Group Concept Mapping as a Strategy for Defining Patient-Centered Outcomes In PROs and PRO-PMs

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Objectives

- Evaluate strengths and limitations of commonly-used strategies for engaging patients
- Review group concept mapping (GCM) as a viable method for engaging patients
- Present examples of GCM applications in defining patient-reported outcomes (PROs)
- Review strengths and limitations of GCM in defining PROs

Importance of quality measures

- There is an increasing focus on health care quality measurement as a means to reduce unnecessary utilization and improve health outcomes for patients.
- This has led to a proliferation of performance measures but the current emphasis in measurement is focused on what providers do and may not reflect the health outcomes that are most relevant and meaningful to patients.[1]
- The National Quality Forum has suggested aligning patient priorities with care delivery through first defining patient reported outcomes (PROs), developing these outcomes into validated measures (PROMs), and identifying specific outcomes that best measure provider performance (PRO-PMs).[2]

Patient-driven conceptual frameworks

- Conceptual frameworks developed primarily by providers or researchers without appropriate patient input may not reflect patient priorities. Indeed, research suggests that there is disagreement between what healthcare providers and patients perceive regarding outcomes that matter most to patients.[3]
- Clinicians and researchers generally rely on methodologies with limited engagement potential when attempting to capture the "patient voice," but here is a lack of randomized controlled research supporting these methods.[4-7] Table 1 shows the advantages and disadvantages of various techniques to involve patients as participants in development of conceptual models.[4-7]

Group Concept Mapping (GCM): Participatory tool for patient outcomes

Overview

- GCM (Concept Systems, Inc.; https://www.conceptsystems.com/home) is a mixed-methods (qualitative and qualitative) approach that facilitates the exploration and quantification of how patients conceptualize a construct, and allows for qualitative and quantitative comparisons across groups.
- Concept mapping has been used to assist in developing hypotheses and theories, to build conceptual models, and to explore the context surrounding health-related outcomes.[8]
- Steps include:
  > **Statement Generation.** Concept elicitation utilizes literature reviews and stakeholder brainstorming (interviews, survey techniques) to generate items that will comprise conceptual categories.
  > **Structuring.** Using electronic (online concept mapping software) or paper medium, patients and stakeholders sort statements into meaningful groupings, and rate statements on one or more dimensions (e.g., importance, relevance).
  > **Representation.** Concept mapping software allows creation of "cluster maps" that define conceptual groupings, membership of items within groupings, and orientation in space to define conceptual similarity. Different cluster solutions based on the number of distinct conceptual groupings can be generated.
  > **Interpretation.** This stage may involve the production of a report and convening of a group of stakeholders to discuss the implications and dissemination of the resulting conceptual model.
- GCM has been advanced as an inclusive and participatory methodology, as it relies on bottom-up development of basic ideas (statement generation) and organization of concepts (structuring).[9] However, it is often underutilized in measure development.

GCM Applications in Defining Outcomes

Patient-Reported Outcomes – RWJF Provider Performance Measurement Project

- GCM helps to establish content validity by assessing the priority, importance, and inclusion of content in conceptual models, facilitating the development of a solid psychometric foundation.
- Reviews across studies suggest that concept mapping possesses a high degree of reliability and validity, despite variability in participation and task completion.[10] Table 2 shows examples of studies that have utilized GCM.

Patient-Reported Outcomes – Performance Measurement

- **Statement Generation.** To illustrate how patient input can be utilized to develop a conceptual model using GCM, preliminary results from the "Good Healthcare" Study are presented here. First, patients (n=157) recruited through PatientsLikeMe (an online patient research network) and non-patient stakeholders (e.g., clinicians, researchers, patient advocates, etc.; n=17), provided descriptions and examples of "good healthcare" by responding to open-ended prompts through an electronic survey.
- **Structuring.** This process generated 1800 statement that were reduced to 79 unique aspects of healthcare that were rated and sorted by patients and non-patient stakeholders in a Structuring exercise using the GCM software. Non-patient stakeholders were asked to rate the importance of each aspect of healthcare to patients. For this study, participants were asked to rate the importance of each item in healthcare (1-5, not important - extremely important).
- **Representation.** Table 3 shows cluster names and representative items.

Figure 1 provides a visual representation of how statements were sorted by patients, whereby statements that are closer together on the map were more frequently sorted together by patients. A greater number of layers in a cluster represents the importance of that cluster. The size of clusters represents the variability of items within the grouping. That is, patients viewed the content of these statements as being meaningfully related. Further, the cluster layers represent average ratings of importance of the statements within each cluster.

- **Interpretation.** Large numbers of patients can provide valuable qualitative and quantitative input in an efficient and cost-effective manner. Rather than eliciting concepts to build a one-dimensional model, the GCM process builds the model from the "ground up" and informs not only the composition of groupings, but their conceptual breadth, importance, and similarity to each other.

GCM Strengths and Limitations

As a technology-driven, mixed methods solution, GCM offers distinct advantages over traditional methods. However, this method is also subject to the limitations described in Table 4.

Conclusions

- Developing a comprehensive conceptual model with patient input is essential to produce PROMs and PRO-PMs that are relevant and meaningful to patients.
- Traditional strategies for incorporating patient input may be inadequate for purposes of reaching saturation and for results to be representative of the larger patient population.
- Overall, GCM represents a valuable participatory concept development strategy that can enhance traditional researcher-driven methods in PRO and PRO-PM development. This technique allows a richer portrayal of components of a patient-driven conceptual model.
- Researchers should remain cognizant of the strengths and limitations of GCM, and more research is needed to standardize GCM procedures.

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Table 1: Traditional Methods of Engaging Patients in Conceptual Development [4-7]

METHOD	DESCRIPTION	ADVANTAGES	DISADVANTAGES
MEMBERS OF RESEARCH ADVISORY GROUPS	Participation of patients as part of research teams	Ongoing involvement; allows patients to learn about projects and contribute at different stages	Needs more patient commitment and maintenance, bidirectional feedback; potential for tokenism; findings may not be representative
TOWN HALLS	Large group forum to gather community feedback on research initiatives	Modest cost, may result in much feedback	One-time event, may not get feedback from all participants; may select for more vocal participants
SURVEYS	Qualitative and/or quantitative tool to gather patient perspectives	Gather data from a large group of participants, lends itself to quantitative and qualitative analysis	May lack flexibility, depth, and nuance in gathering patient perspectives
FOCUS GROUPS	Group stakeholder discussion with agenda	Gather input from multiple stakeholders in real time, allows interactions between contributors, can adapt questions to discussion	May have unequal distribution of input; scheduling participants may be an issue; sample may not be representative; cost is a factor
INTERVIEWS	One-to-one interaction with semi-structured or structured format	Gather rich qualitative information, can adapt questions to discussion	Labor intensive; typically a small sample; findings may not reflect opinion of population

Table 2: Use of Concept Mapping in Defining Measures and Outcomes

MEASURE	DESCRIPTION	SAMPLING
CURRENT OPIOID MISUSE MEASURE (COMM)[11]	Clinician tool for monitoring of aberrant medication-related behaviors in chronic pain patients	Pain management and addiction specialists
HEALTH EDUCATION IMPACT QUESTIONNAIRE (heiQ)[12]	Instrument for the evaluation of education programs for patients with chronic conditions	Consumers of patient education programs and hospital outpatients
INFLUENZA INTENSITY AND IMPACT QUESTIONNAIRE (FLUIIQTM)[13]	Clinical instrument used to identify symptoms of influenza infection	Individuals with laboratory-confirmed influenza and expert physicians
PATIENT OPIOID EDUCATION MEASURE (POEM)[14]	Clinical tool to help identify knowledge gaps and expectations in patients treated with opioids	Clinicians treating patients with chronic pain
SCREENER AND OPIOID ASSESSMENT FOR PATIENTS WITH PAIN, REVISED (SOAPP-R)[15]	Clinician tool determine how much monitoring required for patient based on individual risk factors	Pain management and addiction specialists and chronic pain patients who had been on opioid medication for at least six months
PARKINSON'S DISEASE (PD) OUTCOMES[16]	Compared the priorities in outcomes measurement in clinical PD trials between people with PD and health care providers	People with PD (PwPD) and health care professionals (HCPs)

Table 3: Cluster Labels and Rating of Importance

CLUSTER NUMBER	CLUSTER LABEL	SAMPLE STATEMENT	RATING OF IMPORTANCE (1=not important 5=extremley important)
1	Doctor-Patient Communication	My doctor/provider takes time to explain (diagnosis, treatment options, prognosis, side effects) in sufficient detail	4.59
2	Doctor Characteristics and Behavior	I am treated with respect	4.44
3	Appropriate Care	My care is thorough	4.61
4	Outcomes	Treatments are effective	4.51
5	Patient as an Active and Informed Participant in their Care	I understand my diagnosis and my options for treatment	4.67
6	Office Attributes	The office is well organized	4.15
7	Team Communication	I am able to contact my doctor's office with any needs, even between visits	4.43
8	Insurance Limitations	The costs for office visits and treatments/medicine are reasonable	4.27

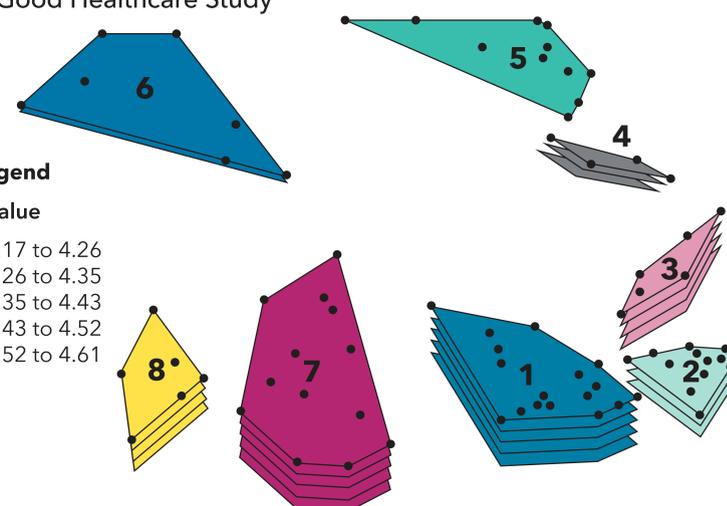**Figure 1:** Sample Cluster Map Generated by Patients in the Good Healthcare Study

Cluster Legend

Layer	Value
1	4.17 to 4.26
2	4.26 to 4.35
3	4.35 to 4.43
4	4.43 to 4.52
5	4.52 to 4.61

Table 4: Advantages and Disadvantages of GCM with Patients

ADVANTAGES	LIMITATIONS
Evidence of reliability and validity.[10]	Patient participation may be limited by difficulties with computer literacy, physical dexterity limiting computer use, inadequate online access; sorting cannot be easily completed on mobile devices.
Ability to incorporate multiple stakeholder views into a single conceptual framework	No more than 100 statements should be included due to respondent burden and the increased likelihood of attrition.[17]
Meaningful results can be accomplished with as few as 10-20 participants per group	Difficulty understanding the sorting activity (due to limited literacy or other language barriers?)
Helps to ensure content validity of conceptual model.[18]	When participants complete the GCM activities independently and anonymously, there is a greater risk for attrition and/or low effort
Patient participation may result in relevant content that utilize patients' own language, helping to reduce potential researcher bias	If relying only on patient perspective, may miss important concepts that would benefit from patient input
Saturation can be evaluated to ensure that the statement pool adequate captures all aspects of the construct	Order-effect due to fixed statement presentation
Able to aggregate data by groups and statistically compare results by group (diagnoses, age, etc.)	Consistent with other types of electronic research, patient demographic or clinical variables could not be verified (it is based on patient report)
GCM activities can be independently and anonymously, thus reducing the likelihood of social desirability and other biases	A minimum of 10-20 participants per subgroup are required for statistical comparison, which can be a problem when recruiting patients with rare conditions or hard-to-reach groups
If needed, a large number of patient responses can be aggregated and compared quickly, enhancing the potential for generalization to broader populations	Lack of widely accepted procedures for reducing the number of statements derived during statement generation.[9,18]