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Family Model of Diabetes Education with a Pacific Islander Community

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Structured Abstract

Purpose—The purpose of this study is to use a community-based participatory approach to pilot test a family model of diabetes education conducted in participants' homes with extended family members. Approximately 50% of Marshallese adults have type 2 diabetes, and prior attempts at diabetes education have not been shown effective due in large part to very high attrition.

Research Design and Methods—The pilot test included six families (27 participants) who took part in a family model of diabetes self-management education (DSME) using an intervention driven pre-test/post-test design with the aim of improving glycemic control as measured by A1C.

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Questionnaires and additional biometric data were also collected. Researchers systematically documented elements of feasibility using participant observations and research field reports.

Results—Over three-fourths (78%) of participants were retained in the study. Post-test results indicated a 5% reduction in A1C across all participants and a 7% reduction among those with type 2 diabetes. Feasibility of an in-home model with extended family members was documented, along with observations and recommendation for further DSME adaptations related to blood glucose monitoring, physical activity, nutrition, and medication adherence.

Conclusions—The information gained from this pilot helps bridge the gap between knowledge of an evidence-based intervention and the actual implementation of the intervention within a unique minority population with especially high rates of type 2 diabetes and significant health disparities. Building on the emerging literature of family models of DSME, this study shows that the family model delivered in the home had high acceptance and that the intervention was more accessible for this hard-to-reach population.

The northwest Arkansas region is home to the largest Marshallese population in the continental United States (US).^{1,2} The Marshallese are a Pacific Islander community that face many health disparities due in large part to their current and historical relationship with the US.^{3–9} Between 1946 and 1958, the US Pacific Nuclear Weapons testing program was responsible for detonating 76 atomic and thermonuclear weapons in the Marshall Islands, which is equal to 7,200 Hiroshima-sized bombs.³ The US later assumed trusteeship of the Marshall Islands, which required that the US protect the Marshallese against the loss of land and resources while also promoting their health and well-being.¹⁰ In 1986, the Compact of Free Association (COFA) redefined the relationship between the US and the Marshallese, and the Republic of the Marshall Islands (RMI) became an independent country. The COFA agreement allows Marshallese citizens to freely enter, lawfully reside, seek education, and work in the US without a visa. In exchange, the RMI agreed to the US military's continued presence in their country and permitted the US military to conduct ballistic missile testing in the RMI.

The US military's weapons program has had a profound effect on the health of the people of the RMI. The native Marshallese diet consisted of fresh plants and seafood and the incidence of obesity and diabetes was extremely low.¹⁰ The nuclear fallout from US weapons testing resulted in long-term contamination of the native food supply, creating a reliance on imported processed foods high in refined carbohydrates and saturated fats.¹¹ The US provided canned meats and white rice as food commodities during and after nuclear testing; and these continue to be the preferred foods of the Marshallese after they migrate to the US.^{6,11} This non-native diet coupled with a more sedentary lifestyle has resulted in the Marshallese suffering from a disproportionate burden of diabetes. While there is limited health data on the Marshallese, the available literature documents significant health disparities in the prevalence of type 2 diabetes. Age-adjusted incidence of type 2 diabetes in Marshallese adults, aged thirty or older, is 27% on Ebeye in the RMI.⁸ Health screenings conducted by the University of Hawaii and University of Arkansas for Medical Sciences Northwest (UAMS NW) found the incidence of type 2 diabetes to be 44.2% in Hawaii and 46.5% in Arkansas.^{12,13} A local needs assessment in Arkansas, funded by the Centers for

Disease Control and Prevention, revealed that diabetes is a top concern for the Marshallese community, with 75% of the respondents listing diabetes as a primary concern.¹⁴

In 2012, UAMS NW began engaging the Arkansas Marshallese in a community-based participatory research (CBPR) process to understand what health disparities the community wanted to address. The Marshallese stakeholders chose diabetes. Using a CBPR approach and exploratory qualitative research methods,^{1,6,15,16} investigators worked with stakeholders to gain a better understanding of the burden of diabetes in the community, as well as the barriers to care, with the goal of collaboratively addressing the health disparities identified. Investigators began to understand how family and matriarchal kinship play a key role in the life of the Marshallese patient with diabetes.⁶ The Marshallese community suggested that for the individual to change, the family must change. In the Marshallese culture, family includes extended members and many households include multiple generations. For example, the same word that is used for mother is also used for aunt and the same word that is used for sibling is also used for cousin.^{15,17,18} Based on this information, the Marshallese leaders of the CBPR partnership proposed that diabetes education be implemented within an extended family model so that the entire family could benefit from the education, and the patient could be supported in their efforts to make lifestyle changes.

Diabetes Self-Management Education (DSME) is an evidenced-based practice that has been found to improve glycemic control and reduce the complications and cost of diabetes management. Though often taught in a group setting, traditional DSME focuses on individual behavior change.^{19–24} Traditional DSME may not be as effective in collectivist cultures such as the Marshallese. Prior studies that implemented traditional group-based DSME in the Marshallese population have had limited success.^{25,26} Reddy et al. (2005) reported 100% attrition and closed their diabetes educational sessions in Oahu early due to lack of participation.²⁵ A later study conducted by the same team with Marshallese living on Ebeye in the RMI found a statistically significant improvement in weight loss and blood pressure. They also cited trends toward increased statin use, participation in nutritional counseling, and glucose self-monitoring, but were unable to document significant improvements in glycemic control.²⁶

The evidence regarding the influence a patient's family has on glycemic control is evolving, and it appears that the family may play an effective role in supporting patients with diabetes.^{27,28} Preliminary findings suggest that a culturally targeted diabetes intervention that includes family members produces more successful results than traditional DSME. A 2007 study by Denham et al. found that treating diabetes as a family disease could influence the planning of educational interventions by including family support members in assessment, deconstruction, and reconstruction of dietary routines.²⁹ These early studies have shown some success in many minority groups as well as other vulnerable populations such as children. In a recent study targeting urban-dwelling adult American Indians and their families, a Family Education Diabetes Series was implemented, and researchers found that social and group-supporting activities are the most important elements affecting behavior change and ongoing disease management.³⁰ Similar research has been conducted with Hispanic patients where a family-based diabetes intervention showed improved diabetes self-efficacy, increased family support for patients, greater diabetes knowledge, and lower

BMI for family participants.³¹ Another family-based study focused on patients with the most poorly controlled diabetes also reported similar positive biometric outcomes and noted improvements in psychosocial well-being and adherence to dietary and exercise recommendations.³² These studies support the growing evidence that a family model may benefit both the patient with diabetes and their family members as well. Treating diabetes as a family disease influences the planning of educational interventions by including family support members in assessment, modification, and the development of new dietary routines.²⁹

Research Design and Methods

The interprofessional CBPR study team was comprised of five clinical faculty (one nurse/certified diabetes educator (CDE), two pharmacists, and two endocrinologists), two Marshallese community co-investigators (one community leader and one community health worker), and the lead investigator of the CBPR partnership. The pilot study utilized a pre-test/intervention/post-test design to measure change in hemoglobin A1C as well as other biometric measures. Questionnaires were administered at the pre- and post-test events, and focus groups were held for each family once the intervention was complete. In addition, we systematically documented the feasibility of a family model of DSME using participant observations and research field reports.

Data Collection

Six Marshallese individuals with diabetes were identified and invited to join the study, and these participants invited their family members to become participants in the study and fully participate in all study activities. After all willing family members provided consent, a pre-intervention data collection event was conducted. Participants were asked to fast for at least eight hours prior to the event. Three questionnaires were administered to participants with diabetes and the core questionnaire was administered to all participants, regardless of diabetes status. The core questionnaire included basic demographics and topics such as past medical history, current medications, healthcare access and insurance, and social history. The two diabetes-related questionnaires measured self-efficacy and self-care activities. Biometric data was collected using point of care tests for A1C, LDL, HDL, triglycerides, total cholesterol, and glucose. A urine collection for microalbumin/creatinine ratio was initially requested from participants; however, participants refused the collection. In addition, blood pressure, height, weight, and waist and hip circumference was measured. Each participant with diabetes was provided a glucometer (Walmart ReliOn brand), test strips (Walmart ReliOn), lancets, and a sharps disposal container. The same procedures and measurements were collected at the post-intervention data collection event.

To capture qualitative data, the lead researcher and a research assistant observed and recorded participants' reactions, behaviors, and interactions among family members, during the educational sessions. After each educational session, the CDE and Marshallese community health worker documented process notes related to feasibility and potential improvements to the DSME curriculum to make it more culturally appropriate for the Marshallese community and family model of delivery. The CBPR research team met

monthly to discuss and document what was working well and what was not. Observations and meeting notes were captured as qualitative data.

Intervention

Participants received a total of ten hours of diabetes education over six weekly sessions. Consistent with the American Diabetes Association recommendations, the DSME topics included: healthy eating, being active, glucose monitoring, understanding blood glucose and taking medication, problem solving, reducing risks and healthy coping, mitigating complications of diabetes, and goal setting.^{33–35} Educational sessions were provided in the families' home or a location of their choice, and included all consented family members as equal participants. Five families chose their home and one family chose their church. A CDE taught the educational sessions. While the CDE led the educational sessions, a Marshallese community health worker was present to translate words and concepts as needed and a qualitative researcher documented observations during each session. The educator allotted time at each visit to answer questions and discuss blood glucose measurements from the preceding week.

Analysis of Quantitative Data

Descriptive statistics were conducted on biometric and survey data. Due to the small sample size and non-normal distribution of continuous outcomes, non-parametric tests were used. Exact chi-square tests for tables larger than 2×2 and Fisher's exact tests for 2×2 tables were applied to compare the differences in proportions. To test the distributional equality in continuous outcomes, correlated-samples Wilcoxon signed rank test was utilized. Analyses were performed with both SPSS and SAS statistical software packages. An alpha level of .05 was chosen as the level at which associations were considered statistically significant.

Analysis of Qualitative Data

Research field reports, CBPR meeting summaries, and post-event focus group transcripts were coded for core themes related to glucose monitoring, physical activity, nutrition, and medication adherence, which are the cornerstones of DSME.³⁶ Emergent themes related to feasibility were also identified and coded. Themes were discussed and confirmed with the entire CBPR team (including Marshallese community co-investigators).^{37,38}

Results

Quantitative Results

Participant Survey Findings—Twenty-seven participants, making up six families, were enrolled in the study. Table 1 outlines the participant profiles by diabetes status. Participants were predominantly female (77%), 18–44 years of age (57%), HS graduates or less (71%), and uninsured (56%). Those reporting a diagnosis of diabetes tended to be older and have a lower level of educational attainment than those without a diagnosis of diabetes.

Ratings of health and exercise frequency did not vary significantly with regard to diabetes status. For overall health status, only 15% reported “Excellent” or “Very Good” health.

Those participants reporting “Excellent” or “Very Good” health did not have diabetes or pre-diabetes. Despite large numbers of respondents reporting “good,” “fair,” or “poor” health, the majority of all of respondents (73%) indicated that they exercised at least two to three times per week, for at least 30 minutes at a time. Thirty-one percent reported getting physical activity more than five times per week at half hour or more intervals.

More than half of study participants (59%) answered “no” or “don’t know” when asked if they had a primary care doctor. Those with diabetes were significantly more likely to have a primary care doctor (33%) than those without diabetes (7%), $p < .05$. While over half (56%) of respondents reported having had a routine checkup within the last year, 25% of those with diabetes indicated that they had never had a routine checkup and 22% of those with undiagnosed pre-diabetes or diabetes reported never having a routine checkup or having one more than five years ago. In contrast, there were no respondents without diabetes that had not had a routine checkup within the last two years. Nearly half of the participants (48%) reported forgoing healthcare because they could not afford to see a doctor. This number was skewed by those with diabetes. Nearly 65% of those with diabetes stated that they needed to see a doctor, but did not because of cost, while only 31% of those without diabetes reported the same.

Participant Retention and Attrition—Of the 27 participants who enrolled in the study and completed the pre-intervention data collection, 21 completed the post-intervention data collection, resulting in a retention rate of 78%. One (1) participant family completely dropped out of the study. This participant was unable to recruit additional family members to participate and cited a lack of family support as the primary reason for withdrawing from the study. The other five (5) non-completers attended some educational sessions, but did not complete the post intervention data collection event. Family members of the five who did not complete the post-event data collection stated that the participants moved out of the household. Table 2 illustrates the characteristics of those who did and did not complete the study.

Biometric Data—The pre-intervention test results revealed that 44% of participants (12) had undiagnosed diabetes (A1C = 6.5% and greater) or pre-diabetes (A1C = 5.7–6.4%). Pre-intervention A1C results yielded a mean of 9.7% for participants with diabetes and 8.1% for the entire sample (Table 3). Participants’ lipid profiles did not reveal any significant dyslipidemia.

Post-intervention data showed a mean A1C of 9.0% for participants with diabetes and 7.7% for the entire sample. Thus, over the period of the study, there was a 7% reduction in A1C among participants with diabetes and a 5% reduction in A1C among all participants.

Variations between families were evident; some families had better outcomes than others (Table 4). Families 2, 3, and 4 had an A1C reduction, while Families 1 and 5 remained virtually the same. The CBPR team reviewed process notes and discussed the possible reasons for this. The research team postulates that there was notable variation in engagement levels of family groups, and this may have impacted results. Table 4 outlines changes in

selected measures as well as study retention by family unit. Possible explanations for these variations are discussed in the conclusion.

Qualitative Results

The four cornerstones of DSME are blood glucose monitoring, physical activity, nutrition, and medication adherence.³⁶ Qualitative observations will be presented according to these four categories. In addition, emergent themes relating to the feasibility of implementing DSME within an Arkansas Marshallese family group are presented. The themes that emerged from the observations included: the feasibility of data collection events, the family dynamics in a home environment, and family engagement and support.

DSME Cornerstones

Blood Glucose Monitoring—The intervention team observed that participants had little understanding of blood glucose, basic internal anatomy, or biological function of the body. The Marshallese language does not have words for many internal organs; nor are there common words to describe how internal organs function. DSME sessions often started by asking questions such as “do you know what your pancreas does?” This type of quizzing about internal anatomy was not effective, and researchers observed the participants becoming embarrassed and defensive when they were asked questions about anatomy. The lack of knowledge about basic anatomy meant additional time was needed to explain internal organs - such as the pancreas - and their function. Additional time was also needed to explain why persons with diabetes need to check their blood glucose regularly, how different foods affect blood sugar, and how the glucometers work. The CDE found it necessary to review glucose monitoring at each educational session.

Physical Activity—When physical activity was discussed, purposeful activities such as yard work and house cleaning were regarded as more acceptable by participants than formal exercise. Participants reported that walking around the neighborhood for exercise would be odd and is not seen as culturally appropriate within their community. While participants under forty years old reported practicing for traditional dances and playing sports such as baseball, basketball, and volleyball and discussed ways to increase these activities, older participants reported very little physical activity and found it more difficult to formulate plans to increase physical activity. Participants also reported that they show respect to elders by allowing them to sit still while younger people do daily activities. This show of respect greatly reduces the amount of daily physical activity for older Marshallese adults. In addition, all families noted that most formal exercises, sports, and dance must be done in groups of men only or women only to adhere to cultural standards of behavior.

Nutrition—Standard nutritional approaches used with DSME curriculum were not well understood by participants. Marshallese families reported that they lacked knowledge regarding many foods available in the US and how these foods are prepared. In addition, serving sizes and basic measurements of food were not well understood. Additional cultural adaptation of the basic meal plans presented in the DSME was required because most of the foods on standard meal plan charts are not the foods that the Marshallese families recognized or routinely consumed. Participants also lacked a basic understanding of

nutrients -carbohydrates, protein, and fat - that are the foundation of diabetes nutritional counseling. Participants reported understanding that sugar affected their diabetes, but did not understand that simple carbohydrates had a similar effect. Participants with diagnosed diabetes discussed the difficulty of eating differently than the rest of the family. Meals are very rarely eaten alone and were discussed as social events that include extended family and friends. Participants explained that to honor or thank someone, it is culturally appropriate to offer food and that refusing food is seen as disrespectful.

Medication Adherence—Participants discussed numerous misconceptions about and barriers to medication adherence. Participants reported that they thought they were only supposed to take the medication until it ran out and did not understand that they were supposed to refill their medication. Educators spent significant time discussing how diabetes medication worked, the importance of taking your medication consistently, and refilling prescriptions after they ran out. Participants also reported that the cost of medication was a primary barrier. Many participants (56%) did not have insurance and 52% stated that they could not afford to purchase their medications or see the doctor to obtain updated prescriptions. Even participants with insurance reported not being able to afford the co-pay for prescriptions. Currently, Marshallese COFA migrants are excluded from Medicaid and Medicaid expansion under the Affordable Care Act.⁹

Feasibility

Data Collection Events—While the team successfully conducted pre- and post-event data collection in the home environment, biometric data collection among Marshallese participants had challenges. Weight and waist measurements needed to be collected in a private location, which was often difficult in a small home. Researchers did not capture hip measurements on men due to feedback that it was culturally inappropriate for a female data collector to take that measurement. Many participants did not fast if data collection events took place after noon. The initial protocol called for collecting urine to conduct micro albumin/creatinine ratio analysis, but the first two families refused collection. After further discussion with our CBPR advisory board and the Marshallese community health worker, this collection was dropped because the urine collection was seen as culturally inappropriate. The participants also reported difficulty interpreting the continuum of responses on a Likert scale and preferred responses that were yes or no.

Family Dynamics and Home Environment—A home environment requires flexibility. Educators have less control over the environment and had to make changes based upon the dynamic within each family. For example, three (half) of the families had children under five who were present at each meeting. There were frequent interruptions with children and family members coming in and out of the DSME sessions. Most of the homes were small and often educators and participants sat on the floor. While homes were a more challenging environment for educators and clinicians, participants reported many benefits to receiving DSME in the home environment. Specifically, participants did not have to overcome barriers to transportation and they did not have to find childcare. Participants also reported feeling more comfortable and relaxed.

Family Engagement and Support—There were varying levels of family-member engagement observed by the research team. Those family members with diagnosed and undiagnosed diabetes and pre-diabetes were observed as having the highest level of engagement. In all of the five families who completed the study, there was a family member who the research team identified as being a primary family caretaker and DSME “encourager.” Sometimes this person had diagnosed or undiagnosed diabetes, and sometimes they did not. This person was female in all but one family. The “encourager” typically was not the primary participant, but instead the child or spouse of the primary participant. Consistent across all families was the “encourager” role in continuously engaging family members in the education process.

Conclusions

Limitations

The study has some limitations that need to be acknowledged. The sample size of six families (27 individual participants) is small; however, the sample size was appropriate for a feasibility pilot with a population where the DSME had not previously been successful. The pilot allowed researchers to document feasibility and identify additional adaptation needed for a larger randomized control trial. The study’s primary outcome measure was A1C; however, A1C levels have been shown to be influenced by race and ethnicity.^{39,40} While A1C is considered the best measure of long-term glycemic control, future studies may need to consider other markers including fructosamine and glycated albumin, given the potential limitations of A1C.

While the pilot study sample was small, it is encouraging to see a mean A1C reduction of 5% across all participants and a 7% reduction among those with type 2 diabetes. The information gained from this pilot helps bridge the gap between knowledge of an evidenced based intervention – DSME - and the actual implementation of the intervention among a Pacific Islander sub-population with especially high rates of type 2 diabetes and significant health disparities. Building on the emerging literature on family models of DSME, this study shows that family models may help increase retention in hard-to-reach populations. Prior studies with Marshallese participants were not successful primarily because of poor retention.²⁵ Participant retention was reasonably high for this study; only one family dropped out of the study and 78% of all participants completed the study which indicates a high level of participant acceptability.

Varying levels of family-member engagement were observed. Researchers did not utilize a specific engagement scale; however, the implementation team discussed family engagement at length. Three of the six families were observed as having high levels of engagement and three families had lower levels of engagement. The three families with the highest level of engagement saw notable decreases in A1C. One family with lower levels of engagement dropped out, and the other two families with lower levels of engagement remained virtually the same with respect to A1C. Documentation of family engagement measures would allow researchers to identify and test whether the level of engagement influences outcomes.

Total cholesterol levels were lower than would be expected, given the suboptimal glycemic control seen among participants. Because the sample size is small and not all participants fasted, this a tentative, yet interesting observation. Additional data collection with fasting lipids is needed to better characterize the degree and frequency of lipid abnormalities in this population.

Based on the emerging evidence related to family models of DSME, the pilot provides insight into the feasibility of providing DSME in a home environment with family participants who do and do not have diabetes. While additional adaptations are necessary for implementation in a clinical setting, an extended family model may be a crucial factor in ensuring better outcomes for the Marshallese and other collectivist communities.

Further research is needed to reduce the health inequalities and significant disparities in type 2 diabetes care and outcomes experienced by the Marshallese. Field process notes suggest that DSME curriculum cultural adaptations are needed in each of the four cornerstone areas of DSME (glycemic control, nutrition, physical activity, and medication adherence). Based upon the results of this pilot study, the interprofessional research team is conducting a randomized control trial of a culturally adapted DSME curriculum delivered in a family model.

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Table 1

Participant Demographics and Health Factors by Diabetes Status

	n*	Diabetes [†]	No Diabetes [†]	p-value [‡]
Age				
18–44	15	4 (15%)	11 (42%)	.002
45+	11	10 (38%)	1 (4%)	
Sex				
Male	6	5 (19%)	1 (4%)	.165
Female	21	9 (33%)	12 (44%)	
Education				
High School Graduate or Less	17	11 (46%)	6 (25%)	.182
Some College or College Graduate	7	2 (8%)	5 (21%)	
Insurance Coverage				
Yes	12	4 (15%)	8 (30%)	.128
No	15	10 (37%)	5 (19%)	
Health Status				
Excellent/Very Good	4	0	4 (15%)	.041
Good/Fair/Poor	23	14 (52%)	9 (33%)	
Weekly Exercise				
5 × week or less	18	8 (31%)	10 (38%)	.216
>5 × week	8	6 (23%)	2 (8%)	
Primary Care Doctor				
Yes	11	9 (33%)	2 (7%)	.021
No	14	4 (15%)	10 (37%)	
Don't know	2	1 (4%)	1 (4%)	
Time Since Routine Checkup				
Never/More than a year ago	10	5 (22%)	5 (22%)	.685
Within the past year	13	5 (22%)	8 (34%)	
Couldn't get care due to cost				
Yes	13	9 (33%)	4 (15%)	.174
No	12	4 (15%)	8 (30%)	
Don't know	2	1 (4%)	1 (4%)	

* Total sample = 27; categories with less responses indicate missing values

[†] Diabetes status determined by A1C values at pre-intervention data collection; A1C ≥ 6.5% indicates diabetes

[‡] Fisher's exact test; $p < 0.05$

Profile of Retention and Attrition

Table 2

	Pre-Intervention Mean and Standard Deviation						
	Diabetes Status*		Age	Total Cholesterol (mg/dL)	A1C(%)	A1C (mmol/mol)	BMI
	Diabetes	No Diabetes					
Completers	11	10	49.1 (12.9)	170 (42)	8.9 (3)	74 (32.8)	31.1 (5)
Non-Completers	2	4	37.9 (15.6)	149 (24)	6.4 (1.3)	46 (14.2)	35.2 (7.4)
Total Sample	13	14	45.5 (14.3)	155.7 (37.4)	7.7 (2.6)	61 (28.4)	32.1 (5.7)

* Diabetes status determined by A1C values at pre-intervention data collection; A1C \geq 6.5% indicates diabetes

Table 3

Pre- and Post-Intervention Biometric Results

	Pre-Intervention (mean and SD)	Post-Intervention (mean and SD)	t	p-value*
BMI	31.2 (5.0)	31.3 (5.6)	-0.3	.782
Total Cholesterol (mg/dL)	157.6 (40.8)	167.2 (43.7)	-1.4	.178
HDL (mg/dL)	38.4 (12.7)	41.7 (12.3)	-1.8	.087
A1C (%)	8.1 (2.8)	7.7 (2.4)	1.5	.142
A1C (mmol/mol)	65 (30.6)	61 (26.2)		

*Includes completers only (n=21)

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Table 4

Change in A1C, Total Cholesterol, HDL, and BMI by Family

Family ID	Enrolled	Completed	Mean Change in Selected Measures				
			A1C (%)	A1C (mmol/mol)	Total Cholesterol (mg/dL)	HDL (mg/dL)	BMI
1	3	3	0.1	1.1	21.3	14.8	0.2
2	3	2	-1.85	-20.2	39.5	1.5	0.75
3	6	4	-0.53	-5.8	4.3	2.75	0.05
4	8	6	-0.43	-4.7	9.3	-1.83	0.08
5	5	4	0.1	1.1	-23.3	1.6	2.15