Monitoring Factors that Affect Chronic Illness Symptoms Will Starling

A Thesis Presented to the Central Magnet Faculty

In Partial Fulfillment of the Requirements of Graduation

May 2022

Abstract

This research and product aimed to better quality of life for people with chronic illness and accelerate the rate of chronic illness research. An online app was created to monitor patients and their individual environments, and various data were gathered about factors that may influence patients' health. The collected data are simplified and presented to the user so that he or she can reflect on wellness patterns and make better health-related decisions. A survey was done to collect information on commonly shared symptoms of chronic illnesses and possible health influencers in order to better serve the needs of patients in the app.

Dedicated to my mother, DeAnn Starling, who inspired me to create this
product; as well as all who experience chronic illness. May there be
hope that one day there will be a cure for chronic illness.

Acknowledgements

Thank you to...

My field-of-study advisor, Dr. Emily Hines, for helping me decide on the medium to build my app and giving me development tips

My mentor, Mr. Ryan Hughes, for industrial insight on my product and modeling what life as a computer scientists and app developer looks like

My English teacher, Dr. Laura Roland, for guiding me along the thesis-writing process

My family, who endlessly advocates for me and supports me

Everyone else who has made me the person I am today

Table of Contents

Table of Lists/Figures	vii
Additional Items	viii
Chapter 1: INTRODUCTION	1
Problem Statement	1
Problem Relevancy	1
Chapter 2: REVIEW OF LITERATURE	4
Defining Chronic Illness	4
Factors and Demographics of Health	4
Self-care, Self-management, & the Pandemic	6
Chapter 3: DESGIN DEVELOPMENT, RESULTS, AND DISCUSSION	9
Section 1: Conceptual Design Process	9
The Need for the App	9
Understanding Patients' Needs and Struggles: A Survey	10
App Content and Functionality	10
App Release and Development	14
Section 2: Preliminary Product Design	15
The Survey	15
Survey Creation, Response Usage, and Drawbacks	15
Survey Results	16
The Powers and Limitations of App Lab	18
Section 3: Final Design	19
Chapter 4: CONCLUSION	24

Study Summary	24
Limitations	
Implications	
Suggestions for Future Study	25
References	27
Appendix A	30

Table of Lists/Figures

Figure 1	12
Figure 2	13
Figure 3	14
Chart 1	16
Chart 2	17
Chart 3	18
Figure 4	20
Figure 5	20
Figure 6	23

Additional Items

Link to app: bit.ly/wsthesisapp

Link to survey: bit.ly/wsthesissurvey

Link to all survey results: bit.ly/wsthesissurveyresults

Chapter 1: INTRODUCTION

Problem Statement

Chronically ill patients have symptoms that change based on environmental and physical factors that go unnoticed which cause patients to not function optimally. Patients can monitor their symptoms and change their habits to avoid things that might unknowingly make them feel worse, improving their health. This self-care and self-awareness allow patients to be more productive and live a more normal life.

Problem Relevancy

According to the Centers of Disease Prevention and Control [CDC] (2021), Chronic diseases are conditions lasting one year or more which require ongoing medical attention or limit daily activities. They affect sixty percent of Americans, lead in causes of death and disability, and (along with mental health conditions) account for 90% of the nation's \$3.8 trillion in health care expenses.

Chronic illnesses are a costly and deadly problem. Two chronic illnesses, heart disease and stroke, kill almost 900,000 Americans every year – one third of all annual deaths in the country. Other common chronic conditions include but are not limited to cancer, diabetes, obesity, arthritis, Alzheimer's disease, and epilepsy (CDC, 2021). Americans with chronic illnesses compose 75% of the country's healthcare costs alone. Twenty-five percent of Medicare recipients have four or more chronic illnesses, accounting for two-thirds of its medical expenses (Coleman & Newton, 2005). Chronic illnesses also inhibit productivity for society since they limit patients' ability to work, indirectly hurting the country economically.

Most chronic diseases can be prevented by making healthy habits like sleeping enough, eating well, exercising frequently, avoiding tobacco and alcohol, and getting regular health screenings. Being prepared for emergency situations, disasters, and triggers can help manage illness (CDC, 2021). Self-management and self-care, as opposed to seeking treatment, is more important long-term because they are catered to more practical and emotional issues and less on finding a cure – after all, not many (if any) treatments exist for chronic illnesses. More practice of self-management improves quality of life – however, more research is needed on the subject (Coleman & Newton, 2005). One small five-year rheumatology study, however, found pain levels, coping/self-efficacy (belief in ability; outlook), and depression had an effect of determining patients' health: better outlook increased health ratings (Rahman et al, 2008). Furthermore, people with chronic illnesses are more susceptible to mental illnesses like depression, but treating both the chronic illness and caring for the patient's mental state seem to decrease effects of mental and physical illness (National Institute of Mental Health, 2021). That connection is why self-care and self-management strategies for people with chronic illness is necessary. It improves daily life physically and mentally for patients, even though there may not be a cure for their sickness.

Chronic illnesses often begin with complex causes and a long onset period between getting the illness and feeling its symptoms. These characteristics make research on the sicknesses difficult. Symptoms also vary greatly in severity and number, making the coping process different for each patient (Better Health Channel, 2020).

Some meteorological data correlate with changes in symptom severity of chronic illnesses, especially those with chronic fatigue syndrome, fibromyalgia, and rheumatoid

arthritis. Barometric pressure, humidity, and temperature sensitivity were the most significant data points (Bossema et al, 2013).

Because of the sheer complexity and variety of chronic illnesses and their symptoms and their toll on society, a new accessible system to track patients' health, physical, and environmental data must be created. Analysis from that platform should help them discover the best ways to self-manage their disease and symptoms.

Chapter 2: REVIEW OF LITERATURE

Defining Chronic Illness

In scholarly literature, the term "chronic disease" is an umbrella term that lacks a shared definition. The U.S. National Center for Health Statistics says it is a disease that lasts "three months or more." MedicineNet adds it "cannot be cured by medication," while the World Health Organization (WHO) argues it is a disease that is not "passed from person to person... [but is] of long duration and generally slow in progression." Some sources clearly omit certain diseases like asthma or fail to recognize that some diseases are so fatal that a patient would die before their illness is technically classified as a chronic illness (Bernell & Howard, 2016). Since some sources inherently have different definitions of what each illness is, some statistics and survey data may not entirely match up from source to source.

Factors and Demographics of Health

According to the CDC (2021), "public health can be affected by disruptions of physical, biological, and ecological systems, including disturbances originating here and elsewhere." The rate at which public health is affected can vary from person to person based on the demographics of each individual: "age, economic resources, and location" are important variables (CDC, 2021).

Young people are particularly under researched. One very small study (n=21), though, mentioned that young people have struggled with emotional support and mental health because of their change in image, ideas for their future, and relationships caused by "symptom unpredictability" and the diagnosis of a chronic illness as a kid (Kirk & Hinton, 2019). Young people have not fully developed physically and mentally to the

scale that older adults have, so the trauma from diagnosis and conforming to a new, restricting lifestyle may be much more detrimental than it might be to an older person. Thirty-three studies have noted at least one of several personal factors such as depression, anxiety, pain intensity, and "catastrophizing" (imagining a worse outcome than what would actually occur) and contextual factors like parenting characteristics were "consistently associated with higher levels of disability." All studies included children and adolescents with chronic pain (Sinclair et al, 2016).

Some chronic diseases affect older patients more. Arthritis, for example, affects twenty-five percent of adults; and Alzheimer's Disease is the fifth most common source of death among all adults over age sixty-five (CDC, 2021). Arthritis also seems to be worsened by changes in barometric pressure (Allaraka, 2021). However, barometric pressure also just changes how everyone's body functions: blood pressure drops causing dizziness and blurry vision, sinus headaches and pressure increase, blood sugar decreases causing fatigue, and joint pain increases from adjusting fluid near the joints when barometric pressure decreases (Kaplan Sinus Relief, 2020).

Climate change, extreme temperatures, water-borne or animal-born disease, allergens, wildfires, and floods are classified as natural or human-made stressors which could lead to detrimental health effects. From forcing relocation or injury to developing chronic illnesses like asthma or depression, environmental effects can harm people on a wide spectrum. The topic of the decreasing state of mental health of individuals in America has been increasingly popular in America. The impacts from climate change like higher temperature correlate with higher suicide rates; and after Hurricane Katrina, anxiety and post-traumatic stress disorder increased. In fact, patients with severe mental

illnesses like schizophrenia are at a much higher risk in hot weather because of complications from their medicines (CDC, 2021). Although people naturally have short-term negative responses to harsh and sudden environmental changes, the mental effects could continue or trigger worse physical conditions. Due to the unknown nature and cause of many chronic illnesses, that one stressful event could be the beginning of a much longer suffering from the development of a chronic illness/ more chronic illnesses.

Some patients believe that they have temperature sensitivity, causing more pain. Studies seem to conflict over whether this is related to climate or not. It seems as if more research needs to be done (Jamison et al, 1995). One large internet survey (n=2,600) of patients with fibromyalgia reported that eighty percent of patients said "weather changes" and "emotional distress" seemed to be the top two triggers of their disease (Dellwo, 2020). Few analyses from a different smaller survey with fibromyalgia patients (n=333), though, support that atmospheric pressure can contribute to more pain (Bossema et al, 2013).

Self-care, Self-management, & the Pandemic

"Self-care is a process of adaptation in response to learning about oneself and about ways to live well with illness. Developing capacity to self care impacted significantly on the way participants experienced illness, their view of themselves and of their future" (Kralik et al, 2010). Therefore, self-care for chronic illness is extremely relevant and important. Since symptoms, symptom severity, and factors that affect symptoms change from person to person or disease to disease, self-care allows people to manage their body and how they feel by treating their own individual symptoms. An app

that would track all of the personal, environmental, or physical factors and pain ratings of a patient quickly would inform patients on what to prioritize in their self-care practices.

As previously mentioned, natural disasters like Hurricane Katrina caused lots of stress, increasing the amount of illness in areas affected by the event. The recent pandemic is no exception to this scenario and affected a much greater population than any other disaster in decades. People were not only afraid of getting sick but also maintaining a livable income to buy necessities. Populations with a lower socioeconomic status suffered from chronic illness development and sickness from the pandemic at a greater proportion than people from other classes (CDC, 2021).

When people who showed COVID-19 (SARS-CoV-2) symptoms were told to stay home and everyone became stressed from adjusting to the new circumstances the disease brought, people tried to relieve stress by taking care of themselves. Staying home was especially critical for people with chronic illnesses because they are at significantly higher risk for severe illness and death from COVID-19. Modern Healthcare states that self-care may have led to more people discovering that they do have a chronic illness from taking time to focus on their own health and mental state. At the same time, people could not get out of their houses to go to a doctor and find out what is wrong with them or treat their newly developed yet preventable chronic illnesses (Johnson, 2021). Isolation from others during the pandemic contributed to increased mental health illness across the country, even though technology did help (Jonas, 2020).

When tracking factors like mood, patients can learn their health triggers. For example, a person with anxiety can learn which situations cause a panic attack, or people with chronic illness can see if stress can increase pain (Williams, 2018). After this data is

gathered, patients can develop coping mechanisms, avoid certain scenarios, or prepare for factors that may be out of their control. Becoming aware of triggers and taking charge of health through self-management can improve quality of life for many patients (Royal College of Nursing, 2021). Healthline recommends writing symptoms, diet, daily activities, and sleep schedules down, but there are so many factors and symptoms to be written down that journaling like this could be overwhelming (Cafasso, 2021). An app that does this for you would be convenient and save time for people with chronic fatigue who want to learn more about themselves, practice self-care more efficiently, and try to live a more normal life.

References

- Allaraka, S. (2021, March 5). How does barometric pressure affect humans?

 MedicineNet. Retrieved from
 https://www.medicinenet.com/how_does_barometric_pressure_affect_humans/art icle.htm
- Bernell, S. & Howard, S. (2016, August 2). Use your words carefully: What is a chronic disease? *Front Public Health*. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4969287/
- Better Health Channel. (2020, May 23). Chronic illness. Retrieved from https://www.betterhealth.vic.gov.au/health/healthyliving/chronic-illness Boomershine, C. (n.d.). RHEUMATOLOGY.
- Bossema, E., Middendorp, H., Jacobs, J., Bijlsma, J., & Geenen, R. (2013, June 4).

 Influence of weather on daily symptoms of pain and fatigue in female patients with fibromyalgia: A multilevel regression analysis. *Arthritis Care and Research*, 65(7), 1019-1025. https://onlinelibrary.wiley.com/doi/full/10.1002/acr.22008
- Cafasso, J. (2021, June). Fibro fatigue: Why it happens and how to manage it. *Healthline*.

 Retrieved from https://www.healthline.com/health/fibromyalgia/fibromyalgia-fatigue#management
- Centers for Disease Control and Prevention. (2021). Centers for Disease Control and Prevention Family of Sites. Retrieved from https://www.cdc.gov/
- Coleman, M. & Newton, K. (2005, October 15). Supporting self-management in patients with chronic illness. *American Family Physician*, 72(8), 1503-1510. https://www.aafp.org/afp/2005/1015/p1503.html

- Dellwo, A. (2020, March). The link between fibromyalgia & weather changes. *Verywell Health*. Retrieved from https://www.verywellhealth.com/fibromyalgia-and-weather-changes-4129576
- Jamison, R., Anderson, K., & Slater, M. (1995, May). Weather changes and pain: perceived influence of local climate on pain complaint in chronic pain patients. Pain, 61(2), 309-315.
 - https://www.sciencedirect.com/science/article/abs/pii/030439599400215Z
- Johnson, S. (2021, April 20). Chronic disease wave looms post-pandemic. *Modern Healthcare*. Retrieved from https://www.modernhealthcare.com/safety-quality/chronic-disease-wave-looms-post-pandemic
- Jonas, W. (2020, July 6). Self-care in a post-pandemic world. Retrieved from https://drwaynejonas.com/self-care-in-a-post-pandemic-world/
- Kaplan Sinus Relief. (2020, May 6). Low barometric pressure & fatigue. Retrieved from https://www.kaplansinusrelief.com/blog/low-barometric-pressure-fatigue/
- Kirk, S. & Hinton, D. (2019, January 16). "I'm not what I used to be": A qualitative study exploring how young people experience being diagnosed with a chronic illness. *Child: care, health and development*, 45(2), 216-226. https://onlinelibrary.wiley.com/doi/abs/10.1111/cch.12638
- Kralik, D., Price, K., & Telford, K. (2010, August 15). The meaning of self-care for people with chronic illness. *Journal of Nursing and Healthcare of Chronic Illness*, 2(3), 197-204. https://onlinelibrary.wiley.com/doi/full/10.1111/j.1752-9824.2010.01056.x

- National Institute of Mental Health. (2021). Chronic illness and mental health:

 Recognizing and treating depression. Retrieved from

 https://www.nimh.nih.gov/health/publications/chronic-illness-mental-health
- Rahman, A., Reed, E., Underwood, M., Shipley, M. E., & Omar, R.Z. (2008). Factors affecting self-efficacy and pain intensity in patients with chronic musculoskeletal pain seen in a specialist rheumatology pain clinic. *Oxford Academic*, 47(12), 1803-1808.
- https://academic.oup.com/rheumatology/article/47/12/1803/1786011?login=true
 Royal College of Nursing. (2021, August 14). Self care. Retrieved from
 https://www.rcn.org.uk/clinical-topics/public-health/self-care#:~:text=Self
- Sinclair, C., Meredith, P., Strong, J., & Feeney, R. (2016, May). Personal and contextual factors affecting the functional ability of children and adolescents with chronic pain. *Journal of Developmental & Behavioral Pediatrics*, 37(4), 327-342. https://journals.lww.com/jrnldbp/Abstract/2016/05000/Personal_and_Contextual_Factors Affecting the.9.aspx
- Williams, S. (2018, October 31). 3 Reasons to track your mood. *Serenity Mental Health Centers*. Retrieved from https://serenitymentalhealthcenters.com/

Appendix A

Chad Boomershine's Rheumatology Questionnaire

		ieasi	e com	piet								ease let us know.		
Name		_		_	Date	e of B	irth:		_/_	To	day's	Date:/ Phone#		
Yes		1y m	edical	, per	sona	l, ins	uranc	eory	work	inform	natio	n has changed.		
Have y	you been smok	ing c	regul	tes o	Ves.	ingr	No.	If V	NO_	_ If	es, n	ow many times per day? ek and minutes each time		
	u run out of m											ek and initiates each time		
	you taken your											/hy not?		
lave y	you seen any of	her	docto	rorv	visite	d a h	ospita	al/em	erge	ncy ro	om si	ince your last visit? Yes No		
lave y	you taken ANY	medi	ication	ns or	any	other	subs	tance	s fro	m fan	nily, fr	riends or off the street? Yes No		
rema	ale, could you t	ecor	me pr	egna	intry	es	_ No		Yes,	give	oirth o	control method:		
Vhat	problems do yo	u wa	ant ad	dres	sed t	oday	?							
irectic o 10, w	ons: For each ques where 0 indicates	tlon, no pre	circle t	he nu	umber 0 indi	that I	est in a total	dicate ly disa	s how	much proble	of a pr m.	roblem each symptom is CURRENTLY on a scale		
1.	FATIGUE: Hov		ch of	a pro	oblen	n is F	ATIGU	JE or	FEELI	NG T	RED?			
	NO PROBLEM		1	2	3	4	5	6	7	8	9	10 TOTALLY DISBLING PROBLEM		
2.	FOG: How mu	ch o	f a pro	bler	n is T	HINK	ING,	MEM	ORY	and/o	r CON	CENTRATION?		
	NO PROBLEM	0	1	2	3	4	5	6	7	8	9	10 TOTALLY DISBLING PROBLEM		
3.	FUNCTION: H	ow n	nuch c	of a p	roble	em is	perfo	ormin	g you	r dail	y ACT	IVITIES (dressing, bathing, walking)?		
	NO PROBLEM		1	2	3	4	5	6	7	8	9	10 TOTALLY DISBLING PROBLEM		
4.	INSOMNIA 1:	How	much	ofa	pro	blem	is FAI	LLING	ASLE	EP?				
	NO PROBLEM		1	2	3	4	5	6	7	8	9	10 TOTALLY DISBLING PROBLEM		
5.	INSOMNIA 2:	How	much	of a	prol	blem	is STA	AYING	ASLI	FFP?		To the state of th		
	NO PROBLEM		1	2	3	4	5	6	7	8	9	10 TOTALLY DISBLING PROBLEM		
6	INSOMNIA 3:													
٥.	NO PROBLEM		1	2	3									
7						4	5	6	7	8	9	10 TOTALLY DISBLING PROBLEM		
/.	BLUES 1: How													
	NO PROBLEM		1	2	3	4	5	6	7	8	9	10 TOTALLY DISBLING PROBLEM		
8.	BLUES 2: How	muc	h of a	prol	blem	is AN	XIET	or F	EELIN	IG NE	RVOU	95?		
	NO PROBLEM	0	1	2	3	4	5	6	7	8	9	10 TOTALLY DISBLING PROBLEM		
9.	RIGIDITY: How	mu	ch of a	pro	blem	is ST	IFFN	ESS IN	MU	SCLES	and/	or JOINTS?		
	NO PROBLEM	0	1	2	3	4	5	6	7	8	9	10 TOTALLY DISBLING PROBLEM		
10.	OUCH!: How m	nuch	of a p	robl	em is	PAIN	1?							
	NO PROBLEM	0	1	2	3	4	5	6	7	8	9	10 TOTALLY DISBLING PROBLEM		
fice U	SE ONLY: Wt		_ B/P_			P		Res	p		_02_	T FPS :		
edicat	tions:					Dor	a lact	GH ₂ -1						
					_	_Dat	e last	filled	-		# Remaining # Remaining			
	V.				1	Dat	o last	filled	_		_	# Kernalning		