Concept mapping in palliative medicine research

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Abstract: Palliative care adopts a share care model that emphasizes the collaboration among patients, families, and health care providers. Different views and different priority of care are often reported. Concept mapping is a research methodology that can best obtain a big picture as well as a clustering of sub-themes that are identified by different parties involved in palliative care. Concept mapping adopts qualitative method to identify themes, and then uses quantitative techniques such as multidimensional scaling to create a map that shows the patterns of relationships between themes. The method draws the shared expertise of a studied group by constructing graphic models of an issue in palliative medicine examined by the group. This paper will introduce the approach of concept mapping and its use in palliative medicine research. Issues such as sample size calculation and validity and reliability will be discussed.

Key Words: Palliative medicine; research; concept mapping; sample size calculation; validity; reliability

Introduction

Palliative medicine has been well established in many developed countries. Several frameworks and models are available for the understanding of palliative service needs. However, the provision of palliative medicine in Asia is far from satisfactory, especially in China and India (1). For instance, the promotion of advance care planning and pediatric palliative care are two examples that require a lot more exploration and development in most Asian countries (2). There are urgent needs for more basic research to support the development of palliative care models for theory-building and practice. Concept mapping (3), a research approach that combines the strength of qualitative and quantitative methods, is advocated as an effective way to obtain and analyze data for the development of a conceptual model of care (4,5).

Concept mapping: Purposes and steps

Palliative medicine adopts a share care model that emphasizes the collaboration among patients, families, and health care providers. Different views and priorities of care are often reported. Multiple factors such as cultural and family values, health care system, and disease characteristics will greatly affect clinical decision making and outcomes. In order to integrate all these factors and elements, concept mapping is a research methodology that can best obtain a big picture as well as a clustering of sub-themes graphically in terms of building conceptual model for palliative care (4). The approach firstly uses a qualitative method to elicit areas of concern (in the form of brainstorming statements), and then structures the statements by sorting and rating. Finally, quantitative techniques such as multidimensional scaling are used to create a map that shows the patterns of relationships among these concerns (3,4). The whole process can be clearly described in the six classical steps of concept mapping (3, p.1): (I) preparation (selection of participants and development of focus), (II) the generation of statements, (III) the structuring of statement, (IV) the representation of statements in the form of a concept map, (V) the interpretation of maps, and (VI) the utilization of maps, mainly on planning or evaluation of service.

The research team proposes the use of concept

180

Chan et al. Concept mapping in palliative medicine research

mapping in two palliative care research projects: (I) to develop a family-centered model of palliative needs of pediatric patients; (II) to develop a culturally-relevant conceptual model to explain the end-of-life decision making phenomenon among Hong Kong Chinese. We chose concept mapping, as this approach encompasses the shared expertise of a studied group for creating a model, to explain, predict, plan and evaluate practice areas that are under-developed in Hong Kong. It emphasizes the benefit of merging qualitative and quantitative data and provides statistical evidence to strengthen the validity of a conceptual model of care (5).

Challenges of using concept mapping

As discussed in previous literature (3-5), the innovative use of concept mapping is not free from methodological challenges. The two main challenges that are relevant to our proposed studies are sample size calculation and validity and reliability issues.

Sample size calculation

Although Trochim (2) suggests that 10-20 subjects is a working number for most studies, there is no solid theoretical basis to support the sample size calculation for performing concept mapping using multidimensional scaling. Therefore, we have planned our sample size empirically based on the reported sample sizes of recent published papers of similar topics and population. In order to achieve an empirically large enough sample size, we decided to take the upper quartile (75th percentile) of the captured sample sizes as a guideline for our proposed studies.

Validity and reliability

In concept mapping approach, validity refers to the degree to which a map can truly reveal a topic under investigation and reliability refers to how well a map can be replicable (6). The initial qualitative phase of concept mapping is largely subjective in nature and the subsequent phases of rating, sorting, and clustering call for an objective agreement upon a concept or issue. Complex and sometimes spontaneous and unpredictable group interactions are involved in the production of a concept map.

To our knowledge, there is no major guideline that is available to safeguard the validity and reliability issues

of concept mapping. The research team borrowed ideas proposed from Trochim (6), an expert of the field and other studies (4,5), and asserted the following mechanisms to enhance the accuracy that a concept map can achieve to represent the reality. First, we include a broad variety of relevant people in the study, such as clinicians, patients in various stages of a disease, family members, hospital administrators, healthcare policy makers, and use purposive sampling to enhance the representation of participants. Heterogeneity of participants can insure a broad range of viewpoints to be captured in a conceptual framework. Second, we involve the participants in all 6 steps of the concept mapping process. They stay on task, letting group cohesiveness progressively increase along the process. In such arrangement, participants can better understand and articulate the concept maps than those who only engage in a small part of the process. The final conceptual framework can also be expressed in the language of the participants rather than in researchers' language. Third, we allow participants to submit anonymous statements in written format in addition to verbal brainstorming of statements. Topics such as end-of-life decision or power struggle between clients and clinicians are sensitive and controversial in nature. Some participants may be reluctant to openly express their ideas that are subject to potential criticism.

Implication and conclusions

Concept mapping is a useful and practical tool for producing a visual presentation of an issue under investigation. Although the final product of concept mapping appears to be a computerized graphic and pattern-driven map, the utilization of such map continues to require input from participants and researchers. In the two palliative care projects we propose, the main purpose for developing a concept map is to guide the service planning. Therefore, a planning group or task group involving the participants and researchers are formed and divided up into sub-groups to examine specific clusters. They can utilize the statement within a cluster as clues for what kind of service should be implemented. These clues can also be used to guide the operation and implementation of service.

Other studies may consider using a concept map as a basis for the evaluation of service, for example, to guide the formation of a questionnaire to measure the outcome of service. The cluster can be viewed as a measurement construct and individual statement can represent items within a construct (7). Concept mapping is a promising

approach in basic research and has the potential to contribute to applied research such as randomized trial in the arena of palliative medicine.

Acknowledgements

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