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# Prevalence and Risk Factor of Diabetic Foot Ulcers in a Regional Hospital, Eastern Indonesia

Saldy Yusuf<sup>1,2</sup>, Mayumi Okuwa<sup>1</sup>, Muhammad Irwan<sup>2</sup>, Saipullah Rassa<sup>2</sup>, Baharia Laitung<sup>2</sup>, Abdul Thalib<sup>2</sup>, Sukmawati Kasim<sup>2</sup>, Hiromi Sanada<sup>3</sup>, Toshio Nakatani<sup>1</sup>, Junko Sugama<sup>1,4\*</sup>

Email: \*junkosgm@mhs.mp.kanazawa-u.ac.jp

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#### **Abstract**

Indonesia is one of the top ten diabetes mellittus (DM) countries. However as the main complication of DM, there was lack of studies related to diabetic foot ulcer (DFU). Thus, the aim of this study was to survey the prevalence of DFU risk factors and DFU among type 2 diabetes mellitus (T2DM) patients. An epidemiological study was conducted at an outpatient endocrine clinic in a regional hospital, eastern Indonesia. All T2DM participants attending research setting that were ≥ 18 years were included. Demographic and foot care behavior were assessed using minimum data sheet (MDS). Meanwhile, presence of risk factors was evaluated by using 5.07/10 g Semmes-Weinsten Monofilament (SWM) for neuropathy and presence of angiopathy was evaluated with Ankle Brachial Index (ABI) by using a hand held Doppler (Bidop ES-100V3, Hadeco-Kawasaki, Japan) both dorsal and posterior tibialis foot. At the end of study, 249 T2DM participants were enrolled. The prevalence of DFU risk factors was 55.4% (95% CI: 53.7% - 57.0%), and prevalence of DFU was 12% (95% CI: 10.3% - 13.6%). Based on a logistic regression, predictors for DFU risk factors included age (OR: 1.04; 95% CI: 1.005 - 1.074) and daily foot inspection (OR: 0.36; 95% CI: 0.186 - 0.703). Meanwhile, the predictors for presence of DFU were insulin (OR: 9.37; 95% CI: 2.240 - 39.182), shoes (OR: 0.05; 95% CI: 0.007 - 0.294), spiritual belief that DM was a disease (OR: 0.04; 95% CI: 0.004 - 0.326) and belief that DM was a temptation from God (OR: 0.13; 95% CI: 0.027 - 0.598). In conclusion, we recommend to educate high risk patients to understand positive foot care behavior as essentially preventive strategies to prevent presence risk and DFU.

\*Corresponding author.

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<sup>&</sup>lt;sup>1</sup>Division of Health Sciences, Graduate School of Kanazawa University, Kanazawa, Japan

<sup>&</sup>lt;sup>2</sup>Wound Care Clinic, Griya Afiat, Makassar, Indonesia

<sup>&</sup>lt;sup>3</sup>Department of Gerontological Nursing/Wound Care Management, Faculty of Medicine, University of Tokyo, Tokyo, Japan

<sup>&</sup>lt;sup>4</sup>Wellness Promotion Science Center, Institute of Medical, Pharmaceutical and Health Sciences, Kanazawa University, Kanazawa, Japan

# **Keywords**

# Prevalence, Diabetes Complications, Risk Factors, Diabetic Foot Ulcers

# 1. Background

Prevalence of Diabetes Mellitus (DM) in Indonesia is high. As one of the top ten DM countries [1] [2], prevalence of DM in Indonesia has been increasing from year to year. In 1983, prevalence of DM in Indonesia was 1.63% [3], increased 5.7% in 2007 [4] and is predicted to be 6.0% in 2030 [1] or was equal to 8.5 million in 2013 and will be 14.1 million patients in 2035 [2]. In addition, a national survey reported a high number of undiagnosed DM in Indonesia (4.3%) [4] [5]. Therefore, prevalence of DM in Indonesia is potential to be higher than available data.

One of the major DM complications is the development of diabetic foot ulcer (DFU). International Working Group on Diabetic Foot (IWGDF) has proposed neuropathy and angiopathy as the main risk factors for development DFU [6]. Role of these risk factors has been explained biomechanically [7] and biologically [8]. In Western, neuropathy is determined by demography factors [9], while the development of DFU is mainly related to trauma, neuropathy and deformity [10]. However, most of the studies focused only on neuropathy or angiopathy.

Unlike in Western countries in Indonesia, there are only a few studies related to prevalence, associated factors for presence of risk and DFU. Previous study concludes that the main complications of DM in Indonesia are neuropathy (13% - 78%), microvascular complication (16% - 53%) and DFU (7.3% - 24%) [5]. However, there is inadequate information related to associated factors for presence of risk and DFU. In addition, the external data from Western country studies cannot be generalized into Indonesian setting since characteristics of demography, lifestyle and behavior are different. This fact leads to limitation of preventive strategies to prevent presence of risk and DFU based on Indonesian type 2 diabetes mellitus (T2DM) characteristics. Thus, objective of this epidemiology study is to evaluate prevalence, associated factors for presence of risk and DFU among T2DM patients in Makassar, eastern Indonesia.

#### 2. Methods

# 2.1. Setting and Participants

Strengthening the reporting of observational studies in epidemiology (STROBE) guideline was used to design and report this epidemiological study [11]. Previous study reported that Ujung Pandang (now Makassar) was one of the most prevalent DM cities in Indonesia [12], including for asymptomatic DM [13]. Thus, research setting was conducted in outpatient endocrine clinic, Wahidin Sudirohusodo hospital, a regional hospital in Makassar (834 beds), which considered representative in eastern Indonesia.

Sample size was calculated by using power analysis equation [14], where P refers to the lifetime prevalence of DFU as 25% [15]. Thus, our calculated sample size was 288 participants. Study populations were all T2DM patients who attended the research setting from May 2013 to February 2014 for DM therapy. Inclusion criteria were T2DM patients who have  $\geq$  18 years old, this was our denominator and presence of DFU was numerator of study. T2DM patients who attended hospital other than endocrine outpatient clinic were excluded. Diagnosed T2DM patients are based on physician endocrine assessment and glycemic status according to American Diabetes Association (ADA) 2013 criteria [16], which are written in hospital medical records.

#### 2.2. Variables

Dependent variables were presence of risk and DFU. Presence of risk was neuropathy or angiopathy as proposed by IWGDF [6]. Neuropathy was evaluated by using 5.07/10 g Semmes-Weinsten Monofilament (SWM) at four points of each foot (dorsal hallux, metatarsal I, III and V) [15], absence of one of the four sites is considered as neuropathy [17]. Meanwhile, presence of angiopathy was evaluated with Ankle Brachial Index (ABI) by using a hand held Doppler (Bidop ES-100V3, Hadeco-Kawasaki, Japan) both dorsal and posterior tibialis foot. An ABI  $\leq$  0.9 considered has peripheral ischemic [18]. Since there was inconsistent normal range of TBI, we reported as

mean and standard deviation instead of categorical data [19]. DFU define as presence full thickness lesion on the skin as proposed by IWGDF [20].

Independent variables were demography, clinical foot problems and foot care behaviors. Participants' demographies were age, sex, occupation, religion, education, smoking status, DM therapy, duration of DM, body mass index (BMI), blood pressure and HbA<sub>1C</sub> (at the time of visit or at least two months of previous data) was analyzed in hospital laboratories. Clinical foot problems were skin problems (dry skin, callus-corn-fissure and tinea pedis), nail problems (nail deformity and onychomycosis), foot deformity, ABI and Toe Brachial Index (TBI) status.

Foot care behaviors were interviewed by using questionnaire, including foot inspection, foot washing, nail trim, footwear inspection, and footwear practice. Participants' cultural and spiritual belief related to foot care behaviors was also interviewed by using open questions (do you have spiritual or cultural belief related to your foot care?). These items were developed based on clinical experience in Indonesian setting. To control bias, all of foot assessments, including determination of DFU were done by one investigator (Wound Care Nurse). All of assessments were written into paper-pencil form by co-authors and stored by primary investigator. Participants' anonimity was maintained by using identical number (ID number).

# 2.3. Data Analysis

Both ordinal and nominal data were described as absolute values and percentages (n, %), while continuous data were reported as mean and standard deviation. Missing data were replaced with its group mean (11 TBI, 19 ABI, and  $12 \text{ HbA}_{1C}$  data).

Univariate data were analyzed by  $\chi 2$  test or Fisher exact test for categorical and Independent t test for continuous data. Cut off P < 0.1 and logical reasons were used to select candidate of predictors into multivariate analysis. Possibilities for multicollinearity were diagnosed by reading variance inflation factor (VIF) by using regression linear. All of predictors with VIF < 5.0 were entered into logistic regression with Forward LR methods. The significance level was set up at 95% with P = 0.05 (two tailed). All data were analyzed by SPSS version 16.0 software (SPSS, Inc. Chicago, IL).

# 2.4. Ethical Consideration

Ethical considerations were approved from Kanazawa University, Japan (Number: 438) and Hasanuddin University, Indonesia (Number: 0866/H4.8.4.5.31/PP36-KOMETIK/2013). All of participants and family were received explanation and signed informed consent prior to data collection.

# 3. Results

#### 3.1. Prevalence of Risk and DFU

There are 280 T2DM patients who have registered in the research setting, 259 participants agree to participate (response rate 92.5%). At the end of the study, 10 participants are unable to complete assessment and remain 249 participants in the analysis. Participants without any risk are 90, with risk 112 (with neuropathy 14, neuropathy or deformity 64, and neuropathy or deformity or ischemic 34), history of DFU 14, history of amputation 3 and current DFU 30 of 249 participants. Overall, prevalence of presence of risk factors (excluding history and presence of DFU) is 55.4% (95% CI 53.7% - 57.0%) and prevalence for DFU (including history and presence of DFU) is 12.0% (95% CI: 10.3% - 13.6%).

#### 3.2. Univariate Analysis

In univariate analysis we evaluate candidate of predictor for presence of risk and DFU based on demographic, clinical foot assessment and foot care bahaviors. With regard to demographic factors, age is older (P=0.021) for presence of risk, meanwhile religion (P=0.032), education (P=0.023), DM therapy (P=0.020) and percentage of HbA<sub>1C</sub> (P=0.029) are associated with presence of DFU (**Table 1**). Based on clinical foot assessment, deformity (P=0.000) and ABI (P=0.000) are associated with presence of risk factors. However, only dry skin has an evidence role in presence of DFU (P=0.001) (**Table 2**).

Related to participants' foot care behaviors, foot inspection has been less frequently at risk group, including

Table 1. Univariate analysis of demography, general health and diabetes mellitus (DM) status for presence risk factors and diabetic foot ulcers (DFU).

			Pre	sence R	isk			Diabetic Foot Ulcer (DFU)						
		Risk 90 (%)		ce Risk 2 (%)*		otal )2 (%)	p		DFU 9 (%)	D	sence FU 0 (%)	To n: 249		p
Age (years) †	59.7	±8.6	62.7	±9.2	61.3	±9.1	0.021	61.54	±9.21	58.33	±11.20	61.15	±9.51	0.143
Sex: Female	56	(62.2)	61	(54.5)	117	(57.9)	0.316	125	(57.1)	20	(66.7)	145	(58.2)	0.333
Occupation														
House Wife	31	(34.4)	31	(27.7)	62	(30.7)		64	(29.2)	11	(36.7)	75	(30.1)	
Employed	25	(27.8)	21	(18.8)	46	(22.8)	0.077	51	(23.3)	11	(36.7)	62	(24.9)	0.080
Retired	34	(37.8)	60	(53.6)	94	(46.5)		104	(47.5)	8	(26.7)	112	(45.0)	
Religion: Islam	79	(87.8)	96	(85.7)	175	(86.6)	0.685	191	(87.2)	30	(100)	221	(88.8)	0.032
Education														
Elementary School	13	(14.4)	8	(7.1)	21	(10.4)		22	(10.0)	8	(26.7)	30	(12.0)	
Junior High School	8	(8.9)	11	(9.8)	19	(9.4)	0.205	19	(8.7)	5	(16.7)	24	(9.6)	0.022
Senior High School	28	(31.1)	31	(27.7)	59	(29.2)	0.295	64	(29.2)	6	(20.0)	70	(28.1)	0.023
University	41	(45.6)	62	(55.4)	103	(51.0)		114	(52.1)	11	(36.7)	125	(50.2)	
Smoking status														
Never	67	(74.4)	72	(64.3)	139	(68.3)		150	(68.5)	25	(83.3)	175	(70.3)	0.068
Smoking	23	(25.6)	40	(35.7)	63	(31.2)	0.130	69	(31.5)	5	(16.7)	74	(29.7)	
DM Therapy														
Oral	29	(32.2)	45	(40.2)	74	(36.6)		79	(36.1)	6	(20.0)	85	(34.1)	
Insulin	30	(33.3)	32	(28.6)	62	(30.7)		68	(31.1)	16	(53.3)	84	(33.7)	
Oral and Insulin	29	(32.2)	33	(29.5)	62	(30.7)	0.692	68	(31.1)	6	(20.0)	74	(29.7)	0.020
Nothing	2	(2.2)	2	(1.8)	4	(2.0)		4	(1.8)	2	(6.7)	6	(2.4)	
Duration DM (years)†														
<10	49	(54.4)	57	(50.9)	106	(52.5)		114	(52.1)	18	(60.0)	132	(53.0)	
11 - 20	28	(31.1)	40	(35.7)	68	(33.7)		74	(33.8)	6	(20.0)	80	(32.1)	
21 - 30	10	(11.1)	11	(9.8)	21	(10.4)	0.929	23	(10.5)	5	(16.7)	28	(11.2)	0.358
>30	3	(3.3)	4	(3.6)	7	(3.5)		8	(3.7)	1	(3.3)	9	(3.6)	
Body Mass Index (Kg/m²)†	26.1	±3.9	26.1	±4.0	26.1	±4.0	0.917	26.10	±4.0	26.08	±4.1	26.10	±4.0	0.974
Blood Pressure (mmHg)†														
Systolic	133.9	±19.0	138.5	±20.1	136.5	±19.7	0.098	136.5	±19.3	134.0	±18.4	136.24	±19.1	0.496
Diastolic	82.8	±8.8	82.8	±9.2	82.8	±9.0	0.980	83.0	±9.1	81.0	±10.2	82.77	±9.2	0.266
HbA <sub>1C</sub> (%)†	8.07	±2.70	7.58	±2.42	7.80	±2.55	0.180	7.86	±2.61	8.95	±2.07	7.99	±2.57	0.029
HbA <sub>IC</sub> IFCC (mmol/mol)†	64.66	±29.56	59.36	±26.52	61.72	±27.97	0.181	62.38	±28.61	74.43	±22.66	63.83	±28.19	0.028

<sup>\*</sup>Excluded presence history DFU amputation. Data are n(%) unless indicated by † are mean ( $\pm$ SD). p values determined by Chi Square  $x^2$  or Fisher exact test for categorical data and Independent t test for continuous data.

Table 2. Presence of Skin, nail and deformity problems for presence risk factors and diabetic foot ulcers (DFU).

	Foot at Risk				Diabetic Foot Ulcer (DFU)									
		Risk 90 (%)	R	sence lisk 2 (%)*		otal 02 (%)	p		DFU 19 (%)		nce DFU		otal 49 (%)	p
Skin Problems														
Dry Skin	12	(13.3)	22	(19.6)	34	(16.8)	0.261	36	(16.4)	13	(43.3)	49	(19.7)	0.001
Callus, Corn, Fissure	34	(37.8)	45	(40.2)	79	(39.1)	0.773	90	(41.1)	16	(53.3)	106	(42.6)	0.239
Tinea Pedis	25	(27.8)	34	(30.4)	59	(29.2)	0.756	63	(28.8)	10	(33.3)	73	(29.3)	0.670
Nail Problems														
Nail Deformity	33	(36.7)	44	(39.3)	77	(38.1)	0.771	85	(38.8)	17	(56.7)	102	(41.0)	0.075
Onychomycosis	57	(63.3)	76	(67.9)	133	(65.8)	0.552	146	(66.7)	24	(80.0)	170	(68.3)	0.151
Forefoot Deformity†	0	(0.0)	79	(70.5)	79	(39.1)	0.000	87	(39.7)	15	(53.6)	102	(41.3)	0.221
Ankle Brachial Index‡	1.04	±0.95	0.95	±0.14	0.99	±0.13	0.000	0.99	±0.13	0.97	±0.18	0.99	±0.13	0.529
Abnormal (<0.9 or >1.3)	0	(0)	34	(30.4)	34	(16.8)	0.000	36	(16.4)	8	(26.7)	44	(17.7)	0.200
Normal (0.9 - 1.3)	90	(100)	78	(69.6)	168	(83.2)	0.000	183	(83.6)	22	(73.3)	205	(82.3)	0.200
Toe Brachial Index	0.47	±0.18	0.45	±0.15	0.46	±0.17	0.423	0.47	±0.17	0.41	±0.17	0.46	±0.17	0.081

p values determined by Chi Square  $x^2$  or Fisher exact test for categorical data and Independent t test for continuous data. \*Excluded presence history DFU amputation. †Forefoot Deformity including; hallux vagus, bunion, varsus deformity, hammer toe. ‡ABI > 1.3 were ignored and read only TBI data if presence.

daily foot inspection (P = 0.003), entirely foot inspection (P = 0.002), and supported for foot inspection by family (P = 0.007). Related to the presence of DFU, daily five time foot washing or more (P = 0.014), supported for foot washing by family (P = 0.021) and using shoes as footwear (P = 0.003) are associated with presence of DFU. In addition, cultural belief (P = 0.036) and spiritual belief (P = 0.007) related DM status has an evidence role in presence of risk and presence of DFU, respectively (Table 3).

#### 3.3. Multivariate Analysis

Based on multicollinearity diagnostic we excluded supported for foot inspection (VIF 6.84) and daily foot washing (VIF 6.99). In addition by using logical approach we also excluded systolic blood pressure and occupation (not related to foot problems), forefoot deformity, ABI and TBI (used to distinguish risk category) and religion (100% of DFU in group are Muslims).

Logistic regression was conducted to evaluate predictors of presence of risk and DFU. When all candidate predictors from univariate analysis entered together; age and daily foot inspection status were associated with presence risk, with an odds ratio (OR) 1.04 (95% CI: 1.005 - 1.074) and 0.36 (95% CI: 0.186 - 0.703), respectively. Meanwhile predictors for presence of DFU are DM therapy (insulin) OR 9.37 (95% CI: 2.240 - 39.182), type of footwear (shoes) OR 0.05 (95% CI: 0.007 - 0.294) and spiritual belief that DM was a disease OR 0.04 (95% CI: 0.004 - 0.326) and belief that DM was temptation from God OR 0.13 (95% CI: 0.027 - 0.598) (Table 4).

# 4. Discussion

# 4.1. Prevalence of Risk and DFU

Prevalence of risk and DFU are higher in Indonesia. The current study found that prevalence of risk (neuropathy and angiopathy) in this study was 55.4%. These findings are within global prevalence of risk 40% - 70% [21].

Table 3. Practical behavior related to foot care for presence risk factors and diabetic foot ulcers (DFU). Practical Behaviors Foot at Risk Diabetic Foot Ulcer (DFU) No Risk Presence Risk No DFU Presence DFU p p n: (%) n: (%)\* n (%) n (%) Foot Inspection n: 89 n:107 n:213 n:30 Inspect foot daily 35 (39.3)21 (19.6)0.003 63 (29.6)12 (40.0)0.292 n: 87 n: 110 n: 213 n: 26 Inspect foot entirely 33 (37.9)18 (16.4)0.002 56 (26.3)7 (26.9)0.952 n: 213 n: 29 n: 87 n: 110 (9.2)(13.8) Supported by family for foot inspection (0.9)0.007 9 (4.2)0.103 Foot Washing n: 90 n:112 n: 29 n: 30 Washing foot daily (85.6)100 (89.3)0.520 194 (88.6)23 (76.7)0.081 n: 29 n: 89 n: 111 n: 217 0.714 173 18 0.014 Five time or more foot washing (77.5)88 (79.3)(79.7)(62.1)n: 90 n: 112 n: 218 n: 27 Using moisturizer after foot washing (10.0)0.473 (11.9)3 (11.1)1.000 17 (15.2)26 n: 112 n: 217 n: 30 n: 89 Supported by family for foot washing 0.021 (4.5)5 (4.5)0.697 11 (5.1)6 (20.0)Nail Trim n: 90 n: 219 n: 30 n: 112 Weekly nail trim (47.8)49 (43.8)0.573 101 (46.1)17 (56.7)0.331 Nail trim tool n: 89 n: 112 n: 218 n: 29 Knife, blade or scissor 30 (33.7)25 (22.3)0.081 59 (27.1)10 (34.5)0.509 Nail clipper or nail file 59 (66.3)87 (77.7)159 (72.9)19 (65.5)n: 29 n: 90 n: 112 n: 218 (31.0) Supported by family for nail trim (18.9)17 (15.2)0.571 41 (18.8)9 0.141 17 n: 218 n: 29 Foot Wear Inspection n: 90 n: 111 Daily foot wear inspection 28 (31.1)28 (25.2)0.429 62 (28.4)9 (31.0)0.828 n: 90 n: 110 n: 216 n: 29 (10.3) 0.196 Inspect foot wear entirely (28.9)24 (21.8)0.526 54 (25.0)3 n: 90 n: 110 n: 216 n: 28 Supported by family for foot wear (4.4)3 (2.7)0.760 9 (4.2)0 (0.0)0.713 inspection n: 29 Foot Wear Practice n: 90 n: 108 n: 215 Try foot wear before buy (96.7)102 (94.4)0.514 206 (95.8)26 (89.7)0.159 n: 89 n: 30 n: 216 n: 111 (71.9)69 (62.2)0.175 147 8 (60)0.410 Measure foot wear before buy 64 (68.1)

Continued										
	n	: 90	n:	109		n:	216	n	: 30	
Using foot wear inside home	30	(33.3)	35	(32.1)	0.880	75	(34.7)	2	(40.0)	0.684
	n	: 90	n:	111		n:	218	n	: 30	
Using foot wear outside home	85	(94.4)	102	(91.9)	0.583	203	(93.1)	6	(86.7)	0.262
	n	: 90	n:	111		n:	218	n	: 29	
Using shoes as foot wear	37	(41.1)	41	(36.9)	0.563	84	(38.5)	3	(10.3)	0.003
Cultural belief related to DM status	n	: 90	n:	112		n:	219	n	: 30	
Nothing	60	(66.7)	90	(80.4)		163	(74.4)	21	(70)	
DM can be avoided by cultural approach	5	(5.6)	1	(0.9)	0.036	8	(3.7)	1	(3.3)	0.858
DM is just about food problems	25	(27.8)	21	(18.8)		48	(21.9)	8	(26.7)	
Spritual belief related to DM status	n	: 90	n:	112		n:	219	n	: 30	
Nothing	5	(5.6)	6	(5.4)		12	(5.5)	5	(16.7)	
DM is just a disease	26	(28.9)	36	(32.1)	0.500	64	(29.2)	2	(6.7)	0.00=
DM is temptation from God	55	(61.1)	61	(54.5)	0.692	129	(58.9)	20	(66.7)	0.007
Others	4	(4.4)	9	(8.0)		14	(6.4)	3	(10)	

p values determined by Chi Square  $x^2$  or Fisher exact test for categorical data and Independent t test for continuous data. \*Excluded presence history DFU amputation.

Table 4. Multivariate logistic regression analysis of predictors for presence risk factors and diabetic foot ulcers (DFU).

Predictors	OR (9	95% CI).
Predictors For Presence Risk		
Age	1.04	(1.005 - 1.074)
Daily foot inspection		
No	Refe	erence
Yes	0.36	(0.186 - 0.703)
Predictors For Presence DFU		
DM therapy		
Oral	Refe	erence
Insulin	9.37	(2.240 - 39.182)
Oral or Insulin	2.38	(0.507 - 11.199)
Nothing	1.99	(0.077 - 51.267)
Type of foot wear		
Barefoot or Sandal	Refe	erence
Shoes	0.05	(0.007 - 0.294)
Spiritual belief related to DM status		
No Spiritual belief	Ref	erence
DM was a disease	0.04	(0.004 - 0.326)
DM was a temptation from God	0.13	(0.027 - 0.598)
Others spiritual belief	0.24	(0.028 - 2.157)

This percentage still remains higher compared to India [22]. Meanwhile, current prevalence of DFU is 12%. These findings are higher compared to China (most populated DM country) [23] and in comparison with global prevalence 1.4% - 5.9% [21]. In addition, our previous study also confirmed high prevalence of DFU in home care setting 26.0% [24]. Prevalence of risk and DFU in Indonesia is potential to be higher since the prevalence of undiagnosed DM in Indonesia was higher [4] [5], including prediction of prevalence DM in Indonesia [1] [2]. Thus, the findings indicate the importance of preventive strategies to prevent risk and DFU in Indonesia.

#### 4.2. Predictors for Presence of Risk

There are two predictors for presence of risk, age and daily foot inspection. Current study also finds that age is associated with presence of risk. These results are consistent with previous study that increasing age linear with increasing risk for neuropathy and angiopathy [25]. Regarding daily foot inspection status (OR: 0.36), participants who perform daily foot inspection were less prevalent to presence of risk factors. The findings indicate the importance of foot inspection to prevent presence of risk factors.

# 4.3. Predictors for DFU

The strengths of this study are, besides insulin therapy, mainly predictors for presence of DFU related to foot care behaviors (using shoes as footwear and spiritual belief that DM was a disease or temptation from God). These predictors are preventable by increasing knowledge related to foot care.

Current study revealed that participants who used insulin were associated with presence DFU, similar with Europe [26] and in Asia study [23]. This finding might be explained by the fact that DM therapy reflect severity of glycemic status which increase risk for DFU. In addition,  $HbA_{1C}$  was associated with presence DFU in univariate analysis, but diminished in multivariate analysis as well as others studies [26].

Another important result is that the spiritual belief is associated with presence of DFU. As we know, the role of spiritual belief against DFU has not been explained in previous studies. Current study indicates that spiritual belief of DM is a disease or temptation from God has less likely to presence of DFU compared to who has no spiritual belief. One of the potential answers is that the spiritual belief might give results to positive behaviors related to foot care. Previous study confirmed that spiritual belief associated with positive coping among T2DM patients [27] and has a role in controlling glycemic status [28].

Another predictor is related to footwear practice. In this study, using shoes as footwear is less likely to presence of DFU compared to who use sandals. Most of the Indonesian people use sandals as footwear which only covers the plantar of foot area, as a result the foot remains at high risk from external trauma. Even though effectiveness of footwear to prevent DFU remains unclear [29], these findings emphasize the important effect of shoes as footwear to prevent DFU compared sandals.

# 5. Limitations

We note there were three limitations in this study. First, the sample size was relatively small and failed to reach a calculated sample size since the last month of study that there was no more additional attendance. Secondly, research setting was conducted only in one hospital, which partially reflected clinical problems in Indonesia. In addition, since the setting was a regional hospital in eastern Indonesia, which received referrals from other hospitals, the attendance participants were at high risk status. As a result half of participants were at risk group. Last, limitation was related to research design. Research design of current study is a cross sectional epidemiological study. Consequently, the result of this study indicated about relationship data for presence of risk and presence of DFU rather that causal-effect. Thus, further multisite prospective study can be represented to evaluate prevalence of DFU in Indonesia.

# 6. Conclusions

As we know, this is the first epidemiological study in Indonesia which investigates prevalence, associated risk factors and predictors of DFU. Even though the prevalence of DFU is high, identification associated factors for presence of risk and DFU has not been integrated into national guideline [30]. Thus, preventive strategies should be introduced at early stage to prevent presence of risk and DFU.

Interestingly, we note among all predictors (for presence of risk and DFU) can be modified by into positive

behaviors. So far, many studies are related to the associated factor for presence of risk and DFU has focused on physiological problems (neuropathy and angiopathy) and seem to ignore patients' behaviors related to their illness status. In fact, previous study has revealed that the importance of patients' belief is determinant for foot care [31]. Thus, modified belief on behaviors is more important rather than belief of illness [32]. In conclusion, we recommend to educate high risk patients to understand positive foot care behavior as essential preventive strategies to prevent presence of risk and DFU.

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# Breastfeeding Knowledge, Attitude and Intention among Female Young Adults in Ibadan, Nigeria

# Oluwatosin Leshi\*, Folake O. Samuel, Marian O. Ajakaye

Department of Human Nutrition, Faculty of Public Health, University of Ibadan, Ibadan, Nigeria Email: \*ttlesh@gmail.com

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# **Abstract**

Background: The decision to breastfeed is largely dependent on mothers' breastfeeding knowledge and attitude which are usually formed in their adolescence and early adulthood. It is important to focus research on female young adult who are at the verge of stepping into motherhood. Methods: The breastfeeding knowledge, attitude and intention of 457 female young adults in Ibadan, Nigeria were assessed through validated breastfeeding knowledge, attitude and intention scales. Results: Majority (87.5%) of the respondents had never given birth and 74.6% had previously participated in breastfeeding discussions. About half (52.1%) knew breastfeeding should be initiated within one hour of birth while 49.9% reported that pre-lacteal feed should not be given to newborn babies. Correct definition of exclusive breastfeeding was given by two-third of the respondents and three-quarter specified that breastfeeding was beneficial to both mother and child. Overall 43.1% of the respondents had good breastfeeding knowledge. About 80% of the respondents agreed that breastfeeding should be initiated within one hour after delivery, 37.8% were of the opinion that breast milk only was not sufficient for infants in the first 6 months of life while about half of the respondents agreed that water should be introduced to babies before 6 months. In all, 53.8% had positive attitude towards breastfeeding. Only a third of the respondents had good breastfeeding intention although 90.6% claimed that they intended to breastfeed. Only 35.9% indicated to have known all it took to breastfeed and 54% intended to introduce breastmilk within 1 hour of birth while 60% had the intention of breastfeeding exclusively. There was significant association between breastfeeding knowledge and attitude as well as breastfeeding knowledge and intention. Conclusion: Female young adult demonstrated relatively fair breastfeeding knowledge and attitude but poor intention to breastfeed. Intervention to improve breastfeeding knowledge, attitude and intention of this population is recommended.

<sup>\*</sup>Corresponding author.

# **Keywords**

# Breastfeeding, Knowledge, Attitude, Intention, Young Adult

# 1. Introduction

Malnutrition contributes to more than half of global under-five childhood deaths and well over two-thirds of these deaths which occur in the first year of life are often associated with inappropriate feeding practices [1]. Breastfeeding is regarded as the most cost-effective public health measure that significantly impacts infant morbidity and mortality in developing countries [2] [3]. The decision to breastfeed is influenced by both the knowledge and attitude of mothers towards breastfeeding. This decision is however, probably formed as early as adolescence [4] and perhaps, also in early adulthood. Young adults are the age group in the population which can easily be influenced by peers, lifestyle, and sociocultural beliefs. The current choices of the youth have been reported to affect their future reproductive practice [5] [6]. Breastfeeding intention of future parents could be greatly influenced by their current knowledge and attitude towards breastfeeding. Following this reasoning, Marrone and colleagues had pointed out the need to understand young adults' breastfeeding knowledge and attitude [7]. This is because attitude which eventually influences practice toward breastfeeding is formed early in life [8]. Several studies have investigated the breastfeeding knowledge and attitude among adolescents and young adults, some of which are secondary school students [9], adolescent mothers [10] [11] and university students [7] [12]-[15]. However, there is a dearth of similar research in Nigeria focusing on female young adults who are at the verge of stepping into motherhood. Yet this is important in addressing childhood malnutrition through optimum breastfeeding of mothers especially in Nigeria, where suboptimal breastfeeding practices are widespread. The aim of this study is therefore to assess breastfeeding knowledge, attitudes and intention of female young adults in Ibadan, Nigeria.

### 2. Methods

# 2.1. Study Design and Sample

This cross-sectional study was conducted among young female adults who had just recently graduated from tertiary institutions in Nigeria, and enrolled into the mandatory National Youth Service Corps (NYSC) scheme in Ibadan, the capital city of Oyo State, Nigeria. The NYSC scheme was set up in 1973 by the Nigerian government to involve the country's graduates in the development of the country. Graduates from tertiary institutions such as, universities, polytechnics, and monotechnics who are not more than 30 years of age are required to take part in the compulsory National Youth Service program for one year. The aim of the program is to ensure national integration and unity among youths from various region of the country, and a means of inculcating the spirit of selfless service. The "corpers" as the NYSC members are commonly called, are posted to communities far from their community of origin thereby exposing them to people of other ethnicity, language and social-cultural characteristics.

The metropolitan area of Ibadan comprises of five Local Government Areas (LGAs) of which three (Ibadan North, Ibadan South-East, and Ibadan South-West Local Government Areas) were randomly selected for the study. A total of 457 out of a total of 1200 female corpers were recruited based on their willingness to participate in the study. Questionnaires were administered to them at their weekly Community Development Service (CDS) meetings at the LGA headquarters.

#### 2.2. Instruments

From August to October 2014, a semi-structured, self-administered questionnaire was used to obtain information from the study participants.

The process of questionnaire development was guided by review of literature on breastfeeding knowledge, attitude and intention [7] [9] [12]-[16] from which questions and scales were constructed which are culturally appropriate to the study population. The questionnaire was divided into four sections; the first section was designed to elicit the socio-demographic information, this included the age, state of origin, course studied, religion,

marital status, intended age of marriage, and if participant had ever given birth. The second section elicited information on breastfeeding knowledge of the respondents. This included questions on previous participation in breastfeeding discussion, breastfeeding initiation, duration, mode of breastfeeding, definition of exclusive breastfeeding and colostrum, benefits of breastfeeding and breastfeeding cessation. The third section covered the attitude of respondents towards breastfeeding. The questions were optioned to be "strongly agree", "agree", "neutral", "disagree" and "strongly agree". This included questions on infant feeding practice, comparison of breast milk to infant food and public embarrassment of breastfeeding. The fourth section was to elicit information on breastfeeding intention of the respondents. This included questions on intended age to carry out infant feeding practices for child starting from initiation of breast milk to the cessation, intention of respondents to breastfeed later in future, influence of relatives/families support on breastfeeding and cultural barrier on breastfeeding. The questionnaire was pilot-tested among 40 female corps members outside the study location.

Breastfeeding knowledge scale was constructed and consisted of 12 point score. Participants with correct and incorrect responses were score 1 and 0 respectively thus allowing for a total score of 12 (ranging from 0 to 12). The Cronbach's alpha of the knowledge scale was 0.78. The attitude scale consisted of 10 point attitude statements with responses ranging from either agreed or disagreed. The breastfeeding intention was assessed through a 10 point questions with potential responses of "Yes", "No" and "Undecided". The Cronbach's alpha for attitude and intention components were 0.75 and 0.84 respectively. Participants with score of 8 and above in the breastfeeding knowledge scale were considered to indicate a good breastfeeding knowledge, while, those with score below 8 were regarded to have poor knowledge. From the attitude and intention scales, on the other hand participants with score below 6 were regarded to have negative attitude and poor intention toward breastfeeding while positive attitude and good intention to breastfeed were defined as participants scores of 6 and above respectively on the breastfeeding attitude and intention scale.

# 2.3. Data Analysis

Data were entered into Epidata version 3.1, cleaned, and then analyzed with IBM SPSS 20.0. Descriptive statistics were implored to describe the socio-demographics information, breastfeeding knowledge, attitude and intention of the respondents. To assess the internal consistency and reliability, Cronbach's alpha was calculated for knowledge, attitude and knowledge scales. Chi-square test was used to assess the relationship between breastfeeding knowledge, attitude and intention with level of significance set at 0.05.

## 2.4. Ethical Issues

Ethical approval was sought from the University of Ibadan/University College Hospital Ethics Committee. Approval was also sought from the relevant authorities of the NYSC scheme. Respondent's informed consent was obtained after explaining the purpose of the research. Participation in the study was entirely voluntary and no financial inducement whatsoever was involved. Voluntary withdrawal at any stage of interaction was guaranteed for all respondents. All information was handled with strict confidentiality.

#### 3. Results

#### **Socio-Demographic Characteristics**

Table 1 presents the socio-demographic characteristics of the 457 study participants. Three-quarter of the Youth corps members were Yoruba, about 12.3% were Igbo, and 0.8% were Hausa while 11.2% of the female corps members belonged to the minority ethnic groups. Most (81.2%) of the respondents were Christian while 18.8% were Muslim. The mean age was 25 (±3.0) years with 63.3% and 35.4% within 20 - 25 years and 26 - 30 years respectively. About 70% of the female corps members were single while 17.1% were married; about half of the respondents intended to marry within 1 year after the interview. Although majority (87.5%) of the female corps members had never given birth, three-quarter of them had been involved in formal or informal breastfeeding discussion before. About 60% of the respondents became aware of breastfeeding through the social media, about 25% through family and friends, and 20.6% at health facilities. Majority (73.5%) agreed that fathers have a role to play in ensuring optimum breastfeeding.

The knowledge of the female young adults in the current study toward breastfeeding deviated from the current international recommendations. As shown in **Table 2**, a little more than half of the participants knew that mothers

Table 1. Socio-demographic characteristics of the respondents.		
Variables	Frequency	Percentage
Ethnicity		
Yoruba	346	75.7
Igbo	56	12.3
Hausa	4	0.8
Minority group	51	11.2
Religion		
Muslim	86	18.8
Christian	371	81.2
Age in years $(n = 395)$		
Less than 20 years	2	0.5
20 - 25 years	250	63.3
26 - 30 years	138	34.9
Greater than 30 years	5	1.3
Mean (SD) = $25 \pm 3$ ) years		
Marital status		
Single	323	70.7
Engaged	56	12.3
Married	78	17.1
Intended year to marry $(n = 234)$		
Less than 1 year	30	12.8
About 1 year	111	47.4
About 2 years	52	22.2
About 3 - 4 years	41	17.5
Median = 1 year		
Ever given birth		
Yes	57	12.5
No	400	87.5
Ever involved in any formal or informal breastfeeding discussion		
Yes	341	74.6
No	116	25.4
Source of information		
Social media	276	60.4
Family/friends	115	25.2
Religious places	28	6.1
Medical places	94	20.6
Seminar	20	4.4
Total	457	100

Table 2. Breastfeeding knowledge of the female corpers.

Variable	Frequency	Percentage
Initiation of breastfeeding by the mother		
Within 1 hour after birth	238	52.1
After 1 hour of delivery	71	15.5
Don't know	148	32.4
Feeding of pre-lacteal liquid		
Yes	229	50.1
No	192	42.0
Don't know	36	7.9
Knowledge of colostrum		
Yes	175	38.3
No	282	61.7
Description of colostrum (n = 175)		
Correct description	58	33.1
Wrong description	117	66.9
Only breast milk is sufficient for infants n the first 6 months		
Yes	317	69.4
No	140	30.7
Introduction of water to the infant		
Before 6 months	135	29.5
6 months and above	211	46.2
Don't know when to introduce water	111	24.3
Definition of exclusive breastfeeding		
Correctly defined	302	66.1
Incorrectly defined	128	28.0
Don't know the definition	27	5.9
Complete covering of the nipples and its surroundings is one of the appropriate positioning for breastfeeding		
Yes	337	73.7
No	120	26.3
Women with small breast cannot produce sufficient breast milk		
Yes	53	11.6
No	404	88.4
Benefit of breastfeeding		
Only to mother	6	1.3
only to baby	100	21.9
Both mother and baby	335	73.3
Not beneficial to mother and baby	16	3.5

Continued		
The mode of breastfeeding a baby		
At mothers will	20	4.4
As baby demands	344	75.3
As scheduled by mother	34	7.4
Don't know	59	12.9
Introduction of complementary food to the infants		
Before 6 month	16	3.4
At 6 month	251	54.9
After 6 month	123	27.0
Don't know when to introduce complementary food	67	14.7
Cessation of breastfeeding by the mother expected		
Before 24 months	279	61.0
24 months and above	90	19.7
Don't know	88	19.3
Median time for cessation = 12 months		
Total	457	100

should initiate breastfeeding within one hour of delivery, and 50.1% thought that pre-lacteal liquids should be introduced to an infant in the first three days after delivery. Out of 38.3% of the respondents that indicated their knowledge of colostrum, only one-third gave the correct description of colostrum.

Correct definition of exclusive breastfeeding was given by two-thirds of the respondents and most of them specified that breastfeeding is beneficial to both mother and child. About 70% of the respondents believed that breast milk alone is sufficient for infant's growth in the first 6 months of life. Three out of 10 female corps members reported that water should be introduced to the infant before 6 months while less than half indicated the introduction of water after 6 months. It was however revealed that about one-third of the respondents indicated not have known when to introduce water to the infant. The correct definition of exclusive breastfeeding was given by two-third of the respondents and three-quarter specified that breastfeeding is beneficial to both the mother and the child.

The mode of breastfeeding indicated by most (75.3%) of the respondents was as baby demands. About 55% of the female corps members knew that complementary food should be introduced by 6 months. The median time indicated for breastfeeding cessation was 12 months; 61% indicated that breast milk should be ceased before 24 months while 19.4% indicated 24 months and beyond Overall, the mean knowledge score was  $7.02 \pm 2.3$  out of a maximum score of 12 and about 6 out of 10 of the female corps members had poor breastfeeding knowledge.

**Table 3** presented the participants attitude towards breastfeeding. While about 80% of the participants agreed that breastfeeding should be initiated within 1 hour of delivery, about 60% agreed that colostrum protect the infants from infections. Four out of 10 respondents were of the opinion that breast milk is not sufficient for the infant in the first 6 months of life. About half of the participants agreed that water should be introduced to babies before 6 months of life while 3 out of every 10 respondents were of the view that breastfeeding in the public is embarrassing. Seventy seven percent were of the opinion that breastfeeding is cheaper than formula feeding while about 74% disagreed that formula feeding is healthier than breastfeeding. About 56% disagreed that Herbs/herbal drinks are beneficial to the health of babies especially in the first 6 months. Three-quarter of the female corps members strongly disagreed that the size of breast determines the amount of breast milk produced by mother. Generally, a little more than half (53.8%) of the participants have a positive attitude toward breastfeeding (**Figure 1**).

Table 3. Breastfeeding attitude of respondents.

Attitude statement	Agree (%)	Neutral (%)	Disagree (%)
A mother should breastfeed her baby within one hour of delivery	78.8	9.4	11.8
Colostrum protects the baby from infections	63.1	13.1	23.8
Breast milk only is not sufficient for a baby in the first 6 months of life	37.8	10.7	51.4
Water should be given to a baby before six months of life	49.4	16.6	33.9
Herbs/herbal drinks are beneficial to the health of babies especially in the first 6 months	29.7	14.7	55.5
Breast milk is cheaper than infant formula	77.0	5.0	18.0
Formula feeding is healthier than breastfeeding	18.1	7.7	74.2
Breastfeeding in public is embarrassing therefore should be discouraged	27.2	19.9	53.0
The size of breast determines the amount of breast milk produced by mother	15.3	9.2	75.5
Breastfeeding cannot be continued when semi solid or soft food is introduced to a baby	17.3	9.8	72.9

Disagree = strongly disagree/Tend to disagree; Agree = strongly agree/Tend to agree.

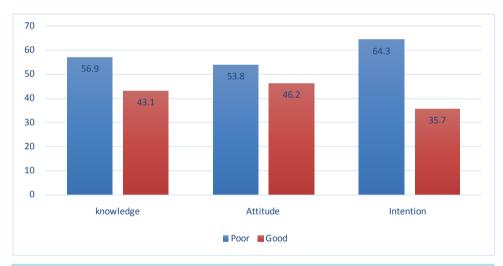


Figure 1. Breastfeeding knowledge, attitude and intention category of the respondents.

The intention of the study participants is as shown in **Table 4**. Although majority (90.6%) of the respondents intended to breastfeed their future children, only 35.9% indicated to have known all it requires to breastfeed while 55.4% reported to have been well prepared for breastfeeding. Fifty four percent intended to introduce breastmilk within 1 hour of birth while 22.8% were yet to decide. The median age that the respondents intended to introduce water to their future children is 4 months with one-third intended to introduce water to their infants before 6 months of life, 40.9% from 6 months and 25.8% were yet to decide. About 60% intended to breastfeed exclusively while 9% were yet to decide. Four out of 10 respondents indicated not have decided on when to introduce complementary food but only about 2% indicated less than 6 months. Overall, the breastfeeding intention of the female young adults in the current study was found to be poor (**Figure 1**). **Table 5** reported a significant association between breastfeeding knowledge and attitude (p < 0.00) as well as breastfeeding knowledge and intention (p < 0.00) of the respondents

#### 4. Discussion

Breastfeeding decisions and practices have been reported to be greatly influenced by breastfeeding knowledge

Table 4. Breastfeeding intention and attitude with intention category of female corpers.							
Variables	Frequency	Percentage					
Do you think you know all it takes to breastfeed							
Yes	164	35.9					
No	293	64.1					
Do you think you are well prepared for breastfeeding							
Yes	253	55.4					
No	204	44.6					
Will you breastfeed your child later in the future							
Yes	414	90.6					
No	43	9.4					
If yes, how will you breastfeed your child? (n = 414)							
At mothers will	36	8.7					
As baby demands	321	77.5					
As scheduled by mother	57	13.8					
Intended time to introduce breast milk to child							
Within 1 hour of birth	247	54.0					
After 1 hour of delivery	85	18.6					
Day 2 and above	21	4.6					
Yet to decide	104	22.8					
Intended age to introduce water to child							
Before 6 month of age	152	33.3					
6 months and above	187	40.9					
Yet to decide	118	25.8					
Median age = 4 months							
Intended age to introduce complementary food							
Less than 6 months	8	1.8					
6 - 11 months	205	44.9					
12 months and above	49	10.7					
Yet to decide	195	42.7					
Intention to breastfeed exclusively							
Yes	277	60.6					
No	139	30.4					
Yet to decide	41	9.0					
Total	457	100.0					

Table 5. Breastfeeding knowledge, attitude and intention relationship.

		Poor knowledge N (%)	Good knowledge N (%)	$\chi^2$	P value
Attitude	Negative attitude	116 (44.6)	14 (7.1)	77.47	0.000
Attitude	Positive attitude	144 (55.4)	183 (92.9)	77.47	0.000
	Total	260 (100.0)	197 (100.0)		
T	Poor intention	176 (67.7)	42 (21.8)	04.47	
Intention	Good intention	84 (32.3)	154 (78.2)	94.47	0.000
	Total	260 (100.0)	197 (100.0)		

and attitudes [17]-[20]. Evidence has shown that infant feeding decisions are highly dependent on maternal attitudes and intentions toward breastfeeding, which in turn, may be formed as early as adolescence [16] [21] and early adulthood. Exploring the breastfeeding knowledge, attitude and intention of young adult will help in planning and understanding the strategies that may be used in intervention program to this sub-population before they step into parenthood. This study however assessed breastfeeding knowledge, attitude and intention of Nigerian female young adults.

The findings from this study revealed that less than half of the respondents had good breastfeeding knowledge; this result is found to be similar what was reported among Korean undergraduates [15], Saudi Arabian young mothers [22] and Nigerian female students [23]. However, contrast findings were reported among female undergraduates in United States [13] Hong Kong [24] China [14] where the most of the respondents had relatively good and moderate breastfeeding knowledge. Previous studies have reported Nigerian women to have adequate knowledge towards breastfeeding [25]-[29] comparing this findings with the findings from the current study, there is a likelihood of decline in the proportion of Nigerian women with adequate breastfeeding knowledge in the nearest future and this may further reduce optimum breastfeeding practices among Nigerian mothers.

The first hour of an infant's life is of great importance for the initiation and continuation of breastfeeding, it also to establish the emotional bond between mother and the baby [1], initiation of breastfeeding within an hour of birth was therefore recommended [1]. Delay in initiation of breastfeeding after the first hour has equally been reported to increase the risk of neonatal mortality, in particular neonatal deaths due to infections [30] [31]. The proportion of the young adults in this study with adequate knowledge of breastfeeding initiation was close to the percentage reported among mothers with post-secondary education with the actual initiation of breastfeeding within one hour of child birth in the recent national demographic and health survey [30]. Findings from this study align with similar studies among US adolescents [13] and Tanzanian young mothers [32] but not in conformity with what was reported among female undergraduates in Mainland China [14]. According to Wen and colleagues [33], mothers who had completed tertiary education were more likely to be aware of the breastfeeding recommendation than those who had school certificate or less. In this study, an appreciable number of the respondents knew the correct definition of exclusive breastfeeding and were aware that only breastmilk is sufficient for infants in the first 6 months. This is in line with the study of Lou and colleagues [14].

The crucial role of colostrum from a mother breast as the first immunization a baby received after delivery has been proven by researchers [34] [35]. Findings however from this study indicate poor knowledge of colostrum among the female young adult in Ibadan. In a study among mothers to-be in Saudi Arabia, 67.1% students were unaware of the importance of colostrum [36]. Also in a related study among female undergraduates in Nigeria [37], majority of the respondents reported their lack of knowledge on the immunological protection of colostrum. These findings on wrong description of colostrum are similar to what was obtained among the young adult in the current study. In a study among first-time mothers in China [38], it was reported that almost all mothers (99%) knew breastfeeding was good for the baby's health, while 22% of mothers did not think breastfeeding was beneficial to the mother's health. From the current study, it was found that majority of the young adults reported their awareness of the benefit of breastfeeding to both the mother and the infant.

Decision to breastfeed has been reported to be highly dependent on the attitude towards breastfeeding, which are probably formed as early as adolescence [21] and also in early adulthood. It was also reported that positive

parental attitudes towards infant feeding are important component in ensuring optimum child nutritional health [39]. This may be as a result of a positive relationship between attitude and optimum practices. About half of the respondents from this study had positive attitude towards breastfeeding. Studies have however found a form of association between positive attitude towards breastfeeding and optimal infant feeding practices especially breastfeeding [25] [40]-[42]. Contrast to our study, majority of mothers to-be in Saudi Arabia were reported to have positive attitude towards breastfeeding [36]. Other studies have also established that older students show positive attitude towards breastfeeding [7] [13].

Several studies have reported a wide variation in the acceptability of public breastfeeding among members of similar populations [14] [18] [43]-[45]. It is noteworthy to report that the attitudinal response of young adult in the current study towards discouragement of breastfeeding in the public was low.

The acceptability of breastfeeding in the public among young adult in this study is higher than what was obtained among the young adult in China [14]. Studies have reported mothers' hesitation to breastfeeding their babies as a result of their concern on insufficient supply of breastmilk [33] [46] [47]. In the current study, about half of the respondents had a positive attitude to sufficiency of breastmilk for infants in the first 6 months of life. Previous studies have reported female young adults to disagree with the common notion that women with small breasts cannot make enough breast milk [14] [15]. It is also encouraging to note the positive attitudinal response of the respondents from this study towards the amount of breastmilk produced not being determined by the size of the breast.

Actual breastfeeding practices of mothers have been associated with their breastfeeding intentions before birth [48] [49]. Participants in the current study generally demonstrated poor breastfeeding intention. Studies have repeatedly found that women's pre-birth breastfeeding intentions are a good predictor of the actual duration of breastfeeding [49] [50]. Ninety percent of the participants expressed their intention to breastfeed in the future. This percentage is higher than that of the female undergraduates [13] and female adolescents [43] in USA, as well as Hong Kong female university students [24].

It is important to note that majority of the study respondents intended to breastfeed in the future, only about one-third of the respondents revealed to know all it requires to breastfeed their future children while about half reported to have been prepared for breastfeeding. In a study by Wen *et al.*, [33] majority of the respondents in their study plan to initiate breastfeeding within the first hour of birth, this is in contrast to the current study where only about half of the respondent intended to initiate breastfeeding with one hour of birth while about one-fifth was yet to decide. A recent study among undergraduates in Nigeria reported a higher proportion (65%) of its responded intending to initiate breastfeeding in the first 6 hour of birth [37], this result is however not in line with the WHO recommendation of initiation within one hour of birth. This study further disclosed that young adults were fairly aware of breastfeeding and its benefit in relation to both the mother and child. According to Wen *et al.*, [33] the main reasons given by the mothers for planning to breastfeed was as a result of their understanding of health benefit of breastfeeding to both the mother and the child. Findings from this study is similar to what was obtained among First-Time Mothers in China [38] where majority of expectant mothers planned to breastfeed their babies while more than half of mothers planned to exclusively breastfeed their babies.

Studies have established that the intention to breastfeed is a strong predictor for actual initiation and duration of breastfeeding [8] [48] [49] [51]. Addressing mothers' awareness and intention to breastfeed has been reported to improve breastfeeding practice [38] [48], however addressing this issue prior to motherhood especially in early adolescence and early adulthood is deem important and will go a long way in improving the eventual practice in motherhood. Breastfeeding knowledge of young adults and adolescents has previously been associated with breastfeeding attitude and intention in relation to other studies [13] [43] [45] [51]-[53] our study found significant association between breastfeeding knowledge and attitude as well as intention.

# 5. Conclusion

Findings from this study have provided us with information on breastfeeding knowledge, attitude and intention among future Nigerian mothers. Although we reported a relatively good breastfeeding knowledge and averagely positive attitude however their breastfeeding intention was poor. Improving the knowledge and attitude of the female young adults towards breastfeeding will influence a positive breastfeeding intention hence increase the likelihood of optimum breastfeeding among future mothers. It is therefore recommended that this intervention

should be targeted on ensuring adequate breastfeeding knowledge and good breastfeeding intention.

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The authors declared no potential conflicts of interest pertaining the research, authorship and publication of this article.

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# The Process of Support by Nursing Professionals for Families Having a Member with Borderline Personality Disorder

# Yasuyo Nishimoto\*, Naohiro Hohashi

Division of Family Health Care Nursing, Department of Nursing, Graduate School of Health Sciences, Kobe University, Hyogo, Japan

Email: \*yasuyo-n@panda.kobe-u.ac.jp

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#### **Abstract**

The purpose of this study was to explore the process of family support provided by nurses to families with a borderline personality disorder (BPD) patient. Semi-structured interviews were conducted with 16 nurses who had provided care to BPD patients. Data obtained from the interviews were qualitatively analyzed using a modified grounded theory approach. As an overall core category of family support processes practiced by nurses for families with BPD patients, family support practiced without awareness that the nurses were supporting families was extracted. Through this process, nurses held perceptions that were premises for family support, which were formed through their individual nursing experiences and perspectives. Nurses also had diverse perceptions concerning the image of families. Through the integration of perceptions that were premises for family support and perceptions of an image of the family, nurses underwent a process of "determination and ambivalence about the need for family support." Then, nurses provided "family support practice" when they acknowledged the need for family support. During the "family support practice," nurses had difficulties in providing family support. When family support was not successfully provided, nurses provided "family support practice with seeking more effective ways through trial and error." For cases in which nurses did not acknowledge the need for intervention, they intentionally chose "not to provide family support." Furthermore, during the "family support practice," nurses had contradictory perspectives of family support. Such family support processes ultimately led to an awareness of the same family support required for the future. Family support was provided with "family support practice" and "family support practice with seeking more effective ways through trial and error." In some cases, however, the process ended in "not to provide family support intentionally." Experiences and perspectives in providing family support are important factors in carrying out future family support. Developing the positive implications of these factors and reducing psychological strain on nurses may ensure smooth implementation of family

<sup>\*</sup>Corresponding author.

support. Thus, nurses need to recognize that they are supporting the family, which is identified as a core category.

# **Keywords**

Family Nursing, Process of Family Support, Borderline Personality Disorder (BPD), Modified Grounded Theory Approach (M-GTA)

# 1. Introduction

Borderline personality disorder (BPD) presents various signs in interpersonal relationships, self-image, and emotions such as instability and impulsivity. It usually appears in early adulthood and is diagnosed in various circumstances [1]. In order to be diagnosed with BPD, at least five of the nine criteria must be present: 1) frantic efforts to avoid real or imagined abandonment; 2) a pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation; 3) identity disturbance: markedly and persistently unstable self-image or sense of self; 4) impulsivity in at least two areas that are potentially self-damaging; 5) recurrent suicidal behavior, gestures, or threats, or self-mutilating behavior; 6) affective instability due to a marked reactivity of mood; 7) chronic feelings of emptiness; 8) inappropriate, intense anger or difficulty controlling anger and 9) transient, stress-related paranoid ideation or severe dissociative symptoms. Intense or uncontrollable emotion is one of the symptoms, and patients typically show repeated dependence and aggressive behavior toward others [1]. The patients might also suffer from chronic feelings of emptiness and disconnectedness, and when they find themselves unable to handle such emotions, they often engage in such behavior as self-inflicted injury or heavy drinking. Furthermore, many harbor deep anxieties of abandonment often allude to suicide as a means of retaining relationships with others, which is manifested in such selfdestructive impulsive actions as wrist-cutting and overdosing. Other types of negative behavior take the forms of overspending or sexual aberrations.

In most cases, difficulties that the family faces due to problematic behaviors of the patient serve as the impetus for visiting a medical facility, rather than difficulties that the patient feels himself. Previous studies have found that BPD patients perceive their caregivers' attitudes as lacking in affection, over-protective, controlling, and lenient [2] [3]. In such families, family dysfunction may occur with difficulties in role performance both within and outside the family. Because the patient affects the family and vice versa, and in some cases treatment should involve a family component [4], this disorder requires support for the entire family unit.

The lifetime prevalence of BPD is 5.9% [5] and the frequency of BPD in the general population is known to be 0.7% to 2.0% [6]. However, the prevalence of BPD in psychiatric patients is much higher with 20% to 60% among inpatients and 11% to 34% among outpatients, making encounters with BPD patients and their families fairly common among psychiatric practitioners. Although this disorder had been referred to as "borderline cases" until the 1980s, BPD was currently recognized as a disorder and guidelines [7] for treatment were developed in 2008. However, no established standard treatment method has yet to be developed, and in general patients do not receive treatment from mental health professionals [8]. Given such background, multidisciplinary team care has been shown to be effective, through use of a combination of treatment methods in accordance with patients' conditions.

Likewise, the methods of support for families with BPD patients have not been established. In addition, many nurses with experiences in caring for BPD patients have encountered difficulties in providing caring for such patients [9]. Thus, developing a support model for BPD patients and their families is an urgent issue, and investigation of nursing support as is currently being provided is required. Few existing studies, however, have reported on families with BPD patients, and none of these has focused on family support.

Understanding the current family support and nursing process that may influence the future direction of family support may lead to identifying issues in nursing practice for families with BPD patients, improve the quality of care, and reduce the sense of difficulty that nurses encounter in their daily practice. Therefore, the purpose of this study is to investigate qualitatively the processes of family support that nurses provide to families with BPD patients.

## 2. Methods

#### 2.1. Definition of Terms

Family is operationally defined as "a family including the patient," and the process of family nursing is operationally defined as "a process of family support including nurses' perceptions and thoughts about the families including patients with BPD, practice of family support, and future direction of support."

# 2.2. Study Design

A modified grounded theory approach (M-GTA) developed by Kinoshita [10] was used in this qualitative functional study. The M-GTA is based on several basic characteristics including intentionality in theory generation, the principle of grounded-on-data, empirical evidence, meaningful interpretation, and application for validation. These characteristics were adopted from the original grounded theory approach (GTA) [11]. In M-GTA, data coding method was further specified to facilitate application. The analysis process was also modified for others to understand, and improved by means of emphasizing the views of researchers. The fundamental element of M-GTA is research about social interaction in which humans interact each other, thereby making it appropriate for studies in the field of human services. Furthermore, it is appropriate for research in which studied phenomena are concerned with the feature of process of phenomena. The phenomena explored by the current study occurred in nursing practice in the fields of human service, and consisted of interactions between nurses and families with BPD patients. Therefore, M-GTA was used in this study to investigate a series of such processes.

# 2.3. Participants

Participants of this study were 16 nurses who had experienced interactions with families of BPD patients in the course of their work as inclusion criteria. They were purposefully and continuously selected based on the content of previously conducted interviews. In other words, participants who could provide information relevant to this study were selected and investigated, and recruitment of the participants was ongoing by means of the theoretical sampling method.

#### 2.4. Data Collection Methods

The settings of this study were two psychiatric hospitals and one home-visit nursing station that provided medical care for BPD patients. Information packages, including purpose and summary of the study, ethical considerations such as voluntary nature of participation and preservation of anonymity, were distributed through each facility's staff. Semi-structured interviews were conducted with nurses who agreed to participate, between October and November 2014. The interviews were conducted individually in a location where the privacy was protected or according to preferences of the subjects. Although duration of the interviews was in principle set for 60 minutes, the actual duration was flexible according to the subjects' circumstances. The contents of the interviews were about issues related to family members of BPD patients and features of such families from the view point of the nurse. The nurses were also asked concerning the experiences and feelings of BPD patients in providing family support, and how they perceived the features of families with them.

As the interviews were semi-structured, the subjects spoke freely within the general framework of the interviews. The interviews were recorded using an IC recorder with the consent of the subjects. In cases when the subjects declined to be recorded by the IC recorder, notes were taken instead with their consent, and a detailed field notes were taken within the interview day. A verbatim record was created based on the IC recorder audio data and notes.

#### 2.5. Data Analysis

Data were analyzed qualitatively and inductively using M-GTA. Based on M-GTA, subjects of analysis were "nurses who had experiences providing family support to families with BPD patients," and a theme of analysis was "how the subjects perceived the families and provided support for them, what the nurses experienced through the support practice, and what consequences about the future family support they reached." While compiling the obtained data and the theme of analysis, we looked at certain points, and generated concepts by means of interpreting why we looked at them and what were the implications for the subjects. Constant comparative

analysis and theoretical sampling were repeated, and analysis and data collection were continued until theoretical saturation was reached.

Relationships between generated concepts were investigated and classified into categories, and a diagram was created to explain the phenomena that were the subjects of analysis. To ensure credibility and validity of data, the subjects' thoughts or ideas, and that the subjects agreed with the validity of the researchers' interpretation, were confirmed by the researchers during each interview. Twelve researchers with expertise in the field of family nursing were involved in the analysis process, with supervision undertaken.

## 2.6. Ethical Considerations

This study was conducted with the approval of the university's ethics committee. Participants were informed about this study by oral explanation and written information. The provided information included overview of the study; arbitrary property of the investigation; and maintaining of anonymity. The participants were also informed that non-participation or withdrawal from participation would not cause any disadvantages, and that study content would not affect any of their assessments in their workplaces. Informed consent was obtained with signature of the participants.

# 3. Results

# 3.1. Participants

A single interview was conducted with each nurse (n = 16) who had an experience of interacting with families of BPD patients in their nursing practice. The interview duration ranged from 30 to 60 min, with the mean duration 43 min. **Table 1** shows the demographics of the subjects. Mean age of the subjects was 41.6 years (range: 29 - 59 years), average years of experience as a nurse was 17 years (range: 6 - 28 years), and average years of experience in psychiatry was 13.5 years (range: 5 - 25 years).

# 3.2. Analysis Results

Concepts and categories involved in the study are described as follows: concepts, []; categories, <>; and core categories, <<>>. Responses obtained from each subject in the interview are expressed in "", and items that

Table 1. Demographics of the participants.

ID	Age (years)	Sex	Years of nursing experience	Years of nursing experience in psychiatry	Experience of studying family nursing
Ns <sup>a</sup> 1	40s	Male	25	24	No
Ns 2	40s	Female	22	22	Yes
Ns 3	30s	Male	13	13	No
Ns 4	40s	Male	20	20	Yes
Ns 5	20s	Female	7	7	No
Ns 6	40s	Female	21	5	No
Ns 7	40s	Male	7	7	No
Ns 8	40s	Female	10	10	No
Ns 9	50s	Female	26	15	No
Ns 10	40s	Female	21	20	No
Ns 11	30s	Male	14	7	No
Ns 12	30s	Male	13	11	No
Ns 13	40s	Male	6	6	Yes
Ns 14	50s	Female	25	10	No
Ns 15	30s	Male	14	14	No
Ns 16	40s	Female	28	25	Yes

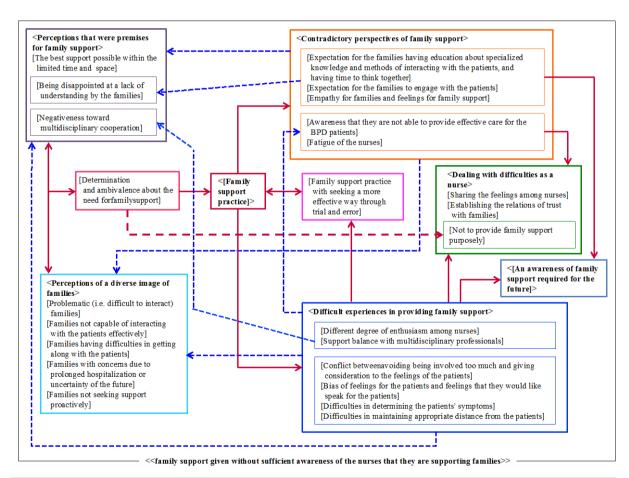
a. Ns = Nurse.

were both concepts and categories were expressed in <[ ]>. The author added notes in ( ) for content of comments that were hard to understand from the comment alone. ID numbers are the same as ones shown in **Table 1**. Results of the analysis identified 26 concepts, seven categories and one core category (**Figure 1**).

# 3.3. Storyline

Throughout the support process, support for families with BPD patients was provided based on <<family support given without sufficient awareness of the nurses that they are supporting families>>. Nurses had an attitude to provide [the best support possible within the limited time and space], while at the same time having <perceptions that were premises for family support> that were shaped by past experiences in family support such as [being disappointed at a lack of understanding by the families] or individual nurses' perspectives such as [Negativeness toward multidisciplinary cooperation]. Nurses recognized [families having difficulties in getting along with the patients] and [families with concerns due to prolonged hospitalization or uncertainty of the future] in providing care for BPD patients. Meanwhile, nurses have <perceptions of a diverse image of the families> such as [problematic (i.e. difficult to interact with) families], [families not capable of interacting with the patients effectively] and [families not seeking support proactively].

Nurses integrated <perceptions that were premises for family support> and <perceptions of animage of the family> which in turn led to [determination and ambivalence about the need for family support]. When nurses recognized the need for support, <[family support practice]> was provided. During <[family support practice]>, nurses experienced a [conflict between avoiding being involved too much and giving consideration to the feelings



**Figure 1.** Process of support by nursing professionals for families having a member with a borderline personality disorder. Solid red lines: Arrows indicate the progression of the family support process, Broken red lines: Among the arrows indicating the progression of the family support process, arrows indicate consequences in which family support was not conducted, Broken blue lines: Arrows indicate the influences between concept and category.

of the patients] due to [difficulties in determining the patients' symptoms], [difficulties in maintaining appropriate distance from the patients], and [bias of feelings for the patients, speaking for the patients]. They also had <difficult experiences in providing family support> which arose from care environment issues other than the family issues, such as [different degree of enthusiasm among nurses] or [support balance with multidisciplinary professionals]. When the family support did not go well due to <difficult experiences in providing family support>, they provided [family support practice with seeking a more effective way through trial and error]. When nurses did not find the need for support, they chose [not to provide family support purposely]. < Difficult experiences in providing family support> resulted in negative appraisal such as [fatigue of the nurses] or [awareness that they are not able to provide effective care for the BPD patients]. Meanwhile, nurses recognized the need for family support with [expectation for the families having education about specialized knowledge and methods of interacting with the patients, and having time to think together], [expectation for the families to engage with the patients], and [empathy for families and feelings for family support], resulted in having <contradictory perspectives of family support>. To deal with <contradictory perspectives of family support> and <difficult experiences in providing family supports, nurses took actions of <dealing with difficulties as a nurses, such as [sharing the feelings among nurses], [to intentionally withhold family support], and [establishing the relations of trust with families] to maintain <family support practice>. This process of family support ultimately led to <an awareness of family support required for the future>. This was a cyclical process that <contradictory perspectives of family support> and <difficult experiences in providing family support> influenced <perceptions that were premises for family support> and <perceptions of a diverse image of the families>.

# 3.4. Details of Each Category and Developed Concept

• << Family support given without sufficient awareness of the nurses that they are supporting families>> Definition: Situations that nurses interact with families without awareness that they are providing nursing intervention for families.

Ns.5 "As far as I know, there isn't much...well, I guess it (interaction between nurses and families) occurs sometimes when the doctor speaks at the time of hospitalization, or during hospitalization when families come to see the patients on occasion, nurses may talk to them, but I think it's very rare for the nurses to, you know, intervene in that."

Ns.6 "It's not in the form of 'family support,' the patient's mother, it's usually a mother accompanies the patient, sometimes I take plenty of time to listen to the mother, but it's not really in the form of support."

Ns.12 "Um, I don't know if I can say that I've been giving what I can call 'family support.' Hmm...I do believe that family support is necessary, though."

Ns.13 "Mm, well, it's not exactly 'family support' as you'd find in a textbook, but really, I'm just a nurse with no authority, so, I don't really have so much experience speaking directly or approaching to the family form myself."

#### 3.4.1. Perceptions That Were Premises for Family Support

Although nurses had an attitude to provide [the best support possible within the limited time and space], they also had <perceptions that were premises for family support> that were shaped by past experiences in family support such as [being disappointed at a lack of understanding by the families] or individual nurses' perspectives such as [negativeness toward multidisciplinary cooperation].

• [The best support possible within the limited time and space]

Definition: The nurse's recognition that they are providing family support within their job responsibilities, in the limited time frame and place.

Ns.1 "I respond to them when they come within the available range of time..."

Ns.4 "Yes, well, in the acute phase, it's hard to say just how much we can accomplish in a hospitalization period under 3 months...it's very hard, I think."

Ns.13 "Well, let's see...I have studied the ideal intervention or something, in the textbooks, so I'm aware that it's necessary, and it's always in the back of my mind to do it, but when it comes in my daily work, it was too hard to actually do it by according much weight to it."

Ns.7 "Well, I don't take a time especially for that; more often, I just speak to them when they come to visit the patient. So...I wonder, what can I do with it? I don't really have a sense of achievement...no." "Well, so I try my best to speak to them at least when they come to visit the patient, that's what I have been doing."

• [Being disappointed at a lack of understanding by the families]

Definition: A feeling of sadness and imperfection as a nurse when the family blames health professionals with being involved in the patient's pathology, despite the nurses trying to relate to the family with empathy.

Ns.2 "Well, the lack of understanding of the illness may be part of it, but when the target of accusation is shifted from themselves (nurses) to the hospital, they (nurses) seem to feel a strong sense of relief, so there are some nurses who develop an inclination to blame the hospital."

• [Negativeness toward multidisciplinary cooperation]

Definition: Circumstances of having insufficient awareness about multidisciplinary cooperation, or believing that it is better not to cooperate proactively.

Ns.2 "The psychologist is often involved in care for patients, but they don't become involved in care for families at all."

Ns.5 "Ah, well, as far as I'm aware, as well as primary doctors, the PSWs (= Psychiatric Social Workers) of the counselling division probably get involved in helping the patient finding a house or something. And for matters like insurance, etc., well, as far as I know, there aren't any other professionals that get involved."

Ns.14 "The doctors...well, hmm...let me think...well, it's with the doctors...the communication between doctors and nurses doesn't always go so well, so..."

# 3.4.2. Perceptions of a Diverse Image of Families

While being aware of families requiring family support, such as [families having difficulties in getting along with the patients] and [families with concerns due to prolonged hospitalization or uncertainty of the future], nurses also recognized that they wanted to maintain distance between themselves from some families, such as [problematic (*i.e.* difficult to interact) families]. In such cases, the nurses recognized their perceptions of a diverse image of the family> who required no family support, such as [families not capable of interacting with the patients effectively] and [families not seeking support proactively].

• [Families having difficulties in getting along with the patients]

Definition: Families that have difficulties in dealing with the patient and have no idea what they can do.

Ns.3 "The patients, well, um, sometimes express what they want, but the family would not agree with them, and I think it's the biggest problem when they are in such a conflict."

Ns.5 "I think families are really distressed by how to relate to the patients, and I think that makes them avoid the patients themselves."

• [Families with concerns due to prolonged hospitalization or uncertainty of the future]

Definition: Families that have concerns about the inability to visit frequently, being unable to respond to the patient's needs, a vague feeling of anxiety, or uncertainty of the future of the patients.

Ns.2 "Mm, it's usually all right for families who live close by, but families of patients who come to be hospitalized from far away are also traveling from far away to see them, so I feel that it can be a big burden for them as well."

Ns.8 "...yes, I think so. I think they're worried about their children's future, particularly about such young patients."

• [Problematic (*i.e.* difficult to interact) families]

Definition: Types of families in which nurse recognizes problematic (*i.e.* families that are difficult to interact with).

Ns.2 "And, they (families) often change their attitudes, don't they?"

Ns.4 "For the patients themselves it's normal, but for the family...well, they can have a role in the patients' development processes in various circumstances, for example, some families pampering the patients, or neglecting them..."

Ns.12 "Well, it's true that sometimes the parents are a little eccentric as well...and there were many families that didn't want their family matters to be pointed out...yes, there have been many cases like this. So they refuse to listen to us at all..."

• [Families not capable of interacting with the patients effectively]

Definition: Families showing unreasonable responses that can negatively affect the patients.

Ns.6 "When I hear from families that they withheld medication from the patient because the patient didn't eat a meal, I think that they really need to learn more about caring for the patient."

Ns.14 "Sometimes it's really frustrating. Sometimes I wish that they would listen a bit more to the patient,

because the patient may become a little bit more relaxed then. But these families wouldn't listen much to the patient."

• [Families not seeking support proactively]

Definition: Families no seeking support proactively despite the apparent needs for support.

Ns.3 "Sometimes I notice families are in trouble, but they can't reveal it, and they're in trouble, they definitely are, but it seems like they are desensitized to such troubles, so, I try to speak to them in such cases."

Ns.15 "I think that a lot more families just muddle through at home by themselves."

#### 3.4.3. Determination and Ambivalence about the Need for Family Support

Nurses integrated <perceptions of a diverse image of the families> and <perceptions that were premises for family support>, and made judgements about needs for family support with [determination and ambivalence about the need for family support]. They also took their own experiences, abilities, and need for intervention as a nurse, into consideration.

Definition: Circumstances that nurses might find themselves in trouble judging the need for family support. An attitude of nurses that they link their judgements or circumstances of lack of proactive support to providing support.

Ns.12 "Well, I am a nurse, so I don't know for sure if I can intervene that much (as family support)..."

Ns.5 "I think it's different greatly depending on the age of the nurses or their level of experience. Nurses with more experiences may step in further, so sometimes I leave such intervention to senior nurses. A young nurse may not be convincing for the family...it might be just me, but if the family says, 'what do you know about this?' then there's nothing I can say, so when I need to say something important directly to the family, I ask experienced nurse to do it. That's what I do."

#### 3.4.4. Family Support Practice

When the need was determined through the process of <[determination and ambivalence about the need for family support]>, nurses provided <[family support practice]>. Various types of family support were provided, such as checking the situation when the inpatient spent time at home, providing information regarding to the patient, offering advice when families were in trouble with caring for the patient, or having multidisciplinary conferences. However, such support was provided as <<family support given without sufficient awareness of the nurses that they are supporting families>>.

Definition: Family care provided by nurses

Ns.2 "Well, for patients who have been diagnosed as well, but in most cases the doctors, um, meet the family in the form of disease education as a part of family education...also when setting boundaries (limits), nurses also accompany, like nurse participation in education, and that is one of the ways we provide support.

Ns.4 "I think so, we make clear what we can do or cannot do, otherwise families would be confused."

Ns.8 "In general, when they come to pick the patient up to spend time outside or for spending a night away, I speak to the families a little bit, and that's when I inform them what the patient's life in the ward is like, like a report...."

Ns.11 "Well, I don't provide any specific family support, but in terms of support that I can provide, well, I listen to them, as I assume that families have experienced difficulties. So, I listen to the families' stories carefully and even for just a short period, at least during the hospitalization, families can take some break time. I think it can be a kind of support for them."

Ns.16 "It's just observing the circumstances. And listening to their problems, what to do in a certain situation, or listen to their complaints and so on."

#### 3.4.5. Difficult Experiences in Providing Family Support

Nurses had <difficult experiences in providing family support> through <[family support practice]>. The experiences included difficulties in nursing derived from the patient's disorders such as [difficulties in determining the patients' symptoms], [difficulties in maintaining appropriate distance from the patients], and [conflict between preventing being involved and giving consideration to the feelings of the patients]. Through interactions with the patients and families, nurses experienced [bias of feelings for the patients and feelings that they would like to speak for the patients] and [having a realization that family environment and symptom control closely relate each other]. Nurses also experienced difficulties due to circumstances other than families, such as [different

degree of enthusiasm among nurses] and [support balance with multidisciplinary professionals].

• [Difficulties in determining the patients' symptoms]

Definition: Difficulties experienced in considering to what extent nurses should help, with not knowing if specific behaviors of the patients are due to their characters or symptoms of their disorder.

Ns.7 "Well, you know, you can't just read books to understand this illness. You have to hear it from people who have experienced it a lot. Then you may understand, like, well, it's because of family environment, something like this."

• [Difficulties in maintaining appropriate distance from the patients]

Definition: Difficulties arising between psychological distances that is to construct a relationship of trust with the patient and that is to prevent codependence.

Ns.7 "Yes, that's true. When we keep too much distance, they will think we are not caring for them, but if I get too close, you know...(laugh), sometimes they bring in love letters."

Ns.15 "A little close, but not too close. If you get too close, in the worst case, they may behave violently, so you can't get too close. The determination of distance is difficult, isn't it."

• [Conflict between preventing being involved and giving consideration to the feelings of the patients]

Definition: Circumstances that nurses recognizes the need for interaction being involved in the patients while paying attention not to be involved in the patients' disorders.

Ns.4 "Like being involved, well, it may be unavoidable, though."

Ns.6 "I try not to get involved, but sometimes I get frustrated, well. It's so hard not to be involved."

• [Bias of feelings for the patients and feelings that they would like speak for the patients]

Definition: Nurses' experiences of feelings in which they empathize with the patients and would like to speak for the patients.

Ns.5 "I guess that's one of the roles of the nurse to protect the patient in that way, and I believe there's something that we can say to the family in that sense."

Ns.14 "Arrangement...So that the patient can live a calm, relaxed life."

• [Different degree of enthusiasm among nurses]

Definition: Inadequate information sharing among nurses regarding their perspectives of the families and nursing practice they performed.

Ns.3 "Well, I don't know, to what extent other nurses provide care, I think it depends on each nurse, so I have never shared it with others."

Ns.8: "Some nurses may engage in the support, but I don't, because I don't think it's necessary. Nurses who want to, they can do, but there is not any point pushing ourselves."

• [Support balance with multidisciplinary professionals]

Definition: Nursing experiences in which nurses try not to overplay according to therapeutic measures of the physicians and integrated nursing practice.

Ns.5 "Well, how can I say, I don't think we offer that kind of support very much in this facility. Doctors do it, and we follow what the doctors set as boundaries (limits)."

Ns.7 "Well you know, like having our nose in...it's hard to put our nose in."

• [Family support practice with seeking a more effective way through trial and error]

Definition: Family support that individual nurses provide in their own sense of requirement, as they are unable to respond to diversity of the families.

Ns.11 "Yes, I do say it. At least once a month, I ask families to come see the patient. Well, no particular procedure, but just my own line."

Ns.15 "Well...it's like a trick, it's like what I feel like."

Ns.16 "Really, by trial-and-error."

• [To intentionally refrain from family support]

Definition: Attitude not to provide proactive support to avoid placing additional burden on families and nurses Ns.8 "I don't see families seeking support, so why do we have to? I don't."

Ns.9 "Is BPD an illness? Sometimes I can't help feeling like it's nothing but simply selfishness. I can't play along with their selfishness, and that's also the wish of the family. It doesn't work even if I try to get involved, so I don't think it's necessary."

#### 3.4.6. Contradictory Perspectives of Family Support

There were conflicts between negative feelings toward family support (i.e. [fatigue of the nurses] and [aware-

ness that they are not able to provide effective care for the BPD patients]), and awareness of the needs for support (*i.e.* [expectation for the families having education about specialized knowledge and methods of interacting with the patients, and having time to think together], [expectation for the families to engage with the patients], and [empathy for families and feelings for family support]).

• [Fatigue of the nurses]

Definition: Fatigue of the nurses arising from difficulties in interactions with BPD patients and their families.

Ns.6 "Families often bitterly complain with an aggressive manner. So, if the nurse is like the one who can talk straight in the nurses' station, she'd be fine. But if the one like swallows her emotion over, she may become overwhelmed."

Ns.16 "Hmm, it's tough. Its' very tough for me."

• [Awareness that they are not able to provide effective care for the BPD patients]

Definition: Nurses' awareness of their incapability caused by characteristics of BPD

Ns.1 "Like being pushed around or disturbed, you know, it's hard to have a good impression of the patients, I know it sounds really bad." "No, in fact, I admit I have a hard time with them."

Ns.13 "I am bad at caring for them...Well, I don't like doing so very much. Because I've had quite hard experiences with them."

• [Expectation for the families having education about specialized knowledge and methods of interacting with the patients, and having time to think together]

Definition: Expectation that education of specialized knowledge and methods of interaction, and having time to think together can help families facing the patients.

Ns.2 "Well, I expect understanding of the disorder, and when there's something, like the patient attempted suicide or such episodes, I hope families can face the patient without becoming upset. They usually get very upset."

• [Expectation for the families to engage with the patients]

Definition: Hopes for families being able to face the patient genuinely, rather than solely making successful responses.

Ns.2 "Response, well, becoming a family being able to face the patient is my expectation."

Ns.11 "Instead, when the patient is discharged, you know, families are required to face the patient again."

• [To intentionally refrain from family support] [Empathy for families and feelings for family support]

Definition: Circumstances that nurses feel the need for support through recognizing and understanding difficulties the families face.

Ns.3 "Often families are desensitized, or they cannot express their needs, they have such aspects, which requires some intervention, I guess...I want to reduce their burden, and I think reducing families' burden would have a positive influence on the patients, so I'd like to do so."

#### 3.4.7. Dealing with Difficulties as a Nurse

Having been through <contradictory perspectives of family support> and <difficult experiences in providing family support>, nurses attempted to cope with their own stress by [sharing the feelings among nurses]. They also attempted [establishing the relations of trust with families] to promote better family support. In some cases, they decided [not to provide family support purposely].

• [Sharing the feelings among nurses]

Definition: Circumstances that common understanding and share of feelings can be moral support for nurses Ns.2 "Well, I really value sharing such feelings between staff...I think it's the most important thing."

• [Establishing the relations of trust with families]

Definition: One of the methods to lay out the circumstances for providing family support

Ns.12 "Yes. I tried this (=establishing relationship), after taking a break for a certain period, when I felt that building human relationship with families was becoming possible, or when I was asked for advice at the right moment."

#### 3.4.8. An Awareness of Family Support Required for the Future

The ultimate consequences led to nurses' awareness of family support for the future, and it influenced their <perceptions</pre> that were premises for family support> and <perceptions</pre> of diverse images of the families>.

#### 4. Discussion

This study illustrated the process of family support that nurses provided for families with BPD patients. This was a comprehensive process based on "family support given without sufficient nurses' awareness of the nurses that they are supporting families." In Japan, it is generally recognized is providing care to BPD patients is difficult, and supporting the families of such patients even more challenging. The first step in establishing family support may be a modification of the circumstances in which nurses are not aware that supporting families is also part of their daily practices. Such circumstances are also observed in other care domains with fewer opportunities to interact with families of patients. However in this study, nurses recognized that they are not providing any support, irrespective of the fact that they felt the need for family support through the care process of the patients. Such a false perception may lead to the nurses' sense of inadequacy, and undermine their motivation to subsequently provide family support. Nursing practice is one form of human caring [12], and so is family support. Considering Caritas' ten concepts of caring, such as instilling of faith-hope, development of a helping-trusting, human care relationship, and promotion of transpersonal teaching-learning, inadequate awareness of practicing represents a serious detachment from establishing effective care, with negligible achievement of these concepts.

Determination of need for support, which is based on the presumption of family support and an image of families, directly leads to the family support practice. To facilitate this process, reducing negative factors that can affect the need for family support derived from perceptions for premise, and enhancing an awareness of the need for family support through "perceptions of the image of the family," Are required. As "perceptions of an image of the family" show different images of families such as needing, or not needing care, some cases resulted in the intentional withholding of family support. However, insufficient support services in the community and need for such services have been demonstrated by previous studies. Providers of such support services need education and training for behavioral modification to avoid discrimination, recognize the service recipients' needs, and provide more effective support [13]. By first understanding the circumstances of the families, such as being unable, for example, to disclose their concerns due to a fear of health professionals' negative bias, may lead in turn to meaningful family support. Recent studies indicated that inadequate mother-child interactions could aggravate the transmission of borderline symptoms from mother to child [14], which has been observed in problematic (*i.e.* difficult to interact) families. Therefore, the difficulties in interactions can be seen not only with the patients but also families, resulting in greater challenges to family support than nursing practice focused merely on patients.

In the course of providing family support, difficulties arising among nurses or multidisciplinary professionals, and the patients' disorders, can be exhausting for nurses. The results of this current study suggested that nurses were able to maintain themselves carrying on with their nursing practice by dealing with difficulties as part of the nursing profession. Therefore, change and arrangements of family environment to facilitate implementation of support service are also required [15]. Although perspectives on the management side regarding education and training for nurses were not mentioned in the current study, their enhancement will also be urgent issues. Furthermore, as difficult experiences in providing family support can be factors impeding the family support process, reducing differences in degrees of enthusiasm among nurses and keeping a balance in support with multidisciplinary professionals may facilitate the support process. Recently, multidisciplinary cooperation has been actively promoted in patient support services such as discharge support. However, according to the results of this study, care for the BPD patients revolved mainly around treatment strategies of psychiatrists, and nurses were engaging in the care with careful attention not to overstep the boundaries of their position. In Japan, the Ministry of Health, Welfare and Labour has been promoting team medicine [16] since 2010. Each discipline of professions are expected to fulfill their respective roles by providing support accordingly. Transforming difficulties in the multidisciplinary approach into advantages will be required for providing more effective family support.

#### 5. Conclusion

In this study, 16 nursing professionals having experience in caring for families with a BPD patient were the subjects of semi-structured interviews, thereby clarifying the family support process being provided to such family members. Twenty-six concepts, seven categories and one core category were extracted. At the basis of factors that impeded progress in the family support process was <<Family support given without sufficient awareness of the nurses that they are supporting families>>, making the implementation of <[Family support

practice]> the most important consideration in their nursing practice. Furthermore, <[Determination and ambivalence about the need for family support]> was found to play a direct influence on <[Family support practice]>, and determining the importance of the two stages of <Perceptions that were premises for family support> and <Perceptions of (a diverse image of) families>, may be a precondition for providing such support. However, <Contradictory perspectives of family support> and <Difficult experiences in providing family support> influence these, and appear to result in discouraging nursing professionals from taking a more active role in family intervention. By attaching affirmative meanings to these categories, and by further augmentation of <Dealing with difficulties as a nurse>, it is believed that the family support process to members of families with a BPD patient will be further advanced. Moreover, through the favorable progression of this process, it is believed that cases in which family support is not currently being intentionally provided will be implemented, thereby bringing about quality of life improvements in families with BPD patients.

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#### **Declaration of Conflicting Interests**

The authors declare that they have no competing interests.

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#### **List of Abbreviations**

BPD: borderline personality disorder

M-GTA: modified grounded theory approach

GTA: grounded theory approach

Ns: nurse

PSWs: psychiatric social workers

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### Integration of Health Promotion into Nursing Practice: A Case Study in Pakistan

#### M. A. Vastani<sup>1</sup>, R. Karmalani<sup>2</sup>, P. M. Petrucka<sup>3</sup>

<sup>1</sup>Aga Khan University, Dar es Salaam, Tanzania

Email: muneerah.vastani@aku.edu, rozina.karmalani@aku.edu, pammla.petrucka@usask.ca

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Open Access

#### **Abstract**

The purpose of this study was to understand the concept of health promotion and perceptions related to the integration of health promotion in nursing practice in Pakistan. The study utilized the qualitative single case study approach to explore and describe the concept of health promotion, its significance and ways to integrate health promotion strategies in nursing practice. The data were collected from three different sources; focus group discussion among final year Post-RN BScN students, key informant interviews of practicing nurses, faculty, and MScN students, as well as a document review of the Post-RN BScN curriculum. Data analysis included a content and thematic analysis, yielding four major themes—"Health Promotion as Diverse", "Health Promotion as Necessary", "Health Promotion as Nursing Role", and "Health Promotion as a Strategic Imperative". Further, the findings highlighted the competencies, support mechanisms, and barriers which select nurses faced while integrating the health promotion strategies in practice.

#### **Keywords**

Health Promotion, Pakistan, Nursing, Integration

#### 1. Introduction

According to the Ottawa Charter for Health Promotion (1986), health promotion is a process to help individuals and communities to gain increased control over the health in order to achieve holistic health (*i.e.*, physical, mental, and social-well-being) [1]. Health promotion is critical in addressing population health challenges rooted in social, physical, economic, and political context which require inter-sectoral efforts. There are five main

<sup>&</sup>lt;sup>2</sup>Aga Khan University, Karachi, Pakistan

<sup>&</sup>lt;sup>3</sup>University of Saskatchewan, Saskatoon, Canada and Academics without Borders Volunteer—Aga Khan University, Karachi, Pakistan

health promotion strategies including building healthy public policy, creating supportive environments, strengthening community action, developing personal skills, and reorienting health services. [2] The intent is to achieve empowerment and community development in order to achieve well-being. Through an inclusive approach which focuses on consideration of the determinants of health (such as income and social status, healthy child development, education, etc.) [3]. "Health promotion strategies are aimed at reducing differences in current health status and ensuring equal opportunities and resources to enable all people to achieve their fullest health potential" [1]. The nursing profession, although including health promotion as a core nursing competency, continues to lack a clear definition of health promotion other than to connect it to health education, prevention, counseling/advocacy, and empowerment [4]-[6].

It has been nearly four decades since the health care system of Pakistan formally adopted a Primary Health Care approach to promote health and prevent diseases. The strategy to achieve "Heath for All" was articulated globally at that time. However, this goal has not yet been realized in Pakistan. As one of the top ten most populous countries, Pakistan's people remain challenged by communicable and non-communicable diseases, insufficient health human resources, and a seemingly endless list of indicator failures. There are many contributing factors to this persistent dilemma, such as inadequate basic health care access, lack of education, as well as a range of socio-political issues. Whether one looks to poverty, literacy, or productivity, it is clear that there is a long way to go to achieving this desired end. This paper considers a research project which looked at the perceptions of select registered nurses in furthering the health promotion agenda in Pakistan through integration of health promotion into nursing practice.

Pakistan has an annual population growth rate of 1.59% concomitant with its high birth rate of 25.7/1000 [7]. The level of infant mortality rate is 69/1000 live births, under five mortality is 86/1000 live births, and maternal mortality rates are estimated at 170 per 100,000 live births [8]. One only needs to look at the impacts of insufficient investment in health at 2.8% Gross Domestic Product [9] and 2.4% for education yielding a 54.9% total adult literacy rate (male 66.6% and female 49.4%) [10]. Over one-quarter of the population earns less than one dollar per day—which gravely affects the ability to achieve the goal of "Health for All" [11]. In addition, the poor social status and low literacy is affected by the gender bias, with women often experiencing the realities of differential access to resources resulting in a negative propensity in their health indicators. [12] [13].

In 2012, Pakistan's doctor patient ratio is 1/1000 and nurse patient ratio was 1.50/1000 people [14] [15]. Although there are significant deficits in the availability of access to health providers, there is evidence that these individuals potentiate a positive impact on the health status of their clients, families, and communities.

Many authors [16]-[18] have indicated that health promotion is an area where nurses have a great potential, but have traditionally been absent or silent. An integrative review by Kemppainen, Tossavainen & Turunen [19] affirmed nurses' roles in health promotion as primarily disease prevention and increasingly as promoters of health

In 2004, the Ministry of Health in Pakistan introduced the *National Action Plan for Prevention and Control of Non-communicable Disease and Health Promotion*, which mapped policy and implementation of the first health promotion/public health blueprint [20]. However, there continues to be a lack of evidence of the impacts of this action plan. A literature review, limited to English only articles published between 2010 and 2015, was done using the keywords "Pakistan", and "health promotion". Addition of the keyword "nurs\*" reduced the article capture to less than ten articles, so we proceeded with the wider base. Two databases, Scopus<sup>TM</sup> and Ovid<sup>TM</sup>, were searched yielding 108 and 70 articles respectively. On manual review of the Scopus<sup>TM</sup> search, 28 articles related to maternal, newborn, and child health, 11 related to health promotion interventions, 7 each related to disease specific efforts, smoking, and other (*i.e.*, evaluations, assessments, capacity building activities), and the 48 remaining were non-relevant or outside the search parameters. Only 17 of the 70 articles yielded on the Ovid<sup>TM</sup> search were relevant of which 11 were duplicates from the Scopus findings. Three of the new six articles were intervention based (all on the same project), two were smoking related, and one was conceptual. This clearly demonstrated a significant gap in the literature related to health promotion in Pakistan.

In this study, nurses' concept(s) of health promotion and their perceptions about the significance of integration of health promotion in nursing practice in Pakistan were explored. In addition, the study examined the existing contexts, approaches, opportunities and barriers experienced by select nurses in attempting to integrate health promotion into their practices. Three study questions were posed. What is Pakistani nurses' understanding about the concept of health promotion? Do Pakistani nurses perceive the need for integration of health promotion in nursing practice? How do Pakistani nurses integrate health promotion in nursing practice?

#### 2. Method

This study was a descriptive single case study design. The Aga Khan University School of Nursing (AKUSON) in Karachi was selected as a single case because of its unique leadership role in nursing education and practice in Pakistan. The study would be classified as an instrumental case descriptor which provides initial insights into an issue [21]. Further, the research questions posed align with Yin's conjecture that case studies are the preferred strategy for "how" and "why" questions [22].

Purposive sampling was used with the following inclusion criteria:

- Students must be currently in their final semester of either the Post-RN Bachelor of Science in Nursing (BScN) or Masters of Science in Nursing (MScN) at the AKUSON in Karachi, Pakistan;
- Registered nurses were either employed as registered nurses and graduates from AKUSON, or employed as nursing faculty members and graduates from AKUSON, and
- Providing a voluntary informed written consent.

#### 2.1. Data Collection and Analysis

As suggested by Zucker [23], it is important for multiple and chronological perspectives in a case study. In order to address these elements, the research team utilized three data collection methods; specifically, key informant interviews, focus group discussion, and a brief document review.

In the case of the key informant interviews, eight (8) participants were selected including 2 community health nurses, 2 acute care nurses at the AKU hospital, 2 MScN students at AKUSON, and 2 nursing faculty at AKUSON. All were affiliated with the AKUSON as graduates of the Post-RN BScN programme. The interviewer used a prepared guide which included eleven semi-structured questions used in each of the one on one interviews. All interviews were tape recorded and transcribed by the principal researcher. The average length of interview was 45 to 60 minutes.

In the case of the focus group discussion, participants included nine (9) final year Post-RN BScN students, representing half the cohort for that year of the program. The focus group discussion was conducted using a fifteen question/prompt guide developed specifically for this project and informed by the extant literature. Again, the session was recorded and transcription was completed by the principal researcher.

In terms of the document review, the elements were the composite parts of the AKUSON Post-RN BScN curriculum. The document review considered 15 course grids of the Post-RN BScN curriculum at AKUSON in order to determine the number of hours committed to health promotion across the program offerings.

Data analysis was primarily content analysis in accordance with Miles and Huberman's [24] steps of data reduction, data display, and conclusion/verification. Specific codes were used to cluster data with emergent categories and sub-categories made obvious. These were then used to generate a series of four over-arching themes. The themes were subsequently reviewed and reflected upon resulting in a tentative interpretation outlining relationships of the themes.

The credibility of the study was supported by an extensive literature review which highlighted extant evidence as well as the gaps in evidence based studies related to this topic. Additionally, the principal researcher's previous involvement in teaching and working in the area of community health and health promotion were integral to the study's credibility. Further, the use of triangulation of the multiple data sources strengthened the study's credibility. Transferability was enhanced through the collection of data from three relevant groups (*i.e.*, nursing students, faculty members, and practicing nurses). In addition, purposive sampling, and a continuous audit trail were imperative to potentiating transferability. Dependability was confirmed by review of transcription notes, cross-checking of emerging codes, as well as reflections and audit trail of the emergent issues/themes emanating from the focus group discussion and key informant interviews. Finally, confirmability was ascertained by the return to the literature to affirm or refute findings and interpretations.

#### 2.2. Ethical Approval

Approval for the study was obtained through the Aga Khan University Ethics Review Committee.

#### 3. Results

The research generated four major themes primarily from the key informant and focus group data. Each theme is

described herein and visualized in **Figure 1**. In addition, as this research progressed, it was made obvious that the participants were struggling to bring health promotion to the forefront of their roles as nurses, whether students, practitioners, or educators.

#### 3.1. Theme One—Health Promotion as Diverse

Across all participants, the term "health promotion" was seemingly synonymous with the word "diverse". Participants spoke of health promotion in terms of diversity in settings, life stage, and level of care. This diversity aspect stressed that health promotion can and should occurred anywhere, with anyone, to address any of their concerns and health needs.

The participants spoke of the importance of an all-encompassing (holistic) approach to health promotion. They envisioned and clarified the definition of health promotion as:

- Promoting and maintaining well-being through lifestyle and environmental change;
- Promoting and maintaining quality of life; and
- Enabling people to become promotive and productive. In the words of one key informant:

Health promotion is enhancing quality of life or taking up some strategies to improve the quality of your living, not physical health only, but enhancing quality of your life as social, physical, emotional, spiritual, and improving living experience as a whole.

#### 3.2. Theme Two—Health Promotion as Necessary

The participants provided a passionate perspective on the imperative for health promotion within the Pakistan context. They emphasized the deficit position of the current context and the desire to move positively towards embedding health promotion for the good of all members of their society.

Through the dialogues, participants indicated that, through health promotion, there would be:

Increased patient's health education/awareness in community

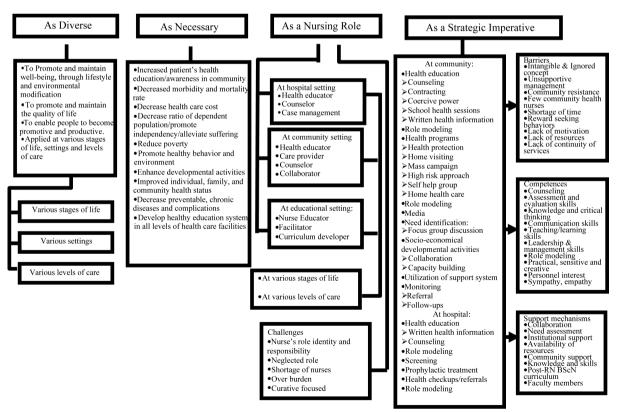


Figure 1. Framework: integration of health promotion in nursing practice.

- Decreased morbidity and mortality rate.
- Reduced health care cost and poverty.
- Increased healthy behaviors and environments.
- Enhanced developmental activities.
- Improved individual, family, and community health status.

Further, one key informant indicated that:

Health promotion is very important in our country than in other countries, as we cannot bear the expenses of illness or diseases. So if there is health promotion, then the financial burden will be less on individual as well as on government.

#### 3.3. Theme Three—Health Promotion as a Nursing Role

Across both groups of informants, it was clearly articulated that nurses have a role and, in fact, are doing health promotion. This sentiment was most strongly voiced by the community nurse participants. Within this theme, participants mentioned the unique presence of nurses in three distinct settings (*i.e.*, hospital, community and educational institutions) where health promotion efforts may (and do) occur. It is noted that the role of health educator and counsellor in relation to health promotion were most commonly mentioned as occurring in hospital and community settings. Other health promotion roles mentioned by setting were case manager (hospital setting), collaborator (community setting), and facilitator (educational setting). This extended role into health promotion is being fostered, according to one participant, through the Post-RN and BScN programs which are introducing health promotion as a foundational nursing role.

In the words of one key informant:

Nurses can play a significant role by connecting the community, education, health, and social development. Therefore, I think a nurse with enhanced understanding about health promotion can play quitedifferent roles in capacity ranging from grassroots level to the consultancy level.

#### 3.4. Theme Four—Health Promotion as a Strategic Imperative

The final theme "Health Promotion as a Strategic Imperative" emerged during the discussion of challenges and opportunities for integrating health promotion into the various nursing settings. The participants mentioned that they were challenged in bringing health promotion to their practices due to shortages of time and staff, as well as a lack of focus on non-curative roles and responsibilities. Essentially, health promotion activities were described as a neglected aspect of the traditionally curative focused nursing environment as highlighted in the following contribution:

In Pakistan, nurses have lot of potentials and abilities to work for health promotion. However, the circumstances such as shortages, technical foci, and demands with the environment make it more difficult for nurses to spend their time in the health promotion activities and with the workload they are carrying at the moment, integrating health promotion is really very difficult.

#### 3.5. Health Promotion: Nursing's Next Frontier?

In the dialogues, there was an energy and momentum to articulate what is needed to facilitate the integration of health promotion into nursing. The emphasis was in two key areas—knowledge/skills/attitudes of practitioners and barriers/facilitators to integration.

#### Knowledge/Skills/Attitudes

It is noted, from the document review, that 14% (272 of 1939 hours) of the Post-RN BScN is devoted to health promotion core content. This knowledge stream may be increased to 26% with the selection of a health promotion senior practicum opportunity by any student.

The participants indicated that, in addition, to core nursing knowledge, there are a number of competencies necessary to the integration of health promotion strategies within nursing practice. Amongst those mentioned were:

- Assessment and evaluation skills.
- · Counseling skills.
- Critical thinking.

- Communication skills.
- Teaching/learning skills.
- · Leadership/management skills and
- Role modeling.

Through the dialogues and document reviews, a number of attitudinal attributes were revealed as important to the integration of health promotion into nursing practice including:

- Being practical.
- Sensitivity (including sympathy and empathy).
- Creativity.
- Demonstrating personal interest.
- Motivation and
- Respectfulness.

#### **Barriers** and Facilitators

The participants shared their perceptions on the barriers and facilitators to integration of health promotion into their nursing practices.

One of the most common challenges faced was that health promotion is intangible and an often ignored concept not only by the public but also by the health professional team and policy makers. The most common **barriers** experienced while integrating health promotion strategies, according to the participants, included:

- Unsupportive management.
- Community resistance.
- Lack of community health nurses.
- Unmet expectations.
- Shortage of time.
- Reward seeking behaviors.
- Lack of motivation, resources and utilization and
- Limited continuity of services.

Conversely, the participants spoke of a number of facilitative elements which foster the integration of health promotion strategies into their practices. The most common **facilitators** discussed included:

- Collaboration.
- Availability of information and resources.
- Institutional and community support.
- Nursing knowledge and skills.
- Post-RN BScN curriculum and
- Support of faculty members.

#### 4. Discussion

There was extensive and passionate discussion by all participants with respect to how best to integrate nursing's presence in health promotion in Pakistan which resulted in articulation of essential nursing knowledge/skills/ attitudes as well barriers and facilitators to this progression. In addition, the findings were reviewed in relation to existing evidence.

#### 4.1. Synthesis

The first theme of "Health Promotion as Diverse" is clearly reflected in other documents, such as the Northern Territory Department of Health [25] which emphasized that, at its essence, health promotion provides "supportive social, economic, and physical environment through diverse but complementary strategies and works in collaboration with a wide range of sectors" to empower individuals and populations to achieve their health needs under the rubric of the social determinants of health.

In relation to the second theme—Health Promotion as Necessary, there is significant alignment with many authors who speak of the benefits of health promotion's upstream approach which averts future health costs, improves overall health and well-being while minimizing loss of social capital to a society by reducing the burden of chronic diseases and addressing health inequities [26]-[29].

Moving forward with "Health Promotion as a Nursing Role" is reflected by Chiverton, Votava, and Tortoret-

ti's comment that "nurses in education, practice, and research settings can participate in the advancement of health promotion not only to the mainstream but to the forefront of nursing practice" [30].

Both key informant and focus group participants mentioned their understanding of the potential for nursing to undertake a more significant role in health promotion especially citing their awareness of the socio-economic determinants and community development capacities. The common strategies for health promotion in nursing practice mentioned by participants, regardless of setting, were health education, role modeling, and preventive measures. Overall, the prominent and frequent mentioned strategy reported in both the setting of hospital and community was health education. Of note, it was often acknowledged by the participants that, although as students they were integrating health promotion elements into their nursing care, once they were in practice they seldom integrated such strategies—which clearly indicates a knowledge to practice inconsistency.

According to the Council on Linkages between Academia and Public Health Practice [31], there are eight domains of competencies including analytical/assessment skills, policy development/program planning skills, communication skills, cultural competency skills, community dimensions of practices skills, public health science skills, financial planning and management skills, and leadership and systems thinking skills. There is close alignment of these domains with the knowledge, skills, and abilities outlined by the participants and extracted from the documents. Of note, aside from the public health science skills, and specifics such as financial planning systems thinking skills, the lists are highly synergistic.

#### 4.2. Study Limitations

This is a single site, cross-sectional study with a limited number of participants. As stated by Merriam [32], findings of a case study are a part of a reality, so generalizations must be interpreted cautiously. Further, the AKUSON is a private university, a part of the Aga Khan Development Network, which may impact the student and alumni perspectives and practice values.

#### 4.3. Summary

In reflecting on the four themes outline, it became apparent that they were inextricably linked to each other. As a result, a tentative framework (Figure 1) reflected the potential inter-relatedness of the themes as a way to integrate health promotion in nursing in Pakistan. The framework is an attempt to reconstruct the participants' understandings of the context in which they are providing care. It presents the essential elements of a guiding framework to embedding health promotion in a variety of nursing settings. The framework potentially highlights the theoretical and conceptual aspects necessary to integrate health promotion for nurses as well as provides insights into the essential knowledge, skills, and abilities as well as environmental barriers and facilitators to achievement of such integration. It succinctly depicts these key elements, their relationships and inter-relationships, and suggests a systematic way forward.

#### 5. Conclusion

This study contributes to the evidence regarding health promotion and nursing in Pakistan, a topic which has enjoyed limited consideration in the literature. Four themes—Health Promotion as Diverse, Health Promotion as Necessary, Health Promotion as a Nursing Role, and Health Promotion as a Strategic Imperative—were derived from a series of key informant interviews and a focus group. Together with the participants' contributions on the knowledge/skills/attitudes and barriers and facilitators to integration of health promotion in nursing, a tentative framework was presented.

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#### **Abbreviations**

AKU Aga Khan University

AKUSON Aga Khan University School of Nursing

BScN Bachelor of Science of Nursing MScN Master of Science of Nursing

Post-RN Postgraduate Studies for Registered Nurses



## Comparison Study of Art Therapy and Play Therapy in Reducing Anxiety on Pre-School Children Who Experience Hospitalization

#### Sri Ramdaniati, Susy Hermaningsih, Muryati

Nursing Department of Bandung Health Polytechnic, Ministry of Health, Bandung, Indonesia Email: sri.ramdaniati@yahoo.com

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#### **Abstract**

Pain and hospitalization caused a crisis in the child's life. At the pre-school children, the stress of the disease makes children become less able to cope with separation. As a result, many children show anxious behavior though more vague than toddler age children. Various ways have been conducted by nurses to treat anxiety in children, but the most effective types of the intervention have not be found. Types of intervention that can be done are art therapy and play therapy. This study aims to compare the effects of art therapy and play therapy in reducing anxiety on children who experience hospitalization. A quasi-experimental research design with pre-post test two group design is used. The sample was 23 children pre-school age for art therapy group and 25 children for play therapy with sampling techniques performed purposive sampling. Intervention of art therapy and play therapy each performed for 3 days with duration about 30 minutes. Anxiety levels before and after the intervention were measured by using the facial affective scale. The results show that there is a difference in anxiety between before and after the action in the art therapy group (p = 0.00) and that there are differences in anxiety before and after the action in the play therapy group (0.00). But statistical tests using Man Whitney U indicate that there is no difference in anxiety levels in pre-school children who do art therapy and play therapy (p = 0.26). So, it is concluded that the art therapy and the play therapy can reduce the level of anxiety on pre-school school children that experience hospitalization. Based on these conclusions, it is recommended that the art therapy and the play therapy can be used by nurses and the choice of the intervention should be submitted to the child.

#### **Keywords**

Art Therapy, Play Therapy, Pre-School Children, Hospitalization

#### 1. Introduction

Hospitalization is a process for reasons of planning or emergency that requires the child to stay in the hospital in order to undergo treatment and medication. Nevertheless, hospitalization remains a major problem and causes anxiety and fear in children [1]. Hospitalization can also cause stress for children related to the change of environment and the status of their health. According to Hockenberry, Wilson and Winkelstein [2], the main thing that can cause stress on the process of hospitalization is the separation of parents, loss of control, and fear of bodily injury and pain. In addition to stress, hospitalization also causes fear and anxiety in children aged 4 - 6 years [3]. If anxiety in children is not addressed, it will result in withdrawal and rejection of the implementation of the medical or nursing action, the length of stay and increase of the severity of health conditions [4].

Various interventions can be done by nurses and parents to overcome anxiety and fear in children, such as creating a pleasant atmosphere, providing support, and giving explanation [5]. Research by Ramdaniati & Setiawan [6] explains that the play can reduce fear in children. In addition to playing, art therapy is a collection of therapeutic approaches that involve the creative arts. Art therapy programs vary and may include aspect of drawing, painting, photography, sculpture, dancing, creative writing and storytelling [7]. Some research suggests that stress and fear in children can be reduced with the use of the method of drawing [8]. Rollins [9] explains that drawing helps children communicate his experience so as to reduce stress and anxiety. Play therapy is the use of play as a therapy used to reduce distress, and fear in children [10]. According to Armstrong [11], playing for children is not a sheer pleasure, but it is a way to express the anxiety and fear of a situation so clear that any type of game is granted. Decreasing fear and anxiety is meaningful. This study aims to compare the art therapy with the play therapy in reducing anxiety on preschool children who experience hospitalization.

#### 2. Methods

A quasi-experimental pretest-posttest two group design was initiated during 3 month period ending 8 October 2015 with a sample size of 48 children pre-school age for both treatment groups. Samples are taken by purposive sampling of pre-school age children who are being hospitalized in Al Islam Bandung Hospital. Inclusion criteria were aged from 3 - 6 years old, the first day of hospitalized and having compos mentis counciosness and the exlusion criteria were children who had limited motion in the upper extremity (not able to move right and left hands to draw or play a puzzle) and children who are pain.

The study was approved by ethical commission of Bandung Health Polytechnic and before the enrolment of this study, the parents received verbal information about the research including procedure, benefit and also gave written informed consent to participate in the study. The research process begins with the selection of the appropriate sample inclusion criteria, then the children are grouped into 2 groups of interventions based on their own choices, namely drawing (art therapy) and puzzles (play therapy). Furthermore, researchers take measurements of anxiety before the intervention using the modified facial affective scale [12] consisting of four images of the face, then intervention for 15 - 30 minutes in a 3-day, after that researcher taking second measurement for identified anxiety level after the intervention. The data collected is then processed and analyzed gradually ranging from univariate continued with bivariate. Univariate analysis using frequency distribution and proportion, while bivariate analysis using wilxocon test for each group and Man Whitney U for measurements both treatment groups with statistical significance difference or p value below 0.05.

#### 3. Result

Based on **Table 1**, it can be seen that the average age of children who are respondents in this study is 4.21 years to 4.40 years, with the same age range between 3 to 6 years in accordance with the criteria inclusion that has been set.

Table 2 shows that more than half of the respondents in this group are male and have never been hospitalized.

**Table 3** shows that in group play therapy, more than half respondents are male and have never had the experience to be hospitalized.

**Table 4** shows that in the group art therapy, children's anxiety levels before treatment are subjected to severe anxiety (43.5%), followed by moderate anxiety (34.8%) and mild anxiety (21.7%) and none of the respondents who do not experience anxiety. While at the time after treatment, more than half do not experience anxiety and

Table 1. Frequency distribution of respondent age at the play therapy and art therapy group (n = 48).

Characteristics Age	Mean	SD	Min-Max
Group Art Therapy	4.21	0.99	3.0 to 6.0
Group Play Therapy	4.40	1.08	3.0 to 6.0

**Table 2.** Frequency distribution of respondents characteristics at the art therapy group (n = 23).

Characteristics	F	%
Gender		
Gender Male	14	60.9
Female	9	39.1
Treated experience		
Ever	10	43.5
Has never been	13	56.5

**Table 3.** Frequency distribution of respondent characteristics at the play therapy group (n = 25).

Characteristics	F	%
Gender		
Gender Male	14	56
Female	11	44
<u>Treated experience</u>		
Ever	7	28
Has never been	18	72

**Table 4.** Frequency distribution of anxiety levels before and after treatment at the art therapy group (n = 23).

Anxiety levels										
No.	Intervention	Not a	anxiety	Mild	Mild anxiety n		moderate anxiety		Severe anxiety	
		F	%	F	%	f	%	f	%	Total
1.	Before	0	0.0	5	21.7	8	34.8	10	43.5	23
2.	After	12	52.2	8	34.8	3	13.0	0	0.0	23

none of the respondents who experienced severe anxiety.

Based on **Table 5** can be seen that the play therapy group obtained the data that is currently before the treatment more than half of respondents (52%) had moderate anxiety and no one responden who do not experience anxiety. At the time after treatment, most do not experience anxiety and no one responden experiencing moderate and severe anxiety.

**Table 6** shows that, based on analysis by using wilxocon test showed significant differences (p < 0.05) between anxiety before and after the action in each group play therapy and art therapy group.

Results of the analysis in **Table 7** shows that the statistical test p value > 0.05, which means that at 5% alpha there is no significant difference between the level of anxiety in the *play therapy* and *art therapy* group by using *Man Whitney U Test*.

#### 4. Discussion

Anxiety is a condition that is often found in children who undergo hospitalization. Almost at every stage of development of the child's age, anxiety and fear due to hospitalization is still a major problem in nursing services subsidiary as disclosed by Ambarwati [13] that hospitalization can cause stress and anxiety at all age levels. For preschool children hospitalization is a frightening experience [14] and Ramdaniati [15] also explained that 53% of pre-school age children who are undergoing hospitalization experience fear.

Various efforts have been made by caregivers to overcome the problems that arise as a result of hospitaliza-

**Table 5.** Levels of anxiety before and after treatment at the play therapy group (n = 25).

Anxiety levels										
No.	Intervention	Not w	orried	Mild	anxiety	moderate	e anxiety	Severe	anxiety	
		F	%	F	%	f	%	f	%	Total
1.	Before	0	0.0	8	32.0	13	52.0	4	16.0	25
2.	After	16	64.0	9	36.0	0	0.0	0	0.0	25

Table 6. Distibution of anxiety levels before and after treatment at the group play therapy and art therapy.

Variables	Mean Rank	P Value	n
Group <i>Play Therapy</i> Pre Intervention Post Intervention	12.5	0.00	25
Group Art Therapy Pre Intervention Post Intervention	12.0	0.00	23

Table 7. Differences anxiety levels at the play therapy and art therapy group.

Variables	Mean Rank	p Value	n
Play Therapy Art Therapy	22.60 26.57	0.26	48

tion. One of the nursing actions to reduce the impact of hospitalization is playing. For children, play is a routine job. Playing is an activity that is done voluntarily and there is no coercion or pressure from outside or liabilities [16]. Play is a reflection of the ability of physical, intellectual, emotional and social and play a good medium for learning because the children can speak (communicate), learn to adapt to the environment, and do what can be done [17]. Play can be carried by healthy or sick children. Although the child was ill, but there remains a need for play [18].

Games consists of various types and kinds, depending on which side of judgment. In this study, researchers tried to compare the effects between the two games is *play therapy* and *art therapy* in reducing anxiety in preschool children. *Play therapy* is done using a puzzle as media and *art therapy* for children were asked to draw what she likes in a picture book provided. Selection of the type of game based on the child's own choice. Children choose the type of game he likes. Games that like by the child makes the child feel good about the game, while if the child does not like his game then the child will not enjoy the game.

Based on the results listed in **Table 5** in the previous section, the results of the univariate analysis in *play therapy* showed that 52% of pre-school children experiencing moderate anxiety at the moment before the game, followed by mild anxiety and no anxiety as much as 32% and as much as 16%. This condition is changed after the intervention in the form of puzzles for 30 minutes for 3 days. Most children (64%) had not experienced anxiety and the rest (36%) experienced only mild anxiety. Then performed bivariate analysis to compare the changes that occur. Results of the analysis in **Table 6** in the previous section shows that *the play therapy* with the use of the puzzle has significant value <0.05 at alpha of 0.05. This means that the play therapy by using puzzles can reduce anxiety levels pre-school age children significantly. The results are consistent with research conducted by Kaluas, Ismanto and Kundre [19] which states that playing puzzle and storytelling can reduce anxiety preschool children who experienced hospitalization at the hospital. Another study also had the same result is research de Breving, Ismanto and Onibala [20] which uses the game as well as *an ice cube* as one action *atraumatic care* in children aged 1 - 14 years who experience anxiety. Research results by Hela and Tjahyono [21] in the RS. William Booth Surabaya also support the conclusion that this research through play therapy affect the child's anxiety level with a significance value of 0.00.

In addition to viewing of the play therapy using puzzzle, this study also looked at the effects of art therapy against anxiety pre-school children. Drawing is a form of art therapy are performed as one of the interventions in

this study in order to reduce the level of anxiety in the pre-school age children who experience hospitalization. Results of univariate analysis of the results of this group showed that at the time before the intervention, almost half of the respondents had a severe anxiety, followed by moderate and mild anxiety and no one who does not experience anxiety. This condition changed when measurement after intervention demonstrated that no one is experiencing severe levels of anxiety. From the tables can be seen that in descriptive, art therapy can reduce anxiety levels of children. Furthermore, after the bivariate analysis using the *Wilcoxon test* to compare the conditions before and after the act of art therapy showed that the 0.00 significance value which gives the sense that art therapy can reduce anxiety levels significantly in pre-school age children.

The result of this are in line with research Wowiling, Ismanto and Babakal [22] and Pravitasari and Warsito [23] which uses coloring techniques as a form of art therapy that is performed at pre-school age children in order to reduce anxiety. In the study it was obtained *p value* of 0.00 which means that the art therapy influence on the anxiety level of pre-school children. Coloring technique drawing on research conducted by Kapti, Ahsan and Istiqomah [24] is also a positive effect on maladaptive behavior of children who experience hospitalization. Meaningfulness use art therapy to reduce children's anxiety in this study are not always in line with the results of previous studies. Purwandari's research [25] explained that the art therapy does not give effect to decrease the level of anxiety in school children but are effective in lowering the pulse rate is one of the physiological response of anxiety. This distinction is made possible because of differences in the age of respondents, where the research Purwandari respondents are school-age children in the 6 - 12 year range, while respondents in this study were pre-school children who still have high levels of anxiety.

The results of the study mentioned above can be analyzed that the drawing as a form of art therapy performed capable of being distractor, expressive space for children as well as a medium of communication that is able to describe the condition of children's anxiety during hospitalization. Besides drawing or coloring can reduce tension, it also giving a relaxing effect on the body and can provide emotional stimuli in the limbic system that occurs in the hypothalamic control of maladaptive behavior, including anxiety responses. Although obviously not be denied the possibility of the influence of the presence of a parent or other factors that contribute simultaneously reduce anxiety in children.

Table 8. Advantages and disadvantages of art therapy and play therapy.

#### Advantages Disadvantages Materials cost money and must be managed. Performed capable of being distractor Requires an appropriate setting, especially for fluid Expressive space for children as well as a medium of communication that is able to describe the condition of Some populations (e.g., older adults) may not see the children's anxiety during hospitalization relevance of artwork to their problem Can reduce tension Requires more planning to incorporate into Also giving a relaxing effect on the body information-giving or highly directive counseling modes Can provide emotional stimuli in the limbic system that It can not increase ability to explore and practise Art Therapy occurs in the hypothalamic control of maladaptive children's social skills It can not help children to make friends and learn about Therapeutic in itself because client gives symbolic their ever expanding world shape and form to feelings Can serve to express fears which children find too frightening to talk abou An active therapy-clients regain sense of control over healing Play therapy can be seen as a distraction to the actual It provides a safe space for emotional expression problem. helping to empower the child and learn how to express This type of therapy has positive short term effects, but their thoughts and feelings in constructive ways it may be harder for the abuse victim later on in life. The It fosters decision-making and acceptance of victim may suppress the abuse using play therapy but responsibility eventually the memories will come back as they grow It facilitates the development of problem-solving, older (not always, but more often than not) Play Therapy coping skills and resilience expanding the awareness and self-esteem and increase the relationship of trust between the patient and health It encourages confidence and concentration It fosters imagination and creativity It supports emotional healing and growth

In both groups can be seen that at the time before treatment mostly mild to severe anxiety but at the time after the action mostly do not experience anxiety and only a few are experiencing anxiety was, in fact none had severe anxiety. It shows that both therapies together can reduce anxiety in children who are experiencing hospitalization. But when seen from the results of the bivariate analysis in **Table 7** can be explained that the value of significance (p value) obtained is 0.26 or greater than 0.05. This means that there is no significant difference in anxiety levels between the use of art therapy and play therapy in reducing anxiety on pre-school children. Nevertheless, basically the second game can be given to pre-school age children who experience anxiety. Selection of the type of therapy that should be given not based on the opinions of nurses but should be based on the child's favorite, so that they will enjoy the play.

Playing for a child is a necessity. The importance of play, playing techniques as well as efforts to divert attention is to be understood by every nurse. Play can be a psychological preparation efforts for children in the face of a disease that happened and help the process of coping confront actions that will be undertaken. The right play can reduce misunderstanding and fear of child, helping to empower the child, expanding the awareness and self-esteem and increase the relationship of trust between the patient and health care workers [26]. Based on the explanation above and some references [27], art therapy and play therapy have some advantages and disadvantages will show in **Table 8**.

#### 5. Conclusions & Suggestions

The conclusions that can be drawn from this study are: 1) There is a significant difference in anxiety between before and after the action in the art therapy group; 2) There is a significant difference in anxiety between before and after the action in the play therapy group and 3) There are no significant differences in anxiety in pre-school age children in the art therapy group and the play therapy group.

Based on the above conclusion, nurses who work in the children units can use drawing (art therapy) and puzzles (play therapy) to reduce anxiety in pre-school children who experience hospitalization. The type of the therapy is best left to children to choose to have broad opportunities to express.

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## Quantitative Analysis of Nursing Observation Employing a Portable Eye-Tracker

#### Norie Suetsugu<sup>1\*</sup>, Masafumi Ohki<sup>2</sup>, Tsunehisa Kaku<sup>2</sup>

<sup>1</sup>Department of Nursing, Faculty of Medicine, Saga University, Saga, Japan

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#### **Abstract**

Background: Observation is an important skill for making appropriate nursing decisions and engaging in good practice. However, experts' observation behavior and cognitive processes cannot be easily verbalized or documented in an objective and accurate manner. Quantitative analysis of the observation behavior of nurses with rich clinical experience will yield effective educational data for fostering and improving nursing students' observation skills. Objectives: To improve nursing assessment education, the differences in the information gathering processes between clinical nurses and nursing students were analyzed by using a portable eye-tracker. Design: An experimental study. Settings: The experiment was performed at a university in Japan. Participants: The participants were 11 clinical nurses with at least 5 years of clinical experience for postoperative patients, and 10 fourth-year nursing students. Methods: In a mock hospital room, wherein we recreated a situation where a patient in postoperative day 1 was confined to a bed, participants wore an eye-tracking camera and engaged in nursing observation to make an early postoperative ambulation assessment of the patient. Participants' gaze points and gaze fixation durations were extracted from the gaze measurement data and compared. Results: Clinical nurses had shorter observation times and gaze durations than did nursing students, and focused more on the patient chart, intravenous drip, and indwelling drain. Students gazed for longest at the measuring devices for vital signs. Conclusions: We quantitatively analyzed differences in nursing observation according to clinical experience. Although no significant difference was found in gaze points, nursing students had a greater tendency to focus on information that was numerically displayed. Nurses with clinical experience conducted observations by gazing at information that they needed to focus on the most according to the patients' postoperative course.

<sup>&</sup>lt;sup>2</sup>Department of Health Sciences, Graduate School of Medical Sciences, Kyushu University, Fukuoka, Japan Email: \*sue43@cc.saga-u.ac.jp, ohki@med.kyushu-u.ac.jp, kakut@med.kyushu-u.ac.jp

<sup>\*</sup>Corresponding author.

#### **Keywords**

Nursing Observation, Eye-Tracker, Postoperative Ambulation Assessment, Quantitative Analysis

#### 1. Introduction

Observation is an important skill for making appropriate nursing decisions and engaging in good nursing practice. Nurses' observational skills are attained and refined through accumulating clinical experience. There are two primary paradigms in expertise research: analyzing the technical characteristics of experts with abundant experience, and comparing the technical characteristics of experts and non-experts. Even in the nursing field, there are many studies involving interviews with skilled nurses and analyzing subjective data in order to elucidate such nurses' clinical decision-making process. However, experts' observation behavior and cognitive processes cannot be easily verbalized or documented in an objective and accurate manner. Observation is an action conducted through the five senses. For humans, out of the five senses, most information is gathered via the sense of sight. For instance, gaze is used for selectively gathering information [1]. As such, gaze measurement methods using eye-tracking cameras are believed to be effective means of obtaining detailed and objective assessments of human behavior or decision-making processes. From the late 1970s onward, research studies employing eye-tracking instruments have been conducted in the fields of cognitive psychology, pedagogy, and human engineering in order to elucidate the characteristics and decision-making processes involved in linguistic acquisition, ocular movement while driving, and visual searches of skilled technicians [2]-[5]. In recent years, it has become easier to measure ocular movements via miniature, lightweight mobile eye-tracking cameras that do not restrict observers' behavior [6]. From the 1990s onward, nursing studies have determined the efficacy of ocular counter-rolling instruments in the analysis of behavior to prevent accidents during drug administration and in providing feedback during simulation education in emergency nursing [7] [8]. However, there appears to be no similar studies on nurse expertise. This led us to the notion of quantitatively analyzing observational skills, which are fundamental to nursing practice, by tracking nurses' gazes in a setting that involves making nursing judgments. This would allow us to clarify the differences in observation skills between expert and novice nurses. In order to elucidate experts' visual search patterns, it would be desirable to employ an experimental setting that resembles the actual nursing practice environment. Employing eye-tracking instruments would enable us to objectively identify the characteristics of observational skills and compare them among different levels of clinical experience. This would involve measuring a series of nurse observation behaviors with an eye-tracking camera equipped while nurses act freely in an environment simulating a clinical setting.

This study aimed to determine the difference in nursing observation characteristics depending on the existence of clinical experience. Specifically, we compared the eye-tracking data of clinical nurses (experts) and nursing students (novices) during nursing observation to make an early postoperative ambulation assessment of a postoperative day 1 patient. Quantitatively analyzing the observation behavior of nurses with rich clinical experience will yield effective educational data for fostering and improving nursing students' observation skills.

#### 2. Methods

#### 2.1 Participants

Clinical nurses selected as participants for this study were at least level 4 (proficient) or higher according to Benner's 5-stage nursing skill levels [9]. The participants for this study were 12 nurses that worked at a university hospital and who had 5 or more years of clinical experience, of which 3 or more years were in the surgical field. The average clinical experience of nurses was 10.6 years (range: 6 - 25 years). Nursing students comprised 11 fourth-year university students (average age: 21 years) who had engaged in surgical nursing practice within their fundamental nursing education. All study participants provided informed consent, and each one signed for approval at this study. The study design was also approved by ethics review boards of Saga University and Kyushu University.

#### 2.2. Eye-Tracker

For gaze measurement, we used the Talk Eye Lite eye tracker, manufactured by Takei Scientific Instruments Co.,

Ltd. This device comprises a goggle-type eye-tracking camera and miniature lightweight control unit worn on the waist and utilizes a computer to record data. The ocular movement measurement mechanism involves a central pupillary image processing method wherein weak infrared rays are cast at the cornea to generate a reflected image of the light source, and the location of this image is then detected. The sampling frequency is 30 Hz, with the angle detection being 50 degrees horizontally and 20 degrees vertically. The data items detected are the direction of the gaze, gaze duration, gaze movement speed, pupil diameter, and the presence of blinking. It has been found that wearing glasses or soft contact lenses has virtually no impact on measurement.

#### 2.3. Simulation of Nursing Observation

In a mock hospital room that recreated the situation of a patient being confined to a bed, clinical nurses and nursing students were asked to engage in observation to make an ambulation assessment of a patient in post-operative day 1.

Patient was played by the simulated patient who had received training. The vital signs of the patient actor were measured immediately before the experiment and it was confirmed that they showed no health abnormalities. Patients were instructed to not speak to the nurses or students during the observation experiment save to answer questions simply and exhibit anguished expressions as if in pain.

**Figure 1** shows a participant equipped with an eye-tracking camera conducting a nursing observation. The simulated situation involved a patient recovering from a video-assisted thoracic surgery on right lung conducted the previous day; the patient was confined to the bed and was awake. Patients received oxygen via a mask, continuous intravenous drip infusion, and continuous intravenous infusion of epidural anesthesia. An indwelling urinary catheter was implanted in the patient's body while a thoracostomy tube was implanted in the patient's right thorax. The thoracostomy tube was attached to continuous low-pressure suction units and was in the process of drainage during the observation period. The mock hospital room had the patient's postoperative course record, and there was blood within the drain bag and urine in the urine drainage bag; devices displayed vital signs and emission volume indicating gradual recovery.

Participants were presented with the patient record, including the surgery performed before the experiment, both in writing and verbally. Participants entered the mock hospital room after being equipped with the goggle-type eye-tracking camera and undergoing equipment calibration to ensure that it accurately recorded their gazes. The tracking and recording of participants' ocular movement using the eye-tracking camera commenced as soon as they entered the room. No time restriction for making the ambulation assessment was given; the observation was regarded as complete when the participant gave their judgment.



Figure 1. Simulation of nursing observation.

#### 2.4. Data Analysis

A gaze was defined as a state in which a line of sight was sustained for over 150 milliseconds with the ocular movement angle change being less than 5 degrees per second. After the completion of the observation, the gaze points and the total gaze duration of these points were calculated from the eye-tracking data of clinical nurses and nurse students. The difference in gaze duration between nurses and students was compared with the Mann-Whitney U test using the statistical analysis software JMP (ver. 11). The p-value less than 5% was considered statistically significant.

#### 3. Results

Since obvious measurement errors were found in the data of one clinical nurse and one nursing student, these two participants were excluded from further analysis. Thus, the results of 11 nurses and 10 students were analyzed. Nurses and students that completed the nursing observation all determined that the patient could leave the bed. The average and one standard deviation of observation time required to complete the assessment was 7 mins 21 secs  $\pm$  1 min 59 secs for nurses and 13 mins 48 secs  $\pm$  5 min 3 secs for students. Students spent a significantly longer time (p < 0.001).

**Figure 2** shows the differences in gaze points and gaze movement between students and nurses when inspecting patients' faces. The students tended to gaze at the periphery of gaze points (e.g., the patient's face) by slightly changing the position of their gaze and showed considerable gaze movement. Meanwhile, nurses showed fewer gaze points and less gaze movement.

We extracted the points at which one participant gazed at least from the beginning to the end of the observation period, revealing 18 gaze points overall as shown in **Table 1**. These points were the *patient's face*, *chest*, body (except chest), clinical thermometer, manometer, stethoscope, pulse oximeter, wristwatch, patient chart, memo pad, gauze bandage, indwelling drain, continuous aspirator, intravenous drip, epidural anesthesia kit, urine bag, bed, and bedding.

**Figure 3** shows a comparison of nurses and students in the percentage of participants who gazed at each point. The points at which over 50% of both nurses and students gazed were the *face*, *stethoscope*, *manometer*, and *pulse oximeter*. The points at which there were twice as many or more nurses than students gazing were the *patient record*, *intravenous drip*, and *indwelling drain*. Conversely, the points for which the percentage of students was twice or more that of the nurses were *the body* (*except chest*), *clinical thermometer*, *wristwatch*, *memo pad*, and *bed*. Notably, none of the nurses gazed at the *wristwatch* while 7 out of 10 students did.

Figure 4 shows a comparison of gaze duration at each point between nurses and students using box plots. The white lines in the boxes are the median values while the lower and upper limits represent minimum and maximum values, respectively. The points at which we noted statistically significant differences in gaze duration between nurses and students were the *body* (*except chest*) (p = 0.048) and the *memo pad* (p = 0.003). At both points, the gaze duration of the students was longer. For *wristwatch*, one student gazed at it at most for 23 seconds. Although no statistically significant difference was found, the points at which the average gaze duration of the nurses was longer than was that of the students by three times or more were *patient record*, *intravenous* 



Figure 2. Gaze points and eye movements (a) Nursing student's view, (b) clinical nurse's view. Dots and lines represent gaze points and eye movements, respectively.

Table 1. Gaze points and durations.

Gaze	Gaza point		age gazed %)	_	ze duration ec)	Maximum gaze duration (sec)		Average gaze duration (sec)		
object	F	Nurse student		Nurse	Nurse student		Nurse student		Nurse student	
	Face	73	100	1.7	1.5	4.3	8.0	1.59	2.04	
Patient	Chest	27	30	0.0	0.0	0.3	13.5	0.06	1.40	
	Body (except chest)	18	60	0.0	0.3	0.8	1.4	0.09	0.39	
	Clinical thermometer	18	40	0.0	0.0	0.4	2.6	0.07	0.39	
	Stethoscope	64	90	0.5	1.1	7.9	3.3	1.53	1.45	
Devices	Manometer	91	90	3.1	0.7	5.9	13.3	2.78	2.72	
	Pulse oximeter	82	70	0.6	1.1	5.9	9.5	0.97	2.41	
	Wristwatch	0	70	0.0	1.3	0.0	23.2	0.00	4.64	
	Patient chart	36	10	0.0	0.0	1.5	0.2	0.20	0.02	
Records	Memo pad	27	80	0.0	1.0	0.4	10.0	0.07	2.38	
	Intravenous drip	36	10	0.0	0.0	0.2	0.2	0.06	0.02	
	Gauze bandage	9	20	0.0	0.0	0.2	0.2	0.02	0.04	
	Indwelling drain	45	10	0.0	0.0	1.1	0.2	0.16	0.02	
Catheters	Continuous aspirator	27	40	0.0	0.0	0.3	1.6	0.06	0.29	
	Epidural anesthesia kit	18	30	0.0	0.0	1.4	0.8	0.23	0.15	
	Urine bag	18	20	0.0	0.0	0.4	1.4	0.06	0.21	
Others	Bed	9	20	0.0	0.0	0.2	2.7	0.02	0.31	
Omers	Bedding	2	30	0.0	0.0	0.2	2.1	0.04	0.37	

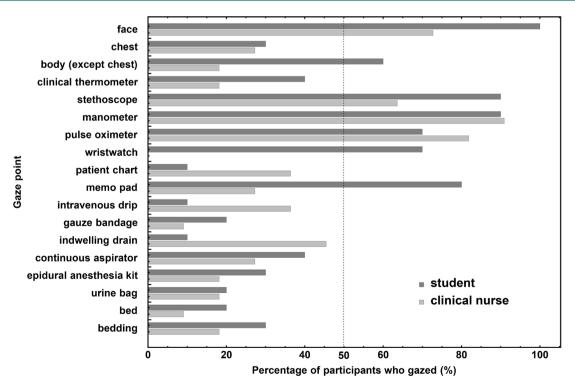


Figure 3. Percentage of participants who gazed at the 18 gaze points.

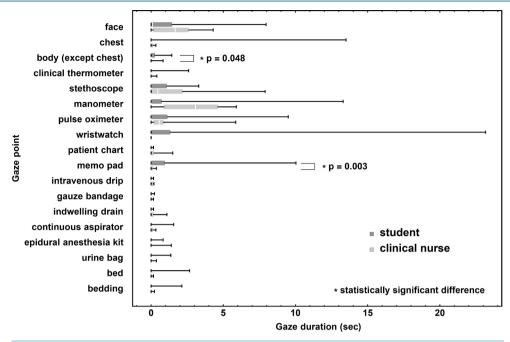


Figure 4. Gaze duration at the 18 gaze points.

*drip*, and *indwelling drain*. Regarding vital sign measurement devices, the median gaze duration was longer for students than for nurses for the *stethoscope* and *pulse oximeter*. The median gaze duration for the *manometer* was longer for the nurses than for the students.

The 18 gaze points were classified into 5 different categories of patient, vital sign measurement devices, records, catheters, and others as shown in **Table 1**. **Figure 5** displays that integrated gaze duration for each category in a boxplot. Of the 5 categories, the vital sign measurement devices had the longest gaze duration for both nurses and students and showed a significant difference from other categories. The category with the second longest gaze duration was patient; when comparing the patient and records categories, there was no significant difference for students but there was one for nurses (p = 0.03). Only the records showed a significant difference between nurses and students, with students having longer gaze durations (p = 0.03).

#### 4. Discussion

This study showed that clinical nurses spent at least half the time than did nursing students in performing observations to obtain an early postoperative ambulation assessment. The nursing observation was performed according to an objective: namely, to determine whether a postoperative day 1 patient can leave their bed or not in this study. Early postoperative ambulation is an important nursing assistance for preventing postoperative complications. The necessary points to observe for making an accurate ambulation assessment are vital signs, the patient's physical condition (judged from preoperative strength and operative stress), the degree of pain, potential risks of collapsing or symptom deterioration, and the patient's volition [10]. The participating nurses in this study all had over 6 years of clinical experience in the surgical field and had conducted ambulation assessments of postoperative patients. Because of this background, they were able to identify specific observation points necessary for making an accurate judgment and found it easy to make decisions because the mock situation and simulated patient were similar to situations they had experienced in the past where patients were able to leave the bed. These factors are believed to have led nurses to complete the observation within a shorter period than the students [11] [12]. However, it is believed that the time required to make a judgment in an actual clinical setting would be shorter than that found in the present study because the nurses would preoperatively know the patient's physical and mental background information. Students, compared to nurses, had larger gaze movement, more gaze points, and spent more time gazing at each point because they had to interpret each piece of information in a serial manner. It is believed that these factors extended students' observation duration.

The gaze point refers to an area in which the observer showed interest. The points at which most participants

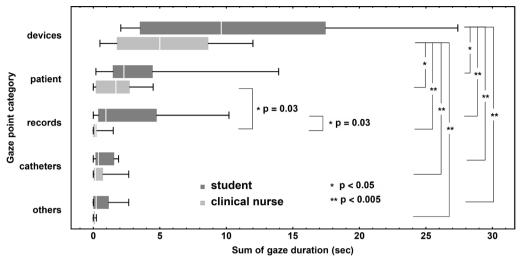


Figure 5. Gaze duration at the five gaze point categories.

gazed were the face, stethoscope, manometer, and pulse oximeter, indicating that they gazed at the patient's expression and vital sign measurement devices. In this observation experiment, participants had to rely greatly on their visual perception for the information needed to make a judgment because we had the patient show expressions of pain while limiting their verbal statements and had actual operating medical equipment and drip infusions. As shown in Figure 2, while there was a clear difference in gaze movement between nurses and students, there were no significant differences in the gaze points necessary for making an ambulation assessment. Concerning the wristwatch, while students gazed at it, no nurses did so; this is because the students palpated the pulse by following basic procedures—namely, counting the number of breaths by checking the patient's chest movements and gazing at their own wristwatches while measuring. In contrast, nurses checked pulse count using the numerical value displayed on the pulse oximeter; in other words, they used medical equipment. However, pulse oximeters, which measure the pulse of arterial blood and oxygen saturation by issuing a light beam onto the skin, lose accuracy when peripheral blood is low, the probe experiences an attachment failure, or when there is too much ambient light [13]. Thus, it might be necessary to palpate the pulses in accordance with the basic procedure as the students did in order to ensure an accurate nursing diagnosis. The points at which at least twice as many students as nurses gazed were the body (except chest), clinical thermometer, memo pad, and bed. It is believed that students gazed at the body (except chest) and bed because they were taught to do so as part of nursing observation basics during their fundamental nursing education. As for the memo pad, 80% of the students gazed at it to record vital signs data, and their gaze duration were significantly longer than was that of nurses. As mentioned above, it can be inferred that the students performed observations that were faithful to the basic procedures.

Compared to nurses, students' gaze duration on the *chest* was longer, suggesting that they required more time to determine the breathing state. In contrast, nurses likely quickly noted the breath count and rhythm while observing the patient's breathing, without gazing at the chest area. The points at which nurses spent a longer time gazing compared to students were the *patient record*, *intravenous drip*, and *indwelling drain*. The reasoning for this finding is that the nurses confirmed the successive course of the patient immediately after the surgery by looking at the *patient record* so that they could predict the patient's current state. It is believed that the nurses gathered information on patient safety by checking the *indwelling drain* and *intravenous drip* implanted in the patient. Bleeding is a symptom that cannot be overlooked in this simulated patient's situation. Thus, the drainage amount and properties from the *indwelling drain* is an important information source for assessing postoperative bleeding, which explains the longer duration of nurses' gazing at it [14]. On the other hand, the gaze duration for the *continuous aspirator* and the *gauze bandage* applied to the wounded area was longer among students, perhaps because they focused on the drainage accumulated in the drainage bottle of the *continuous aspirator* and were checking for bleeding on the *gauze*. In other words, nurses tended to focus on current bleeding while students tended to focus on overall bleeding volume during observations related to postoperative bleeding.

In Figure 5, the 18 gaze points were divided into 5 categories and compared. Under this classification, both

the nurses and the students gazed at *vital sign measurement devices* significantly longer than they did the other 4 categories. This is believed to be because gazing at these devices was necessary to ascertain the measured vital signs. Although no significant difference in gaze duration between the *patient* and *records* categories was found for the students, there was a significant difference for the nurses, which indicates that they looked at the *patient* more than they did the *records*.

There are considered to be two ways of looking at the world: direct vision and peripheral vision. Direct vision occurs when an image is formed at the central area of the retina when consciously gazing at a single point. Peripheral vision, by contrast, occurs when the image forms on the peripheral area of the retina and reflects the peripheral area of a scene; it is a viewing method that comprehensively captures spatial positional relation and movement information [15]. The gaze duration measured in this study using an eye-tracking camera was the duration of direct vision. Peripheral vision is also considered to be important factor in actual nursing assessments conducted by sight [16] [17]. In addition, nurses who observe postoperative patients on a daily basis conduct observations by presupposing required information other than visual information in advance. Thus, it is believed that nurses make assessments by drawing on their accumulated knowledge during observations. Further evaluations of nursing assessment processes must consider these points.

Although nursing students took more than twice as long as nurses did in the observation period to make an assessment, they were still able to make a correct assessment concerning the patient's ambulation. This is believed to be because these nursing students were in their 4<sup>th</sup> year of university, meaning that they knew the fundamentals of nursing care. Students (*i.e.*, novices) gathered numerical information—mainly vital sign measurement data and bleeding volumes—and used it for conducting their nursing assessment. However, there are cases when no change occurs in vital sign values immediately after a physical abnormality occurs [18]. Thus, nursing assessment education for novices must foster skills that enable them to not only interpret numerical information, but also be able to link this with other information in the situation. The quantitative analysis of nursing observation behavior in this study visualized the relationships between the information in the scene and aided in elucidating the nursing assessment process.

#### 5. Conclusion

Differences in nursing observation behavior according to the existence of clinical experience were analyzed quantitatively in this study. Although no significant difference was found in terms of gaze points, the nursing students had a tendency to focus on information that could be easily represented numerically. We also found that nurses with clinical experience conducted observations by gazing at the information that they needed to focus on most at any given time according to the patients' postoperative course.

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## Experiencing Participation in Health Care: "Through the Eyes of Older Adults"

#### Samal Algilani, Inger James, Annica Kihlgren

School of Health and Medical Sciences, Örebro University, Örebro, Sweden Email: samal.algilani@oru.se, inger.james@oru.se, annica.kihlgren@oru.se

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#### **Abstract**

Background: Patient participation is well understood by health care professionals but not many studies have focused on the older adults and their perceptions of patient participation. Aim and Objectives: To report an analysis of the concept of participation from the perspective of the older adult. Design: Concept analysis. Methods: An integrative review approach was undertaken and the searches were limited from January 2003 to December 2014, guiding question was; "what constitutes patient participation according to the older adult?" Results: Through the eyes of the older adults, a two-way communication should be initiated by the staff. Equality and sharing power between older adults and staffs was perceived as a precondition. Been given time was an essential issue, implying that older adults wished to have enough time from staffs and be in the right context surrounded by the appropriate environment in order to experience participation. Conclusion: In order to experience participation for older adults, it is important that the health care professionals are aware of how and in what ways they can contribute to participation among older adults. The need or wish to create participation is not enough; the health care professional needs to see and understand participation through the older adult's eyes. Thus, a person-centered nursing approach is relevant for the health care professional in order to both give and maintain the experience of participation to the older adult.

#### **Keywords**

Concept Analysis, Patient Participation, Older Adults' Perspective, Nursing

#### 1. Introduction

Although patient participation is a complex and broad concept, it is common and used on a daily basis in health care by health care professionals. Patient participation is defined as "patient involvement in the decision-making

process in matters pertaining to health," in the National Library of Medicine's Medical Subject Headings, [MeSH] [1].

While the concept of patient participation is well understood by health care professionals, it is equally important for patients to be aware of and conscious about it. Since, to be aware makes it possible to take part. To actively take part in one's own care results in making better decisions related to self-care and to being which are more likely to be content with the care received and its outcomes. Brennan [2] described the normative decision theory and its applicability to using patient preferences in order to plan care and to construct measures of patient satisfaction meaningful to the patient. A study indicated that experts working with safety issues in health care reported that if their patients play a more active part, it would help to prevent medical errors [3]. According to the International Council of Nurses (ICN), nurses should listen to the needs of the patient as expressed by the patients <a href="http://www.patienttalk.info/psinfopatients03.htm">http://www.patienttalk.info/psinfopatients03.htm</a>. Furthermore, WHO emphases patient participation partly to meet patients' needs and partly to provide more effective care, for example, in management of chronic diseases and prevention of medical problems

<a href="http://www.euro.who.int/">http://www.euro.who.int/</a> data/assets/pdf file/0010/185779/e96814.pdf?ua=1.

The Swedish National Board of Health and Welfare [4] emphasizes the importance of the interaction between the caregiver and the patient. Moreover, it has declared that during the interaction, specific health-care needs are identified and this provides better outcomes for the patient [4] [5].

A study done in Sweden showed that, according to the patients, patient participation was about having knowledge and interacting with health care professionals [6]. This study confirms that patient participation is important for the patient and for the quality and outcome of care. The findings are also consistent with new Swedish legislation the "Patient Act," which emphasizes patient involvement and the patient's right to participate in all decisions [7]. The background to and the intention of the law are a shift of power to the patient [8].

Patient participation is a well-researched concept. Several studies focus on adults as a general group and/or focus on patient participation in different contexts [9]-[11].

However, the views of adults on patient participation, a complex and multifactorial concept [12], cannot be seen or described as though adults are a homogenous group. Rather, they need to be explored from the perspectives of different age groups in order to capture the essence of the concept. In a survey from 2008, the authors concluded that patient participation differed substantially because of the patients' preferences and would be best elicited by assessing the need of the individual patient [13]. Not many studies have focused on the older adult and their perceptions of what constitutes patient participation. A review from 2010 concluded that there was a lack of research showing patient participation from the perspective of the older adult. The authors of the review found seven key themes in the literature: the concept of participation, the need for older people to be involved, autonomy and empowerment, patients' expectations, benefits of participation, factors influencing participation, and precursors to participation [14]. Although this review covered several important areas, it did not deal with what constitutes patient participation from the perspective of the older adult. A review from the United Kingdom in 2012 was conducted using the term" shared decision-making" with a focus on older adults and it showed that older adults valued involvement in decisions concerning their treatment and care. However, this review described what constituted participation from the perspective of the older adult. This gap in knowledge suggests that more research is needed to map out what constitutes participation in health care according to the older adult [15].

This crucial need to describe participation in health care from the older adult's perspective comes to be aware of the aging population globally. In the Western world, the number of people reaching an old age is rising and it is estimated that soon the older population will outnumber the younger population [16]. By 2050, 22% of the world population will be older adults [17]. Sweden has one of the highest proportions of older adults in the world, especially in the group of 80 and over. Due to better living conditions, life expectancy will increase [18].

Because health care professionals will meet this group of patients in all contexts where health care is provided, it is important to explore and describe patient participation according to the older adult. Understanding the older adults' can enhance and promote the caring conversation that nurses and other health care professionals conduct. A first step in filling the gap is to review the literature and discover the scope out of what constitutes patient participation from the view of the older adult.

Thus, the aim of this study was to review the literature on what constitutes participation from the perspective of the older adult in the encounter in a health care setting.

#### 2. Material and Methods

An integrative review approach was undertaken with the guiding question, "what constitutes patient participation according to the older adult?" The choice of method was in order to define the concept further and to have the possibility of combining different data from quantitative studies as well as qualitative studies.

Integrative reviews are the broadest type of research review methods that allow for combining data from the theoretical and empirical literature. Moreover, integrated reviews incorporate defining concepts [19]. This study used the methodology of Whittemore and Knafl during the whole process, including *problem identification stage*, *literature search stage*, *data evaluation stage*, and *data analysis stage*. Problem identification has been thoroughly described in the above section, which explained the lack of knowledge and importance of conducting this review.

#### 2.1. Literature Search Stage

Concepts closely related to participatory care were used in the search process to see whether they had corresponding terms or explanations on the MeSH-tree. Related concepts were chosen in consultation with two experienced researchers in the field of concept development/concept analysis. Among the concepts were "participatory medicine", "participatory care", "interdependence", "collaborative care", "cooperative care" and "patient participation" (in PsychINFO "client participation"). Only patient participation had an explanation as a MeSHterm: "patient involvement in the decision-making process in matters pertaining to health." Although the other concepts did not have any explanation, they were used in rest of the search to capture the core of the concept. Three electronic databases were used to conduct the review: PubMed®, CINAHL and PsycINFO. All the searches were limited to January 2003 to December 2014 to capture the most recent research, to the English language to receive articles written only in English, and to +65 years of age to obtain articles involving older adults. In PubMed and CINAHL, the search word "patient participation" resulted in too many search results so the search range was reduced to six years, thus January 2008 to December 2014. Inclusion criteria were: according to the older adult, cognitively intact older adults, and studies conducted in Western countries. Exclusion criteria were studies about co-operation/participation between professions. When duplicates were removed, a total of 15 articles were included in the review because they met the aim of the study (see Figures 1(a)-(c)). Lastly, a control search was conducted and one more article was found, for a total of 16 articles.

#### 2.2. Data Evaluation Stage

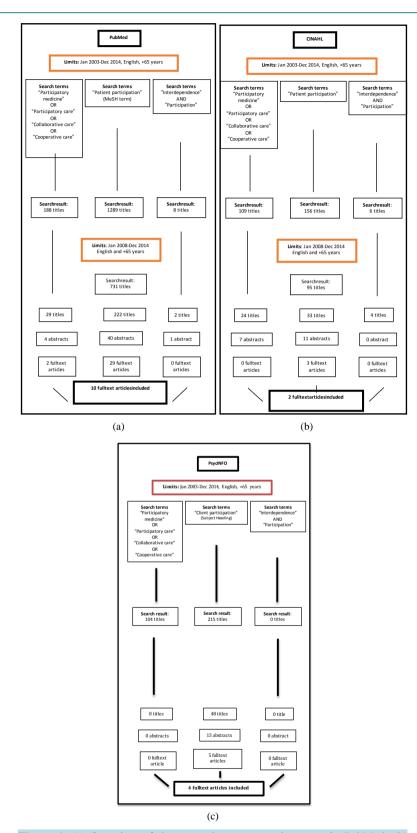
The study included all the articles that were peer-reviewed and focused on experiences/perceptions on patient participation from the perspective of the older adult. The final sample was a total of 16 articles; both empirical and theoretical articles were included to gain a broader description on what constitutes patient participation according to the older adult. At this stage, a matrix was created in order to sort out data that corresponded to the aim (see **Table 1**).

#### 2.3. Data Analysis Stage

Inductive content analysis with open coding was used to analyze the data retrieved [20]. The primary research methods of analysis, which were developed for qualitative design, are applicable to the integrative review method [19]. Inductive content analysis with open coding took five steps: first the data was obtained, (e.g. the literature that corresponded to the aim was read through and notes were written in the text while reading). Then the data was read through again and as many headings as possible were written in the margins to describe all aspects of the content. The headings were then moved onto coding sheets and categories were freely generated, which created subcategories. Further, the categories were grouped under higher order headings, which in turn provided the categories. The categories then resulted in four main themes (see **Tables 2(a)-(c)**).

#### 3. Results

The studies in this review include reports, reviews and empirical papers. A summary of 16 articles addressed the main aim of the review and formed the base findings. Four main themes emerged from the literature: *a two-way communication, being on equal terms, being given time and being in the right place* (see Tables 2(a)-(c)).



**Figure 1.** (a) Overview of the research strategy and process in PubMed; (b) Overview of the research strategy and process in Cinahl; (c) Overview of the research strategy and process in PsycINFO.

Table 1. A matrix of the included articles.

Database	Citation	Year	Context/ participant	Label	Definition	Critical attribute/	Result
	Susan Mary Benbow					characteristics	
PubMed	"Patient and carer participation in old age psychiatry in England. Part II: models of participation"  International Psychogeriatrics. 2012, 24,	2012	Old age psychiatry Review Models of participation is reviewed.	Partnership/ collaboration	Participation is a spectrum	Older adults Staff/Patient/ carers	Participation is similar status, shared power, equality of influence over the agenda.
	185-196.						
	Erika Leemann Price, Sylvia Bereknyei, Alma Kuby, Wendy Levinson, Clarence Henry Braddock		Senior centers and nursing homes				Inviting the involvement of trusted
PubMed	"New elements for informed decision making: A qualitative study of older adults' views"	2012	5 focus group interviews with 59 older adults 65 – 85 and older years	Patient participation	Informed decision making	Older patients- physician	others and exploring the impact of the decision in the context of the patient's life.
	Patient Education and Counseling, 2012, 86, 335-341.						D: 1 1 :
	Christina Foss						Being heard requires self-confidence to be able to participate. Participation depended
PubMed	"Elders and patient participation revisited—a discourse analytic approach to older persons' reflections on patient participation"	2011	At home 1 - 2 weeks after discharge from hospital In depth interviews 18	Patient participation	Participation means balancing your own needs against the need of others	Patients-health care staff	on the hospital's pace.  Participation is not practiced in a direct and outspoken manner but in subtle ways, not as a right but as an
	Journal of Clinical Nursing, 2011, 20, 2014-2022.		older adults (10 men, 8 women) 80 - 92 years.		or others		opportunity and it need strategies and self-confidence from the older adults to gaining influence.
	Christina Foss, Dag Hofoss		Hospital discharge process				The majority of the older adults did not experience real
PubMed	"Elderly persons' experiences of participation in hospital discharge process"	2011	interviews via questionnaires with 254 older adults 80+	Participation	Participation is co-deciding	Patients-health care staff	participation. They want to influence different examinations and treatments.
	Patient Education and Counseling, 2011, 85, 68-73.		mean age 86,9 years				Being able to co-decide in the discharge process.
	Rebecca Johnson, Lori L. Popejoy and M. Elise Radina		Nursing home relocation			Patients-family, friends others	Being involved in your decision making when relocating to a nursing home. Some of the older
PubMed	"Older Adults' participation in nursing home placement decisions"	2010	Semi structured interviews with 16 older adults 60 - 97 years (9	Participation	Decision-making participations	Older adults' participation in the nursing	adults reported that they have a total or some participations in the decision-making
	Clinical Nursing Research, 2010, 19, 358-375.		women, 7 men)			home relocation decision.	about mowing to a nursing home others reported from minimal to no participation.

#### Continued

PubMed	George Demiris  Independence and shared decision making: the role of smart home technology in empowering older adults  31st Annual International Conference of the IEEE EMBS  Minneapolis, Minnesota, USA, September 3-6, 2009, 6432-6436.	2009	Community dwelling older adults Smart home technologies Dephi study Review Smart home designers Researchers 48 dwelling older adults	Shared decision making	It is an active and empowered role	Older adults and clinical encounter	Shared decisions was perceived as being able to make decisions about treatment options during clinical encounter and having control over what technology to use, when and how.  Because smart home technology can interfere the private life.
PubMed	Anne W. Ekdahl, Lars Andersson, Maria Friedrichsen  "They do what they think is the best for me." "Frail elderly patients' preferences for participation in their care during hospitalization"  Patient Education and Counseling, 2010, 80, 233-240.	2010	Recently hospitalized frail older adults Interviews with 15 "fragile" elderly patients	Patient participation	Participation means information and good communication.	Patients (and health care staff)	Participation (in medical decisions) means receiving information and good communication the older adults do not want to take an active part in medical decisions about their treatment. But they wanted to be given the chance to be heard and to express their thoughts and feeling about symptoms and illnesses.
Pubmed	Helena Harder, Rachel Ballinger, Carolyn Langridge, Alistair Ring, Lesley J. Fallowfield "Adjuvant chemotherapy in elderly women with breast cancer: patients' perspectives on information giving and decision making"  Psycho-Oncology, 2013, 22, 2729-2735.	2013	Women aged ≥ 70 years with newly diagnosed  EBC (Early Stage Breast Cancer)  Structured interviews with 58 women 70 - 83 years	Breast- cancer-treatme nt decision	Level of participation in treatment decision making	Patient and clinician ie. doctor and family	The majority (58.5%) of the women wanted to make a shared decision about adjuvant chemotherapy with a clinician. 22.6% delegated the decision to a clinician 18. 9% made their own decision.
PsycInfo	Elisabeth Lindberg, Ulrica Hörberg, Eva Persson, Margaretha Ekebergh  "It made me feel human": A phenomenological study of older patients' experiences of participating in a team meeting.  International Journal of Qualitative Studies on Health & Well-Being, 2013, May 28, 20014.	2013	Team meetings (TM) in hospitals Interviews with 15 patient 74 - 94 years (12 women 3 men)	Participation	The encounter between the career and the patient needs to be developed (in order to get away) from the view of the patient as an object to view the patient as a unique person	Patient and career	There is a desire in caring and TM to be recognized and confirmed as a unique but vulnerable human gives feelings of participation.

#### Continued

PsycInfo	Veronica Vicente, Maaret Castren, Fredrik Sjöstrand, Birgitta W Sundström  "Elderly patients' participation in emergency medical services when offered an alternative care pathway"  Int J Qual Stud Health Well-being, 2013, Feb 26, 8, 20014.	2013	The choice of health care when being offered an alternative care pathway by the emergency medical services.  Ambulance service and a geriatric ward  Semi structured Interviews with 11 older adults (9 women, 2 men)	Patient participation	Interpersonal relationship	Patient and career in the ambulance service	"There was a ray of hope about a caring encounter and about being treated like a unique human being." Participation is about being seen and cared about.  To be treated with an open and friendly attitude, respect integrity by creating an atmosphere where older adults gain courage to express their needs.
PsycInfo	Vernee N. Belcher, Terri R. Fried, Joseph V. Agostini, Mary E. Tinetti  "Views of older adults on patient participation in medication-related decision making"  Journal of General Internal Medicine, 2006, 21, 298-303.	2006	Older adults were recruited from senior centers and from primary care practice.  Interviews 51 older adults 65 - 89 years	Participation in medication-rel ated decision making	Physicians' attitudes and behaviors as well as system factors were obstacles or could facilitate participation.  Physician and system factors that were felt to facilitate or impede patient participation included communication skills, the expanding number of medications available, multiple physicians prescribing for the same patient, and a focus on treating numbers	Patients and physicians	Participation can be on different levels. Physician can facilitate participation, asking questions, being active in decision making, let the patients' know about their medications and conditions, trust the physician. The role of the physician was important to participation. Not all patients WANT to participate in decision making(that is also participation).
PsycInfo	Hilde Bastiaens, Paul Van Royen, Danica RotarPavlic, Victor Raposo, Richard Baker  "Older people's preferences for involvement in their own care: a qualitative study in primary health care in 11 European countries"  Patient Education and Counseling, 2007, 68, 33-42.	2007	Older adults within primary care  Semi structured interviews with 406 older adults (222 women, 184 men) in 11 countries 70 - 96 years.	Patient participation	Patient involvement in care	Patients and general practitioners	Good communication, building a trusting relationship, being respected, having enough time and receiving information.  A"caring environment" is more important than the outcome of involvement.  An important base for patient involvement is the doctor, practice, and health care organization.

#### Continued

CINAHL	Elin M. Aasen, Marit Kvangarsnes, Kåre Heggen "Perceptions of patient participation among elderly patients with end-stage renal disease in a dialysis unit" Scandinavian Journal of Caring Sciences, 2012, 26, 61-69.	2012	Elderly patients in a dialysis unit Interviews with 11 older adults/patients (4 women, 7 men) 72 - 90 years.	Patient participation	The health-care teams have the power and dominance. The patients have a passive role.	Patients and health care staff	Conditions for participation are influenced by the context (environmental conditions). In this study: feelings of being controlled, sensing a loss of freedom and powerlessness. Combination of trust and fear can create passiveness and be a possible obstacle to communicate and shared decision making.
CINAHL	Elizabeth M.M. Tutton  "Patient participation on a ward for frail older people"  Journal of Advanced Nursing, 2005, 50, 143-152.	2005	Hospitalized older adults 19 interviews with older adults/patients aged 60 were the majority were over 75 years. 3 FGD and 2 interviews with staff	Patient participation	Participation is a dynamic process that is integral to the work of nurses and carers. The process is enacted through the themes of facilitation, partnership, understanding the person, and emotional work	Patients and health care staff	Participation is not seen as a hierarchy but as a process that depended on the context of care giving. Partnership was an essential process in participation by identifying values and beliefs of the older adult and was also based on negotiation.
Pubmed	Julie P. W. Bynum, Laura Barre, Catherine Reed, Honor Passow, "Participation of very old adults in health care decisions" Medical Decision Making, 2014, 34, 216-230.	2014	Subjects from regions with high and low health care utilization.Subsidi zed housing, senior centers, and subsidize delder day care. Semi structured interviews 29 older adults 80 - 93 years	Patient participation in health care decisions making in the clinical setting decision making	A decision episode was defined as Including a judgment about taking or not taking an action.	Patients and clinicians ie. doctors	Participation varied among the patients, they participate to some degree and have the potential to be active participants in decision making. There is a need of open communication about options which could facilitate patients participations in health care decisions
PubMed	Hanneke W. M. Van Laarhoven, Inge Henselmans, J. (Hanneke) C. De Haes  "To treat or not to treat: who should decide?"  The Oncologist, 2014, 19, 433-436.	2014	Outpatient clinic Case study One older adults MR C 79 years old	Shared decision making	The focus should be put on the steps taken for decision, not the amount of "sharedness"	physicians doctor at an	Some older adults can find it difficult to cope with the burden of decision making. Health care personnel can have to take on the responsibility for decision. However, it is critical to explore older adults' values and adopt their perspective.

Table 2. (a) Subcategories and categories for the main theme: A two-way communication; (b) Subcategories and categories for the main theme: being on equal terms; (c) Subcategories and categories for the main theme: being in the right place and Being given time.

(a)

Subcategories	Categories	Main Theme
Receiving information		A two-way communication
To receive information		
Important to be informed		
Good communication		
Good communication between older adults and staff	To be informed about health status	
Wanting information about	10 be informed about hearth status	
- illness		
- planned investigation		
Health care staff explains what is going on		
To make efforts to get information		
Participation is not a right		
Participation is an opportunity	Participation is indirect	
Participation is a process		
The hospital could make the decisions on behalf of the older adult		
To be given the chance to be heard	To be heard	
Being Heard		
The possibility to express thoughts and feeling about symptoms and		
illnesses	To be able to influence	
To be able to influence examinations and treatment		
To participate in medical decisions		
It is about negotiation	Negotiation	

(b)			
Subcategories	Categories	Main theme	
To be recognized as a unique and vulnerable human			
To be confirmed as a unique and vulnerable human			
Treated like a unique human being			
Being seen	To be treated as an individual		
Being cared about	To be treated as an individual		
Treated with an open attitude			
Treated with a friendly attitude			
For staff to identify values and beliefs of the older adult			
Similar status			
Shared power			
Given space to the voice of the older adult			
Equal influence over agenda	Equality/shared power		
Co-decide on how practical problems are solved after discharge			
Not seen as a hierarchy		Being on equal terms	
Patient activation		8 1 1	
Having control over:			
- what technology to use			
- who should have access			
- the conditions of care			
Being able to make decisions about treatment options (during clinical			
encounter)			
Shared decision with physician	To have a choice		
Not wishing to take an active part in medical decisions	To have a choice		
Being involved when relocating to a nursing home			
Not wanting to participate in decision making			
Having the choice of (other) health care alternatives			
Accepting or rejecting what was offered To take an active decision			
Non adherent or to do what you self-want			
Trusting the physician			
Build a trusting relationship	Tourstine and the making		
Inviting the involvement of trusting others The relationship between the nurse and the older persons affect	Trusting relationship		
the older person's participation			
Respect the integrity of the older adult (by staff)			
	Being treated with respect		
Being respected (by personnel)			

(c)

Subcategories	Categories	Main theme
Caring environment more important than outcome Influenced by context Dependent on practice Dependent on health care organization Exploring the impact of the decision in the context of the patient's life	Environment- and context-dependent	Being in the right place
Staff take time and sit down Dependent on hospital pace Having enough time	To be given time	Being given time

#### 3.1. A Two-Way Communication

According to the older adults, communication between the older adults and health care professionals was a central element in experiencing participation in care [21]-[25]. In discussing communication, they did not focus only on speaking with each other, although that was seen as important, but also on connection on several levels. The older adults talked about the ability and possibility to influence their care, meaning that they wanted to take an active part in the planning of different examinations and treatments and have a say in medical decisions concerning their care [22] [24]. Others wanted information but did not want to take an active part in medical decision making. They mean that the hospital could make the decisions on behalf of them because the hospital made the right decisions [22].

Being heard by health care professionals was a significant and self-evident factor of participation and differed from being listened to. According to the older adults, being heard was not seen as a requirement but they wished to be given the chance to be heard [22] [23], which represented good communication [22].

Participating in their own care was mentioned in terms of negotiating their way to participation [25]. Participation was experienced as something that lies under the surface of what is said and done. It was seen as something indirect and subtle, not as a right but as an opportunity that has to be taken to achieve participation [23] [25], where participation could change over time and become a dynamic process [25].

Opportunity for participating in their care was seen as something that was given by health care professionals and taken by the older adults. A direct and verbal communication between the older adults and health care professionals was perceived as a central factor in experiencing participation. For the older adult it was crucial to receive information about an illness and planned investigations and to have the possibility of expressing feelings about symptoms and illnesses [22] [26]. Some patients found it so crucial that they made their own efforts to get information [26] and others do even more struggling for shared decision-making [27]. According to the older adults, it was also important that the health care professionals explain what is going on [21] [22] regarding treatment [28], were they want to have a well-informed decision making [28].

#### 3.2. Being on Equal Terms

Being on equal terms in decisions regarding health was something that emerged and thus seen as a salient dimension for experiencing participation in health care [21] [24] [25] [29]-[35]. To be treated with an open and friendly attitude, to be seen and cared about, as a unique and individual human being was perceived as valuable for participation [34] [35]. It was seen as important to be asked questions by health care professionals and that the health care staff identify values and beliefs of the older adult [25] [29] [36] where the voice of the older person needs to be given space [35].

Older woman wanted to participate in clinical decision making about their chemotherapy treatment. However, a majority wanted to share the decision with their clinician where his or her recommendation was important for their decision were they could accept or reject chemotherapy. Only18.9 % made their own decision [26].

Being able to participate was described in terms of shared power between the older adult and the health care professionals. Sharing power meant similar status and equality in influencing the health care plan, both during hospitalization and when being discharged [24] [25] [30]. It meant being partners with shared responsibility in the decision-making process. Shared decision making was not described as about the amount of "sharedness" but as a stepwise process taken together [36], without hierarchy [25].

The older adults took an active role in own health; they asked questions about anything they wanted to know

and were also able to assert their own beliefs and values [26]. Others involved their family members when they made decisions regarding receiving chemotherapy [28]. Respecting the role that an older adult adopts to respond to her or him as an individual [36].

To have the possibility of choices and to be able to make them was a pressing issue for the older adults in experiencing participation [26] [29] [31] [32]. In situations such as if and when to relocate to a nursing home, having treatments during clinical encounter and if technology was to be used, the older adults wished to be involved in the decision making [29] [31] [32].

To be able to make the choice of not wanting to participate in decisions regarding health care was also a way of feeling involved [29] [36]. Experiences of participation could also be obtained by being respected by the health care professionals [21] and the professionals respecting the older adults' integrity [34].

Trust was a basic concept that concerned many people around the older adults, including physician, nurses and relatives. To trust your physician, to involve the ones you trust in the care agenda and to have a trusting relationship with nurses and/or nurses' aides were all key points in the pursuit of experiencing participation [21] [29] [33].

#### 3.3. Being in the Right Place

According to the older adults, being in the right place, for example, on the right hospital ward when receiving care, generated experiences of being involved and resulted in feelings of participation. Participation is consequently dependent on context, environmental conditions and organization. Contributing factors for experiencing participation were dependent on practice and also health care organization [21].

External factors such as environment and context were of importance and also seen as a condition to experiencing participation [27]. Contextual factors concerned both external and internal factors that were derived from the older adult's own context. The older adults found it significant to explore how a decision could affect the context of the life of the older adult [33].

#### 3.4. Being Given Enough Time

The older adults saw time as an important aspect and a contributing factor for experiencing participation [22] [24] [25].

Time was a pressing issue and the older adults emphasized it when they were addressing the concept of time. The presence of time was so important that the absence of it could enable feelings of alienations with the health care staff. The feeling of being involved or alienated could depend on the pace in the ward, according to the older adults [23]. The older adults also approached this issue by saying that the health care professionals needed to take the time and sit down with the older adults and talk [22]. The time allocated was also seen as important for participation, not meaning how much time the older adults should be given, but having enough time [21].

#### 4. Discussion

#### 4.1. Discussion of the Methodology

The aim of this review was to describe what constitutes participation in a health care setting from the perspective of the older adult, by looking at current research. We have achieved this even though one article was a review of models of participation.

The integrative approach proved the possibility of retrieving a comprehensive understanding of the concept of interest [19]. The review has contributed to a broader and more comprehensive understanding of the concept of participation in a health care setting. The authors sought to be systematic and rigorous, and the integrative review approach emphasized the importance of these two qualities [19].

With the methodology chosen, this review obtained findings that could be applicable for nurses working in health care settings when caring for older adults. To deepen the understanding of the concept and really frame it, a mixed method approach could have been applied. According to Whittemore and Knafl [19], using a mixed method technique provides the possibility of reducing errors and thus helping to deepen and capture the concept of interest [19]. One way to further deepen the concept and receive confirmation of the findings would be to conduct qualitative interviews with older adults in different health care settings. Whittemore and Knafl confirm that qualitative research also gives less room for errors and more room for confirmation of the findings [19].

The findings of this review were obtained because certain and only a few key search terms were used when conducting the search in the databases. There is a possibility that using more key search terms would have resulted in more suitable and relevant articles to frame the concept of interest. Several articles had to be excluded because the studies contained more age groups than those +65 years of age and it was impossible to distinguish statements from those +65 years of age.

This review reveals the importance of really focusing on the older adult and what is important for them in experiencing participation, putting aside age, sex and health status. Other articles and papers have clearly shown what is important for the older adult when it comes to participation and focused on the older adult and what they value [4] [15] but they have not really asked the older adults what it takes to experience participation.

#### 4.2. Discussion of the Findings

According to the older adult in the current study, participation comprises a two-way communication, being on equal terms, finding the time and being in the right place. Health care professional should initiate communication, equality, giving enough time and to make sure that the older adult is in the right place for participation to take place, in order for the older adult to experience participation.

Through the eyes of the older adults communication should be initiated by the health care professional, as it was needed in order to perceive participation. The communication was about the information being given and about indirect communication, meaning the ability to influence one's care and to be given the possibility of being heard. This indicates that if the two-way communication does not work, feelings of participation will be lost and this may lead to a person being displeased with the health care. This was clearly confirmed in a study conducted in 1999, showing that information given in simple ways can provide satisfaction with care [37]. However it can also be perceived as power aspect and questions can arise of why the information should be provided in a simple way to grown up adults with long life experience. There may be a power structure at play, so-called ageism, where the staff sees the elderly as a group who are weak, not having knowledge and/or are frail [38] [39]. For example, it has been stated that older adults are not informed of health-care staff because the information can be seen as meaningless to frail older adults [38]. Further, this tells us how crucial it is that health care professionals give information to the older adults.

The importance of giving information because, as seen in this review, older adults do not see it just as being given information but as something that makes them feel involved in their care and thus satisfied with it. According to the older adults, it was also important that the health care professionals explain what was going on [21] [22].

Although the findings of this review suggest that communication is important in all contexts, it is of value to have the individual in mind, meaning that different levels of communication can be of different importance for older adults. This review presents the results from a group perspective, but it is still valuable to consider the older adult's subjective view in order to increase experiences of participation and thus satisfaction with care. Participants in a study conducted in Canada had various opinions about being part of decision making: some were comfortable with just being heard out and others wished to have a real influence [40]. However, it is not always enough to hear out (listen to) the older adults. Older adults can try to avoid conflicts by complying, which can be interpreted as the older adults not wanting to make decisions [26].

Equality and sharing power between older adults and health care staff in the health-care setting was perceived as a precondition for experiencing participation. "Respect," "integrity" and "similar status" were the terms used by the older adults when talking about feelings of participation [21] [34].

These terms revealed that the older adult wished to take part, be involved in the care, but it was the staff providing for the care that needed to involve the older adults and invite them to participate. This exposes the fact that just wanting to participate did not result in participation but there was a need for interaction to co-create participation. This is confirmed in research indicating that participation is about social interaction [41] and something that is determined by patients and health care professionals together through communication and shared decision making [42]. However, there is a question of whether it is enough to have shared decision making in all situations and contexts. The Swedish law state that the patient should have participation and that the power of the care should be shifted to the patient [7]. In addition, regardless if the patient is living in an ordinary housing or a nursing home, it is the older adults' home, and in your own home you want to decide for yourselves.

In this review, time was considered an essential issue, implying that older adults wished to have enough time from health care professionals in order to experience participation. Taking it a step further, time was also something that had to be given by health care professionals so the older adult could experience participation. It is important to mention that in-patients may have difficulties experiencing participation because of the hospital pace and of not having enough time with health care staff.

In one study, nurses working in hospitals needed strategies such as routinization and prioritizing to manage time [43]. Time is of the essence in a hospital ward, therefore it is preferable if the older adults are informed by health care personnel regarding the time aspect if it affects the care of the older adults. Giving information to the older adults may increase feelings of participation if the older adults know about the time aspect. According to the same study there is a reliance on patients in supporting nurses' effort to manage their time [43]. However, we mean this perspective can be harmful. Older adults can adapt to the staffs lack of time and give up their own participation and needs and by that the staff regain control over time which can result in an institutions-centered care instead of person-centered care [44].

In order to experience participation, older adults have to be in the right context and surrounded by the appropriate environment. As a result the emphasize is on the health care staff making older adults feel that they are in the correct place and thus contributing to the older adult's experience of participation. This means that if and how much a patient wishes to participate depends on the context and the patient's relationships with the health care professionals [40]. This is also confirmed by another study that emphasizes the importance of the relationship with the health care staff [45]. This can be tied together with the fact that being able to experience participation due to context is something that has to be provided by the health care staff.

Altogether, the main findings revealed that for older adults to be able to experience participation, factors like communication, equality, being given enough time and being in the right place were in order. But more important, the older adult revealed that for them to experience participation the health care professionals are the key and thus can make it happen by initiating the factors above. One way to initiating it is trough person-centered care. An approach means that it is the older adults' perspective that is prevailing in the performance of care and the decision making process not the organization's procedures or the professional's routines [46]. It's a part of the profession to create a relationship so that the older adults' perspective can be adopted [47]. Further there is a need of engagement and commitment in the relationship, it is namely in the interpersonal relationship that health care professionals become aware of the older adults beliefs and values [47]. These beliefs and values will become controlling for participation. The right to participate is also stated by the law and the guidelines for health care in Sweden. Experiencing participation when receiving care will lead to increased quality of care and in turn help the older adult attain optimal functionality [48]. In this integrative review it came out that it was important for the older adult to feel important enough to be given time, to be asked questions, to be seen as an equal, to be informed and to be in the right environment. The perception of being important can lead to experiences of subjective health and in turn experiences of optimal functionality. The older adults emphasized the importance of being seen as a human being, building trusting relationships with health care professionals, indicating that the older adults wished for quality in the encounter with health care. One way to receive quality may be through the experience of participation since it includes factors for experiences of quality in care.

#### 5. Conclusions

According to the older adults in this study, to feel participation the need or wish to participate is not enough; the health care professionals need to initiate and invite the older adult into a relationship, on equal terms where participation is created. It should create a two-way communication, give the older adult enough time and take the responsibility to make the older adults feel that they are in the right place. Thus, a person-centered nursing approach is relevant for the health care professional in order to both give and maintain the experience of participation for the older adult. By that, the health care professional can understand participation through the older adults' eyes (see Figure 2),

The elements which are shown in Figure 2 show a future and clinical implication and a tangible and concrete concept that might be used as a framework in nursing care.

#### **Contributions**

Study design: SA, IJ, AK; data collection: SA; data analysis: SA, IJ, AK and manuscript preparation: SA, IJ, AK.

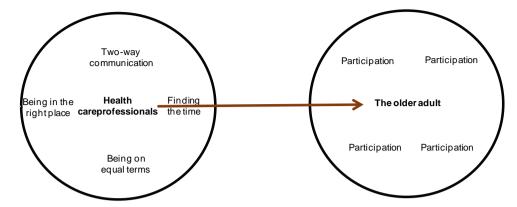


Figure 2. The important elements that the health care professional need to see and understand participation through the older adult's eyes.

#### **Conflict of Interest**

No conflict of interest has been declared by the authors.

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