Measuring Person-Centredness of Care

Definition of Person-Centred Care

Person-Centred Care (PCC) is a philosophy that views individuals using healthcare and social services as equal partners in planning, developing, assessing and monitoring care to ensure it meet their needs.[1] This means placing individuals and their families at the centre of all decisions, and viewing them as experts of their own preferences, values, family and social circumstances, and lifestyles. These individuals and their families work together with care professionals to achieve the best care outcomes.[1] Research has demonstrated the importance of PCC in developing a high quality of care which enhances outcomes for both care recipients and care professionals. PCC can improve individuals' experience of care, motivate them to lead a healthier lifestyle, and be more involved in decisions concerning their care. This results in a positive impact on their health.[2,3] Similarly, offering care with a person-centred approach can enhance care professionals' levels of job satisfaction, confidence, and accomplishment.[4]

Although the various models and approaches of PCC share the same recognition of the care recipient as a central and active agent in their care, there are differences in their components/dimensions and emphasis, depending on the populations in which they are practiced in.[5] For example, PCC for persons with disabilities places values in their rights, especially self-determination and normalisation. On the other hand, PCC in the field of dementia care emphasises the upholding of personhood for persons living with dementia and persons with severe intellectual disabilities. This emphasis is in response to some cultural associations between progressive or severe cognitive impairment with some degree of deterioration or loss in aspects of self and identity.[5] This article on Person-Centred Dementia Care sums up literature and resources discussing the principles and application of PCC for persons living with dementia and the benefits of person-centred dementia care.

For years, many academics, healthcare practitioners and policy makers have attempted to define and operationalise PCC. However, due to the multifaceted and subjective nature of PCC, there remains no universal agreement on its definition nor a "gold standard" tool that sufficiently measures all aspects of PCC in the existing pool of literature.[1] This is also true of the measurements in the field of person-centred dementia care. It is therefore important to understand and define what PCC is to a care setting, its reasons to measure PCC, as well as the outcomes that it aims to achieve through adopting this approach. This will help to determine and select the most appropriate measurement tools and approaches which are best aligned with its needs.

Measurements of Person-Centred Dementia Care

There are many existing measures of PCC. Some measures focus on PCC as a broad holistic concept while others measure specific subcomponent(s) of PCC, such as communication or shared decision making. Since there is no perfect single tool that measures all aspects of PCC, empirical evidence has recommended a combination of various tools and methods to be the most robust measure of PCC, which is essential to test and differentiate worthwhile strategies and initiatives that help care providers to be more central to their care.[1] Surveys, used together with proxy indicators, interviews, and observations may provide a more holistic picture of PCC. In order to effectively measure care outcomes, there must be, firstly, a thorough evaluation and careful selection of tools that have valid psychometric properties, and secondly, triangulation of all information collected from care recipients, their families and care professionals to minimise any subjective bias associated with self-reporting measures.[1]

An extensive review[1], which screened more than 200,000 studies that measured PCC and eventually reviewed a total of 921 studies, summarised and discussed the commonly-used approaches and tools measuring PCC. A list of 160 most commonly researched measurement tools (with embedded hyperlinks to the abstracts of the journal articles) has also been created and is available for download at https://www.health.org.uk/publications/helping-measure-person-centred-care. The table below provides an overview on measures of PCC, as summarised in this review:[1]

Who measures PCC?	Why is PCC measured?	Where is PCC measured?	What is measured?	How is PCC measured?	When is PCC measured?
Mostly by academics in collaboration with healthcare teams	To measure: ● Quality of services ● Benefits of a specific improvement initiative ● Whether individuals' needs and preferences are met	● Most were conducted hospital settings ● Remaining were done in primary and community care settings, nursing homes and care centres	● **Definitions:** How care recipients or care professionals define PCC ● **Preferences:** Care recipients' care preferences, or care professionals' attitudes and values ● **Experiences:** The level of person-centredness of care ● **Outcomes:** Impact of PCC	4 most commonly ways used to measure PCC: ● Surveys and interviews to gather opinions of care professionals ● Surveys and interviews to gather opinions and preferences of care recipients ● Observations of clinical encounters ● Examinations of care recipients' records	Different PCC measures and methods are conducted at various points in care recipients' care continuum. For example, surveys and proxy indicators can be administered and collected more frequently on a routine basis, while interviews and observations can be conducted annually.

Amongst the existing studies which have been conducted on PCC, several studies have also reviewed tools commonly used in the evaluation of care delivery and services for older adults, as well as persons living with dementia. A combination of these measures has been similarly administered in long-term care, acute care and home care settings to evaluate the multiple components and outcomes of their care approaches and interventions.[6-8] Across the studies reviewed, person-centred dementia care was measured through:

1. The use of proxy indicators, such as prevalence of challenging behaviours, use and dosage of psychotropic medications, and quality of life;
2. Systematic observations of the care and services provided;
3. Perceptions of care recipients and their families;
4. Perceptions of care professionals working in the setting;
5. Evaluation of the physical environment of the care setting; and/or *(For more information on instruments that solely assess the physical environment of a care setting, please refer to this article on Design Principles & Audit Tools.*
6. Evaluation of the family's involvement in care.[6-8]

Some of these instruments are extensive and require more resources (such as manpower and time) to complete, while others are shorter, easier, and faster to complete. The table below lists the instruments, which a number of reviews [6-8] have summed up, compared and discussed regarding their (1) purposes, (2) how they are used, and (3) their psychometric properties:

To observe the care and services provided	**To measure PCC according to care recipients' own judgement**	**To measure PCC according to the setting's care professionals**	**To evaluate family involvement in care**
1. Dementia Care Mapping 8th Edition (DCM8) 2. The Care Observational tool (CARES) 3. The Observational Measure of person-centred care for spouses of people with dementia	1. Resident Person-Centred Practices in Assisted Living (Resident PC-PAL) 2. Preferences for Everyday Living Inventory (PELI) 3. The English Person-centred Climate Questionnaire – Patient version (PCQ-P) 4. Client-Centred Care Questionnaire (CCCQ) 5. The Person-Centered Inpatient Scale	1. The English Person-centred Climate Questionnaire – Staff version (PCQ-S) 2. Person-centred Care Assessment Tool (P-CAT) 3. Staff Assessment Person-Directed Care (PDC) 4. Measures of Individualized Care (IC) 5. Staff Person-Centred Practices in Assisted Living (Staff PC-PAL)	1. Family involvement in care

Tools that have been used in the Singapore Context

At Dementia Singapore, the Dementia Care Mapping 8th Edition (DCM8)[9], the VIPS Assessment Tool[14], and the Person-Directed Dementia Care Assessment Tool (PDDCAT)[16] are instruments which are frequently used to evaluate the person-centeredness of care and services provided at New Horizon Centres and other intermediate and long-term care settings, and programmes developed in collaboration with other institutions. These tools have been chosen for their specificity to the field of dementia. Additionally, while the DCM is used to observe the well-being of persons living with dementia and the quality of care provided by care professionals, the VIPS Assessment Tool and the PDDCAT are qualitative tools that offer a holistic and extensive evaluation on multiple domains of a care environment for persons living with dementia. Despite the insufficient evidence on their psychometric properties, the latter two instruments are very detailed measures which have the principal objectives of guiding care settings to change their care models, and facilitating care professionals to self-evaluate and to develop plans to improve various aspects of their care provision in order to implement the PCC approach.[8]

The choice of these instruments is supported by a recently published study, where a group of dementia care practitioners and researchers measured and explored the relationships between the quality of life, well-being and person-centred care of residents in seven nursing homes in Singapore. The study used a combination of tools listed below to measure and analyze their respective elements:

- Residents’ quality of life was measured using the proxy EQ-5D-5L version completed by direct care staff;
- DCM was used to observe residents’ wellbeing and care quality;
- Resident Satisfaction Survey was administered on residents with communication ability; and
- PDDCAT was adopted as a measure and improvement tool for PCC, where each domain was independently assessed by groups of care staff.[17]

The following content provides more details on the DCM, the VIPS Assessment Tool and the PDDCAT. Click on the names of the tools (with embedded hyperlinks) to directly access them:

1. Dementia Care Mapping 8th Edition (DCM8)[9]
   - **Who uses the tool:** Health and social care professionals, who are certified DCMappers.
   - **Where is the tool used:** Commonly used to observe persons living with dementia in a range of care settings, including hospitals and intermediate and long-term care services (i.e., day care centres and nursing homes).
   - **Why is the tool used:** Care professionals has used the tool for several purposes, such as:
     - In quality improvement projects to monitor and evaluate existing and new programmes and services;
     - To improve the organization of care during for groups of residents in a care setting; and
     - For individual assessment and care planning;
     - For staff development and training needs analysis.[10]
   - **What does the tool measure:** This observational tool records (1) the well-being of persons living with dementia, (2) their behaviours, and (3) the interactions between persons living with dementia and their care professionals. This will then determine the well-being of persons living with dementia.
   - **How to use the tool:** DCM observations involve continual observations of 5-6 participants living with dementia over a sustained period of time in communal areas of care settings. 2 types of codes are recorded down at 5-minute intervals throughout the observation period:
     - Behavioural Category Code (BCC, 23 behavioural categories): The type of activity or behaviour the participant is mainly engaged in during the 5-minute time frame; and
     - Mood and Engagement (ME) Value: The state of well-being the participant experiences while engaging in the activity or behaviour. This is on a 6-point scale ranging from very distressed and very great signs of negative mood (-5) to very happy, cheerful and very high positive mood (+5).
   - Additionally, staff's behaviours and interactions with the participant, known as Personal Detractors (PDs) and Personal Enhancers (PEs) are recorded as well. PDs have the potential to undermine the personhood of persons living with dementia, while PEs support their personhood.[11] These are recorded in qualitative notes by the mapper and not coded in a systematic manner.
   - **Strength(s) of the tool:**
     - May come closer to viewing Quality of Life (QoL) from the perspective of the person living with dementia than many other available measures;[12] and
     - Widespread clinical appeal and is extensively used in dementia care practice.[12]
   - **Psychometric properties of the tool:** A study has summarised the results of several studies assessing the psychometric properties of DCM, which has shown mixed evidence on its psychometric properties. The study also explained what each type of validity and reliability refers to. More research is required to further establish each of the following type of validity and reliability of the tool:[13]

Validity	Reliability
- **Face validity:** Studies collecting staff responses through questionnaires and discussions upon the presentation of DCM results discovered that these staff believed DCM to be a valuable indicator of resident well- or ill-being and believed it to be reflective of the relationship between well- or ill-being and care delivery. Staff also believed DCM results would help enhance the quality of care. - **Content validity:** It is difficult to determine the tool's content validity, as it is related to sampling characteristics like the duration of the mapping period and the number of participants. However, these characteristics vary across the different studies, which also made different recommendations. - **Concurrent validity:** Results of studies yielded significant associations between higher WIB scores, and positive outcomes of engagement, pressure area care, care planning and care staff satisfaction. However, correlations between WIB and quality of life scores ranged from weak to strong. - **Construct validity:** A number of studies reported that DCM is able to measure well-being separately from other constructs, like cognitive, behavioural and functional impairments, where negative associations were found between WIB scores and these constructs. - **External validity:** Several studies showed that DCM scores varied across different settings. Mean group and individual WIB scores were higher in assessment and day hospitals, assisted living facilities, and adult day centres than in continuing care and respite settings, like nursing homes.	- **Good internal consistency:** It is difficult to assess the tool's internal consistency, likely due to the fact that DCM is not a summative rating scale. Having said this, a study has established internal consistency by examining the association between key DCM indicators, where statistically significant correlations were found between WIB scores and activity participation (time spent actively or passively engaging in activities believed to promote well-being), and WIB scores and social withdrawal (time spent in BCCs social withdrawal, unattended distress, communicating without a response, and repetitive self-stimulation). - **Considerable to moderate test-retest reliability:** Only 1 study has established the tool's test-retest reliability; results reflected the presence of considerable test-retest agreement between WIB scores and more moderate agreement for activity participation and social withdrawal. - **High inter-rater reliability:** It is part of the tool's protocols that multiple raters must ensure a high level of agreement (at least 70%) by simultaneously observing and coding the same participants for at least an hour prior to actual data collection. Many studies reported concordance coefficients ranging from .70 to .80.

Another study reported that residents in small, dementia-specific assisted living facilities experienced lower mean group WIB scores and less diversity of interactions and activities than those in large, non-dementia specific sites.	

- **Permission to use the tool:** To use the tool, health and social care professionals have to first attend DCM training to be a certified DCMapper by the Bradford Dementia Group. Please visit Dementia Singapore Academy's page to find out more and sign up for the DCM training courses in Singapore.

2. The VIPS Assessment Tool[14]

- **Who uses the toolkit:** Health and social care professionals.
- **Where can the toolkit be used:** Used in various care settings such as hospitals, home care services, nursing homes, day care centres and community programmes.
- **When is the toolkit used:** The toolkit can be used any time, over and over again, for care professionals to monitor the progress of their care and services.[14]
- **What the toolkit measures:** The VIPS framework is an evidence-based structure to guide good practices in person-centred dementia care in care settings. It guides care professionals to reflect and enhance their interactions and communications with persons living with dementia and their families to be more person-centric from early diagnosis to palliative care. The framework has a list of 25 indicators grouped in 4 categories (Values, Individuals, Perspective and Social) that care professionals can use as a benchmark to measure the person-centredness of their care delivery and services for persons living with dementia and their families.[15] The table below lists down the 25 VIPS indicators:[14]

Values	Individuals	Perspective	Social
V1. Vision	I1. Individual Support and Care	P1. Communication	S1. Inclusion
V2. Human Resources	I2. Recognising and Responding to Change	P2. Empathy and Acceptable Risk	S2. Respect
V3. Management Ethos	I3. Personal Possessions	P3. Physical Environment	S3. Warmth
V4. Training and Practice Development	I4. Individual Preferences	P4. Physical Health Needs	S4. Validation
V5. The Service Environments	I5. Life Histories	P5. Challenging Behaviour as Communication	S5. Enabling
V6. Quality Assurance	I6. Activity and Occupation	P6. Advocacy	S6. Part of the Community
			S7. Partners, Families, Friends and Relatives

- **How to use the toolkit:** The Care Fit for VIPS website provides an online assessment toolkit that is free to access and use, the VIPS Assessment Tool, which allows care professionals to rate their care delivery and services according to the 25 VIPS indicators. The website also provides online resources that can assist care professionals in developing quality improvement action plans after completing the assessment tool. The VIPS Assessment Tool is an ongoing evaluation toolkit that enables care professionals to log in and change their ratings any time to understand how their care delivery and services may have progressed. The toolkit can be completed in its entirety at once, or have each VIPS area assessed at a time.
- **Permission to use the tool:** Care professionals will have to register for an online account with the Care Fit for VIPS website to access the VIPS Assessment Tool.

3. Person-Directed Dementia Care Assessment Tool[16]

- **Who uses the tool:** Health and social care professionals.
- **Where can the tool be used:** Long-term care settings for persons living with dementia.
- **What the tool measures:** The tool helps to identify an initial baseline of strengths and areas for improvement in a dementia long-term care setting that the care team can then use to develop action plans to enhance **nine** aspects of the setting (please refer to the list below). Over time, the tool can be used to re-assess and measure the progress, and/or identify new areas of focus across these 9 aspects:

1. Environment
2. Language and Communication
3. Care Plans
4. Activities
5. Problem Solving Processes for Working with Behavioural Communication
6. Communication and Leadership
7. Team Structure and Roles
8. Policies and Procedures
9. Staff Knowledge and Training

- **How to use the tool:**
  - The numbered scale is for evaluators to indicate the presence or absence of the item, and whether it is a strength or a weakness that needs to be worked on (the number is an indicator of that one item, and NOT a numerical value to be added to others and scored);
  - The columns "Strengths" and "Improvement Areas" are for evaluators to indicate the exact situation witnessed, comment made, or example for the working document; and
  - The tool can be divided into individual sections and assigned to one or more people who do not work in the environment being observed and evaluated, as they may discover the most important information in the environment. Obtaining multiple perspectives during different shifts is ideal too. To minimise skewed information, the follow-up observations and evaluations should be done by all or some of the same people who did the first observation.
- **Strength(s) of the tool:**
  - Evaluates multiple aspects of a long-term dementia care setting in detail; and
  - Provides several resources for the management and staff of a care setting to refer to as they work to improve their care practices and culture.
- **Psychometric properties of the tool:** Not established, as this tool is not meant to be a licensing document or a prescriptive standard, and not meant to be scored.
- **Permission to use the tool:** Cite the State of Wisconsin, Department of Health, to use the tool; no other permissions are required.

Conclusion

These reviews and studies on measures of person-centred dementia care were conducted in countries outside of Singapore. More research is needed to examine and establish their quality and usefulness in this local context. Additionally, some of the above tools which were specific to the field of dementia have been noted to have mixed support for their respective psychometric properties. Similarly, some of them may not have had their reliability and validity substantially established. However, these instruments still offer an adequate foundation for the journey to build and enhance the person-centredness of a dementia care environment. To find out more about the application of these tools in the Singapore context, please visit Dementia Singapore Academy's Consultancy service page and connect with the team to set up a discussion.

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