ISSN- 0301-1216
Indian J. Prev. Soc. Med. Vol. 56, No.1, 2025

Content Validation and Development of KAP Tool for Maturity Onset Diabetes of the Young (MODY)

V Leelavathi [1] , PL. Sridevi Sivakami[2]

ABSTRACT

This study focuses on the development and content validation of a Knowledge, Attitudes and Practices (KAP) questionnaire designed specifically for Maturity Onset Diabetes of the Young (MODY). MODY is a monogenic form of diabetes which is often confused with other diabetes like Type 1 or Type 2 diabetes. The MODY KAP tool aims to assess knowledge about MODY's genetic basis, symptoms and management, attitudes towards early diagnosis and specialized care and practices related to lifestyle modifications and genetic counseling. A panel of six experts, including three diabetologist, one dietitian, one statistician and one academician evaluated the relevance and clarity of the 35-items tool. The results demonstrated strong content validity, with scores (S-CVI of 0.97 and UA of 0.86) across the Knowledge, Attitudes and Practices sections. This tool has the potential to enhance MODY awareness and contribute to better management. Further research should focus on pilot testing to assess its applicability in larger populations and refine any items as needed for practical implementation.

Keywords: Awareness, Diabetes, Knowledge, Maturity Onset Diabetes of the Young (MODY).

Introduction

Maturity Onset Diabetes of the Young (MODY) is a rare, genetically inherited autosomal form of diabetes caused by mutation in specific genes that affect insulin production[1]. Unlike Type 1 and Type 2 diabetes, MODY characterized as under the age of 25 years[2]. Despite these MODY was being misdiagnosed as Type 1 or Type 2 diabetes due to overlapping of symptoms[3]. Misdiagnosis can lead to inappropriate treatment, as MODY doesn't always require insulin therapy and management strategies differ based on the specific genetic mutation involved[4]. Existing diagnostic and management tools and management tools mainly focus on highly prevalent types of diabetes, leaving a significant gap in understanding and addressing MODY.

Knowledge, Attitudes and Practices tools were the proven tools in assessing the gaps in knowledge by detecting the misconceptions and advocating for improved approaches to addressing diverse health issues[5]. This KAP tool are used to assess patients' and health care professionals' knowledge bases, as well as their attitudes about the diagnosis and treatment of a certain ailment and their routine management procedures[6]. However, most of the KAP tools currently available are only designed for Type 1 and Type 2 diabetes, with no focus on MODY. This creates a major research gap in the development of a KAP tool for MODY especially for developing awareness among the populations on this rare disease.

This study addresses the gap in the development and validation of KAP tool specifically designed for MODY. This need for the tool was because of the misdiagnosis of these cases which leads to inappropriate treatment.

1. PhD Scholar, Avinashilingam Institute for Home Science and Higher Education for Women, Coimbatore, India
Email: mailleelavathi95@gmail.com; Ph: +91-9486266243
2. Associate Professor, Avinashilingam Institute for Home Science and Higher Education for Women, Coimbatore, India
Email: sridevi_fsmd@avinuty.ac.in

Corresponding author: V Leelavathi, PhD Scholar, Avinashilingam Institute for Home Science and Higher Education for Women, Coimbatore, India; **Email:** mailleelavathi95@gmail.com**; Ph:** +91-9486266243

Submission	21.11.2024	Revision	19.12.2024	Accepted	24.01.2025	Printing	31.03.2025

Prior Publication*: Nil*; Source of Funding:* Yes; *Conflicts of Interest*: None, *Article # 556/770-752

Early diagnosis and appropriate timely treatment in management of these patients was also a point which paved the way for the development of this MODY KAP tool. This MODY KAP tool aims in making people aware of MODY's clinical characteristics, diagnostic criteria, genetic characteristics, purpose of early diagnosis and management. The KAP tool will also evaluate the attitudes and practices toward the diagnosis and treatment of MODY. The novelty of this study is the development of first KAP tool specifically for MODY. The developments of MODY KAP tool after a panel of expert evaluation, this tool improves the understanding and management of MODY through their questions and facilitates early diagnosis and promote personalized treatment.

Methodology

Study Design: A cross sectional study was conducted to develop and validate a Knowledge, Attitude and Practices (KAP) questionnaire specifically for Maturity Onset Diabetes of the Young (MODY). The main objective of the study is to ensure the validity of the list of items for the tool using Yusoff's (2019)[7] content validity method, thus developing a questionnaire that is valid and reliable to measure MODY Knowledge, Attitude and Practices for young adults.

Development of the KAP Tool: The MODY KAP tool was developed after a thorough review of literature. The tool was divided into the following three sections:

- **Knowledge:** The first section consisted of 15 items that highlights the major aspects of MODY such as genetic causes, clinical features, family history and its difference from Type 1 and Type 2 diabetes.
- **Attitudes:** The second section encompassed with 10 items with the beliefs and perceptions of MODY such as the importance of early diagnosis, the role of genetic counselling and the need for specialized care.
- **Practices:** The third section also contained with 10 items which focuses on the behaviors such as lifestyle modifications, involvement in genetic testing and diabetes education.

The number of 35 items was designed to cover the key knowledge, attitudes and practices by ensuring that the tool remained precise and user friendly.

Expert Panel: A panel of six experts were selected to validate the content of the KAP tool. The expert panel consisted of three diabetologists, a dietitian, an academician and a statistician. These experts ensured a well structured evaluation of the tool from the key aspects, focusing on the clinical, dietary, educational frameworks and statistical integrity.

Content Validation Process: The validation of the KAP tool was followed by Yusoff's (2019)[7]content validity method which focuses only on the item relevance. The experts evaluated all the 35 items of KAP using four point Likert scale (1- Not relevant, 2-Somewhat relevant, 3-Relevant, 4- Highly relevant). The validation involved the following methods:

Item Content Validity Index (I-CVI): I-CVI was calculated by dividing the number of experts who rated each item 3 or 4 by the total number of experts. The I-CVI acceptability score should be 0.83 for six experts, as stated by Yusoff (2019).

Universal Agreement (UA): UA was used to assess that all the experts agreed on the relevance of each item, with a UA score of 0.83 indicating complete acceptance.

Scale Content Validity Index (S-CVI): S-CVI was the average of I-CVI.

Proportion of Relevance: This was used to assess the overall content quality by calculating the proportion of items rated as relevant (3 or 4).

The items that did not meet the I-CVI or UA scores were revised or removed based on the experts' feedback to ensure clarity and relevance.

Data Analysis: Data were analyzed using descriptive statistics (mean scores and standard deviation), Item Content Validity Index (I-CVI), Scale Content Validity Index (S-CVI) and Universal Agreement (UA). These were used to summarize the experts' ratings for each section from the KAP tool and overall content validity.

Ethical Considerations: Ethical approval was obtained from the Institutional Ethics Committee with the ethical number of AUW/IHEC/FSMD-19-20/XPD-25 before the start of the study. The experts provided informed consent and their identity was maintained anonymous for confidentiality.

This structured approach in the development and validation of the KAP tool will enhance the content of KAP tool. This in turn enhances the awareness purpose of the tool.

Results and Discussion

The content validation results were consolidated and provided in five tables which shows the experts in agreement for the relevance and clarity of each item.

Experts Agreement on MODY Knowledge Items: Table 1 highlights the content validation results for MODY knowledge items which was regarding the key aspects of MODY.

Table- 1: Experts Agreement on MODY Knowledge Items

Items Number	Questions	Average Scores	Experts in Agreement	I-CVI*	UA**	Inter-pretation
MODY-K 1	Have you heard of Maturity Onset Diabetes of the Young (MODY) before?	3.83	6	1.00	1	c
MODY-K 2	Do you know that MODY is a rare form of diabetes that is caused by genetic mutations?	3.83	6	1.00	1	c
MODY-K 3	Can MODY be present in children or young adults?	3.67	6	1.00	1	b
MODY-K 4	Is MODY different from the more common types of diabetes, such as Type 1 and Type 2?	3.83	6	1.00	1	b
MODY-K 5	Are there specific genes associated with MODY?	3.83	6	1.00	1	c
MODY-K 6	Is MODY inherited in an autosomal dominant or autosomal recessive manner?	3.50	5	0.83	0	a
MODY-K 7	Are there different subtypes of MODY, each caused by mutations in specific genes?	3.50	5	0.83	0	a
MODY-K 8	Is it possible for individuals with MODY to have normal or near-normal blood sugar levels without the need for insulin?	3.83	6	1.00	1	c
MODY-K 9	Is MODY commonly misdiagnosed as Type 1 or Type 2 diabetes due to its similarities in symptoms?	3.83	6	1.00	1	c
MODY-K 10	Can MODY be passed down through multiple generations within a family?	3.83	6	1.00	1	c
MODY-K 11	Is it possible for individuals with MODY to require insulin treatment as the condition progresses?	3.83	6	1.00	1	c
MODY-K 12	Are there specific genetic tests available to identify the subtype of MODY and guide treatment decisions?	3.83	6	1.00	1	c
MODY-K 13	Does every MODY sub-type need different kind of treatment for controlling blood sugar?	3.83	6	1.00	1	c
MODY-K 14	Can a person with MODY still develop complications associated with diabetes, such as kidney problems or eye issues?	3.83	6	1.00	1	c
MODY-K 15	Does any type of MODY can be controlled with diet alone?	3.67	5	0.83	0	A

*I-CVI =Item Content Validity Index, **UA-Universal Agreement. **a-**Revision needed as per UA scores, **b-** Revision needed as per experts' suggestion in suggestion column, **c-**No revision needed.

The results of table 1 shows that the 15 knowledge items with the key aspects of addressing the genetic causes of the MODY, clinical characteristics, its difference from Type 1 and Type 2 diabetes and the importance of genetic testing were rated highly relevant by all the experts. This indicates that the knowledge section effectively captures the essential components needed for understanding MODY. This provides essential information for the general population, health care professionals and patients. Most of the items received agreement from all four experts with the perfect I-CVI (1.00) and UA (1). Items. The I-CVI scores fall within the range of standard I-CVI score of 0.83 as stated by Yusoff (2019). The scores of this section ranged from 3.50 to 3.83. However, three items (MODY- K6, MODY-K7 and MODY-K15) received a lower UA score of 0 which indicates revision of those items. In MODY-K6, the question was slightly reframed as " Is MODY inherited in an autosomal dominant manner? " because of the unclearity of the question. In MODY-K7, the question was completely changed to "Can MODY be managed with oral medications in some cases?", as it was reported as irrelevant by the experts. And in case of MODY-K15, the question was slightly modified as "Does any type of MODY can be controlled with diet and exercise?" because of its unclearity. In two cases experts gave suggestions in slight modification of the items, even though the UA and rating score was excellent in MODY-K3 (UA-1, Score-3.67) and MODY-K5 (UA-1, Score-3.83). The revised question of MODY-K3 and MODY-K5 was "Can MODY be present in children and young adults?" and "Is MODY associated with specific gene mutations unique to each subtype?" respectively. Overall, the high I-CVI and rating scores among most of the items reflect a strong content validity for the MODY-Knowledge section. This ensures that the MODY-Knowledge section will create a significant impact on the knowledge of the targeted people.

Experts Agreement on MODY Attitude Items: Table- 2 deals with the expert agreement on MODY Attitude section. This section highlights the attitudes towards early diagnosis, genetic testing, genetic counseling and specialized care for MODY patients.

Table- 2: Experts Agreement on MODY Attitude Items

Items Number	Questions	Average Scores	Experts in Agreement	I-CVI*	UA**	Interpre-tation
MODY-A 1	Do you believe that people with MODY should be treated with understanding and empathy?	3.17	4	0.67	0	a
MODY-A 2	Do you think it is essential to raise awareness about MODY in the community?	3.67	6	1.00	1	c
MODY-A 3	Do you believe that early diagnosis of MODY can lead to better health outcomes?	3.83	6	1.00	1	b
MODY-A 4	Should schools and workplaces be more accommodating to individuals with MODY, similar to other chronic conditions?	3.67	6	1.00	1	c
MODY-A 5	Do you think there is a need for more public funding and research efforts dedicated to studying rare forms of diabetes like MODY?	3.67	6	1.00	1	b
MODY-A 6	Would you participate in community activities or campaigns to raise awareness about MODY and its management?	3.67	6	1.00	1	c
MODY-A 7	Do you think that healthcare professionals should receive specialized training on MODY diagnosis and management?	3.67	6	1.00	1	c
MODY-A 8	Do you think there should be more research and resources dedicated to understanding and managing MODY?	3.83	6	1.00	1	b
MODY-A 9	Do you believe that increased awareness and early diagnosis of MODY can lead to better outcomes for individuals with the condition?	3.83	6	1.00	1	b
MODY-A 10	Do you feel that families with a history of diabetes should be routinely screened for MODY to identify potential cases?	3.83	6	1.00	1	C

*I-CVI =Item Content Validity Index, **UA-Universal Agreement. a-Revision needed as per UA scores, b- Revision needed as per experts' suggestion in suggestion column, c-No revision needed.

The table 2 result shows that the attitude sections with 10 items were rated highly relevant by the experts with 1.0 as I-CVI and UA scores. Most of the items received high rating scores ranging from 3.17 to 3.83 in the attitude section and also meet out the standard I-CVI scores of 0.83 as stated by Yusoff (2019). Only one item (MODY-A1) with zero agreement with the least rating and I-CVI score of 3.17 and 0.67 among all the 10 items. Because of its irrelevancy, the question of MODY-A1 replaced with another new question ("Do you believe awareness about MODY is important for better diabetes care? ") as suggested by experts. Among the 10 items, a few items like MODY-A3, MODY-A5, MODY-A8 and MODY-A9 also needed some changes. Because the experts found similarity between MODY-A3 and MODY-A9, as well as with MODY-A5 and MODY-A8. MODY-A3 was retained and MODY-A9 was revised ("Do you think personalized treatment plans are essential for managing MODY?"). And in case of MODY-A5 and MODY-A8, MODY-A5 was revised ("Do you think managing MODY can lead to improved health outcomes?") and MODY-A8 was retained.

Furthermore, the experts agreed to the attitude questions related to the importance of genetic counselling, early diagnosis, specialized care, educational campaigns and the other MODY attitude questions. These findings show the importance of raising awareness about MODY and changing the attitudes towards among the population.

Experts Agreement on MODY Practices Items: Table 3 focuses on the experts' agreement on MODY Practices items. This section deals with practices carried out in day to day life regarding MODY. The questions were framed in the theme of MODY genetic testing, early diagnosis, and discussion of family history with health care providers, diet and exercise.

Table-3 : Experts Agreement on MODY Practices Items

Items Number	Questions	Average Scores	Experts in Agreement	I-CVI*	UA**	Interpre-tation
MODY- A 1	If diagnosed with MODY would you discuss genetic testing with your healthcare provider to understand the specific type?	4.00	6	1.00	1	c
MODY- A 2	If diagnosed with MODY, would you actively seek out a healthcare profession or clinic with expertise in managing the condition?	4.00	6	1.00	1	c
MODY- A 3	Do you avoid sugary and high-carbohydrate foods?	3.83	6	1.00	1	b
MODY- A 4	Have you discussed your family's history of diabetes with your healthcare provider?	3.83	6	1.00	1	b
MODY- A 5	Do you engage in regular physical activity, such as walking or exercise (for 30-45 minutes/day)?	3.83	6	1.00	1	c
MODY- A 6	Do you maintain healthy weight?	4.00	6	1.00	1	c
MODY- A 7	Do you follow healthy dietary practices?	3.83	6	1.00	1	c
MODY- A 8	Do you read food labels and pay attention to sugar content when making food choices?	3.67	6	1.00	1	c
MODY- A 9	Have you ever attended diabetes-specific workshops or events to gain more knowledge about MODY management?	3.50	5	0.83	0	a
MODY- A 10	Have you ever taken a any test to determine if you have MODY or if you are at risk for it?	3.50	6	1.00	1	c

*I-CVI =Item Content Validity Index, ****UA**-Universal Agreement. **a-** Revision needed as per UA scores, **b-** Revision needed as per experts' suggestion in suggestion column, **c-**No revision needed.

The outcome results of the practice section were also same as the outcome of attitude section. That is, nine items in the practices section scored as relevant with the I-CVI and UA scores of 1.0, except MODY-P9 (I-CVI with 0.83 and UA with 0).The I-CVI scores of the items in this section meet out the standard I-CVI score of 0.83 as stated by Yusoff

(2019). The rating scores of the 10 items range from 3.50 to 4.00. MODY-P9 question revised to "Have you ever attended diabetes workshops or events to gain more knowledge about MODY?", as it has rating score of 3.50.Experts also gave suggestions in modifications of MODY-A3 and MODY-A4. So, the questions of MODY-A3 and MODY-A4 modified as "Do you limit sugary and high-carbohydrate foods?" and " Have you ever discussed your family's history of diabetes with your doctor?". The higher rating score range, I-CVI, UA and less modification of items shows that attitude section was more acceptable among experts groups.

Table 4: Summary of Expert Validation Scores for MODY KAP Sections

Section	Expert 1 (Doctor)		Expert 2 (Doctor)		Expert 3 (Doctor)		Expert 4 (Dietitian)		Expert 5 (Academician)		Expert 6 (Statistician)	
	Scores	PR*	Scores	PR*	Scores	PR*	Scores	PR*	Scores	PR*	Scores	PR*
MODY Knowledge	3.8	1.00	3.7	0.87	3.1	0.93	4	1.00	4	1.00	4	1.00
MODY Attitudes	3.5	1.00	3.7	0.90	2.9	0.90	4	1.00	4	1.00	4	1.00
MODY Practices	3.8	1.00	3.6	0.90	3.4	1.00	4	1.00	4	1.00	4	1.00
Overall MODY KAP	3.7	1.00	3.7	0.89	3.1	0.94	4	1.00	4	1.00	4	1.00

*PR-Proportion of Relevance

The scores provided by the six experts for the MODY KAP tool demonstrated a high level of agreement in the relevance and accuracy of the content. The knowledge section received good ratings scores ranging from 3.1 to 4.0 and a high PR value (0.87 to 1.00) which indicates an agreement on the relevance of the items. However, expert 3 provided a lower rating score of 3.1, stating a slight revision in the items. The attitude section had a wider range of rating scores ranging from 2.9 to 4.0 because of a lower rating from expert 3. But the PR values were good (0.90 to 1.00). This suggests that most of the items' relevancy and only some items might have not met the aspects of attitudes towards MODY. The practice section received high scores ranging from 3.4 to 4.9 and a good PR values ranging from 0.90 to 1.00. These values of the practice section indicate a strong agreement among the experts on the relevancy of the item in the practice aspects of MODY management. The overall high PR value (0.89 to 1.00) and good rating scores (3.1 to 4.00) across all the sections reflect the strength of the MODY KAP tool. Furthermore, a little change may be required in a few questions based on the slightly lower scores from the expert 3.

Summary of Content Validation Scores for MODY KAP

Table 5 provides the overall content validation summary scores for MODY KAP. This table also shows the number of items in each section, number of items rated relevant or irrelevant, means scores and deviation scores for each section, S-CVI and UA along with interpretation.

Table- 5: Summary of Content Validation Scores for MODY KAP

Section	No. of Items	No. of Items Rated as Relevant without experts' suggestions		No. Items Rated as Irrelevant	Mean ± SD	S-CVI*	UA**
MODY Knowledge	15	10	2	3	3.77 ± 0.49	0.97	0.80
MODY Attitudes	10	5	4	1	3.68 ± 0.54	0.97	0.90
MODY Practices	10	7	2	1	3.80 ± 0.44	0.98	0.90
Overall MODY KAP	35	22	8	5	3.75 ± 0.49	0.97	0.86

*S-CVI =Scale Content Validity Index, **UA-Universal Agreement

Table 5 shows the summary of content validation in all aspects. The MODY Knowledge's section had a total of 12 relevant items (a per ratings), among them 10 items did not need any modifications and two items need some modifications. This knowledge section has a mean score of 3.77±0.49, a high S-CVI of 0.97 and a good UA of 0.80. This indicates a strong content validity but suggests that some items in MODY Knowledge section need some revision regarding key aspects and clarity. The MODY Attitude section got a mean score of 3.68±0.54, with 5 items rated as relevant without any modifications and four items that need to be revised. It also has a high S-CVI of 0.097 and UA of

0.90. This shows that it covers the perception of experts but requires some refinement. The MODY Practices section scores the highest among all the other sections, with a mean score of 3.80±0.44, high S-CVI of 0.98 and UA of 0.90. This reflects a good relevancy of items and acceptance among the experts on MODY attitude section. The overall relevancy of MODY KAP was good with 30 relevant items and only 5 irrelevant items, with a mean score of 3.75±0.49, with S-CVI of 0.97 (which is above the standard CVI score of 0.83 as stated by Yusoff (2019)) and UA of 0.86. This content validation ensures that this MODY KAP tool find the knowledge gaps, improves attitudes and encourage changes in practices that lead to better MODY diagnosis and management.

Conclusion

The development and validation of KAP tool for Maturity Onset Diabetes of the Young (MODY) successfully filled the significant gap in diabetes education by creating a tool specifically for MODY. This study undergone a rigorous content validation of the MODY KAP tool, the high S-CVI (0.97), PR (0.89 to 1.00) and UA (0.86) scores with 86 percent of relevant items made this MODY KAP tool a highly relevant tool after slight modifications. Even though one item in attitude section received lower I-CVI, the overall CVI was more than the standard value of 0.83 and also the question was replaced with another question for achieving good standards. The results of the content validation study of MODY KAP tool recorded this tool as a reliable instrument for assessing knowledge, attitudes and practices related to Maturity Onset Diabetes of the Young by achieving the good overall CVI. The validated KAP tool created a framework for MODY awareness, diagnosis and management. It also helps in improving early diagnosis and promotion of appropriate treatment strategies for MODY patients. In future, the research could focus on pilot testing of the MODYKAP tool with the expanded population and integrating it into healthcare training programs. By enhancing MODY awareness among healthcare professionals, this tool can contribute to better patient outcomes and reduce the misdiagnosis of MODY as Type 1 and Type 2 diabetes.

Acknowledgment: The authors would like to acknowledge the "UGC-National Fellowship for OBC 2018-19" to grant this study fellowship.

Ethical Clearance: The study's ethical approval came from the Institutional Human Ethics Committee of Avinashilingam Institute for Home Science and Higher Education for Women, Coimbatore. The ethical approval of this study is AUW/IHEC/FSMD-19-20/XPD-25.

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Citation: Leelavathi V, Sivakami PL. Sridevi. Content Validation and Development of KAP Tool for Maturity Onset Diabetes of the Young (MODY). Indian J Prev Soc Med, 2025; 56 (1): **44-50**.