Assessing the efficacy of best practices for obtaining culturally relevant and medically accurate pedigrees from Marshallese patients

Brittany Burnside, B.S., Gene Hallford, Ph.D., April Brown, Ph.D., Philmar Mendoza Kabua, M.S., and Lori Williamson, M.S., C.G.C.
Republic of the Marshall Islands background and history

Genetic Counseling and the Family Health History

Challenges in collecting FHH info from Marshallese patients + Published Best practices
BACKGROUND
The Republic of the Marshall Islands (RMI)

An island nation in the North Pacific; part of Micronesia.

Consists of more than 1,200 islands created mainly by 29 large atolls.

The United States (US) used the northern atolls (primarily Bikini and Enewetak) as sites for nuclear weapons testing in the 1940’s and 1950’s.

67 nuclear bombs were detonated.

Castle Bravo: 1,000 times the force of the bombs dropped in Japan during WWII (Barker, 2013).
The Republic of the Marshall Islands (RMI)

Continuing impacts of nuclear testing (Barker, 2013; Simon et al., 2010):

- Displacement
- Increased incidence of cancer, birth defects, and diabetes
- Trauma
- Loss of the traditional way of life

Subsequent human subjects research by US researchers without the subjects’ informed consent was used to justify lack of US reparations, decreasing the trust many Marshallese individuals feel towards American researchers and healthcare providers (Barker, 2013).
Migration to the United States

Primary drivers (Duke, 2014):

- Healthcare access
  - Increased incidence of type 2 diabetes, thyroid disorders, and cancer, at least partly as a result of nuclear legacy (Duke, 2014; Hamilton et al., 1987; Simon et al., 2010).

- Economic opportunity

- Education

The majority are in Northwest Arkansas, where the low cost of living, well-established Marshallese community, and abundance of low-skilled jobs in the poultry industry continue to draw more Marshallese migrants (Brown, 2021; Duke, 2014; McElfish et al., 2018)
Health Disparities

Barriers to healthcare (Balli et al., 2019; McElfish et al., 2017; McElfish et al., 2020; Nguyen-Truong et al., 2021):

- Poverty
- Navigating a complex healthcare system
- Differences in expectations and healthcare customs (i.e. preventative care, refilling prescriptions, lifelong chronic disease management, and attending appointments at scheduled times)
- Language barrier and access to interpreters
- Mistrust of the medical system as a result of past research
- Lack of health insurance
Genetic Counseling and the Family Health History (FHH)

FHHs are helpful in:

- Determining whether genetic testing is indicated
- Selecting a genetic test
- Interpreting genetic test results
- Understanding and predicting risk
- Developing rapport
- Guiding individual screening measures
- Creating positive behavior and lifestyle changes

(Valdez et al., 2010; Wu & Orlando, 2015)
Genetic Counseling and the Family Health History (FHH)

A large portion of the population is likely to meet guidelines for additional screening or other non-routine risk management based on family history alone (Ginsburg et al., 2019; Wu & Orlando, 2015).
Challenges in collecting FHHs from Marshallese Patients

Featuring recommendations from Blocker et al. (2020)
Blocker et al. (2020)

- Interviews with community members
- Discussed as Blocker et al.’s findings but originate from Marshallese community
Challenges and their solutions

01 Language Barrier
Utilize Community Health Workers (CHWs) to interpret when possible.

02 Understanding accurate biological relationships (broader meaning of relationship words, adoption culture)
Clarify the purpose of the questions; specify biological relationships

03 Cultural taboos surrounding speaking about illness
Build strong rapport; apologize before asking insensitive questions

Blocker et al. (2020)
Challenges and their solutions

04 Privacy of sex/gender-related health topics
Providers and interpreters should be the same gender as patients

05 Provider-Patient Trust
Begin with “iakwe” and friendly conversation; show you understand why they are there rather than asking; explain the purpose of your questions

06 Finding strong meaning in nonverbal cues
Utilize positive body language and facial expressions

Blocker et al. (2020)
Summary of Guidelines from Blocker et al. (2020)

Beginning the appointment:

- Greet them with “iakwe”
- Begin appointments with friendly small talk
- Tell them you know why they are there in clinic
- Use a CHW
Summary of Guidelines from Blocker et al. (2020)

During FHH collection:

- Specify immediate family members/close family members
- Specify biological relatives
- Be aware of how they use family relationship words
- Explain why you are asking your questions
- Say, “I’m sorry if this is insensitive but...” before asking intrusive personal questions about medical history
- Watch nonverbals (body language, tone)
Summary of Guidelines from Blocker et al. (2020)

Other:

- Ensure providers, patients, and interpreters are same gender when possible
- Attend community events so they know you from outside the clinic
THIS PROJECT:

Take it into the clinic and see how well it works
INCLUSION CRITERIA

- Marshallese adults
- Living in the United States
- Fluent in Marshallese or English
- Raised in Marshallese culture
METHODS

Recruitment

• North Street Clinic
• Facebook and Instagram
• Flyers
• Word of mouth
North Street Clinic
RESEARCH PARTICIPANTS NEEDED
Participants will be asked to provide family health history information to a genetic counseling student and respond to a survey. Participation will take approximately 1 hour.

IN PERSON OR VIRTUAL

PARTICIPANTS WILL RECEIVE A $40 WALMART GIFT CARD

MUST BE:
- Marshallese
- 18 or older
- Raised in Marshallese culture

CONTACT:
Brittany Burnside (English): 801-899-5187
bburnside@uams.edu
Lynda Riklon (Marshallese): 479-236-2176
lariklon@uams.edu
Richard Laraya (Marshallese): 479-347-1661
richard@mei.ngo

AIKUJ ARMEJ NÂN BÖK KUNAER
Jenaaj kajjítök bwe ro rej bök kunaer ren kwalok laajrak in melele ikijjien ejmour an baamle ko aer ŋan juën ríijkulu in genetic counseling im bök kunaer ilo juën survey. Enaaj bök 1 awa aetokan.

ILO NEMÀIM ARMEJ AK ONLINE
Enaaj etal juën $40 Walmart gift card ŋan ro rej bök kunaer

KWOJ AIKUJ:
- Rimajöl
- 18 iïo ak ruttolök
- Drik im ruttolök kin mantin Majöl

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richard@mei.ngo
METHODS

Recruitment

• North Street Clinic
• Facebook and Instagram
• Flyers
• Word of mouth

Collect FHH

• Informed consent
• FHH Guide
• Follow guidelines from Blocker et al. (2020)
Family Health History Collection Guide

Participants will be asked about who their biological relatives are, going up 3 generations, including siblings, aunts and uncles, parents, and grandparents. They will also be asked about children and grandchildren. When the family tree is mapped out, they will be asked to share who in the family is affected by the following conditions:

- Heart attacks or heart disease
- Cancer
- Diabetes
- Recurrent pregnancy loss or stillbirth
- Autism or intellectual disability
- Birth defects, such as cleft lip, clubfoot, heart defects, etc.
- Deafness
- Any health problems that have been passed from generation to generation
- Any other health conditions that have not been asked about

_relevant follow-up questions will be asked, including but not limited to age of onset, age and cause of death, medical management of a condition, etc._

They will also be asked about the following:

- Consanguinity
- Whether anyone in the family has had genetic testing
- Which atoll their family is from

This list of questions was generated based on clinical practice and known health conditions prevalent in the Marshallese community.
“Some health conditions are caused by germs, like COVID-19. Some are caused by the environment, the way radiation can cause cancer. Others are caused by lifestyle. Some health conditions, though, are passed through families; they are inherited, or genetic. My job is to ask questions about your family health history to see if there are any health conditions that could be passed down, so that we make sure to give you appropriate medical care.”
“I’ll ask you who is who in the family and draw them out. Then, I’ll go through this list of questions about health conditions and ask you if anyone in the family has them. While I do this, I’m specifically asking about close biological relationships. I know there are a lot of adoptions in Marshallese culture, and if anyone is adopted, I have a way to write that to honor the family structure, but make sure and let me know. This is because the biological relationships are what influence our genetics.”
## METHODS

### Recruitment
- North Street Clinic
- Facebook and Instagram
- Flyers
- Word of mouth

### Collect FHH
- Informed consent
- FHH Guide
- Follow guidelines from Blocker et al. (2020)

### Survey
- 11 questions
- English or Marshallese
- Assessed feelings of cultural respect, whether info was withheld, additional feedback
METHODS

Compensation and follow-up
- $40 Walmart gift card
- Appropriate screenings or referrals

Data analysis
- FHH information
- Referrals/screenings
- Survey responses

RESEARCH COMPLETE
Representing 18 atolls:

Ailuk, Ailinglaplap, Arno, Aur, Ebon, Enewetak, Jaluit, Kwajalein, Likiep, Majuro, Maloelap, Mejit, Mili, Namdrik, Namu, Utrik, Wotho, and Wotje.

DEMOGRAPHICS

N = 24

33% MALE
N = 8

66% FEMALE
N = 16
<table>
<thead>
<tr>
<th>Condition</th>
<th>n</th>
<th>Mdn</th>
<th>Min.</th>
<th>Max.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Autism</td>
<td>9</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Birth defects, other</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Cancer, unspecified</td>
<td>4</td>
<td>1.5</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Cancer, brain</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Cancer, breast</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Cancer, cervical</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Cancer, colon</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Cancer, female reproductive</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Cancer, kidney</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Cancer, childhood leukemia</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Cancer, stomach</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Cancer, stomach</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Cancer, thyroid</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Cancer, uterine</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Cancer, total</td>
<td>15</td>
<td>2</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Total early-onset cancer</td>
<td>11</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Cleft (lip or lip and palate)</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Diabetes</td>
<td>23</td>
<td>6</td>
<td>1</td>
<td>27</td>
</tr>
<tr>
<td>Gout</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Hearing loss, excluding in old age</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Heart attack</td>
<td>6</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Heart defect, congenital</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Heart disease/heart condition</td>
<td>6</td>
<td>1.5</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Heart murmur</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Heart conditions, total</td>
<td>12</td>
<td>2</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Developmental disabilities excluding autism</td>
<td>8</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Miscarriage/stillbirth/ectopic pregnancy</td>
<td>8</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Seizures</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Thyroid disorder, unspecified</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

n = number of FHHs that reported the condition.
Mdn = median # of affected family members reported by those with Fhx of the condition
Min. = minimum # of affected family members
Max. = maximum amount of affected family members
<table>
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<th>Max.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>9</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Cancer, total</td>
<td>15</td>
<td>2</td>
<td>1</td>
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<td>23</td>
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<td>1</td>
<td>27</td>
</tr>
<tr>
<td>Heart conditions, total</td>
<td>12</td>
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<td>1</td>
<td>6</td>
</tr>
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<td>Miscarriage/stillbirth/ectopic pregnancy</td>
<td>8</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

Consistent with previous reports*: cancer, diabetes, and heart disease

Additional: autism and pregnancy loss

*n = number of FHHs that reported the condition.

Mdn = median # of affected family members reported by those with Fhx of the condition

Min. = minimum # of affected family members

Max. = maximum amount of affected family members

*McElfish et al., 2019
Clinical Utility

- Referral to adult genetics based on existing but unmanaged genetic diagnosis
- Referred to cancer genetic counselor due to personal history of cancer
- Received screening for thyroid, colon, and prostate cancer and a referral to a cancer genetic counselor
- Child referred to pediatric genetics for autism evaluation

16% (4 of 24) received FHH-based referrals or screening
Clinical Utility

As a screening tool, FHH collection proves to be useful as a way of identifying individuals who may benefit from additional intervention.

This study shows a lower percentage of participants receiving additional medical action than other studies:

- O’Neil et al. (2009): 82% of FHHs resulted in additional medical management. N = 3,786. 91% white.
- Orlando et al. (2016): 41%. N = 488. 85.7% white.
Patients reported positive experiences having their FHH information collected, including that they felt comfortable and respected and that nothing the interviewer did or said while following the strategies of Blocker et al. (2020) felt insensitive.

<table>
<thead>
<tr>
<th>Response</th>
<th>Overall, I felt comfortable talking with the interviewer about my family information.</th>
<th>Overall, I felt comfortable talking with the interviewer about my personal medical information.</th>
<th>I felt that the interviewer respected my culture.</th>
<th>I felt that the interviewer respected me.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Agree</td>
<td>19 (79.2)</td>
<td>18 (75)</td>
<td>21 (87.5)</td>
<td>21 (87.5)</td>
</tr>
<tr>
<td>Agree</td>
<td>5 (20.8)</td>
<td>5 (20.8)</td>
<td>2 (8.3)</td>
<td>3 (12.5)</td>
</tr>
<tr>
<td>Neutral</td>
<td>1 (4.2)</td>
<td>1 (4.2)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Cultural Appropriateness: qualitative

Question 1a: We know that sometimes people are uncomfortable sharing personal information. This is one thing we are hoping to learn about in this study so that we can do our job better. Was there any information that you withheld from sharing because you were uncomfortable or for any other reason?

1 participant indicated that they withheld information about children who had died.

Remaining 23 participants indicated that they had not withheld information.

Survey B: “I felt very comfortable.”
Survey C: “I felt very comfortable sharing my medical information....”
Cultural Appropriateness: qualitative

Question 1b: What might a medical provider do differently to help you feel more comfortable sharing this information?

Survey I: “Help me more with the pain I have. Comfort me from my pain.”

Survey K: “Probably have the client look at the questions before the interview.”

Survey M: “Understand cultural background when asking questions.”

Survey V: “Willing to communicate/talk with their patients.”
Medical Accuracy: Obtaining Complete Information

With Marshallese patients, it’s important to consider whether patients are offering complete and accurate information.

23/24 reported that they disclosed all relevant information during FHH collection and not withheld any.

• Suggests that following guidelines in Blocker et al. (2020) creates environment where patients are comfortable sharing health information openly.

• Limitation: participants may have withheld info and not disclosed that they had withheld it.
Medical Accuracy: Obtaining Complete Information

Participant who reported withholding information:
• Possible explanations include
  • Cultural reasons
  • Strong emotion
  • Not believing that deceased family members were relevant to the FHH.

Limitations regarding medical accuracy of FHHs:
• Lack of knowledge*
• Conditions going undiagnosed in the RMI
• Cultural taboos around sharing medical information with others

*Common among non-Marshallese patients as well (Mai et al., 2011).
“Probably have the client look at the questions before the interview”

Likely refers to the set of family history questions asked during FHH collection.

Explores another layer of informed consent in research participation AND the genetic counseling session.

Informed consent is particularly important with Marshallese patients due to history of American-led human subjects research following nuclear testing (Barker 2013; Blocker et al., 2020; Nguyen-Truong et al., 2021).

In GC session: importance of thorough contracting

“...counselors should take special note when seeing Marshallese patients, as contracting may be crucial to establishing a positive relationship” (Blocker et al., 2020).
Cultural Appropriateness: qualitative

Question 7: did the interviewer do anything that felt insensitive to you? If yes, please explain.

Survey C: “Not at all, she’s very respectful”

Survey D: “No, the interviewer was very respectful and made sure to make sure I am comfortable.”

Survey H: “No, she was been honest” (sic).

Survey J: “It was fine.”

14 other participants: “No.”
Cultural Appropriateness: qualitative

Question 8: did the interviewer say anything that felt insensitive to you? If yes, please explain.

All responses: “No” “N/A” “No problem” or “none.”
Cultural Appropriateness: qualitative

Question 9: What do you wish the interviewer had done differently?

17 participants: “N/A” “Nothing, she’s doing a great job” “None” “No problem.”

Survey M: “None. She did very well. She was respectful, she acknowledged that she would not want to be insensitive” (emphasis added).

Survey K: “More questions about family diet.”

Survey D: “I had no problem understanding the questions asked regarding the health issues, however some participants (Marshallese) might not know what those health issues mean/entail, so maybe explaining what they mean would help.”
“She acknowledged she would not want to be insensitive”

Specifically refers to one of the strategies from Blocker et al. (2020) utilized in the study: apologize before asking personal questions.

“*I'm sorry if this is insensitive, but...*”
“More questions about family diet”

Survey K also reported a belief that their “family conditions are environmental, not genetic”

- Suggests that they wish FHH collection had more thoroughly explored other causes of familial disease
- Participant possibly did not know or understand that some conditions result from both genetic and environmental factors (multifactorial)

Precedent for addressing environmental factors:

- Cancer GCs: addressing exposures related to cancer risk
- Diet may be informative with diabetes and heart disease

Within GC scope of practice and constraints of GC sessions:

- Assess whether patient and family are managed by proper specialists (such as a dietician).
“I had no problem understanding the questions asked regarding the health issues, however some participants (Marshallese) might not know what those health issues mean/entail, so maybe explaining what they mean would help”

Importance of defining terms: genetics concepts are not broadly familiar and Marshallese language does not always have clear ways to express them.
## Cultural Appropriateness: qualitative

Question 10: What do you wish doctors and other medical professionals knew about you?

<table>
<thead>
<tr>
<th>Participant Desire</th>
<th>Quoted Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>For providers to understand their personal and family health history</td>
<td>That I have conditions that are not getting treated because they're so specialized.</td>
</tr>
<tr>
<td></td>
<td>If the illness run in the family (sic)</td>
</tr>
<tr>
<td></td>
<td>Conditions in my family</td>
</tr>
<tr>
<td></td>
<td>My conditions</td>
</tr>
<tr>
<td></td>
<td>My health history</td>
</tr>
<tr>
<td>For providers to understand underlying causes of health conditions</td>
<td>Why I have kidney failure</td>
</tr>
<tr>
<td></td>
<td>What causes genetic conditions</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>For providers to understand more about the Marshall Islands and Marshallese culture</td>
<td>Environmental factors (from Marshall Islands) that may affect my health</td>
</tr>
<tr>
<td></td>
<td>My culture &amp; custom to serve us better or treat us better. (Cultural Competency)</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Improved rapport</td>
<td>I guess, that all I just want them to know about me (sic)</td>
</tr>
<tr>
<td></td>
<td>Anything is good</td>
</tr>
<tr>
<td></td>
<td>If they ask me, I might be able to answer their questions.</td>
</tr>
</tbody>
</table>
Cultural Competency

Multiple responses throughout the survey reflected on cultural competency:

Survey K: “[I wish medical providers knew] my culture & custom to serve us better or treat us better. (Cultural Competency)” (sic).

Survey K: “I think doing cultural competency should be taught/given to all providers/doctor to better treat the Marshallese patients” (sic).

Survey M: “[Providers should] understand cultural background when asking questions.
Cultural Competency

Generally, participants reported feeling that their culture was respected throughout FHH collection.

- Suggests that the recommendations from Blocker et al. (2020) are effective methods of showing respect to Marshallese patients and honoring Marshallese culture.

Participants also reported that their experience with providers in the US in general would benefit from additional cultural competency training.

- Suggests that the recommendations from Blocker et al. (2020) should be more widely and consistently adopted by providers who serve Marshallese patients.
Verbal Feedback

- “Inherited” vs “bodañ”
- “Brothers and sisters” instead of “siblings”
- Family members who have died
Other Findings

2 FHHs reported that conditions in the family were caused by radiation exposure. Survey K: “I think my family health history is caused by their surrounding and not by genetics” (sic).

2 FHHs reported consanguinity.

1 FHH reported a family member who died as a result of being snatched by a demon.
Snatched by a Demon

- Common scare tactic to get children to listen
- “Fever-like symptoms” leading up to the child’s death
- To write “fever” or “snatched by demon” on pedigree?
This study solidifies the importance of following the guidelines outlined by Blocker et al. (2020). These guidelines are effective in helping patients feel comfortable sharing medical information with providers. Blocker et al. (2020)’s guidelines should be applied more broadly and consistently by providers with Marshallese patients.

Overall, FHH collection proved clinically informative and medically actionable.

FHH collection seemed to advance the patient-provider relationship and build trust, which is an important part of working with the Marshallese community (Blocker et al., 2020 & Nguyen-Truong et al., 2021).

In GC practice: importance of relationship-building should not be overlooked, as relationship is center to the genetic counseling practice (Veach et al., 2018, Chapter 2).
LIMITATIONS

- **66.7% female**
  Limitation in many studies, but particularly as providers and patients should ideally be the same sex (Blocker et al., 2020)

- **Interviewer + committee’s familiarity with Marshallese people, culture, & language**
  May not represent the average provider’s experience

- **Focus on those in NWA**
  May not fully represent broader Marshallese population
NEXT STEPS: FOCUS GROUPS

BODAN

DEMON


SOURCES


ACKNOWLEDGEMENTS
QUESTIONS?
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