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Research Article

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Family Harmony: Reconciling Individual and Collective Responsibility in the Care of Type 2 Diabetes Mellitus in 'Middle-Aged' Korean Americans

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Abstract

Type 2 Diabetes Mellitus (DM) has disproportionately affected Korean American immigrants (KAI) in the United States. Biomedical, more individualistic, management models have focused primarily on individual responsibility for the prevention of costly complications. Traditionally, collectivism has been an important attribute of the KAI community. We conducted a qualitative study to explore the individual and collective values within the context of family while caring for DM in middle-aged (40-64 years) KAI. The following themes emerged from individual in-depth interviews: (1) Personal accountability for family harmony: I do it on my own; (2) Preserving appearance of family harmony at all costs: personal sacrifice for the good of the whole; and (3) Family harmony through mutuality: we take care of each other. The process of reconciliation of the individual and collective ethic requires one to find coping strategies, while considering social roles, gender and intergenerational interactions, in order to maintain harmony in KAI families.

Keywords: Korean Americans; Immigrants; Diabetes; Family; Individualism; Independence; Collectivism; Interdependence; Harmony; Qualitative; Experiences; Gender; Social roles

Introduction

Chronic illnesses, particularly DM, have disproportionately affected immigrant and ethnic minority populations in the United States, including Korean American Immigrants (KAI) [1], one of the fastest growing and understudied immigrant groups. Guidelines to control blood glucose levels include self-care activities such as on-going blood glucose monitoring, medication administration, nutritional therapy, and increasing activity levels [2]. According to illness management frameworks, self-care and treatment choices are heavily reliant on an individual's decision-making that involves personal self-efficacy, the resources to manage diabetes, balancing social responsibilities, and desiring normalcy [3-5]. While the nature of DM and management generally require personal motivation, self-knowledge, goals and decision-making, which are strong, individualistic or independent ideals originated from a biomedical perspective [6,7], the personal management models may not fully explain the experience of immigrants to the United States [8] or take into consideration of the traditional KAI culture and efforts to maintain family and community cohesion [9].

A number of culturally relevant factors may affect illness management of immigrant groups who bring with them a rich and deep traditional history of community. These include family relationships, family roles, value conflict and the predominant world view [10,11]. For example, Asian immigrants have been considered family and community oriented group. This perspective has reflected a collectivistic model that includes attributes such as duty, group harmony, belonging and relatedness, seeking others' advice, context dependence and group affiliation [12]. Collective societies have valued harmony of the group over individual gain [13]. These cultural underpinnings from Confucianism have been internalized for generations and have ensured continuity of the traditional interdependences. There are various levels of acceptance among the individual members on the spectrum of collectivistic or individualistic thought, however [14]. In fact, research has challenged the strict adherence to the collectivist-individualist construct [15] as individuals have been found to negotiate between both ideals [16]. The literature above has shown that many Asian immigrants have arrived to the United States with a strong collectivist influences, valuing family and group harmony, but have been exhibiting individualistic values within their daily lives. This combined ethic may influence the management of chronic illness including DM among KAI within the US health care system; a system based more on individualism.

The purpose of this paper was to examine how KAI rely on both individualistic and collectivist values to initiate the self-care required managing DM. Specifically, the study focused on describing the roles of family in the care of DM of Korean middle-aged adults. In addition, the experienced tensions and coping strategies used by KAI within the context of managing their illness and keeping harmony of family above all else were explored.

Methods

The setting and the informants

The approval from the Johns Hopkins University Medical Institutions Internal Review Board was obtained. Informants selected in the study were a subset of hypertensive KAI from a hypertension control study [17,18] who had agreed to be contacted for future studies. Hence every participant in the current study had completed the parent study at the time of the current study enrollment. The

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sample was drawn from initial pool of 52 participants who met the following criteria: first generation KAI, diagnosed with co-morbid DM and middle-aged (between the ages of 40-64). Twelve participants, 4 men and 8 women, were selected based on the variability in their control of the health indicators (i.e., self-reported level of blood pressure control, weight).

Procedure

We obtained informed consent from every participant before data collection began. A total of 19 interviews were conducted with 12 interviewees in Korean by a bilingual Korean nurse interviewer in a mutually convenient place; interviews ended when the interview was not yielding further new concepts. Sampling and data collection were completed over a seven-month period.

The interview was recorded upon permission from the informants. The unstructured interview allowed informants to discuss pertinent issues related to the caring of their DM. The following are examples of the types of questions asked:

The first-author -English-speaking researcher- was present for all interviews in order to document the informants' environments and to more adequately discuss what the interviewer learned during the interview. Fourteen interviews were conducted face-to-face and five were conducted via the telephone. The initial unstructured in-depth interviews lasted from 1-2 h. A second interview was conducted with six of the informants, lasting 20 to 60 min. A third interview was conducted with one of these informants because the second interview was interrupted before completion. The bilingual interviewer completed a demographic questionnaire after each initial interview, which included self-reported levels of glucose and blood pressure. Additional demographic variables were retrieved from the aforementioned hypertension study. Each informant received twenty dollars as a gift of appreciation.

To maintain integrity of the "researcher as instrument", the first-author conducted "debriefing" interviews with the Korean-speaking interviewer after each interview in this cross-cultural research, in order to understand the emerging data from the interview, to reflect on the interviewer's thoughts and impressions of the informant, and to strategize for future interviews based on the data from the informant. The recorded interviews were transcribed in Korean and then translated into English. Terms describing cultural concepts relevant to the study objectives were kept in Korean. The first-author and the bilingual interviewer compared the English-translated transcripts against the Korean transcripts to ensure accuracy of the translations. A full description of methods and analysis was described elsewhere [9].

Analysis

We managed and analyzed textual data in NVivo 2.0 [19,20] and applied the constant comparative method described by Strauss et al. [21]. We performed open, inductive coding, starting with line-by-line coding to begin building the analysis and allowed the researcher to ask additional questions of the data. We then developed more abstract, conceptual categories grounded in the data and examined relationships between the concepts. Finally, we developed abstract concepts and themes. Data quality was ensured using Guba et al. [22] criteria for trustworthiness. The English-speaking first-author, the bilingual nurse interviewer, and other bilingual researchers on the study team reviewed emerging concepts and themes at regular weekly meetings. The first-author documented discussions as memos and used them to ensure credibility in the interpretation of the findings. In addition, the debriefing interviews that were conducted between the first-author and the interviewer were compared to the evolving analysis to validate that the interpretation of the narratives.

Results

Ages of informants ranged from 51 to 60 years old and were considered a hard-to-reach subgroup due to their long working hours, busy lifestyles and language barriers. Typically, these informants were working 12 or more hours per day, many in family-run entrepreneurial or full-time service-oriented work capacities (i.e., liquor stores, grocery stores and dry cleaners/tailoring), without the benefits of health insurance (10/12 had no insurance). Their lifestyles were such that they came home late at night, ate and went directly to bed. Exercise was difficult to fit into a busy schedule for some. All of the informants lived with at least a spouse, but more often they lived also with children and possibly grandchildren. The process of acculturation varied from adjusting poorly to well among the KAI interviewed in this study. Despite the majority (9/12) of informants having been in the U.S. more than 10 years, only one person spoke some English. All had completed high school with almost half completing at least some college. The interaction with others outside the home was often limited to church members in the ethnic community or sometimes business clients, resulting in more isolation compared to living in Korea. Seven informants perceived their health to be fair to poor (Table 1).

Characteristics	
Ages	51-60 years, Mean age: 55.9
Gender	Women: 8, Men: 4
Education Level	Completed College: 3
	Some College: 2
	Completed High School: 7
Insurance level	Private Insurance: 2
	No Insurance: 10
# Years with DM	1-27 years; Mean 8 years
# Years with HTN	1-27 years; Mean 11 years
Type of Treatment	Insulin: 1
	Oral: 8
	Diet Only: 2
	None: 1
Perception of Health	Poor: 3
	Fair: 4
	Good: 3
	Very Good: 1
	Unknown: 1
Metabolic and HTN Status	BP controlled: 10/12
(BP Control: <130/80)	BG controlled: 6/12

(Glucose control: <140 random)	Unknown BG: 3
	Knowledge of HgA1c: 1
Employment Status	Self-employed: 5
	Employed: 6
	Retired: 1
# Years in US	0-10: 2
	10-20: 3
	20+: 7
Income Stability	Very Stable: 1
	Somewhat Stable: 6
	Somewhat Unstable: 5
Family History	None: 1
	HTN only: 1
	DM only: 8
	DM & HTN: 2
Marital Status	Married: 11
	Widowed: 1
Owns Glucometer	Yes: 10
Checks Blood Glucose	Daily: 2
	Weekly (2-3x): 3
	Monthly (1-4x): 4
	Never: 1
	Unknown: 2

Table 1: Participants characteristics (n=12).

We present results of the analysis according to three major themes: (1) Personal accountability for family harmony: I do it on my own; (2) Preserving family harmony at all costs: Personal sacrifice for the good of the whole; and (3) Family harmony through mutuality: We take care of each other.

Theme 1: Personal accountability for family harmony: I do it on my own

These middle-aged informants found their advancing age to be an indicator of their higher level of knowledge, capacity and consequent personal responsibility to care for him/herself. In their view, in order to prevent future illness, they needed to exert extreme control over their behaviors. Despite living within a traditionally family-oriented community, the informants exuded a strong, sense of prerogative and personal responsibility, using statements such as "I do it on my own" and "No one is responsible but me." The informants understood their personal responsibilities for self-care as it related to DM and they made strict rules for themselves, based on information heard from peers or by television, radio, magazines or health providers.

Exercise and food were perceived as the primary ways of managing DM, known as "so cal jeong" -feeling very thirsty syndrome- or "tang neo pyung"-sugar urine disease. The individual was responsible for how much he or she ate and how much he or she exercised; therefore, the burden of responsibility for glucose control and health weighed on the individual. By controlling activity levels and food intake, one could reach recovery or "cure", or at least prevent complications. This perception was shared by all of the informants. One male participant stated. "I realized that after all, recovering is dependent upon myself... even if I had someone...unless I take care of myself, it doesn't mean anything".

Although the informants asserted that the responsibility was his or hers alone, "doing it on my own," also challenged his or her strength of mind. The individual entered a psychological cycle of making strict rules for foods and exercise, breaking the rules, feeling inadequate at meeting expectations and then promising to change the behavior. The mental discipline required for effective self-care proved to be an emotional matter for some of the informants, causing much personal stress, for example, the idea of a restricted diet. The failure to abide and to eat certain foods represented a lack of discipline, a breakdown in their psychological strength. As another male informant described:

When I eat out, I sometimes eat meat. That means I am losing control. When I am eating something, I tell myself I should not be eating this...So I try to eat less. Sometimes ideas and worries strike me before I eat, to the effect that if I take this food my blood pressure and blood sugar will rise.

Informants experienced excessive worry and guilt about the consequences of breaking rigid rules. Individualist responsibility was influenced by the collective sense of responsibility for the family since some motivations were to maintain peace and protect the family from the potential future conflicts, i.e., avoiding family burden by potential serious complications, as one 58 year old female who immigrated 28 years ago remarked. "The most important thing is having a sound body. Without a sound body, we cannot continue a sound family life".

Informants felt caring for their illness was a priority due to its influence on family. A sound family life was the motivation for making autonomous decisions regarding their health. One female informant relayed her discussion with her doctor: "He used to press me and urge me to change my lifestyle because I have a long way to go for my little children".

Theme 2: Preserving family harmony at all costs: Personal sacrifice for the good of the whole

The findings highlighted that family, gender and social roles defined patterns of parenting when ill, as well as influenced the involvement of family members in the care of a parent, while maintaining harmony at all costs. Obeying each other was the ideal and negotiation between the individual and collective reflected the interest of harmony. At times within the context of greater interdependence, the ill informants made sacrifices for the needs of other family members to the detriment of his/her own health. In addition, informants chose to take on physical and emotional suffering than to disrupt family harmony. One 59 year old widow, who was taking insulin for control of DM, deferred alleviating her own suffering caused by her illness because of her responsibilities as caregiver for her grandchildren. "I couldn't close my eyes with ease. And I had to take care of my grandchildren...it was so hard.".

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In one extreme case of "Personal sacrifice for the good of the whole", another informant worked to provide money for his daughter, who also had DM and lived in Canada because of the high cost of medical care in the U.S. He preferred his own death over watching his daughter suffer as a result of draining all of the family finances caring for his own illness. He did not have insurance, was self-employed, had not had positive experiences with biomedical/modern medicine. He regularly took traditional medicine. His DM was not controlled:

If I have to spend all (the money) to care for myself, I won't have enough money for my daughter. While my daughter is suffering…I couldn't live like that. I have to earn much money for my daughter's sake. If I don't support her, what's going to happen?

Informants also discussed how children and spouses enforced rigid rules to ensure control of their family member's DM, especially around daily monitoring and care, such as food choice, preparation and physical activity for their ill family member. Although the informants had internalized occasional scolding responses from their children, they did not want to disrupt harmony within the family by becoming more ill, by creating further conflict or by appearing disobedient to them in the context of interdependence. Coping strategies, such as hiding were invoked to fulfill personal desires when the guidelines were too strict. While some of the informants were successful at achieving more than the appearance of harmony in their lives, many sought independent solutions to reach the desired state of "harmony" within the family setting, dealing with or repressing their stresses personally and privately. As one female informant explained, "All the troubles and stresses are piled up and getting rotten inside".

To further illustrate, one participant, a widow who lived with her children and was on insulin, decided to take a food supplement advertised on a Korean television station to improve the state of her DM. She attempted to avoid disruption in her obligations to her family though the symptoms that resulted from those actions were detrimental to her health, by not telling her children about her problem:

They were going to yell at my eating...After sometime, I couldn't get up (due to weakness) and my daughter urged me to tell her the reason why I was experiencing the difficulty…So I told her the story and she told it to my son and I was scolded by them. Anyway it hurt my pride at that time.

Another female participant avoided appearing disobedient or undisciplined by hiding undesirable behaviors in order to keep the peace and respect among family members:

They are very much concerned about my eating because I have DM. On my birthday, they used to buy cake for me but they forced me not to eat it and they give me a small piece for just a taste. But there's no way I could ignore (the cake) and not eat it, especially when I was hungry. Whenever and wherever I didn't see my children around, and when I was hungry, I always tried to have (the cake) while I hid.

Theme 3: Family harmony through mutuality: We take care of each other

Values of collectivism were marked by the interdependency of KAI family or community in which the thoughts and actions were driven by the good of the family. This interdependency sometimes complemented and sometimes contradicted the informants' individualism or strong sense of personal responsibility and autonomy. Simultaneously, informants desired and expected the family to take interest, as well as contribute their time and energy toward caring for them as part of the familial responsibility. One woman's statement reflected this reliance: "We have to care for each other". Another informant commented on a deeper level of interdependency when she said, "We (my family) are all obedient to each other.""

The acceptance of care and help offered offset the sense of needing to "do it on my own" all of the time. Wives of the male participants in this study were greatly contributing to the care of their husbands. One male informant who was recently diagnosed, spoke eloquently on the virtues of personal responsibility in the care of his illness, in addition to describing his wife's involvement as essential in diffusing the burden of personal responsibility:

My wife carries half of the load in this. Perhaps she carries 70% of the responsibility…She has to insist that I stick to the diet. Otherwise, I would not be doing what I am supposed to do…She gives support and issues admonishments. Plus I have to make a conscious effort.

Children, in particular, influenced choices regarding types of medical care made by their ill family member. Although participants were tempted by taking some form of traditional remedy, professional adult children educated in the US medical system had at times dissuaded usage by their parents. "Because my children studied in medical science (in US), I was forced to do the right things. But who knows if I were still in Korea, I couldn't stay only on the right track".

The family members fulfilled their roles in caring for their ill parents/spouses while informants continued to exert personal control over their health. As the informants attempted to negotiate their independence and interdependence, there was a tension over who should take control of a situation. Their family members may not have judged the informants' activities as healthy, but the informants' still desired flexibility and gradual change so as to adapt and enjoy life, particularly around food. Although some informants seemed to have achieved greater control over diet than others, they deliberated a great deal about what could be eaten, and what was not allowed.

Many informants refrained from responding verbally within these interactions. The informant whose wife was assisting in diet control of his co-existing illness, admitted to lying to his wife in order to avoid confrontation about his desire for a little more salt in his food. However, later he explained that instead of continuing to deceive his wife, he met conflict with negotiation and resolved the question of control by actively participating and discussing food preparation with his wife. He gave a rationale for how to go about gradual change and negotiating with your family member.

So, it's good to reduce the salt level gradually, on the basis of an agreement…If the person who does the cooking seeks such an agreement beforehand, the person who eats will probably go along in a good frame of mind. If unsalty foods are forced on me, I cannot eat them. I think it is a good idea to offer alternatives beforehand.

This male informant communicated openly with his wife and together made decisions regarding changes in his diet that would be long-lasting. Although the informants spoke more predominantly of hiding behaviors, those who felt open to engage in dialogue were able to establish a mutual sharing of cares around these illnesses, finding resolution and maintaining the peace within the home.

Despite these somewhat emotional interactions, within the course of their narratives, these informants perceived their family members to be supportive as illustrated by this female informant.

I think I am totally okay but the people around me do not want to leave me alone. They are more concerned about me than I am, to see the doctors regularly…although I don't say thank you, I am so grateful.

Discussion

The stories of these informants exemplify the difficulties of maintaining harmony in the family and within one's life when chronic illness is present. In the context of self-management of DM among KAI, individualism and collectivism were present as subtle phenomena, the reliance on self and self-sacrificing one's health to keep harmony within the family. Being from a traditional collectivist society, KAI seemed to adopt the self-care concept, having proud, honorable and diligent virtues as reported in Pang [22]. Their adult children were either absent as they were becoming busier with their own lives, or attempted to take full control and manage their parents' illness, fulfilling their expected role of caring for their parents following the filial piety tradition. Parents assigned more importance to the individual in the context of this illness, speaking of individual determination and resolve in efforts that make the difference in the management of their health issues, namely around food, exercise and treatment in order to protect their families from burden and also when they felt alone in their management [23]. The concept of personal control was strongly stated by many of the participants and has been seen in other studies [24]. The individual felt the responsibility to keep self-control, while meeting family obligations, and managing the tensions involved in negotiating the individual and the collective desires to successfully manage DM. This adoption of the self-care ethic became interwoven into the fabric of a collectivist attitude towards the family and community.

Harmony was defined as, "the state of co-existence and interaction between distinct participants, the different parts of a harmonious whole mutually blend in with each other and enhance each other without sacrificing their uniqueness" [25]. For harmony to exist, traditional social roles remained intact; i.e., obligations of parents to children and expectations of children to parents, including children caring for and making decisions for their parents [26-28]. Research studies of chronic illness management among immigrants have found changing family relationships through the acculturation process. Rising pressures of the American lifestyle make it difficult for family members to meet the traditional obligations to support their family, an act of filial piety [26], causing conflict [23]. Many of our participants struggled with either the lack of involvement of family or meeting the obligation of family-imposed rules, making DM even more emotionally and behaviorally very difficult to manage, which for some resulted in unhealthy coping strategies.

Various efforts were made by the informants to maintain the sense of harmony in their lives. According to our study informants, gender influenced the individual's behavior to maintain harmony. Women tended to sacrifice in a manner that preserved the peace and happiness in daily interactions, often neglecting their own health; women were also found to be active and most often caring their male spouses with DM, especially around the preparation of food. Men tended to look more globally at their responsibility as providers for the family, often neglecting cares and prioritizing financial welfare of the family above their own health. These findings are consistent with other studies of diabetes management in Korean Americans [29,30]. Although these informants' experiences challenged the legitimacy of the familial intimacy and harmony that they desired, they pursued an appearance of harmony within their family [9].

This study had a number of limitations. Although much was done to ensure validity of the findings, translation might not have captured complete cultural nuances in language, particularly in a poetic language such as Korean. In addition, a few of the interviews were done by telephone, which is not the ideal method to conduct the interviews due to the lack of nonverbal data. Furthermore, this research was conducted on a specific group of middle-aged Korean Americans; further research is needed transfer findings to other subgroups of Korean Americans. Finally, this research focused on the individual perspectives of illness management. Future studies should include family members to provide more in-depth perspectives around the interactions and features of family involvement in the care of DM. Nevertheless, the study presents the richness of the data and contributes to the limited knowledge regarding the self-care management experience in KAI with DM.

Practice Implications

Interventions focused on assisting individuals and families to manage the physical and psychological aspects of chronic illness should highlight the strengths of both the individual and collective or interdependent modalities. Providers (primary provider, diabetes educator, registered nurse, social worker and nutritionist) might use the awareness of the KAI's tendency to put the family first by emphasizing that by prioritizing one's care and maintaining an improved quality of life, the individual is prioritizing the betterment of the family future. The health provider may privately assist the individual in negotiating ways to meet their needs as well as his or her family's, especially in dealing with conflict that may arise in everyday living. In addition, health providers should encourage involvement of the family in appointments and education sessions from the onset. It is essential that information be given to both the individual and the major food preparer, which might lessen the tendency for the individual and family to retain such strict guidelines, decrease stress and improve quality life. In addition health providers working with individuals and families should talk about the psychological issues related to having DM, including ways to encourage through the use of positive interaction and support.

Conclusion

In conclusion, the clinical reality for these informants reflected Oyserman's [12] assertion that collectivism and individualism coexisted, based on both Korean and Western ideals. There are both individualistic and collective or interdependent ethics behind the motivations and behaviors of illness care within the family setting in KAI. The current study puts those constructs into an illness and cultural framework, showing the conflicts and the coping strategies involved in reaching the sense of harmony, an important cultural ideal.

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