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Lecture 5:
Nursing sensitive outcomes: clinical instruments (questionnaires) and PROMs and PREMs in context of complex/long-term care

PART II

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Learning outcomes

🔑 Participants know what PROMs and PREMs are as part of Nursing indicator measurements.

🎯 Participants know where to find relevant, valid information regarding PROMs and PREMs measurement in the context of complex and long-term care.

NURSE SENSITIVE INDICATORS and OUTCOMES
Olli & Tervo-Heikkinen 2020, Greenhalgh et al. 2018

How to assess nursing outcomes

✓ Through processes, economy

✓ From the point of physiological aspects

✓ From professionals point of view

➢ Patient Reported Outcome Measures, **PROMs**

➢ Patient Reported Experience Measures, **PREMs**

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Definitions of PROMs and PREMs

PROM = Patient Reported Outcome Measures

PREM = Patient Reported Experience Measures

….are validated and standardized self-reporting instruments using patients' views and opinions to assess their health status and well-being.

Usually are questionnaire-based instruments

…are self-reporting instruments which measure a patients' perception of their experience during hospitalization or while receiving care.

Usually are questionnaire-based instruments

Modified from Pitkänen et al 2018

PROMs
Patient reported outcome measures

Collect information from patients themselves about health status and wellbeing

Ask directly from patients

Use valid patient-reported indicators

PREMs
Patient reported experience measures

Collect information from patients themselves about how well the health service is treating them.

Ask directly form patients

Use valid patient-reported indicators

Clinical Functional Independence Measures

Clinical Measurements

Tests

Objective measurements

From healthacare providers' point of view

Healthcare providers observe and assess patient's health status and ability to function

Using nursing excellence /expertise

PROMs and PREMs

SIMILARITIES

Provide a patient-centric view of healthcare

Data from questionnaires can be used for

research,

quality improvement projects,

clinician performance evaluation,

benchmarking (national databases)
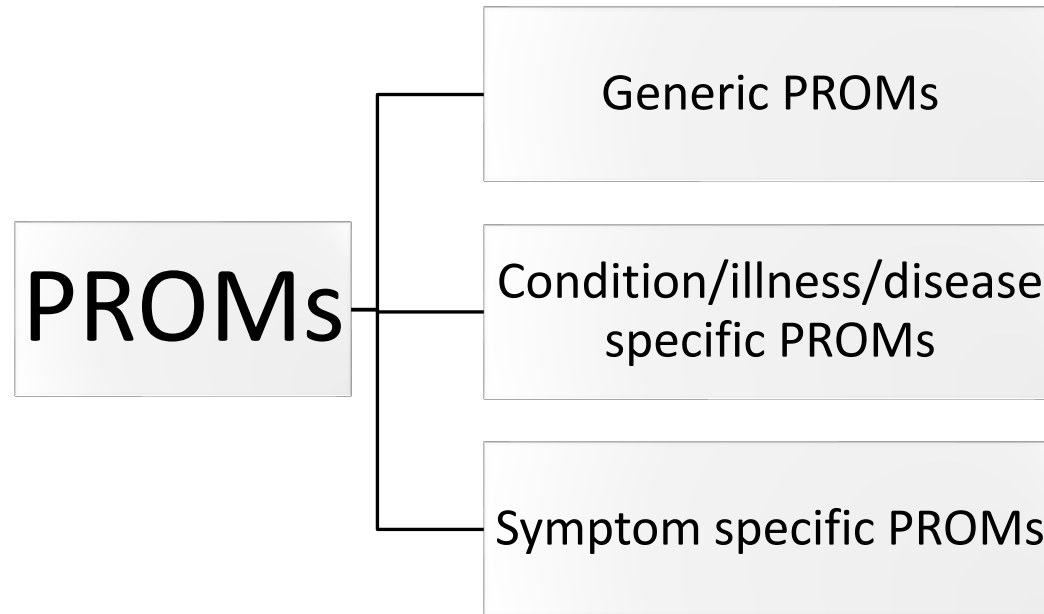-> to allow comparisons in clinical care.

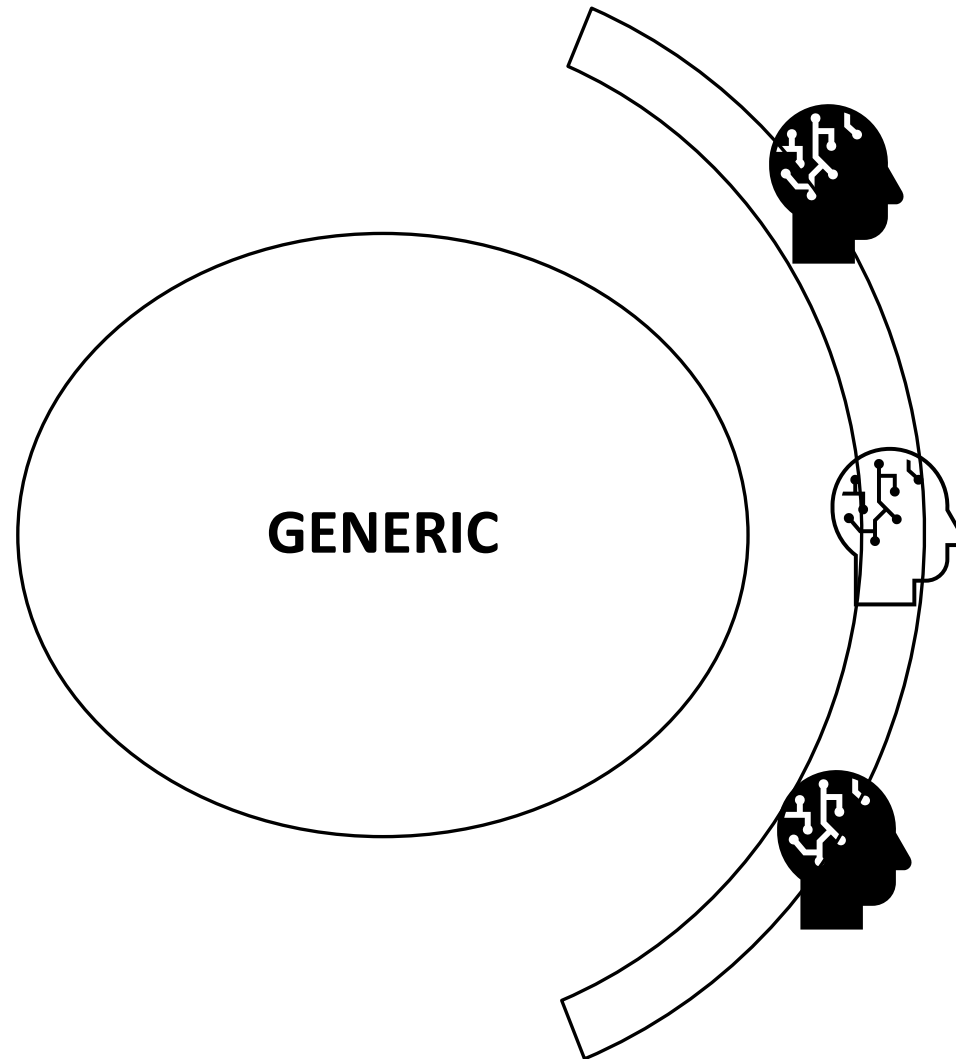economic evaluation.

DIFFERENCES

PREMs do not look at the outcomes of care but the impact of the process of the care on the patient's experience such as communication with healthcare providers and and timeliness of assistance.

PROMs seek to measure a patient's health status

How are PROMs used?

PROMs

- Generic PROMs
- Condition/illness/disease specific PROMs
- Symptom specific PROMs

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GENERIC

Routinely used across a wide range of health services to improve care.

For example: After the surgery procedure PROMs measure a patient's <u>health-related quality of life</u> at a single point in time and are collected through self-completed questionnaires.

For example: EuroQol 5 Dimension (EQ5D-5L™)

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Example of EQ5D-5L™ and EQ-VAS™ combined questioinnare

Source: Kingsley & Patel 2017

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY
I have no problems in walking about ☐
I have slight problems in walking about ☐
I have moderate problems in walking about ☐
I have severe problems in walking about ☐
I am unable to walk about ☐

SELF-CARE
I have no problems washing or dressing myself ☐
I have slight problems washing or dressing myself ☐
I have moderate problems washing or dressing myself ☐
I have severe problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)
I have no problems doing my usual activities ☐
I have slight problems doing my usual activities ☐
I have moderate problems doing my usual activities ☐
I have severe problems doing my usual activities ☐
I am unable to do my usual activities ☐

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Example of EQ5D-5L™ and EQ-VAS ™ combined questioinnare

Source: Kingsley & Patel 2017

PAIN / DISCOMFORT

I have no pain or discomfort ☐

I have slight pain or discomfort ☐

I have moderate pain or discomfort ☐

I have severe pain or discomfort ☐

I have extreme pain or discomfort ☐

ANXIETY / DEPRESSION

I am not anxious or depressed ☐

I am slightly anxious or depressed ☐

I am moderately anxious or depressed ☐

I am severely anxious or depressed ☐

I am extremely anxious or depressed ☐

Example of EQ5D-5L™ and EQ-VAS ™ combined questioinnare

Source: Kingsley & Patel 2017

We would like to know how good or bad your health is TODAY.

This scale is numbered from 0 to 100.

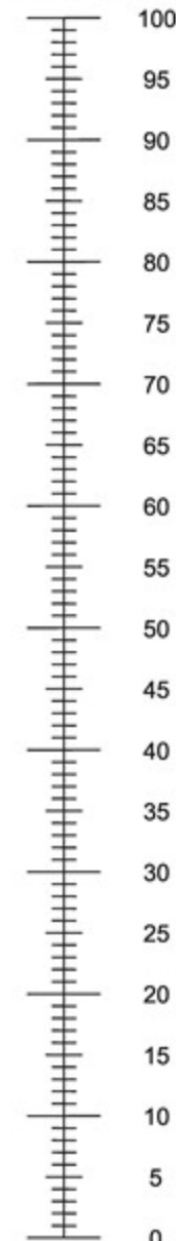100 means the <u>best</u> health you can imagine.
0 means the <u>worst</u> health you can imagine.

Mark an X on the scale to indicate how your health is TODAY.

Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health
you can imagine

100
95
90
85
80
75
70
65
60
55
50
45
40
35
30
25
20
15
10
5
0

The worst health
you can imagine

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Oswestry Disability Index (functional ability)

EORTC QLC – C30, Rotterdam Symptom Checklist RSCL (QoL of cancer patients)

Fall Risk Assessment Tool (FRAT)

Pressure ulcer prevention Braden

Nutritional Risk Screening (NRS)

Alcohol Use Disorders Identification Test (AUDIT)

Oxford Hip Score (OHS) –condition specific measure for hip procedures.

Condition/illness/disease spesific PROMS, **examples**

The Hospital Anxiety and Depression Scale HADS

Beck Depression Inventory BDI

McGill Pain Questionnaire MPQ

Visual Analog Scale VAS

Multidimensional Fatigue Inventory MFI

Symptom spesific PROMS, **examples**

PROMs Patient reported outcomes measures

Directly reported by patients without intervention by clinicians

Relates to the patient's health, quality of life and functional status that is associated with her/his disease, treatment, such as
- physical function
- mood
- fatigue
- pain

Empowers patients to be heard and enable their outcomes to be quantified and measured against normative, quantitative data

Emphasizes patients' individual views and opinions in order to assess their health status and wellbeing

Adding value to healthcare providers view about holistic state of patient's condition by measuring changes in health status and quality of life.

Example: a cancer patient

A patient with cancer diagnoses has been receiving a new drug that have good clinical outcomes in terms of improving patients' length of survival.
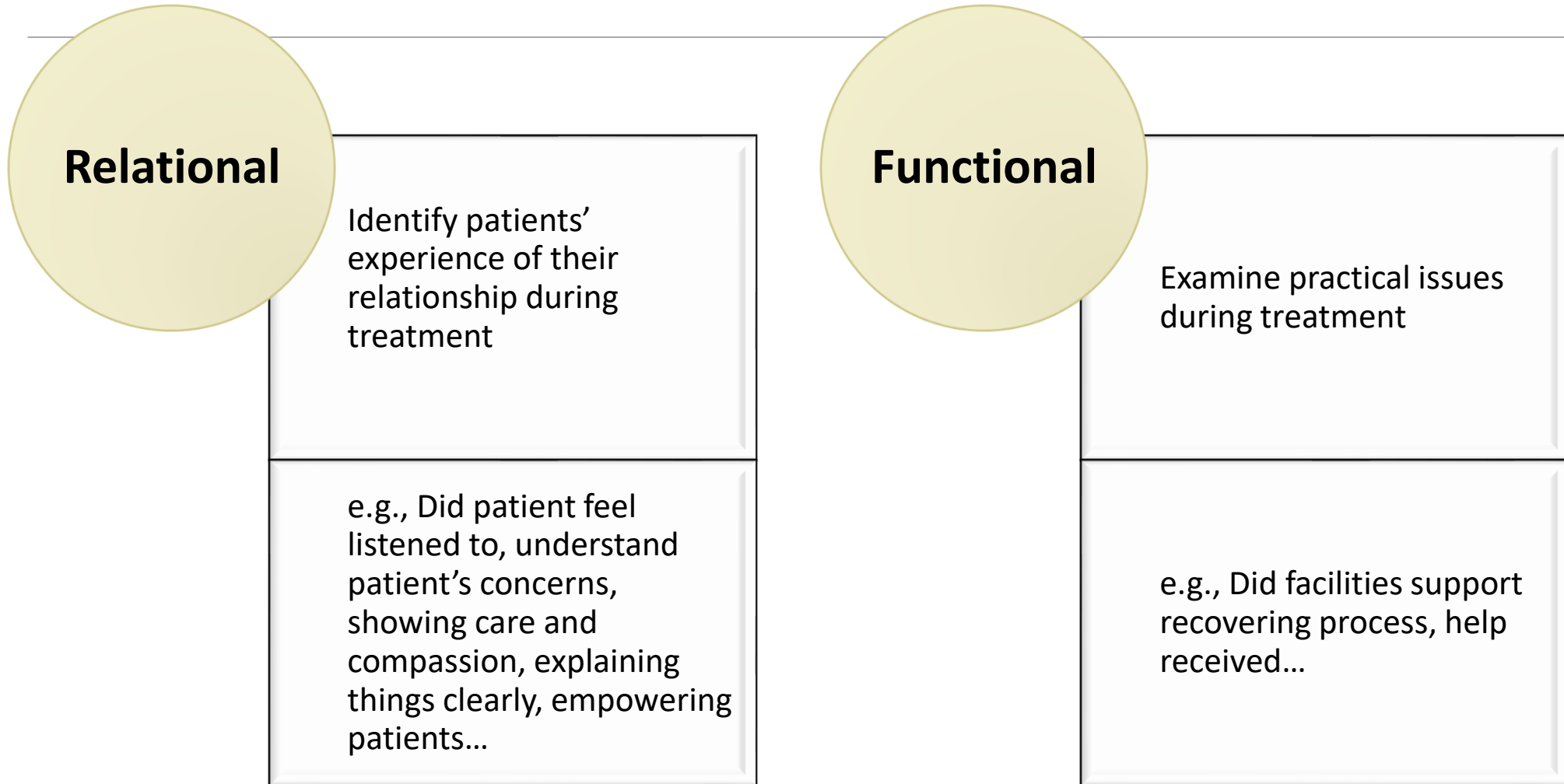
PROMs expose that the patient is non-compliant with the prescribed drug because of multiple side effects which influence patient's everyday life.

The measurement of PROMs gives professionals opportunity to assess the effectiveness of the drug given to the patient from many dimensions

-> including the patient's functional status and quality of life and overall satisfaction with the situation having new drugs

Types of PREMs
(e.g., Kingsley & Patel 2017)

Relational

Identify patients' experience of their relationship during treatment

e.g., Did patient feel listened to, understand patient's concerns, showing care and compassion, explaining things clearly, empowering patients...

Functional

Examine practical issues during treatment

e.g., Did facilities support recovering process, help received...

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Examples of PREMs categories

Environment: hospital / ward /clinic

Care received

Support: emotional, physical

Decision-making (shared decisions with patients and healthcare providers)

Family-centered approach

Interaction with staff

Information received concerning care (test results, examinations etc.)

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What needs to be considered...

Choose the correct measuring instrument ->

to ensure validated, realiable data

How the data are collected and used

Do professionals understand why the data are collected by using PROMs and PREMs

Cost of measuring

Multicultural population -> translation of PROMs and PREMs questionnaires is frequently required

Limitations

PREMs can be synonymous with patient expectation or satisfaction

-> are subjective terms

Do PREMs measure adequacy of healthcare or quality of healthcare?

PREMs can be mixed up by factors not directly associated with the quality of healthcare, e.g., health outcomes.

PREMs can reflect patients' underlying expectations and views for an ideal healthcare experience vs. their actual care experience.

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Journal of
Patient-Reported
Outcomes

Examples of the articles published in the journal

The endometriosis daily diary: qualitative research to explore the patient experience of endometriosis and inform the development of a patient-reported outcome (PRO) for endometriosis-related pain

Implementing patient-reported outcomes in routine clinical care for diverse and underrepresented patients in the United States

Evaluation and validation of a patient-reported quality-of-life questionnaire for Parkinson's disease

Cancer treatment regimens and their impact on the patient-reported outcome measures health-related quality of life and perceived cognitive function

Integrated Palliative Outcome Scale for People with Dementia: easy language adaption and translation

To share or not to share: communication of caregiver-reported outcomes when a patient has colorectal cancer

Health-Related Quality of Life in people with Multiple Sclerosis: How does this Population Compare to Population-based Norms in Different Health Domains?

Examples

AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

| Home | Standards | Our work | COVID-19 | Publications and resources | For consumers |

Home › Our work › Indicators, measurement and reporting › Patient-Reported Outcomes

Patient-reported outcome measures

A useful website

- **High burden cancers -** lung cancer, bowel cancer, breast cancer, prostate cancer, pancreatic cancer, brain and central nervous system cancer

- **Cardiovascular diseases** - coronary heart disease, stroke, atrial fibrillation and flutter, non-rheumatic valvular disease, cardiomyopathy and hypertension

- **Mental health disorders** - anxiety, depression, psychological distress and alcohol use disorders

- **Musculoskeletal conditions** - back pain and problems, osteoarthritis and rheumatoid arthritis

- **Injuries and trauma** - burns, brain injury and orthopaedic trauma

- **Respiratory diseases** - chronic obstructive pulmonary disease and asthma

- **Neurological conditions** - dementia, epilepsy, migraine, Parkinson's disease and Alzheimer's disease

- **Gastrointestinal diseases** - chronic liver disease and inflammatory bowel disease

- **Endocrine disorders -** diabetes

- **Oral disorders** - dental caries and severe tooth loss

- **Hearing and vision disorders** - hearing loss and vision loss

- **Skin disorders** - dermatitis, pressure injuries and eczema

- **Infectious diseases** - HIV/ AIDs and influenza

- **Kidney and urinary diseases** - chronic kidney disease

- **Blood and metabolic disorders** - iron-deficiency anaemia

- **Reproductive and maternal conditions** - genital prolapse and polycystic ovarian syndrome.

Northwestern University • Funding for Health Measures was provided by the National Institutes of Health

Useful websites

THE **NATIONAL PATIENT** REPORTED OUTCOME MEASURES (PROMS) PROGRAMME

NHS England

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