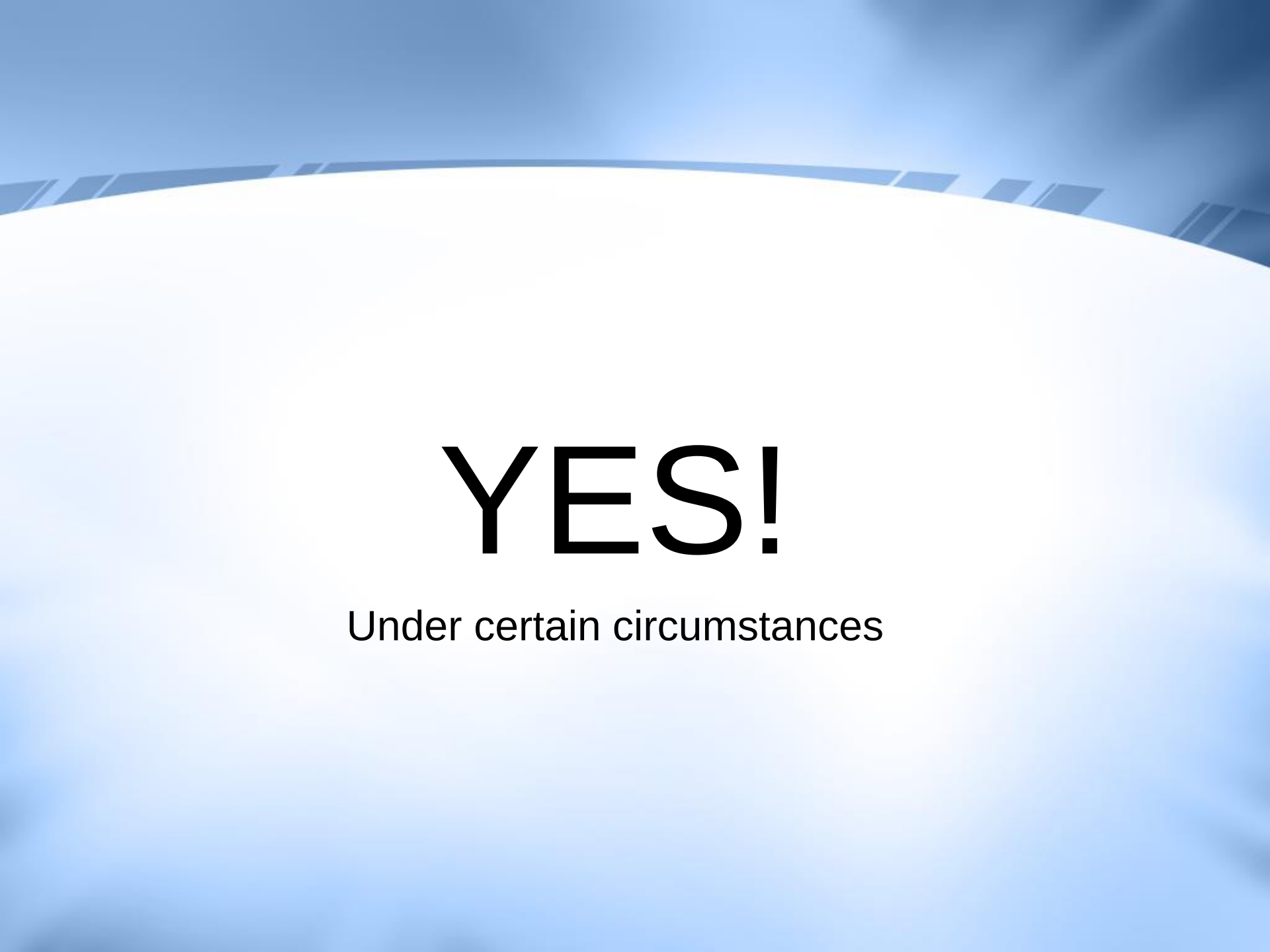


Clinical decision-making

Can and will patients participate?

Janne Florin
jfl@du.se

A large white dome structure, possibly a stadium or a modern building, is shown from a low angle, looking up. The dome is white and curved, with a blue sky and clouds in the background. The sky is a gradient of blue, with some white clouds visible. The dome's edge is visible at the top of the frame.

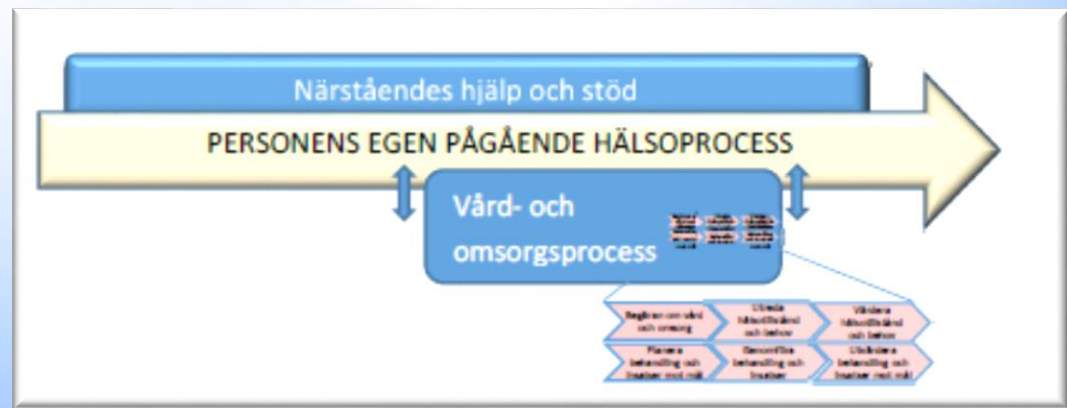
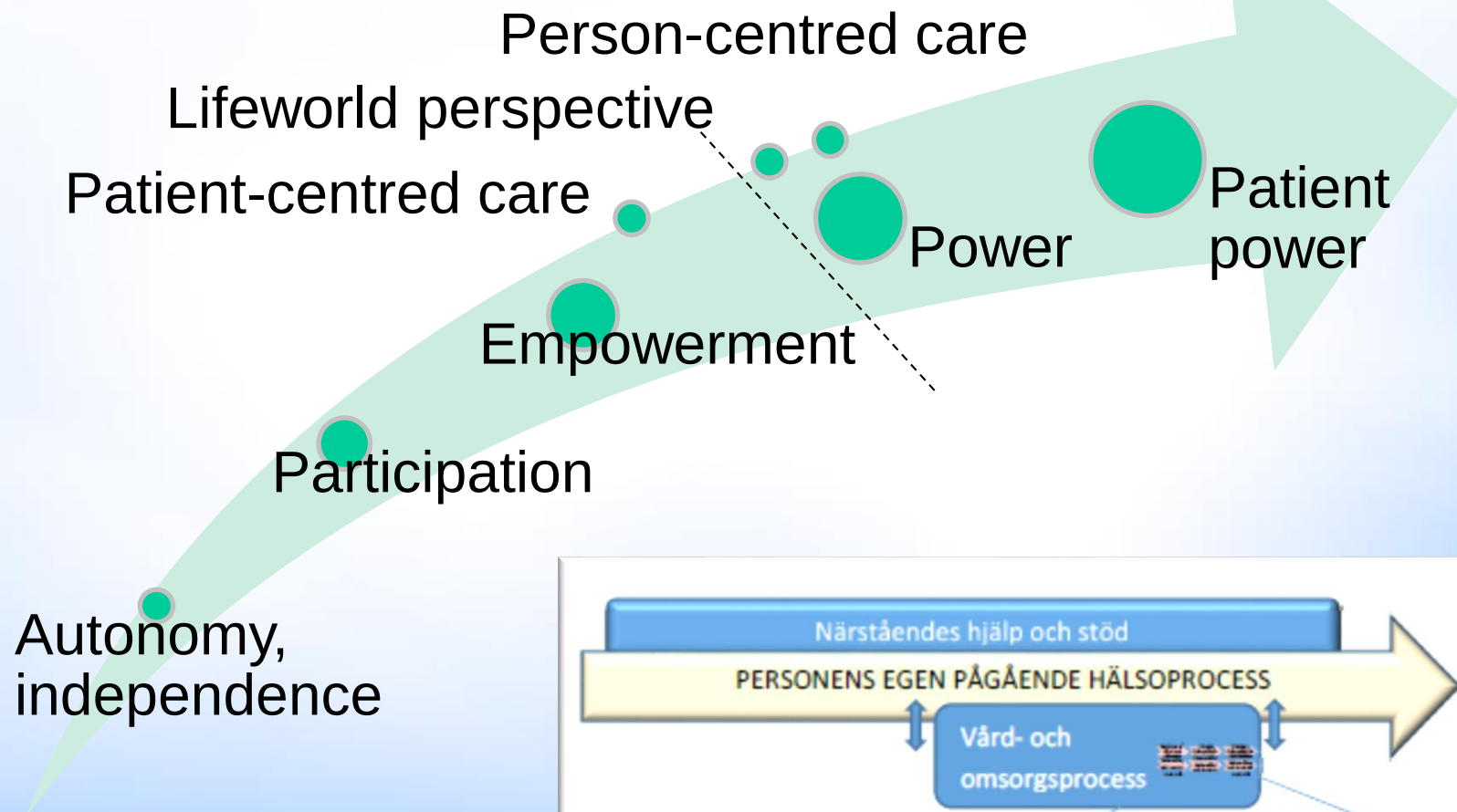
YES!

Under certain circumstances

Participation in a process



Conceptual development

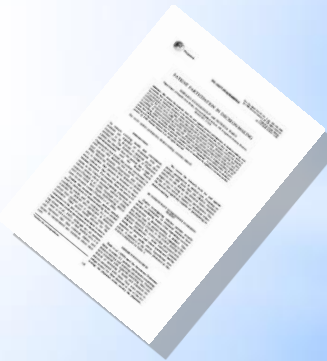


Some definitions...

“participation means getting involved or being allowed to become involved in a decision-making process or the delivery of a service or the evaluation of a service or even simply to become one of a number of people consulted on an issue or matter”

(Brownlea 1987 p. 605).

“...involvement in life situations”. (WHO 2001, International Classification of Function Disabilities and handicap, ICF)



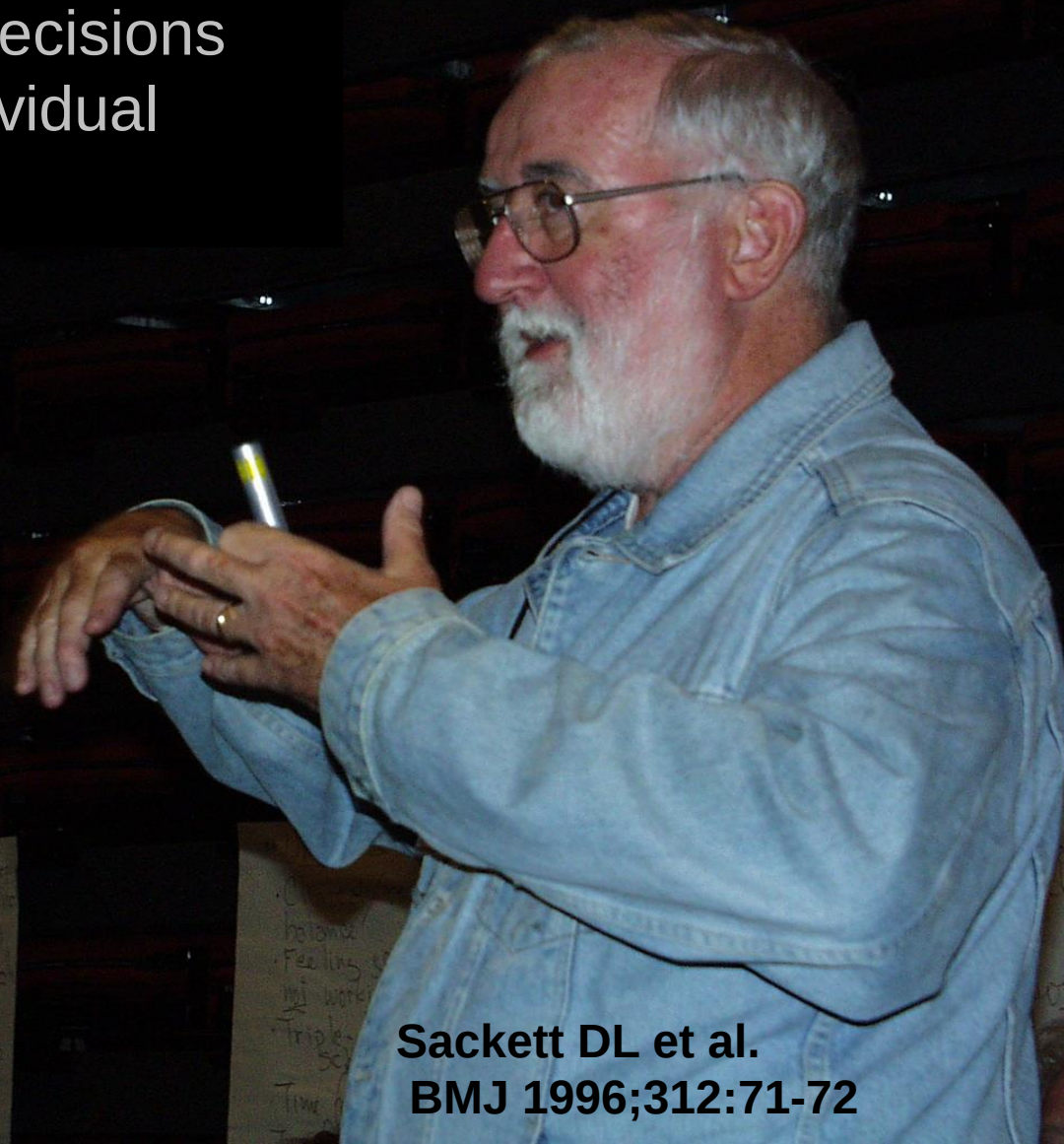
Information and communication

- Knowledge is power
- Increasing patients' knowledge is a mean to strengthen their power and influence
- This affects the balance/interaction between nurse-patient

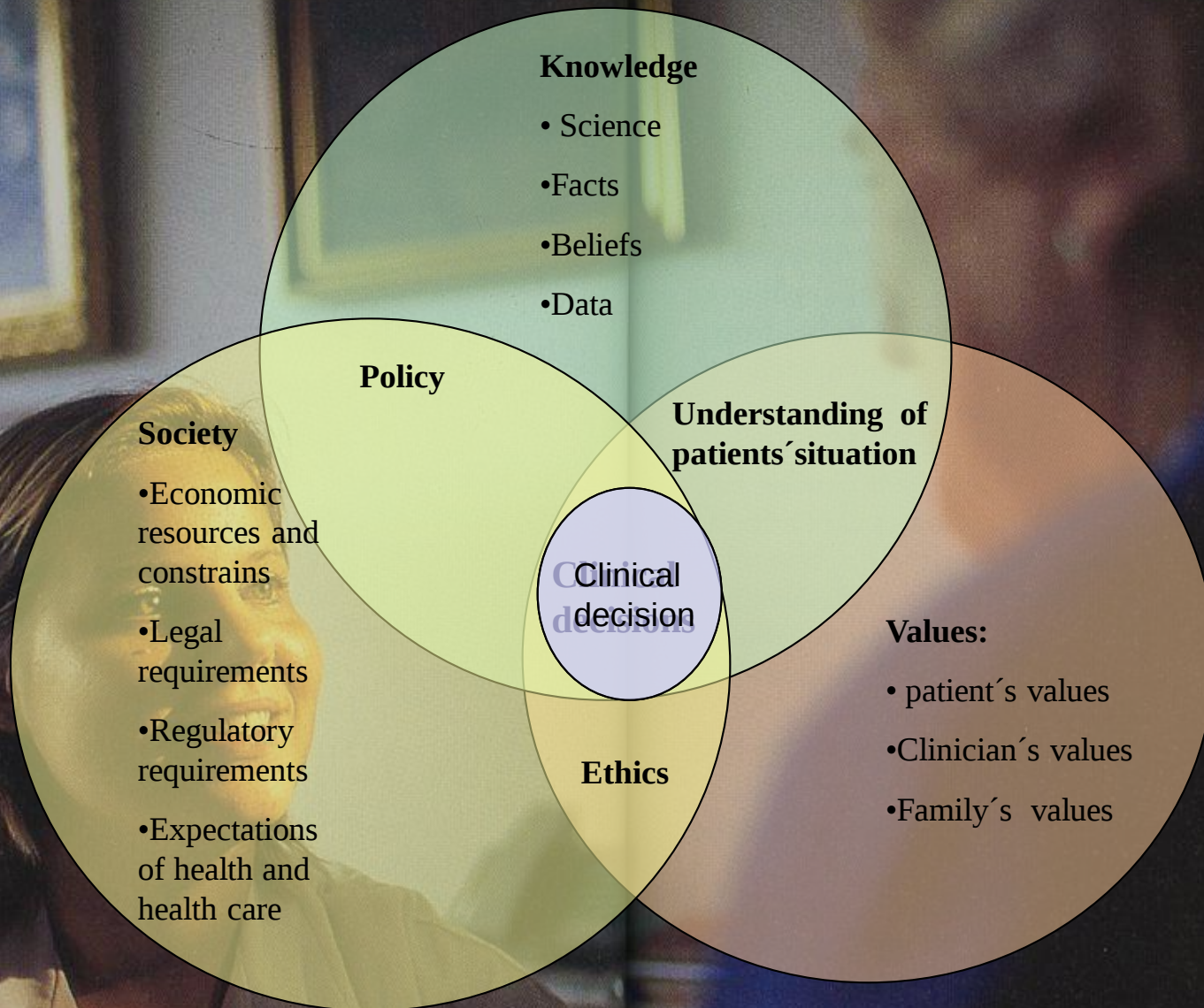
This is what we have wanted,or?

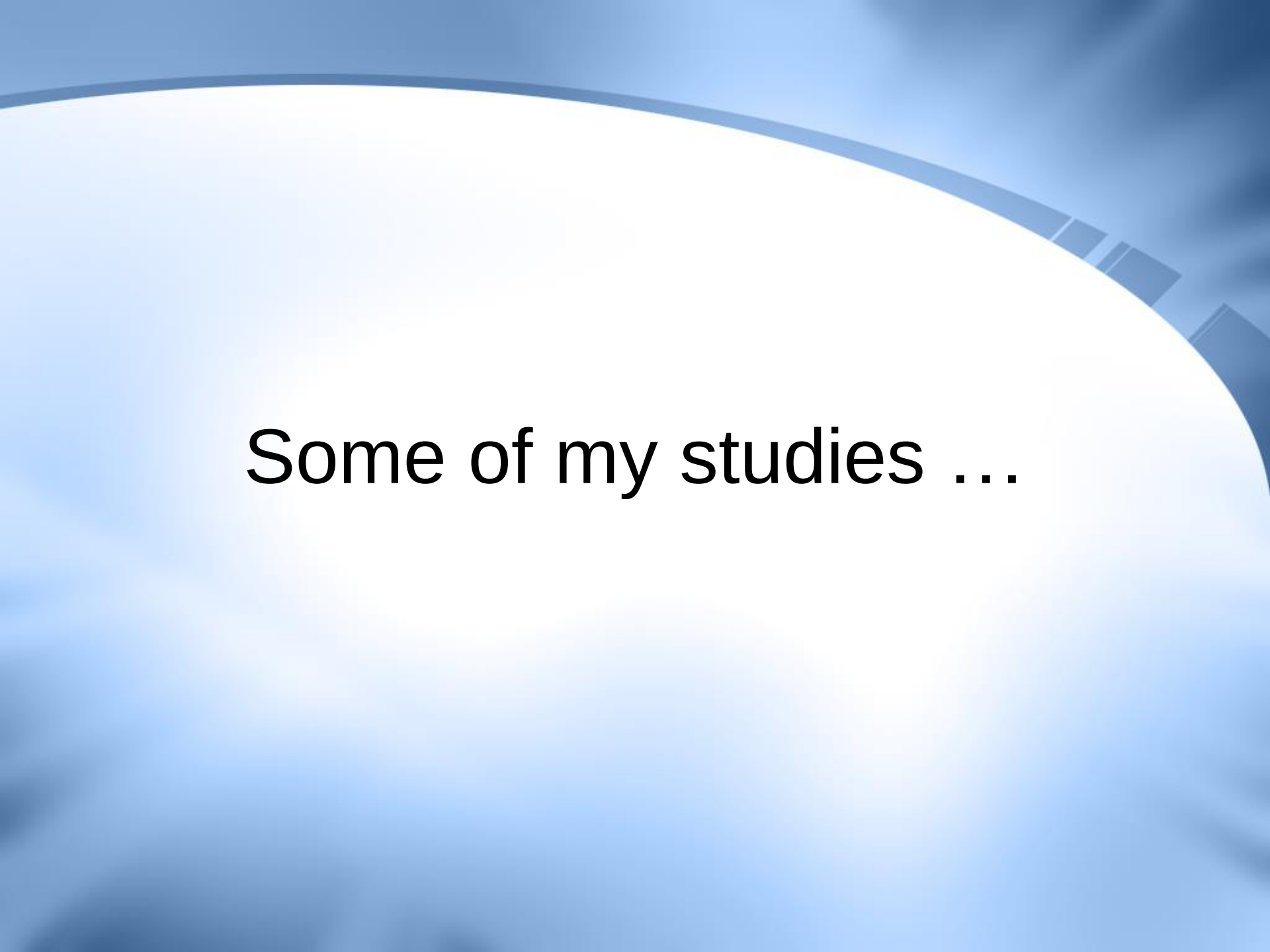


“Evidence based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients”



**Sackett DL et al.
BMJ 1996;312:71-72**



The background of the slide features a blue sky with soft, white clouds. A large, white, semi-circular shape is positioned in the upper half of the frame, creating a bright, central area. The text "Some of my studies ..." is centered within this white area.

Some of my studies ...

How well does the nurse “know” the patient?

- What problems/needs do they have?
- How do they want to participate in their own care?



Studies

Study I. Compare patients and RNs perceptions of **presence**, **severity** and **importance** of nursing problems

Study II: Compare patients and RNs perceptions of the level of participation the patient prefers and experienced having.

- Comparative design
- patient-RN dyads in acute somatic care
- 80 patients md 61 years (23-84 years), 46% female, admitted 5 days
- 30 RNs md 31 years, Work 1,5 years, 1 year at the ward
- Questionnaire
- Asked within 48 hrs from being admitted (md 26 hrs)

Study I: Questionnaire

Table 1 Questionnaire subscales and items (number of items in brackets)

Subscales (number of items)	Items
Communication (3)	Impaired hearing ^{1,3} , vision ^{1,3} , and speech ^{1,2,3}
Breathing/circulation (3)	Breathing difficulties ^{1,2,3} , cough ^{1,3} , and fever ^{1,2,3}
Nutrition (10)	Appetite ^{1,3} , nausea ^{1,2,3} , vomiting ^{1,3} , drinking ^{1,3} , body weight ^{1,2,3} , handling food on plate ² , bringing food to mouth ² , chewing ^{1,2} , swallowing ^{1,2} , and oral hygiene ²
Elimination (4)	Toileting ^{1,2,3} , constipation ^{1,2,3} , diarrhoea ^{1,2,3} , and incontinence ^{1,2,3}
Skin (2)	Ulcer ³ and dryness ³
Activity (6)	Changing position in bed ^{1,2} , transfer to/from bed ^{1,2} , walking ^{1,2,3} , getting dressed ^{1,2,3} , personal hygiene ^{1,2,3} , and showering ^{1,2,3}
Sleep/tiredness (4)	Falling asleep ^{1,2} , staying asleep ^{1,2} , tiredness ³ , and powerlessness ^{2,3}
Pain/sensory perception (3)	Acute pain ^{1,2,3} , chronic pain ^{1,2,3} , and dizziness ^{1,3}
Emotions/spirituality (8)	Anxiety ^{1,2,3} , fear ^{1,2} , stress ^{1,3} , insecurity ³ , self-esteem ^{2,3} , sadness ³ , loneliness ^{2,3} , and spiritual needs ^{2,3}

Concepts found in standardized classifications were: ¹ICF, International Classification of Functioning, Disability, and Health; ²NANDA, North American Nursing Diagnosis Association; ³VIPS model, Well-being, Integrity, Prevention, and Safety.

Study I: Questionnaire

Exempel:										
Ange vad som kännetecknar patientens situation när det gäller nedanstående områden.		Detta beskriver patientens nuvarande situation					Så här viktigt anser jag det vara att patienten förändrar sin situation eller får hjälp av vårdpersonalen att hantera den			
		inget problem	lindrigt problem	ganska svårt problem	svårt problem	mycket svårt problem	Inte så viktigt	ganska viktigt	viktigt	Mycket viktigt
Smärta/sinnesintryck										
Smärta		☒	☐	☒	☐	☐	☐	☐	☒	☐

Covering 43 areas, e.g. pain, constipation....

Studie II: Control Preference Scale

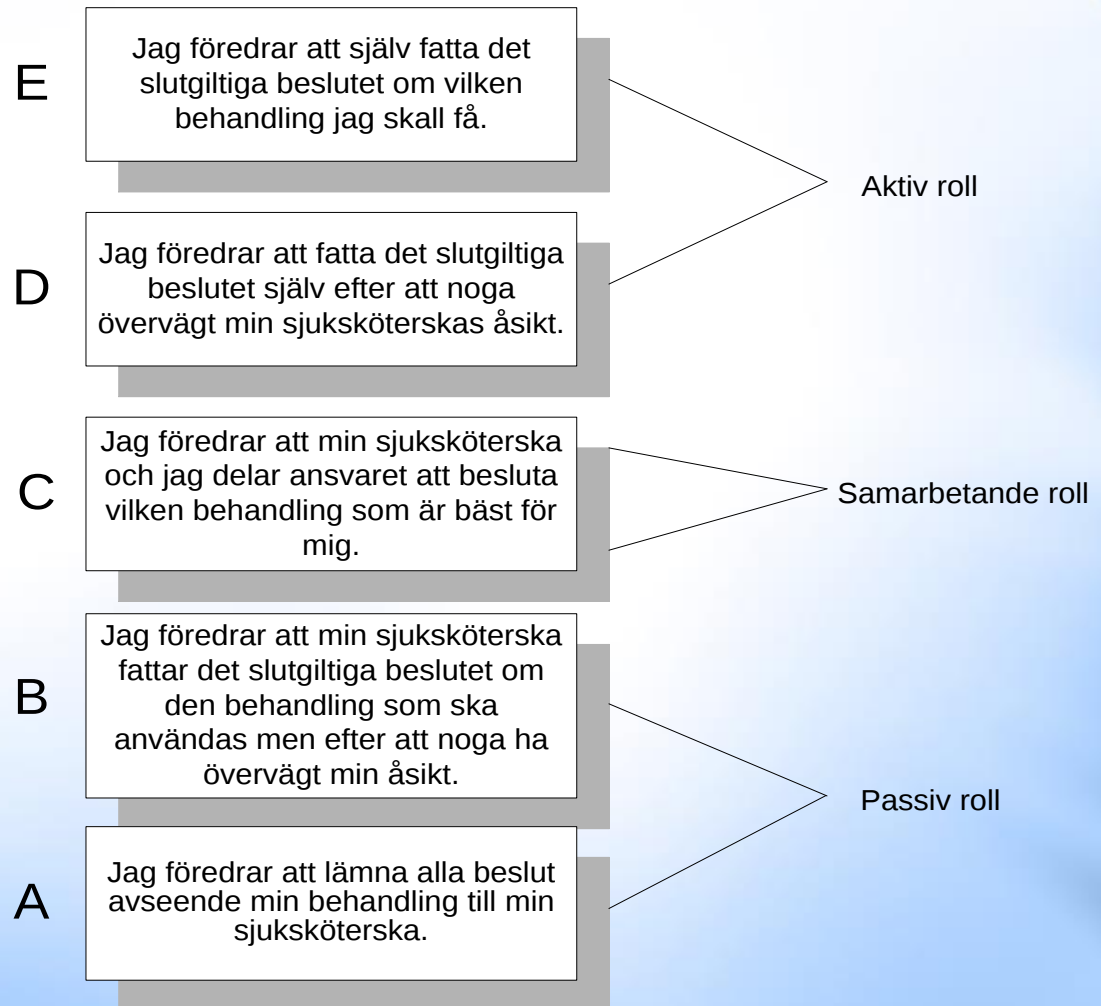
Degner & Sloan 1992

✕ What is your opinion about participating in decision making regarding your nursing care?

✕ in general?

✕ physical needs/problems?

✕ social/existential needs/problems?



Study I: Findings

Number of problems:

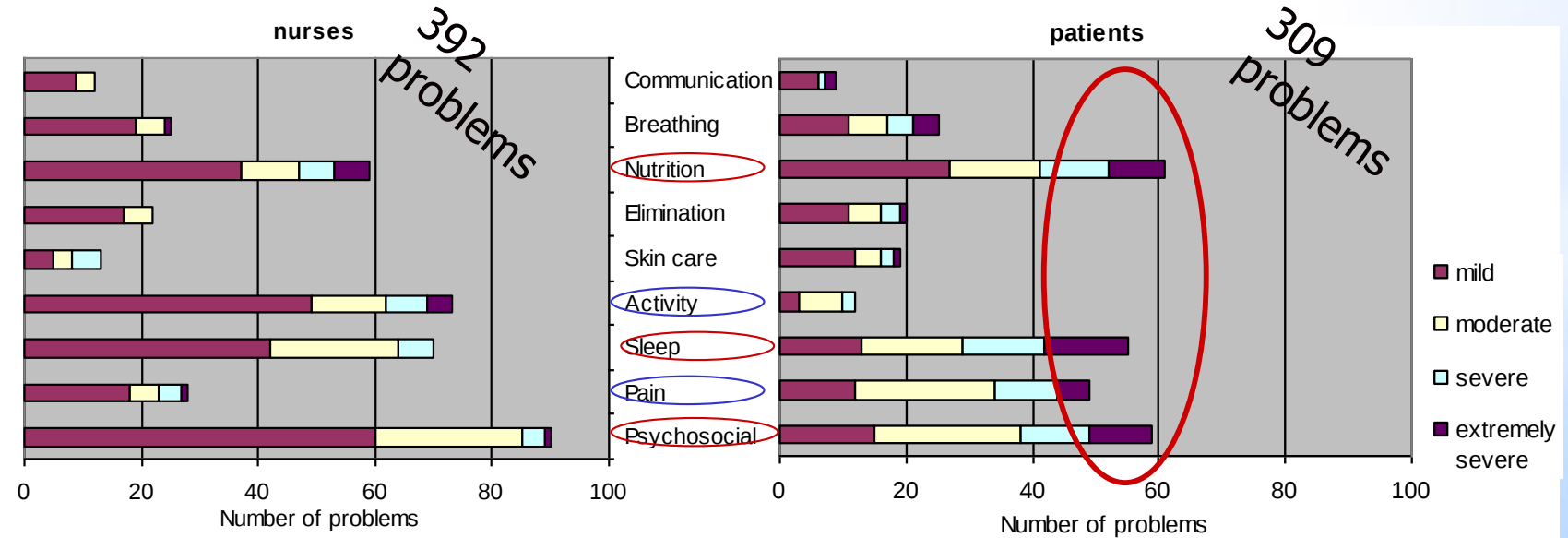
- RN: md 8,5 (IQR 5 to 12, range 1-26)
- Patients: md 7,0 (IQR 4 to 11,75, range 0 till 30)
- Pat.-RN dyad: 57 % of the RNs identified more problem than patients did, 38% identified fewer
- Agreement on 3 problem (IQR 2 to 6; range 0 to 17)
- Sensitivity
 - Total: 0,53
 - Nutrition 0,22
 - Activity 0,80



Mutually identified problems (n = 305)

- RNs **underestimated severity** ($p < 0.001$)
(47 % lower, 27 % equal, 27 % higher severity)
subscales: sleeping, breathing, activity, nutrition
- RNs and patients **estimated importance equally**
(32 % , 44 % lika, 24% högre betydelse)
subscale: breathing ($p < 0.01$)

Health problems that just one in the dyad identified

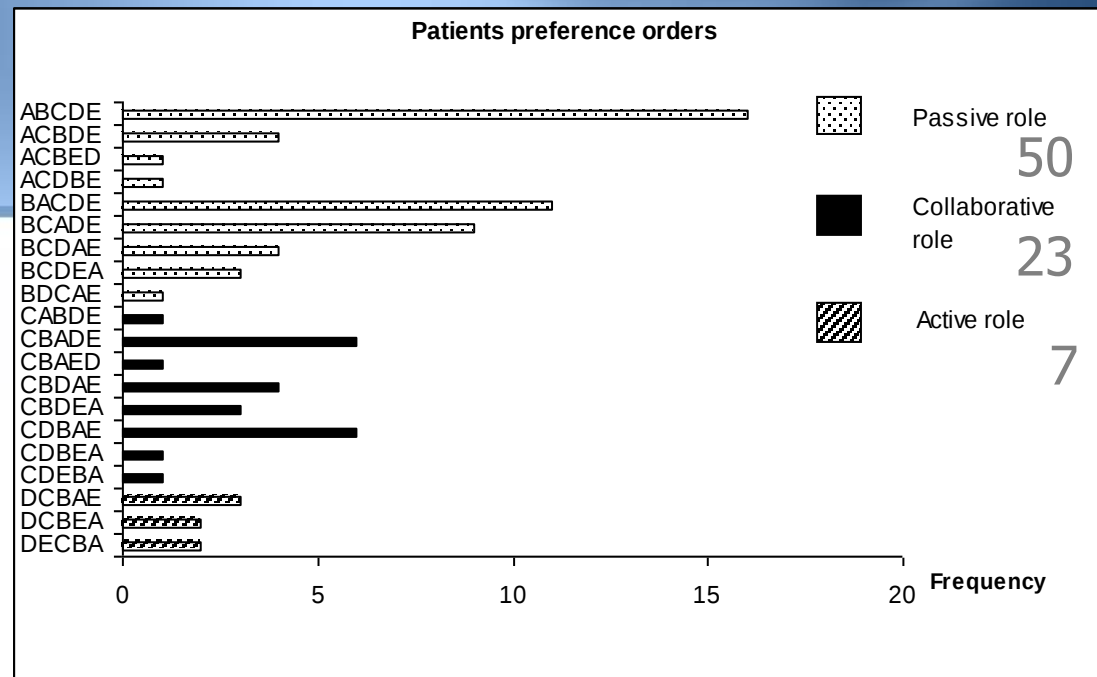


Study II: Findings

Married/co-habiting patients preferred a more passive role in general

Young patients (< 61 years) preferred a more active role for physical needs/problems

No differences in relation to sex

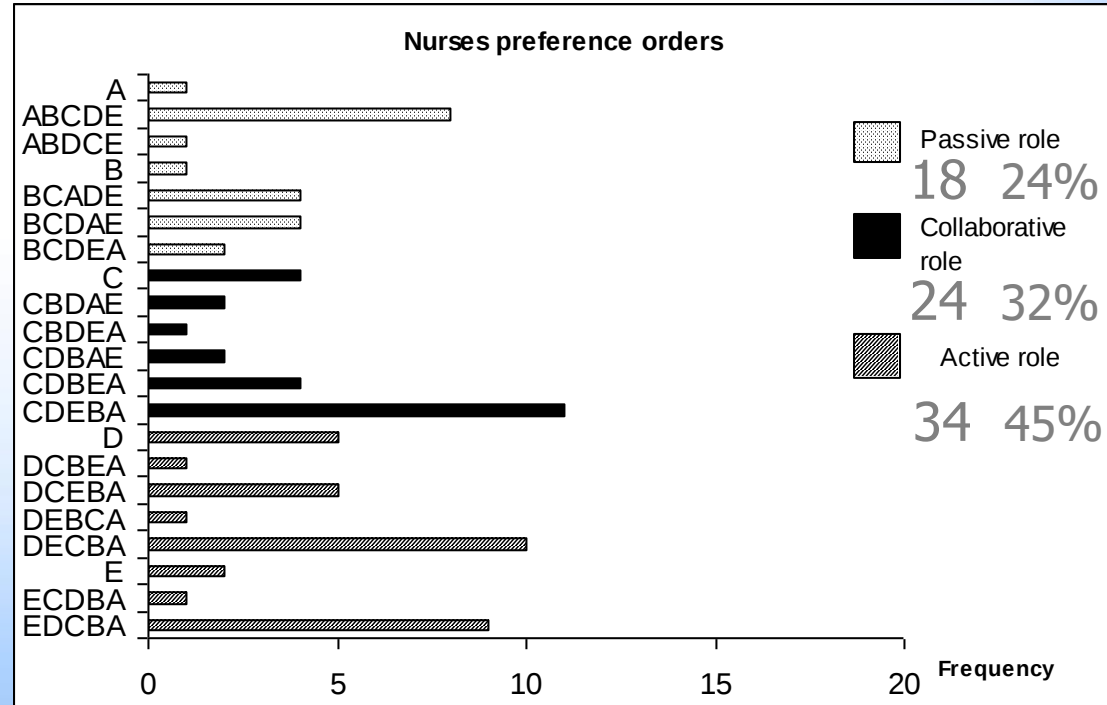
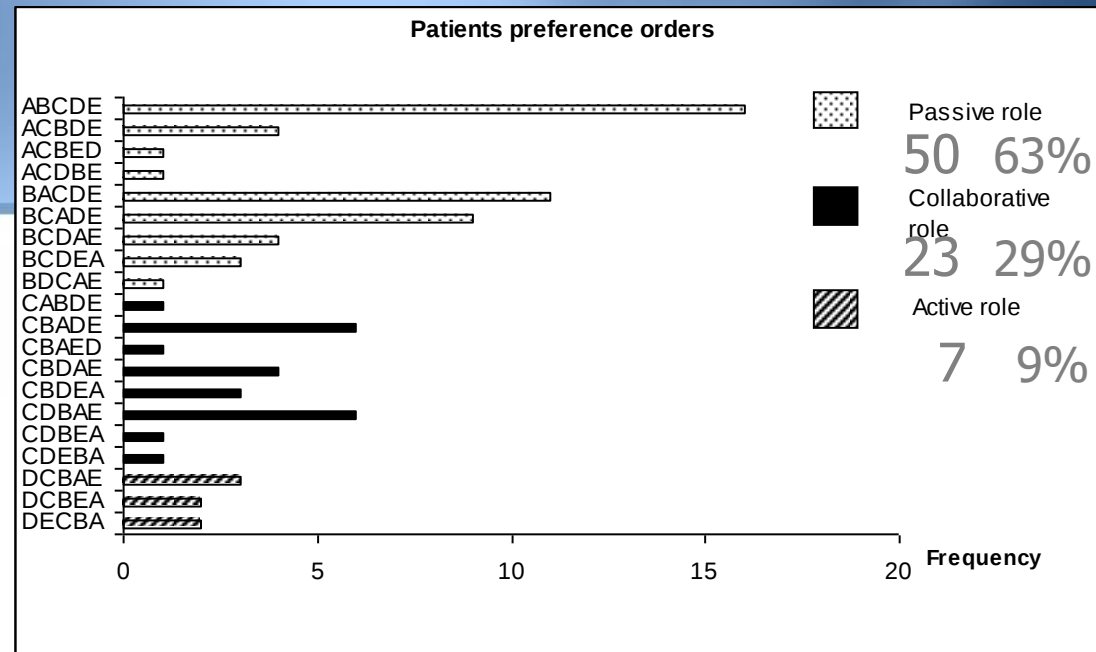


- Patients preferred a more passive role than RNs perceived ($p < 0.001$)

12 (16%) of the RNs identified same participation level as patients

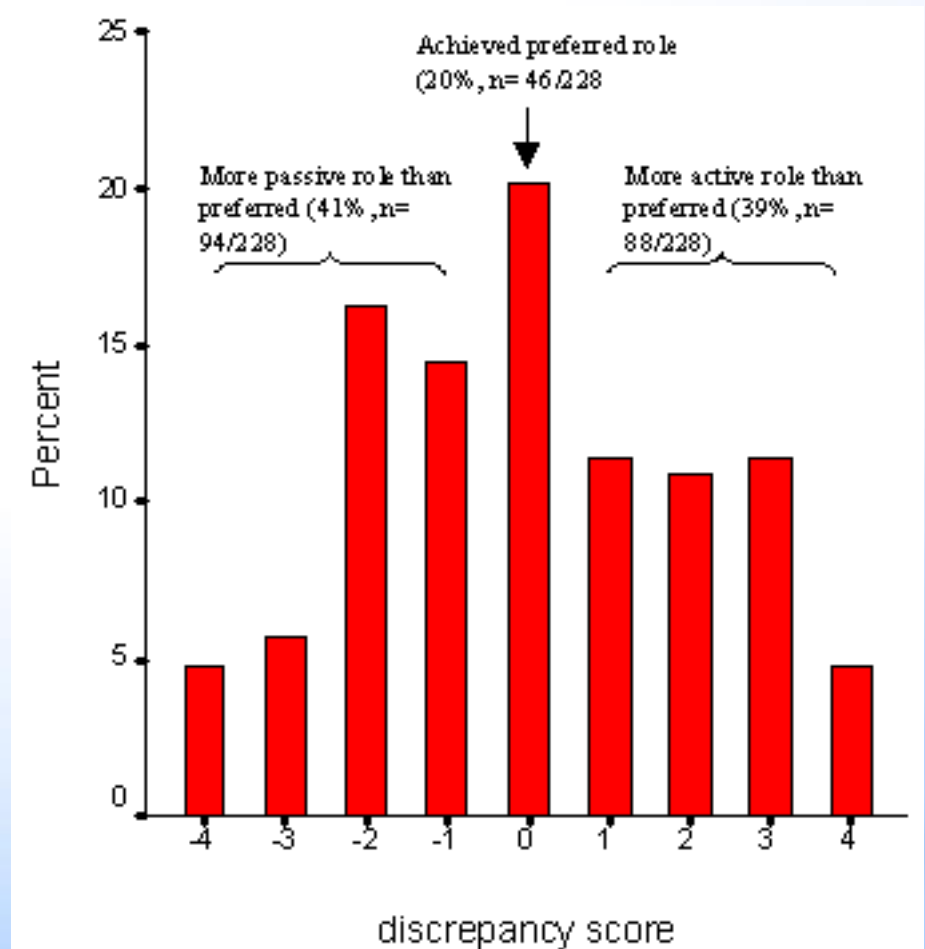
15 (20%) of the RNs identified a lower participation level than patients did

49 (64%) of the RNs identified a higher participation level than patients did



Experienced participation

- Difference between experienced and preferred participation
- More passive role for needs/problems related to *communication*, *breathing/circulation* and *pain*.
- more active role for needs/problems related to *activity* and *emotions/roles*



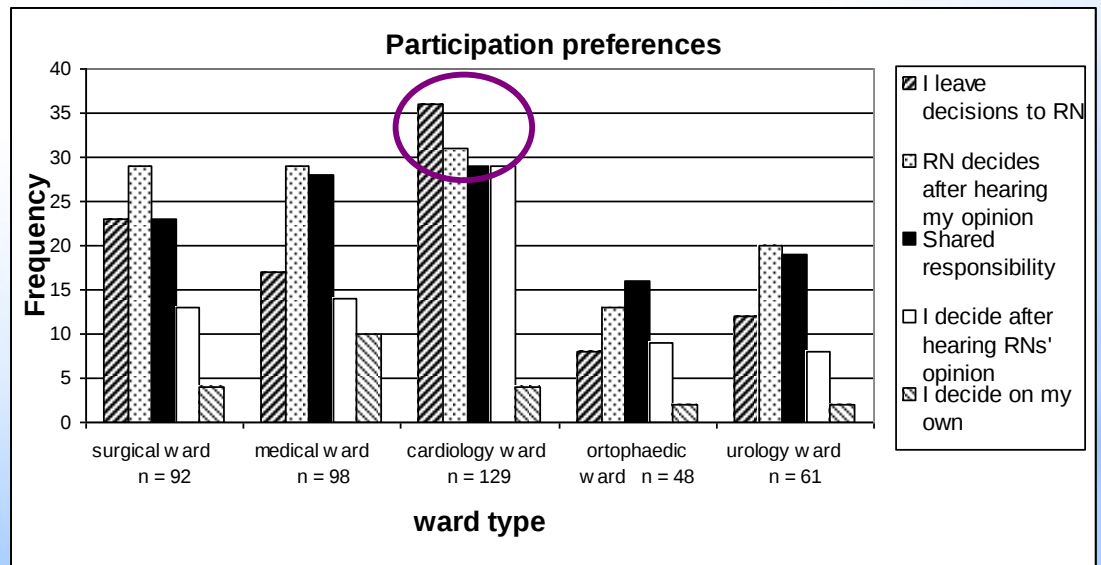
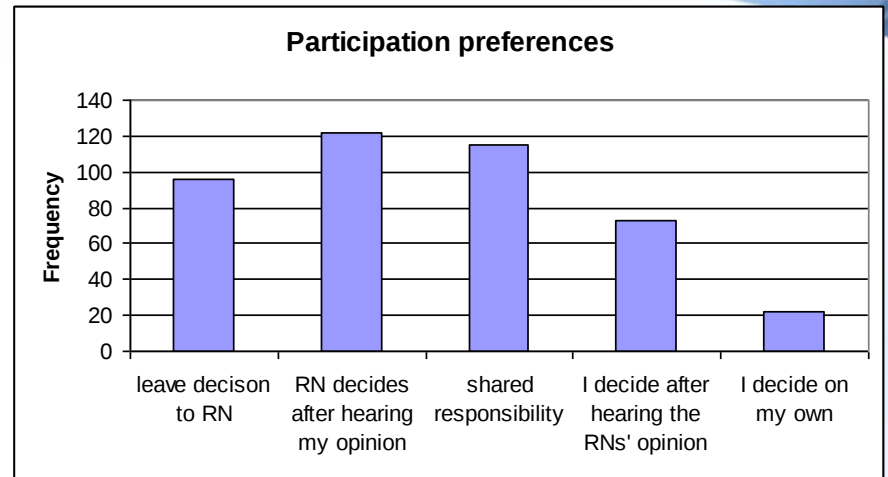
Study III

Aim: Investigate predictors for patient preferences for participation in clinical decision-making

- Cross-sectional survey
- Somatic hospital care, 15 wards
- 428 patients out of 876 consenting to be contacted
- Questionnaire: Control Preference Scale, choose one alternative
- Sent within one week from discharge, one reminder
- Multipel regressionsanalys

Findings

- Preferred a passive role



Who prefers a more active role?

 Sex *Women more active than men*

 Living condition

Living alone more active than co-habitants

 Education

*≥high school more active than lower
education*

 Employment

Pensioners more active than those working

Probability for preferring an active role...



Low educated, working man living together 8 %

High educated, female pensioner living alone 53 %

Conclusions...

- Patients and RNs were not in agreement about
 - current nursing problems, severity
 - patients participation preferences



Who has the interpretative prerogative?

- Patient?
- Nurse?
- Relatives?
-



How do we know that we know?

Information and knowledge

Factors affecting patients participation

Olsson & Quick, Bachelor degree 2016

- Information is provided so that patients understand it and has a need for it (Eldh et al., 2006; Larsson et al. 2011a; Soleimani et al., 2010)
- Patients felt that the nurse valued their knowledge (Eldh et al., 2006; Drach-Zahavy et al., 2014; Larsson et al., 2011a; Tobiano et al., 2015a)
- Knowledge of consequences of not being involved (Aasa et al., 2013; Aasen, 2015; Latimer et al., 2014; McTier et al., 2015; Tobiano et al., 2015a)
- Bedside reporting as a way of getting information (Drach-Zahavy et al., 2014; Tobiano et al., 2015a)

Information and knowledge

- Lack of knowledge about right to be involved (Höglund et al., 2010)
- Lack of sufficient knowledge when decisions was made (Höglund et al., 2010)
- Limited opportunity to prepare for the round (Larsson et al., 2011a)
- Not sufficient information provided (Eldh et al., 2006; Larsson et al., 2011b)
- Care staff used too difficult medical language (Drach-Zahavy et al., 2014; Larsson et al., 2011b)

Relationship with the nurse

- Feelings of being seen by the nurse
(Aasa et al., 2013; Larsson et al., 2011a; Soleimani et al., 2010)
- Feelings of confidence in the staff
(Aasa et al., 2013)
- Patients became passive when they felt that the nurse knew best
(Aasen, 2015; Larsson et al., 2011b; McTier et al., 2015; Soleimani et al., 2010)
- Approached patients with unconcern and lacked ability to create a good relation with the patient
(Drach-Zahavy et al., 2014; Larsson et al., 2011b; Latimer et al., 2014; Tobiano et al., 2015a)
- Nurses were ironic or talked to the patient as if he/she was a child
(Larsson et al., 2011a)

Relationship with the nurse

- Showed respect and saw them as individuals

(Eldh et al., 2006; Larsson et al., 2011a)

- Did not take enough initiative to involve the patient
(Höglund et al., 2010)

- Turned to the relatives instead of the patient
(Larsson et al., 2011b)

- Took time to listen (Larsson et al., 2011a)

- Ignored or interrupted the patient

(Drach-Zahavy et al., 2014)

- Paternalistic attitude and didn't want to share power
(Aasen, 2015; Larsson et al., 2011a; Larsson et al., 2011b; Tobiano et al., 2015a)

Patients situation and characteristics

- Patients health condition was sometimes a reason for not being involved (Eldh, Ekman et al., 2006; Höglund et al., 2010; Larsson et al., 2011b; Latimer et al., 2014; Soleimani et al., 2010; Tobiano et al., 2015a)
- Would not be a nuisance (Tobiano et al., 2015a; McTier et al., 2015)
- Patients with care experience took more initiative to be involved (Drach-Zahavy et al., 2014; Soleimani et al., 2010; Tobiano et al., 2015a)

Organisation

- Took enough time to respond to questions (Aasa et al., 2013)
- Wanted to diminish nurses work load (Tobiano et al., 2015a)
- Lack of time (Höglund et al., 2010)
- Economical restrictions (Latimer et al., 2014)
- Shortcomings in the caring environment (Soleimani et al., 2010)
- Patients perspective was not included in the nurses documentation (Larsson et al., 2011a)
- Constantly meeting different nurses (Larsson et al., 2011b)

What is an active participatory role?

- To be informed –To decide
- Can you be active by being passive?
- How stable is it over time?



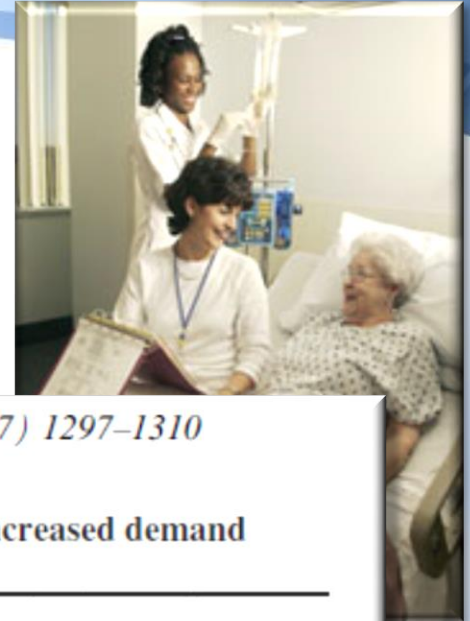
Different approaches...

Professional determined patient involvement

High level of patient power

Informed decision-making

Shared decision making



A.G.H. Thompson / Social Science & Medicine 64 (2007) 1297–1310

Low level of

	Reduced demand	Increased demand
Need for health care		
Type of illness	acute	chronic
Seriousness	high	low
Personal characteristics		
Knowledge/experience	(variable)	(variable)
Personality	passive	active
Professional relationship		
Trust	high	low

Fig. 3. Dynamic dimensions of involvement.

Thompson 2012

Hindering factors for participation...



- Professional attitudes and demands
- Patient characteristics
- Information and knowledge imbalance
- Time frame (Ashworth 1980; Adams 2001)
- Organisational demands?*
- Concept of Patient? Client? Consumer?
- Difference between 'clinical-deciding' och 'clinical-doing' (Entwistle 2000).*

Supporting factors for participation...



- Professional attitudes and demands
- Patient characteristics
- Legal regulations
- Information and knowledge balance
- eHealth applications
- Organisation
- Person-centered care

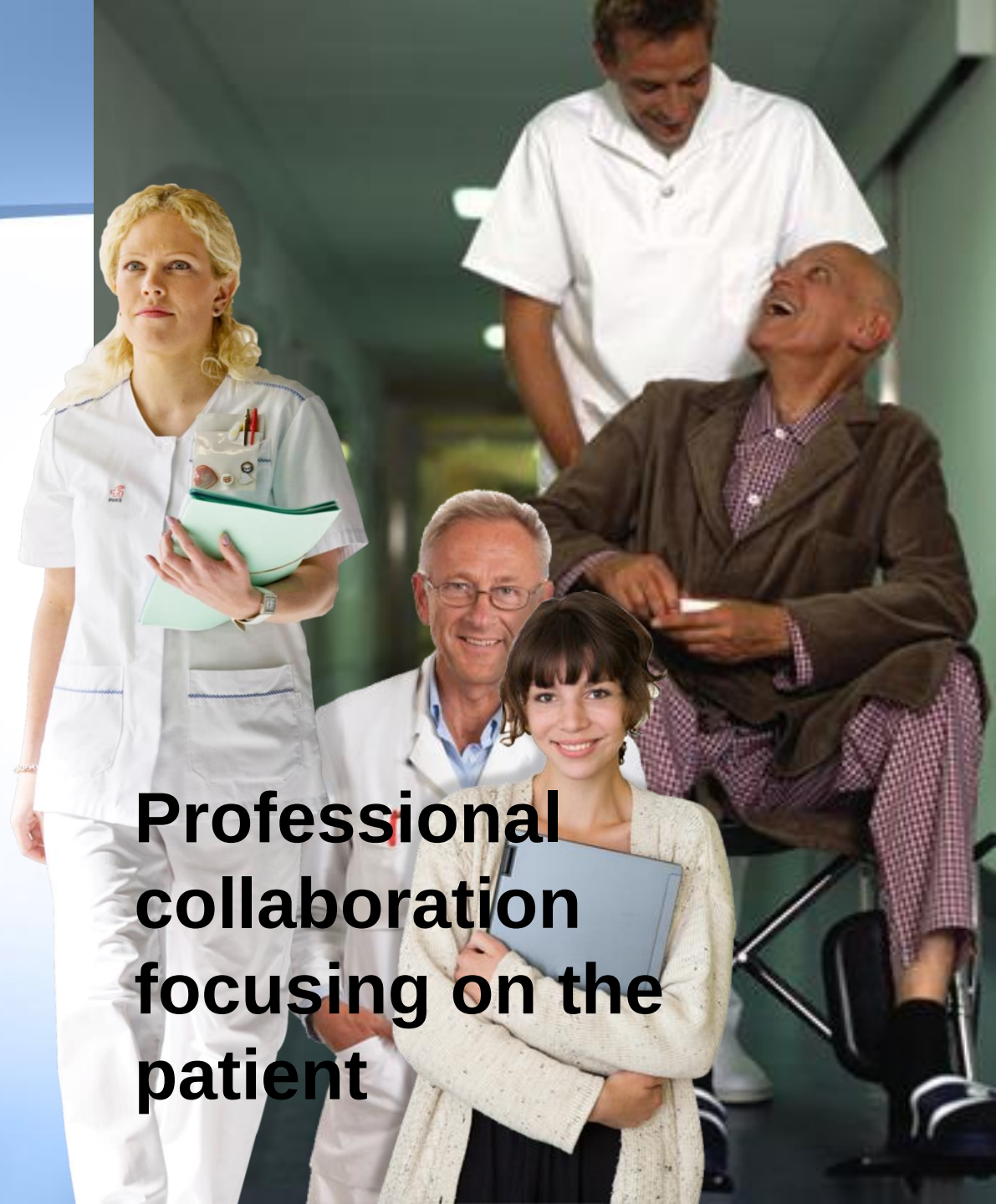
Report of patient participation in health care with a focus on chronic diseases SBU (9 reviews, 2009-2016) Statens beredning för medicinsk och social utvärdering

Tabell 1. Sammanställning av effekter av olika insatser inom ramen för personcentrerad vård^a, delat beslutsfattande^b och stöd till egenvård^c

Metod/ insats	Utfall och effekt	Evidens enligt översikten författare
Personcentrerad vårdplanering ^a	Tilltro till egen förmåga ökar Hälsorelaterade fysiska utfallsmått förbättras Psykisk hälsa ökar Ingen signifikant effekt på subjektiv hälsa	Måttligt starkt Måttligt starkt Måttligt starkt Måttligt starkt
Träning/utbildning för person/patientcentrerat arbetssätt ^a	Blandade signifikanta och icke signifikanta resultat för: konsultationens kvalitet, patientnöjdhet, förändrat hälsobeteende, hälsostatus	Ej evidensbedömda
Insatser för att främja hälso- och sjukvårdspersonalens anammande av delat beslutsfattande ^b	Patientens upplevelse av kontroll vid beslutsfattande ökar Vårdpersonalens tillämpning av delat beslutsfattande (observatörsbaserade utfallsmått)	Otillräckligt Otillräckligt
Patientriktade beslutsstöd ^b	Kunskap om alternativ och resultat ökar Andel patienter med adekvat uppfattning om risker med alternativen ökar Andel beslut där valt alternativ är i kongruens med patientens värderingar Patienters upplevelse av att inte vara nog informerad minskar Oklarhet kring patientens egna värderingar minskar Beslut som fattas enbart av vårdpersonal minskar	Starkt Måttligt starkt Begränsat Starkt Starkt Måttligt starkt

SBU report, continued...

Grupputbildning i egenvård ^c	Tilltro till egen förmåga ökar Ingen effekt på livskvalitet/funktion i de flesta studierna Liten minskning av HbA _{1c} hos patienter med diabetes Förbättrad fysisk kapacitet hos patienter med risk för fall	Begränsat till måttligt Begränsat till måttligt Begränsat till måttligt Måttligt starkt
Mobila applikationer ^c	Signifikanta förbättringar av hälsorelaterade fysiska utfallsmått i vissa studier	Ej evidensbedömda
Motiverande samtal ^c	Fysisk aktivitet ökar i grupper med visa tillstånd, men bara i uppföljning en kort tid efter insatsen Ingen effekt på funktionell träningskapacitet Ingen effekt på eller hjärt-lungfunktion	Måttligt Otillräckligt Måttligt
Chronic disease self-management program (CDSMP) ^c	Små positiva effekter på självrapporterade hälsomått hälsorelaterat beteende och tilltro till egen förmåga Livskvalitet Resursåtgång i vården	Begränsat Otillräckligt Otillräckligt
Patientutbildning i empowerment ^c	Signifikant förbättring på flera hälsorelaterade utfallsmått: tilltro till egen förmåga och egenvård, psykisk empowerment, kunskap om sjukdom och hantering av symtom och livskvalitet	Ej evidensbedömda



**Professional
collaboration
focusing on the
patient**

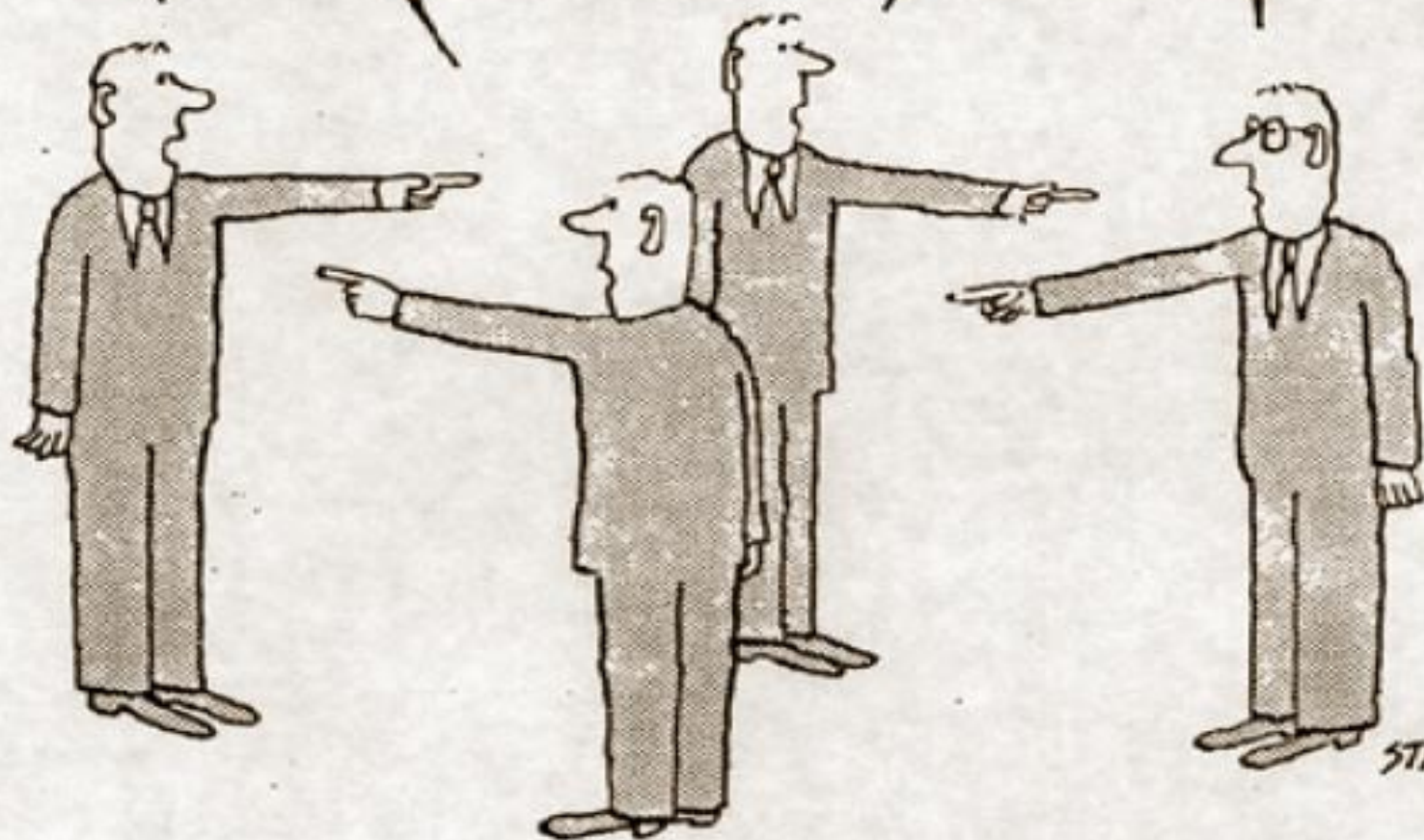
TEAM WORK



Collaboration and teamwork



DET ÄR HAN SOM HAR ANSVARET

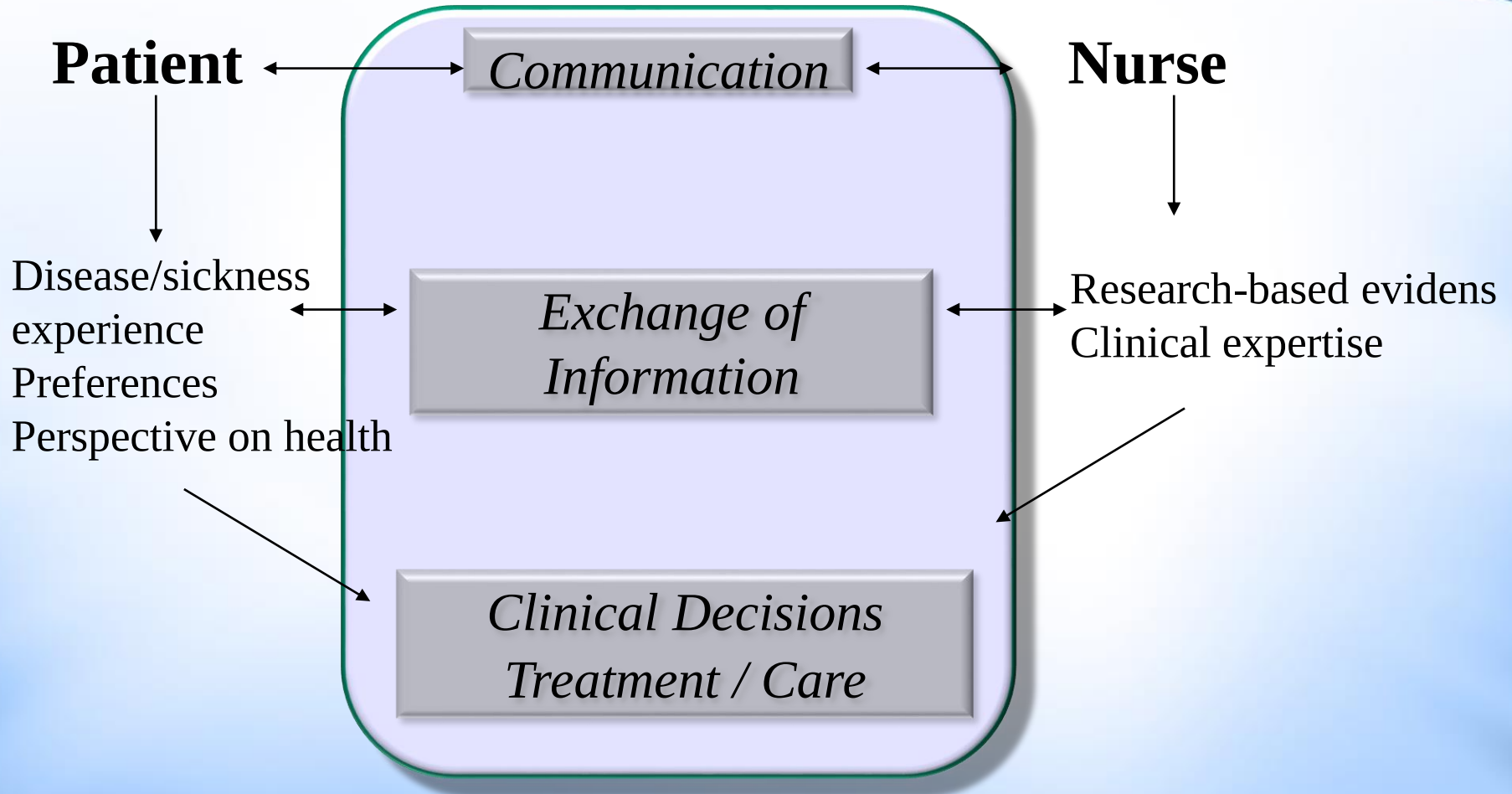


Person-centered care

- Assumes an I – YOU – relationship (Buber 1962, 1988)
- Two subjects meeting (characterized by reciprocity, equality, acceptance och acknowledgement)
- Assuming that a person has abilities (will, dignity, trust in his own ability, relationships, ...)
- Design care with respect for patient values, preferences and wills
- Carer promotes own responsibility and autonomy
- Similarities with empowerment, more than participation

Shared decision making model (Gafni and Charles)

I-YOU-relationship



Bidra med innehåll till journalen

- CHOICE (Ruland)

Patientens perspektiv
som grund för vård

Problemvalg → Plagsomhet → Prioritering for hjelp → Oppsummering

Vennligst kontroller at opplysningene stemmer. [Hjelp](#)

Prioritering for hjelp	Symptomer	Plagsomhet
10	Kvalme	Svært mye
	Økonomiske bekymringer	Svært mye
	Usikker på videre behandling	Svært mye
9	Smerter i muskler eller ledd	Mye
8	Søvnproblemer	Svært mye
	Får ikke i meg nok drikke	Mye
	Får ikke i meg nok mat	Mye
	Diaré	En del
5	Vanskelig å håndtere medisinene	Mye
	Kløe eller utslett	En del
4	Smerter i mage eller tarm	Lite
2	Engstelig	Mye
	Humørsvingninger	En del

FORRIGE RULLE OPP RULLE NED AVSLUTTE



Clinical implications...

- We need to know the patient's perspective on the health situation

Use systematic assessment methods to elicit individual patient perspectives

A trusting relationship (encounter) is a prerequisite for person-centered care

You as a person is the most important tool



How well does the nurse “know” the patient?

What possibilities do they have to do that?

- Have we organized care in a optimal way?
- Do we acknowledge relationship as much as doing tasks?
- Is continuity an important aspect here?



Seek agreement on...

- Why do you seek health care?
- What needs/health problems do you have?
- What is important? Prioritized?
- What is the goal? What should be achieved?
- What do you do? What could we help you with?
- Care plans showing this

Two small tips...

- Depart from the same platform
- Agree on where you are going



To conclude...

- Knowledge about patients' basic assumptions and preferences for participation has great value for RNs
- RNs need to use structured methods for eliciting perspective
- RNs need to find ways of involving patients in decision-making in nursing

The most appropriate way of knowing a specific patient's preferences for participation, and perspective on own health, is through direct assessment and interaction with the patient



Right tools?

Person-centered care
Shared decision-making

Not just tools – more profound than that

Thank you for the
attention!



jfl@du.se

Patient participation in nursing care from a patient perspective: a Grounded Theory study

Inga E. Larsson^{1,2} MSc (Nursing), BSc, RN (Doctoral student and Lecturer), Monika J. M. Sahlsten¹ MSc (Nursing), BSc, RN (Doctoral student), Björn Sjöström³ PhD, RN (Professor), Catharina S. C. Lindencrona⁴ Dr Med Sc., MS (AdmNEd), BS (Ed), RNT (Senior Investigator (ret.)) and Kaety A. E. Plos¹ PhD, BSc (Senior Lecturer)

¹Institute of Health and Care Sciences, The Sahlgrenska Academy at Göteborg University, Göteborg, ²Department of Nursing, Health and Culture, University West, Vänersborg, Sweden, ³School of Life Sciences, University of Skövde and ⁴Department of Health and Welfare, Stockholm, Sweden

Scand J Caring Sci; 2007; 21; 313–320

Patient participation in nursing care from a patient perspective: a Grounded Theory study

Table 2 Categories based on patients' description of patient participation in nursing care

Core category	Categories	Subcategories
Insight through consideration	Obliging atmosphere	Relatedness
		Adaptability
		Invitation to speak
	Emotional response	Sensitiveness
		Thoughtfulness
		Trust
	Concordance	Will
		Dialogue process
		Growth of knowledge
		Support
	Rights	Written agreement
		Information
		Choice
		Decision
		Responsibility

Findings: The patients emphasised the importance of collaboration to improve participation. The core category, Insight through consideration, was generated from four inter-related categories: (i) Obliging atmosphere; (ii) Emotional response; (iii) Concordance; and (iv) Rights and their 15 subcategories.

Conclusions: The meaning structures of patient participation in nursing care revealed from a patient point of view, seemed to mainly consist of not only external factors presented by the institutions – by the professionals – but also internal patient factors. The patients' view of participation should be considered to a greater degree in nursing practice and education, as should also further development of nursing care policy programmes, evaluation and quality assurance criteria. For further development, studies are needed in similar and other settings.

Keywords: focus group, Grounded Theory, nurse/nursing, patient participation.

Submitted 1 May 2006, Accepted 10 July 2006

CONDITIONS FOR PATIENT PARTICIPATION AND NON-PARTICIPATION IN HEALTH CARE

Nurs Ethics 2006; 13; 503

Ann Catrine Eldh, Inger Ekman and Margareta Ehnfors

Key words: content analysis; hermeneutic; non-participation; patient education; patient participation

This study explored patients' experiences of participation and non-participation in their health care. A questionnaire-based survey method was used. Content analysis showed that conditions for patient participation occurred when information was provided not by using standard procedures but based on individual needs and accompanied by explanations, when the patient was regarded as an individual, when the patient's knowledge was recognized by staff, and when the patient made decisions based on knowledge and needs, or performed self-care. Thus, to provide conditions for true patient participation, professionals need to recognize each patient's unique knowledge and respect the individual's description of his or her situation rather than just inviting the person to participate in decision making.

510 AC Eldh et al.

Table 4 Conditions in situations experienced as patient non-participation: subthemes and themes

Subtheme	Theme
When I don't get enough information	When receiving insufficient information
When I don't know what will happen	
When I don't know what has happened	
When I'm not informed so I can take part in a decision	
When I'm not informed on time	When my knowledge is not recognized
When I'm not told where to turn	
When my knowledge is not considered	
When my description of symptoms is not taken seriously	
When what I tell is not as important as test results	When I'm not regarded as an individual
When diagnosis/treatment is established in advance, irrespective of my story	
When feeling that I'm stupid	
When I'm blamed for my problems	
When being regarded as an object	When I don't get the care I regard as necessary
When I'm not seen for who I am	
When I'm not listened to	
When my opinion is not regarded	
When my remarks are ignored and staff do as they prefer	When I get information but no explanation
When I'm referred without dialogue	
When I can't get in touch with the staff	
When the treatment I need is postponed	
When I can't get the care I believe I need	When I don't act
When I'm given results but no explanation	
When treatment is given according to a set protocol	
When information is given according to a set checklist	
When I can't get rationales for procedures	
When I lack energy to ask or tell	
When I don't tell or do	

DOCUMENTATION OF PATIENTS' PARTICIPATION IN CARE AT THE END OF LIFE

Nurs Ethics 2006; 13; 394

Irma Lindström, Fannie Gaston-Johansson and Ella Danielson

Key words: content analysis; documentation; end participation

The aim of this study was to describe how patients' was documented in their health care records during. Two hundred and twenty-nine deceased adult persons in municipalities in a Swedish county and their records in care units. Content analysis was used to analyse participation were described: refusing offered care and desire for everyday life; and making personal decisions to be involved in their care at the end of the life and care offered. Characteristic of the different was activities represented. The description of patients' in time indicated their dissociation from the health care

Table 1 Process of analysis of texts to definition of categories

Text from records	Condensation	Code	Category
The patient does not want food or drink	Does not want food or drink	Refusing	Refusing offered care and treatments
The patient spits out the medication	Spits out medication		
The patient refuses mouth care	Refuses mouth care		
The patient appeals for pain relief	Appealing for pain relief	Appealing	Appealing for relief
The patient appeals for something for sleeping	Appealing for sleeping pills		
The patient is begging constantly for help	Begging constantly for help		
The patient wants to go home and eventually discusses home nursing help	Wanting to go home	Desiring	Desires for everyday life
The patient wishes to go to the hospital	Wishing to go to the hospital		
The patient is longing for a room companion	Longing for company		
The patient has morphine medication that she takes herself	Desires deciding when to take the pain relief drugs	Self-determination	Making personal decisions
In agreement with the patient we decide not to start with cancer therapy	In agreement with the patient, decide on no therapy	Co-determination	

COMPLIANCE versus NONCOMPLIANCE

Patients' perceptions of barriers for participation in nursing care

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Patients' perceptions of barriers for participation in nursing care

Table 2 Barriers for patient participation from patients' perspective

Categories	Subcategories
Facing own inability	Overwhelmed by the illness Not knowing enough Low self-esteem
Meeting lack of empathy	Met without interest Met without a sensitive ear
Meeting a paternalistic attitude	Met by domination Met by secretiveness
Sensing structural barriers	New faces all the time Insufficient documentation No bed available for me

Ethical issues and approval: The ethics of scientific work was adhered to. Each study participant gave informed consent after verbal and written information. The Ethics Committee of Göteborg University approved the study.

Results: The barriers for patient participation were identified as four categories: Facing own inability, meeting lack of empathy, meeting a paternalistic attitude and sensing structural barriers, and their 10 underlying subcategories.

Conclusions: Our study contributes knowledge and understanding of patients' experiences of barriers for participation. The findings point to remaining structures and nurse attitudes that are of disadvantage for patients' participation. The findings may increase the understanding of patient participation and may serve as an incentive in practice and nursing education to meet and eliminate these barriers, in quality assurance of care, work organization and further research.

Keywords: barriers, focus groups, hindrance, nursing care, patient participation.

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