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Determining the Feasibility, Content Validity, and Internal Consistency of a Newly Developed Care Coordination Scale for People with Brain Injury

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Determining the Feasibility, Content Validity, and Internal Consistency of a Newly Developed Care Coordination Scale for People with Brain Injury

Abstract

Background: With the increasing complexity of care, people with disabilities and supportive significant others (SSO) must often coordinate key aspects of their own care, but no validated scale currently exists to comprehensively characterize the activities done to manage and coordinate their care.

Method: This study aimed to improve the feasibility, acceptability, and content validity of the Care and Service Coordination and Management (CASCAM) scale and to test its internal consistency. Questionnaire items were administered to 23 individuals with acquired brain injury and 17 SSO.

Results: Respondents confirmed content validity and that the instrument addresses important care coordination and management issues. The internal consistency of care coordination domains for medical/rehabilitative and independent living needs for people with brain injury and their SSO ranged from $\alpha = .774$ to $.945$.

Conclusion: Care coordination activities by persons with disabilities, including brain injury, and their SSO are multifaceted but feasibly measurable and should be assessed to improve care.

Comments

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Keywords

brain injury, care coordination, content validity, independent living, internal consistency, measure development, occupational therapy, physical therapy, rehabilitation, traumatic brain injury

Cover Page Footnote

We thank Kathy Subasic (data collection and interpretation) and past students who completed related master's projects on pediatric care coordination (Neelima Gaikwad, Kari Satariano) and qualitative views of the role of occupational therapists in enabling care coordination by persons with brain injury and their SSO (Jamie Janssen).

Credentials Display

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Many people must coordinate their own care (McAllister, Presler, & Cooley, 2007), which increases the stress for those who may already be dealing with disease or disability. Navigating the health care system along with daily life can be frustrating to anyone, let alone someone who has had a brain injury. This can lead to gaps in the delivery of needed care.

According to the *Occupational Therapy Practice Framework: Domain and Process* (American Occupational Therapy Association, 2014), care coordination is an instrumental activity of daily living (IADL) that falls into the domain of interest and expertise of occupational therapists. Care coordination is commonly perceived as a nursing or administrative function. While occupational therapists occasionally assist clients and supportive significant others (SSO) with care management and coordination, their skills could allow them to play a larger role in enabling persons with disability and their SSO to coordinate their own care in the community (Moyers & Metzler, 2014).

Like other IADLs, care coordination is required on an intermittent basis. It can be essential to sustaining health and quality of life, and it is particularly critical during transition phases, such as moves between settings, providers, or payers. During these transitions, therapists or care providers may act on an unpaid or informal basis to coordinate care and/or assist the person and his or her SSO (Janssen, 2009). But once clients return home, they and any SSO likely must bear the burden of care coordination themselves.

Brain injury gives rise to a variety of service needs among survivors living in the community. Individuals who sustain a brain injury often experience increased difficulty performing daily tasks, such as bathing, dressing, meal preparation, driving, and employment (Turner, Ownsworth, Cornwell, & Fleming, 2009). They may experience difficulties with attention, memory, executive function (Millis, Rosenthal, & Lourie, 1994), or other physical abilities needed for successful living in the community. Individuals with brain injury often live for decades post injury (Teasell et al., 2005) and may have difficulty generalizing what they learned in the rehabilitation center back into their communities (Fleming, Tooth, Hassell, & Chan, 1999).

Inpatient length of stay by individuals with brain injury has decreased over time, making post-acute and in-community services increasingly vital to enable clients to sustain successful community living (Hawkins, Lewis, & Medeiros, 2005). However, their ability to manage and coordinate daily tasks and productive activities, including health and independent living services, may be overlooked (Jaffee et al., 2009).

There is currently no published measure of the activities that persons with disabilities and their SSO perform to coordinate care in the community, although related measures have been developed. The Patient Activation Measure (Hibbard, Stockard, Mahoney, & Tulser, 2004) was developed to measure whether a person is activated in the patient role. While useful, it does not assess the range of planning, management, and coordination activities that individuals must do to sustain health and

independent living in the community, and it assumes that activation is required. Other indicators of care coordination have been published, though they also are incompletely validated and limited by not addressing care coordination activities performed by the person with disability and his or her SSO (Glasgow et al., 2005; McGuinness & Sibthorpe, 2003; Montgomery, Rowe, & Jacobs, 2010; Palsbo et al., 2010; Palsbo & Mastal, 2011). The Care Transitions Measure has been a central tool to improve care transitions (Coleman et al., 2002), but it does not address long-term management of both medical and independent living needs in the community. A measure that identifies care gap experiences could help to structure a system that assists people with disabilities regularly obtain needed services, adhere to medication and home exercise programs, and

maintain a safe home environment, among other needs (Iverson, 2005; Jaffee et al., 2009).

The Care and Service Coordination and Management Scale

The Care and Service Coordination and Management Scale (CASCAM) was developed to assess activities that people with disabilities resulting from complex diagnoses, such as brain injury, and their SSO perform to ensure quality and coordinated care directed at health care and independent living needs. Such an instrument is needed to identify strengths and needs, enable interventions to provide care, or support the person and family to more independently coordinate their own care. By doing so, clinical discharge planning may become more accurate and individualized for inpatients with brain injury or other diagnoses.

Table 1

List of CASCAM Care Coordination Activities

Medical and Rehabilitation Activities	Independent Living Activities
Arranging for transportation	Coordinating housing-related issues
Asking questions to providers	Dealing with personal finances
Checking to make sure that things happen as planned and on schedule	Locating social supports or activities
Explaining needs to others	Maintaining the household
Listening to and learning from service providers	Managing paid attendants/caregivers
Making requests or demands	Managing unpaid attendants/caregivers
Monitoring the quality of services received	Searching for independent living services
Obtaining and transporting equipment or supplies	Shopping for personal needs
Reading and learning about care needs	Trying to get access to independent living services
Scheduling appointments and services	
Searching for medical/rehabilitation services	
Trying to get access to medical/rehabilitation services	

Initial items for the current study were developed over several years. Understanding of care coordination issues through exploratory studies led to an initial item set (Gaikwad, 2009; Janssen, 2009; Satariano, 2009). These unpublished studies reviewed the literature on care coordination needs after discharge for persons with physical and/or cognitive challenges. This work and subsequent reviews of the literature led to items regarding two domains: (a) health/medical/rehabilitative needs and (b) independent living services (see Table 1). The CASCAM includes 100 multiple choice, rating-scale, and open-ended items. Most used a 0-6 ordinal rating scale of frequency of activities to coordinate medical/rehabilitative services or independent living needs (i.e., conducted once per year, once per month, once per week, once per day, or never). Qualitative elements included encouragement to provide additional comments and perceptions throughout the interview. Open-ended questions were included to encourage reflection on the relevancy of issues raised and to encourage mention of additional issues. Two versions were developed (one phrased for the person with brain injury; the other for the SSO) and are available from the corresponding author.

Purpose

This study had two aims. The first was to determine the internal consistency in the CASCAM care coordination domains. Internal consistency is a basic characteristic of a scale, used to clarify item groupings. Analysis of the alpha and item intercorrelations helps to identify the reliability among items, allowing for the scale to be improved by removing poorly related items or combining

well-related items (Allen & Yen, 1979). The second aim was to improve content validity, clarity, and acceptability.

Method

Thirty-seven volunteers (46.2 ± 15.0 years) were recruited from local brain injury support groups and through word-of-mouth referral from existing volunteers. The sample included community living adults with traumatic brain injury or other acquired brain injury ($n = 23$; eight women, 15 men), and the SSO of anyone with such a diagnosis ($n = 14$; nine women, five men). Consent was obtained according to the local university's Institutional Review Board approval. The inclusion criteria stipulated that participants be at least 18 years of age, have a previous diagnosis of brain injury or be acting currently as the SSO to anyone with such diagnosis, and be living in the community. The exclusion criteria included any medical condition(s) or issues that may interfere with study participation.

Data Collection

The participants were asked to complete the CASCAM. To increase participation, we offered several methods for completion, including by telephone, email, physical mail, in person, and via a custom online survey (Qualtrics LLC, 2016). However, the majority of the participants preferred to complete the CASCAM via telephone. One member of the research team completed all data collection, reading from the CASCAM script (i.e., questions and possible answers where applicable) verbatim if reading items aloud to the participants. Cognitive interviewing, which involves asking participants to think out loud and report impressions

while responding to items (Willis, 2004), was used to validate content. The participants were asked several times if they believed any questions were confusing, worded poorly, or were not relevant to the topic of care coordination for people with brain injury. If so, the participants were then asked how they would suggest changing the items, as well as if any additional items should be added or deleted. No matter the method used, follow-up interviews were available as needed to clarify any responses or to ask the participants any new or revised items. On average, participation included one 45 to 60 min session.

Data Analysis

All quantitative data were transcribed into the SPSS 17.0 analytic program. Quantitative data analysis involved an examination of internal consistency regarding the frequency with which the participants engaged in the various care coordination activities. Cronbach's alpha values were calculated for major domains including medical/rehabilitation and independent living for both versions of the scale. Results were interpreted if they were statistically significant at $\alpha = 0.05$.

The CASCAM questionnaire also was assessed to determine if it successfully addressed issues related to care coordination and management that apply to people with brain injury and their SSO, known as content validity. Analysis was based on the participants' reports about the questions and their experiences with questions that they found confusing or thought should have been rephrased or explained differently.

Results

Demographics

Time post injury for the person with brain injury for all 37 interviews ranged from 1 to 45 years, with a mean of 10.6 years. The majority of the participants described themselves as being Caucasian (91.9%), with a small percentage of participants of Hispanic (5.4%) or Asian (2.7%) descent. Nearly all individuals with brain injury reported having a SSO involved in their service coordination and management at the time of data collection.

Content Validity

The participants responded positively toward the CASCAM, reporting that items were important and that it covered all areas of care coordination that they experienced. Eighty-eight comments by the study sample resulted in the modification of 25 items, which was done prior to internal consistency testing. Effectively, the CASCAM's ability to assess items of importance to persons with brain injury and their SSO was further validated.

Internal Consistency

The degree to which activities formed a homogenous group or scale was examined under classical test theory assumptions using Cronbach's alpha (Streiner, 2003). For 12 items on medical/rehabilitation needs, alpha equaled 0.826 among persons with brain injury and 0.945 among the SSOs. In addition, for nine items on independent living needs, alpha equaled .774 among persons with brain injury and .883 among the SSOs.

The effects of deleting an item were also calculated. For medical/rehabilitation needs, alpha

values ranged between .774 and .827 for persons with brain injury and between .935 and .948 for a SSO. For independent living needs, values ranged between .658 and .767 for persons with brain injury and between .852 to .878 for a SSO.

Discussion

The current study aimed to evaluate the psychometric properties of the main domains of the CASCAM, a scale designed to systematically assess care coordination needs and activities from the viewpoint of individuals with brain injury and their SSO. People with brain injury often require a range of services to address physical and cognitive symptoms. This common variation in symptoms and accompanied services may then logically generalize the results of the current study to other populations.

This topic is of particular concern to the field of occupational therapy in that care coordination is an IADL, and as such should be addressed by an occupational therapist. Like most IADLs, care coordination is required on an intermittent basis, but it is extremely meaningful and sometimes essential. This is particularly true during transition phases in one's life, such as transitioning to inpatient and/or acute care or to outpatient and chronic care. The result may be that the individual will hopefully be able to do things like schedule appointments, navigate the health care system, and advocate on his or her own behalf. In doing so, one may reduce the amount of stress perceived while interacting with medical and rehabilitation staff and increase his or her overall functional independence. In addition, the topic described involves areas of meaningful,

independent living that can assist the person(s) with brain injury to accomplish various tasks related to care coordination, which in turn will improve aspects related to multiple other activities and occupations. This then has the potential to lead to a societal impact in hospitals, communities, and families. In the hospital, health care professionals will be presented with a clearer understanding of the difficulties that people with brain injury and their SSO experience, and transition and treatment plans can be adjusted accordingly. In the community, these individuals will be able to better receive the care and services that they need with a reduced burden, leading to more time to do the things that they enjoy in the community. In the family, the SSO will have a diminished amount of stress, burden, and personal effort, as well as a greater awareness of what his or her loved one is experiencing. As a result, families will have more time to spend with each other. For these reasons, this research was conducted.

Content Validity, Clarity, and Acceptability

Content validation involved determining if the CASCAM contains all theoretical parts of care coordination and if each part is important. This is often done through expert consultation, historically with researchers of the topic area. However, members of our target population can also be considered experts, with cognitive interviewing aiding in this process (Patrick et al., 2011). The CASCAM's strong basis in theory and literature, as well as the modifications from the participants' suggestions, indicates adequate content validity, clarity, and acceptability.

Internal Consistency

Despite the multidimensionality of care coordination, we found a high degree of internal consistency among the main domains. The items used to characterize frequencies of medical/rehabilitation and independent living care coordination activities among persons with brain injury and their SSO demonstrated moderate to high internal consistency (Cronbach's $\alpha = .774 - .945$). This suggests that it is possible to create a summative scale to characterize care coordination activities addressing health versus independent living. The fact that care coordination activities have appreciable internal consistency supports care coordination as a meaningful construct.

A likely explanation for the broad, probabilistic interrelatedness of care coordination activities is that more complex injuries or disease lead to more complex coordination needs. Such are linked, making for the interrelatedness observed. A related explanation is that different health care systems require individuals to assume different levels of responsibility for care coordination. The participants in our study resided in one metropolitan area in the United States, known for the complexity of its care system and for variation in care access, so the participants experienced varying levels of need for coordination and access.

It is possible that individuals had perceptual biases, a "halo" effect (Thorndike, 1920, p. 28), that led to responses that in fact varied more than reported. This is unlikely, as substantial variation in the frequency of coordination activities was evident.

These internal consistency results strongly support the possibility of development of a

summative scale or index of care coordination for individuals with complex interrelated physical and cognitive/psychological brain injury. Further research is needed to clarify explanations.

Limitations

Limitations of this study include the use of a small convenience sample, which may be non-representative. Larger studies with diverse populations are needed to confirm our results regarding generalizability of measurement structure and to characterize the degree of generalization across diagnoses and care systems. This is particularly true for time post injury, as one's care coordination needs may be highest shortly after returning to the community.

It is possible that individuals with brain injury in this sample may have had unreported memory, self-awareness, or other cognitive impairments that may have affected the results. In addition, past experiences with the health care and/or university settings may have caused perceptual biases in some of the participants. At the same time, our sample included individuals living in the community for many years. Relational studies of self-report to more objective service and access indicators would be needed to study these possibilities. At the same time, the drive for person-centered care systems highlights the need to understand how the system is perceived by individuals with brain injury and their SSO.

While Cronbach's α greater than .90 indicate high reliability or internal consistency (Streiner, 2003), this may also mask redundancy and increase length without substantial increase in content validity (Boyle, 1991). The finding that

deletion of an item, in some cases, did not significantly reduce alpha in this set suggests that the current item set might be slightly shortened, especially for SSO actions to coordinate medical/rehabilitation needs.

Although classical test theory methods, such as Cronbach's alpha, provide clues, future research should use Rasch analysis or other item-response theory methods to develop better-structured scales (Bond & Fox, 2015). Such work could provide an equal-interval measure, enhance the CASCAM validity, more clearly identify best and worst fitting items, enhance knowledge of the difficulty of levels of care coordination, possibly shorten the scale, and clarify types of persons or situations that fit/misfit the scale.

Conclusions

Care coordination is a set of complex interrelated activities addressing the care or services needed to sustain or improve health and independent living. The impairments and situations giving rise to these care/service needs and gaps remain highly heterogeneous. The process of coordinating the multitude of needed care can become confusing and even overwhelming to the persons involved. This questionnaire was developed to facilitate systematic understanding, tracking, and quantification of activities that individuals with brain injury and their SSO perform to address care needs from their perspectives. During the process, we improved the clarity, acceptability, and content validity of the CASCAM.

This work shows that the occupation of care coordination by persons with brain injury and their SSO is observable and that these individuals can

report it with high internal consistency and reliability. Major domains include management and coordination of health (medical/rehabilitative) and independent living activities by the person and his or her SSO. These findings strongly suggest that it is possible to provide a summary scale of these domains. Continued use should help to identify needs in health and disability care systems and to help individuals successfully perform their essential role in care management and coordination.

Mark V. Johnston, PhD, is Professor Emeritus in the Department of Occupational Science and Technology, University of Wisconsin- Milwaukee. With over 90 peer reviewed publications and several millions of dollars of research grants, he has spent his career supporting research on factors that affect health and quality of life outcomes for people with disabilities and chronic conditions and sincerely hopes that work to improve self-management and family coordination of care will continue.

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