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Research Article

Theory of Self-Care for People with Mental Disability in a Community

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Abstract

Purpose: The purpose of this study was clarification of the elements of self-care for people with mental disability in a community.

Methods: Using the Japan Medical Abstracts Society online, PubMed, and CINAHL, with keywords of "mental illness," "mental disorder," "psychiatric illness," or "psychiatric disorder," and "self-care", or "self-management," we identified concepts according to the analytical method described by Rodgers'. Additionally, we conducted interviews with supporters about abilities and elements necessary for people with mental disabilities to live in a community. We reconstituted the constituent elements of self-care obtained from concept analysis and from categories obtained from interviews based on their mutual similarities, commonalities, and differences. Finally, we extracted the constituent elements of self-care for people with mental disabilities in a community.

Results: Self-care was composed of six elements of "stability of mental and physical states", "maintenance of daily life", "ability to accept support", "maintenance and development of human relations", "empowerment", and "motivation in life" and 28 element divisions and 86 concrete activities.

Conclusion: The elements of self-care are useful indexes to ascetain the self-care necessary to realize the life-style and life desired by people with mental disabilities and to design support.

Keywords: Life in community; People with mental disability; Self-care

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Introduction

In terms of mental health in Japan, 2004 Vision for Reforming Mental Health Care and Welfare (here in after called Reforming Vision) was compiled by the Health, Labor and Welfare Ministry in September 2004 [1]. Based on the basic concept of "inpatient management to community" set in that statement of vision, concrete measures to realize the basic concept, including the enforcement of a law for comprehensive support of daily and social life (Comprehensive services and Supports for Persons with Disabilities Act) and repeated revision of medical service fees, have been developed. Full-fledged approaches have been initiated. As such various measures have advanced; the hospital discharge rate of people with mental disabilities has been rising markedly.

The death of inpatients in mental health hospitals has not shown marked improvement. The revolving-door phenomenon, by which a patient is hospitalized on and off in the short term, is designated as a chief cause. Unless treatment and self-management can be maintained continuously after remission by hospital treatment, acute exacerbation results in frequent hospitalization. Also, long-term outcome improvement cannot be expected. Because support is increasingly transferred to the community in the future, it will be important to provide support to enhance self-care capability necessary to live in a community for people with mental disabilities, rather than conventional support particularly addressing symptomatic improvement and functional recovery.

Earlier reports have described examination of self-care concepts such as conceptual analysis of self-management for patients with cancer [2], conceptual analysis of self-management for patients with cardiac arrest [3], and conceptual analysis of self-care for patients with schizophrenia [4], the concept of self-care for people with mental disabilities in a community has not been defined yet. One might infer that, because people with mental disabilities are said to have both diseases and disabilities, their mental symptoms should affect on their self-care resulting in various life disabilities [5,6]. Consequently, it is important to present clear concepts of self-care considering the disease characteristics of people with mental disabilities.

Furthermore, we think that we can present more multiple self-care factors by clarifying the recognition of supporters who help people with mental disabilities in a community. Then, we clarify the abilities and skills which are thought to be necessary for people with disabilities by home-care nurses and psychiatric social workers helping them in a community. By unifying individually extracted elements, this study was conducted to clarify the constituent elements of self-care for people with mental disabilities in a community. Because support services to help long-term inpatients leave the hospital are advanced based on the fundamental concept of the reforming vision in the future, we can obtain important suggestions in taking steps for concrete nursing support aimed at having support transferred and established in a community by clarifying the composing elements of self-care in a community.

Methods

Study design

Because this study aimed to show what factors compose self-care necessary for people with mental disorders to live in community, the study design was a qualitative descriptive study.

Subjects

We analyzed articles related to self-care for people with mental disabilities in Japan and overseas and related to home-care nurses and psychiatric social workers providing community support at home-care stations, counseling and support centers, multifunctional care services, and outreach support centers, which gave their consent to this study. Our subjects for analysis were 12 specialists supporting people with mental disorders in the community. The professions of the participants included nine home-visiting nurses and three psychiatric social workers. Among the home-visiting nurses, four were supervisors. They were five men and seven women with mean years of experience in psychiatric community support of 12.1 years (SD 7.7). The home-visiting nurses participating in this study had supported their users not only by observing users' disease or disability conditions or monitoring their drug therapy, helping their communication, and supporting them and their family in recuperation, but also by providing round-the-clock an interprofessional team service or telephone counseling for severe cases or difficult cases. The psychiatric social workers turned out to help their users to solve their life or social problems or encourage them to participate in society.

Data collection method

This study actually used a three-step approach. At the first step, according to Rodgers' method for conceptual analysis, we read the literature related to self-care and summarized the contents, which describe self-care.

We used the Japan Medical Abstract Society online (published in 1977), PubMed (published in 1946), and CINAHL (published in 1981). Because earlier studies did not distinguish clearly between self-care and self-management and because self-management is a part of self-care, we used "people with mental disabilities" and "self-care" or "self-managing or self-management" or "mental illness" or "mental disorder" or "psychiatric illness" or "psychiatric disorder" and "self-care" or "self-management" as keywords. Mental disorder is a state in which a patient is affected mainly by schizophrenia or a mood disorder, developing particular mental or behavioral symptoms and therefore suffering from functional disorders.

Additionally, we conducted a search in fields including mental hospitals and community because support for self-care in mental hospitals is implemented with a view to patients' community life. The search duration was the publishing years of the databases for literature surveys to December 2016. From that search, 375 articles from the Japan Medical Abstract Society online, 90 from CINAHL and 26 from PubMed were identified. Confirming titles and abstracts from reports of the literature and judging their fitness for the theme of this study from the descriptive contents, we finally selected 42 reports of the literature as analytical targets.

At the second step, we conducted semi-structured interviews of supporters who helped people with mental disorders in communities to show what self-care they recognized as necessary for them to live in their community. We considered that if we define questionnaire items and do not structure them, then we could obtain some results beyond our expectations and any pre-set framework. Therefore, we chose to use a semi-structured interview. The reason we conducted semi-structured interviews is that the results obtained at the first step did not specifically elucidate self-care in community life. Therefore, we needed to elucidate the self-care recognized by specialists supporting people with mental disorders in the community.

We conducted 30-90 min semi-structured interviews of examinees who gave their consent to participation in our study. The interview included queries related to the abilities and skills that are considered necessary for people with mental disabilities from the viewpoint of specialists. We conducted interviews in a private room to secure privacy and recorded the interviews with an IC recorder with the consent of the interviewees.

At the third step, we combined the results obtained at the first and second steps and showed self-care required for people with mental disorders to live in their community.

Analytical methods

At the first step, according to the conceptual analysis described by Rodgers [7], we made original coding sheets to categorize attributes and to organize description contents. In categorizing them, reading the context of each term closely, we extracted raw data from appropriate places. We encoded the extracted data with a label to express them simply and to categorize them based on their similarity and difference to clarify the composing elements of self-care.

At the second step, the analysis of supporters' interview contents was conducted qualitatively and inductively according to the following procedure: (1) All interview contents recorded with an IC recorder were described word by word. (2) The parts describing abilities and skills necessary to live in a community were extracted and encoded using units by which a reader can understand the meaning and content. (3) The codes were categorized based on similarity. In addition, the categories were sub-categorized by raising the level of abstraction. To secure the reliability of the results, we conducted analyses while checking data interpretation as needed, supervised by a researcher with experience in qualitative studies from the analytical process.

At the third step, in terms of the constituent elements of self-care obtained by conceptual analysis and the categories obtained by interviews, we reconstructed them based on their respective similarities, commonalities, and differences to extract the final composition elements of self-care of people with mental disabilities living in a community.

Results

The attributes of self-care of the people with mental disabilities in a community clarified by conceptual analyses and composing elements of self-care in community recognized by supporters were reconstructed based on similarities, commonalities and differences. Consequently, six elements of 1) stability of mental and physical states, 2) maintenance of daily life, 3) abilities to accept support, 4) maintenance and development of human relations, 5) empowerment and 6) motivation in life, and 28 element divisions and 86 concrete activities were extracted (Table 1).

Elements	Element divisions	Concrete actions
Stability of mental and physical states	Management of mental condition	Monitoring of mental condition
		Coping actions for symptoms
		Drug compliance
		Actions for visiting hospitals
	Health management	Monitoring of physical conditions
		Physical management
		Actions for visiting the office in poor mental condition
	Stress management	Monitoring of stress status
		Stress coping
Maintenance of daily life	Diet management	Decision of menu
		Buying cooking ingredients
		Cooking
		Clearing a table
		Using cooking instruments
		Buying ready-made meals
		Voluntarily eating food
		Checking the expiration date
	Sleeping management	To maintain satisfying sleeping
	Rest	Consciousness of fatigue
		Rest while suffering from fatigue
	Bathing, changing clothes and applying cosmetics	Cosmetic behaviors including washing face, fixing hairs, shaving and brushing of teeth
		Maintaining the body clean (by bathing)
		Dressing in accordance with time, place and occasion
	Cleaning and laundry	Cleaning the private room
		Distinguishing between something clean and something not clean
		Laundry considering the timing
		Management of bedclothes
	Decluttering	Putting belongings in order
		Disposal of unnecessary items
	Disposal of garbage	Waste sorting
		Taking the trash out (at the designated place and date)
	Shopping	Shopping things necessary to life
	Use of public transportation	Using public facilities such as bank, post office, and city hall
		Using public transportation such as train, bus, and tax
	Use of social resources	Obtaining knowledge of accessible social resources
		Appropriate use of social resources
	Time management	Designing a life schedule
		Life in accordance with schedule
		Being punctual
	Management of items	Management of valuables (seal, passbook and disability certificate)
	Financial management	To use money systematically
		To put money aside
		To save money
	Security management and risk management	To obey traffic rules
		Safe use of fire
		Use of phone
		Anticrime measures (e.g. lock-up)
Ability to accept support	Self-recognition	To clarify what one can do and cannot do
	Actions to request help	To issue SOS signals
		To take counsel with someone
		To accept support

Maintenance and development of human relations	Connectedness to others	To maintain appropriate family relationships
		To maintain appropriate relationships with friends
		To maintain appropriate relationships among people with mental disabilities
		To maintain appropriate relationships with the opposite sex
		To communicate with strangers appropriately
		To maintain appropriate relationships with healthcare staff or welfare workers
		To maintain appropriate relationships with people related to the workplace
		To maintain appropriate relationships with neighborhood residents
		To develop human relations
	Communication skills	With a smile
		Able to greet anyone
		Able to say thanks
		Able to listen to others
		Able to become sympathetic to others' world
		Able to express will and feelings
		Able to turn down offers
		Able to communicate considering others and situations
Empowerment	Self-resources	Self-decision
		Having the ability to solve problems
		Appropriate self-assessment
	Will	To have a feeling of living in a community
		To have the will to live
Motivation in life	Whereabouts	Having a place to spend time in character
		Having a comfortable place
		Having a favorite place to visit
	Goal, dream and hope	Able to have goals
		Able to have dreams
		Able to have hopes
		Able to have fun in life
	Spending leisure time	Having hobbies or culture lessons
		Able to spend time in character
	Going out	Able to go out voluntarily
	Obtaining, managing and using income	Obtaining income by working and helping
		Able to enjoy something at one's own expense
		Able to buy something that one wants with one's own money

Table 1: Constituent elements of self-care of people with mental disabilities in a community.

1) Stability of mental and physical states

These are the core behaviors of people with disabilities living in a community to stabilize mental and physical states. They consist of behaviors aimed at stability of mental and physical states: to do (management of mental symptoms) by "monitoring mental symptoms" and doing "coping behaviors for symptoms" and "hospital visit" and "drug compliance," (health management) by "monitoring physical state," "physical management," and "visiting the office in poor mental condition," and (stress management) by "monitoring stress condition" and "stress coping".

2) Maintenance of daily life

These are concrete behaviors for people with mental disabilities to maintain their daily life. The behaviors for (maintenance of daily life) consist of (dietary management), (sleeping management), (rest), (bathing and cosmetic action), (cleaning and laundry), (decluttering), (disposal of garbage), (shopping), (use of public transportation), (use of social resources), (time management), (management of goods), (finance management), and (safety management and risk management).

3) Ability to accept support

The ability to accept support includes behaviors related to receiving supports from others when people with mental disabilities face various difficulties. They consist of (self-recognition) to assess their own circumstances and abilities and (behavior to request support) such as issuing SOS signals.

4) Maintenance and development of human relations

These include behaviors for people with mental disabilities to maintain and newly develop relationships with different people in a community. The maintenance and development of human relations consists of connectedness to others, including not only specialists but also different types of people and communication skill.

5) Empowerment

These are behaviors that empower people with mental disabilities to live in character in a community. They consist of self-resources such as self-determination, ability to solve problems, and appropriate self-assessment and will of people with mental disabilities for living in a community.

6) Motivation in life

These are behaviors for people with mental disabilities to have motivation in life and raise their QOL. Behaviors to have motivation in life consist of securing whereabouts, having goals, dreams and hopes, spending leisure time in character, and voluntarily going out and gaining, managing and using income.

Discussion

Self-management is designated as a concept related to self-care. In the medical field, the term self-management is used operationally based on the cognitive theory that human behaviors have some conscious or unconscious meaning and they make decisions based on previous experiences [3]. Furthermore, self-management is one factor of self-care to manage disease or to maintain health through healthy habits. It is regarded as a cognitive process of decision making as a response to symptoms or indication. In other words, although self-care is the wide range of concepts including recognition and behaviors of a patient himself or herself, self-management is one factor of self-care, which is distinguished from the former in that it is a definitive concept that insists on recognitive self-decision process related to life management in healthy or ill conditions [3]. However, because self-management is translated into self-care in the dictionary of nursing science, [8] and because it is regarded as interchangeable with self-care, it is assumed that both might not be distinguished for use, even though the concept of self-care is sufficiently wider to include that of self management.

In this study, after unifying the results of conceptual analysis of self-care of people with mental disabilities in a community and the results obtained by interviewing supporters about abilities and skills for them to live in a community, we categorized self-care of people with mental disabilities in a community into six constituent elements: stability of mental and physical states, maintenance of daily life, abilities to accept supports, maintenance and development of human relations, empowerment and motivation in life.

People with mental disabilities often show impairment of self-care abilities because of disease characteristics such as cognitive dysfunction that might include inability to sustain attention and deficits in executive function, positive symptoms such as hallucination and delusion, and negative symptoms such as abulia and autosynnoia. Consequently, nurses' conscious and multifaceted or multiphase observations are presumed to be important. The methods are often entrusted to individual nurses in a clinical setting [9,10]. However, to realize the transfer to, and settlement in, community of people with mental disabilities, it is important to assess the actual situation of self-care adequately based on some indexes and to provide effective support to improve their self-care.

In psychiatric circles, self-care is often assessed using Orem and Underwood theory [11] as an index. This comprises six items that indicate self-care necessary for people to live. However, for this study, we extracted more items of self-care of the people with mental disabilities in a community. The items include the following: what is applied to Activities of Daily Living (ADL) that is fundamentally important to maintain a living such as diet, changing clothes, toilet, and bathing; what is applied to Instrumental Activities of Daily Living (IADL) to maintain higher-level living functions including using a telephone, domestic duties, and self-management such as drug compliance and financial management; what is applied to Social Functioning Abilities (SFA) including social participation, independent-minded creation of life, and aggressive use of accessible social resources; elements leading to motivation in life such as spending leisure time and having goals, dreams and hopes.

In other words, for people with mental disabilities to maintain their own life and healthy functions, sustainable personal growth, and happiness in community, it was demonstrated that they must acquire not only narrowly defined ADL but also behaviors to maintain independent living by self-management of safety, time, things, money, and life through their own cognitive decision-making and the independent-minded behaviors for self-fulfillment through communication with others and society to enhance their quality of life.

Because mental diseases often develop during adolescence as an important stage of life, patients are likely to have difficulty adjusting to social life without work experience [12]. In addition, disease characteristics cause people with mental disabilities to experience many difficulties living in daily life [13].

Supporters have mainly been offering support to enhance ADL with the intention that people with disabilities who have difficulties living can transfer from a stay at the hospital to community and continue the life in community. However, behind the broader self-care elements extracted in this study, supporters' consciousness has been shown to change and develop to the extent that they can aim not only to help people with mental disabilities to live independently as in the past but also to help them live in character and to improve their QOL by elevating IADL and SFA.

Bathing, changing clothes, and application of cosmetics among the self-care elements were also extracted from many reports of the literature and interviews. However, the elements of security management and risk management were only reported occasionally. The number of extracted items varied among elements. Furthermore, what was newly extracted from interviews though not extracted from reports of the literature included motivation in life and abilities to accept supports. In other words, the possibility exists that there is a difference in recognition of necessary self-care concepts among specialists.

As support for the transfer to and settlement in community become increasingly promoted, it will be necessary to consider support for improvement of IADL and SFA and for motivation in life as well as conventional support for ADL from diverse standpoints and to enhance and develop support for the improvement of self-care in healthcare facilities and community aiming to help them live in character.

With the composite elements of self-care in community visualized by concrete behaviors in this study, we can conveniently and clearly assess self-care capabilities for people with mental disabilities to live in a community as they like. We can also use them as indexes to examine necessary support for them. Additionally, they are useful as materials in examining the introduction of social resources for necessary self-care.

The place in which the subjects interviewed this time provide support is a suburb, somewhat distant from downtown and between an urban area and a rural one. Consequently, although we do not know whether the results apply to developing countries, they can be applied to areas located between an urban area and a rural area.

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