

Caring for the Caregiver: Experiences and networks of informal caregivers



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CRCR692

Final Progress Report

Fall 2017

Report Outline

Course Journey narrative:- Page 1-9

Research Methodology: - Page 10- 17

- Introduction section- Done
- Research questions- Done
- Research Methodology- work in progress
- Data collection and analysis- work in progress
- Dissemination plan- Done

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Research Topic:

Caring for the Caregiver: Experiences and networks on informal caregivers

Research goal:

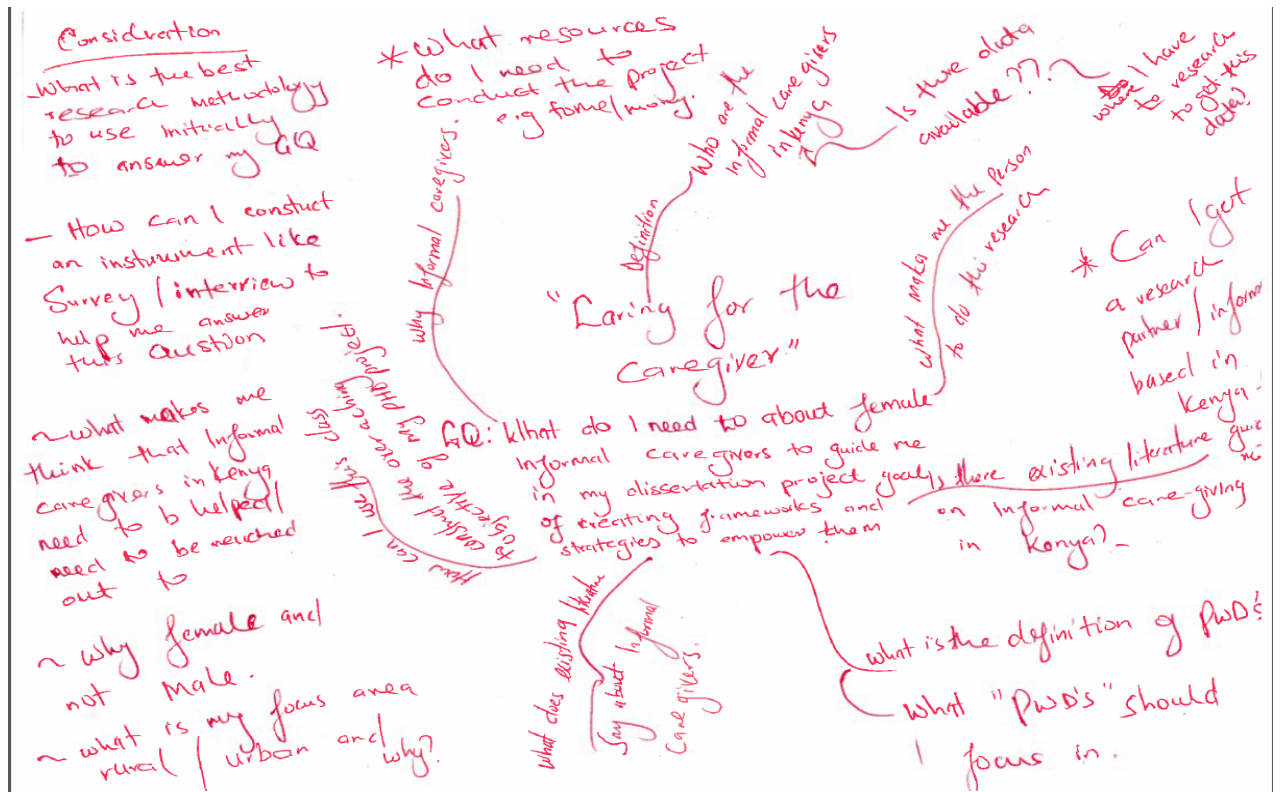
My dissertation study will aim to research and explore the experiences (positive/negative/ neutral) of informal caregivers to children with moderate to severe disabilities and their coping mechanisms while caring for their loved ones in a poor rural setting in my home country Kenya.

Introduction:

Starting this course I was not sure what topic or social injustice issue I will focus on but I knew it was to be based in my home country. Growing up although, in a privileged home, I witnessed so many of the social problems most families around me experienced. I remember growing up and wondering why some people struggled and others did not and I wanted to explore and find out. For example, I had a neighbor who for 10 years I did not know had a child with disabilities. I played and interacted with her other children, went to their home and never did I even think that there was a young girl locked in the basement of the house, shunned from a society based on her disability status. I remember hurting not only for the girl but also for her mother (women in Kenya are main caretakers), who succumbed to the society's attitudes and stigma following the concept of disability and decided to hide what she considered "abnormal" so the society. I remember asking myself and my mother if maybe we could have been better social support for this family. So the fight for inclusion of disability and gender equality are personal fights for me and a great passion. Hence when I began this course I had three different topics that I wanted to work on.

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The mapping sections which were many and iterative helped me ask myself and answer, using deduction technique which reminded me of peeling an onion since it was a painful process for me personally but one that ended up being very beneficial.



The mapping process was for me also a personal journey that leads me to start reflecting on my personal ontology as a researcher. This process helped me reflect on how my thoughts my beliefs can affect my research bias and topics. During my self-reflection in thinking about my personal ontology, I started by asking myself who Esther is. Who am I? What am I all about? How do I view the world or the universe around me? I did wonder why self-reflection was necessary for a research class. Then I realized that self-awareness is important if I want to change my life or the life of others in any way, I needed to know myself before I can act or embark to help others, furthermore knowing who I am allowed me to know my passion that would direct

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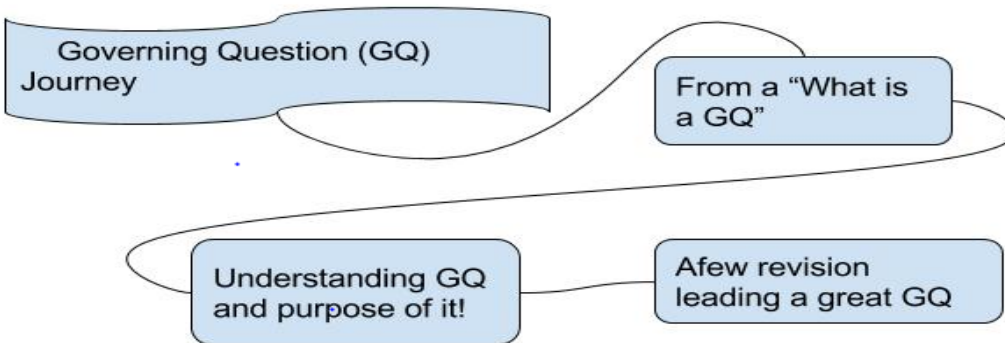
any research I would undertake. I think I have spent a lot of time thinking about others and not taken the time to consider myself. Becoming self-aware does not mean being selfish – it is simply a stepping stone in reaching my true potential and living a life full of purpose and meaning. I plan to continue this self-reflection journey in discovering my personal ontology that will enable me to give more of myself to others and this will benefit my relationships. One thing I know for sure is that I have always loved the process of learning, I have always been fascinated by books, any kind of books but mostly I like to read books that were written in another era...in the 1800's or so. I find it so fascinating how life or way of life was the same yet different many years ago.

Using this process, I realized I was using my personal experiences or thoughts to make a judgment that all caretakers in Kenyan were female. And I started asking myself what if they are not? Furthermore, my first topic was to focus on the challenges female caretakers face in caring for their loved one. This too was a personal judgment as I was using my life experiences to assume that all caretakers struggle and they do it because they don't have an option. What if there were a male caretaker, moreover what if some caretakers loved caring for their loved ones, and maybe see the benefits not the challenges of caretaking? This reflection process helped me scale back and frame my research topic to the experiences and networks of informal caregivers, and research goal to answer i) Who are informal caregivers to children with disabilities in Kenya? ii) What are their existing networks and needs for support?

When began this course I had no idea what a governing question was. After the first few classes and revision with Peter, I was able to understand the concept of using the governing question to mold that which I needed to research on to get to my end goal. Furthermore, a reasonable Governing Question should keep my consideration concentrated on what I have to

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discover that I don't definitely know or that I can't yet explain or express to another person. The inquiry ought to be grounded in what I need to know to get occupied with my particular conditions, not what another nonexclusive individual should know. Furthermore, reflecting on my Governing Question as I frame and conduct my research will help control the many-sided quality of conceivable contemplations resulting to a more effectively organized readings, target stakeholders, my dissertation project (CCTP- Wikispaces)

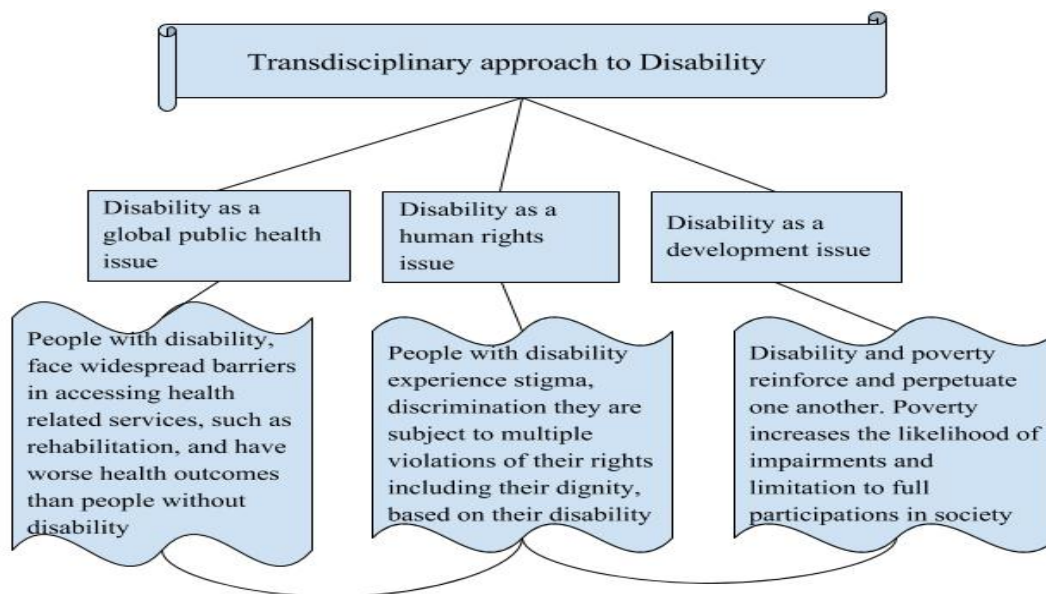


After that this interactive process, I framed my governing question which helped me in the mapping process as: “Given my desire to improve the inclusion for informal caregivers for children with disabilities in my home country Kenya, what can I learn to best guide me in designing a research proposal targeted to not only to have the policies that address the challenges informal caregivers face, but also to engage with the communities, not for profit organizations and government agencies that would need to do a better job in supporting that fraction of the population,

For my dissertation proposal to be accepted, it needs to focus on a real-world social problem. It also needs to be multi-disciplines oriented and should show that the problem being researched is a social problem. Hence the initial interview in this class with an informant in my

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areas of interest, mapping process, breakout sessions were very insightful in understanding disability as a multidimensional problem that was just what I needed for my transdisciplinary approach of defending why Disability is a complex area and a much-needed topic to focus on.



Initial interview conducted during this course was very informative and helped me to reflect more on the research methodology and data collection tools.

Finding from the interview

- **Stigma and Taboo about Disabilities-** This is a reality on the ground in Kenya and hence gave me the backup that my research ideas are authentic and will be a great way to engage the community in discussions.
- **Cultural Beliefs and Attitudes-** It would be great to include in my dissertation research how cultural beliefs impact the inclusion of people with disabilities.

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- Lack of Government support- One of the major obstacles to inclusion cited in this initial interview process was lack of support from the government. It would be great if I included government officials in my study towards PWDs inclusion or their lack of.
- Lack of Training/ Skill sets- In my research, I need to think about adding the intervention of training and skills if it won't broaden the scope too much
- Poor Infrastructure and Lack of Funding- In my research I need to think about adding the intervention of training and skills if it won't broaden the scope too much
- Lack of social connections and support- this was the most revealing information from the interview. Social interconnection was craved and needed by this population. Which leads me to think on a social connection and support angle in my research?

Lessons Learnt from the interview process:

- Better communication tools- conducting an international interview via phone was not ideal. There were multiple network disruptions and in addition, it ended up costing my interviewee participants a lot of money. For my dissertation study that will be conducted online, should be mindful of communication modes. Maybe I will have to conduct my research in person?
- Allocate additional time for the interview- Due to the disruption and the fact that the interviewee wanted to provide more content, we went over the time allocated. I need to plan around these constraints when framing my interviews and giving my interview participant a time frame that makes sense.
- Be Non-judgmental and develop Empathy- Separate personal feelings from the responses from the interviewee and be open-minded to the difference of opinion. I found myself

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being defensive and caught myself almost trying to lead the interviewee to answer “correctly”.

Reminded me of “playing the belief game”

Strategic planning and organization

The research design and organization in the course guided me to look outside of my research process into my personal development, understand my ontology and how to balance my life aspects in order to better be organized to improve efficiency. It also helped me incorporate the strategies I came up with and also discussed with my peers during breakouts. This section guided successfully reading, researching, thinking and writing my dissertation proposal.

Strategic Planning: Journey from Engagement Process to completion of Dissertation Proposal.

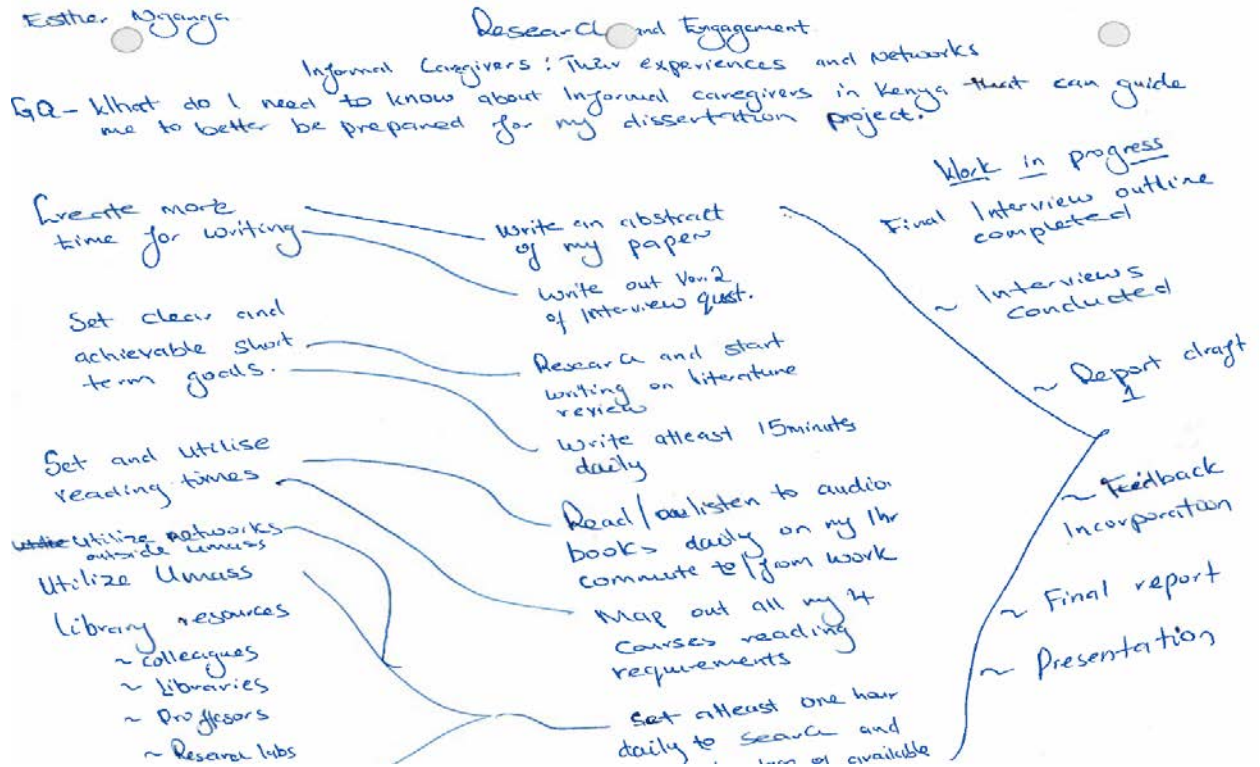
Assessment: Esther Nguyen

- Where am I? - Articulated my Corening Question / Area of research interest / Satisfied with my topic
- Where I want to be - Struggling with writing and creating a conceptual framework / struggling with juggling & deactivating courses.
- 2 Be - Have a breakthrough with the writing process / Attain a command of expertise with my topic.
- Love writing and researching / Have a clear picture of my journey to transition between this class to my dissertation.
- Have a great work/life balance.

How DO I GET THERE

| Work & life / school balance | Writers Mind block: | Transitions: | Attain Expertise |
|---|--|---|--|
| <ul style="list-style-type: none"> - Dedicate family time to family. - Use and Manage my Calendar more effectively. - Plan better - Make better use of my free time - Meditate - Communicate w/ Professor | <ul style="list-style-type: none"> - Meditate - Schedule short reflection breaks. - Try to schedule and actually write for at least 15 minutes a day - Don't beat myself or over freak out of the fact that I am struggling with writing - write / write / write whatever word I can writing is logical to me | <ul style="list-style-type: none"> Step outside of the four classes needs and requirements and map them out and try to make sense of how to better manage them and ensure they are all productive and successfully leading to my dissertation success. | <ul style="list-style-type: none"> - Read - Diverse literature reviews - Research funding / grants availability that can help ease my work requirements to allow me to focus more on academic. - Utilize driving or commute times to listen to audios or use dictation apps. |

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Course journey summary:

When I selected this course as my research elective I was attracted by the title of the course 'Processes of Research & Engagement, the goal was to not only start the process of writing my dissertation proposal but also understand and draft my the research methodology and dissemination plan section of my proposal. While this course did not venture into research methodology and engagements process but focused more on the process of critical thinking and reflection more, I used the skills learned from this class to achieve my goal of finishing the research methodology section. My proposal is an ongoing journey and sometimes also feels like a battle, as I am getting advice from 5 committee members who do not always agree. One committee member has suggested to add a policy and legislative aspect to my proposal and use a mixed method data collection, but that has now been rejected by other committee members. So this is still work in progress which I intend to use the Spring semester to finalize.

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Research Topic:

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Research paragraph:

My dissertation study will aim to research and explore the experiences (positive/ negative/ neutral) of informal caregivers to children with moderate to severe disabilities and their coping mechanisms while caring for their loved ones in a poor rural setting in my home country Kenya.

Research Significance

This study will aim to explore the experiences (positive/ negative/ neutral) of informal caregivers to children with moderate to severe disabilities and their coping mechanisms while caring for children with disabilities in a poor rural setting in Kenya. A key objective of this research is to provide a baseline for new variables for further empirical testing to add to the science-based knowledge of informal caregiving resulting in closing the gap in the research on informal caregivers which is a significant omission considering that the healthcare outcomes of PWD's depend on their informal caregivers. Moreover, the results from this study can be used by disability-related organizations and human rights-based local and national organizations for the advocacy and lobbying in support of this vulnerable group. Furthermore, the caregivers will get a chance for their voice and story to be heard which can lead to empowerment, the creation of self-help and support groups and dialogue engagement with media, community leaders, and organizations and with the Kenyan local government officials.

Research Methodology and engagement to be used

The main aim of the study is to gain a deeper understanding of the perceptions of the caregivers. I will conduct a phenomenology qualitative study in Kirinyaga Kenya so as to understand the subjective experiences of the caregivers in their natural worlds and how they interpret their experiences, photovoice data collection where the participants will be asked to document aspects of their lives which will be followed by in-depth focus group based interviews to evoke a discussion and a narrative to accompany the documentation. Purposive sampling will be used to select the participants for the study who will be: i) informal caregivers: The participants will be recruited from Karira general hospital based in Mwea, Kirinyaga district. The study participants were the caregivers of people with disabilities (who were/are getting treated or admitted to the hospital for the treatment) will recruit to participate in the study. The criteria for an eligible caregiver for the study will be a participant must have been a caregiver for at least 1 year, supporting the patient emotionally and financially, ii) county-level key informants to learn about existing informal caregiver networks and initiatives if any, ii) professional's from health services resource and referral agencies and other organizations with knowledge of Kenya's disability and caregiving programs.

I will use a facilitator who is well known in Kirinyaga to partner in this process and who can be an assistant in this process. The role of the interviewer will be focused on the conversation, whereas facilitator will be assigned the responsibility of audio recording the conversation and summarizing the entire discussion. All the participants will be asked to consent for audio recording of the interviews.

Recorded interviews will be played and the scripts analyzed in order to identify key themes and ideas. The data will be stratified into different subheadings, and a list of codes for the

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different themes will be developed. Relevant parts of the data that represented different views, feelings and experiences were summarized under themes. The themes will be defined, explained, linked and compared. Open, axial and selective coding was used. Open coding will be used to initially classify and label the data, followed by axial coding for identifying the important concepts for the study. The data will be synthesized down, examined and compared to similarities and differences.

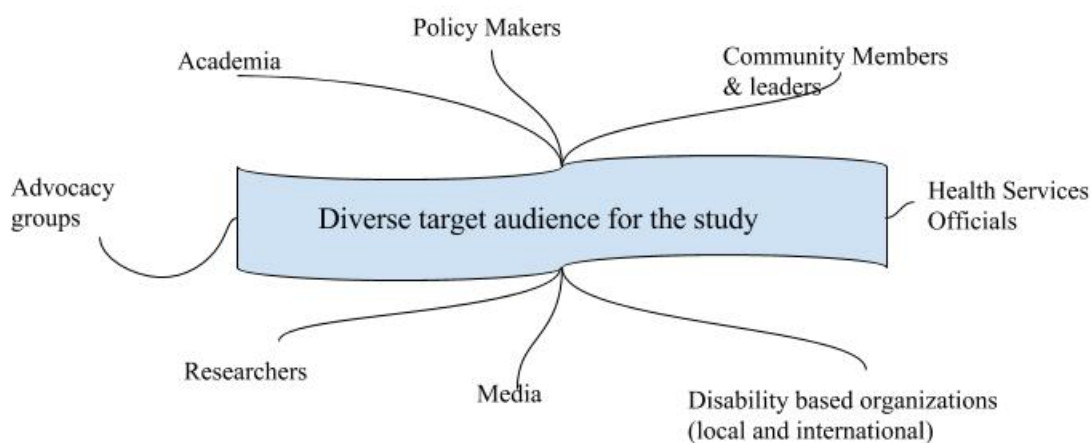
Ensuring the confidentiality of the research subjects is important; the researcher will ensure that the research does not publicize any of the research subject's personal details. Participation in the research is voluntary and the subjects have the freedom to refuse involvement anytime during the process.

Dissemination plan:

The findings will be incorporated into an academic scholarly report that will be shared with Umass and committee staff to fulfill my doctoral requirements. Moreover, the findings will also be shared among key stakeholders of all involved in the research project– persons with disabilities caregivers, policymakers, governments, potential bilateral/ multilateral donors, Local DPOs, other researchers engines with the goal that the production of new evidence will lead to sustained awareness of, and interest in, improving the experiences of people living with disabilities not only in Kirinyaga county but might start the conversation of expanding the research in other regions in Kenya too. Pending any resource constraints, informal caregivers and local community members will perform a song or a play to give them voice and visibility to communicate the photovoice results that will be uncovered in this study so as to initiate and

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engage with diverse target audience like the media, local community members, national and local levels.



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