Clinical decision-making
Can and will patients participate?

Janne Florin
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YES!

Under certain circumstances
Participation in a process

Assessing
Diagnosing
Implementing
Planning
Evaluating
Conceptual development

Autonomy, independence

Participation

Empowerment

Power

Patient-centred care

Lifeworld perspective

Person-centred care

Patient power
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"
Knowledge
- Science
- Facts
- Beliefs
- Data

Policy

Society
- Economic resources and constrains
- Legal requirements
- Regulatory requirements
- Expectations of health and health care

Understanding of patients’ situation

Ethics

Values:
- Patient’s values
- Clinician’s values
- Family’s values

Clinical decision

Content of clinical decisions

Knowledge

• Science
• Facts
• Beliefs
• Data

Policy

Society

• Economic resources and constrains
• Legal requirements
• Regulatory requirements
• Expectations of health and health care

Understanding of patients’ situation

Ethics

Values:
• Patient’s values
• Clinician’s values
• Family’s values

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

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

<table>
<thead>
<tr>
<th>Ange vad som kännetecknar patientens situation när det gäller nedanstående områden.</th>
<th>Detta beskriver patientens nuvarande situation</th>
<th>Så här viktigt anser jag det vara att patienten förändrar sin situation eller får hjälp av vårdpersonalen att hantera den</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smärta/sinnesintryck</td>
<td>Smärta</td>
<td></td>
</tr>
<tr>
<td>Smärta</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Covering 43 areas, e.g. pain, constipation....
Studie II: Control Preference Scale

Degner & Sloan 1992

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

• in general?

• physical needs/problems?

• social/existential needs/problems?

A

Jag föredrar att lämna alla beslut avseende min behandling till min sjuksköterska.

B

Jag föredrar att min sjuksköterska fattar det slutgiltiga beslutet om den behandling som ska användas men efter att noga ha övervägt min åsikt.

C

Jag föredrar att min sjuksköterska och jag delar ansvaret att besluta vilken behandling som är bäst för mig.

D

Jag föredrar att fatta det slutgiltiga beslutet själv efter att noga övervägt min sjuksköterskas åsikt.

E

Jag föredrar att själv fatta det slutgiltiga beslutet om vilken behandling jag skall få.

Aktiv roll

Samarbetande roll

Passiv roll
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*
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

- Multiple regressions analysis
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...

- High level of patient power
- Informed decision-making
- Shared decision making
- Professional determined patient involvement

![Image](Thompson 2012)


<table>
<thead>
<tr>
<th>Need for health care</th>
<th>Reduced demand</th>
<th>Increased demand</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of illness</td>
<td>acute</td>
<td>chronic</td>
</tr>
<tr>
<td>Seriousness</td>
<td>high</td>
<td>low</td>
</tr>
<tr>
<td>Personal characteristics</td>
<td>(variable)</td>
<td>(variable)</td>
</tr>
<tr>
<td>Knowledge/experience</td>
<td>passive</td>
<td>active</td>
</tr>
<tr>
<td>Personality</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional relationship</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trust</td>
<td>high</td>
<td>low</td>
</tr>
</tbody>
</table>

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, delat beslutsfattande och stöd till egenvård

<table>
<thead>
<tr>
<th>Metod/ insats</th>
<th>Utfall och effekt</th>
<th>Evidens enligt översikten författare</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personcentrerad vårdplanering</td>
<td>Tilltro till egen förmåga ökar Hälsoförmåga ökar fysiska utfallsmätt förbättras</td>
<td>Måttligt starkt</td>
</tr>
<tr>
<td></td>
<td>Psykisk hälsa ökar</td>
<td>Måttligt starkt</td>
</tr>
<tr>
<td></td>
<td>Ingen signifikant effekt på subjektiv hälsa</td>
<td>Måttligt starkt</td>
</tr>
<tr>
<td>Träning/utbildning för person/patientcentrala arbetssätt</td>
<td>Blandade signifikanta och icke signifikanta resultat för: konsultationskvalitet, patientnöjdhet, förändrat hälsobeteende, hälsostatus</td>
<td>Ej evidensbedömda</td>
</tr>
<tr>
<td>Insatser för att främja häls- och sjukvårdpersonals anamnande av delat beslutsfattande</td>
<td>Patientens upplevelse av kontroll vid beslutsfattande ökar Vårdpersonalens tillämpning av delat beslutsfattande (observatörsbaserade utfallsmätt)</td>
<td>Otillräckligt</td>
</tr>
<tr>
<td>Patientriktade beslutsstöd</td>
<td>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 Patientens upplevelse av att inte vara nog informerad minskar Oklarhet kring patientens egna värderingar minskar Beslut som fattas enbart av vårdpersonal minskar</td>
<td>Starkt</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Måttligt starkt</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Begränsat</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Starkt</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Måttligt starkt</td>
</tr>
<tr>
<td>Gruppuntbildning i egenvård&lt;sup&gt;c&lt;/sup&gt;</td>
<td>Tilltro till egen förmåga ökar Ingen effekt på livskvalitet/funktion i de flesta studierna Litet minskning av HbA1c hos patienter med diabetes Förbättrad fysisk kapacitet hos patienter med risk för fall</td>
<td>Begränsat till måttligt Begränsat till måttligt Måttligt starkt</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td>Mobila applikationer&lt;sup&gt;c&lt;/sup&gt;</td>
<td>Signifikanta förbättringar av hälsorelaterade fysiska utfallsmått i vissa studier</td>
<td>Ej evidensbedömda</td>
</tr>
<tr>
<td>Motiverande samtal&lt;sup&gt;c&lt;/sup&gt;</td>
<td>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</td>
<td>Måttligt Otilräckligt Måttligt</td>
</tr>
<tr>
<td>Chronic disease self-management program (CDSMP)&lt;sup&gt;c&lt;/sup&gt;</td>
<td>Små positiva effekter på självrapportherade hälsomått hälsorelaterat beteende och tilltro till egen förmåga Livskvalitet Resursåtgång i vården</td>
<td>Begränsat Otilräckligt Otilräckligt</td>
</tr>
<tr>
<td>Patientutbildning i empowerment&lt;sup&gt;c&lt;/sup&gt;</td>
<td>Signifikant förbättring på flera hälsorelaterade utfallsmått: tilltro till egen förmåga och egenvård, psykisk empowerment, kunskap om sjukvård och hantering av symtom och livskvalitet</td>
<td>Ej evidensbedömda</td>
</tr>
</tbody>
</table>
Professional collaboration focusing on the patient
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 and 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)

- Patient
  - Disease/sickness experience
  - Preferences
  - Perspective on health

- Nurse
  - Research-based evidens
  - Clinical expertise

I-YOU-relationship

Communication

Exchange of Information

Clinical Decisions Treatment / Care
Bidra med innehåll till journalen

• **CHOICE (Ruland)**

Patientens perspektiv som grund för vård

<table>
<thead>
<tr>
<th>Prioritering for hjelp</th>
<th>Symptomer</th>
<th>Plagsomhet</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>Kvalme</td>
<td>Svaërt mye</td>
</tr>
<tr>
<td></td>
<td>Økonomiske bekymringer</td>
<td>Svaërt mye</td>
</tr>
<tr>
<td></td>
<td>Usikker på videre behandling</td>
<td>Svaërt mye</td>
</tr>
<tr>
<td>9</td>
<td>Smerter i muskler eller ledd</td>
<td>Mye</td>
</tr>
<tr>
<td>8</td>
<td>Søvnproblemer</td>
<td>Svaërt mye</td>
</tr>
<tr>
<td></td>
<td>Får ikke i meg nok drikke</td>
<td>Mye</td>
</tr>
<tr>
<td></td>
<td>Får ikke i meg nok mat</td>
<td>Mye</td>
</tr>
<tr>
<td></td>
<td>Diaré</td>
<td>En del</td>
</tr>
<tr>
<td>5</td>
<td>Vanskelig å håndtere medisinene</td>
<td>Mye</td>
</tr>
<tr>
<td></td>
<td>Klæe eller utslett</td>
<td>En del</td>
</tr>
<tr>
<td>4</td>
<td>Smerter i mage eller tarm</td>
<td>Lite</td>
</tr>
<tr>
<td>2</td>
<td>Engstelig</td>
<td>Mye</td>
</tr>
<tr>
<td></td>
<td>Humorsvingninger</td>
<td>En del</td>
</tr>
</tbody>
</table>
Health care is fragmentizing patients.
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!

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

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

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

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

<table>
<thead>
<tr>
<th>Core category</th>
<th>Categories</th>
<th>Subcategories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insight through</td>
<td>Obliging atmosphere</td>
<td>Relatedness, Adaptability, Invitation to speak</td>
</tr>
<tr>
<td>consideration</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Emotional response</td>
<td>Sensitivity, Thoughtfulness, Trust</td>
</tr>
<tr>
<td></td>
<td>Concordance</td>
<td>Will, Dialogue process, Growth of knowledge, Support, Written agreement</td>
</tr>
<tr>
<td></td>
<td>Rights</td>
<td>Information, Choice, Decision, Responsibility</td>
</tr>
</tbody>
</table>

The ethics committee of Göteborg University approved the study.
Table 4: Conditions in situations experienced as patient non-participation: subthemes and themes

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

**Table 1** Process of analysis of texts to definition of categories

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

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Saand J Caring Sci; 2011

Patients’ perceptions of barriers for participation in nursing care

Table 2 Barriers for patient participation from patients’ perspective

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

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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