Health literacy in Toronto: Applying the TOFHLA to Identify the Gap between
Physician and Patient

by

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COMMITTEE APPROVAL

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Abstract

This study takes a modern approach applying the TOFHLA to Torontonians in order to identify some of the contributing factors impacting the physician-patient divide.

The TOFHLA questionnaire with added customized pre-screening questions was administered to 100 participants who were directly approached, further using a snowball sampling method.

The Test of Functional Health Literacy Assessment (TOFHLA) is used to assess a patient's level of comprehension of health-related material. The TOFHLA was validated by researchers Baker and Parker et al. in two separate studies in 1995 and 1999.

This study has proven that age, gender, and English as a first or second language has no effect on health literacy level (P>0.05), education (P=0.024) was the main variable involved with positive health literacy levels. This study has successfully outlined areas of improvement such as, patient experience and engagement which influences recovery time.

        Keywords: TOFHLA, health literacy, snowball sampling, health communication, health education, healthcare

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Health literacy levels amongst patients are one of the main predictors for patients having successful health outcomes. Rootman and Ronson (2005) suggest health literacy impacts health both directly and indirectly. Patients put their health at risk when they do not understand prescriptions, as well as health related instructions. Furthermore, people with lower health literacy levels tend to work in an unhealthy environment, with less insurance benefits. This is a negative spiral that hopefully can be stopped with educating patients from a healthcare standpoint prior to discharging them.

The focus of this research is to identify ways to improve physician-patient interactions, ultimately influencing the patient's experience, care, and recovery times. This study is particularly interested in health literacy of both residents (English as a first language) and new immigrants (English as a second language) in Toronto. My study has identified the divide in terms of understanding and communication between physician-patient, as well as the barriers being independent from language, age, and gender.

Literature Review

Health literacy is defined as the social and cognitive skills required by an individual to obtain and educate themselves on the encompassing material in order to maintain good health ("WHO", 2015). Health literacy is often overlooked as a soft skill, or as a concept that is up to the ill individuals to figure out for themselves. Health literacy is also defined by the National Academy of Sciences (2004) as much more than just a measurement of reading skills. It includes writing, listening and speaking alongside conceptual knowledge. It is the degree to which a person is able to both absorb and process very basic information and services available to them to make responsible decisions for their own health. This also accounts for the many times that

individuals encounter things they cannot understand, even from well educated people needing doctor's instructions regarding a drug or process.

The term health literacy is the most contested because of its many definitions, as well as constantly changing definitions. As Chin (2011) further emphasizes there is no universally agreed definition of the concept- as it encompasses so many dynamics of health and literacy. However, the typical formulation used is the "capacity of an individual to obtain, interpret and understand basic health information and services in ways that are health-enhancing" (p.61).

Health literacy is typically defined as the social and cognitive skills required by an individual to obtain and educate themselves on the encompassing material in order to maintain good health. The way in which the WHO (2015) had defined health literacy allows for it to identify and address the environmental and social factors that also influence health. Health education is comprehensive influences much more than just lifestyle decisions, but interaction, participation and critical analysis. This definition arose from two contributing authors and three articles by Nutbeam and Kickbusch in 1998 and 2000 respectively, but more importantly this definition was a product of a WHO conference and preparatory meeting on health promotion in May 11th, 2009 ("WHO", 2015). The definition of health literacy for the scope of my research that was used is by Duell et al. (2015), a trait that one must be able to access, understand, and critically use the information that they are given and available to them in order to autonomously make their own efficient and informed healthcare decisions. Health literacy is typically overlooked as a soft skill, or as a concept that is up to the ill individuals to figure out for themselves. O'Sullivan (2002) states that the literacy issue roots down to the everyday jobs these patients have, literacy is not adequately addressed and many patients are very poorly equipped to

deal with information even in day to day tasks- healthcare aside. Health literacy has moved from a substantially less important focus, to a collaborative effort between the healthcare system, the physician, and the patient.

Functional health literacy is defined as possessing the skills in both reading and writing to cope with everyday situations; this is often used in conjunction with being health literate as per the WHO definition used above. Furthermore, the higher the level of health communication or health literacy a person may possess is typically accompanied by having advanced cognitive skills along with social skills that can be used to analyze more complicated information. Theseskillscan be used in even more complex daily situations (Nutbeam, 2000, pp. 263-264).

Literacy research findings prove that over half of American adults lack the necessary skills to regularly use printed materials for basic everyday tasks. It is difficult to evaluate an individual's skills in relation to the healthcare systems demands for their patients (Nouri et al., 2015, p.566) Wallston et al., (2013) begins to suggest that over a third of adults in the United States currently have sub-par understanding of health literacy. Wallston et al., (2013) defines health literacy as a difficultly understanding one's condition, less adherence to medication, increased chance of death and higher overall healthcare costs- this can be avoided with formally educating patients on healthcare and their condition. Having a poor understanding of health literacy leads to less adherence to following medications, self care begins to decrease, mortality rate increases, and there begins to be an influx of high healthcare costs for all as it creates a negative cycle. Schillinger et al. (2003) article states, it is not known how frequently physicians are actively intervening and trying to make their patients more health literate. Furthermore, the article questions whether health literacy is even truly associated with improved health outcomes.

Rootman and Ronson (2005) also further explain some of the most common misconceptions within the field ofhealth literacy. One of the misconceptions their research had identified is that health literacy is an issue that doesn't affect more developed countries- if you can read you are exempt, and it more predominantly affects uneducated people. Nutbeam (2008) further emphasized the concept and phenomenon of recognizing health literacy and health status. The recent interest in this relationship is what sparked the concept of health literacy, with roots within both clinical care and public health. Nutbeam (2008) suggests in this article that more general strategies to promote literacy, numeracy, and general language skills in varying populations are needed. Furthermore, how poor literacy skills also are very common amongst even the most developed countries. Surprisingly, throughout many of the studies in the literature review- education and literacy played an even bigger role in health literacy that hypothesized. Paasche-Orlow et al. (2005) suggested those who were more educated and thus literate, actually took their health matters into their own hands and altered recommendations from their physician. Conversely, those who were less literate and educated viewed their physician's recommendations as much more powerful, and were more likely to abide by their directions. A adequate sense of health literacy would be best defined by the ability to critically and appropriately assess your care providers recommendations.

The pursuit of both improvement and understanding of health literacy is to promote better health outcomes for all patients. Understanding the root causes of physician-patient miscommunication, poor understanding, and embarrassment typically associated with health issues is the primary point of improvement. Putting health literacy in public focus as well as making it part of the standard of care a patient receives and is entitled to can make a huge

difference. Educating physicians, as well as trying to revolutionize the healthcare system are key

ways to make health literacy a problem of the past. The funding and resources are currently in

place at many institutions, however their methods of delivery are seriously lacking.

The scholarly discussions of health literacy- specifically within the healthcare system

regarding patient discharge, and physician-patient interactions have picked up quite

exponentially over the last decade as Duggan (2007) had noted. The last decade had set

foundations, and acknowledged the issue. Currently, proactivity and action is required in order

to bridge the gaps. Lyles et al. (2015), mentioned that with the integration of technology into the

healthcare system, it is almost impossible for the healthcare system to not be tailored to suit the

many and ever changing needs of patients within the very same system. Furthermore, as Jensen

et al. (2010) has noted, individuals with low health literacy were much less likely to be

resourceful and use technology to access health information elsewhere. Understanding the

scientific aspect of health literacy, and the populations that are affected will allow improvements

to be made to the current system.

Impact

To further emphasize this dilemma, the majority of healthcare providers are oblivious to

the fact that this problem exists, and education systems are not set up or equipped to begin

providing health literacy education on top of regular academic education. Health literacy

statistics should be tracked, monitored, and should be part of an instiutional system which would

allow for the data collection to have high accuracy and reliability for future research.

The majority of health related issues arising from inadequate health literacy allow for

information-seeking behaviors and proactivity from patients to be lost in translation. Without a

doubt, the most crucial component to maximizing health literacy and well-being begins at the

health care provider level. The greater tier and level of sophistication health professionals

possess in the field, the more promising the results are for those patients who have sub-adequate

or at risk health literacy levels (Marks, 2009, pp.329-330).

Carolan (2007) discusses the current relevant rhetoric and how it aims at quantity of

information as the solution to the problem. The greater information outputted, the better the

results. Time and time again studies have proven that information only cannot help patients

understand. Throwing information at the public without the crucial link of comprehension will

not allow for autonomous health care choices to be made. The information that is available

should not be a temporary solution but building upon a long term understanding and retention of

health related information. Furthermore, Carolan also found that there was a large identified

difference between what healthcare professionals believe the patient needs, and what the patient

actually requires and is looking for. Individualized information is much more valued and

effective when used on patients from a health care professional's perspective (Carolan, 2007,

pp.1163-1164). Omachi et al., (2012), emphasized Wallston's et al., (2013) perspective by

suggesting formal education in general leads to higher and better healthcare outcomes. Formal

education opens up better housing and lifestyle opportunities which, in turn leads to better health.

If knowledge and education can lead to better understanding, it can pave a way to improving

health knowledge by their newly acquired ability to steer through the healthcare system.

Study Parameters

As Omachi et al. (2012) and Wallston et al. (2013) were mainly concerned with the

impact of education, overall healthcare status, and the ability to learn. Morris et al., (2013)

looked into how to measure this type of health literacy and its following impacts on overall

health, and quality of care. When we speak of education, it encompasses much more than the

standard association of going to school, being a learned individual, or having a degree. Education,

for the scope of this research is a combination of academic as well as experienced-based skills

and life experiences that cannot be taught. For this study, the impact of health literacy, screening

of individuals, as well as health results were analyzed. This population all had health insurance,

and were categorized in terms of high and low health literacy. This categorization allowed them

to monitor any differences in results or outcomes that can be attributed to another variable; this

may have crucial implications in terms of their prevention methods and screening methods

within the hospital. If the study can accurately identify the vulnerable population at hand, the

hospital and healthcare system in general will be able to use this data to pinpoint and customize

delivery for this vulnerable population. Lindquist et al. (2011), brings an additional perspective

to the previous argument of making people health literate except in terms of admission and

discharge events. Furthermore, Lindquist et al. suggests one of the primary contributors to health

literacy issues is age; many of the health literacy errors are due to medication labels, omissions,

duplications, and dosing errors. The study goes on to suggest that many of these errors are

avoided in the younger populations due to health literacy, education, but also the access to

information that the younger population has over the older population. Silver (2001) mentioned

that a very high percentage of seniors have sub-adequate levels of health literacy. With internet

usage on the rise and readily available via electronic devices, it should be used as a tool in order

to digest health related information pertaining to them. This is a tool that is seldom used by baby

boomers, in comparison to their younger counterparts. Furthermore, the lack of health literacy

and its effects on readmission are strongly correlated. The older population's health literacy is also biased due to their pre-existing beliefs, as well as sociodemographics, and hard-hitting side effects of the medications they already may be on. However, a notable conclusion to the study is that adults with a good health literacy and understanding were less likely to adhere to medications and instructions as their less literate counterparts who listened and abided out of fear of not understanding.

Gallant (2015), suggests the main predictor of health literacy is the ability to self-manage after acquiring a diagnosis and prescriptions to take care of themselves. Surprisingly, Gallant had concluded that higher literacy led to higher rates of improvement in health; lower literacy rates did not appear to yield any findings. These results are more in line with the majority of the current relevant research in the field, if the health literacy rates are high, health outcome is more positively influenced, but if they are low- there is no noticeable difference. Berkman et al. (2011) had examined the costs encompassing health literacy as a nation. As data from these studies is gathered a formal health literacy audit needs to take place. This audit would include and review, how low or high health literacy is related to how the healthcare system is used, what costs are incurred, as well as considering how literacy effects the health outcomes for people of all ages from such a wide demographic.

Language competency is a major component in having a functional health literacy level. The results of my study have indicated that there is no statistical difference between native and not native English speakers when adequate levels of education are factored. The current rhetoric constantly suggests otherwise, as a lesser understanding with the native language itself would only lead to an inadequate level of health literacy at a comprehension level. Competence, the

ability to understand and make use of the information being absorbed is a crucial component that is often overlooked within many studies, as English being the second language is the only predictor (Nutbeam, 2008, p.2077). Competence and higher levels of education of a non native English speaker trump the health literacy level of participants that are native English speakers. Therefore, it wouldn't be effective to single out and magnify a weaker quality a participant may possess and conclude that they have inadequate levels of health literacy.

As the discussion leads from theory to practice, this analysis will closely examine the surrounding issues in creating and achieving health literacy strategy moving forward as a nation. Marks (2009) further suggest that reducing these complications and broken links in the patient-physician communication, lead to motivated and positively influenced patients, wanting to learn and contribute to their health betterment. Furthermore, more real-world applications are needed to be implemented in order for better practices to be absorbed by both physician and patients alike. Health professionals need to be more aware and appropriately trained in delivering tailored care to their patients needs, allowing the patients to take part in the decision-making process involving their health (p.331). We must acknowledge health literacy is a major issue and it is much more than sharing and understanding information but in depth analysis from the bottom up on a major system that takes care of the needs of individuals in this nation ("WHO", 2015).

Methods

TOFHLA

The TOFHLA (Test of Functioning Health Literacy in Adults) is used to measure functional health literacy and comprehension. It draws from and uses health-related materials

such as; prescription labels and appointment papers. It is designed to assess adult literacy in the

health care setting. For health care providers and researchers, to determine the adequacy of their

patients' reading and understanding of health care materials needed for their health care (Nurss et

al., 2001).

Within the TOFHLA survey package Baker et al. 1995) suggests that administering the

TOFHLA allows the researcher to examine a patient's level of understanding health related

material. The TOFHLA used was the full format test, which included 50 reading comprehension

questions as well as 17 numeracy related items. The full TOFHLA is timed and is expected to

take 22 minutes to complete. The correct answers are scored a "1", incorrect scores are "0". The

reading comprehension scores are the sum of individual scores, whereas the numeracy scores are

the weighted (multiplied by 3) sum of individual scores. The TOFHLA is divided into three

categories of functional literacy: inadequate (0–59), adequate (60-74) and functional (75-100)

(Aguirre et al., 2005, p.333).

The area in which these questionnaires were distributed was locally within the city of

Toronto, questioning the general population with surveys in order to gather a general consensus

of health literacy outside healthcare systems. Local areas in downtown Toronto were selected not

only because it is close to home, but also because the biggest hospitals and healthcare institutions

are within the core, and they are the easiest to get to. Baker's et al. (1995) successful study used

a similarly detailed questionnaire approach with the TOFHLA test for both English and Spanish

speaking patients, with an approximate cohort of 500 persons, spanning two institutions for the

study.

The participants that were approached in low risk, low anxiety situations in which spare time is evident, and visible distress or uninterested levels for the participants are at a low- so the intrusiveness of my study was very minimal. For the purpose of my research study 100 participants were recruited in order to get a manageable sample size. Furthermore, as long as the participants were over 18, they were able to participate in my study. They were continuously reminded of the fact that the study is fully voluntary and they have the right to withdraw at anytime. The data was recorded using a survey and questionnaire in order to fulfill the quantitative approach as well as a brief verbal interview with pre-written questions to fulfill the qualitative approach. The data is stored both on hardcopy paper and notes as well as audio/visual recordings that can be used for further analysis. The analysis of the data is mainly quantitative, but also an in-depth qualitative analysis regarding the power dynamic needs to be accounted for, even as a separate portion of the survey from the beginning. Furthermore, Baker et al. (1995) suggested that the survey that was used was a reliable indicator of health literacy measurement within the population and that it revealed a major portion of the population cannot perform basic reading tasks. Some of the rudimentary questions that were asked, with a word box provided were; "you must have a **blank** stomach when you come for **blank,** the doctor has sent you to have your **blank** x-ray". The questions were setup as the order of events would occur in a regular health setting, pre-visit, visit, and post-visit duties for the patient. The categorization of the results are mainly focused on three main categories; health literate, not health literate, and moderate health literacy (Lindquist et al, 2011, pp.173-174).

Health literacy is typically defined into three categories within relevant literature as well as within the TOFHLA itself. These categories are: adequate, marginal, and inadequate levels of

health literacy. Furthermore, when comparing adequate to marginal health literacy levels in Table 2, the data is insignificant. The participant pool, which was split between 47 female, and 53 male participants included n=82 adequate, n=14 marginal, and n=4 inadequate health literacy results. Interestingly, of the 82 participants who scored adequate, 12 of the participants were barely adequate (scoring just above the marginal level). This changes the overall figure to roughly 30 participants or 30 percent of the sample size who falls in the significance level of Table 2- when comparing adequate to marginal health literacy levels. These "borderline" adequate and marginal scores are what allow the statistical analysis to conclude that the categories should be more strictly divided, as a marginal health literacy level may easily sway in either direction.

Baker et al. (1995) had incorporated a post-positivist critical perspective in order to address the issue of health literacy surrounding him. Applying a critical approach to the standard discovery paradigm not only suggests thinking outside the box as a researcher but also can truly provide unique results. Through the use of heavy statistical analysis of the data in order to tell how representative the results are as well as identify the outliers is a crucial component to this study.

Participant Recruitment

Opportunity sampling was used to gather (n=100) participants from public areas such as coffee shops, local businesses, and public libraries. Interested participants were given the research package to be completed, contact information was provided before and after in order to ensure all and any questions that arose were answered. Consent was obtained personally both verbally and via signature from the participants after fully explaining the study in detail. All

sampling was done within downtown Toronto during 9am-5pm on weekends, and 5pm-7pm

during weeknights. This was done to guarantee a vast array of participants that span the health

literacy scale from a variety of backgrounds. Snowball sampling was also used in conjunction

with the haphazard approach when recruiting more participants After the participants had

completed the survey, they were asked to refer a friend or colleague if possible and convenient to

participate in my research study. The research objectives were obtained and analyzed through the

completion and use of the TOFHLA questionnaire that was generally distributed within this

sample size. Culture was specifically excluded as this would have been a separate research

project on its own. It allowed for a baseline of health literacy levels in Toronto to be obtained on

a strict budget but as well as pinpoint areas that would need much further investigation such as

culture.

  After submitting this research idea for ethical review, clearance from the Royal Roads

University Ethical Board as well as Royal Roads University institutional approval was obtained

on November 25th, 2015 in order for me to include participants in my research.

Data Gathering and Analysis

  The data is composed of the TOFHLA questionnaire with added customized questions

(pre-TOFHLA worksheet) that is more tailored to my research. The questionnaire is preceded by

informed consent, as well as a pre-TOFHLA worksheet, following all ethical guidelines. The

TOFHLA has been purchased in order to use for my research interests. License number 102/15

issued on September 16th ,2015. Included within the purchase price, are the rights to reproduce

the questionnaire as needed, as well as use the specified data extraction techniques and marking

schemes on the collected data. The data was analyzed through SPSS (2013) statistical software-

in order to compare the variables influencing health literacy as well as overall TOFHLA score.

Findings

The trends and relationships within the data gathered were analyzed by using SPSS (2013)

statistical software. The dependant variable used was TOFHLA score, in which age, gender, self-

rated health proficiency and exposure, as well as education were compared against each other.

One-way ANOVAs were conducted in order to identify the difference between participant

groups as seen in Tables 1-3. One-way ANOVAs were conducted and to determine whether

participants differed in their TOFHLA score based on their education level, gender, first

language and health literacy level. This analysis revealed a significant positive effect on

TOFHLA score for higher levels of education completed $F(2,97) = 3.884$, $p = 0.024$ and for

health literacy level $F(2,97) = 22.373$, $p < 0.001$. No significant effects were observed for gender

or whether English was a first or second language, as significance levels were 0.837 and 0.161

respectively.

Table 1: One-way analysis of the effect of education on the overall TOFHLA score.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	1607.409	2	803.704	3.884	.024
Within Groups	20074.301	97	206.952		
Total	21681.710	99			

Table 2: One-way analysis of the effect of gender on the overall TOFHLA score.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	9.410	1	9.410	.043	.837
Within Groups	21672.300	98	221.146		
Total	21681.710	99			

Table 3: One-way analysis of the effect of English as a first or second language on the overall TOFHLA score.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	431.604	1	431.604	1.990	.161
Within Groups	21250.106	98	216.838		
Total	21681.710	99			

When conducting the post hoc Tukey and Bonferroni tests, the highest level of significance between groups TOFHLA scores was seen when the analysis compared participants with the highest level of education completed as high-school to university level of TOFHLA scores, the mean difference was the most statistically significant. This is seen in Table 4 at 9.609 or when comparing 0 to 2. Education and literacy are key components to better and sustainable health. Without one or the other, the health and perseverance of an individual in the system is limited (Kickbusch, 2001, pp.289-291).

Table 4: Post Hoc Tukey and Bonferroni tests, relationship between highest level of education completed and TOFHLA score. Dependant variable: TOFHLA Score.

Education 0: high school 1: college 2: university	(I)	(J)	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Tukey HSD	0	1	-6.471	4.954	.395	-18.26	5.32
		2	-9.609*	3.451	.018	-17.82	-1.40
	1	0	6.471	4.954	.395	-5.32	18.26
		2	-3.138	4.382	.755	-13.57	7.29
	2	0	9.609*	3.451	.018	1.40	17.82
		1	3.138	4.382	.755	-7.29	13.57
Bonferroni	0	1	-6.471	4.954	.584	-18.54	5.60
		2	-9.609*	3.451	.019	-18.02	-1.20
	1	0	6.471	4.954	.584	-5.60	18.54
		2	-3.138	4.382	1.00	-13.81	7.54
	2	0	9.609*	3.451	.019	1.20	18.02
		1	3.138	4.382	1.00	-7.54	13.81

*. The mean difference is significant at the 0.05 level.

Interestingly, when performing the post hoc Tukey and Bonferroni tests between participants with inadequate (0), marginal (1), and adequate (2) scores, the significance between these groups of interest was quite surprising (See Table 5). When comparing inadequate (0) to adequate (2) health literacy levels, the data is highly significant as one would expect with $p<0.05$. Surprisingly, when comparing adequate (2) to marginal (1) health literacy levels, the data is insignificant using both the Tukey and Bonferonni analysis' with significance rates at 0.988 and 1.000 respectively, which are greater than p0.05.

Table 5: Post Hoc Tukey and Bonferroni tests, relationship between health literacy level and TOFHLA score. Dependant variable: TOFHLA Score

Health Literacy Level			Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
(I)		(J)				Lower Bound	Upper Bound
0: inadequate 1: marginal 2: adequate							
Tukey HSD	0	1	-42.425*	6.486	.000	-57.86	-26.99
		2	-42.054*	6.401	.000	-57.29	-26.82
	1	0	42.425*	6.486	.000	26.99	57.86
		2	.371	2.560	.988	-5.72	6.47
	2	0	42.054*	6.401	.000	26.82	57.29
		1	-.371	2.560	.988	-6.47	5.72
Bonferroni	0	1	-42.425*	6.486	.000	-58.23	-26.62
		2	-42.054*	6.401	.000	-57.65	-26.46
	1	0	42.425*	6.486	.000	26.62	58.23
		2	.371	2.560	1.000	-5.87	6.61
	2	0	42.054*	6.401	.000	26.46	57.65
		1	-.371	2.560	1.000	-6.61	5.87

*. The mean difference is significant at the 0.05 level.

A hierarchical regression analysis was conducted in Table 6 to determine how education and health literacy level predicted the total TOFHLA score, after controlling for the influence of age and gender. The demographic variables were entered into step 1 of the analysis, and the education and health literacy into step 2. For the regression analysis, the total model was significant, $R^2 = 0.169$, $F(4,95) = 4.83$, $p = 0.001$. The predictors of TOFHLA score were higher education level (Beta = 0.298, $t(95) = 2.89$, $p = 0.005$) and higher health literacy level (Beta = 0.279, $t(95) = 2.923$, $p = 0.004$).

Table 6: A hierarchical regression analysis of age, gender, and education's overall effects on the total TOFHLA score.

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.052ᵃ	.003	-.018	14.930	.003	.132	2	97	.876
2	.411ᵇ	.169	.134	13.771	.166	9.512	2	95	.000

a. Predictors: (Constant), Age, Sex

b. Predictors: (Constant), Age, Sex, Health Literacy Level, Education

c. Dependent Variable: TOFHLA Total Score

A hierarchical regression analysis was conducted in Table 7 to determine how education, health literacy level and whether English is a first or second language predicted the total TOFHLA score. The total model was significant, $R2 = 0.167$, $F(3,96) = 6.43$, $p = 0.001$, however English as a $1^{st}/2^{nd}$ language did not make the model significantly better $deltaR2 = 0.023$, $deltaF(3,96) = 2.599$, $p = 0.1$.

Table 7: Regression analysis of English as a 1st or 2nd language effects on TOFHLA total score.

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.293ᵃ	.086	.077	14.220	.086	9.225	1	98	.003
2	.381ᵇ	.145	.127	13.826	.059	6.663	1	97	.011
3	.409ᶜ	.167	.141	13.714	.023	2.599	1	96	.110

a. Predictors: (Constant), Health Literacy Level

b. Predictors: (Constant), Health Literacy Level, Education

c. Predictors: (Constant), Health Literacy Level, Education, English $1^{st}/2^{nd}$

d. Dependent Variable: TOFHLA Total Score

After controlling for age and gender, partial correlations revealed that TOFHLA score was positively correlated with health literacy level (r = 0.306, p = 0.002) and education (r = 0.303, p = 0.002). As seen in Table 8, the most interesting correlation or lack thereof was between the participants self-rated understanding and relevance (of health related items in their everyday life), and its correlation to the TOFHLA score. The results seem to yield a negative correlation (-0.44) with no significance (0.67) to the TOFHLA score, but significant (0.016) with a negative correlation (-0.244) when comparing understanding and relevance to health literacy level.

Table 8: Correlation analysis between self rated health proficiency and TOFHLA score after controlling for age and gender.

Control Variables			TOFHLA Score	Health Literacy Level	English 1st/2nd	Education	Understanding &Relevance
Gender & Age	TOFHLA Score	Correlation	1.000	.306	.135	.303	-.044
		Sig. (2-tailed)		.002	.186	.002	.670
		df	0	96	96	96	96
	Health Literacy Level	Correlation	.306	1.000	.013	.112	-.244
		Sig. (2-tailed)	.002		.899	.271	.016
		df	96	0	96	96	96
	English (1st/2nd)	Correlation	.135	.013	1.000	.109	.160
		Sig. (2-tailed)	.186	.899		.283	.115
		df	96	96	0	96	96
	Education	Correlation	.303	.112	.109	1.000	.231
		Sig. (2-tailed)	.002	.271	.283		.022
		df	96	96	96	0	96
	Understanding & Relevance	Correlation	-.044	-.244	.160	.231	1.000
		Sig. (2-tailed)	.670	.016	.115	.022	
		df	96	96	96	96	0

The qualitative data collected from this study was also quite interesting, with much more qualitative data than initially set out for. One participant when questioned with prompt 4 (see appendix) "if this were your score, would your blood sugar be normal today?", answered "sorry, I do not have diabetes". This response was obtained after a formal introduction to the research study, informed consent, as well as the pre-TOFHLA worksheet being completed. Not once did

this participant, nor any of the other (n=100) participants raise any concern to me during the

survey- which speaks volumes in terms of the stigma associated with not understanding or

having sub-adequate levels of health literacy Parikh et al. (1996) focused on throughout the

paper. Moreover, all the explanation and feedback has been very positive from the majority of

participants who filled out answers to the questions on the pre-TOFHLA worksheet. Some of the

responses that particularly stood out were "explained everything and ensured I understood",

"informative and thorough" (mentioned at least 8 times), and "professional, listened well,

suggestions were made but gave us a choice as to what to do. Well-outlined, professional offered

possible causes of any ailments described". However, for many of these participants as outlined

in the analysis' in the results, the TOFHLA scores didn't reflect this thorough understanding of

what was being presented to them. The participants much like the patients are reporting what

they believe is the right thing to say when discussing a health professional, typically a medical

doctor. The medical doctor explains the ailment or process involved in technical detail using

scientific jargon, unbeknownst to them, their patients do not digest the majority of this

information. The test of understanding is put upon health professionals for being more

informative and personalizing the prognosis. Furthermore, the patients must truly feel more

comfortable with their health situation. This involves understanding their diagnosis, as well as

prognosis- and the ability to use any tools available to them to make the process smoother. This

can be confirmed and reflected upon during a follow up visit or a pharmacist to run through once

again their understanding of the prescriptions and guidelines set out by the physician.

Discussion

The most important finding this research has produced is that education is the most statistically significant and highest predictor of health literacy success. As seen in Table 7, significance greatly increases when education is added to age and gender in relation to TOFHLA score. This echoes with Gazamararian's et al. (2006) study which suggests that, age and gender do not influence health literacy as much as education. This research has also found that age and gender is not statistically significant when referring to health literacy levels overall, whereas education and health regimen deemed to be extremely statistically significant (Gazmararian et al.,2006, p.1218). With the average TOFHLA score of 83.27 which is 9.27 points above marginal health literacy there is still much effort needed on both ends in order to ensure the population has an accurate grasp of health related information.

An interesting component within the statistical analysis was that in Table 8, understanding and relevance was statistically significant (0.016) in comparison to health literacy level. However, not statistically significant (0.67) when compared to TOFHLA score. Furthermore, in both cases, understanding and relevance was negatively correlated with both TOFHLA score and health literacy level at (-0.44) and (-0.244) respectively. Statistically speaking, this would suggest two things. Firstly, being exposed to health related information and events frequently decreases patients TOFHLA score and health literacy level due to being desensitized to the health related information. Secondly, the perceived exposure to health related information as well as its importance in the participant's everyday lives was overestimated on the participant's behalf. Therefore, when comparing their scores to their actual score it may present itself as the more they are exposed to this information, the less they actually know. A potentially

similar effect was touched upon in Carspecken's (2013) research with physicians in which, alerts on health systems and the high level of energy and focus used to tend to these alerts led to information fatigue. This decline in focus eventually led to physicians being desensitized to these prompts after a period of time and can lead to serious patient safety issues (p.1971). This may pose a similar risk in the participant population as continuous exposure to medications, and daily routines begin to interfere with newly obtained health information.

The current literature and data within the field is quite overloaded biased to American populations and study groups. This study hopes to not only examine the relationship between multicultural Canadians and their healthcare providers, but to also draw attention to this field from a multicultural Canadian level. Having more health literacy information and research on Canadians will help address and identify issues from a different perspective.

Future Research

As the research leads from proposal to practice, through deep analysis, and close monitoring, the health literacy dilemma which we are currently facing is being uncovered. Jordan et al., (2011) noted a key finding that the health literacy data being generated from the population to an individual level may not be as valid as many studies show. Furthermore, their research has shown that there is a great variation between how scoring and individuals are categorized in terms of heath literacy levels. There is also a clear absence of relevant policies and programs for addressing suboptimal health literacy. The roles healthcare providers contribute to health literacy in both health and education systems is crucial and we must understand the importance of our own health but also the further implications of accumulating health related costs nationally because of these issues. Engagement in scientific and health literacy is crucial in

moving forward, equipping the population with the ability to distinguish evidence from

explanations, and bridge gaps in reasoning. Grace further suggests that health literacy is

dependent on scientific literacy in order for people to navigate through their health issues. This

scientific knowledge should surpass those who study science to become scientists and doctors,

but to the general public as this knowledge affects them deeply (Grace et al., 2011, pp.4-6).

Culture as mentioned earlier is a much needed area of exploration within the health literacy field.

This would incorporate many other understandings of health literacy as well as health education

from a cultural perspective, this includes the more encompassing definition of education that

spans beyond academics. Improving these weak links will allow for greater consistency of

patient care, higher levels of patient recovery, as well as higher health literacy rates amongst the

population.

Challenges and Limitations

The main ethical challenge that was faced was the potential vulnerable populations that

were involved. This study had included new immigrants, those who English isn't their first

language, young (over 18 years of age) and older participants. These populations pose ethical

challenges as their fully informed consent needed to be verified, sometimes this would involve

further consultation. Another crucial ethical challenge is sampling these patients at times of dire

need, stress, and confusion. Though sampling participants in survey form is the most accurate to

real life situations, it is also the most delicate of situations. Surprisingly, there were no refusals

or drop outs when conducting this study.

The TOFHLA is much more sensitive than the lesser-known REALM (Rapid Estimate of

Adult Literacy in Medicine). This is possibly due to the TOFHLA detecting problems with

patient's health literacy level as it is picking up many more errors than the REALM. This was

emphasized in a study in which Canadian senior's health literacy did NOT decline with age,

whereas the decline was evident in the American populations (Rootman, 2003, p.405). Rootman

(2003) further suggests that there isn't much Canadian research to fall back onto for confirmation

or comparison, which is why any study using the TOFHLA on Canadian soil is much more

important as it is setting the standard in the field. Furthermore, there was a question in particular

regarding an American healthcare insurance provider that was equivalent to OHIP (Ontario

Health Insurance Plan) for residents of Toronto. This was difficult to administer without altering

the weighted design of the TOFHLA. Very limited amount of tools have been developed in order

to allow health literacy professionals to measure this subjective statistic in various settings

(Barber et al., 2009, pp.252-254). The TOFHLA remains quite a reliable instrument (α=0.98)

and is considered the standard instrument in the fields for measuring health literacy. However,

one of the main criticisms of the TOFHLA is that health literacy encompasses much more than

recognition, reading comprehension, and numeracy. This tool can be improved as it doesn't

account for language, culture, or anxiety and distress (Mancuso, 2009, pp.84-87).

A participant with a marginal health literacy score can be on the higher (adequate), or

lower (inadequate) end of the spectrum. This may suggest that the TOFHLA is better suited as

two categorical levels of health literacy; adequate and inadequate. Understanding the marginality

is there to protect the participant from being categorized as having totally inadequate levels of

health literacy, is ignoring the bigger problem of physicians not educating patients efficiently to

push them into an adequate group of health literacy. This will increase the ever-present stigma

associated with having poor health literacy, but may also increase physician and healthcare

professional intervention in order to break down those patient-physician barriers (Parikh et al., 1996, pp.33-34).

This study was limited to a small radius downtown Toronto. In order to get more sampling from other subdivisions and neighborhoods the budget would need to be greatly increased. These increased costs would also translate into getting the TOFHLA to be administered in English and in French, rather than the standard English and Spanish format. Moreover, a possible comparison between a few different health literacy tools of measurement- this would allow for the accuracy as well as precision to be finely tuned according to the sample group being researched. As with many of these health literacy research tools, this is reading and comprehension based. There is calculated deviation in the representative population as it is difficult to obtain true health literacy results as health literacy itself is directly influenced by reading comprehension. Furthermore, the inclusion of a cultural component would greatly increase the dynamics of this research and make it even more applicable to such a multicultural city. Culture would also bring many alternative perspectives on health and medicine in general. This study and tools of measurement were catered to western medicine. With the inclusion of a cultural component in future research, this would also incorporate the other various fields of medicine such as naturopathic and osteopathic medicine. This was one of the main limitations to this research and tool used is the confinement of participants and their health literacy levels based off of a western medicine system, which may or may not be applicable to them as individuals.

Conclusion

The goal of this study was to determine the level of health literacy of multicultural

Torontonians from a manageable sample size, as well as introducing research on the topic of

health literacy using Canadian data. Furthermore, to identify the problematic variables associated

with participants struggling with health literacy. By identifying common factors influencing

inadequate results, we can use this information to help educate patients as well as healthcare

providers for a win-win situation on both ends.

This study has shown that health literacy can affect anyone. The most crucial component

to overcoming this dilemma is having an educated population. Higher levels of education will

trump language, gender, and age across all statistically relevant fields. This study has

successfully outlined crucial areas for health care professionals to focus their efforts in bridging

the gap between patient and physician, through both interactions as well as care. The results of

this research study magnify the issues with the current system of educating patients as well as

preparing them for discharge.

Identifying that education is a crucial component in health literacy amongst patients will

allow physicians to begin to tailor the healthcare experience better for their patients. Introducing

a basic questionnaire while waiting within the clinic will allow the physician and staff to prepare

better for a patient who will have many questions and won't know how to ask them- or what to

ask. Furthermore, to invest more funding into patient education, as the majority of recovery and

efficacy happens within the confines of the patient's personal life. Smith and Pizzi (2003),

suggested that self-efficacy techniques, as well as educating patients, increases patient

confidence. This confidence in turn influences patient recovery and overall well-being. A well-

read and learned patient is a healthy patient.

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Appendix

TOFHLA WORKSHEET (Circle one)

1. Are you a male or female?

Male / Female

2. What is your age?

18-20 21-30 31-40 41-50 51-60 61-70 70+

3. Is English your first language?

YES / NO

4. What is the highest level of education completed?

   Prefer not to say / Elementary / High-School/ College / University

5. What is your exposure level to health related information? (prescriptions, medication labels, doctor's appointments, commercials and advertisements) (0= never, 10= daily)

0   1   2   3   4   5   6   7   8   9   10

6. Do you think health literacy is relevant in your life? (0= least relevant, 10= most relevant)

0   1   2   3   4   5   6   7   8   9   10

7. How would you describe your last encounter with a healthcare professional, point form is fine (**leave blank if N/A**):

Was the interaction balanced, well-defined, and informative?

Did you leave more confident and better understanding of your condition(s) in order to make better decisions regarding your health in the future?

Study: Health literacy: addressing the physician and patient divide

![Royal Roads University logo]

CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY
Study Title: Health literacy: addressing the physician and patient divide

Investigator/Supervisor: Nicholas Pasquale / Dr. Zhenyi Li

Contact Information:

(XXX) XXX-XXXX, ██████████████@royalroads.ca

(XXX) XXX-XXXX ext. XXXX, ███████@royalroads.ca

Introduction:

You are being asked to take part in a research study. Please read the information about the research study presented in this form. The form includes details on study's risks and benefits that you should know before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the Investigator to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends, and family. This thesis will be publically accessible. **Participation in this study is voluntary.**

Background/Purpose:

You are being asked to participate in this research study, this research is part of my Master of Arts in Professional Communication thesis project. The purpose of which is to collect your responses to the questionnaire

and analyze the data in order to determine the current health literacy dilemma within our city.

The goal of this study is to identify the health literacy problem we are currently facing within Toronto, as well as ways in which change can be implemented to help resolve this crisis. To understand how health communication can be improved between physicians and patients, begins at pinpointing sub-adequate levels of health literacy. If the extent of health literacy issues can be identified, we can begin working on a plan in order to increase health outcomes.

Procedures:

If you agree to take part in this study and sign this consent form, the questionnaire will take approximately 30 minutes of time. A number of various questions and scenarios will be asked, answer them to the best of your abilities.

Also as a part of this research study, we will collect some of your personal information such as your age, highest level of education completed, as well as if English is your first language.

Alternatives to Being in this Study:

This is a research questionnaire study only. You can choose NOT to have your answers collected or analyzed for this study. Your refusal to participate in this study will not affect your ability to participate in any other research study for which you might be considered.

<u>Risks of Participation:</u>

Questionnaire:

Taking the TOFHLA (Test of functioning Health Literacy in Adults) may cause some confusion and may result in being frustrated embarrassed. No names or personal identifiers are needed, this means that the researcher will not be able to tell which participants have high-

low health literacy, furthermore so the researchers will not be able to trace your responses and match it to an individual. If you have any questions about this, please ask the investigator. There also may be other privacy risks that are currently not foreseen.

Benefits:

There is no direct benefit to you from participating in this study. However, your participation in this study may benefit future patients in the health care system.

Voluntary Participation:

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now, and then change your mind later. You may leave the study at any time without affecting your care. We will give you any new information that is learned during the study that might affect your decision to stay in the study in a timely manner.

Confidentiality:

All samples collected on this study will be assigned a numerical code to protect your confidentiality.

Withdrawal from the Study:

After you sign this consent form, if you change your mind about this study, you can request for your answers to be located and destroyed immediately afterwards, after 24 hours it will become part of a data-set in which your answers and the answers of others cannot be separated.

Costs and Reimbursement:

You will not have to pay for any of the procedures or testing involved with this study. You will not be paid for taking part in this study.

Rights as a Participant:

By signing this form you do not give up any of your legal rights, you may withdraw from the study at anytime, and your participation is voluntary.

Conflict of Interest:

The investigator is currently a researcher at Princess Margaret Cancer Centre, however this should not affect your decision to take part in this particular study as it is for graduate thesis work.

Questions about the Study:

If you have any questions, concerns, think you have a study-related injury or would like to speak to the study team for any reason, please call: Nicholas Pasquale at (XXX) XXX XXXX.

You will be given a signed copy of this consent form.

Consent:

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to the use of my answers and information as described in this form. I agree to take part in this study.

_____   _____ _____

Print Study Participant's Name   Signature   Date

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person Obtaining Consent Signature Date

Was the participant assisted during the consent process? YES/NO

If **YES**, please check the relevant box and complete the signature space

below:

The person signing below acted as an interpreter for the participant during the

consent process and attests that the study as set out in this form was accurately interpreted and has had any questions answered.

_____   _____

Print Name of Interpreter   Signature

_____   _____

Relationship to Participant   Language

_____

Date

The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to, and has had any questions answered.

_____   _____

Print Name of Witness   Relationship to Participant

_____   _____

Signature   Date

Figure 1 has been removed from this page due to copyright restrictions. It was a copy of the first

portion of the survey used for this research study, TOFHLA English Version (12pt. font)-

Numeracy. Parker et al. (1995).

Figure 2 has been removed from this page due to copyright restrictions. It was a copy of the second portion of the survey used for this research study, TOFHLA English Version (12pt. font)-Numeracy, Prescription Bottle Labels and Prompts. Parker et al. (1995).

Figure 3: Regression scatterplot analysis of age, gender, and education's effects on TOFHLA score- refer to Table 6.
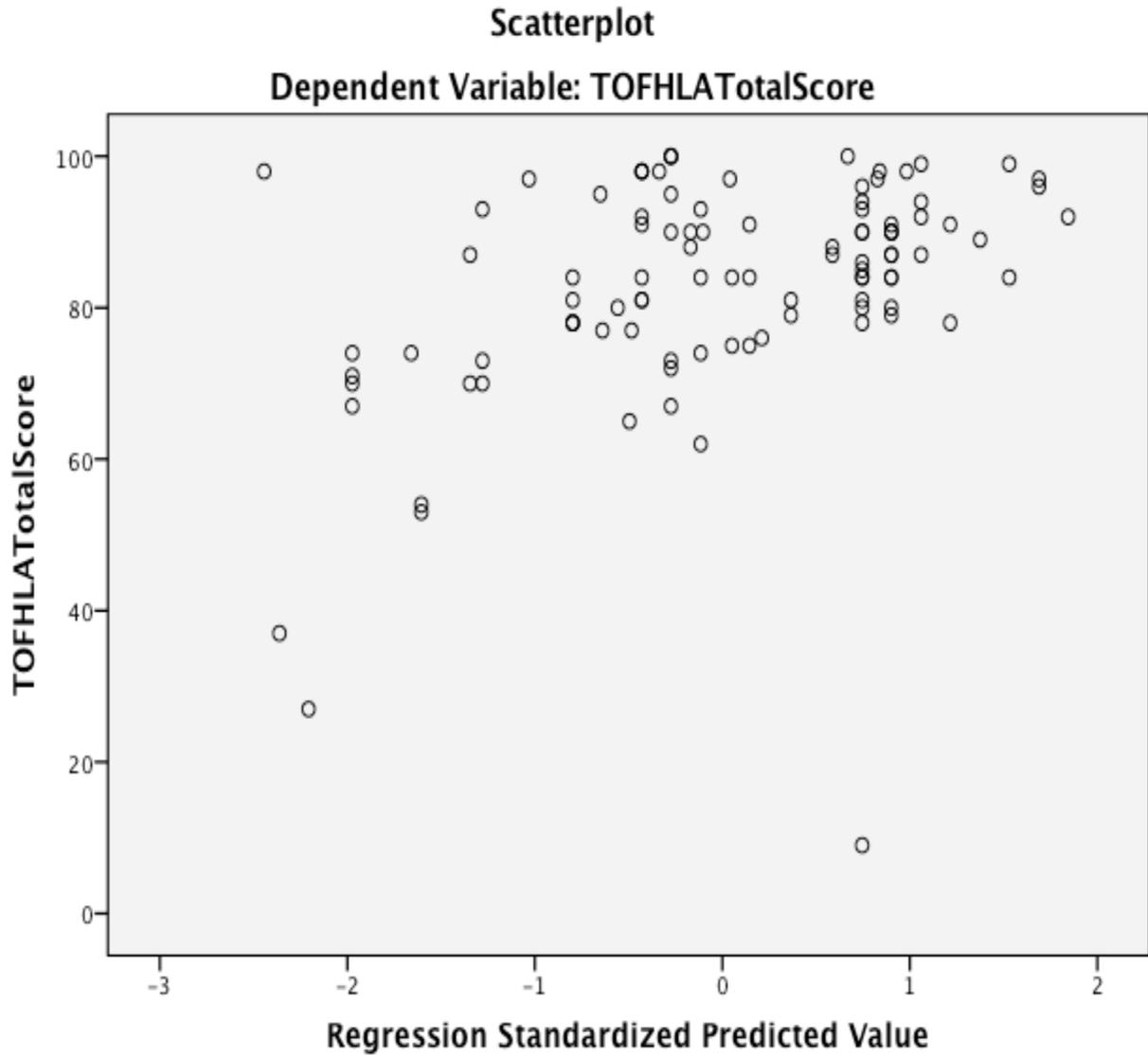
Figure 4: Regression scatterplot analysis of English as a 1st or 2nd language effects on TOFHLA - refer to Table 7.

Scatterplot
Dependent Variable: TOFHLATotalScore