behavior that students previously considered unprofessional, became increasingly more acceptable as students progressed in their training, indicating some erosion of values. Also, in a systematic review and meta-analysis of qualitative literature concerning the experiences of British student nurses in hospital settings, Thomas, Jack and Jinks [47] uncovered negative clinical experiences which endured through time. Such findings raise concern regarding the long term effects of negative experiences. Other professional constraints included a lack of cultural competency while others expressed cultural insensitivity. This is important considering other studies involving students have also reported observations where nurses appear reluctant to provide care to ethnic minorities [48] [49] and where a lack of cultural competence creates barriers to learning about caring [44] as found in our findings.

4.3. Organizational Qualities

The majority of participants described ways in which leadership qualities and organizational obstacles influenced their caring encounters. Findings seem to confirm an air of dehumanization, fragmentation and focus on doing more "faster" with unsustainable staffing and excessive demands on fewer practicing. This growing emphasis on productivity was also cited in Miller's research [19]. This was compounded by having to follow technical apparatus which plotted how much time was allowed per client and per task. Values seemed to reside in the efficient, economical and the procedural where obligation and commitment to clients could be seen at odds with organizational demands. Creating a positive culture in which health professionals can flourish has been described as the responsibility of leaders who should model behaviors that support good caring [50]. Conversely, some of the participants attributed missing care to destructive leadership tendencies. Destructive leadership has been defined as the systematic and repeated behavior by leaders that violates the interest of the organization by undermining and/or sabotaging the organization's goals, tasks, resources and effectiveness and/or the motivation, well-being or job satisfaction of the employee [51]. Participants described rigid systems with lack of coordination, postponement of referral's, staff not feeling cared for by the system and lack of

holistic planning. Concern with establishing camaraderie with staff was also described. Destructive leadership behavior may not be intended to cause harm, but as a result of insensitivity or lack of competence it undermines staff and the organization often at the cost of the staff.

Participants also discussed a lack of caring philosophies and standards absent in organizational structures. Healthcare organizations must critically examine the absence and presence of professional values and whether incongruence between what is espoused, and what is done, propagates less ethical actions. This also includes leaders being consciously aware of how their own ethical standards and actions, influence staff and client outcomes, such as not stopping staphylococcus outbreaks and not acting upon reports of poor quality care as pointed out in in this study. A major task of administrative leaders at all levels is handling complaints of unethical and disruptive behavior and dealing with it immediately. Health care organizations and facilities also need to have codes of conduct defining acceptable and nonacceptable caring behaviors, establishing a process for managing unacceptable behaviors and enforcing codes of conduct even under economical constraints.

Tadd and Read [52] also pointed out that failure to provide dignified care often resulted from systematic and organizational factors as confirmed in our study. At the same time, nurses must deal with organizational constraints alongside moral distress as confirmed by our findings. Moral distress is defined as painful feelings and/or the psychological disequilibrium that occurs when health professionals are conscious of the morally appropriate action a situation requires, but cannot carry out the action, because of institutional obstacles. Many participants seemingly knew what the right thing was to do, or what they felt they should do, or ought to do, in their caring encounters. However, due to workload, inadequate staffing and time allotment they were unable to do what they knew was best for their clients. Many discussed how this created difficult feelings. Such findings have been found by others. In a survey by the Royal College of Nursing [53] where over 2000 UK nurses participated, results showed that 70% of the nurses sometimes left work feeling distressed and 11% always left work feeling distressed, because they couldn't deliver the kind of dignifying care they knew they should provide.

4.4. Communication Constraints

Observational studies have found that dignity may also be influenced by health professionals communicative style as supported by our study [54]. Clear communication has been especially highlighted as important in preventing suboptimal care [55]. Issues related to communication such as not acknowledging clients, not listening, not asking questions, self-focus, not advocating on the client's behalf and labeling clients were discussed by many. Communication is not just about what a person says, but how he or she says it. Effective communication is critical during the countless interactions that occur among health professionals on a daily basis. When effective communication is absent, client care is

compromised. Furthermore, hierarchy differences, conflicting roles, ambiguity in responsibilities and power struggles have also been shown to lead to communication failures that compromise patient safety and quality of care.

Notably, rude language and hostile behaviors were voiced by some participants. Such behaviors are reported to foster medical errors, contribute to poor patient satisfaction and adverse outcomes [56]. Importantly, such intimidating behavior has been found to be such a serious problem that a Joint Commission in the USA issued a Sentinel Event Alert urging organizations to take specific steps to curb this problem. The Joint Commission [57] has also introduced a new standard requiring accredited organizations to create a code of conduct that defines acceptable and unacceptable behaviors and to establish a formal process for managing unacceptable behavior. Improving communication strategies such as these, requires a systems approach, including creating a culture that emphasizes open communication as a crucial component of safe quality care. It has also been shown that using needs assessment and systematic tools for determining goals, identifying discrepancies between optimal and actual performance, and establishing priorities for action can assist organizations to improve communication [58].

4.5. Emotional Strain

Feelings of emotional strain were discussed by the majority of participants. Feelings of powerlessness, loss of professional identity, fatigue, irritability and the need for self-protective behavior were themes often voiced. Others have reported how nurses report dissatisfaction and low morale as they cope with time constraints and staffing shortages which were also discussed by participants. For example, Cummings and colleagues [59] point out that dissatisfaction among nurses is often related to concern over unattended patient care needs, emotional strain and disruption in workgroup collaboration as found in our study. Turkel [60] found that consequences of non-caring experiences includes lack of control, despair, helplessness, vulnerability and being alone. Thorsteinsson [38] also described poor quality nursing care as producing negative feelings such as anger and stress. These feelings were also described by some participants. Importantly, it has also been written that health professionals own distress poses a threat to caregiver's perceptual accuracy of patient experiences [61]. Similarly, it has been shown that when caring behaviors are not visible or when patient needs are not met, patient satisfaction is compromised [62]. Importantly, emotional strain is strongly associated with self-awareness [63]. Many participants expressed the need for the creation of opportunities for self-reflection and dialogue to counteract difficult feelings and reactions. This importance of a supportive environment to reflect, understand and discuss emotional strain is vital in caring has been affirmed by others [64].

In sum, findings of this study resonate well with other research as well as with studies on missed nursing care [14] [15] [16] [17] [18] lending support to the definition of missing care actions as required care that is omitted, either in part

or whole, or delayed in action [13]. One can also question whether some of the missing actions can be regarded as examples of unethical behavior? Healthcare professionals working in clinical practice, administration, education and research are not immune to unethical behaviors. They face ethical dilemmas on a regular basis as evidenced in this study. Notably, shortages in the numbers of professionals to deliver patient care, inadequate staffing levels, cost containment measures, and ineffective leadership have resulted in the escalation of ethical dilemmas faced today in healthcare environments [51] [65] [66] as evidenced in our results.

5. Limitations

The study is limited because of convenience sampling and a small sample consisting of a majority of women, although their age spans differed greatly, limiting the generalizability of the findings. Furthermore, participants were recruited from only one institution although they lived and worked in many geographical areas in Norway and had backgrounds in community health nursing, cancer nursing, nephrology nursing, public health nursing and pastoral care. The probing questions captured a glimpse of the obstacles in giving care at a particular point in the professional experience of each participant. This could be a limitation reading the rapid and constant changes occurring in health systems. However, the focus groups provided a valuable flora for discussion related to what participants perceived as missed care. A relevant follow up study might be to use the same design with students from another country or countries to validate the international nature of the study issue. The names given to the major themes and sub-themes were discussed by two independent researchers, yet the selected terminology used in classifying themes and sub-themes denote specific nursing knowledge. However, interpretations of the themes and sub-themes were reviewed by inviting colleagues with different expertise and backgrounds to review the results. The moderators had previous experience with conducting focus groups. The moderators played a more passive role, using probes when needed, but allowing discussion to evolve openly. Because all of the groups had been recruited in their own classrooms, the atmosphere of the groups portrayed a sense of group membership and cohesiveness. Notably, research has shown that there is a tendency for more self-confident and articulate individuals to be more willing to agree to take part in focus groups. In two of the groups, certain members were more assertive and as a result the more silent participants had to be invited into the dialogue. Also, in groups where there were a majority of older participants, the younger tended to be less articulate. Tape recording the sessions, could have caused feelings of unease for some, and one group commented that it would have been easier to speak together without the tape recorder. However, in all groups participants were able to narrate their experiences and perceptions of what they considered was suboptimal care and the focus groups created a space which was filled with embodied dialogue. Interestingly, some of the most valuable information was discussed towards the end of the group, which could be re-

lated to the fact that the participants felt safe and were more at ease [18].

6. Future Recommendations

The environment within which professionals work, client care demands, time and staffing available to provide that care, all have an impact on patient outcomes. Based on the results of this study and other research, it is recommended that future studies explore and identify the types and reasons for care being missed in various health care settings. Future research is needed which focus on causal factors to missed care and how these factors directly influence the degree to which missing care occurs, as well as explore the specific client and nurse outcomes. Such studies could help inform quality improvement efforts in reducing regular omission of various elements of care and in securing favorable and safe patient outcomes.

Moreover, missed care also needs to be examined within a theoretical context and studied systematically in multiple cultural contexts that openly recognize it as a universal factor in client safety. Consequently, missed care is a client safety issue which would benefit from international collaborative research to enable a shared understanding of the meaning of care which is “missed.” Studies based on more objective measures which capture why clients experience delayed, inadequate or inappropriate care should be developed to more clearly to help define missed nursing care. Since the consequences of missed nursing care presents threats to patient safety, it is also recommended that studies on missed nursing care should be given consideration in state and national policy development globally.

Studies are also needed which also explore professionals own perceptions of caring so that they can evaluate their nursing practices. For example, health care professionals need to reflect upon care practices that leave clients feeling depersonalized. Studies which explore the choices that health professional face when they must deal with factors in their environment, and how they reach the decisions they do in providing care to their clients, should be given priority. Studies are also needed which focus on the identification of patient’s and relative’s perceptions of the attributes of care quality, together with other studies which focus on how client and family perceptions coincide or differ from professional perceptions. Other recommendations also include the need to test the effect of innovative programs or clinical care pathways that address difficult professional-client situations. Furthermore, studies which explore and develop valid and reliable care quality audit indicators for the assessment and evaluation of care quality and client satisfaction are of vital importance should remain paramount.

7. Conclusion

With the inflation of economic constraints on health care, demand to increase care quality and increasing demand of client’s perspectives into care, there is an increasing need to develop a clear understanding of which health professional behaviors may threaten quality care [2]. The findings from this study extend

understanding of what barriers health professionals perceive as inhibiting them from offering quality care. Participants articulated obstacles related to labor constraints, organizational constraints, professional constraints, communication and emotional strain. Many of the findings lend support to the definition of missed nursing care as being care that is omitted, either in part or whole, or delayed. These findings have implications for organizational systems, professional practice arenas, and health care education. Integration of ethical and philosophical reflection on the importance of values in healthcare programs together with principles, rules, and standards of practice that guide both unethical and ethical behavior in challenging situations needs to be openly addressed in order to prevent and reduce attitudes and behaviors related to missed nursing care.

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Older People's Lived Experiences with Participation in Shareholding Networks for the Care of Older People in Rural Areas of Thailand: A Phenomenological Hermeneutic Study

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Abstract

Background: Older people participating in shareholding networks are exposed to diverse situations, which may be associated with dignity. **Aims:** This study aimed to illuminate the meaning of lived experiences when participating in shareholding networks for the care of older people in rural areas. **Methods:** This qualitative study is based on individual interviews. Ten older Thai persons with at least 12 months of lived experiences participating in shareholding networks for older people in rural areas were interviewed. A phenomenological-hermeneutic approach, inspired by Ricoeur, was used to understand the meaning of the narrated text. **Findings:** The structural analysis resulted in four themes: 1) being satisfied with activities, 2) being valued as important, 3) being frustrated and feeling sad, and 4) being bored and feeling disinterest. The meaning of participation in a shareholding network for the elderly can be understood as a pathway to feelings of confidence and presence of others. Confidence and allowing the presence of others mean facing humanity and sensing vulnerability, because in a trusting relationship the person who gives confidence is susceptible to the other's betrayal. **Conclusion:** An individual's dignity should be a high priority in health and social care strategies. Therefore, it is important for healthcare professionals to initiate a dialogue with the shareholding participants for support and information. The narrations in this study can be used as a basis for developing cooperating care with older people in shareholding network focusing on their needs and dignity.

Keywords

Shareholding Networks

1. Introduction

The world's population is rapidly aging. There are some 600 million people aged 60 and over worldwide; this total will double by 2025 and will reach virtually two billion by 2050 [1]. The older population is growing faster in Thailand. Its older population is defined as those aged 60 and over, and it is above 16.98%, which accounts for approximately 11.21 million citizens. According to estimations, this number will double in the next 10 years [2].

The social changes that often take place as people enter advanced ages, such as shifts in social roles and loss of close relationships, may pose additional threats to older persons' health and well-being [3]. In rural areas, older people have less access to services and activities, and experience a lack of support and healthcare deficits as a result of the place in which they live [4]. Making investments into such support will lead to valuable social and economic returns, both in terms of the health and well-being of older people and in enabling ongoing social and community participation [3].

Thailand's changing population structure has not only introduced numerous problems for healthcare in aging communities [5], but it has also threatened to further marginalize older people in society [6]. The majority of older community care users are still in their own homes, but there are few opportunities for them to become involved in planning and delivery of services. Despite national policy addressing the aging Thai population [7], older Thai people have been neglected and need more healthcare and better welfare, as they suffer from health problems, low income and poor housing in their communities. Supporting networks in the community empowers older peoples' inclusion as worthwhile members of that community [8]. As such, community networks of older people, their families, caregivers, and organizations have begun to play critical roles in spearheading and sustaining work processes associated with community-based healthcare for older people [9]. Individual engagement and networks have shown improvement in terms of caring for the health of the older population [10]. As Nuño *et al.* [11] pointed out, shareholding networks in such care are perceived as positive by older persons and family members in rural areas.

Community networks and organizations are considered groups playing key roles in the drive for work processes associated with healthcare for community-based aging. Working in integrated and coordinated teams with older people and their families provides the opportunity to practice holistic care and form rewarding relationships for all those involved [12]. In Thailand, rural areas generally have at least one health center. It may be referred to as a sub-district health promotion hospital (HPH). HPHs take on the role of health promotion, disease prevention, treatment, recovery and participation with other organizations in

the community, based on the criteria of the Ministry of Public Health [13]. HPHs have afforded policies preparations of care for older people in their communities. The strategy has supported participation in shareholding networks for older people's care in the community [13]. In addition, the Local Administrative Organizations (LAOs) are the primary government agencies that provide basic healthcare services in rural areas [14]. The LAOs taking on the role of providing basic healthcare services for older people are in line with the government policy proscribed by each ministry. The LAOs have a role, duty and responsibility to make plans consistent with government policy to provide budgets and resources for the care of older people, and the local administrative offices have been providing social welfare to older and low-income people. Public health personnel developed a system to serve older people's needs for continuity of care [15]. The LAOs promote older persons activities in shareholding networks, and these sub-district municipalities include distribution and compilation of valuable data derived from older persons' wisdom. Supporting more clubs or centers for the care of older people, where the older persons can join social activities and events in their communities, has also been established [16].

The expected increase in the older population in society has contributed to the establishment of community care, and more attention is being given to the prerequisite of user involvement and the potential contribution of older people [17]. Older people do not see themselves as having a role to play in planning or a right to voice their opinions about the provision or delivery of services. This is particularly true of older people in rural areas and among elderly and frail older people [18]. Dignity is central in nursing [19], and the maintenance of dignity has become an important goal in the care of older people; for example, in nursing care [20]. Dignity is a vague and contested concept, usually interpreted with a focus on personal autonomy [21], which may be an overly narrow interpretation. Older persons in need of support and care are exposed to varied situations that meet their needs, and because of this, they might experience dignity within a caring context differently. Initiatives that focus on redress of this situation often include information and try to lay the foundation of confidence, as well as encouraging the acquisition of the skills necessary to take part in the planning process, and this is seen as one way toward accomplishing this.

Traditional elderly care best-practice models that embody the goals of the "culture change" movement in the care of older people have been developed and assessed [22]. For example, the work of Kitwood [23] is the frontline of person-centered care for people with dementia [24]. Both person-centered care and other models of care that are described as relationship centered [25] share fundamental values; for example, dignity, honoring and respecting the older persons as unique individuals, validating their emotional reality and supporting their lived experiences [26]. Relationship-centered care is described as "best practice" or "high-quality care" [27]. According to Bown and Raines [28], this view of care is compatible with the involvement of increasing numbers of more vulnerable older people in community healthcare for older people.

Financial pressures and increased costs due to changes in demographics for health and social care are pushing the burden of care on to individuals, their families and friends. Community networks and organizations are playing key roles in the work processes of revising, planning, controlling, directing and evaluating the outcomes of community-based aging. In local elderly care, the complex challenges of society are met [29]. Even in senior citizens' clubs, specifications of roles and responsibilities for persons involved with care networks for the care of the aging in a community are not established. The municipality, which is dynamic, has caregivers that must adapt to giving older people the care they need. The caregivers must therefore show understanding in order to offer support and care for the elderly based on the experiences of the older people themselves. Consequently, they need to expand their understanding of older people's lived experiences and understand the implications of participating in shareholding networks for the care of older people in the countryside. For that reason, there needs to be development of local networks to encourage older people's involvement in municipal health service. Therefore, to obtain a more in-depth understanding, the aim of this study was to illuminate the meaning of lived experiences of those participating in a shareholding network for the care of older people in rural areas.

2. Method and Design

Drawing upon conventions of qualitative research, this study gathered and interpreted persons' subjective experiences. The qualitative approach allowed nuances, details, and reflections undetectable by quantitative methods to be captured [30].

2.1. Participants and Context

Following Malterud *et al.*'s [31] discussion of sample size and information power in qualitative studies, ten older persons participated in this study. A purposive recruitment procedure was used to select the participants. Nurses in home nursing care were informed about the study. These nurses judged whether each older person's health status, such as rated cognitive status, permitted participation. Persons who wished to participate sent their consent directly to the researcher. The researcher then contacted the participants, and practical arrangements were agreed upon.

The inclusion criteria were: 1) persons aged 60 years and above; 2) residence in a rural community in central Thailand; 3) having lived experiences participating in shareholding networks for older people's care for at least 12 months; and 4) ability to fully understand the purpose and contents of the study. The informants were composed of eight older women and two older men who were 63 - 80 years old (median age = 73 years). They were given verbal and written information about the purpose and procedure of the study.

The study was conducted in one rural sub-district in central Thailand. The sub-district has a senior population composed of 1127 people, or 57 older

people/km². The percentage of older people in the sub-district had increased from 14.67 percent in 2012 to over 21.13 percent in 2016. Two primary government agencies provide local healthcare services; namely, the Local Administrative Organizations (LAOs) taking on the role of providing basic healthcare services for older people in line with the government policy prescribed by each ministry, and sub-district health promotion hospitals (HPHs) taking on the role of health promotion, prevention, treatment and recovery based on the criteria of the Ministry of Public Health.

2.2. Data Collection

The first author (SV) conducted narrative interviews from January to early March 2017. The interviewer asked open-ended questions aimed at encouraging further narration. The questions asked of the participants were as follows:

- *Can you please tell me about your experiences in participating in the shareholding network for older people's care in the community?*
- *Can you please tell me how you feel about participating in the shareholding network for care in the area?*
- *Can you please tell me about when participation in the shareholding network awoke positive feelings?*
- *Can you please tell me about when participation in the shareholding network awoke negative feelings?*

During interviews, the interviewer asked clarifying questions to support understanding or encourage interviewees to develop their responses. The interviews lasted 45 to 60 minutes, were performed in Thai and were digitally recorded and transcribed verbatim. The language in this article has been reviewed by a professional English-language editing service.

2.3. Phenomenological Hermeneutics

A phenomenological hermeneutic interpretation was chosen to analyze the transcribed interviews [32] [33]. Using this method, we made attempts to explain and, from there, understand the meaning of a phenomenon through the interpretation of narrative. To gain understanding, a constant movement between the text as a whole and its individual parts is a necessity. This method implies an interpretation as a form of understanding when applied to life expressions as text. Through this interpretation, a deeper understanding of a phenomenon can be gained from a dialectic movement between understanding and explanation, with the aim of reaching a new, comprehensive understanding.

Phenomenological hermeneutic interpretation consists of three interrelated phases. The interpretation starts with a naive reading of the text to gain a sense of its whole. This provides ideas for the structural analysis, which is characterized by dividing the text into meaning units linked to each other by content. Based on similarities and differences, the meaning units then are organized into subthemes and themes, with the aim of explaining the text. Developed through and supported by the naive reading, the structural analysis, our preunderstand-

ing, and literature, the text was interpreted in its whole and resulted in a new comprehensive understanding [32]. The interpretation was conducted in as open-minded a manner as possible, with an awareness of our preunderstandings as nurses and as researchers in this area.

2.4. Ethical Considerations

The study followed the ethical principles of the Helsinki Declaration [34]. All participants were informed about the study and assured that their participation was voluntary and that they could withdraw from the study at any time. All participants gave their informed consent and were guaranteed confidentiality with an anonymous presentation of the findings. The research was approved by Thailand's Ethical Review Committee for Research with Human Subjects (IRB: SP0032.002/4/3.2/2016).

3. Findings

3.1. Naive Understanding

The informants expressed a range of experiences during their shareholding network participation. These experiences led to different impressions, which did not depend on their home situations. Participation in shareholding networks touched the informants on a deeper level through experiences that were dominated by either positive or negative feelings. Participation in shareholding networks influenced them positively, meaning feelings of dignity in supporting and appealing to their need to be needed. Positive interactions engendered satisfaction, pride, happiness and competence within.

Negative interactions, to the contrary, are characterized by frustrations resulting in not wanting to be a part of shareholding network activities. That awoke feelings of sadness, disappointment, and resignation. Sometimes, these emotions were not directly related to the shareholding network activity itself, but were influenced by the presence of other older people, the context or the government. Being touched in their everyday lives through their experiences participating in shareholding networks means there was emotional engagement with other human beings. This engagement represents a powerful tool, as it influences both activities towards other older persons as well as self-evaluation of shareholding network involvement.

3.2. Structural Analysis

Several structural analyses resulted in four themes and six subthemes illuminating the meanings of older person's lived experiences of participation participating in a shareholding network. An overview of themes and subthemes is given in **Table 1**.

Theme 1: Being satisfied with activities

The theme of being satisfied means, as part of a shareholding network, being able to participate in different shareholding activities. This theme reaches beyond what can be seen in conjunction with being part of an activity. Experiences of

Table 1. Overview of themes and subthemes.

Themes	Sub themes
Being satisfied with activities	Feeling happy
Being valued as important	Feeling proud
	Feeling competent
Being frustrated and feeling sad	Feeling disappointed
	Feeling useless
Being bored and feeling disinterest	Feeling resigned

satisfaction and contentment were highlighted, and the informants experienced feelings of engagement and pride, both emotionally and practically. This engagement affected their self-esteem and confirmed them as people, providing feelings of importance.

“So, the fact that we help one another do good makes us feel good too.”

They felt satisfied when other older persons who needed help received good care and were met respectfully by care professionals. Working in shareholding networks meant participating in easing burdens of the community and exposed them to positive feelings.

Feeling happy. It was essential to the informants that the activity give them an opportunity to participate in activities related to healthcare. They felt involved in “good” activities that not only broke their own loneliness, but also helped other older persons who needed help, and that made them feel happy.

“I feel happy and I have fun participating in activities... then I wasn’t lonely, I met with other people.”

The informants experienced a sense of importance and community with other older persons. To share their own self-care experiences with other older persons gave them feelings of significance.

“...because I feel great every time when I see older adults in the community happy, smiling, meeting each other and sharing experiences. It’s my own happiness.”

They worked hard to help and to share their own experiences with other old persons. Their willingness to participate in healthcare activities, together with the feedback, made them feel useful and happy.

“I was really happy to participate in activities and help with care for older people in the community... I’m happy and I feel pleased about being the giver.”

Theme 2: Being valued as important

The theme of being valued consisted of a feeling, as a participant, of having an assignment. That means that they received confidence from the community and fellow older persons when being a part of the shareholding network. The informants felt confident in their own capability to help others and handle difficulties in ongoing situations as well as forthcoming problems; they acknowledged their own strength and competence, and they felt prepared and experienced. Their feelings of being able to control changes in needs and care gave them a feeling of reliance on the capability of others and on their relations to others.

"We have enough capacity to work with organizations in this community... Our value and capacity... Even if we're old, we can do many things. So all of us can participate in activities in this community and work as a team or cooperative network with all organizations in this community because there are no limits for older persons... it's in the network culture."

The participants had to develop confidence and confidence in order to build a relationship with other older persons in the shareholding activity group. They viewed themselves as needing to feel secure and having confidence in the community before they were able to help others.

"I feel pleased. Even though I'm old myself, I have the opportunity to participate in providing care assistance for other older persons in the community by supporting them with the opportunity to participate in activities with us."

Feeling proud. Meeting other older persons touched the informants significantly. Even if such situation sometimes made them insecure, they recognized a dependency on the other person. This dependency awoke responsibility within the informant. Through that, their experience still had benefit for their community.

"I'm proud to have a responsibility and help others. It's our own willingness to be involved in activities organized by the community for older adults in the community."

When it comes to delivering care to other older persons, the informants felt equal with the fellow older person; in other words, they respected the other's human dignity. They felt pride when they received positive feedback for doing good things for others, and they expressed that it felt good to be able to do this willingly.

"I'm glad and proud to be a member of this community with the opportunity to give back good things to older persons."

Feeling competent. The informants explained that being involved in shareholding activities gave them a sense of being involved in the community. They described the importance of continuously encouraging fellow older persons to participate in the activities to help them not feel alone.

"I was able to volunteer to participate in caring for older adults in this community... just talking with them can help them to not feel alone."

The informants said that feeling a sense of togetherness with other old persons was something that did not occur by itself; instead, they had to work on it. To acknowledge the other as they were listening was seen as something that made the other feel well. The informants stressed their own competence as important, not only for others' well-being; it was also of great importance for their own well-being. Friendship and good social relations were expressed as important for feeling well. They said that older people without family nearby needed relationships with other people.

"I have the capacity to help them. Even though I'm old, I have time, a strong body, knowledge and channels enabling me to provide them with help and advice."

A sense of wellbeing and feelings of competence arose within the informants when the fellow older person gained and was satisfied with the help and support they received from the participant.

"I'm glad and proud to be a member of this community with the opportunity to give back good things to older persons. I'm happy to be involved because I'm an older person who still has benefit for our community."

Theme 3: Being frustrated and feeling sad

The theme of being frustrated expresses the older persons' feelings of disappointment and uselessness. Participating in shareholding network activities means being placed in a vulnerable situation and exposed to negativity or expressions of misunderstanding.

Feeling disappointed. The informants are sometimes exposed to other older persons in the community who do not want to participate in shareholding networks for older people's care. Such occasions are experienced as difficult to handle.

"I feel really down and detached when I meet the ones who don't cooperate. I mean, I invited them...but they didn't come and ignored it, even though they were able to participate in our activities..."

Feelings of sadness of other older people affect their actions negatively. Sometimes, this confused the informants who do not understand why some of older persons in the community did not participate in the care networks.

"I felt really confused and bummed out at the beginning. I wondered why they didn't give any importance to what the organizations and clubs provided for them."

In these instances, the participant negatively evaluated the shareholding activity. At other times, they felt that other older people bothered them; this also caused negative feelings of disappointment.

"I invited them... but they didn't come and ignore it, even though they were able to participate in our activities."

Feeling useless. Feelings of uselessness may emerge when projects for older people's care are perceived as less beneficial or are incapable of functioning usefully. Furthermore, emotions of unfairness are expressed regarding unsuccessful projects. The informants wondered about the projects organized by community organizations, which were inevitably the same projects all the time, and as such did not have the same benefits as when they were first initiated.

"... the free glasses project provided by the government where the municipality gives out glasses for older persons. We already have glasses at better prices and quality. We don't want them. We feel that the government's budget support was wasted. The municipally should ask about our needs before organizing activities."

These occasions were perceived as incomprehensible, and were at times described by the informants as emotionally distressful.

"...when they organize activities to take us on field trips to study dentistry for older adults. I still have good dental health but, when they asked me to coope-

rate, I had to go because it's an activity organized by community organizations."

The informants mean that the projects are not developed from the overall older person's perspective, and they feel they do not reap benefits from the projects.

"...when the same projects were held for many years without change, they don't have the same benefits as before. So the people involved should adjust according to changing problem situations. Organizing the same projects all the time won't meet needs."

Theme 4: Being bored and feeling disinterest

One meaning of being bored is when the informants express feelings of being tired and beginning to reject some projects. Their own needs or health-related problems were regarded by themselves as unimportant, a non-question, in relation to other older persons' needs. All of the attention was focused on the needs of the other person. A kind of "shield" was set up in order to invite the other older persons into the project. When failing "in this duty", feelings of weariness were present. Even if they felt the need to do something on their own, they felt forced to stay close to the project, which resulted in a sense of resignation and sadness.

Feeling resigned. The informants felt bored, as if they had been abandoned, for long waits in lines or long activities, which gave them a sense of wasted time. They felt unfamiliar with their own and other people's feelings, behaviors, and activities. This led to negative feelings of rejection and resignation.

"...the older people waiting in these long lines won't want to come the next time."

3.3. Comprehensive Understanding

Participation in shareholding networks for informants in rural area can be understood as a pathway to feelings of confidence and presence of the other. Experiences are linked to positive feelings of satisfaction, respect and value. Confidence and allowing the presence of the other means being able to face humanity and exhibit vulnerability in oneself. Negative feelings mean frustration and boredom, emotions related to individual views and individual tolerances. Understanding this emotional dimension of shareholding network activities seems to risk causing confusion and distress in the participants. Our interpretation suggests that these feelings echo confusion in the older people's views of their role in shareholding network activities.

4. Discussion

The aim of this study was to illuminate the meaning of older persons' lived experiences when participation in shareholding networks for the care of older people in rural areas. We found four themes, further broken down into sub-themes that shed light on the interviewees' experiences of: "being satisfied", "being valued", "being frustrated", and "being bored". The findings indicate contradictory emotional influences within the informants and affects on their

self-esteem and views of themselves.

The primary relationship within the shareholding network is the relationship between the network participants and the government agencies (LAOs) and (HPHs). This relationship, a form of social relationship, does not emerge without confidence from the government. In the literature, there are three characteristics of confidence. Firstly, the confidence sensor become vulnerable when trusting the recipient because of the recipient's possible incompetence or evil will. To confidence someone is to take a chance. You can never know whether the recipient of confidence will act in the way you expected [35]. Secondly, confidence is not something you can force on someone, not something you can buy. According to Luhmann [36], if you can buy confidence, you have every reason to not trust what they have purchased. A prerequisite for the successful establishment of shareholding networks for the elderly is that the public healthcare system supports the business [37]. In our study, government agencies (LAOs and HPHs) were involved in the shareholding work. This can be understood as the shareholding network having been received confidence from the authority to undertake various activities aimed at the elderly [35] [36].

“Being satisfied with activities” refers to the informants' positive experiences in our study. Natural elements in the care of older persons in the municipality (for example, shareholding networks) include, according to Hamilton & McDowell [38] maintaining dignity, inviting to mutuality, creating hope, etc. This demands emotional engagement from the network's participants. Our narratives show that participation in shareholding network relationships is characterized by both emotional and practical engagement and pride, which brings people closer to each other [39]. Being a part of a shareholding network also means being an active in easing the community's burden. This knowledge seemed to evoke positive feelings in the interviewees in our study. According to Edlund [40], dignity and self-esteem are closely linked and therefore important to respect. Giving dignity-supporting care to other older persons in need of support satisfies the informants and develops their identity.

Being an active participant also means *“Being valued as important”*; that is, a sense of having confidence from the community and fellow older persons. The informants felt confident in their own capacity to help other older persons and handle various ongoing difficulties as well as forthcoming problems. According to them, there was no doubt that they acknowledged their own strength and competence, felt prepared and experienced something they explained stemmed from being part of the shareholding network culture. Their feelings of being able to control changes in needs and care gave them a feeling of reliance on others' capability and on their relationship to others. According to Bauman [41], culture is the continuous and unending structuring activity that constitutes the core of the human mode of being in the world. This was reflected in informants' experiences of the context that enhanced their competence and inter-human relationships with other persons, compared with their experiences from traditional healthcare contexts. Similarly, supporting people in their ordinary context is

perceived as having control over the caring situation [42].

Through integrating the developing self-esteem with a learning process emerging from relational experiences with fellow older persons, the participants' own identities grew. This in line with Fagermoen's [43] view from meaningful nursing practice that professional identity emerges through a process of self-formation in which social interaction and self-reflection are basic processes. The narratives revealed that an important piece of constructive and developing reflections stands together with fellow shareholding members. Reflective practices are validating when interviewees help participants to make decisions that strengthen their competence and identity [44].

"Being frustrated and feeling sad" refers to informants' negative experiences in our study. In the narratives, it becomes clear that meeting older adults in need help may be perceived as constraining. Even if the participants in a shareholding network feel that they have received confidence from the authorities (and confidence, according to Joffe *et al.* [45], correlates with satisfaction), it may feel frustrating when other older persons ignore invitations to be a part of network activities. The informants expressed feelings of disappointment and uselessness when fellow older persons outside the shareholding network ignored them. To be ignored by someone that one judged as being in need of help evoked feelings of frustration. It seems that confidence obtained from authorities simultaneously placed them in a vulnerable situation and exposed them to negative feelings or disconnection from others. This can be understood from Lögstrup [46], who states that confidence is a gift that we give to the other person, and it is up to him or her to receive it or not. According to Warren [35], in a relationship the person who gives confidence is always the one vulnerable to the others' betrayal. In our study, it seems that informants relied on the other older persons, which created liberty for the other to act. Reasonably, the shareholding network participants expected that the other would use it in accordance with his or her wishes and interests, but he or she could never be certain. This means that the giver of confidence becomes vulnerable to the other's malice.

According to Sarvimäki and Stenbock-Hult [47], vulnerability is part of all human conditions and closely connected to our lived experiences as human beings. According to the literature [48], vulnerability is seen as an existential aspect of being old and frail. We interpret the findings as demonstrating that vulnerability depends on how the informants viewed the situation and the degree of harm perceived as inherent to the situation. When harm occurred from unfavorable contextual conditions, such as lack of attention to the interviewee's basic needs, values and preferences, it risked damage to the interviewee's self-image and dignity. Being abandoned by the other exposed the vulnerability of personal and social loss. From a life-world perspective, vulnerability is seen as an inevitable part of life because of our interdependency, but also as something that can be created and perpetuated by certain situations [49].

When informants' views on municipal care projects differed from the municipality's, it evoked feelings of *"Being bored and feeling disinterest"*. We interpret

ret this situation as meaning that the confidence given by the municipality and the interviewees' placement in a vulnerable position evoked the question of power and impotence. This negatively influenced the persons' dignity, and according to Shotton and Seedhouse [50], this is common when we find ourselves in inappropriate circumstances, in situations where we feel foolish, incompetent, or inadequate.

Interviewees' feelings of unfairness or resignation seemed to be of significance when they explained instances in which their views on healthcare projects fell short and that their decision mandate weighted easy compared to the municipality's mandate. They talked quite freely and honestly about their views when reflecting on situations that caused a sense of abandon, leading to feelings of rejection and resignation. The meaning of being abandoned and alone with all responsibility seemed to touch upon moral aspects of human existence of which we only have only scratched the surface in this study.

This study suggests that the meaning of participation in shareholding networks for older people in rural areas can be understand as a pathway to feelings of confidence and presence of the other. The informants had a desire to feel needed and have something meaningful to occupy themselves. Therefore, a major task for the network when establishing a caring culture is to invite older persons through someone who cares for them in a dignified way [51], so that the individual older person feels relaxed and secure in the caring situation [52]. In other words, the goal is to make things easier for other older people in the municipality who live at home, so that they, on basis of their own wishes and choice, can live their life as best they can [53]. For our informants, it was important to continue to feel valued and part of a community. Studies show the importance of socializing with others when the family is far away. In such cases, participants in shareholding networks have an important duty to perform when there is no natural community or social context surrounding this group of older persons [54].

5. Methodological Considerations

In this study, we used a phenomenological hermeneutical method to interpret the lived experiences of older people when participating in shareholding networks for the care of older people in rural areas. According to Ricoeur [33], there is not only one way of interpreting a text, there are several possible interpretations. The interpretation we present is the one that we found to be most likely. Interviews with a narrative approach were used, and during the interviews, shareholding participants talked freely about their experiences and encounters with healthcare personnel and fellow older persons outside the shareholding network. We reflected on our preunderstanding by using probing questions to avoid misunderstandings and to restrain our preconceptions. The number of interviewed shareholding participants was deemed sufficient because the interviews were rich, in-depth and contained various descriptions of lived experience. The findings cannot be generalized, but are transferable to similar situa-

tions and encounters. Formulating the findings of such research involves expressing oneself in a manner that touches the reader [55]. The findings can be used only to shed light on the meaning of participants' lived experiences and to influence older people's perceptions of their own lives. According to Ricoeur [33], however, the reliability of this study lies in the recognition of others. Knowledge gained from this study may therefore be used as a basis to clarify the meaning of participation and to raise awareness about older persons care in a rural context.

6. Conclusion

Through their narratives, the informants have shared their experiences of participation in shareholding networks for older people's care. The meaning of participation in shareholding networks for older people in rural areas can be understood as a means to develop their feelings of confidence and presence. This can be developed by investing them with the authority to undertake various activities aimed at the elderly, entrusting the shareholding network. Confidence and allowing the presence of the other mean facing humanity and a sense of vulnerability because, in a relationship, the person who gives confidence is exposed to potential betrayal. This means that the giver of trust becomes vulnerable to the other's malice. Therefore, the individual's dignity should have a high priority in health and social care strategy. It is a challenge for healthcare professionals to handle older people's experience of confidence when involve them in their own care. The narrations in this study can be used as a basis for developing cooperating care with older people in shareholding network focusing on their needs and dignity. It is important for healthcare professionals to initiate a dialogue with the shareholding participants for support and information.

Conflict of Interest Statement

The authors declare that there are no conflicts of interest.

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