Conceptualisation, development and validation of a community-based Patient Complexity Instrument (PCI) for district nurses

Dr Sue Thomas PhD RN
Aneurin Bevan University Health Board and RCN Wales
Aims

The study aimed to:

• Address a gap in contemporary district nursing practice: to be able to articulate the daily, combined observations made of patients and their breadth of individual circumstances and needs

• Identify key factors relating to the complex needs of community-based patients, as perceived by district nursing experts in Wales

• Assist in “enabling nurses to assess the severity of patients' conditions, whether they are likely to deteriorate, and what their ongoing needs will be” (Welsh Government & National Health Service Wales, 2013)

• Contribute to the portfolio of acuity tools for the Chief Nursing Officer (CNO) for Wales, as directed by Welsh Government & National Health Service Wales
Objectives

The objectives for the study were to;

• Undertake a concept development for patient complexity
• Undertake a construct development of a patient complexity instrument/measure
• Develop items for a Patient Complexity Instrument
• Establish the validity and reliability of each subscale within a Patient Complexity Instrument, according to its psychometric properties
## The All-Wales PCI Development Team

<table>
<thead>
<tr>
<th>Aber Bro Morgannwg University Health Board (UHB)</th>
<th>Jayne Hopkins</th>
</tr>
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<tbody>
<tr>
<td>Aneurin Bevan Health Board UHB</td>
<td>Patricia Hapgood, David Hopkins, Lynwen Law, Sue Pinkstone, Tanya Spriggs, Lorraine Ware, Jo Webber</td>
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<tr>
<td>Betsi Cadwaladr Health Board UHB</td>
<td>Bethan Jones, Marnel Owen, Elizabeth Powell, Delia Roberts</td>
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<tr>
<td>Cardiff and Vale Health Board UHB</td>
<td>Kay Jeynes</td>
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<tr>
<td>Cwm Taf Health Board UHB</td>
<td>Paul Crank, Angela Hopkins, Sonia Jones, Julie Powell, Mair Thomas, Lynda Williams</td>
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<tr>
<td>Hywel Dda Health Board UHB</td>
<td>Emma Hawkins, Annwen Jenkins, Sharon Jones, Ruth Keil, Jill Paterson, Jane Phillips, Keryl Raynel, Karen Thomas, Yvonne Thomas</td>
</tr>
<tr>
<td>Powys Teaching Health Board</td>
<td>Marion Baker, Jason Crowl, Paul Labourne, Carol Shillabeer</td>
</tr>
<tr>
<td>National Leadership and Innovation Agency for Health (NLIAH) now WEDS</td>
<td>Charlette Middlemiss, Matt Wyatt</td>
</tr>
<tr>
<td>National Wales Informatics Service (NWIS)</td>
<td>Anne Owen</td>
</tr>
<tr>
<td>RCN Wales</td>
<td>Sue Thomas</td>
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## Methodology

<table>
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<tr>
<th>Stage</th>
<th>Stages of instrument development and validation</th>
<th>Aim</th>
<th>Research Approach</th>
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<tr>
<td>1</td>
<td>Theory and concept building</td>
<td>Instrument development</td>
<td>1. Group Concept Mapping (GCM)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>(Kane &amp; Trochim, 2007)</td>
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<td></td>
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<td></td>
<td><em>(Qualitative and quantitative)</em></td>
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<tr>
<td>2</td>
<td>Items development</td>
<td></td>
<td>2. Rasch analysis</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>(Bond &amp; Fox, 2007)</td>
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<tr>
<td>3</td>
<td>Scale development</td>
<td></td>
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<tr>
<td>4</td>
<td>Psychometric Testing</td>
<td>Instrument validation</td>
<td></td>
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</tbody>
</table>

(DeVellis, 1991; Netemeyer, Bearden & Sharma, 2003; Streiner & Norman, 2003; Wilson, 2005)
Timeline of the PCI development

- Sept 2013: 5 x GCM structured conceptualisation and consensus workshops across Wales with 29 expert participants
- Jan 2014: Scale development of the PCI
- June 2014: Item confirmation and development of items for the Patient Complexity Instrument (PCI)
- Sept 2014: 7 x Training sessions for district nurses in the use/testing of the PCI. Further face-validity testing of content.
- Oct 2014: Data collection using the PCI by 119 district nurses for 526 patient assessments
- Jan 2015: Rasch analysis of the test data
- April 2015: Amendments made to PCI in light of results from Rasch analysis
- June 2015: Data collection using the amended PCI by 100 district nurses for 957 patient assessments
- Sept 2015: Final PCI

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Consensus research: Concept Mapping

- Group Concept Mapping (GCM) is a participatory methodology, which enables a diverse participant group to develop a shared conceptual framework
- Helps individuals think as a group, without losing their individuality
- Uses information from individuals to:
  - identify group shared vision
  - encourage teamwork
  - facilitate group decision making
  - represent group ideas pictorially
Group Concept Mapping (GCM) process

1. Brainstorming – ideas generation (produced as statements)
2. Statement analysis and synthesis
3. Unstructured sorting/organising of statements
4. Multidimensional scaling and cluster analysis of statements to observe results
5. Generation of interpretable maps and data displays of key ‘issues’
1. Brainstorming

- Five face-to-face workshops were held across Wales between July and October, 2013.
- Twenty nine nurses of all levels were asked “what specific information should a district nurse record as part of an assessment of patient complexity?” in order to identify the necessary items for inclusion in the instrument.
2. Statement analysis

• Following group brainstorming, ten statements were generated by each individual participant, collated, then sorted into “piles that made sense to them”

• Sort-pile “data synthesis” - edited by researcher for relevance, clarity, duplication etc. (*not* removal or prioritisation). Final data set of 38 statements/items

• Sort data entered into Global Max™ software by researcher (ST attended training at Ithaca, NY)

• Global Max™ software enables quantitative and qualitative analysis and results of stakeholder participants’ aggregated data.
Quantitative Analysis of Qualitative Data

Quantitative analysis includes:

- **Similarity Matrix** from sort data - paired sorting decisions made by all participants

- **Multidimensional scaling (MDS)** of similarity matrix - plots sorting results as points on X, Y axis (distance indicates theoretical similarity or not between the sorted data items)

- A **point map** is generated – with each statement represented by a number
Multidimensional Scaling - Point Map
Quantitative Analysis of Qualitative Data

• Hierarchical Cluster Analysis - apportions the MDS points into groups (or clusters)
• Qualitative results seen as clusters (from sort data, not as with thematic analysis)
• Data clusters for this study revealed a range of environmental, sociological, psychological, behavioural, physical and organisational factors
• Illustrated by a Concept Map
Concept Map for Patient Complexity

Clinical

Psychological and capacity

Unpredictability

Communication and expectations

Risk, safety and environment

Social and family support

Resources
Concept Map

• Visually reveals the concept of patient complexity

• Possible to see items that are conceptually closer together, e.g. communication/expectations and psychological/capacity (anchors)

• Also possible to see items that are conceptually further away from each other, e.g. communication/expectations and risk, safety and environment (bridges)

• Important to remember all cluster items have been agreed as being core components of a concept; but the map helps to add further information to the analysis and understanding of the enquiry
Results of phase 1

- Results concurred with other research\(^1,2,3,4\), that it is inadequate to consider clinical features alone in an assessment of community-based patient complexity.
- Risks and safety, environment, patient cognition and mental capacity, resources, support networks, patient dependence, coping, and family and carer factors are considered as important as the physical support needs of the patient.
- A comparative analysis was undertaken of the results with an existing taxonomy\(^15\) to establish whether it contained the items identified through the consensus research.
- Amendments were made to the existing taxonomy to reflect gaps found during the mapping exercise. These included 1. family/carer and 2. safety aspects.
- The amended instrument became known as the Patient Complexity Instrument (PCI)\(^16\).
### The Patient Complexity Instrument items (v1)

<table>
<thead>
<tr>
<th>Items</th>
<th>Descriptor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification and agreement of personalised care plan for and with this patient</td>
<td></td>
</tr>
<tr>
<td>Scale and scope of physical and psychological nursing needs</td>
<td></td>
</tr>
<tr>
<td>Support systems for this patient</td>
<td></td>
</tr>
<tr>
<td>Factors relating to key carers (usually family)</td>
<td></td>
</tr>
<tr>
<td>Any resources required to meet holistic needs and goals for this patient</td>
<td></td>
</tr>
<tr>
<td>How safely the care will be delivered for this patient in the current environment</td>
<td></td>
</tr>
</tbody>
</table>

### GCM Clusters

<table>
<thead>
<tr>
<th>GCM Clusters</th>
<th>The Patient Complexity Instrument items (v1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Psychological and Capacity</td>
<td>1 Engagement</td>
</tr>
<tr>
<td>2 Communication and Engagement</td>
<td>2 Clinical Need</td>
</tr>
<tr>
<td>3 Clinical</td>
<td>3 Social Contact</td>
</tr>
<tr>
<td>4 Social and Family Support</td>
<td>4 Family and Carers</td>
</tr>
<tr>
<td>5 Resources</td>
<td>5 Resources</td>
</tr>
<tr>
<td>6 Risk, Safety and Environment</td>
<td>6 Safety</td>
</tr>
<tr>
<td>7 Unpredictability</td>
<td>7 Unpredictability</td>
</tr>
</tbody>
</table>
# Items/Domains of the Patient Complexity Instrument

<table>
<thead>
<tr>
<th>ITEM</th>
<th>DESCRIPTOR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engagement</td>
<td>Identification and agreement of personalised care plan for and with this patient</td>
</tr>
<tr>
<td>Clinical Need</td>
<td>Scale and scope of physical and psychological nursing needs</td>
</tr>
<tr>
<td>Social Contact</td>
<td>Support systems for this patient</td>
</tr>
<tr>
<td>Family and Carers</td>
<td>Factors relating to key carers (usually family)</td>
</tr>
<tr>
<td>Resources</td>
<td>Any resources required to meet holistic needs and goals for this patient</td>
</tr>
<tr>
<td>Safety</td>
<td>How safely the care will be delivered for this patient in the current environment</td>
</tr>
</tbody>
</table>

*The Community-based Patient Complexity Instrument (Thomas, 2015)*
<table>
<thead>
<tr>
<th>Score each column</th>
<th>Engagement</th>
<th>Clinical</th>
<th>Social Contact</th>
<th>Family and Carer</th>
<th>Resources</th>
<th>Safety</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>This patient lacks capacity Or does not agree to engage in a shared care plan</td>
<td>This patient requires constant supervision and immediate access to nurse intervention to avoid harm or sustain life</td>
<td>This patient is isolated &amp; vulnerable to immediate risk or harm</td>
<td>The carer or family is isolated &amp; vulnerable to immediate risk or harm Or there is no carer</td>
<td>Imminent crisis or failure to progress care plan, care plan in dispute Or resources not available</td>
<td>Patient safety is unachievable by remaining in this environment</td>
</tr>
<tr>
<td>4</td>
<td>This patient has fluctuating capacity Or chooses not to engage in some aspects of a care plan</td>
<td>This patient has changeable needs and requires nurse supervision within a comprehensive plan of care</td>
<td>This patient has limited family support, social connection or activities</td>
<td>There is carer or family strain</td>
<td>Urgent referral (same day) to any multi-disciplinary/sector/agency team or member, or specialist service</td>
<td>Patient safety is unpredictable by remaining in this environment</td>
</tr>
<tr>
<td>3</td>
<td>This patient has capacity but there is some patient difficulty with engaging in a shared care plan</td>
<td>This patient has established ongoing need and requires scheduled nursing team interventions</td>
<td>This patient has support, social contact or activities available within informal family or community</td>
<td>Carer or family coping strategies are in place, including patient’s dependents</td>
<td>Referral for any aspect of a multi-disciplinary/sector/agency team or member</td>
<td>Environmental or other factors present difficulties for patient, carer or nurse which might impact on patient safety</td>
</tr>
<tr>
<td>2</td>
<td>This patient has capacity and agrees to engage with a shared care plan</td>
<td>This patient has stable or predictable need and requires some nursing team intervention and support</td>
<td>This patient has regular family or social contact and support for daily activities</td>
<td>The carer or family has regular family or social contact and support</td>
<td>On-going nursing assessment, intervention &amp; care planning</td>
<td>Minor factors from within the home or the external environment present easily manageable risks to patient safety</td>
</tr>
<tr>
<td>1</td>
<td>There is full patient-led engagement with shared care plan</td>
<td>This patient is self-caring and requires minimal nursing team support</td>
<td>This patient is fully independent Or well supported by family or community</td>
<td>The carer or family is fully independent and requires minimal support Or there is no need for carer support</td>
<td>Task-oriented, delegated nursing team care and support</td>
<td>There is no identifiable environmental or other apparent risk to the patient</td>
</tr>
</tbody>
</table>

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Phase Two

- Use of the PCI leads to a score being attributed to each of the items used to measure the patient’s level of complexity
- From which clinical decisions will be made, care plans developed (and staff deployed)
- It is therefore important that different scores represent clinically meaningful differences for practitioners and others relying on results generated by the instrument
- The purpose of phase 2 was to ensure that the PCI is valid and reliable in context and for its specified use
Method for phase 2

- Cwm Taf UHB was study site for phase 2
- Enabled participatory philosophy and expert input to be maintained (esp. during case study development and training sessions)
- The PCI was tested by CTUHB district nurses during regular patient assessments
- Scores from approx. 1,400 patient assessments were collected for input to Rasch analysis software (RUMM2030\textsuperscript{17})
- Rasch analysis\textsuperscript{18} was performed with the aim to produce a well-targeted instrument.
Data analysis
Category Probability Curves

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Results for phase 2

• The instrument is constructed with appropriate items for identifying patient complexity as a ‘uni-dimensional’ construct.
• The instrument is reliable for use with different subgroups of district nursing patient caseloads; namely males and females of all age groups.
• The instrument’s response options are discernible for differential selection by participants.
• The instrument was constructed so there is good spacing between the instrument’s response options.
Update and Impact

• PCI being used in areas of Wales
• International interest and testing (UK, Scotland, Australia, Canada)
• Included in Welsh Community Care Information System (WCCIS)
• Website = www.pci.wales

• Further studies to test the contribution of the PCI within the all-Wales Nurse Staffing Programme for DN, including:
  • Does it contribute knowledge about acuity or professional judgement?
  • How does it work in practice?
Welcome

Welcome to the Patient Complexity Instrument (PCI) website.

The Patient Complexity Instrument (PCI) is designed for assessing the complexity of a community-based adult patient’s care needs and producing an indicative score (1-5) within each of the six Likert scales, as perceived by the assessing District Nurse (DN).

The PCI is constructed of the issues identified by DN’s in Wales as important for assessing the multiple, overlapping and interlinking biopsychosocial needs (or complexity) of patients on their caseloads.

The PCI allows DN’s to generate a description of a patient in the context of their home and community-based circumstances, to identify any areas of need that may require a range of care and support interventions to be planned.

The PCI may be used for a number of different purposes e.g.
- for undertaking a holistic, biopsychosocial assessment of need with an individual patient which results in a plan of care,
- briefing colleagues about an individual patient’s situation,
A definition of community-based patient complexity from a district nursing perspective:

The interaction of factors in a patient’s life, including biological, psychological, social, environmental and support systems, which requires a shift in an expectation of predictable outcomes (Thomas, 2017).
Thank you

For further information
Please contact: susan.thomas30@wales.nhs.uk