

# Type 2 Diabetes: A Lifelong Information Seeking Process

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## Abstract

This study explores the health information behaviour of women with type 2 diabetes at least 5 years after the diagnosis. It asks: What is the role of information resources on diabetes in the lives of retired women with type 2 diabetes? How do they search for, encounter, and navigate (or avoid) information about diabetes and diabetes self-management, especially as they have already been managing their diabetes for several years? Data is collected using the Information Horizons Interview method on three participants between the ages of 55 and 65, where the drawing of their “information horizon” is elicited. The findings demonstrate that contrary to previous research that indicates information seeking of diabetics decreases over time, diabetes information seeking is a lifelong process, and while participants develop similar habits with regard to source types, their individual source preferences are influenced by direct experience with the source, comfort and rapport with the source, accessibility and expected comprehensibility of the source, and the sources’ perceived reliability and authority.

## INTRODUCTION

This study explores the health information behaviour of women with type 2 diabetes. The participants are retired women in Toronto between the ages of 55 and 65, with at least one post-secondary degree, who have had type 2 diabetes for at least 5 years.

The research questions are: What is the role of information resources on diabetes in the lives of retired women with type 2 diabetes? How do they search for, encounter, and navigate (or avoid) information about diabetes and diabetes self-management, especially as they have already been managing their diabetes for several years?

The main themes are the source preferences of my participants due to experience with the source, comfort and rapport with the source, accessibility and expected comprehensibility of the source, and the sources’ perceived reliability and authority. The participants used similar types of sources on diabetes information in similar ways, but had their own individual preferences on the specific sources they consulted and valued.

I chose to investigate this topic because type 2 diabetes runs in my family, so I have seen some of this information acquisition process and was interested in exploring it in more depth.

## LITERATURE REVIEW

The topic of diabetes is moderately discussed in information behaviour literature. Beth St. Jean conducted a leading study in this field and discusses the different findings in her dissertation “Information Behaviour of People Diagnosed with a Chronic Serious Health Condition: A Longitudinal Study” (2012) and several articles including, “Factors Impacting Information Seeking and Use by People with

Type 2 Diabetes: A Call to Work Toward Preventing, Identifying, and Addressing Incognizance” (2017). She interviewed 32 diabetics over 18 within a year of their diagnosis or an exacerbation, and followed up 4-6 months later (18 Info.).

Interested in how diabetics’ information searching changes over time (86), St. Jean referenced work on the impact of coping with a diagnosis on attitudes towards information, moving from initial avoidance to active seeking (70-79). She additionally found that participants decreased diabetes information seeking over time (187), experienced ‘incognizance’ where they had been unaware of an information need at the right time (196), both sought and encountered information, and focused on information that would help them “engage in health behaviours” (196).

My study could build on her findings, as participants are further from their diagnosis and have had time to develop a basis of knowledge around their condition and its management, which may influence their information habits.

“Turning to Peers: Integrating Understanding of the Self, the Condition, and Others’ Experiences in Making Sense of Complex Chronic Conditions” (Aisling O’Kane et al 2016) investigates information behaviour of people with migraines and diabetes, especially the role of online and interpersonal peer sources (477). Thematic analysis of interviews and online communities found participants explore information about what is common for the symptoms and lifestyle management of their condition to validate their own experiences (483) because symptoms and management techniques vary widely (486). Seeking and understanding information takes significant effort due the process of combining “large, varied sets of information” — and barriers to comprehend and access medical information (494).



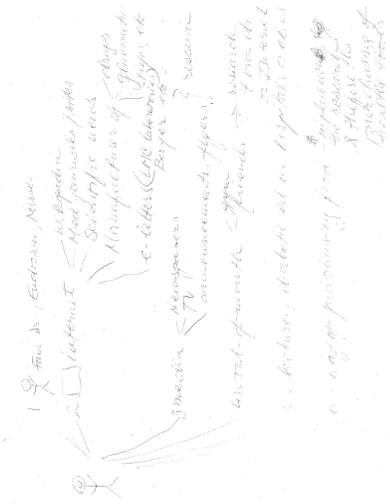


Figure 3: IHI Map from Neo (Participant 2), who ranks her sources by most reliable and most often consulted.

Figure 4: Source Type Table

Type	Source	M 3	N 2	T 1
Body		+	+	+
	A1C & Glucose Measures	+	+	+
	Logs		+	
	Feelings	+		+
Experts		+	+	+
	GP	+	+	+
	Endocrinologist		+	+
	Diabetes Nurse		+	+

	Registered Dietician	+	+	
	Alternative Doctor			+
Places		+	+	+
	Bookstore, Library, & Little Free Library			+
	Diabetes Clinic			+
	Health Centre	+		
	Hospital		+	
	Gym		+	+
	Synagogue		+	
Peers		+	+	+
	Friends With Diabetes	+	+	+
	Specific Friend Group		+	+
	Family	+	+	+
	"Networking"/strangers			+
Groups		+	+	+
	Diabetes Conference			+
	Diabetes Education	+		
	Healthy Kitchen	+		
	Gym Class		+	+
	Research Study		+	
	Diabetes Group		+	
	Canadian School of Natural Nutrition Webinars			+
Media		+	+	+
	Radio			+
	TV		+	+
	Newspapers & Magazines		+	+

	Fliers, Pamphlets, & Posters	+	+	+
	Cookbooks for Diabetics	+		+
	Nutrition Books on Diabetes			+
Online		+	+	+
Subscriptions:		+	+	+
	Newspapers & Magazines	+		+
	Diabetes Canada	+		+
	Manufacturer Newsletter		+	
	Pulse Canada	+		
Unsubscribed:		+	+	+
	Medical Journals	+	+	+
	Manufacturer Websites		+	
	Wikipedia	+	+	+
	Mayo Clinic	+		+
	WebMD	+		
	Forums, Comments, Advice Columns & Blogs (peers)	+		+
	Canadian School of Natural Nutrition Online Library			+
	Recipes	+	+	+

This table demonstrates my participants' unique source preferences and use of similar source types for diabetes and management information. Participants all subscribe to an online source, and return to certain online and physical sources. Participants used peers and groups as sources. Specific physical locations are used for seeking, browsing, and encountering. The body is an important source of information. All participants use medical experts as a resource.

Yet each participant has individual source preferences, influenced by direct experience, educational background, perceived reliability, and comprehension. The particular sources where participants described the rationale of their preferences were: nurses, doctors, medical journals, and the internet.

Nurses are a favourite source for two participants. Neo participates in clinical trials, and prefers the trial nurse she sees once a month because of her personal connection and “professional” information. This combination of qualities holds true for Trinity who talks about “everything” with her diabetes clinic nurse every 6 months, and has constant access on the phone. The most comfortable source for Morpheus however was the dietician for the same reasons.

Doctors were less personable and accessible, but trusted as a higher authority — if supported by experience. Neo described her doctor as “a fountain of knowledge.” Morpheus also deferred to her doctor as first source she would check on a health issue, and where she would confirm information from all other sources. When Trinity experienced complications from a medication and felt disregarded by her doctor and specialists, she perceived them as necessary, specialized, yet limited sources whose personalities and biases became barriers to information.

Medical journals were a favourite source for Neo, who found her economics background lent to complete comfort with technical language. Morpheus found her psychology background useful in understanding abstracts, but would go no further as she felt her cognitive ability was not as strong as it used to be. Trinity has a background in nutrition, and avoids sources that are “too scientific” in their language.

Participants felt the internet held a lot of information of inconsistent quality, so they often returned to sources they felt they could trust. Wikipedia was a typical starting place to see if a search was worth pursuing further. Participants used other, more reliable sources to confirm an online search. For Morpheus this was her doctor, for Neo her doctor and medical journals, and for Trinity her two diabetes nutrition reference “bibles.” Participants also browsed trusted sources online for new information. This involved subscribing to email newsletters and repeatedly checking sources for new information.

## DISCUSSION

All participants described information encountering as part of their diabetes information habits. They were attuned to advertisements, news, and conversations with peers for new and possibly relevant diabetes information. All three participants mentioned they would read an article they came across that mentioned diabetes. At least in terms of diabetes information, my participants had the “tendency to stop and ‘collect’ useful or interesting information they bump in to” (26 Erdelez). Erdelez would characterize my participants as

“super-encounterers” because they are conscious of and value this habit, and involve encountered information in their other information processes (28). Trinity in particular belongs to a group of friends that encounter books on topics they knew would interest another, and exchange these books with regularity.

Two of my participants described information grounds as part of their information acquisition experiences. Neo was surprised to find that attending exercise classes at the gym facilitated the exchange of diabetes information with other women. Trinity found she acquired information about diabetes and health at her two gyms as well. The gym is an information ground because unlike diabetes education classes and conferences, the purpose for gathering is to exercise, which is “a purpose other than information sharing” (187 Fisher).

Participants described different kinds of information avoidance. Morpheus ignores information on protein powder and foods with artificial sweeteners because she believes artificial foods are unhealthy, aligning with the tendency “to seek information that is congruent with their prior knowledge, beliefs, and opinions” (Case 354). Trinity avoids information about “the extreme side effects of diabetes” due to fear, which fits with the rejection response to an extreme threat (Case 355) and chooses not to investigate or fill many prescriptions from her doctor, because of her “direct experience” (Case 357). Neo describes being confronted repeatedly with information on the importance of weight loss and exercise for diabetes by family, but rejecting the information, aligning with the description of “self efficacy” inhibiting information seeking due to “beliefs about their own ability to carry out effective responses” (355).

Participants differed from the research from O’Kane et al because peers were seen as an inconsistent source that needed to be confirmed by other more reliable sources, although encountering information from peers could begin a search.

None of my participants currently used the diabetes support programs O’Kane investigates. Neo stopped attending when she discovered the internet. Morpheus found them valuable initially, but no longer. Trinity dismissed them as “outdated.”

All of my participants stated clearly that there was not any information they wished they had known earlier, unlike in St. Jean’s research on incognizance.

Because my participants dismissed support groups, yet all discussed the challenges finding helpful information on diabetes, there may be space for a library-hosted mentoring system where diabetics share seeking strategies, facilitated by a librarian.

Further research could investigate different demographics of diabetics, at a more specific distance of time from diagnosis, or other chronic health conditions.

## **METHODOLOGICAL REFLECTIONS**

During the graphical elicitation my participants forgot sources they mentioned in the interview and had to be heavily prompted to recall the seeking process again. Sources were left out and topics that were not information related were included. In particular, my first participant initially drew a map of her emotional state before she could begin searching for information, and did not include sources until prompted. My second participant went on a tangent regarding the impact of finances on grocery shopping while drawing her map.

The ethical issue I encountered was how to re-direct participants while they were obviously emotionally invested in telling a tangential personal narrative during the interview.

Perhaps the method could be improved by including the map earlier in the interview, with the participants adding to it as they move through questions, and by including a designated space for more contextual factors on larger paper.

## **CONCLUSION**

I began this study uncertain whether or not my participants would still be actively searching for information on diabetes and diabetes management after so many years, and because Beth St. Jean found in her study that information seeking seemed to decrease over time. I expected that most of the information my participants would mention would be found by encountering or casually browsing news and social media. I could not have been more wrong.

These findings show that information seeking about diabetes and about managing diabetes is a process that, like the condition itself, is chronic. “How do I manage my diabetes?” is an evolving query in an ongoing cycle of Berrypicking, where the information need is never resolved (Marcia Bates 1998). I chose not to use Bates’ model for analysis because I wanted to explore more of the motivation and source preference aspects that were brought up in the interviews. However, it absolutely applies — if the model was tying itself in knots, rather than a non-linear forward progression.

My participants became tired of certain sources, and became frustrated and developed distrust with some — but they never stopped searching. They return to many sources constantly and follow newsletters and new developments in the field. When I asked what motivated a search, my final participant replied “most days around 1 o’clock.” I do not know if the demographic of my participants particularly lent to more active information behaviour than the general population, but the “red thread” of diabetes information is heavily woven into the tapestry of these women’s daily lives.

Yet, surprisingly only one participant mentioned using libraries. Neo found libraries to be outdated, and Morpheus found them inaccessible. Perhaps libraries can become a better resource or information ground for diabetes

information as this area of health information behaviour is investigated more thoroughly, and other researchers continue to build on St. Jean and O’Kane’s research. Chronic conditions affect many potential library patrons, and learning how to serve them more effectively is always a worthy goal.

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## AUTHOR’S BIO

Kieran McGarry is a student at the University of Toronto Faculty of Information in the Library and Information Science and the Critical Information Policy Concentrations. Her areas of interest are in disability, women’s, queer, and literature studies. She volunteers with the Hart House Library.

## APPENDIX 1

Interview Guide:

1. Hello, how are you today?
2. Thank you for participating. As you may know, I am a graduate student under the direction of Professor Jenna Hartel at the Faculty of Information, University of Toronto. For a course on information behaviour, I am conducting a research study to better understand the health information seeking of people with diabetes. I have recruited subjects to participate in an "information horizon interview" which will take approximately 30 to 45 minutes. Your participation in this study is voluntary. If you choose not to participate or to withdraw from the study at any time, there will be no penalty. During the research process, your responses will be audio recorded. The audio recording will be transcribed within one week and then destroyed. Your name and all identifying information will be removed from the transcript, which will be kept indefinitely and used for the purposes of a class assignment. The results of the research may be published, but your name will not be used. *Please note, you do not need to be specific about your medication and treatment plans.* If you have any questions concerning this research study, you may email me or Professor Hartel. I am giving you a copy of this ethical statement for your records with the emails on it.
3. I am going to be asking you some questions about the information you look for regarding health, wellness, nutrition, and diabetes. This is a semi-structured interview, which means that my questions are all supposed to get you to talk about your experience. If you feel that I’m missing something feel free to add it, and if you have any questions or something isn’t clear, ask away. Near the end of the interview I will ask you to do a simple drawing of what is called an “information horizons map.” So we’ll get started whenever you’re ready, I’ll hit record.
4. [Grand Tour Q] So tell me about when you were diagnosed with Diabetes? How did the diagnosis change your daily life?
5. [Mini Tour Q] Can you tell me about a more recent change in health or lifestyle that prompted information seeking? (eg. diet, fitness, medication, a new technology) What information did you look for first? Can you take me through the process?

6. Do you usually look for information about changes in your health, lifestyle, or treatment? Is there a typical system for searching, some resources or several that you come back to?
7. When are you motivated to search for health, nutrition, or diabetes information?
8. What do you feel are some of the most helpful sources of information about diabetes or diabetes management?
9. What resources for health information are you the most comfortable accessing?
10. Do you have friends or a social circle with whom you discuss health, nutrition, or diabetes?
11. Have you ever encountered some useful information about health or diabetes that you were not actively searching for? What was it and where did you encounter it?
12. Can you tell me about some information you learned that changed your mind about something health, nutrition, fitness, or diabetes related?
13. Is there some information about diabetes or health that you disagree with? (eg. misinformation)
14. How do you respond or react when you see this information? Whether interpersonally, online, or social media?
15. Have you utilized any workshops, support groups, or online forums for people with diabetes or other common health concerns?
16. Have you actively monitored new discoveries or information about diabetes since your diagnosis? Why? (If yes, how have you done this?)
17. How do you assess a health or nutrition resource? Are there things you look for to assure accuracy and trust or comfort? Are there elements that would cause you to move on or disregard a resource?
18. Do you follow any internet pages or blogs about diabetes, health, nutrition, or fitness?
19. Was there information you wish you had known earlier? How did you discover it? When do you wish you had known it?
20. Is there some new diabetes or health information you discovered lately? How and where did you find it? Were you looking for it at the time? Did you share it with others?
21. Do others approach you with unsolicited information about health, nutrition, or diabetes?
22. Do you keep any reference sources with information related to diabetes or health in general? (eg a diabetes-specific cookbook, fitness guide, a bookmarked webpage etc) How useful do you find them or how often do you utilize these sources (if you use them)?
23. Finally, what information sources and seeking processes would you recommend for someone who has recently been diagnosed with diabetes so they can learn to manage their diabetes?
24. Now, I am going to ask you to draw your “information horizons map.” The first thing is to put yourself on the

paper, and then draw in the information resources you use when searching for health, nutrition, and diabetes information. You can show how you might begin and move through a search, or how you did move through a search you did recently, and tell me about it as you’re drawing it.

25. “so what happens next?” & probe!

## APPENDIX 2

[So what sorts of resources were you looking at?]

Trinity: Well, first of all, the almighty, deadly internet. That’s always the first search engine. Then that leads you to books and speakers and there’s always lots of magazine articles and health journals. And I have a background in nutrition so I will always go back to my old resources, a certain author for example that’s written a textbook about a certain health topic. I have my own little medical library. So just going through different searches from internet to books to library to magazines to the odd newspaper article sometimes introduces you to a new theory or a new author, talking to people.

[So, the specialist changed your mind, but also the resources you were looking at were also challenging what your original doctor had told you?]

Trinity: My endocrinologist was just focused on bringing my numbers down diabetically. The ear-throat-nose specialist became concerned about my thyroid. The diabetes is always there, but every specialty just always focuses on the organ or the area of your body that they want to heal or keep under control. Likewise, going to the dentist, if you have systemic problems with diabetes that causes problems with the dentist, then they’re only concerned about your teeth and your gums, and don’t really understand the ramifications of your meds. they all kinda work in isolation of each other, not really understanding how they’re all connected. And most medical doctors don’t really understand like the whole connection between mind body spirit, in healing. I would make the connections. But the doctors don’t. It’s a battle of sorts.

[Have you actively monitored new discoveries or information about diabetes since your diagnosis?]

Neo: Yes. All the time. So first it was through professional journals, then professional websites, then via manufacturers like Bayer, or Otho, manufacturerers always news, and again going back to the endocrinologist. Also family doctor, I do my yearly checkups. And believe it or not even with my cancer treatment I opted for a trial. So I am a guinea pig for science.

[When you started the new trial, can you take me through your process of looking for info?]

Neo:…then generally I think in my case I’m attuned to news, TV or internet or print, what else is being discovered, what else is being tried. Oh you hear about an insulin pump, and then you read who does that apply for? Does that apply for

me? Maybe that would be more of a hindrance than a help, and so on. So you again is a lot to learn, and as a layperson, even an educated layperson it is complicated and to research requires more and more and more education.

[When are you motivated to search for health, nutrition, or diabetes information?]

Morpheus: Many afternoons around 1pm.

[Was there a place on the internet that you started your search?]

Morpheus: I like sites like WebMD and The Mayo Clinic which is a very respected hospital in New York State. I looked at their websites and they were very useful. I went to my doctor several times, yay for OHIP in Ontario because there wasn't really any second thoughts about going until the problem was solved.

APPENDIX 3

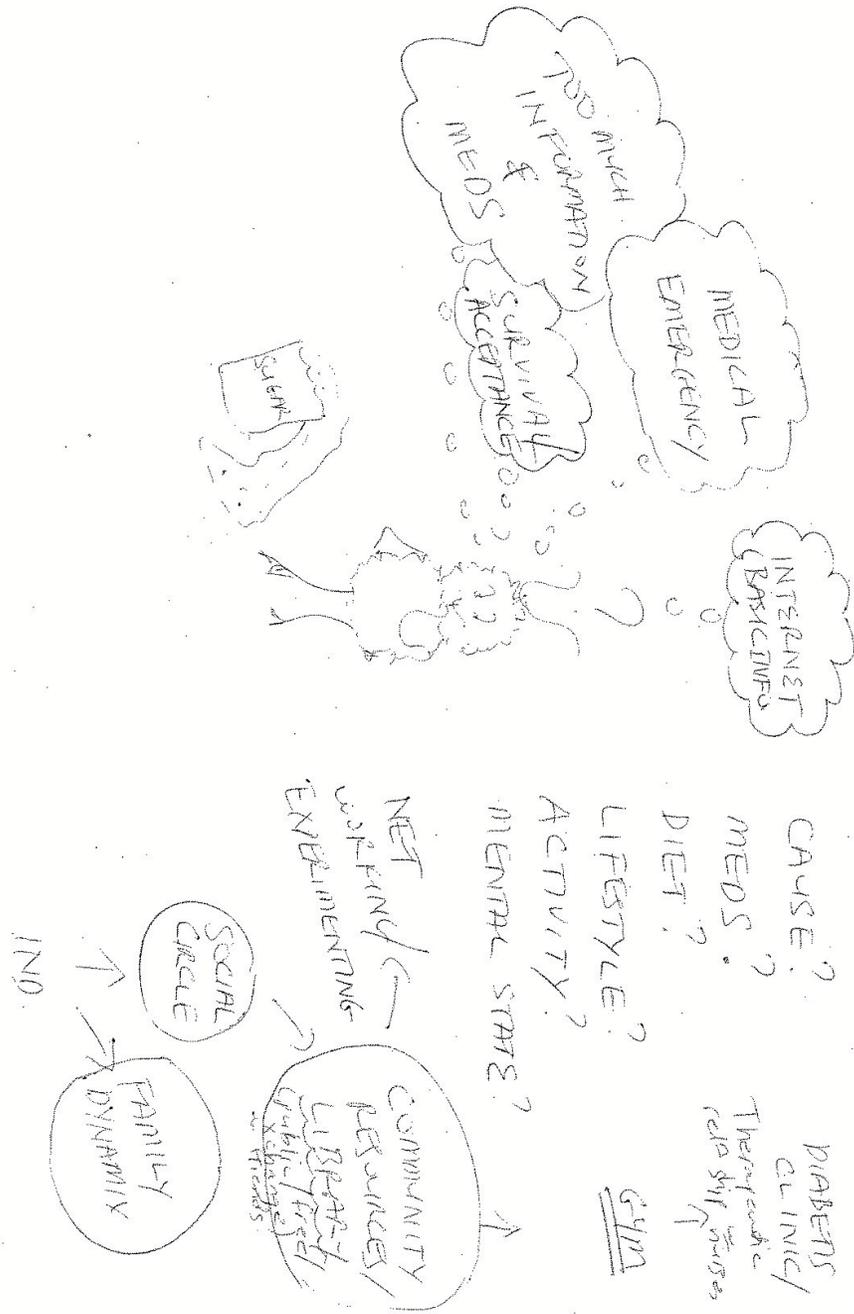


Figure 1

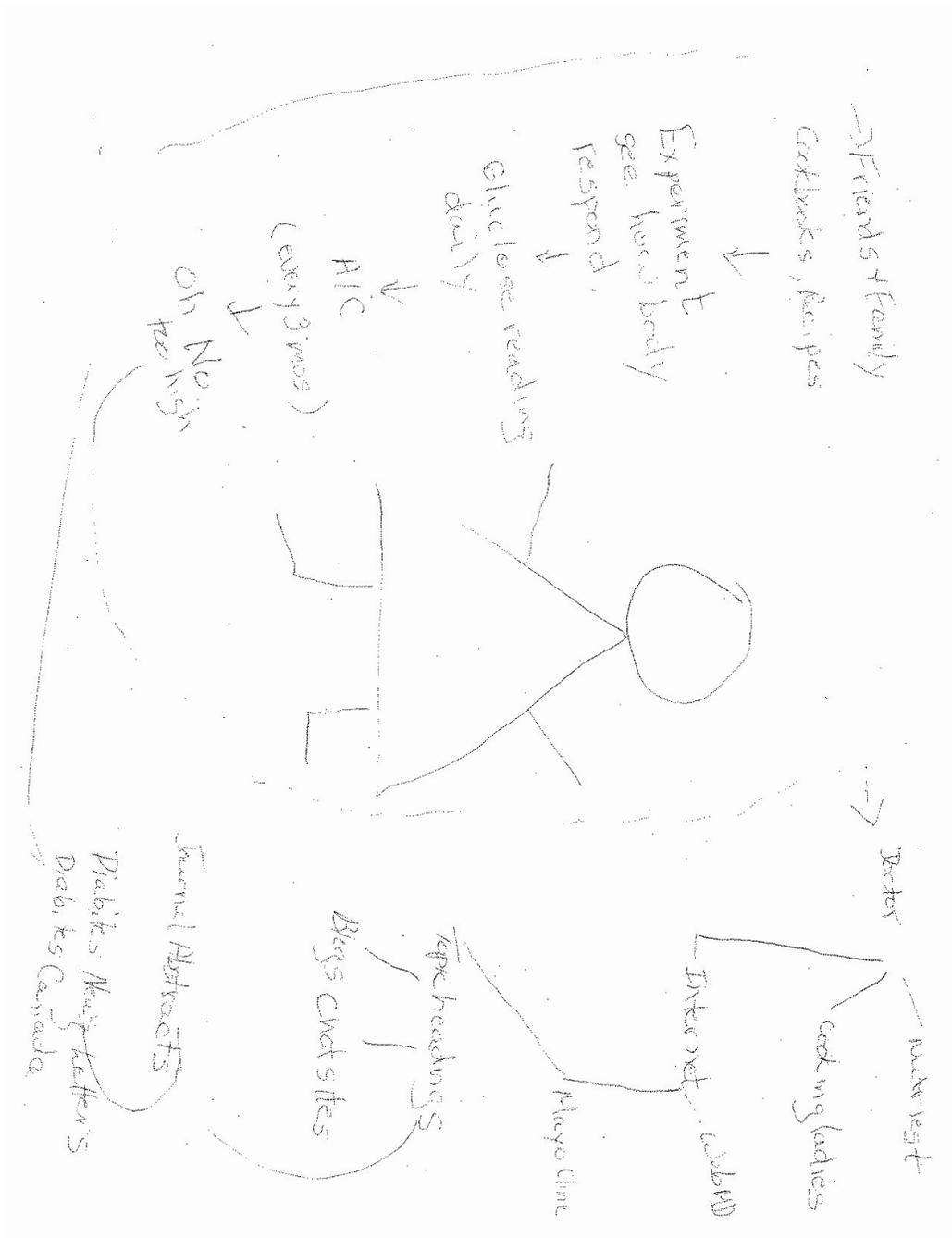


Figure 2

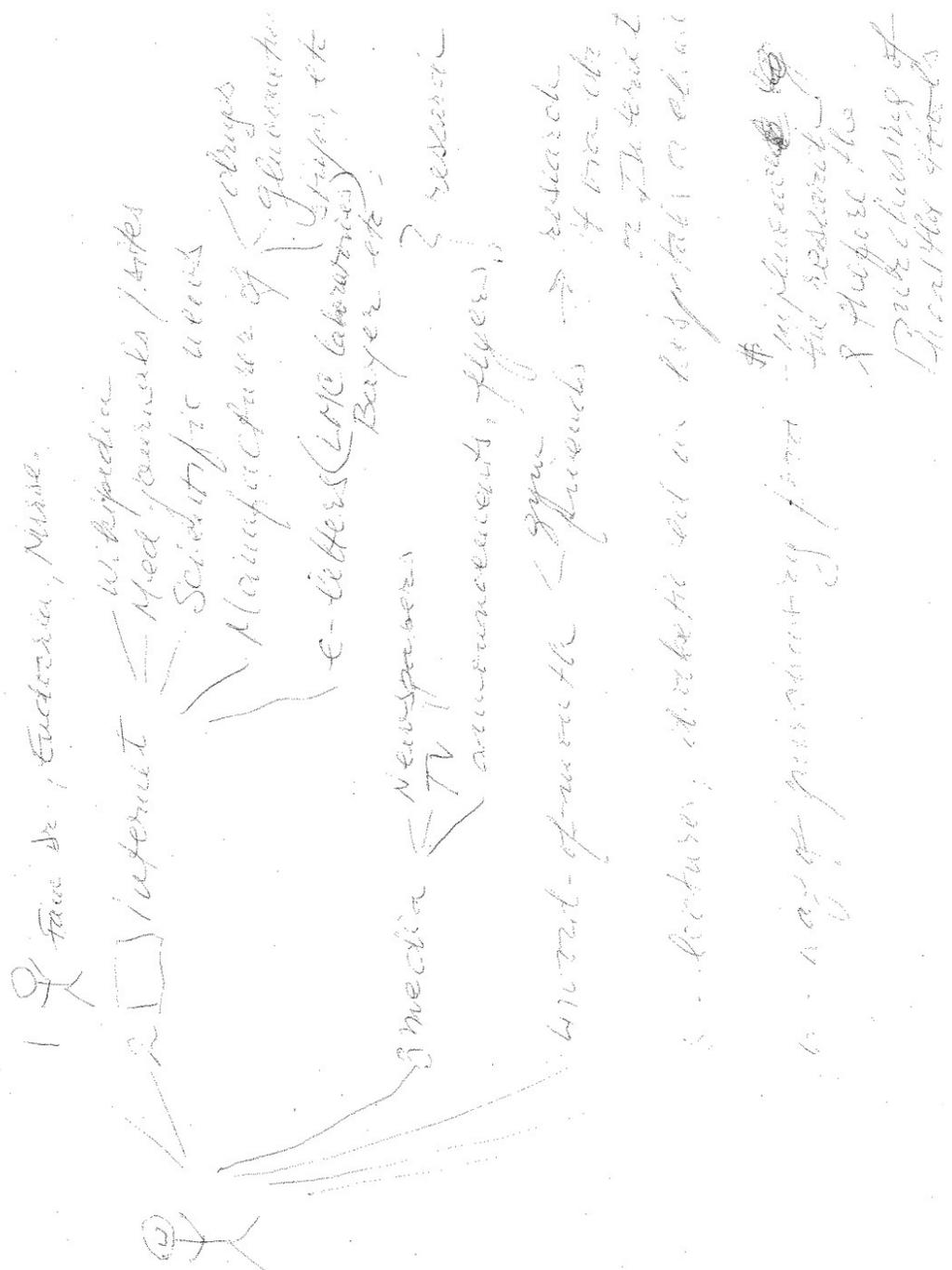


Figure 3