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ORIGINAL ARTICLE

Consensus development of components of continuity of care for stroke patients: a Delphi methodology

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Abstract

Aims The study aimed to develop consensus on the components of continuity of care for stroke patients in the cultural context of China.

Subjects and methods Thirteen experts were recruited purposefully to finish this study. A Delphi approach was adopted to reach consensus on the components of continuity of care, and 75% agreement was used as cutoff.

Results Three rounds of consultation were completed. Consensus (75% agreement) was obtained on 45 of the 49 statements. The final agreed list of statements represented three domains: the structure, process and outcome of continuity of care.

Conclusions It represents the first attempt to develop consensus on the components of continuity of care for Chinese patients with stroke. According to the established framework and components of continuity of care, health professionals can successfully implement continuity of care for stroke patients and improve the quality of care.

Keywords Continuity of care · Stroke · Rehabilitation · Delphi method

Introduction

Stroke is the leading cause of long-term disability and the second leading cause of mortality worldwide (Johnston et al. 2009). An estimated 15 million people worldwide experience a stroke every year, and one third of them are left permanently disabled, placing a substantial burden on family and health systems (Murray et al. 2012). In China, stroke is the first leading cause of mortality and adult disability (Zhou et al. 2016). An estimated 2.5 million new stroke cases occur every year in China, and there are 7.5 million stroke survivors (Liu et al. 2011). Approximately 33% of the survivors are affected by long-term problems during the process of recovery, such as spasticity (Urban et al. 2010), incontinence (Wissel et al. 2013), communication disorders (Berthier 2005) and activity limitations (Lynch et al. 2008), but they do not feel prepared to manage their problems upon discharge from acute stroke treatment (Philp et al. 2013). Continuity of care can provide patients with a seamless transfer from hospital to home and enable patients' rehabilitation at home. Thus, continuity of care is important for patients' rehabilitation after being discharged.

Continuity of care is defined as uninterrupted, seamless and integrated care. Haggerty et al. (2003) divide continuity of care into three parts, informational, relational and management continuity. Informational continuity, defined as the use of information on past events and personal circumstances to make current care appropriate for each individual, depends mainly on the accuracy of the patient record. Relational continuity bridges not only past to current care but also provides a link to future care. Management continuity, defined as a coherent approach to the management of a health condition in accordance with a patient's changing needs, is manifested in coordinated discharge planning involving the patient and his or her caregivers (Haggerty et al. 2003).

Continuity of care has proved to be effective among chronically ill patients. Several types of continuity of care exist such as discharge planning, home-based rehabilitation, community-

Headline of the contribution It is important to establish a comprehensive stroke strategy to facilitate long-term management for stroke survivors. This study aimed to develop the components of continuity of care for stroke patients, which can improve the standard of long-term management provided to stroke survivors and best organize continuity of care services.

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based support and follow-up care (Frances and Siu 2015). However, there is a lack of consensus about what constitutes continuity of care and lack of criteria for quality in the process. Continuity of care for stroke patients remains highly fragmented and poorly organized, and it is rarely patient-centered (Wissel et al. 2013). Many stroke survivors will not receive a comprehensive rehabilitation review, contributing to patient suffering and caregiver burden. In China, the continuity of care for chronic patients has just started. There is no consensus about the components of continuity of care for stroke patients. Considering the manner in which continuity of care should be organized is still an open question, it is important to establish a comprehensive stroke strategy to facilitate long-term management for stroke survivors. The study aimed to develop the components of continuity of care for stroke patients, which can improve the standard of long-term management provided to stroke survivors and best organize continuity of care services.

Donabedian's structure-process-outcome model is a basic framework of healthcare quality assessment, and Donabedian recommends that healthcare quality be evaluated in terms of structure, process and outcome (Moore et al. 2015). Structure includes all of the factors that affect the context in which care is delivered (Donabedian 2003). This includes physical and human resources. Process contains all acts of healthcare delivery. Outcome contains all the effects of healthcare on patients including changes to health status, behavior or knowledge as well as health-related quality of life (Donabedian 2003). According to Donabedian's model, improvements in the structure of care should lead to improvements in the process of care, which should in turn improve patient outcome (Moore et al. 2015). This model has been extensively used as a quality of care framework in diverse healthcare settings. It is an effective approach to improving the quality of continuity of care (Wang et al. 2016). Therefore, Donabedian's model was adopted in the development of the components of continuity of care for stroke patients to improve the quality of care.

Methods

Developing the components of continuity of care for stroke patients requires empirical evidence as well as cultural considerations of feasibility and validity. First, guided by Donabedian's structure-process-outcome model, we formulated a preliminary draft of the components of continuity of care based on literature review and group discussion. Then, we used consensus methods among related experts to combine available evidence and expert opinion to finalize the components of continuity of care for stroke patients. The study was exempt by the local ethics committee as it only asked the opinions of experts. Willingness to participate was implied when the experts had responded to the first questionnaire.

Formulating a preliminary draft of the framework and components of continuity of care based on Donabedian's model

According to Donabedian's structure-process-outcome model, the framework of continuity of care contains three domains (structure of continuity of care, process of continuity of care and outcome of continuity of care). We drafted the components of each domain based on literature review and clinical experience. Literature in PubMed, OVID, EMBASE, Web of Science, Sino-Med and CNKI was comprehensively searched using a similar strategy for each database. The exact search string included "(stroke OR cerebral apoplexy OR cerebral hemorrhage OR cerebrovascular accident OR cerebral infarction) AND (continuity of care OR continuum of care OR continuance of care OR continuous care OR transitional care OR long-term care OR discharge planning) AND randomized controlled trial". The search was limited to articles published in English and Chinese before January 2017. A list of statements about continuity of care was drafted from the findings of the literature review and included the aspects that were not explicitly mentioned in the review but that we felt were relevant to clinical practice.

Recruitment of the Delphi Expert Panel

We used purposeful sampling of potential experts. Experts were invited based on their experience in areas of clinical content, research or administration related to stroke care or rehabilitation. Inclusion criteria were as follows: (1) at least 3 years work experience; (2) involvement in stroke care or stroke care education or research. Twenty experts were invited by e-mail to participate in our Delphi process, and 17 indicated their willingness to take part. The expert panel consisted of four doctors, six nurses, four managers or head nurses of stroke units and three university teachers. All experts did not communicate with each other and did not receive any monetary compensation for participation.

Delphi process

The experts participated in three rounds of the Delphi process during a 3-month period from April to June 2017. The survey questionnaire was sent to each expert by e-mail, and they were given 3 weeks to complete each survey round. One week before the conclusion of each round, a reminder e-mail was sent. Experts mailed completed questionnaires to the researcher. Nonresponders to a given survey round were excluded from subsequent rounds.

Round 1 The questionnaire in the first Delphi round consisted of two parts. The first part posed questions about the characteristics of the experts. The second part contained a list of components of

continuity of care with free text for experts to eliminate or minorly reword some of the statements and contained open-ended questions for experts to propose additional components of continuity of care that might have been omitted. Anonymity among experts can prevent domination of the ideas expressed by one particular person. The resulting opinions were sorted and distilled into statements by the researchers, which then formed the basis of the second round questionnaire.

Round 2 The experts who completed the first survey were sent a second questionnaire by e-mail. They were asked to indicate their level of agreement with each statement that constituted best continuity of care. They ranked their agreement or disagreement in a structured way using a Likert scale (i.e., 1 = strongly agree; 2 = agree; 3 = neutral; 4 = disagree; 5 = strongly disagree). No standard threshold for consensus exists (Keeney et al. 2006), and a previous study defined consensus as agreement of at least 75% (Eskes et al. 2015). Therefore, through a process of group discussion by the authors, we also predefined 75% agreement as cutoff. Consensus of agreement was determined by 75% (or above) of experts giving "strongly agree" or "agree" responses. Similarly, consensus was also reached if 75% of experts gave "disagree" or "strongly disagree" responses. If consensus was reached on some statements, then those statements were not presented in the subsequent round. Opportunity was also given for the addition of new ideas or opinions.

Round 3 The third round questionnaire, containing the statements for which consensus had not been reached, was sent to all the experts who returned the second round survey. The experts were also provided a summary of the round 2 results, with a note about the individuals' previous personal responses, so that they could see how their own responses related to those of the group. They were invited to re-rank their responses and were given an opportunity to explain why their views differed from others. The experts could be also given a new list of statements about the components of continuity of care to consider (not on the original list, but generated during round 2) and asked their level of agreement with each statement that constituted continuity of care. If consensus was not reached, another round might be set up. However, if there was little change between rounds 2 and 3, the decision could be made to halt the process there.

Data analysis

Data analysis was carried out using SPSS18.0 software. Descriptive statistics were used to summarize the participants' characteristics and their opinions for closed questions at each round. The number of components of continuity of care that reached consensus was calculated after each round. Open comments were analyzed qualitatively and clustered into main themes.

Results

Preliminary draft of the framework and components of continuity of care

According to Donabedian's structure-process-outcome model, the framework of continuity of care was divided into three parts: structure of continuity of care, process of continuity of care and outcome of continuity of care. The components of each part were mainly generated from the findings of the literature review. In the literature search, the Chinese database consisted of 25 publications, and the English language search yielded 236 articles. We went through all the papers and took notes about the structure, process and outcome of continuity of care mentioned in the papers. Based on the notes and considering the aspects relevant to clinical practice but not mentioned in the review, we drafted a list of 52 statements. Of these, 18 related to the structure of continuity of care, 20 related to the process of continuity of care and 14 related to the outcome of continuity of care.

Delphi expert panel

Initially, 17 experts consented to participate. Of these, 15 completely finished the survey and responded in the first round (88%). Only these responders received the second and third questionnaires, and the response rates in round 2 and round 3 were 87% (13/15) and 100% (13/13), respectively. The characteristics of the expert panel were presented in Table 1.

Delphi process

In the first round, we refined some statements based on the experts' suggestions. Some statements were eliminated since they seemed to be a poor fit with the conditions in China. For example, day hospitals and rehabilitation centers were commonly recommended as medical agencies to implement continuity of care in the literature. However, this recommendation was viewed as a poor fit since only a few day hospitals and rehabilitation centers exist in China. Some statements were judged to be too similar or redundant and were merged into a single statement. From the open-ended questions in round 1, we identified four additional components to be judged. At the conclusion of round 1, there were 45 components to be rated in round 2 (Table 2). Of these, 16 related to the structure of continuity of care, 16 related to the process of continuity of care, and 13 related to the outcome of continuity of care.

In the second round, consensus was reached on 41 of the 45 statements, whereas 4 statements relating to the structure of continuity of care remained open for a future consensus discussion in the subsequent rounds (Table 2). From the open-ended questions in round 2, we identified four additional statements

Table 1 Baseline characteristics of experts

Baseline characteristics	Round 1 N (%)	Round 2 or 3 N (%)
Number of participants	15	13
Age		
30–35	6(40.0)	5(38.5)
36–40	5(33.3)	5(38.5)
> 40	4(26.7)	3(23.0)
Gender distribution		
Male	4(26.7)	3(23.0)
Profession distribution		
Doctor	4(26.7)	3(23.0)
Stroke care nurse	5(33.3)	4(31.0)
University teacher	3(20.0)	3(23.0)
Manager or head nurse	3(20.0)	3(23.0)
Highest level of education		
Doctoral degree	3(20.0)	2(15.4)
Master's degree	10(66.7)	9(69.2)
Bachelor's degree	2(13.3)	2(15.4)
Years of working experience related to stroke care or rehabilitation		
3–5	3(20.0)	3(23.0)
6–10	8(53.0)	7(54.0)
> 10	4(27.0)	3(23.0)

relating to the process of continuity of care to be judged (Table 2). Thus, eight statements were to be rated in round 3.

In the third round, the four statements relating to the process of continuity of care reached consensus while the statements relating to the structure of continuity of care did not reach consensus (Table 2). No additional statement was proposed in this round.

In total, 49 statements were considered by the experts during the Delphi rounds. The experts reached consensus regarding 45 of the 49 statements for inclusion in the final list of components of continuity of care (Table 2). Of these, 12 related to the structure of continuity of care, 20 related to the process of continuity of care and 13 related to the outcome of continuity of care.

Discussion

Evidence shows that continuity of care is crucial to improve stroke patient's health and functions (Wang et al. 2017). However, due to lack of consensus on what constitutes continuity of care for stroke patients (Haggerty et al. 2003), the implementation of continuity of care for stroke patients varies greatly among different care providers. It is important to develop a standardized framework of continuity of care to improve the quality of care.

According to Donabedian's structure-process-outcome model, the framework of continuity of care contains three domains (the structure, process and outcome of continuity of care). Since the Delphi method is considered an effective way to obtain group consensus (Jones and Hunter 1995), consensus has been reached about the components of each domain by the Delphi method. Areas of specialty for the group included clinical content (e.g., stroke neurology, stroke rehabilitation, physical medicine and rehabilitation, stroke nursing), research and administration related to stroke care and rehabilitation. This resulted in a group of experts that was homogeneous in relation to the field of investigation, but heterogeneous in terms of professional background, which ensured that the expert panel could make a valuable contribution to the development of the components of continuity of care.

After three Delphi rounds, the experts reached consensus regarding 45 components of continuity of care for stroke patients. Of these, 12 relate to the structure of continuity of care, 20 relate to the process of continuity of care and 13 relate to the outcome of continuity of care. The structure of continuity of care includes the implementation agency, team and object, which are the basic physical and human resources involved in continuity of care. As stroke rehabilitation involves care issues concerning the physical, psychosocial and spiritual aspects, multiple agencies and multidisciplinary teams should be involved in stroke care. In China, general hospital and community healthcare centers are available to provide continuity of care for stroke patients now. The implementation team consists of a nurse, physician, physiotherapist, occupational therapist, speech therapist, psychologist and care coordinator. Though a social worker was recommended as part of the multidisciplinary stroke rehabilitation team in the literature review (Fisher et al. 2011), given the scarcity of social workers in China, they were ruled out by the experts in the first Delphi round. As continuity of care concerns the quality of team work, the degree of consistency and coordination between different service providers, and the quality of communication between different agencies, someone should play this role. Therefore, a care coordinator was recommended as one of the team members in round 1.

The process of continuity of care includes the hospital-initiated support for discharge, post-discharge follow-up service and the quality management of the process. The discharge support in hospital is pivotal in the continuity of care for people who are in need of medical, social and rehabilitation care (Olson et al. 2011; Phillips et al. 2004; Wong et al. 2011). A number of studies highlighted that effective early discharge support is crucial to improve continuity of care between hospital and home (Phillips et al. 2004). Well-defined hospital-initiated support for discharge should include four phases: (1) patient assessment (assessment of the patient's physiological, psychological, social and cultural needs); (2) development of a discharge plan (identifying discharge

Table 2 Components of continuity of care for stoke patients

Components of continuity of care for stroke patients	Percentage of experts rated these statements as components of continuity of care (strongly agree or agree %)	
	Round 2	Round 3
Domain 1: the structure of continuity of care		
1. Implementation agency	100	–
1.1 General hospital	100	–
1.2 Community healthcare center	100	–
2. Implementation team	100	–
2.1 Nurse	100	–
2.2 Physician	92.3	–
2.3 Physiotherapist	100	–
2.4 Occupational therapist	84.6	–
2.5 Speech therapist	84.6	–
2.6 Psychologist	84.6	–
2.7 Care coordinator	92.3	–
3. Implementation object (stroke patients preparing to be discharged and consenting to being referred to continuity of care)	100	–
4. Implementation regulations	53.8	46.2
4.1 For management continuity	53.8	46.2
4.2 For information continuity	53.8	46.2
4.3 For relational continuity	53.8	46.2
Domain 2: the process of continuity of care		
1. Hospital-initiated support for discharge	100	–
1.1 Patient assessment	100	–
1.2 Development of a discharge plan	100	–
1.3 Provision of service	100	–
1.4 Service referral	100	–
2. Post-discharge follow-up service	100	–
2.1 Follow-up content	100	–
2.1.1 Medication management	100	–
2.1.2 Rehabilitation exercise	100	–
2.1.3 Lifestyle counseling	100	–
2.1.4 Self-care instructions	100	–
2.1.5 Emotional support	92.3	–
2.2 Follow-up method	100	–
2.2.1 Home visit	100	–
2.2.2 Telephone support	100	–
2.3 Follow-up period (as long as patients need and benefit from it)	92.3	–
3. Quality management of the process	–	92.3
3.1 Team cooperation	–	92.3
3.2 Information transfer	–	92.3
3.3 Relational continuity between care providers and patients	–	92.3
Domain 3: the outcome of continuity of care		
1. Patient compliance	100	–
1.1 Medication compliance	100	–
1.2 Rehabilitation exercise compliance	100	–
2. Health status	100	–
2.1 Neuromotor function	92.3	–
2.2 Cognitive function	84.6	–

Table 2 (continued)

Components of continuity of care for stroke patients	Percentage of experts rated these statements as components of continuity of care (strongly agree or agree %)	
	Round 2	Round 3
2.3 Speech function	84.6	–
3. Activity of daily living (ADL)	100	–
4.Quality of life (QOL)	100	–
5.Medical resource utilization	100	–
5.1 Emergency department use	100	–
5.2 Hospital readmission rate	100	–

strategies for the patient, carer and community provider); (3) provision of service (including information delivered, education provided); (4) service referral or coordination of service (assuring a smooth, planned and gap-free transition of patients to the next level of care) (Yam et al. 2012). Hospital-based rehabilitation for stroke patients has its limitations because patients' needs change over time and many of the care issues only emerge when patients return home. The post-discharge follow-up service is helpful for their rehabilitation at home. Based on the literature review, stroke patients usually need help in medication management, rehabilitation exercise, lifestyle counseling, self-care management and emotional support (Wang et al. 2016). Home visit and telephone calls are common follow-up methods. Concerning the follow-up period, evidence showed that 4 weeks is an adequate continuity of care period to bring about effects (Frances and Siu 2015). However, an international panel of experts recommended that the length of follow-up intervention should be as long as patients need and benefit from it (Fisher et al. 2011), for which the experts in our study reached consensus. Besides, considering the three-element model of continuity of care—informational, relational and management continuity, proposed by Haggerty et al. (2003) and Reid (2002)—some statements related to process management were recommended by some experts in round 2. Informational continuity refers to proper care and appropriate and correct medical information provided by the healthcare system and medical staff over time. Relational continuity refers to a continual and high-quality therapeutic relationship maintained between healthcare providers and patients over time. Management continuity ensures that patients get orderly, coherent, complementary, timely and complete services in accordance with a patient's changing needs (Haggerty et al. 2003). Quality management of the whole process (including the early discharge care and post-discharge follow-up service) is very important to ensure the informational, relational and management continuity, which was proposed by the experts during the second round and reached consensus in round 3.

The indicators used to evaluate the outcome of continuity of care varied in different studies, and few studies comprehensively evaluated the effects of continuity of care for stroke patients (Bray 2012; Saywell et al. 2012; Ytterberg et al. 2010). Multi-dimensional evaluation indexes have been recommended to assess the outcome of continuity of care (Olson et al. 2011). The components of the outcome of continuity of care for stroke patients contain indicators related to patient compliance, health status, ADL, quality of life and medical resource utilization, which can assess the outcome of continuity of care completely and effectively.

The main strength of this study was the use of a Delphi technique to achieve consensus on the components of continuity of care for stroke patients. This method gives equal weight to the opinions of each expert, allows anonymous inclusion of experts across various places and avoids the domination of the consensus process by one expert (McKenna 1994). The attrition rate in the questionnaire survey is a recognized problem, and the high dropout rate in the final round of the Delphi process may substantially influence the results (Murphy et al. 1998). We achieved high response rates in every round, so we consider our results robust. Some limitations should be mentioned. First, the experts recruited in our study are from China, which may limit the scope of application of the study. Second, only 13 experts finished the whole Delphi process, although, when chosen carefully, a small number of people (> 6) can be representative of a target group (Keeney et al. 2006; Vella et al. 2000); relatively small improvements in reliability may be achieved in groups > 15 (Vella et al. 2000). Lastly, because there is no standard threshold for consensus (McKenna 1994), the level of consensus was chosen arbitrarily.

Conclusion

In conclusion, using the Delphi technique, we were able to reach a consensus about the components of continuity of care

for stroke patients. This consensus should help to achieve a standard procedure and better clinical practice in long-term post-stroke care.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that there is no conflict of interest regarding the publication of this paper.

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