Cultural caring expressions of family members towards self-management among patients with diabetes mellitus

Dalyal Nader Al-Osaimi

Abstract: *Patients with unique needs require specific care attention and this varies depending on the cultural affinity. In case of diabetes mellitus considered as a global health challenge, the care plan must capture the cultural affiliation of both patients and the family to ensure acceptability of the treatment designed to facilitate recovery towards quality of life. The study is aimed at analyzing the cultural attributes of family support towards caring for patients medically diagnosed with diabetes mellitus as basis to craft family-based management model. Employing a qualitative design, eighteen participants were identified purposively based on the pre-determined criteria. Descriptive profile of the participants (carers) includes the age ranging from 35-62 years old, rendering care service with the patient for almost 12 years on the average, and living along with the medically diagnosed DM patients. Data collection like in-depth interviews, focused-group discussions were utilized to generate significant statements and themes. The results generated themes such as (1) familial role as an important component of success in treatment care plan, (2) patience and emotional control as cultural support strategies in the success of care plan implementation; (3) meaning of care as an expression of love, respect and gratitude. The study further highlights on the family as cultural component of care in the integration of solutions in overcoming obstacles in client-care with diabetes mellitus.*

Keywords: *Cultural Care; Diabetes Mellitus; Family Support; Nursing Care; Support System.*

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Introduction

The growing concerns of patients with diabetes mellitus (DM) also means assurance of a culturally-acceptable care design. The family as the core of any social structures is called to care the patients outside of health care settings and the caring expressions vary on, they understand the dynamics of care and disease progression. Diabetes Mellitus (DM) is a group of metabolic disorders characterized by chronic hyperglycemia resulting from defects in insulin secretion, insulin action, or both. It represents a major global health challenge, with an estimated 540 million people living with diabetes in 2020, and this number is projected to increase to 552 million by 2030[1]. In the Asian region, the estimated population suffering from the disease is expected to increase by 60% by 2030[2]. This leads to considering DM as a prominent public health problem [3.] Various complications can occur not limited to retinopathy, but also cardiovascular disease, amputation, and even death [3]. Diabetes mellitus in terms of self-management is relatively complex, considering that clients must attend themselves for regular medical check-ups, compliance with medication administration and treatment procedures, blood glucose monitoring, symptom control through active physical involvement such as exercise, diet control and modification to meet the unique needs of clients[4].

The family, considered a functional unit at the forefront of supporting clients with diabetes mellitus, plays a crucial role. As a support system, the family will be able to critically identify the client's level of self-management since it occurs in a closed social space. Hence, the success of identification-and-implementation of care designs are dependent to the family attributes and functions and are major cornerstone towards management. Family attributes are characteristics often associated to cultural affiliations greatly influenced by values, functions and shared relationships to, within and among family members. Additionally, attributes of support, love and religious affiliations are pivotal to the overall adherence to treatment regimen which likely affected by the dynamic changes when uncertainties surfaced to family as a major support system.

A better understanding of family attributes and functions is necessary, as this is an important support system in diabetes management. Clarifying the needs and ways to support the family as a support system is necessary to maintain balance in diabetes care. Understanding the cultural family attributes as expressions of caring related to self-management in diabetes care provides an important basis for developing efficient and sensitive involvements that enhances cooperation between families as a unit and individuals, as a whole, to move together. This paper intended to strengthen the culturally-appropriate care to patients medically diagnosed with diabetes mellitus; the support system expected of to frame better approaches of patient care.

Methods

The study employed qualitative design to capture the family's cultural caring expressions in the management of patients medically diagnosed with diabetes mellitus. Eighteen participants were purposively identified based on the pre-identified selection criteria (at least 10 years and above in the care of medically diagnosed diabetic patients, a family member living on the same roof as that of the patients, and are willing to share narratives on the experiences of care to concerned patients) from rural communities of Philippines, Thailand, and Malaysia. The identification was based on the data information provided through referral mechanisms form local health counterparts.

The researcher prepared an open-ended guide questions with probing question sets to exhaust data acquisition based on the study objectives. In-depth interviews, focused group discussions were maximized to illicit responses among the identified participants. Field notes, observation sheets were utilized to ensure that all data are duly captured.

Prior to data collection, proponent accomplished the forms and requirements for ethical consideration which was duly given code assignment. During the actual data collection and site visits, the researcher explained the study intention, its benefits and importance to improve the body of knowledge and care performances in general. The recruitment process was properly executed, strictly followed based on the approved protocols. Participants were also informed of their rights and the privilege to stop should the interview sessions no longer warrants safety and security to everyone taking part of the study.

The study moreover, observed the collection of information procedures aside from the securing the ethical clearance. After the approval phase, the proponent provided information guide for participants to supply the needed data in the established criteria based form the agreed qualifications. An audio-assisted recordings were produced from the narratives of the participants for approximately 60-90 minutes per participant to be carried out for transcriptions and analysis of data.

The proponent employed thematic clustered analysis to describe the cultural support of the students experiencing home care to patients with diabetes mellitus. OpenCode Software were also utilized to help identify the emerging themes.

Results

The study was participated by 18 eligible participants from across the identified environment. These were immediate family members who had taken care of diabetic patients for over ten years and were directly involved in the active patient care.

Attributing to the participants profile, mostly are women ages 28-62 years old who took the lead in the delivery of care to diabetic patients. Mothers, wives and grandchildren constitutes mainly in the execution of care from assistive mechanisms to fulfill the activities of daily living (ADLs), giving of maintenance medication, therapeutic works like assistive mobility, change of clothes and even feeding- all are done by the aforementioned family care providers.

In the narrative, family providers do not receive formal trainings on the proper way of delivering the care, yet they are grounded by the idea that diabetic family members are as equally important that of the well members in the core. Strong family ties bind them to support each other in varied ways possible in the optimization of service afforded to the sick household.

In the advent of technology where self-taught videos on ways to care patients with DM conditions, the carer subscribed to the online accessed information through mimicking executions especially on the giving of insulin injections and changing of dressings to those with diabetic-related wounds. Nevertheless, those concerned did not hinder the family carers to continue giving assistance and support to the patient. It became even a driving force to strengthen emotional bonds, owning responsibilities, learning the value of oneness as a cultural expressions of care.

The meaning of cultural care experiences as carers of DM patients

1. **Sacrificial patience and emotional efforts are critical in the success of care**
   Family carers never denied that the caregiving component to patients with unique health needs is an overwhelming tasks. The experience is exhaustive since the disease progresses to chronicity thus even attention is demanded.

   Members of the family reported burnout, burdened to both time, resources and the need to learn new skills to effect improvement to health conditions of the patient. Despite the feeling of exhaustion, they carer did not stop the caring efforts knowing that this is rooted on cultural upbringing in the family; when one is in need- the others must take in the role to help and support. This gesture displayed sense of responsibility and accountability. A strong sense of familial obligation as narrated by the participants.

   "it is a feeling of respect, obligation and sense of responsibility as member of the family " (P 4,8,16,18).

2. **Familial role as support system towards health improvement**
   The participants shared that the strongest form of support system in any form of health recovery and improvement is the family presence. Medications although instrumental in the physiological recovery, the diet and monitoring schemes,

family served as unifying force that ascertains full execution of the plans defined. In Asia countries especially in Philippines, participants recognized that in the absence of a family as a component of care and culture, clients receives less care. Human component in care completes and optimizes the delivery of care rendition.

Patience emerged as a key role in ensuring that treatment plan is properly taken cared and executed fairly. The ability to accept client's health condition, coping with the changes and religiously following the treatment plans are needing stronger family support. The family members also identified the attribute of patience as a necessary cultural component to maintain the on-going care process thereby reducing the conflict issues that could potentially breaks the family ties.

"Usually I say, come on, do you still want live longer? Then you must take your medications and never give up on life; we are here for you on your road to recovery. Just be patient and so do we to you" *(P1, 3, 4,7, 8,9,11,14, 17,18)*

3. **The meaning of care as an expressions of love, respect and gratitude.**
   The theme explained that care emerged cross cultural beliefs and affiliations. Love in any language straight from the heart which binds everyone to pursue the caring essence to the patients with challenging health condition. Caregiving as essence of love suggests familial responsibility and appreciation from the patient is sufficient enough to continue the caring moments.

Caregiving is interpreted as a moral expressions of love and genuine kindness which is irreplaceable in any Asian family dynamics. This understanding exists that despite differences, family caregiving as a form of sincere care is rooted in love and affection.

"I sincerely want to do it because it is the best thing to do. Family is love and we need to care for each other" *(P2,3,5, 6,8,10,11,13,14,16,17,18)*

Discussions

The results of the study signals three major themes towards expressing cultural care towards successful self-management. The expressions highlights family, emotion and meaning of care as critical components in ensuring culturally-responsive care. These attributes have been evidently expressed by the family carers in caring to a medically diagnosed diabetic patients which accords with social support -house philosophy (1981), Wills (1985). The hypothesis explained social support not only originates from the outside system, but are greatly obtained to individual network that influences health outcomes and protection from the adverse effects related to

non-caring custom. Social relationship on one hand offers protection, resources required of to continue the care from the concerned family members.

It should be noted however, that the social support house hypothesis (1981) is not only applied to one family caring with diabetes problem, but include those needing family as a strong support system in carrying out the plan of care. In the Social Support-House theory (1981), it only reveals what forms of support are, but has not yet explained why families can survive while caring, how families interpret the support they provide and what psychosocial impacts on the family caregivers.

Some theories such as the Caregiver Burden & Caregiver Adaptation Theory (Zarit et al., 1980; Pearlin et al., 1990), which states that families who care not only provide support, but also experience physical burdens, emotional burdens, economic burdens, and social burdens. However, the family structure adapts well through acceptance, role adjustment, and reframing the meaning of illness, as revealed by the participants. It can be uttered that family support is not only a provision, but also an adaptation approach for family members who care for the burden of chronic DM care.

In addition, the Meaning-Based Coping theory (Folkman & Moskowitz, 2000) states that families survive not only because of their abilities, but because they give meaning to care and link illness with life values, faith, and family relationships. This can be shown from the results of this study that family members who care for care interpret care as a moral responsibility, a form of gratitude and a manifestation of love. As revealed from the interview results, "caring for the wife is the husband's responsibility," and "feeling happy to be able to repay grandmother's kindness." This shows that family support is not just a functional action but is *meaning-driven* .

In the theory of Family Resilience (Walsh, 2016) it is revealed that families are able to survive in caring for clients with chronic diseases through 1) Belief systems, 2) Family organizational patterns, and 3) Communication processes. From the results of interviews and FGDs to care for DM clients, families must adjust their diet, activities, economic roles and time and routines, as revealed from the results of the interviews "Now the family's diet has changed." (P17) , and "We reduce sugar together." (P16) from these two statements show how families who care must follow the diet of sick family members, because it is for the common good. This illustrates that DM is not only an individual disease but the presence of this disease triggers a transformation of the family system.

Role Theory & Filial Obligation (Biddle, 1986; Sung, 1995) is also applied by families in managing sick members. In this theory, the family's role as caregiver is influenced by status (child, husband, wife), cultural norms, and social expectations. From the research results, families do not choose roles, but are accepted as

obligations. This means that as family members whose family members suffer from chronic diabetes, they are left with no option but the role to care for.

It can be said that family support is shaped by the construction of cultural roles, not only biological relationships. In this study, family members also play a role as informal co-providers, not just passive supporters, such as family actions that remind people to take medication, regulate diets, and determine check-up times. This action is in accordance with the Self-Management Support Theory (Chronic Care Model) (Wagner et al., 2001) which states that DM management is effective if there is an active client, caregiver as co-manager, and a community support system.

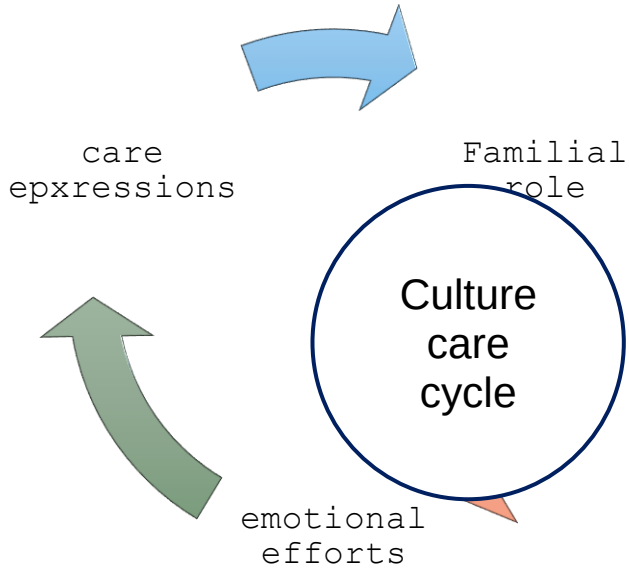

Fig 1: *The cycle of cultural care model*

The cycle of culture care suggest that for the care to exists, three major attributes must be seen. These rhythm evolves in the premise that culture is a defining component that binds the elements of care, family and emotional efforts. In the absence of any, culture care do not exists. Culture care is evident when union of these three are found in the caring environment.

Conclusions and Recommendations

The participants in the study means family members with concerned affection and great love and care to the sick family member ages 35-62 years with 12 years and

above caring encounter with the family member medically diagnosed with diabetes mellitus. The family's role as main support system includes being a provider care, financial and emotional services as expressions of cultural caring in nursing. Love, responsibility are the language of caring in cultural context shared among Asian families with patients having a challenging health concerns. It is suggested that a model cycle of cultural care be examined through advance studies related to care practices involving cultural representations. This model can be applied for future quantitative studies to test its validity, reliability in coming up with an instrument to measure culture care in fields of nursing care.

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