Exploring the Utility of Patient Stories on Social Media for Healthcare Quality Improvement

by

Moutasem Zakkar

A thesis
presented to the University of Waterloo
in fulfillment of the
thesis requirement for the degree of
Doctor of Philosophy
in
Public Health and Health Systems

Waterloo, Ontario, Canada, 2020

Examining Committee Membership

The following served on the Examining Committee for this thesis. The decision of the Examining Committee is by majority vote.

External Examiner	Dr. Farah Ahmad Associate Professor, School of Health Policy and Management, York University
Supervisor(s)	Dr. Craig Janes Professor, School of Public Health and Health Systems University of Waterloo
	Dr. Samantha Meyer Associate Professor, School of Public Health and Health Systems University of Waterloo
Internal Member	Dr. Plinio Morita Assistant Professor, School of Public Health and Health Systems University of Waterloo
Internal-external Member	Dr. John McLevey Associate Professor, Department of Knowledge Integration University of Waterloo
Other Member(s)	Dr. Dan Lizotte Assistant Professor, Department of Computer Science Western University

Author's Declaration

This thesis consists of material all of which I authored or co-authored: see Statement of Contributions included in the thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Statement of Contributions

Moutasem Zakkar was the sole author for Chapters 1, 7, which were written under the supervision of Dr. Craig Janes and Dr. Samantha Meyer and were not written for publication.

This thesis consists in part of four manuscripts written for publication. Exceptions to sole authorship of material are as follows:

Research Presented in Chapters 3, 4, 5:

These chapters included three research studies that were conducted at the University of Waterloo by Moutasem Zakkar under the supervision of Dr. Craig Janes and Dr. Samantha Meyer.

Moutasem Zakkar designed the studies with consultations from Dr. Craig Janes and Dr. Samantha Meyer, who contributed to the papers by providing overall theoretical guidance and detailed suggestions on the papers' structure and writing.

Research Presented in Chapter 6:

This research was conducted at the University of Waterloo by Moutasem Zakkar under the supervision of Dr. Daniel Lizotte.

Moutasem Zakkar designed the study with consultations from Dr. Daniel Lizotte, who contributed to the paper by providing overall theoretical guidance and detailed suggestions on the paper's structure and writing.

Abstract

This thesis explores the phenomenon of patient stories on social media. This phenomenon represents the intersection of two phenomena: patient experience and social media. Healthcare experience refers to the interactions of a patient with the healthcare system members, including the nurses, physicians, and staff, and the resultant emotional and behavioural effects of these interactions on patients, including patient satisfaction, patient commitment to health, and patient adherence to treatment plans. Social media refers to the internet-based applications that enable people to communicate, interact, publish, and exchange all types and formats of information, including text, pictures, audio, and video. Patient stories on social media refer to patients' posts that describe their healthcare experiences.

This thesis aims to assess the utility of patient stories on social media for healthcare quality improvement and explore the health system and policy factors that can positively or negatively affect this utility in the healthcare system in Ontario. The thesis is comprised of an introduction chapter, a theoretical perspective chapter, four studies presented in chapters 3 to 6, and a conclusion chapter. Additional material is provided in several appendixes, including a definitions section in Appendix 1.A.

The first study seeks to understand the perspectives of healthcare providers and administrators in Ontario regarding the factors affecting the patient experience. Qualitative data were collected between April 2018 and May 2019 by interviewing 21 healthcare providers and administrators in Ontario. Interviewees included physicians, nurses, optometrists, dietitians, quality managers, and policymakers. The study findings show that there are two perspectives on patient experience: the biomedical perspective, which prioritizes health outcomes and gives high weights to healthcare experience factors that can be controlled by healthcare providers, while ignoring other factors, and the sociopolitical perspective, which recognizes the impacts of healthcare politics and the social context of health on patient experience in Ontario.

The second study explores the perspectives of healthcare providers and administrators on patient stories on social media and whether they can be used for evaluating healthcare experiences. Data were collected between April 2018 and May 2019 by interviewing the 21 healthcare providers, and administrators in Ontario noted in study one. Study findings show that several barriers prevent healthcare providers from realizing the benefits of social media, including the professional healthcare standards and codes of conduct, the time and effort required to process these stories, and the significant number of stories on social media, which also increase the time needed to process these stories.

The third study analyzes the social media policies of the healthcare regulatory authorities, which are the regulating and licensing bodies in Ontario, and explores how these policies encourage or discourage the use of social media by healthcare providers. The study uses document analysis and qualitative content analysis to analyze social media policies and guidelines of some healthcare colleges in Ontario issued between 2013 and 2019. The study findings show that in the healthcare system in Ontario, social media is perceived as a source of risks to the healthcare professions and professionals, and therefore, policies are developed to mitigate those risks. Healthcare regulators emphasize that the codes of conduct and the professional standards of healthcare extend to social media, despite the distinct context of social media. The study found no systematic recognition of patient stories on social media as a source of information that requires the attention of healthcare professionals.

The fourth study analyzes patient stories on the Care Opinion platform, which is an online platform that enables patients to post stories about their healthcare experiences and enables the providers to respond to these stories. The study explores the elements of healthcare experience in these stories, the characteristics of the stories that receive responses from healthcare providers, and the association between the satisfaction level of the patient expressed in these stories and the likelihood of receiving a provider response. The study collected 367,573 patient stories from the Care Opinion platform that were posted between September 2005 to September 2019. The study uses topic modelling (Latent Dirichlet Allocation), sentiment analysis, and logistic regression to analyze the data. Data analysis identified 16 topics in these stories. These topics can be grouped into five categories: communication, quality of clinical services, quality of services, human aspects of healthcare experiences, and patient satisfaction. Stories that describe healthcare experience of a family member, or reflect patient thankfulness, gratitude, or satisfaction with communication are associated with a high likelihood of receiving a provider’s response; however; the sentiment score of a story, which I used as a proxy for patient satisfaction, was insignificant.

The thesis concludes by identifying several barriers that impede the use of patient stories on social media for quality improvement. These barriers are the beliefs and priorities of healthcare providers, the social media policies of the healthcare regulatory authorities and professional healthcare standards and codes of conduct that restrict patient-provider communication, the time and effort required to process patient stories, and the credibility of patient stories.

Acknowledgments

Two persons have been instrumental for the completion of this thesis: my co-supervisors, Dr. Craig Janes and Dr. Samantha Meyer. Many thanks to you both for the prompt, constructive, encouraging, and insightful comments about this dissertation over more than three years. Thank you, Dr. Meyer, for your empathy, support, and encouragement during the times when my work in this dissertation did not go smoothly, and for your thought-provoking "so what!" comments. Thank you, Dr. Janes, for providing the strategic guidance and exceptional mentorship when my work was at crossroads.

I am very grateful to my thesis advisory committee for the timely and constructive feedback, and thoughtful responses to my questions throughout my work in this dissertation: Dr. Plinio Morita, who provided valuable feedback on the initial plan of this dissertation, Dr. John McLevey, who provided thought-provoking comments on the initial plan of this dissertation, and Dr. Daniel Lizotte, who stepped and enriched my dissertation with his "did you do" questions.

My gratitude also goes to Dr. Jenny Flagler-George, who was; at the time of doing my research, a program manager at the Waterloo-Wellington Local Health Integration Network, for helping me connect with and recruit some of my research participants who are known to be very hard to reach.

I am very grateful to my research participants who shared with me their invaluable perspectives and deep expertise regarding many of the critical questions in my research.

Many thanks to Dr. Ian McKillop for advising me to come to the wonderful University of Waterloo, and for sharing with me his experience regarding the complex healthcare system.

Finally, I own a tremendous debt of gratitude to my guardian angel; my wife Heba, and my children Kareem, Seema, and Adam for their love, patience, and confidence, and for making my life very happy and joyful.

Dedication

To Heba, Kareem, Seema, and Adam

Table of Contents

List of Figures

List of Tables

CHAPTER 1

Introduction

The concept of patient experience refers to two intertwined components: the patient's lived experience of illness (i.e., illness experience), and the patient's experience with the healthcare system (i.e., healthcare experience)[1]. The former refers to the social, emotional, and economic effects of illness on patients and their families[2]. The latter refers to the interactions of patients with the healthcare system, including their interactions with nurses, physicians, and staff members[3]. The two components are interconnected. The patients' illness experiences affect their health needs and expectations of healthcare; whereas; the patients' healthcare experiences affect their experiences with illness[1]. However, in the healthcare quality literature, the term patient experience usually refers to a patient's experience with the healthcare system, which I refer to as healthcare experience.

In the Oxford Dictionary, the word "experience" has several meanings, including "a practical contact with and observation of facts or events." and "an event or occurrence that leaves an impression on someone."[4] Therefore, the term experience refers to both an event and its outcomes. Consequently, healthcare experience refers not only to patient's interactions with healthcare providers but also to the resultant emotional and behavioural responses of patients[3], including patient satisfaction, patient commitment to health, and patient adherence to treatment plans[1]. These responses are affected by the degree of conformity between the patient's expectations about healthcare services and the reality of these services[5].

Improving healthcare experience has been one of the targets of many quality improvement initiatives[3,6,7]. In 2008, the Institute for Healthcare Improvement (IHI) developed the Triple Aim, which is a set of three goals that a healthcare system should achieve in balance: improving people's health, improving patient experience, and reducing healthcare costs per capita[8]. In 2015, the Ministry of Health and Long-Term Care in Ontario announced the Patient First Action Plan, which became the Patient First Act in 2016, the goal of which is to improve the patient experience with healthcare and create a healthcare system that is responsive to patient needs[9].

Additionally, the integrated people-centred health services (IPCHS) initiative of the World Health Organization was launched in 2015, and it asserts the importance of continuity and coordination of care for improving patient experience[10].

In the healthcare system, survey instruments are the main tools used for evaluating patient experience[11,12]. Additionally, there has been an emerging source of patient experience information that can provide a means for healthcare providers and administrators to understand the experiences of their patients. This source is social media.

Social media refers to the internet-based applications that enable people to communicate, interact, publish, and exchange different formats of information, including text, images, audio, and video information[13]. Social media has been used for almost all human activities, including education, entertainment, social networking, marketing, commerce, healthcare, and politics[14,15]. Social media has enabled patients to communicate about their healthcare experiences and express their satisfaction or dissatisfaction with their healthcare providers. For example, RateMDs (www.ratemds.com), established in 2004, enables people to post and rate their healthcare providers. As of February 2020, it contains 2.6 million reviews of about 1.7 million healthcare providers, and these reviews have been read by 161 million persons[16]. Nevertheless, there have been some concerns with regard to the credibility and objectivity of patients' post on provider review websites, as I discuss in sections 1.1.3, 1.1.4, and 1.1.5.

This thesis seeks to assess the utility of patient stories on social media for healthcare quality improvement and explore the health system and policy factors that can positively or negatively affect this utility in the healthcare system in Ontario.

In this chapter, I provide a literature review on patient experience and patient stories on social media. I start by exploring what patient experience is. I next move to discuss research methods that are used to evaluate patient experience by researchers, healthcare providers, and healthcare administrators. Next, I discuss health social media, which refers to social media that contains health-related information. I next present patient stories on social media. Next, I discuss four aspects of the patient stories phenomenon that have not received full attention in the literature: the quality of the stories, the organizational enablers for utilizing patient stories, the perspectives of healthcare providers and administrators regarding patient stories, and the technical processes required to process the large volumes of these stories. I end my review by identifying the knowledge gaps that this thesis seeks to address.

1.0 Literature Review Process

The literature review was guided by the research questions and the theoretical perspective that I adopted, which is described in the next chapter. There were also several factors that informed the review plan, including my experience as a dentist who has worked with patients for several years, and my engagement and discussions with faculty members during my course work where I had had the chance to present and discuss my research interests since my first year at the University of Waterloo in 2016. Additionally, the research study[17] that I conducted to earn a master's degree in health information science from the University of Western Ontario had greatly informed not only my literature review planning but also the planning of the whole thesis. In that study, I explored the perspectives of health policy data analysts and decision support experts in Ontario on the use of an interactive platform (i.e., an information dashboard) to inform policymaking. Furthermore, because I used an exploratory mixed-method study design, each of the four studies comprising my thesis raised several theoretical questions that necessitated continuous consultation of the literature.

My knowledge exploration process started by reading an important reference in the patient experience field, titled "*Understanding and Using Healthcare Experiences,*" Published by Oxford University Press in 2013. This volume contains a variety of papers that explore patient experience and the research methods used to explore it. It gave me a broad understanding of the different dimensions of patient experience and enabled me to focus my literature review process. I have benefited from existing electronic literature databases, including PubMed, Scopus, and Google Scholar. I used a combination of keywords that guided my searching process. I have also used many other keywords (Table 1.1), depending on the knowledge areas that I needed to explore. At the beginning of the review process, the inclusion of a research paper was determined by its relevance and the number of times it has been cited. However, as I proceeded in my review and developed a better understanding of the phenomenon, I tended to select the papers that help crystalize the different aspects of it.

Table 1.1: Keywords Used in The Search Process

Topic	Keywords
Patient Experience	“Patient Experience”, “Patient Satisfaction”, “Evaluation”, “Surveys”, “Questionnaire”, “Patient Expectations”
Social Media	“Social Media” , “Benefits”, “Risks” , “Concerns”, “Policy“

1.1 Background

In 2019, I conducted a narrative review of patient experience[1]. In that review, I developed a framework and classification scheme for identifying patient experience dimensions, which distinguishes between the determinants and manifestations of the patient experience. The determinants are the factors that affect this experience. The manifestations are emotional and behavioural outcomes of a patient’s experience, including patient satisfaction and patient commitment to treatment plans[1]. This framework is used in all the studies in this thesis.

1.1.1 Conceptualizing Patient Experience

From the biomedical perspective, eliminating the body’s abnormalities and restoring its normal functions are the main goals of the healthcare system[18]. It is during this restoration journey that healthcare experience takes place[3].

However, despite the existence of a definition of the patient experience, it remains a complex multidimensional phenomenon[2] that is difficult to conceptualize[2,19] because it has been linked to other constructs that are also complex to conceptualize, including patient-centred care, patient preferences, and patient satisfaction[19].

In the healthcare quality literature, there is disagreement over what the outcomes of healthcare experiences are and what elements of patient experience are essential to achieving those outcomes. This disagreement reflects ideological differences among healthcare stakeholders, which affect the scope of research studies and interpretation of results[2,19,20].

Firstly, many healthcare providers adopt a biomedical perspective to patient experience that prioritizes the achievement of health outcomes over the creation of ideal healthcare experiences[2,21–24]. From this perspective, the outcomes of patient experience are mainly the health outcomes that are achieved with a minimum negative impact on patient safety. This perspective ignores patients' accounts of their illness and their expectations as well.

Secondly, healthcare administrators adopt the patient as-a-client perspective[2], which is rooted in the New Public Management paradigm[25], and it seeks to apply the different concepts of business and marketing on healthcare by treating the patient as a client. From this perspective, patient experience represents not only the physical experience of disease but also the experience with the healthcare system. Different elements of the healthcare system can affect the patient experience, including the quality of healthcare, patient-physician communication, and the patient-centredness of care[26]. From this perspective, patient experience outcomes include, in addition to health outcomes, patient satisfaction.

Lastly, social scientists and medical anthropologists adopt a phenomenological perspective on patient experience[2], which seeks to understand the lived experience of patients with illness and illness's emotional and social impacts[27]. It also seeks to understand patients' views of the different aspects of illness, including its nature, causes, progress, consequences, risks, and treatment. Those views are shaped by the patient's culture, norms, beliefs, emotions, and previous life experiences[28,29].

This conceptual disagreement and the multidimensionality of the phenomenon may affect how data on patient experience is collected and analyzed, and how results are being interpreted[30–33]. Because different research studies measure different sets of patient experience dimensions, these studies can produce conflicting findings regarding the relationship between the ideal patient experience, on the one hand, and health outcomes on the other hand. Therefore, some studies report a positive relationship, while others report no relationship or even a negative relationship[33–36].

There are also inherent methodological difficulties that patient experience researchers may face. These difficulties are described in the next section.

1.1.2 Patient Experience Research

Qualitative and quantitative research methods have been used to explore patient experience and examine the different factors that affect it.

Qualitative research methods provide a reliable means for understanding the perspectives of patients and healthcare providers about the different aspects of healthcare quality and exploring the contextual factors that affect these perspectives[37]. These methodologies help researchers gain an in-depth understanding of the phenomena being explored. However, they require more time and effort to collect and analyze the data compared to quantitative research methods[12]. Qualitative research methods that have been used in patient experience research include ethnography, field observations, focus groups, and narrative interviews[38].

Quantitative research is also warranted for explaining how phenomena occur and examining the relationships among the variables that affect these phenomena. In health research, quantitative methods have been used to examine association and causation relationships among variables of interest and health outcomes[37]. Surveys comprise the main quantitative method used in patient experience research and healthcare quality control[11,12]. In 2010, a review conducted by the Change Foundation identified 24 patient experience survey instruments in Ontario[39]. Surveys enable healthcare providers to define which elements of patient experience are to be measured.

There are two types of patient experience surveys: dedicated and non-dedicated surveys. Dedicated patient experience surveys such as Health Quality Ontario survey measure only patient experience. Common elements that are frequently measured include access to health services, communication with staff, quality of service, shared decision-making, and patient satisfaction[40–42]. The non-dedicated surveys are patient-reported outcomes (PROMs) surveys, which are used to evaluate the health outcomes in clinical trials, and the patient's needs and effectiveness of interventions during treatment[43]. PROMs have been used as proxy measures for patient experience. Underpinning this use is the association between positive patient experience and favorable health outcomes[7].

There are several challenges in patient experience research that may affect the scope of research, data collection, and knowledge translation. These challenges are discussed in the following subsections.

1.1.2.1 Survey Quality Challenges

In the healthcare system, survey instruments are the main tools used for patient experience evaluation[11,12]. The quality of a survey instrument has two dimensions: reliability and validity. The reliability of the instrument denotes its capability to produce similar test results when used on the same or similar participants over several times. The validity of the instrument denotes its capability to measure what it intends to measure[44].

In all types of surveys, several instrument design factors can affect the reliability and validity of the survey instrument. These include the characteristics of the target population (e.g., age, gender, culture), the topic that is being examined (e.g., attitudes, facts), question design (e.g., wording, implications), response type and scale, survey administration modes, and the social context where the study is taking place[45,46]. Additionally, there are factors related to sampling and data collection in patient experience surveys, which impact the validity of the survey instrument.

Privacy concerns: Patients' concerns about their privacy remain key challenges in health service research[47–49]. Patient privacy is a human right[50]. Protecting patient privacy is an ethical principle in healthcare and health service research[50–52]. Patients may avoid research studies that seek to explore the quality of medical services and the impact of these services on their experience because participation in these studies can expose some aspects of their health conditions.

Representativeness of the sample: Inclusion of the different groups of patients identified culturally, socially, economically, or demographically is a challenge faced by researchers when evaluating patient experience. Inclusion is one of the ethical goals of research studies, and it is one element of the principle of justice in research[51,53].

Ryan[54] identifies several factors that affect the "inclusivity" of patient experience research. First, the assumptions made by researchers or ethics boards about the vulnerability and welfare of specific groups can lead to unfair exclusions of these groups from the research study[51]. Certain age groups, people with learning disabilities, or people with some chronic conditions are frequently excluded because of the "over protectionist" assumptions of researchers or research ethics boards[51,54]. Secondly, access to certain groups of patients, such as sex workers or drug users, may be difficult. In many hospitals, patient observation and interviews can be very difficult to conduct under the patients' privacy laws. Thirdly, research methods can also impede the participation of some people. Some people may not be comfortable talking about their experience in interviews. Other people may be less tempted to participate because they need the help of a family member, who may not always be available to fill in a questionnaire[51,54].

Additionally, some people may be denied from accessing healthcare services because they cannot afford the cost of these services. Valentine et al.[55] assert that researchers should be attentive to the denied users and argue that excluding them can harm the validity of the research[55].

The timing of the study: Another challenge is related to data collection and the timing of the study. A study may occur at different stages of the healthcare experience, including disease diagnosis, treatment, and rehabilitation. The health status of the patient may vary considerably on these different stages and different encounters, including primary care encounters, inpatient care, and long-term care[45]. This variance in health status affects patient expectations, perceptions, and satisfaction. Therefore, understanding patient experience requires examining it on several encounters with the healthcare system and not only focusing on single encounters[34].

Response bias: patient experience surveys can be affected by response bias. There are several types of response bias that can affect the validity of the survey findings, including social desirability and non-response biases. Social desirability bias is widespread in attitudinal and interview surveys[56]. It is a response bias that results from the inclination of respondents to give socially acceptable answers to survey questions even if those answers are not true[57]. It is common in patient satisfaction surveys, which generally report unrealistically high levels of patient satisfaction[33,58,59], which is manifested in a positive skew of the survey results, which denotes a clustering of responses towards favourable ends[59].

In addition to the social desirability bias, many factors can lead to positive skew. Sitzia et al.[33] argue that the positive skew in patient satisfaction survey stems from the multidimensionality of the patient experience phenomenon more than from the format of the questions, and they assert that asking questions about specific dimensions of patient experience would probably reveal more patient dissatisfaction[33]. Patients are more likely to positively rate their experiences if the evaluation is done during the patient service encounter in contrast to a more rational evaluation for those experiences when the evaluation is done after completing the service encounter[58]. Other factors include patients' ingratiation with health care providers to sustain the continuity of care, patients' self-justification of their endeavour to seek healthcare, patients' gratitude to healthcare providers, and patients' hopelessness of any changes in service quality[33].

Nonresponse bias can also affect patient experience surveys and lead to skewed results[33,58–60]. It occurs when there are significant differences between respondents and non-respondents in the sample, which can lead to biased survey results[61]. Non-respondents, regardless of how big or small the response rate is, may be dissatisfied with healthcare. Furthermore, in all types of health service surveys, including patient experience surveys, increasing the response rate may not have a fundamental impact on the survey results, nor may it reduce the nonresponse bias[60,62]. Therefore, analyzing nonresponse bias should be an integral part of survey quality[62,63]. Several methods can be used to assess the nonresponse bias, including comparing the survey results with other surveys, follow-up studies of nonrespondents, and replication of the study[62].

1.1.2.2 Knowledge Translation Challenges

The Canadian Institutes of Health Research provides the following definition for knowledge translation (KT):

> "*KT is a dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically-sound application of knowledge to improve health, provide more effective health services and products and strengthen the healthcare system.*"[64]

Many patient experience surveys do not provide meaningful information to clinicians, patients, and hospital boards, and the uptake of patient experience survey results is generally weak in the healthcare system[32,58,65]. There are systemic and data factors behind this weak uptake.

First, the aggregate form of the data provided by these surveys and patient privacy protection laws pose methodological challenges to researchers' ability to link this data to health outcomes, which is essential for healthcare quality improvement[32]. Secondly, understanding the data provided by these surveys requires adequate training in quality improvement for healthcare providers[66]. Thirdly, the usability of some patient experience measures such as patient satisfaction measures may be low. Patient satisfaction measures have been criticized for being "simplistic," positively skewed, and lacking a practical value for healthcare quality improvement[33,55,58]. On the other hand, patient experience measures that are linked to specific aspects of healthcare quality or healthcare processes, including timeliness, communication, and respect for the patient, can be more meaningful to healthcare providers and administrators than satisfaction measures[33,55,67–69]. Fourthly, the complexity of healthcare and the demand for better health outcomes and efficiency force healthcare providers to concentrate more on the outcomes of health services than on the patient experience[21].

1.1.2.3 Qualitative Research Challenges

Qualitative research methodologies provide researchers with a plethora of theoretical frameworks and data collection and analysis methods that enable them to explore the insights of social phenomena and people's experiences. However, they pose several methodological challenges that qualitative researchers may face. First, the explorative nature of qualitative inquiries necessitates flexibility in terms of sample size, types of participants, and study duration[70]. Second, many qualitative researchers use interviews to collect data. Interviews require flexibility from researchers, in terms of the number and scope of interview questions, and timeliness of the interview[70]. Interview questions should be carefully designed to avoid leading interviewees towards favourable directions to the researchers[71]; and to reduce social desirability bias, which results from the inclination of respondents to give false but socially acceptable answers to interview questions[57]. Third, interview data requires transformation into a textual format in a tedious and time-consuming process titled transcription[72]. Despite the merits of qualitative research, these challenges can make it unfavourable and expensive for healthcare providers[12].

However, the emergence of social media has resulted in influxes of large volumes of qualitative data that describe diverse types of social experiences, including patient experiences, customer experiences, and student experiences, provided in social media platforms such as "Patient Like Me," Yelp, and Reddit. The availability and continuous accumulation of this data have fostered the development of qualitative and quantitative methods for data analysis[73,74].

1.1.3 Health Social Media

In this thesis, I use the term "health social media" to refer to social media that contains health-related information. Based on who creates social media content, there are two types of health social media: professionals' health social media and laypeople's health social media.

Professionals' health social media includes the websites and mobile applications that are managed and used mainly by healthcare professionals for knowledge exchange, news dissemination, health promotion, and public health surveillance[75]. The content in this media is generated mainly by healthcare professionals. Examples of this type include Promed (http://www.promedmail.org), which is a network of epidemiologists and public health experts, and Twitter or Facebook pages of the ministries of health worldwide.

Laypeople's health social media includes websites and mobile applications that are used mainly by laypeople, including patients, caregivers, and all the people who are not part of the healthcare system. It has been used by laypeople to exchange knowledge and experiences of health, wellbeing, sickness, and healthcare. Examples of this type include discussion forums such as that on WebMD (https://messageboards.webmd.com), and the health pages on Reddit (www.reddit.com). Several types of information (i.e., posts) can be found in laypeople's health social media, including personal knowledge of health issues, health news, people's experiences of illness, and people's experience with healthcare[76]. Through personal knowledge posts, people share their knowledge about health and health behaviours. These knowledge posts reflect people's health literacy levels. Health news posts usually include original news items extracted from news websites. Posts about people's experience with illness and healthcare describe people's personal or familial experience with illness and healthcare. Laypeople seek to achieve two goals when participating in health social media: increasing their personal health management capabilities, and building social relationships[77]. However, the literature is scarce about people's motivations to share their healthcare experience on social media[78].

1.1.4 Patient Stories on Social Media

There are two types of social media platforms that host patient stories: dedicated and undedicated platforms. The undedicated social media platforms are the platforms that are not dedicated to collecting patient stories such as Facebook, Twitter, and Reddit. These platforms are used by diverse types of users for different and multiple purposes, including personal blogging, marketing and advertisement, education, health promotion, gaming, and political campaigns. Patients have also used these platforms to post stories about their illness and healthcare experiences. For example, Reddit (www.reddit.com) includes several discussion forums on illness and patient experiences such as "cancer," "caregivers," "tales from medicine," and "Chronic Pain." These platforms enable users to post their stories and comments on other people's stories. These platforms have little, if any, moderation of content.

The dedicated social media platforms are the platforms that are fully dedicated to collecting patient stories and facilitating patient-provider communication and feedback regarding these stories. An example of this type is Hao Dai Fu, a Chinese website (www.haodf.com), which, in March 2020, contained 4,024,818 patient reviews for doctors across China[79]. A survey study, in 2012, explored the benefits of using physician rating websites by the US population for choosing healthcare providers and found that 40% of Americans believed that these websites are "somewhat important," and 19% believed that they are "very important"[80].

Patient stories can help physicians to identify aspects of healthcare that can be improved[31]. These stories represent recent healthcare encounters, and they are available in large volumes, which reduces data collection costs. Also, these stories can shed light on issues in healthcare that are not always exposed by traditional patient experience surveys, including the patient's lived experience of illness, emotional and financial burdens of illness, and patient satisfaction[30,31]; therefore, they have a high potential for healthcare quality improvement[30,81].

However, there are four aspects of the patient stories phenomenon that have not received wide attention in the literature: the quality of the stories, the organizational enablers for utilizing patient stories, the perspectives of healthcare providers and administrators regarding patient stories, and the technical processes required to process the large numbers of these stories.

1.1.5 The Quality of Information on Laypeople's Health Social Media

Social media has also been used by laypeople to publish and exchange low-quality health information, an issue that has become very evident during the current coronavirus pandemic. In February; 2020, the World Health Organization declared that its teams have been working 24 hours a day to track and manage an "infodemic" of Coronavirus, which refers to the influx of information of varying quality; some of which is fake or inaccurate; that makes it difficult for people to find helpful information about Coronavirus[82].

In the business quality literature, quality is defined as the "fitness for use," which entails the product's "freedom from deficiencies"[83]. However, the fitness for use concept is context-dependant and multi-dimensional, and the different sectors, including healthcare, the media, the industry, and education, adapt and interpret this concept based on their needs[84]. In the informatics field, the same concept has also been used to represent the information quality[85]. However, Stvilia et al.[85] argue that in the informatics field, the information quality concept needs to be operationalized based on the context and type of information. This operationalization requires defining quality criteria for each context, such as financial information quality criteria, health information quality criteria, and social media information quality criteria[85].

In the informatics field, there are many dimensions for the fitness for use, including credibility, accuracy, and believability. These dimensions have been used in different research studies to refer to the broader concept of information quality[86]. Metzeger[87] uses the concept of information credibility to represent the overall information quality. There are five dimensions of information credibility: accuracy, authority, objectivity, currency, and coverage. Accuracy refers to the absence of errors in the information. Authority refers to the credibility of the authors of the information and their explicit capabilities for authoring in the specific information domains. Objectivity represents the degree to which the purpose of the information is known to the users and whether the information is explicitly labelled as facts or opinions. Currency represents the degree to which the information is usable at the present time. Coverage represents the depth and breadth of information[87].

The literature is scarce and inconclusive regarding the quality of the information in laypeople's' health social media. Some studies suggest that this quality may be low[88,89]. Also, a few studies suggest that social media platforms are subject to selection bias, because they may be used by specific sociodemographic segments of users, and therefore, the stories may not accurately represent the patient population[30,90]. In chapter 4, I also present my empirical study of the perspectives of healthcare providers and administrators about the quality of patient stories on social media, and I discuss their concerns in this regard. However, as discussed above, the different types of information require defining specific quality criteria, based on which quality dimension can be assessed. As for patient stories on social media, these quality criteria have not been developed yet.

Nevertheless, and despite the noted limitations, patient stories on social media have been identified as possibly having a good degree of credibility[30,91,92]. A survey by Cole, Watkins, and Kleine[93], evaluated the quality of 25 health-related thread posts collected from Reddit and other social media platforms. The study used five information quality criteria: the scientific accuracy, the scientific completeness, the usefulness, how practical the information is, and how reaction-provoking the information is. The posts were about living with or managing the diverse health conditions of HIV, diabetes, and chickenpox. Participants included medical doctors, patients, and caregivers, and they evaluated the quality of the posts. The study found that most of the information was "of reasonably good quality"[93]. Furthermore, since 2014, the Care Quality Commission in England has launched an intelligent monitoring system to monitor the quality of healthcare services in hospitals and medical practices. The monitoring system uses traditional patient surveys in addition to analyzing patient stories posted on the commission's website[94].

1.1.6 Organizational Enablers for Utilizing Patient Stories

The healthcare quality literature is scant of empirical studies or case studies on how healthcare organizations can utilize patient stories on social media and the organizational enablers and technical processes that can enable such utilization in the healthcare system.

However, existing evidence suggests that social media has been perceived as a source of risks to the healthcare professions and professionals, and therefore, policies are developed in the healthcare settings and the health system organizations to mitigate those risks[95–97]. In the healthcare domain, professional and organizational social media risks may occur. Professional risks can affect healthcare professionals, and they include breaches of patient privacy and confidentiality, crossing the professional boundary, the potential conflict of interest, distortion of professional image, misinterpretation of health information by laypeople, and violating healthcare ethics and professional practice standards by healthcare professionals[98]. These risks can also have a damaging impact on the reputation of related organizations such as hospitals, family practices, or other healthcare settings. They can also damage the reputation of the respective medical professions, such as nursing, medicine, and dietetics[95,99,100]. The social media policies in healthcare settings and the professional codes of conduct developed by healthcare regulatory authorities govern how healthcare providers and administrators interact with patients on social media and define possible consequences for violating these policies.

Additionally, the utilization of patient stories may be dependent on the organizational context in the healthcare system. Coulter et al.[66] argue that although patient experience has been measured at different levels in the healthcare systems in many countries, including hospitals, local levels, and national levels, the resultant data has not been used effectively to improve healthcare quality[66]. The researchers assert the need to build a supportive environment in healthcare systems that believes in the benefits and value of creating an ideal patient experience and is able to deliver good quality healthcare. This environment requires leadership commitment, strategic planning, engagement of patients and families, training of staff on healthcare quality, financial and human resources, and performance monitoring[66]. However, Schlesinger et al.[31] argue that while patient stories are an important means to convey patient concerns and the challenges they face with healthcare, healthcare providers may be skeptical about the utility of these stories for healthcare quality improvement[31]. Moreover, obtaining meaningful information from these stories requires developing rigorous processes that guarantee collecting stories from diverse groups of patients and encouraging patients to describe the aspects of healthcare experiences that are amenable to quality improvement[31]. In the healthcare systems, which are already overwhelmed by the increasing demand for healthcare and pandemics, the development of the technical and organizational processes may be very important in order to benefit from patient stories efficiently.

In section 1.1.8, I discuss the technical processes that can be used to analyze patient stories on social media.

1.1.7. The Perspectives of Healthcare Providers and Administrators

In the healthcare system, healthcare providers and administrators represent the primary users of patient experience data, regardless of its sources, being surveys or patient stories on social media. Therefore, understanding the perspectives of healthcare providers and administrators on patient stories is essential. Although the literature is scant on studies in this regard, several studies can shed light on these perspectives.

An empirical study by Speed et al.[101] found that reputation damage that may result from patient stories is a crucial concern for providers and administrators[101]. The study interviewed 41 participants, including healthcare providers, administrators, and patients. The study argues that the anonymity of patients that post stories may enable them to post unfounded information regarding their experiences that can be harmful to the healthcare team. Also, to protect their anonymity, the patients may not provide enough details regarding their experiences, and this may prevent the healthcare team from responding meaningfully to these sorties[101].

Another empirical study by Martin et al.[102] explores the views of 107 healthcare providers and administrators in the UK regarding the value of patient experience narratives collected in hospitals for quality improvement. Although participants believed that these narratives can provide rich insights about healthcare practices that may expose issues in healthcare, they believed that these narratives are “soft data” that require further validation using “hard data”; the data collected through surveys and statistical quality control methods[102]. Participants expressed their concerns regarding the reliability and validity of this data and the ability of patients to provide accurate information about their healthcare experiences[102].

Menon[103] explores the perspectives of 41 cosmetic surgeons in the USA regarding physician online rating websites. The study also analyzed the ratings of study participants on these websites. Although many participants had positive reviews, most participants expressed their concerns regarding the credibility of these reviews and the potential physician reputation damages that these reviews can cause[103]. Participants questioned the ethical motivation of websites operators to keep negative reviews. However, the study argues that underneath these concerns lie concerns about threats to physicians’ authority that stems from their domain expertise, which is essential to the continuity of their profession. These websites threaten the power imbalance between patients and physicians by enabling patients to assess the performance of physicians publicly and share their healthcare experiences with other patients[103]. Many participants acknowledged changing how they interact with patients in order to achieve more positive online reviews[103].

Patel et al.[104] discuss the concerns of general practitioners in the UK about physician online reviews websites. Twenty physicians were interviewed. Participants believed that the validity of patient reviews can be jeopardized because patients posting these reviews may be biased and because they do not represent the whole patients of the clinic[104]. Patients may also lack the scientific expertise to understand the nuances of the professional practices, and they can make inaccurate claims. Participants were concerned that some physicians may manipulate the ratings by encouraging their patients to post positive reviews. Participants believed that many online reviews websites lack the capability to authenticate the patients’ reviews. Patients may be exposing some private information about their health conditions in their reviews, and they may also expose some of the physician’s private information[104]. Patient’s anonymity can turn their reviews useless because providers may not be able to validate these reviews. Physicians believed that these reviews may harm their reputation and their relations with patients[103].

In summary, empirical evidence suggests that healthcare providers and administrators have concerns regarding patient stories. These concerns include patient anonymity, which prevents providers from validating the reviews and reduces the usefulness of stories. There are concerns about the validity and credibility of the stories, patient bias, patient's ability to evaluate their healthcare experiences, and physician’s ability to manipulate the reviews. Online reviews can pose threats to the physician's authority and reputation, patient-provider relationships, and patient and provider privacy. There are also concerns about the ethical motivation of website operators and the lack of patient authentication capability in those websites, which may encourage some patients to post false claims about their healthcare experiences.

1.1.8 Analyzing Social Media Data

The internet has enabled the abundance and influx of digital data. According to a report by Raconteur, a company specialized in analyzing and estimating internet usage, in 2019, 294 billion emails were sent, and 500 million tweets were tweeted every day[105]. Another report by Domo estimates that in 2018, every minute, Reddit received 1944 comments, and YouTube streamed 4,333,560 million videos[106]. The availability and production of these large volumes of data, accompanied by the low cost of electronic data storage means have fostered the development of computational methods that enable searching, analysis, and extracting meaningful information from the large volumes of data; the functions that are almost impossible to do by humans due to the large size of data[107–109].

Two groups of these computational methods that are used to analyze textual data on the internet are natural language processing and text mining. Natural language processing refers to the use of “computational techniques for analyzing and representing naturally occurring texts for achieving human-like language processing for a range of tasks or applications”[110]. These tasks include information retrieval, information extraction, and machine translation [111].

Text mining refers to the use of computational algorithms (i.e., machine learning) for analyzing unstructured text data. These algorithms transfer the data into a numerical format to perform the analysis[112]. Text mining is used to achieve several types of functions, including document classification, document clustering, and web mining[112]. It also utilizes natural language processing techniques to perform these functions. Document classification aims at assigning labels (i.e., tags) to a group of documents based on models that are built using other classified documents[113]. Document clustering aims at grouping documents into clusters based on the content of those documents[112]. Web mining includes a set of techniques that allow crawling, indexing, and searching on the web[111].

Text mining has been used in several health domains, including event-based public health surveillance, pharmacovigilance, health behaviour monitoring, and patient experience evaluation. Event-based public health surveillance systems use internet sources, such as social media, emails, and online newspapers, to detect or predict the occurrence of public health epidemics[114]. One example of these systems is the Health Map (https://www.healthmap.org/en/), which collects data from authentic internet sources such as World Health Organization alerts, epidemiologist online networks, and the Euro Surveillance public health outbreaks website. This data is analyzed using NLP and text mining to produce a real-time map that represents the public health alerts in different parts of the world[114]. Twitter data has also been used for health surveillance to track disease on time and place[115].

Patient stories on social media may contain rich and self-reported information about the outcomes of treatment, including adverse drug events[92]. Liu and Chen[81] developed a text mining system to analyze patient discussion forums and detect adverse drug events. The system uses NLP and the unified medical language database, the consumer health vocabulary database, and the FDA drug safety database to extract adverse event information from the discussion forums[81]. Many people describe their health behaviour in their posts on social media. These posts can be analyzed using text mining to provide insights about different dimensions of people's health behaviours and design appropriate health promotion interventions[116]. Myneni et al.[117] use text mining to analyze the discussions of the members of QuitNet, an online social network for smoking cessation[117]. NLP and topic modelling are used by Chen et al.[118] to analyze the posts on social media websites such as Vapor Talk and Hookah Forum to explore people's experiences and attitudes towards smoking. The study identifies several topics that were discussed in these websites, such as the use of e-cigarettes, smoking harms and quitting[118]. Twitter data has been analyzed by many health researchers. Huang et al.[119] use topic classification to explore how Twitter is used to market e-cigarettes. The study analyzed more than 73,672 tweets related to e-cigarettes and found that 90% of the these tweets were commercial tweets for promoting e-cigarettes[119].

Text mining and NLP can also be used to analyze patients' stories on social media to understand the patient experience of illness[120]. These methods can reveal many insights regarding the patient experience of illness and healthcare that may not be captured through patient-reported outcome measures[120]. Doing-Harris et al.[121] used lexical-based classification, sentiment analysis, topic classification, and topic modelling to analyze 51,234 free-text comments from patient surveys in the University of Utah hospital system. The study identified the main aspects of patient experience that were mentioned in the comments, and these aspects included explanation, appointment wait time, appointment access, practice environment, friendliness, and empathy[121]. Varanasi et al.[122] used manual content analysis, text classification, and sentiment analysis to analyze free-text comments of patient satisfaction surveys of emergency departments in a large hospital system in the metro Detroit area[122]. Griffiths et al.[94] present the *Patient Voice Tracking System*, which uses text mining to capture and classify patient ratings for hospitals from NHS Choices, Patient Opinion, Facebook, and Twitter to create a near real-time aggregate score for those hospitals[94].

Eaneff et al.[123] present a retrospective observational study that uses patients profiles from Patients Like Me (www.patientslikeme.com) to describe the common symptoms of neuromyelitis optica spectrum disorders[123]. Frost et al.[124] analyze 3500 treatment histories for two drugs: modafinil and amitriptyline, which were reported across several Patients Like Me communities. The study identified common treatment conditions and outcomes that were reported by the patients[124]. Ru et al.[125] used the stories of patients with chronic conditions such as asthma and diabetes to analyze the effectiveness of specific drugs used to treat these conditions. The stories were collected from Patients Like Me, Twitter, WebMD, and Youtube. The study used sentiment analysis to analyze the stories[125].

Beginning in 2010, text mining has witnessed a new wave of evolution with the use of deep learning methods[126]. These methods enable researchers to overcome the limitations of traditional text mining methods that relied on human efforts to deign the text labels or to interpret the predicted features[126]. Deep learning uses a layered model structure to learn text features and word contect[126]. It has been used to perform many NLP tasks such as lexical analysis and part of speech tagging[127], text-based dialogue systems (i.e., chatbots)[128], question answering platforms[129], and sentiment analysis[130]. Deep learning has also been used to generate word embeddings, which are vector representations of words. A word vector captures semantic and syntactic information of words[131]. Existing word vector models have been created by analyzing a large corpus of data from Google and Facebook[132], and they can be used for several NLP functions such as machine translation, sentiment analysis, named entity recognition, part of speech (POS) Tagging, and semantic analysis[131].

Liu et al.[133] develop a deep learning method to assign labels to text documents (i.e., extreme multi-label text classification). The method was tested on a dataset of 2 million Wikipedia documents and 500,000 labels, and it outperformed exiting traditional methods[133].
Chatterjee et al.[134] develop a sentiment analysis method that combines supervised machine learning and deep learning to assign a set of emotional labels to documents.
Yousefi-Azar et al.[135] develop a method that uses deep learning to summarize documents.
Xue et al.[136] use deep learning and regression modelling to predict the Big Five personality scores of social media users. The study presents a method that uses deep learning and word embeddings to extract linguistic features of social media posts. The method also extracts statistical features of the posts, including the rate of emoticons and the rate of capitalized words. These features are then used as predictors in a regression model to predict the personality score.[136]

Deep learning has also been used to analyze health and medical data. Chen et al.[137] use deep learning to analyze radiology free-text reports and detect the presence, chronicity, and location of pulmonary embolism. Jiang et al.[138] use deep learning to develop a biomedical word embedding model based on a corpus of 50 thousand papers from Medline, and they use this model to extract drug interactions information from medical and health-related papers[138].

However, while the fields of text mining and NLP have been developing rapidly, there remain some challenges[92,120]. The lay language used in social media can be full of colloquialisms and misspellings. Patients may not use the correct medical terms to describe their experiences. Some posts on social media may be too short to be used for sentiment analysis. Patient posts may lack contextual information, such as place and time, which can impede semantic analysis of the posts[92,120].

1.1.9 Knowledge Gaps in Health Social Media

In this literature review, I show that the phenomenon of patient stories on social media has several dimensions. Patient stories can be linked to other phenomena: social media, patient experience, healthcare quality, and it can be explored using the methods used to explore and evaluate these phenomena. However, despite the breadth of knowledge in these fields, there remain many knowledge gaps that require more research. In this thesis, I address the following knowledge gaps:

Understanding the perspectives of healthcare providers: In section 1.1.1, I discuss the conceptual complexity of patient experience and how the healthcare stakeholders may disagree on the dimensions of the patient experience. In section 1.1.2, I also discuss how existing evidence suggests that some healthcare providers find it difficult to use patient experience survey results because of the "analytical complexity" of the methods used in these surveys[32].

In section 1.1.4, I show how patients may use social media to describe their healthcare experiences, and I explain in Section 1.1.7 that healthcare providers and administrators may have some concerns about the validity, credibility, and possible negative impacts of these stories on provider's reputation and on the patient-provider relationship.

Understanding the perspectives of healthcare providers regarding health social media in general and patient stories, in particular, is important to evaluate the utility of patient stories on social media. According to the Evidence Standards Framework for Digital Health Technologies[139], which defines a set of standards for increasing the effectiveness of digital health technologies, healthcare providers must participate in the design and development of these technologies[139]. Therefore, the first study in this dissertation included consulting with healthcare providers and administrators in Ontario to understand their perspectives regarding the factors that affect the patient experience. In the second study, which uses the data collected in the first study, I explore the perspectives of healthcare providers and administrators in Ontario regarding the utility of patient stories on social media.

Understanding the necessary policy changes: In section 1.1.7, I discuss how social media has been perceived as a source of risks to the healthcare professions and professionals and therefore, policies are developed, in healthcare settings and at multiple healthcare system levels, to mitigate these risks[95–97]. These policies govern how healthcare providers and administrators interact with patients on social media and define possible consequences for violating these policies.

Understanding the impact of social media policies and the codes of conduct in the healthcare system on the utilization of patient stories in social media is essential. This understanding helps to determine the policy changes, if any, required to regulate the interaction between the patients and healthcare providers on social media and create a safe and transparent environment where both parties can tell their stories and views regarding the different aspects of healthcare without fearing legal or organizational consequences. However, the literature is scarce regarding social media policies in the healthcare system in Ontario and the theoretical foundations that can support their development. Therefore, to address this issue, I analyze in the third study in this dissertation the social media policies of the healthcare regulatory authorities, which are the regulating and licensing bodies in Ontario, and explore how these policies encourage or discourage the use of social media by healthcare providers.

Evaluating the meaningfulness of patient stories on social media: In section 1.1.7, I discuss how healthcare providers and administrators may have concerns about the validity, credibility, and usefulness of patient stories, and about potential negative consequences on healthcare providers' reputation. The existence of these concerns suggests that online patient stories platforms may be ignored or discredited by healthcare providers and administrators.

However, the literature is scant regarding studies of how healthcare providers and administrators use patient story platforms, and how they respond to patient stories and the factors that affect their responses. A study by Emmert et al.[140] explores more than 1 million patient reviews on the German platform Jameda (www.jameda.de) that were posted from 2010 to 2015. The study found that healthcare providers responded only to 1.58% (16,640/1,052,347) of the reviews[140].

Nevertheless, one factor that can impact the use of patient stories by healthcare providers is the quality of the stories. In section 1.1.5, I discuss information quality criteria, including information coverage, which represents the depth and breadth of information[87]. I believe that the level of coverage in a story may affect whether and how a provider responds to it.

Therefore, the content of patient stories is another factor that should be explored to assess the utility of these stories. Analyzing the content of the stories and the provider's response pattern enables us to understand whether the providers' concerns impact how they perceive the value of online physician reviews platforms.

I also discuss in section 1.1.8, that social media contains large volumes of data that grow continuously. These large volumes of data are hard to analyze manually, and they require the use of computational methods such as text mining. Patient stories on social media also exist in large volumes, and harnessing these stories requires developing data mining methods and tools that allow extracting, analyzing, and generating meaningful insights about this data[30,120,141].

Therefore, in the fourth study in this dissertation, I analyze patient stories on the Care Opinion platform (www.careopinion.org.uk), to explore the elements of healthcare experience that these stories describe and the characteristics of the stories that receive responses from healthcare providers.

1.1.10 Summary

Patient experience is a key component of healthcare quality. Healthcare quality initiatives have paid variable attention to the factors that affect the patient experience. However, research on patient experience has faced several challenges, including stakeholders' disagreement on the scope of patient experience, quality and measurement challenges, and knowledge translation challenges. These challenges have affected the ability of patient experience research and measurement to produce meaningful and actionable data that can help improve the quality of healthcare. Therefore, policy and process-level changes may be required in the healthcare system and healthcare settings to improve and support the evaluation of the patient experience and increase the utility of this evaluation[32]. Methods and guidelines should be developed for collecting and analyzing patient experience data and interpreting the analysis results[30–32].

Social media has emerged as a means for the patients to post stories about their healthcare experiences and express their satisfaction or dissatisfaction with these experiences. Many social media platforms contain patient stories, some of which, such as Care Opinion, are dedicated to collecting patient stories and facilitating patient-provider communication. In contrast, other platforms, such as Facebook, are undedicated to patient stories, and they host diverse types of content.

Patient stories can help patients choose their healthcare providers and share their experiences with patients who may have similar health conditions[31,76,80]. They can also help physicians identify aspects of healthcare that can be improved[31]. These stories represent recent healthcare encounters, and they are available in large volumes, which reduces the data collection costs. Also, these stories can shed light on issues in healthcare that are not always exposed by traditional patient experience surveys, including the patient's lived experience of illness, emotional and financial burdens of illness, and patient satisfaction[30,31]; therefore, they have a high potential for healthcare quality improvement[30,81].

However, many factors can impact the utilization of patient stories on social media in the healthcare system. First, the evidence suggests that social media has been perceived as a source of risks to the healthcare professions and professionals[98], and therefore, policies are developed by healthcare regulators to mitigate those risks and govern how healthcare providers and administrators interact with patients on social media[95–97]. These policies may encourage or discourage the use of social media by healthcare providers.

Second, empirical evidence suggests that healthcare providers and administrators have concerns regarding the validity and credibility of patient stories. These stories may pose threats to providers' authority and reputation, patient-provider relationships, and patient and provider privacy. These threats can discourage healthcare providers and administrators from using and responding to these stories. Therefore, to evaluate the utility of patient stories on social media, it is essential to explore the perspectives of healthcare providers regarding health social media in general and patient stories in particular.

The existence of providers' concerns regarding patient stories suggests that healthcare providers and administrators should ignore online patient story platforms. However, the literature is scant on studies on how healthcare providers and administrators respond to these stories and the factors that affect their responses. Therefore, analyzing the content of the stories and the provider's response pattern enables us to understand whether the providers' concerns impact how they perceive the value of the online patient story platforms.

1.2 Thesis Purpose and Organization

By addressing the knowledge gaps identified in section 1.1.9, this thesis aims to assess the utility of patient stories on social media for healthcare quality improvement and explore the health system and policy factors that may positively or negatively affect this utility in the healthcare system in Ontario.

The thesis uses an exploratory sequential mixed-method design that is guided by a theoretical perspective, which is presented in Chapter 2. The remainder of the thesis is comprised of four studies presented in chapters 3 to 6, and a conclusion chapter.

The first study (Chapter 3) is a qualitative exploratory research study that seeks to understand the perspectives of healthcare providers and administrators in Ontario regarding patient experience and the factors that affect it. This study helps to understand the perspectives, needs, and priorities of the providers and administrators, who are the prospective users of patient stories in the healthcare system in Ontario. As I explain in section 1.1.1 in this chapter, these two groups may have different perspectives on patient experience and its relation to healthcare quality and outcomes. Therefore, it is crucial to understand these perspectives in order to assess how patient stories fit within the agenda of these two groups. This study helps to fill the first knowledge gap, which is understanding the perspectives of healthcare providers.

The second study (chapter 4) is an exploratory qualitative research study that aims to explore the perspectives of healthcare providers and administrators in Ontario regarding the utility of patient stories posted on social media. The study helps to understand these groups’ concerns and expectations about the benefits of patient stories and; therefore, it also helps to fill the first knowledge gap.

The third study (chapter 5) employs qualitative document analysis to explore the health system policies related to the use of social media by healthcare professionals in Ontario. The study helps to understand the impact of these policies on the utilization of patient stories on social media. Therefore, the study helps to fill the second knowledge gap, which is understanding the necessary policy and process-level changes required to enable the utilization of patient stories in the healthcare system.

The fourth study (chapter 6) employs statistical analyses, natural language processing, and text mining to analyze patient stories on the Care Opinion Platform, which is a social media platform dedicated to collecting patient stories in the UK. Analyzing the content of the stories and the provider's response pattern enables us to understand whether the providers' concerns impact how they perceive the value of online physician reviews platforms. The study helps to fill the third knowledge gap, which is evaluating the meaningfulness of patient stories on social media.

Altogether, this work contributes to the understanding of the role that social media can play in improving patient experience and amplifying the voice of patients in the healthcare system. The reader will notice that some background information from this chapter is being repeated in the other chapters, but this is inevitable because each study will be published separately in a different journal.

CHAPTER 2

Theoretical Perspective

2.0 Preamble

The theoretical perspective or framework, according to Collines et al.[1] is:

> "The use of a theory (or theories) in a study that simultaneously conveys the deepest values of the researcher(s) and provides a clearly articulated signpost or lens for how the study will process new knowledge."

It reflects the ontological and epistemological beliefs of the researcher[2]. It helps researchers identify what issues are important to explore and who the best informants are[3]. The theories that are part of the theoretical perspective underpins the whole research project. They impact how the researcher conceptualizes the phenomenon under the study and what and how the data will be collected and interpreted[2].

Because my ontological and epistemological beliefs influenced my theoretical perspective, I discuss my worldview in the next section.

2.1 My Worldview

In this dissertation, I situated myself within the critical realist paradigm or what is known as postpositivism. Ontologically, critical realism acknowledges that there is a single reality in any phenomenon. Epistemologically, however, this reality cannot be completely idefined[4,5] and "the absolute truth can never be found"[6]. Critical realism, is, therefore, theory-laden, according to Fletcher[7]:

> "Critical realism treats the world as theory-laden, but not theory-determined. Critical realism does not deny that there is a real social world we can attempt to understand or access through philosophy and social science, but some knowledge can be closer to reality than other knowledge. The theories that help us get closer to reality, i.e. that help us identify causal mechanisms driving social events, activities, or phenomena, are selected and formed using rational judgment of these social events."[7]

The knowledge can also be gained through observations and experiments. It can also be collected from people (i.e., informants) using a variety of instruments, including surveys and interviewes[4]. However, critical realism acknowledges also it is difficult for the researchers to be objective throughout the research process and that researcher's beliefs and values affect their theoretical perspective, the framing of the research problem, their understanding of facts and knwoledge[8,9]. Lincoln and Guba[9] argue that qualitative research studies cannot be value-free:

> "Inquiries are influenced by inquirer values as expressed in the choice of a problem, or evaluand, and in the framing and focusing of that problem. They are also influenced by the choice of the paradigm that guides the investigation, and by the choice of the substantive theory utilized to guide the collection and analysis of data and in the interpretation of findings." [9]

Social studies, such as this dissertation that are conducted under the critical realist paradigm, strive to understand the contexts of the phenomena under study, including the social, cultural, and political contexts, and they try to explore the emic views of people on these phenomena[5]. The theories that comprise the theoretical perspective in this dissertation assert the importance of understanding the emic views of healthcare providers and administrators in the healthcare system on the use of social media for quality improvement, and the impact of the social context on such use.

As evident in the next section, my worldview impacted the selection of the theoretical perspective that I have adopted in this dissertation. Additionally, my beliefs and values have also impacted my theoretical perspective. In the first theoretical study that I conducted on patient expereince[10], which has also profoundly informed this dissertation, I explicitly describe my personal view on patient experience:

> "We believe that the appreciation of patient experience should not be subject to the never-ending complexity of the healthcare system and the different views and priorities of the healthcare system stakeholders. We also believe that with the lack of conclusive evidence for the association between patient experience and healthcare quality, the argument for patient experience should adopt a human-rights-based approach, which is the approach used in World Health Report 2000, as we have explained in this paper. Such an approach asserts

> that patients have the right to receive high-quality healthcare that is respectful, empathetic, and attentive to their health and non-health needs." [10]

In the next section, I describe the theoretical perspective that informed this dissertation.

2.2 Theoretical Perspective

In this dissertation, I explore the phenomenon of patient stories on social media. I treat social media as a system for collecting these stories and facilitating the communication between patients and healthcare providers about these stories. This system has two groups of users: the patients and healthcare providers. To understand this phenomenon, I employ a theoretical perspective that consists of particular theories and concepts, each of which sheds light on certain aspects of this phenomenon. These theories and concepts are explained in the next sections.

2.2.1 Socio-Technical Systems Theory

I use the socio-technical systems theory to explore the phenomenon of patient stories on social media. From this perspective, the online patient story platform can be conceptualized as a technical system that is embedded within a sociopolitical context (i.e., organizational structures and policies) and is used by groups of actors (e.g., patients and healthcare providers) to achieve specific goals (e.g., expressing satisfaction, complaining, or quality improvement). These three elements interact with each other through feedback loops that enable actors to influence the design of the system and the making of policies that control the performance of the system.

Socio-technical systems theory was developed by researchers at the Tavistock Institute in the UK in the 1950s to explain performance issues and dissatisfaction of workers that had been happening in some companies as a result of using new manufacturing systems[11]. The theory has underpinned several approaches for designing work systems and information systems[12,13] and evaluating existing ones[11,12,14]. The main tenet of the theory is that technical systems, such as manufacturing or information systems, are used or operated within social and organizational contexts that can impact the use and performance of these systems, regardless of the technical quality of these systems[12,15]. The theory argues that any socio-technical system is subject to factors belonging to different contexts within and outside the organizations, including the technical, social, political, cultural, and legal contexts[15,16]. These factors impact the work and performance of organizations and their technical systems.

Geels[17] identified three elements that should be analyzed to understand a socio-technical system: the technical system, the actors, and the institutions. The technical system is comprised of technical artifacts and technical infrastructure that are designed to perform specific tasks such as producing an item in a factory or sending an email message. The actors are the people using the technical system, including factory workers and employees of an organization. These actors may comprise several social groups that have common goals, interests, or cultural or professional backgrounds, including companies, patient groups, universities and advocacy groups. The institutions are entities that have the power to set the rules that control and constrain the work and interactions of the actors, including labour unions, governmental bodies and judiciary entities[17].

To understand the power relations among the actors and the sociopolitical context of the technical system, I use another theoretical lens situated within health sociology.

2.2.2 Health Sociology

Health sociology analyzes the patient experience with illness and the social context of health and illness and examines the social factors that impact the conditions that directly or indirectly cause health inequalities and illness and impact people's access to healthcare[18,19]. Health sociology also studies the power relations in the healthcare system and the interaction between healthcare providers and patients[19,20]. It deviates from the biomedical perspective of health by emphasizing the significance of social factors on people's health, health behaviours, illness, and experiences with healthcare[19,21–23]. One of the approaches in health sociology is the critical approach, which uses conflict theory to analyze the politics in the healthcare system and the relationships among the different groups in that system[19]. This approach foregrounds the social contexts and outcomes of conflict, and, by doing so, it deviates from the functionalist view of the healthcare system, which sees the system as a set of harmonized, linked processes that together work to meet or achieve agreed-to goals[19]. Moreover, conflict theory asserts that inequalities in power, resources, and interests are intrinsic characteristics of all social structures and that there are always some groups that benefit from those inequalities and therefore, strive to maintain them and perpetuate the social structures that produce them[24,25].

I draw in particular on Weber's sociology of domination, which primarily focuses on power, stratification, social groups, and conflict to understand and discuss power relations and priority differences between the healthcare providers and administrators in the healthcare system in Ontario (Chapter 3), and the role that healthcare regulators and medical associations in Ontario play to govern healthcare professions (Chapter 5).

2.2.3 Weber's Sociology of Domination

For Weber, power, economic capabilities, and social status create social groups that have different goals and interests. Social stratification and the goals and interests of the dominant groups are preserved by the creation and nurturing of certain norms, values, and beliefs that direct the actions of the members of these groups.

In his seminal work *Economy and Society*, Weber defines power as:

> "Power refers to every chance, within a social relationship, of enforcing one's own will even against resistance, whatever the basis for this chance might be."[26].

Weber asserts that authority is a legitimate power[27], and identifies three types of legitimacy: charismatic, traditional, and legal legitimacy[27]. Traditional legitimacy, such as the legitimacy of senior clerics, is based on historical traditions, cultural practices, and/or religious beliefs. Charismatic legitimacy, such as the legitimacy of some political leaders, is based on the characteristics of individuals, such as their leadership skills or their deeds. Legal legitimacy, such as the legitimacy of police officers or licensed engineers, is based on laws, regulations, or constitutions[28].

Weber argues that power, economic capabilities, and social status determine stratification in society[25,29]. Economic capabilities refer to people's capability to buy and sell goods, and the factors that affect such capability, including people's education, occupation, and income. Social status refers to the social rank that people in society are assigned based on economic, political, religious, or cultural factors. These causes of stratification create social groups that have different power, status, and economic capabilities. Conflict arises as a result of the pursuit of these groups to protect or change their position by changing any of the causes of stratification[28].

Weber identifies several social groups, including political parties, labour unions, and lobbies[29]. At the stage where the primary motive for members of a social group to respect the rules and obey the commands of its authority is to protect their interests and status, then that authority reaches the state of dominance[26,27]. Professional groups such as labour unions and professional associations are the democratic expression of the conflict of interests and power differences among the social groups that they represent[27]. These groups maintain their social positions and protect their goals and interests by the creation and nurturing of certain norms, values, and beliefs that direct the actions of the members of the groups[30,31]. From a Weberian perspective, to understand professions, professionalization (i.e., the process of becoming a professional), and professional practices (i.e., codes of conduct) requires recognizing power relations and interests within and outside the professions[32].

For Weber, the different elements of culture, including norms, values, and art reflect the worldviews of the rulers, elites, and religious leaders and define the socially acceptable means and desirable targets for power conflicts[30]. Ideas and worldviews have a more substantial influence on people's actions than norms and values[31]. Weber discusses how Protestant beliefs influenced the rise of capitalism and argues that norms, values, and beliefs are constructs of power conflicts and a means to preserve the ideal and material interests of the dominant groups[33,34].

According to Weber, people perform economic activities using a form of rationality that can be either formal or substantive[26]. Formal rationality refers to the "purposeful calculation of the most efficient means and procedures to realise goals"[26]. The substantive rationality, on the other hand, refers to the performance of activities that is directed, influenced, or motivated by factors other than efficiency, including ethics, politics, and values[26]. Formal rationality was, according to Weber, a key factor in the emergence of capitalism and the development of the West[35]. Weber sees bureaucracy as a form of managing modern organizations using formal rationality[35]. Cockerham[35] argues that although modern healthcare systems have primarily performed using substantive rationality—healthcare service delivery is guided by ethical, social and scientific standards to achieve health outcomes, the increasing demand for and the cost of healthcare has pushed the system more towards formal rationality—healthcare services delivery is guided by efficiency and cost containment calculations[35]. This inclination of the system towards formal rationality has been accompanied by an increase in the power of health care administrators at the expense of healthcare providers[35], as I explain in the next section.

2.2.4 Power Relations in the Healthcare System

Alford[36] identifies three main social groups in the healthcare system: healthcare providers, healthcare “bureaucrats” (i.e., administrators), and the community. Power differences and conflict of interests between these groups affect the delivery of healthcare and impede the reform of the healthcare system. Ignoring these structural factors may turn all calls for reforms “chimerical” [36].

Healthcare providers represent the dominant group that holds the most significant powers in the healthcare system. The members of this group share common beliefs about health and healthcare, and they also hold professional expertise to provide health services. Physicians, in general, hold the most prominent power in this group[36]. Healthcare administrators provide different types of non-medical or non-health-related expertise in the healthcare system, and they include policymakers and healthcare administrators, and, according to Alford, represent the challenging power whose main goals are the efficiency of the system and quality of care. Policymakers, in general, hold significant power in this group. Lastly, the community represents patients, who are the “repressed” group in the healthcare system because they hold less power than the other groups, and their interests are less vital than those of the other two groups[36]. These groups develop distinct beliefs and views that impact their interactions with the other groups. Those beliefs, according to Tajfel[37], have three functions. First, they influence and justify interactions with other groups. Second, they provide explanations and positions regarding social problems such as poverty and illness. Third, they support identity awareness and membership rationalization for group members[37].

The evolution of power relations in the healthcare system has been associated with the development of organized medicine, which is explained in the next section.

2.2.5 Organized Medicine

Medicine is a self-regulating profession. In most countries, medical associations regulate the main elements of medical practices and services and exert varying degrees of control over the clinical quality of those services. Nevertheless, physicians remain relatively autonomous in shaping those services and making important decisions throughout the patient journey. Freidson[38] argues that structuring and controlling the delivery of healthcare to ensure high financial returns and avoid competition pressures that would drive down costs are the main goals for medical associations rather than altruism or empathy[38]. With the legitimate powers that they have (i.e., authority as per Weberian nomenclature), the medical associations control the nuances of the medical practice and direct it towards the achievement of these goals. The ideas and goals of the medical associations shape the norms and values of the medical practice and affect patient experience more than the ideals promoted and taught in the medical schools and more than the beliefs and values of many individual physicians[20]. The role of the medical associations can be understood under the Weberian conflict theory and his thoughts about the dominance of the authority in social groups as discussed in the previous section.

2.2.6 The Source of Professional Power in Healthcare

Physicians are formally licensed, and thus authorized, as knowledgeable medical service providers (i.e., experts). Domain knowledge or domain expertise has been a source of power for healthcare providers. In ancient and modern societies, knowledge has always given varying degrees and types of power, including economic and political powers, to those who possess it, including shamans, lawyers, engineers, and doctors[39].

Derber et al.[39] argue that "monopolies of knowledge can bring class power as surely as monopolies of capital."[39] To retain their power, knowledge holders or experts have used several methods, including the use of sophisticated technical languages to communicate with each other, the controlled professional training, and the licensure.[39]

For healthcare providers, domain expertise and the resulting power have led to a socio-technical function termed medicalization, which refers to the process of classifying or defining a set of health or behavioural conditions as a medical condition[40]. In the biomedical literature, this process depends on the etiology and epidemiology of the abnormal conditions. However, the very identification of a condition as an abnormal one that needs medical interference can be socially and culturally dependent, according to Zola[41], who argues that abnormality may be selectively conceptualized based on existing social norms or values in addition to somatic or mental symptoms[41]. Many social groups benefit financially from medicalization, including healthcare providers and pharmaceutical companies. People who may be labelled as patients through processes of medicalization may also benefit from it, but they can also be harmed if they are stigmatized as a result of being labelled as patients[19]. Classifying a condition as a medical problem entails that medicine is the authentic source of solutions for it and that healthcare providers are the only authentic experts to provide such solutions[19].

In my first empirical study (chapter 3), I show and discuss how some study participants that are healthcare professionals believed that their knowledge and expertise are more critical to healthcare than the bureaucrats' knowledge. I also discuss how medical power enables healthcare professionals to decide what elements of healthcare experience "count" and what are the best methods to assess these elements.

2.2.7 Summary

In this dissertation, I employ a theoretical perspective that consists of specific theories and concepts, each of which sheds light on certain aspects of this phenomenon.

According to the socio-technical systems theory, the online patient story platform can be conceptualized as a technical system that is embedded within a sociopolitical context (i.e., organizational structures and policies) and is used by groups of actors (e.g., patients and healthcare providers) to achieve specific goals (e.g., expressing satisfaction, complaining, or quality improvement).

To understand the power relations among the actors and the sociopolitical context of the technical system, I use a critical approach in health sociology, which uses conflict theory to analyze the politics in the healthcare system and the relationships among the different groups in that system[19]. I draw in particular on Weber's sociology of domination, which primarily focuses on power, stratification, social groups, and conflict to understand and discuss power relations and priority differences between the healthcare providers and administrators in the healthcare system in Ontario (Chapter 3), and the role that healthcare regulators and medical associations play to govern healthcare professions in Ontario (Chapter 5).

In the next four chapters, I present the four studies that comprise this dissertation.

Forward to Chapter 3

As I discuss in the introduction chapter of this thesis, to analyze the utility of the technical system (i.e., the patient stories on social media), the researcher needs to explore the beliefs of the potential users and the sociopolitical context where the system may be used; regardless of how good the technical quality of this system is.

My literature review on patient experience shows that the two dominant groups in the healthcare system, which are healthcare providers and administrators may have different perspectives on the importance of the different elements of the patient experience. Healthcare providers prioritize health outcomes, whereas healthcare administrators call for paying attention to the other elements in this experience, such as healthcare quality. The two groups also have different priorities. Healthcare providers focus on fulfilling the health needs of the population, whereas administrators prioritize cost containment and the system's efficiency.

Therefore, the first study in this dissertation consisted of interviewing healthcare providers and administrators to understand their perspectives on patient experience. The interviews were anchored around a particular recent initiative in the healthcare system in Ontario, which is the "Patient First" initiative. This initiative was developed in 2015 by the Ministry of Health and Long-Term Care in Ontario, and later became the Patient First Act in 2016. It drew on principles of patient-centredness, quality of care, public health, and health promotion[1]. However, the initiative focused solely on patient experiences with healthcare and remained silent about patient experiences with illness. Also, while the initiative stressed the importance of educating people to make healthy choices, it remained silent about increasing people's chances to make healthy choices by removing financial and social barriers to make such choices.

While I was collecting the data, a new government was elected in Ontario, and it has started its healthcare reform by restructuring the healthcare system and introducing significant cuts to programs and a complete revamping of the distribution of funding and administrative processes. The appointment of the new government allowed me to discuss the impact of healthcare policy interventions on patient experience with study participants.

CHAPTER 3

Perspectives of Primary Healthcare Providers and Healthcare Administrators on Patient Experience in Ontario: A Qualitative Exploratory Study

Purpose: The experience of patients with healthcare has been associated with healthcare quality, suggesting that improving healthcare quality may lead to a positive experience. However, other factors may affect patient experience but have either been discredited, such as patient expectations, or received little attention in healthcare quality literature, including a patient's socioeconomic status, and priority differences between healthcare providers and administrators on key health policy issues that affect the healthcare system's ability to fulfill the health needs of people. This study sought to understand the perspectives of healthcare providers and administrators in Ontario regarding the factors affecting the patient experience.

Study Design: Qualitative data were collected between April 2018 and May 2019. Twenty-one semi-structured interviews were conducted. Interviewees included physicians, nurses, optometrists, dietitians, quality managers, and policymakers. Thematic analysis was used to analyze the data, utilizing and extending a previously developed patient experience framework.

Findings: Several themes emerged in the data, and they represent two perspectives on patient experience: the biomedical perspective, which prioritizes health outcomes and gives high weights to healthcare experience factors that can be controlled by healthcare providers, while ignoring other factors, and the sociopolitical perspective, which recognizes the impacts of healthcare politics and the social context of health on patient experience in Ontario.

Originality/value: The study is timely in light of the current changes in the Ontario healthcare system, as it sheds light on several factors that affect patient experiences and have not received much attention in the literature, including the provider's consideration of patient satisfaction, unrealistic patient expectations, patient responsibilities, provider burnout, the disconnect between healthcare providers and administrators, and the scope of professional practices.

3.1 Introduction

People seek healthcare services and interact with the healthcare system to alleviate or mitigate the impacts of illness on health and wellbeing. The patient experience refers to interactions of a patient in the context of illness and healthcare and the resultant perceptions and effects, and it consists of two components that are represented in (Figure 3.1): the lived experience of a patient with illness (i.e., illness experience), and the healthcare experience of a patient (i.e., healthcare experience)[2]. The former refers to the social, emotional, and economic effects of illness on patients and their families[3]. The latter refers to the interactions of patients with the healthcare system, including their interactions with nurses, physicians, and staff members[4]. The two components are interconnected. The individuals' illness experiences affect their health needs and expectations of healthcare. On the other hand, patients' healthcare experiences affect their experiences with illness[2]. However, the two components receive unequal attention from healthcare stakeholders. Healthcare experience receives more attention because it can be more controlled within the healthcare system than the illness experience, which may be affected by factors that are beyond the control of the healthcare system, including various cultural and socioeconomic factors such as patients' illness beliefs, income, occupation, and education[3,5–9].

Healthcare experiences have primarily been associated with healthcare quality (i.e., improving healthcare quality creates a positive healthcare experience)[4,10–13]. As presented in (Figure 3.1), many factors can affect healthcare experiences. The weight given to each factor depends on the availability of evidence on its relationship with healthcare quality and healthcare outcomes[2,14,15]. In general, patient-provider communication, staff empathy, and patient safety receive bigger weights and more attention than the other factors such as patient expectations, and patient satisfaction[2,14,16–18].

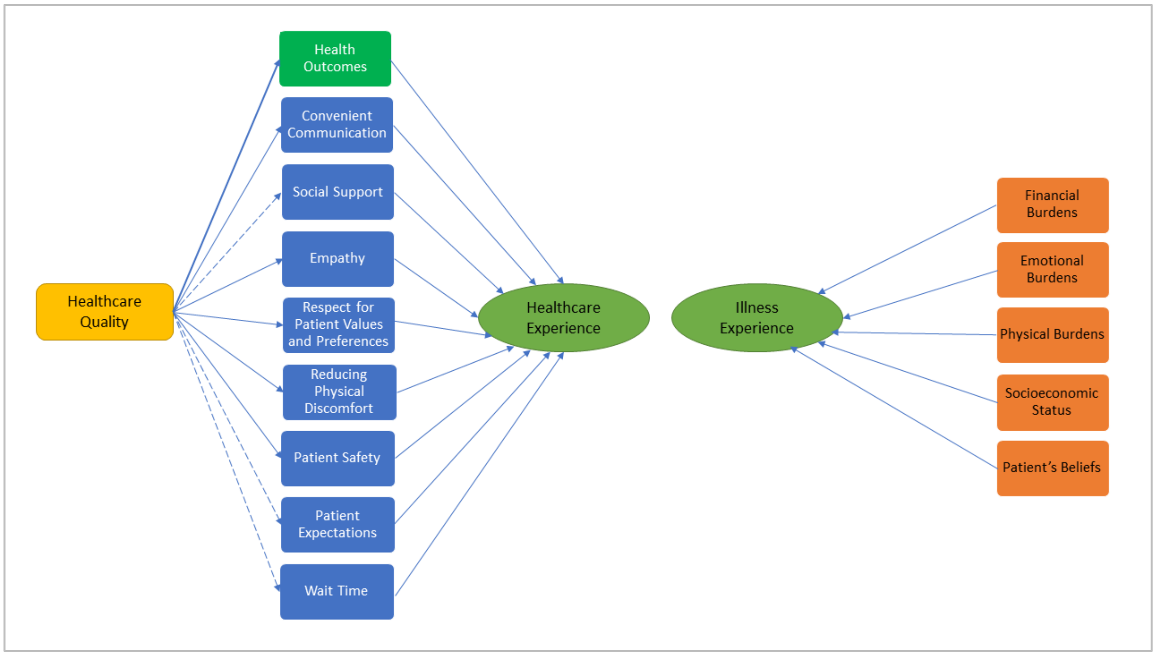


Figure 3.1: The Components of Patient Experience

3.2 Background

Health policy interventions can directly or indirectly impact the patient experience. In June 2018, the Ontario Progressive Conservative (PC) party won the provincial election. The PC government created a new healthcare plan that aims at improving the quality of care and achieving better governance. To achieve these aims, the government has established the "Ontario Health Agency" that will be responsible for directing and coordinating the different components of the healthcare system, monitoring healthcare quality, providing clinical guidance, reducing the cost of healthcare by eliminating overlap in administration and infrastructure, and boosting effective integration of e-health into the healthcare system[19]. The plan has introduced significant cuts to programs and a complete revamping of the distribution of funding and administrative processes to reduce the costs of healthcare.

The new plan includes budget cuts for overall healthcare, hospitals, mental health, drug overdose prevention, autism care, ambulance services, and public health services[20]. Despite the government's promise not to layoff nurses, budget cuts have forced hospitals to reduce their nurses and administrative staff [21]. The government has also merged many healthcare organizations such as eHealth Ontario, Health Quality Ontario, Cancer Care Ontario, and the

Local Health Integration Networks (LHINs) into a single organization. The government also has laid off hundreds of administrative staff in those organizations, and, as a result, it has been subject to criticism by some labour unions such as the Canadian Union of Public Employees. The Ontario Nurses Association has called the government's new healthcare plan a "shot-in-the-dark" and asked the government to "consult with the experts"[21,22]. The Ontario Medical Association has raised concerns regarding proposed budget cuts in public health and preventive care[23] but has welcomed the recommendation of the Ontario Premier's council on improving healthcare and ending "hallway medicine"[24].

Although the impact of the new plan on the quality of healthcare and patient experience has not been evaluated, healthcare reform that mainly seeks cost reduction through reducing available healthcare services and service coverage can disproportionally affect vulnerable people[25,26]. There is a large body of evidence that healthcare austerity policies in Europe, which were adopted after the economic crises in 2008, resulted in increases in food insecurity, mental health problems, and unmet health needs[27], and negatively affected health equity, health outcomes, and healthcare quality[28–30]. Therefore, the changes proposed by the Ontario government that relate to reducing hospital budgets and other essential healthcare services such as public health and mental health can be expected to impact illness and healthcare experiences of the patients. The transition of power in Ontario, with each government bringing its new healthcare reform plan and new political agenda, provides a clear example of the impact of politics on healthcare and patient experience. Moreover, the critical responses of some healthcare provider associations to the new plan are an indicator of the gap between the perspectives of healthcare providers and policymakers.

3.2.1 A Conceptual Framework

In this study, I develop a multi-perspective patient experience framework, which extends extend the patient experience determinants and manifestations framework developed by Zakkar[2] (Figure 3.2) that classifies the different dimensions of patient experience into two categories: the determinants and the manifestations[2]. The determinants of patient experience include the experience of illness, patient's subjective influences such as patient expectations, quality of healthcare services, and the politics of healthcare. The manifestations of patient experience include patient satisfaction and patient engagement[2].

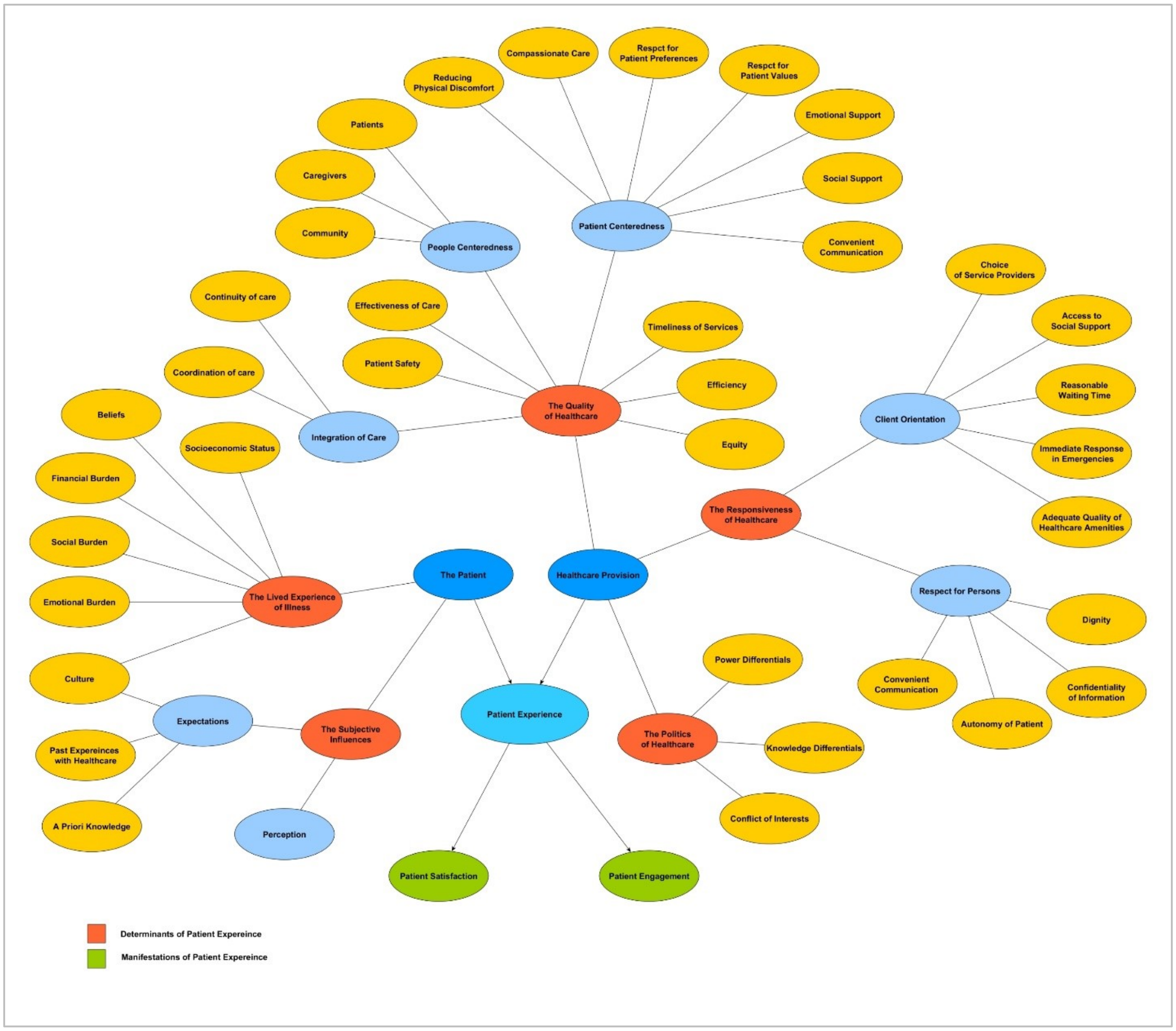


Figure 3.2: The Patient Experience Determinants and Manifestations Framework[2]

This study extends the aforementioned framework by incorporating two additional perspectives on health and illness — the biomedical and the sociopolitical perspectives —, and classifying the determinants of patient experience accordingly. This framework is represented in Figure 3.3.

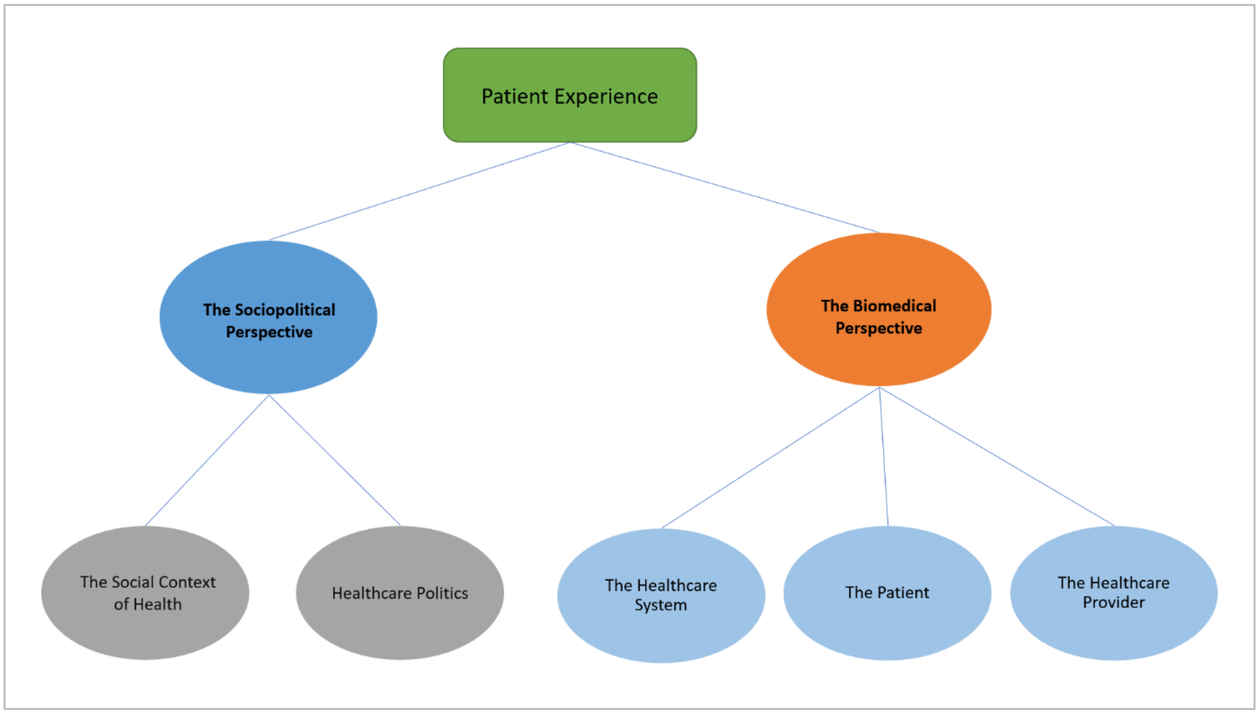


Figure 3.3: The Multi-Perspective Patient Experience Framework

The biomedical perspective conceptualizes and defines disease as "deviations from the norm of measurable biological (somatic) variables"[31] and largely ignores or assigns less importance to the impacts of the social and psychological factors on health[31,32]. The sociopolitical perspective, on the other hand, focuses on the impact of power differentials within the healthcare system on interactions and structures within this system[33,34]. As I explain in the following sections, under each of these perspectives, only certain aspects of the patient experience are considered by healthcare providers.

The multi-perspective patient experience framework was developed following an iterative process (Figure 3.4). First, I identified certain aspects that require elaboration in the patient experience determinants and manifestations framework, including the relationship between the determinants and the healthcare model, which may be biomedical or biopsychosocial[31]. Second, I reviewed the literature to identify and use existing knowledge. Third, I developed the initial version of the framework, which was reviewed by two of my colleagues that made several suggestions for improvement. Fourth, I used the initial version to prepare the interview guide for the empirical study presented in this paper. The study revealed more information that enriched the framework. This iterative process continued during the study and ended after comprehensive reviews and editing of the present paper.

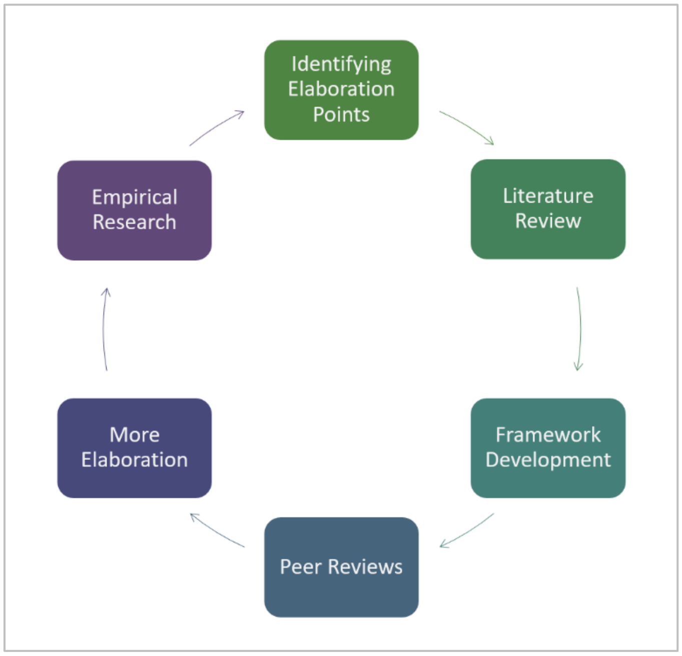


Figure 3.4: Framework Development Process

Although patient experience denotes the patient's lived experience of illness and the patient's healthcare experience, in this paper, the concept refers mainly to the patient's healthcare experiences.

3.2.1.1 The Biomedical Perspective on Patient Experience

The biomedical perspective on patient experience is the dominant perspective in healthcare and healthcare discourse[33,35], prioritizing the achievement of health outcomes over the enabling of ideal healthcare experiences[14,31,32,35]. The different elements of patient experience and the factors that affect them receive varying attention from healthcare providers depending on the availability of evidence that links these elements to healthcare quality and outcomes[2,14,15].

There are three classes of factors that affect patient experience: healthcare provider factors, patient factors, and healthcare system factors. These factors are represented in Figure 3.5.

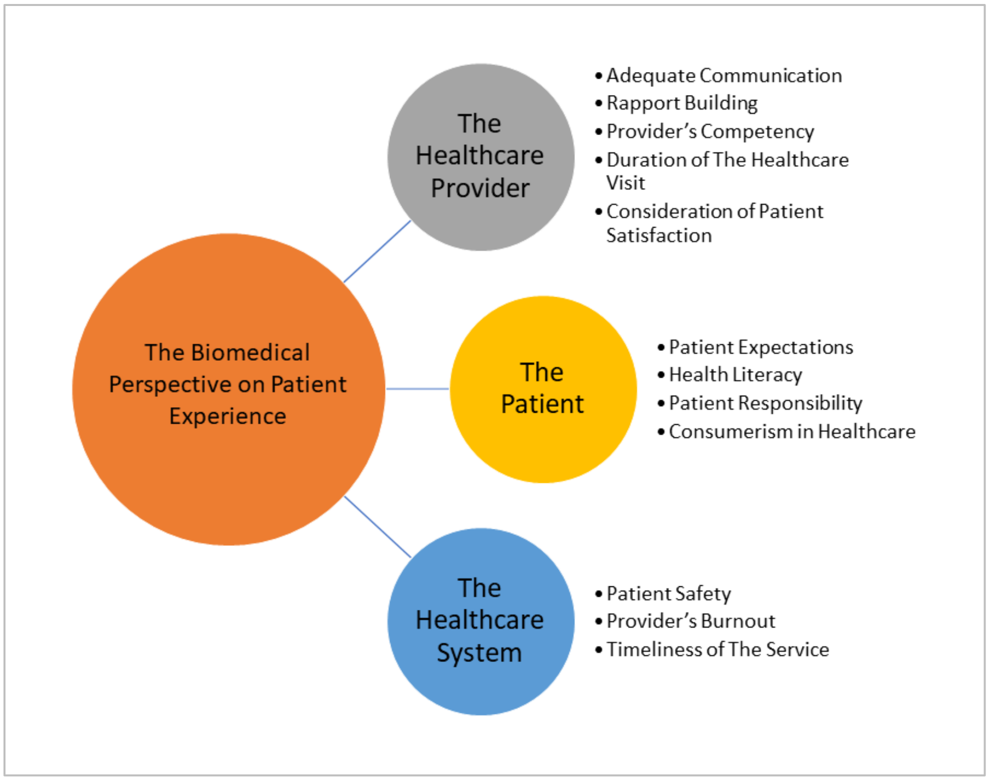


Figure 3.5: The Biomedical Perspective on Patient Experience

The healthcare provider factors: These factors affect the patient-centredness of healthcare, which is one of the aims of healthcare quality[9]. There are six aims for healthcare quality: patient safety, the effectiveness of care, patient-centredness, timeliness of services, efficiency, and equity[9].

Patient-centredness focuses on providing a satisfactory healthcare experience to the patient[9], and it identifies a set of factors that affect the patient experience. These factors are respecting patient's values, preferences, and needs, coordination and integration of healthcare services, the communication between the patient and medical staff, the physical comfort of patients, the level of compassion in the care provided to patients, and the social support available to patients[9].

Other factors have also been identified in the literature, including the duration of the healthcare visit, provider's competency, and the healthcare provider's consideration of patient satisfaction. The duration of the healthcare visit may impact healthcare experiences. A short visit time reduces the quality of patient-provider communication and prevents the patients from describing their health conditions and the illness experiences[36–38]. Provider's competency represents the provider's ability to provide effective and safe healthcare, which are part of the aims of healthcare quality[9,39].

The healthcare provider's consideration of patient satisfaction refers to whether healthcare providers consider patient satisfaction to be a desired outcome of healthcare. Patient satisfaction is an affective evaluation by the patients of their experiences with healthcare[40]. This evaluation is influenced by subjective factors, such as patients' expectations and patients' perceptions of their healthcare experience. It is also influenced by the quality of the healthcare services[4,10–12]. Historically, patient satisfaction received considerable attention by quality managers in the 1990s as a proxy indicator for healthcare quality; however, more recently, questions have been raised as to whether it is a reliable indicator of quality[41]. Nevertheless, recent quality initiatives such as the integrated people-centred health services (IPCHS) initiative of the World Health Organization[42] recognize patient satisfaction as an outcome of healthcare quality.

The patient-related factors: These factors are patient expectations, health literacy, patient responsibility, and consumerism in healthcare.

Patient expectations represent assumptions about healthcare performance, and they are influenced by a priori knowledge of the patients, and past healthcare experiences of patients and their families[5]. During healthcare service encounters, patients may have expectations about their healthcare experiences (i.e., service quality) and about healthcare outcomes. The World Health Organization's World Health Report 2000 asserts that the healthcare system should focus more on some legitimate expectations of the patients about their healthcare experiences, including the expectations of being treated respectfully, privacy protection, convenient communication with healthcare providers, reasonable wait times, and autonomy[43–45]. In the literature, most research studies have focused more on patient expectations about healthcare outcomes than on patient expectations about healthcare experiences, and many studies have found a positive relation between optimistic patient expectations about healthcare outcomes and the achievement of these outcomes[46–48]. Studies of patient satisfaction assert a strong relationship between meeting the expectations of patients about their healthcare experiences and their overall satisfaction[49–51]. However, the literature is scarce about how patient expectations can be classified as legitimate and realistic, or illegitimate, and unrealistic and who would determine such a classification.

Health literacy denotes, “The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”[52]. From a healthcare quality perspective, health literacy affects how patients communicate with healthcare providers and how they engage with healthcare and their whole healthcare experience[13]. Patients with reasonable health literacy have better health outcomes[53,54], are more likely to be satisfied with their communication with the healthcare providers[55], and are more likely to access healthcare services[56].

Patient responsibility is a patient-related factor that affects the patient’s health and healthcare experience. In the health promotion and public health literature, there are various perspectives on the scope of responsibility (i.e., what a person is responsible for) and the level of personal responsibility (i.e., how much a person is responsible for). However, health promotion programs that focus on individual health behaviours but ignore the effects of socioeconomic and political contexts on people’s health choices have been criticized for blaming the victim instead of providing appropriate solutions[57]. In the sociology literature, the term “responsibilization” has been used to denote what is termed as a “neoliberal rationality” that promotes the idea that empowered individuals have the autonomy and agency to decide on everything in their life, including work, education, and health[58]. In the healthcare context, responsibilization leads to a perspective that people can and should be held responsible and accountable for their health, health behaviour, and healthcare choices[59]. The negative impacts of neoliberal economic and political rationalities, such as responsibilization, on health, are well-researched[60,61]. Polzer et al.[62], for example, argue that responsibilization and social inequality are intertwined in the neoliberal policies that advocate for empowered and responsible citizens while at the same time perpetuating social inequalities and thus exposing socially disadvantaged people to more health risks[62].

Consumerism refers to “manipulative advertising and marketing practices” in order to promote consumption[63]. In the neoliberal free-market state, consumerism has long been associated with people’s freedom and right to choose and obtain the commodities that best suit their needs and capacities with only minimal control from the state[64,65]. Critics of the free-market argue that consumerism is a marketing tool used for driving corporate profits while hiding the vast disparities in society by creating an illusion of freedom of choice[66]. In healthcare contexts, consumerist ideology promotes the idea that welfare systems such as healthcare and education are economic burdens on the state and the society and may be better delivered by the private sector and in a free-market environment[62,65]. Seen from this perspective, health services are a class of commodities, and people should be given the freedom to choose their healthcare providers, treatment options, and lifestyles, and this freedom of choice can only be achieved by a privately-delivered and privately-funded healthcare system[67]. There are some nuances to this approach, however. Some healthcare quality initiatives suggest treating patients as "clients" in a professional relationship with providers in order to improve the quality of healthcare without necessarily commodifying services[9]. For example, the "responsiveness" of health care is an approach that has been described in the World Health Organization's World health report 2000. The approach calls for a healthcare system that responds to the non-health needs of the patients[45]. In this formulation, two elements underpin the responsiveness of the healthcare system: respect for a patient and client orientation. The respect for a patient entails respecting a patient's dignity, values, and confidentiality of their information, and enabling them to participate in their healthcare (i.e., autonomy). The client orientation requires providing timely care, adequate quality care amenities (i.e., clean settings, clean food), access to social support from a person's family and friends, and the ability to select a healthcare provider[45].

Health system factors: These factors affect the quality of healthcare and patient experience, and they are the timeliness of the service, patient safety, the wellbeing of healthcare providers.

<u>The timeliness of the service</u> refers to providing the required healthcare service in a reasonable time[9]. Patient safety is an essential component in healthcare quality[13], and it is one of the ethical principles of healthcare and medicine[68,69]. <u>Patient safety is the outcome</u> of the interaction of several factors in the healthcare system, including communication among the staff, and healthcare processes and protocols[9,70].

Additionally, the 2018 edition of *Crossing the Quality Chasm,* sheds light on another factor that affects the quality of care, which is <u>the wellbeing of healthcare providers[13]</u>. In the same vein, the idea of <u>frontline burnout</u> refers to the overall negative physical, mental, and emotional impacts of service delivery on healthcare service providers[71].

In the healthcare context, professional burnout syndrome is a mental disorder characterized by low work enthusiasm, emotional tiredness, depersonalization, and a weak appreciation of personal achievement[72]. Shanafelt et al.[72] surveyed 7200 physicians in the USA and found that 45.8% of physicians had at least one symptom of burnout[72]. Nurses and other healthcare professionals may also suffer from professional burnout syndrome[73]. The syndrome is also associated with physical exhaustion and work overload[74].

There are several adverse outcomes of the frontline burnout. It can cause compassion fatigue in providers, which denotes the emotional and psychological burdens that healthcare providers and social workers may face as a result of their daily interactions with patients or clients[75]. It can also negatively impact the quality of healthcare, patient safety, and the overall patient experience, and it can lead to increases in healthcare costs and reduce the size of the healthcare workforce[73,76].

3.2.1.2 The Sociopolitical Perspective on Patient Experience

The sociopolitical perspective on patient experience uses a social science lens to recognize the effects of politics-related factors in the healthcare system and the social context of health on patient experience[33,77]. It is represented in Figure 3.6.

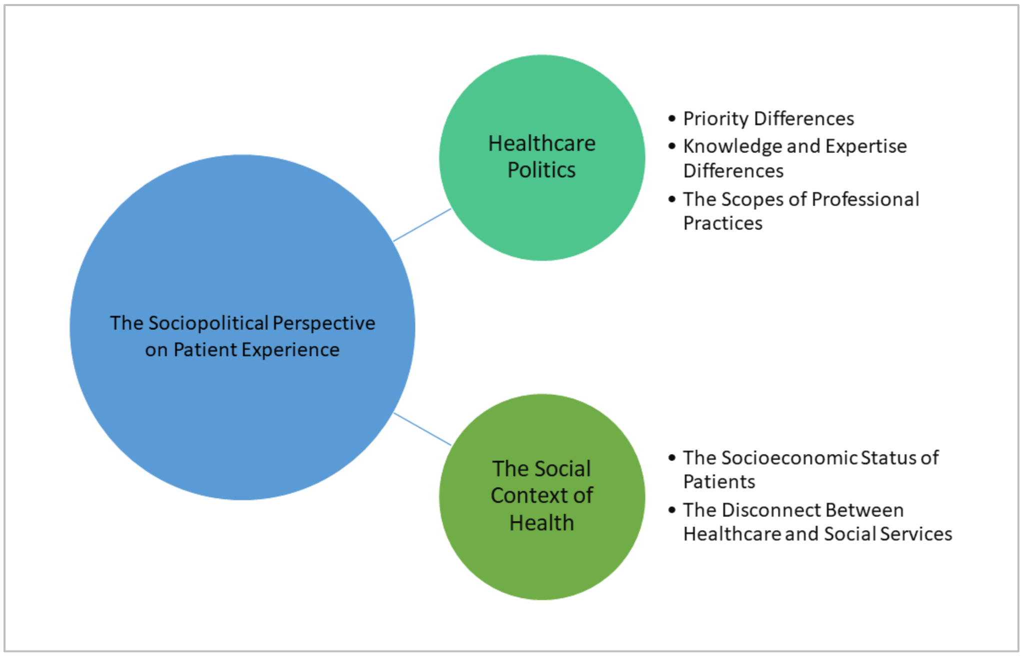


Figure 3.6: The Sociopolitical Perspective on Patient Experience

Politics-Related Factors

Politics represent stakeholders' power relationships and conflicts, and the strategies used to resolve these conflicts[78]. In the healthcare system, politics refers to power differences and the conflict of interests among healthcare providers and healthcare administrators. Healthcare providers consist of all healthcare professionals who are licensed to provide healthcare services, including nurses, physicians, dietitians, and physiotherapists. Healthcare administrators consist of all healthcare system members who provide managerial and administrative services, including quality managers, policymakers, and administrators. The power and conflict dynamics produce differences in priorities and may also cause disagreement on health policies, which can have an impact on patient experience[79–82].

The conceptual framework identifies several political factors within the healthcare system in Ontario. These factors are the priority, knowledge, and expertise differences between healthcare providers and healthcare administrators; and the scopes of professional practice.

Firstly, healthcare providers and healthcare administrators often have different goals and priorities. For healthcare providers, healthcare outcomes and patient safety are typically top priorities. On the other hand, for healthcare administrators, the cost-efficiency of the healthcare system is a key priority[2,51,81–83]. As I present in the discussion section, these differences can result in policy interventions that affect the healthcare system's ability to fulfill people's health needs. Budget cuts and staff layoffs can affect healthcare quality[79], and can lead to limited participation of healthcare providers in health policymaking[84].

Secondly, differences in knowledge and expertise between healthcare providers and healthcare administrators can also amplify priority differences. Healthcare providers typically possess medical expertise, which is built through long and continuous education, supported by professional certification, and augmented through experiences gained by interacting with patients. This expertise is a significant source of epistemic power for healthcare providers[85]. In the literature, this expertise is also depicted as an essential element in evidence-based health policymaking[86]. On the other hand, healthcare administrators, though some may also be medically trained, are required by their positions to focus on management processes, cost-containment, and sustainability[81,82]. Differences in knowledge and expertise can create disagreements concerning healthcare priorities and health policy, and they can also lead to a disconnect between the two parties[84], which in turn, can reduce the effectiveness of health policy, impede policy implementation, and have adverse consequences for the quality of healthcare[86–88].

Lastly, the scope of healthcare providers' professional practices can have an impact on patient experience. The scope of practice of a healthcare profession refers to the type of healthcare services that can be provided by a respective profession's members[89].

The scope of practice is defined by governmental regulations that delineate the boundaries of each healthcare profession. It is also defined in consultation with the healthcare professional associations, which exert varying degrees of power to influence the scope definition and protect the interests of their members[90]. Disputes among healthcare professions over specific services in the scope may also occur, such as the dispute between chiropractors and physical therapists in the USA regarding the spinal manipulation issue[90]. Dower et al.[89] argue that the legally set scopes of healthcare practices may not always be consistent with the evolution of the professions, the overlap among specific skills of some professions, and the healthcare needs in society[89]. Dower et al. assert the need for more flexible scoping regulations that take into consideration the patients' perspectives and healthcare needs[89].

The Social Context of Health

The framework recognizes the effects of the social context of health and the disconnect between healthcare and social services on patient experience.

The social context of health represents a set of factors known as the social determinants of health, and they include a person's income, education, occupation, gender, and ethnicity. They affect people's health choices and vulnerability to illness, and they also affect people's lived experiences of illness and their ability and opportunities to access and comprehend health information and allocate enough time in their life to think about their health and seek care[91–93]. Therefore, these factors may also affect people's healthcare experiences.

The boundaries of the healthcare system determine the type of health determinants—the pathological and the social determinants— that it tackles, and whether the system delivers healthcare services only or both healthcare and social services. Healthcare and other welfare systems have always been challenged by providing health and social services efficiently and equitably[91,94,95]. Hence, most healthcare systems tackle only the pathological determinants of health[10].

In most countries, including Canada, there is a separation of health and social services. Also, in Ontario, the type of healthcare services and the level of financial coverage by the government vary. Public health services, primary care, and hospital and ambulatory care are covered for all citizens, whereas medications, rehabilitative care, and mental health are only partially covered. This leaves those in lower socioeconomic groups subject to financial and social burdens of illness.

In summary, this study develops a conceptual framework that recognizes two perspectives on health and illness, which are the biomedical and the sociopolitical perspectives, and classifies the determinants of patient experience accordingly. I use this framework to understand the perspectives of healthcare providers and administrators in Ontario regarding the factors that affect healthcare experiences.

3.2.2 Purpose of This Study

This study seeks to understand the perspectives of healthcare providers and healthcare administrators in Ontario regarding the factors that affect the patient experience.

3.3 Methods

This study is a qualitative exploratory research study. Data were collected between April 2018 and May 2019. Twenty-one semi-structured interviews were conducted using an interview guide (Appendix 3. A) that focused on eliciting provider perspectives on the factors that affect healthcare experiences, illness experiences, patient satisfaction, patient-centredness, and the relationship between healthcare providers and healthcare administrators. The development of the interview guide was informed by the study purpose and by the patient experience determinants and manifestations framework developed by Zakkar[2]. The interview guide was updated frequently based on the ideas that emerged during the interviews, which enabled the researcher to probe into these ideas. The average interview length was 50 minutes.

3.3.1 Setting and Participants

Participants consisted of family physicians (n=3), specialized physicians (n=1), optometrists (n=2), physiotherapists (n=1), nurses (n=6), nurse practitioners (n=1), psychiatrists (n=1), dietitians (n=2), healthcare quality managers (n=2), and policymakers (n=2); in Ontario.

Purposive sampling[96] was chosen in order to recruit participants with the experience needed to shed light on the different dimensions of the patient experience. Knowing that healthcare professionals can have different perspectives with regard to patient experience, we wanted to recruit participants from different healthcare professions in order to get more diversified views. Two factors affected the sample size in this study. First, the target population is known to be a hard-to-reach population. Most of the prospective study participants were healthcare providers, who are very busy providing healthcare services. The busy schedule of study participants made direct communication with them almost impossible and limited my capability to recruit participants promptly. Secondly, in the purposive sampling, participant recruitment can be stopped when the researcher believes that all aspects of the phenomenon under investigation have been discussed with the participants[97]. In this study, and after I had interviewed the 21st participant, I was satisfied with the depth and breadth of the interviews, and I decided to stop data collection.

3.3.2 Ethics Approval

This study received the ethics approval (ORE #22793) from the University of Waterloo's Research Ethics Board.

3.3.3 Data Analysis

I used thematic analysis to analyze the data[97,98]. In an iterative process, the data was read carefully to identify prominent meanings or main categories, which were used to code the data and identify prominent themes.

In this study, I used a theory-led approach to thematic analysis[99], in which researchers develop a coding frame based on their a priori knowledge, literature review, and the research questions. A coding frame is a hierarchical list of codes. It provides a systematic way of reading, comparing, and organizing qualitative data[100]. The aforementioned conceptual framework (Section 3.2.1) informed the development of the coding frame used in data analysis and guided my coding process. The theory-led thematic analysis is deductive in nature because the theory dictates how the qualitative data is read, organized, and interpreted. In my analysis, I read the data several times to be able to understand the different meanings in it and code different parts of data using the appropriate codes. Figures 3.5 and 3.6 in section 3.2.1 represent the coding frame.

Nevertheless, I also used inductive reasoning by remaining open to emergent concepts and the discovery of new aspects of the phenomena. Inductive reasoning is paramount and inevitable in qualitative data analysis[96]. The use of inductive reasoning enabled me to extend the framework as I explain in the results section. I used NVivo version 12 for my data analysis.

3.4 Results

Several themes emerged in the data. These themes represent the factors that affect healthcare experiences, and many of them are consistent with the conceptual framework in this study. However, additional factors that had not been part of the framework emerged, including a patient's health literacy, patient responsibilities, consumerism in healthcare, and the scope of professional practice.

The themes are grouped into two categories: the biomedical perspective on patient experience, and the sociopolitical perspective on patient experience. In the presentation of the themes, direct quotations from study participants are provided.

3.4.1 The Biomedical Perspective on Patient Experience

The biomedical perspective is the predominant perspective in the healthcare system. It focuses on healthcare quality and health outcomes. Three themes emerged representing three types of factors that were identified by study participants, and they are related to the providers, the patients, and the healthcare system

3.4.1.1 Provider-Related Factors

This theme describes the factors that affect healthcare experience and are related to healthcare providers or can be controlled by them. These factors are healthcare provider's competency, adequate communication between the provider and the patient, rapport building, the duration of the healthcare visit, and the consideration of patient satisfaction.

Participants believed that a provider's competency is essential. Participant #2, a psychiatrist, said:

> "<u>I think they should also expect that physicians are competent in their field</u>. For example, I am conscientious in terms of using medications in treatment because it can harm the patient if used needlessly."

The communication between the patient and the provider is also vital in healthcare. Most participants asserted the importance of communication for answering patients' questions, educating the patients, and clarifying treatment options.

Participant #10, a nurse, said:

> "Patients want answers to their questions in a way that they can understand and then inform them about the resources that are going to help them improve their health, stay connected to the clinic, and be able to reach out if they have a question."

Rapport building refers to the ability of the providers to establish a trust and respect relationship with their patients. It is a crucial element in the patient-centred healthcare[42]. Participants asserted that building rapport with patients enables continuity of care.

Participant #4, a family physician, asserted that the patient-doctor relationship takes time to develop and rejected the idea that the workload in a clinic prevents family physicians from establishing a rapport with their patients:

> "<u>I completely disagree that busy physicians cannot build a rapport with their patients</u>. I think you could be in downtown Toronto and have an excellent rapport with your patients. It is not easy, and I understand that there are physicians who are burnt out, who don't feel good, and who feel very disconnected, but I think that there are many physicians who are genuinely trying to understand their patients."

The duration of the visit refers to the time a healthcare provider spends with a patient in a single encounter. Study participants believed that the duration of the visit is an essential factor in healthcare experience and suggested that financial rewards may incentivize healthcare providers to spend more time with their patients.

Participant #17, a nurse, said

> "I think that the <u>seven-minute limit per visit just compounds the complexity of healthcare and reduces the quality of care</u> we are providing especially to our seniors, which are a big population, and for them there is a multitude of issues to cover and discuss, so I think we are just kind of missing things at each point of care."

Participant #14, a specialist physician, argued that although patients complain about the short duration time, providers cannot spend a longer time with a patient because their income may drop, and asserted that a good doctor would spend enough time with a patient regardless of the incentive:

> "Even if you give physicians more time to spend with patients, they will still do that very quickly and then use the remaining time to do other things, meaning that they won't use the extra time to know more about their patients or spend more time with them. I believe that good doctors will spend the same amount of time with their patients regardless of the income, meaning they would sacrifice their income to provide better care. However, we need to figure out what is the ideal appointment time, after which there won't be significant benefits to the patients."

There was disagreement among study participants on the necessity of achieving patient satisfaction and the relationship between the quality of healthcare and patient satisfaction. For some participants, satisfaction may be more related to the characteristics of the patients, including the patient's expectations, preferences, mental health, and socioeconomic status, than the quality of the services.

Participant #3, a family physician, believed that achieving good health outcomes is more important for the patient experience than achieving patient satisfaction:

> "I do struggle with patient satisfaction because I don't think that patient satisfaction equates to good medical care. If my job is to make you satisfied when you come in to see me with a cold, and your expectation is to get an antibiotic then if I say to you it is a virus, and it is going to go away on its own, and you don't need an antibiotic, you may not be satisfied because you didn't get a prescription, but still I provided you good care because you didn't need that prescription. So, I worry that if we are going to satisfy patients all the time, then sometimes, we are going to be compromising the quality of medical care."

However, other participants believed that patient satisfaction reflects a good quality of care.

Participant #17, a nurse,

> "I think that there is a very positive relationship between patient experience and the quality of healthcare, and while I agree that we need to provide more good care than satisfactory care, we still need to make sure that the patient had a satisfactory experience."

Participant #5, a policymaker, believed that patient dissatisfaction can reveal issues in the healthcare system that may require policy interventions:

> "Primary care providers may not like patient satisfaction, and this is why you look at patient experience issues at the systems level. So, if we know that a lot of people with lower income status are not satisfied with the primary care they are receiving, then it is up to the health system as a whole to figure out what are we going to do to better support those people and here we can actually call for a policy change around prescription coverage for example."

3.4.1.2 Patient-Related Factors

Participants identified several patient experience factors that are related to patients. These factors are patient expectations, patient's health literacy, patient's responsibilities, and patient's utilization of healthcare services.

Patients may have some expectations concerning the type and quality of healthcare services. Some study participants believed that there are realistic patient expectations, and these expectations are timeliness of care, quality care, rapport with providers, clean healthcare setting, responsiveness to patient needs, competent care, respectful treatment, empathy, sophisticated and transparent communication, and friendliness.

Participant #3, a family physician, said:

> "I think the term that I would use is realistic expectations, and these include timeliness, so would expect to be seen, depending on the urgency of the problem, at a certain period of time, friendliness, promptness, communication, empathy, skill, I think people expect a conclusion, which may be a diagnosis or a treatment, depending on their conditions, and they expect a follow up if appropriate."

Participants have also identified several unrealistic expectations. Notably, these unrealistic expectations are all service expectations, and they include services that cannot be done in a single visit, services that are unnecessary or irrelevant to the patient’s health conditions, services that are out of the scope of the healthcare system, services that are not funded by the system, or services that are beyond the expertise of the healthcare provider. These unrealistic expectations were identified to be associated with the healthcare system’s limited capacity, a patient’s cultural background, patient’s personal preferences, a patient’s political beliefs about the type of services the government should provide, or the understanding of political promises given to people by the government. Participants stressed the importance of discussing these expectations with the patients to explain why they cannot be met.

Participant #16, a policymaker, described how a patient’s request for an unnecessary medical procedure may be unrealistic.

> “Patients may ask for a test or procedure that they have heard about, or one of their family members knows about it, <u>but it may not be the best procedure for their current health conditions</u>. I think, in the end, many of those things come down to communication, so the ability of the provider to make it clear to patients why certain decisions will be made or why some expectations may not be the best approach given their circumstances.”

Some participants believed that expectations may be legitimate, but because they are beyond the system’s capacity, they become unrealistic:

Participant #5, a policymaker, said:

> “Sometimes, it is difficult to say that a request is an illegitimate request because it feels very legitimate for the person, and from the outset, I wouldn’t say ‘well that sounds ridiculous and illegitimate,’ but that is something that we cannot do, so it may be difficult to define what is legitimate in healthcare.”

A few study participants believed that health literacy has a significant impact on patients’ ability to understand their health conditions, how they seek healthcare, and how they communicate with healthcare providers.

Participant #15, a family physician, said:

> “Health literacy is a major factor that I cannot control, so there is no question that an individual’s capacity to understand their health conditions impacts their satisfaction, so the

> more they are in tune with what conditions they have, the more likely they are to understand what I am saying to them."

Some participants believed that patients have specific responsibilities regarding their health, healthy lifestyle, and healthcare and that patients should also educate themselves about their health conditions.

Participant #1, a nurse practitioner, said:

> "Sometimes, I think that patients depend far too much on the healthcare provider to provide all of their healthcare needs. However, I like to see a system and a culture where the patient has that onus as well on themselves by saying: 'I will take my own health in my own hands and these are the things that I need to do'; so a kind of meeting their healthcare providers in the middle".

Some participants believed that patients should be educated consumers of healthcare services so that they can navigate the healthcare system, explain their needs, and maximize their benefits during short encounters with physicians. However, most participants believed that adopting consumerism in the Canadian healthcare system should not jeopardize the existence of the healthcare system as a welfare system that provides healthcare for all Canadians.

Participant #6, a nurse in preventive care, said:

> "People should be educated to be effective consumers of healthcare, People should be informed or educated on how to approach their healthcare provider, present their needs and ask questions, and how to best make use of that limited time interaction with their physician and that may translate to a better quality of health and better satisfaction."

Some participants believed that the current healthcare system in Canada has been achieving good health outcomes and argued against the marketization of healthcare in Canada.

Participant #1, a nurse practitioner, said:

> "I would argue that our healthcare outcomes are really quite good in comparison to a consumerist based model of care like the USA model because we are able to provide healthcare for all, and despite people's income they can receive a high quality of care, which is safe and competent, although not service-friendly all the time."

3.4.1.3 Healthcare System Factors

This theme describes the factors that affect healthcare experience and are related to the healthcare system. These factors are timeliness of the service, the frontline burnout, and patient safety.

Participants believed that patients should be able to get healthcare services quickly.
Participant #10, a registered nurse, said:

> "When get referred to a specialist or me, patients want timely appointment; timely interaction, so they want a quick response to be able to get to the doors quickly and not having to wait weeks and months. Also, they should be able to pick an appointment that suits their time rather than a narrow window of time."

Participants believed that the frontline burnout has negative effects on the quality of care, patient safety, and the personal lives of the providers. It can also cause compassion fatigue to the providers. Participants identified several causes for the frontline burnout, including healthcare workload, budget cuts, and laying off staff.

For some participants, the burnout results from the increasing workload.
Participant #10, a nurse, said:

> "We have a specialist that comes a few days a week, and on those days the scheduling manager packs in the number of patients as many as he can, for that physician to see, because it all gets billed, and for many years we have felt that it is overloaded, and the poor physician is running from patient to patient spending only a few minutes with each, and then it gets back-logged, and the patients are waiting for an hour or more, they get upset, and the clerical staff gets upset because the patients are getting mad at them, and the nurses get frustrated as well. Excellent care is not only about the patient, but it is also doing the highest quality of care as possible, and it is also about the staff, but if the staff is all burnt out, they are not going to be able to do it."

The workload can also prevent physicians from meeting their personal needs and responsibilities.

Participant #3, a family physician, said:

> "Time is a challenge. when I have got twenty hours a month to divide between reading journals; doing charts; filling insurance forms; going to my son's hockey game and spending time with my wife; where do these things fit in the priority list ?; and that is the big challenge; in terms of making changes in the patient experience or anything else."

Healthcare providers are also responsible for informing the patients about budget cuts and limits to service coverage, which can be emotionally stressful to both parties.

Participant #15, a family physician, said:

> "I think where physicians struggle is if there are cutbacks from the government and then the physicians are forced to say that this is a decision made by your physician when physicians have no decision power, we don't want to be the scapegoat for the public, we don't want to be accused of not having time for the patients while it's the government's decisions that are causing all of these troubles."

Some participants believed that patient safety is an essential factor in healthcare and that it is more important than patient expectations.

Participant #9, a dietitian, said:

> "I think the bottom line is that there are certain core values that we have to maintain when caring for patients: looking out for their best interest, ensuring that we are not harming them. So, if someone is ill and the best treatment is A or B then we need to provide that, regardless of what their expectations and experiences are."

3.4.1.4 A Picture of Patient Experience in Ontario

Study participants described specific outcomes of patient experience in the current healthcare system in Ontario. This experience may be affected by many of the factors discussed in the previous themes. However, study participants asserted the negative impact of a few specific factors, which are healthcare workload, staff burnout, budget cuts, and healthcare visit duration. Study participants believed that these factors can affect the patient's safety and patient satisfaction and reduce the healthcare system's ability to fulfill the healthcare needs of some vulnerable people in Ontario.

Participant #7, a quality manager, described the effect of the healthcare workload and staff shortage on patient safety:

> “We often hear from patients who have been harmed by the healthcare system that they see that healthcare providers work multiple shifts. Because there are not enough human resources allocated to a unit or a clinic, you overwork your staff, and this is just one type of tension that we see. There are always budget limitations, so even though clinicians would want to provide care in a certain way, it may require more equipment, but there is not a lot of budgets.”

Participant #10, a nurse, described how the workload in the clinic may result in staff burnout and patient dissatisfaction:

> Our clinic has always been overloaded, and this has been going on for many years, and nothing has changed, and they are still packing patients, and everyone is upset, the staff and the patients. The manager says that we have to see this number of patients, we have to hit the quota, so it is all about the quota, not about the patient."

Participant #13, a nurse, criticized the focus of health policy on efficiency while neglecting the patients’ healthcare needs:

> “Actually, it seems to be the running theme over and over again, you get a new government in and they want to find efficiencies, so it is so frustrating, and with the upcoming changes by the new government to the healthcare system in Ontario, how many programs are going to get cut? We always know that it is the frontline workers that get the deepest cut, but what have we got out of all of the changes that have been made by the consecutive governments? Sure, you found efficiencies, but you hurt the most vulnerable people in your population, the people that actually need those healthcare services in the first place.”

Participant #5, a policymaker, believed that the short duration of the healthcare visit may be related more to seeing a large number of patients than fulfilling the needs of every patient:

> "I also think that the way physicians currently bill disincentivize them to spend a longer time with the patient because the more they see, the more they bill. So, it is a tricky conundrum and a tricky place where primary care providers are put in."

3.4.2 The Sociopolitical Perspective on Patient Experience

The sociopolitical perspective on patient experience recognizes the effects of politics-related factors in the healthcare system and the social context of health on patient experience. Two themes represent this perspective: the politics-related factors and the social context of health.

3.4.2.1 Politics-Related Factors

This theme describes the politics-related factors that may affect the patient experience. These factors are the priority differences between healthcare providers and healthcare administrators and the scopes of healthcare professional practices. Study participants believed that these factors can negatively affect the performance of the healthcare system and the quality of healthcare.

Priority differences between healthcare providers and healthcare administrators denote the disagreement between the two parties on some issues in healthcare, such as patient experience and patient satisfaction. Participants' comments reflect a state of disconnect between healthcare providers and healthcare administrators.

Participant #3, a family physician, asserted that regardless of what policymakers believe about the ideal patient experience, and regardless of patient satisfaction, such an experience can only be created by achieving good health outcomes:

> "I think that at the end of the day, it doesn't matter what the policymaker says; it is an interaction between a patient and myself, and the priority for me is to have the best clinical outcomes possible, and that prompts patient satisfaction. If I am providing you with the best medical care, then that is patient first, in my view. If that best medical care is something that you are not happy with, I still think it is patient first. I do not think that I have to make you happy or have you satisfied to be patient first, and maybe that is the difference with the policymakers because the policymakers maybe are looking at satisfaction surveys as opposed to clinical outcomes survey."

However, Participant #8, a quality manager, rejected the idea that achieving health outcomes entails disregarding patient experience:

> “I think that we may hear from healthcare providers that there is not a clearly defined link between improving patient experience and improving healthcare outcomes. However, it is not where I come from. I believe that we can have good clinical outcomes, good value for money, and great patient experience; I think that the push back that we are getting from physicians is that they are too busy focusing on clinical outcomes, so they don’t have time, energy, or the efforts to be able to put into the patient experience. However, we have examples of physicians, nurses, or managers who can focus on both.”

Some participants believed that policymakers have little if any background in the healthcare service delivery, and therefore they may not adequately understand healthcare processes, patient’s needs, and patient experience.

Participant #10, a nurse, said:

> “Sometimes you look at policymakers and quality managers, and you see that they have no healthcare background and they have not had a frontline care experience with the patient, so you ask yourself how can they make these policies when they have not been in trenches, so they don’t really know what is going on, they have not been in our shoes !”

Participant #21, a nurse, believed that healthcare administrators focus more on efficiency and less on fulfilling the healthcare needs of people.

> “As you know, those top healthcare managers are mostly business people or MBA people, and they are used to manage systems and money and think less about humans, they are not healthcare professionals or nurses.”

Priority and knowledge differences can create a disconnect between healthcare providers and healthcare administrators, which can negatively affect healthcare quality. Some study participants acknowledged this disconnect and believed that healthcare administrators unilaterally make health policy in Ontario. Consequently, this policy was said to focus mainly on reducing healthcare budgets, and therefore, some policy interventions failed, including eHealth and EMRs.

Participant #15, a physician, said:

> "How many historical examples do you need in Ontario to see how healthcare has been mismanaged, and its resources have been misspent in projects such as eHealth and EMRs, those are not decisions made by physicians! When you see this fiasco happening at the managerial level where they will implement something, and two years later they will implement something else and whatever has been done goes to waste, you realize that somebody who is making those decisions has not thought it through, and I know that the business needs to evolve, but you make these decisions unilaterally without consultations."

Participant #2, a psychiatrist, criticized the exclusion of healthcare providers from policymaking and believed that because of this exclusion policy interventions have failed to improve the quality of healthcare and reduce its costs:

> "I think that once upon a time doctors had more say about policy, however over the last thirty years policymaking has been taken away from doctors and it is now in the hands of administrators, and I think that healthcare was way better than what it is now, and certainly the cost has not come down."

Participant #16, a policymaker, believed that the disconnect between the healthcare providers and administrators may be because of the lack of understanding of both parties regarding the needs and priorities of each other, which can explain the resentment of some healthcare providers about the new health policy in Ontario. Also, this lack of understanding can affect the quality of healthcare:

> "I think that there can be a disconnect between people that develop the policy and the people that have to implement the policy at the frontlines. I think each party sometimes doesn't understand what the other party's needs or what it looks like to do that from their perspective. This disconnect can impact the quality of healthcare. You can see this trend playing out in Ontario with the current government looking at making some cuts to services, so from provider's perspective that looks like reducing expenditure on healthcare; but from the policymaker's perspective it is cutting services that there is no evidence that we should be doing them".

Another politics-related factor that may affect patient experience is the scope of professional practices. Participant #1, a nurse practitioner, explained how nurse practitioners are prevented from providing some primary healthcare services that are assigned, for political reasons, to physicians; preventing Canadian citizens from fully benefiting from their services:

> “The Ontario Medical Association (OMA) holds so much power in the healthcare world, and as a nurse practitioner, I may not be able to work on my full scope because the OMA has blocked some of those abilities for me as a capable healthcare provider, and so that is also blocking the patient from coming first because I am not able to work at my full scope, and I am not able to provide care without the influence of a medical doctor at least to hire me. So, it is really not fair to me as somebody that has that training, and it is not fair to the patient because lots of trained nurse practitioners who can provide competent primary healthcare are not necessarily able to find a job in this field.”

3.4.2.2 Social Context of Health

This theme describes the effects of the social context of health on patient experience. The social context includes several factors, known as the social determinants of health. However, study participants tended to refer to socioeconomic status to describe people’s financial capacity and social class.

Some participants believed that a low socioeconomic status affects a patient’s ability to adopt a healthy lifestyle and follow the healthcare provider’s recommendations. It was also said to affect the continuity of healthcare, health outcomes, and patient satisfaction, particularly if these patients need some healthcare services not fully covered by public health insurance. Some participants asserted that many social context factors that affect health and patient experience, including poverty and housing, are out of the control of the healthcare system.

Participant #9, a dietitian, described how a patient from a low socioeconomic status may not be able to get healthy food:

> “If I talk about healthy eating to a person from a wealthy background or the middle class, I can go through what healthy eating is, or eating more vegetables or fruits. But when I say the same things to a person of lower socioeconomic status, it is not always accepted well because healthy eating may not be attainable financially for those people, so their experience may be a little different than the person that can afford to buy healthy food.”

Participant 20, a physiotherapist, believed that socioeconomic status can affect the continuity of care, and health outcomes:

> "As Canadians, we all have access to universal healthcare but only to a point, so patients can come in and go through the system, and they are admitted, and they can come back on an outpatient basis, but once that care ends, and if patients need ongoing care, it is only affordable to those that are either have insurance coverage or are wealthy enough to pay out of pocket. So, the socioeconomic status will determine how much care a person can receive in our current system."

Participant #15, a family physician, believed that socioeconomic status can affect people's health literacy and understanding of their health conditions and how they communicate with healthcare providers:

> "People from a high socioeconomic status will have more questions and will require a longer appointment time, and they come to the clinic after they have gone to the internet and got three or four resources that they want to discuss with you, and that is because they have plenty of time at home looking at their medical conditions, they have access to computers and various sources of medical information. Now, compare that to a patient of lower socioeconomic status who comes to me. They basically have done nothing, and they actually have come from work because they have to take an hour off to come and see me; they have no knowledge about their medical conditions, so they are going to have very few, if any, questions to me."

Participant #16, a policymaker, suggested that the disconnect between healthcare and social services impedes the healthcare system's ability to target some social factors that may have a profound impact on people's health:

> "I think the current design of the healthcare system doesn't link social services and medical services, particularly well in many cases, so there are practical limits. I actually do feel that a lot of the divisions that we have created in healthcare where we have cut off things like housing, food, and exercise and made them separate from healthcare but only just come back to bite us in the foot. Poverty, for example, isn't medical, but it 100% impacts someone's health, which in turn, impacts their healthcare utilization and their experience.

> If a doctor prescribes a two-week off from work for the patient, and that patient cannot take those days off, then the patient may be frustrated and dissatisfied."

Participant #4, a family physician, believed that the healthcare system may not be able to fulfill all the needs of the patients:

> "We certainly don't have answers to all things that ail people; sometimes their principal issues may be housing or money or loneliness or lack of connectedness or spiritual or some other things, which we may not actually have expertise or relevance for them."

3.5 Discussion

This study aimed to identify the factors that affect healthcare experiences and the outcomes of these experiences from the perspective of healthcare providers and administrators in Ontario.

I have defined two perspectives on patient experience in the healthcare context: the biomedical perspective and the sociopolitical perspective. These perspectives are represented in figure 3.7.

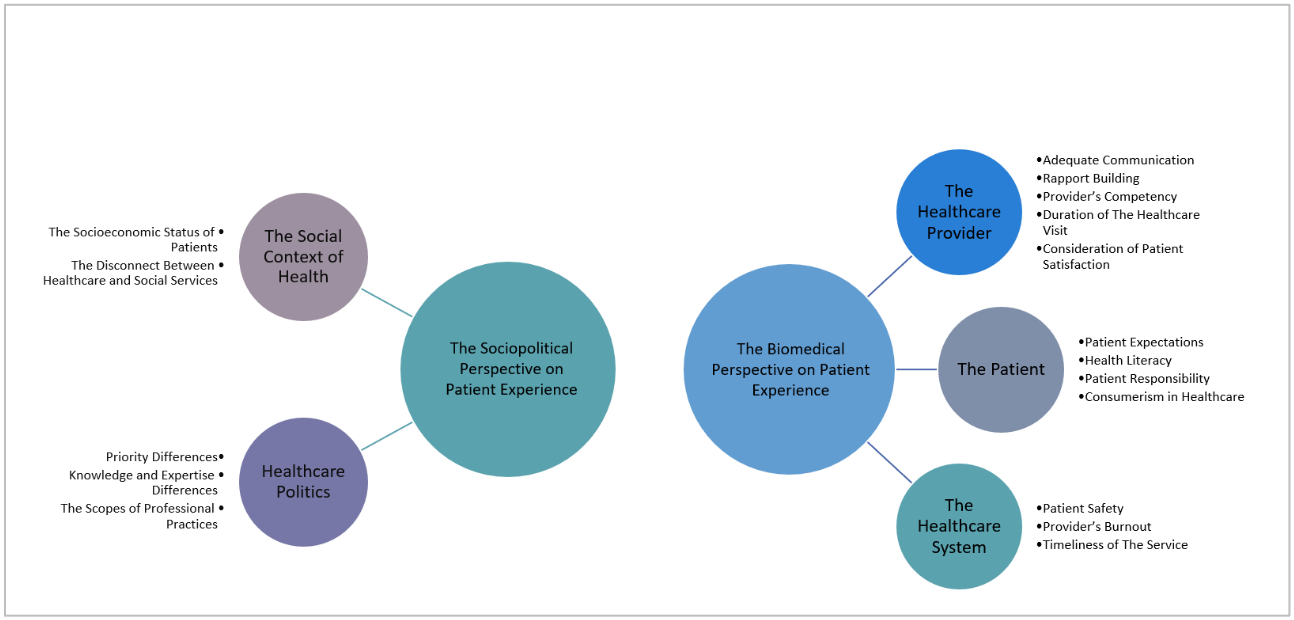


Figure 3.7: The Multi-Perspective Patient Experience Framework

3.5.1 The Biomedical Perspective on Patient Experience

This perspective is the dominant perspective in healthcare, and it focuses more narrowly on biomedical health outcomes over other aspects of healthcare experiences. The findings of the study can be organized according to whether aspects of the patient experience can be attributed to the provider, the patient, or the healthcare system.

Provider-related factors: These factors affect the healthcare service encounter or visit and can be controlled by the healthcare provider or healthcare staff.

Some of these factors are consistent with the current healthcare quality literature, and they are the provider's competency, the quality of communication between the provider and the patient, and the ability of the provider to build a rapport with the patient. These factors underpin several healthcare initiatives that aim to improve the quality of healthcare and patient experiences, such as healthcare quality[4,9,12,13], patient-centredness[9,13], people-centred health services[42,101], or healthcare responsiveness[43,45].

The duration of the healthcare visit is another factor identified in the study. The study findings suggest that visit duration can affect healthcare experiences, especially for patients who may have multiple issues such as the seniors, and that healthcare providers should be incentivized to increase visit duration. An empirical study of more than 12,000 primary care visits in Slovenia[102] found that visit duration can be impacted by many factors, including patient's age, gender, health literacy, and health conditions; and the provider's age and clinic workload[102]. However, there is little attention in the literature to the relationship between visit duration and healthcare outcomes and patient satisfaction. This scarcity may be due to the hesitancy of providers to share relevant data with researchers, or because of the complexity associated with linking most elements of the patient experience, including visit duration, with health outcomes. However, visit duration may affect the quality of communication between the healthcare provider and the patient, which can also affect the patient's experience. Additionally, given the fact that most publicly funded healthcare systems are witnessing budget and service cuts, it may not be feasible for the government to create a provider incentive program to provide adequate consultation time. Therefore, I believe that visit duration requires more research to identify what the ideal service duration is and how it is related to health outcomes and patient experience.

The provider's consideration of patient satisfaction is another factor that was identified in the study. There was disagreement among study participants on the necessity of achieving patient satisfaction and the relationship between the quality of healthcare and patient satisfaction. The literature is inconclusive regarding the relationship between healthcare outcomes and patient experience on the one hand and patient satisfaction on the other hand[11,41,103–107]. Nevertheless, this study suggests that it is important to understand the perspective of healthcare providers on patient experience and patient satisfaction. Without such understanding, quality improvement initiatives may be ineffective. Therefore, I believe that further research is required in this regard.

Patient-related factors: These are patient expectations, patient health literacy, patient responsibility, and consumerism.

Our study findings identified several patient expectations about healthcare quality that have been discussed in the literature[43,44,50], including timeliness of care, quality care, rapport with providers, clean healthcare setting, transparent and sophisticated communication, responsiveness to patient needs, competent care, respectful treatment, and empathy of staff.

Additionally, the study findings show that patients may have unrealistic expectations about healthcare services. These unrealistic expectations include receiving services that are too long to fit in a single visit, are unnecessary to their health conditions, are out of the scope of the healthcare system, or are beyond the expertise of the healthcare provider. In the literature, most research studies have focused more on patient expectations about healthcare outcomes than on patient expectations about healthcare experiences, and many studies have found a positive relation between optimistic patient expectations about healthcare outcomes and the achievement of these outcomes[46–48]. Also, there is limited attention in the literature to how patient expectations can be classified as legitimate and realistic or illegitimate and unrealistic.

Health literacy is another patient factor identified in the study, which has a significant impact on patients' ability to understand their health conditions, how they seek healthcare, and how they communicate with healthcare providers. The findings are consistent with existing literature, which associates health literacy with patient engagement, good communication between the patient and the healthcare provider, and good health outcomes[53,54,108].

Patient responsibility is a patient-related factor that affects the patient's health and healthcare experience. The study findings show that healthcare providers and administrators believe or expect that patients are responsible for their health and health choices and should educate themselves concerning their health conditions. Several research studies on healthcare discourses in Canada link the focus on patient responsibility to the neoliberal ideology of policymakers.

They argue that the growing orientation in health and social policies is towards holding people more accountable for their health and health choices[109], mental health[110], and their children's health[111]. However, given the fact that there is a large body of evidence on the impact of the social determinants of health, including income and education, on people's health, health choices, and health literacy, these provider's expectations may be unrealistic for patients of low socioeconomic status. Moreover, the impact of these provider expectations in the Canadian healthcare system on patient experience is not explored by researchers, and further research may be required.

<u>Consumerism</u> is a patient-related factor that affects the patient's health and healthcare experience. The study findings suggest that healthcare providers and administrators prefer educated patients who can consume health services wisely. The conceptualization of a patient as an educated consumer is common in the literature[13,108]. The data also suggest that healthcare providers in Ontario are not in favour of transforming the healthcare system into a free-market system where patients become buyers for health services. However, there is a dearth of literature on the perspectives of healthcare stakeholders in Canada on healthcare consumerism, and more research is required in this area.

Healthcare system factors: These factors are the timeliness of the service, frontline burnout, and patient safety.

Our study shows that <u>the timeliness of the service</u> is a vital factor that affects healthcare experience, which confirms existing literature on healthcare quality[9]. In 2017, wait time indicators in primary healthcare in Ontario, such as the same or next day appointment and seeing a specialist, are poor in comparison to most other OECD countries[112]. Many factors can increase wait times, including staff shortage and healthcare workload. However, further research is required regarding the impact of wait time on the overall quality of healthcare and healthcare outcomes in Ontario.

The heavy workload and the shortage of staff can also result in <u>burnout of healthcare providers</u>. The communication between the provider and the patient regarding health service availability and coverage can also add more pressure on healthcare providers. The data are consistent with existing knowledge in this field[72–76]. Although there is a growing body of literature on the frontline burnout, further research is required to explore this issue in the Canadian healthcare system and to explore the possible adverse effects of patient-provider communication on healthcare providers.

Patient safety is another healthcare system factor that has always been a critical component of healthcare quality[13]. The study shows that healthcare providers pay more attention to patient safety than patient satisfaction and that healthcare workload in Ontario can compromise patient safety. In 2017, and according to the Canadian Institute for Health Information, healthcare systems in Ontario performed poorly in terms of patient safety indicators, such as post-operation foreign bodies left inside patients, and post-operation pulmonary embolism after hip and knee replacement surgeries, compared to the other OECD countries[113]. In the literature, there is a large body of evidence that positively associates healthcare workload and patient safety[114,115]. However, there is a scarcity in research on the factors behind the current poor patient safety indicators in Canada and Ontario.

3.5.2 The Sociopolitical Perspective on Patient Experience

This perspective recognizes the impacts of politics in the healthcare system and the social context of health on patient experience. The study findings suggest two politics related factors, which are the priority differences and the scope of healthcare practices.

The study findings suggest that differences in priorities, knowledge, and expertise between healthcare providers and healthcare administrators may exist in Ontario and that these differences can negatively affect the performance of the healthcare system and quality of healthcare, and they can result in a disconnect between the two groups. These findings reinforce existing knowledge about healthcare politics in the healthcare systems, including the Canadian healthcare system[84].

The state of political disconnect is known in political science as the policy alienation, and it represents a psychological disconnect of frontline workers from policy interventions[116]. Policy alienation occurs as a result of the increasing pressure of policymakers on frontline workers, such as healthcare providers, to achieve performance goals that conflict with the professional standards that these workers follow[116].

In the past few years, the Ontario government has been facing many economic challenges that have led to a focus on efficiency and cost-containment. On the other hand, the organized medical professions in Ontario traditionally adopt the biomedical perspective on healthcare that prioritizes health outcomes, and they have worked to protect the financial interests of healthcare professionals. These differences in priorities create conflict and a disconnect between the two groups that may affect the quality of healthcare and the implementation of health policy interventions[84,117].

The scope of healthcare practices is another politics-related factor identified in the study findings. Some providers, such as nurse practitioners, may be underutilized. However, in the Canadian healthcare context, this factor has not gained much attention from researchers. The evidence is also lacking about its impact on the quality of healthcare or the patient experience. Nevertheless, studies on the scope of practice in the USA suggest that it can affect workforce utilization, service provision, healthcare workload, and the wait time in the healthcare system[89], all of which this study shows have an impact on patient experience.

Another sociopolitical factor that affects patient experience has to do with the social determinants of health. The study findings suggest that a low socioeconomic status affects a patient's ability to adopt a healthy lifestyle and follow the healthcare provider's recommendations. It can also affect the continuity of healthcare, health outcomes, and satisfaction of patients if these patients need some healthcare services that are not fully covered by public health insurance. The study findings also suggest that healthcare providers are concerned about excluding certain services, such as medications and rehabilitation treatments from the public health insurance in Ontario, and they are also concerned about excluding more services to reduce healthcare costs, which may magnify the burden of disease for people of low socioeconomic status. There is a large body of evidence that social determinants of health affect people's health and wellbeing[91,94,118,119]. Also, in Canada, there is a large body of empirical evidence showing that people of low socioeconomic status have higher mortality and morbidity rates[118–121], are exposed to more health risks[122,123], and are at greater risk for depression than the other Canadians[124]. However, the health policy of the new government of Ontario is still in its early days, and its impact on people of low socioeconomic status requires further research. Moreover, the emergence of the COVID-19 pandemic has practically forced the government to put on hold its health reform and adopt emergency measures that have prioritized strengthening the healthcare system and boosting its capacity to respond to the challenges of the pandemic.

3.5.2.1 Compromising People's Healthcare Experiences

In light of the study findings, the ideologies and policies of the two dominant groups in the healthcare system, which are healthcare providers and the healthcare administrators, can amplify the burden of disease and compromise people's health and healthcare experiences in four ways. The first way is the selective consideration of specific aspects of the healthcare experience, such as quality of communication between patients and providers and timeliness of the healthcare services, while giving less attention to other aspects of this experience, such patient's socioeconomic status, patient expectations, and patient satisfaction[16–18]. The second way is the adoption of policies that promote the responsibility of people for their health and health behaviours while ignoring the quality problems of healthcare[125] and patients' socioeconomic barriers that prevent the patients from seeking healthcare, buying drugs, following-up services, or adopting a healthy lifestyle[59,126]. The third way is cutting healthcare budgets and laying off healthcare staff, which can increase the wait time for the patients and the workload for the available medical staff leading to frontline burnout, and it may threaten patient safety and prevent healthcare providers from paying attention to many aspects of healthcare experiences. Budget cuts can also result in the cancellation of essential healthcare services, which prevents vulnerable people from receiving the care that they need[25–30]. The fourth way is controlling and regulating the medical professions' scope of practices, licensing procedures, and the size of the healthcare workforce, which may have unintended consequences on the healthcare system's ability to respond to the health needs of the population and can increase the workload of the healthcare providers. Sustaining high financial returns and avoiding competition pressures that would drive down the costs of healthcare may be the main goals of the medical associations[35,127,128]. The medical associations can control the nuances of the medical practice and retain bargaining power against the government, keeping the cost of healthcare very high and forcing the government to reduce costs through reducing healthcare service coverage and governmental expenditure[81,84].

3.5.3 Interpreting the Results in Light of the Theoretical Perspective

In chapter 2, I discussed Max Weber's conflict theory. This theory helps understand many themes that emerged in this study.

First, the Weberian thoughts about social groups and social conflict can shed light on power relations in the healthcare system. For Weber, power, economic capabilities, and social status create social groups that have different goals and interests. The social stratification and the goals and interests of the dominant groups are preserved by the creation and nurturing of certain norms, values, and beliefs that direct the actions of the members of these groups. These ideas help understand the study findings regarding the patient experience. The study findings show that under the biomedical perspective, healthcare providers, which make the dominant group in the healthcare system, adopt and support a specific view regarding patient experience. This view prioritizes health outcomes and recognizes specific aspects of the healthcare experience, such as quality of communication between patients and providers, while giving less attention to other aspects of this experience, such as patient's socioeconomic status and patient expectations. This view ensures a very controlled process of healthcare delivery that enables the providers to provide their services ins a short time, see more patients, and make more money rather than having to engage with each patient for a long time as would be required if the providers decided to understand the other aspects of patient experience such as the socioeconomic background and expectations.

Second, holding people accountable and responsible for health (i.e., responsibilization) and health choices (i.e., health consumerism) can also be examined using Weber's ideas about lifestyle and choices[129]. For Weber, belonging to a specific social group entails the ability to enjoy a certain lifestyle and consume a certain level of goods[129]. According to Cockrham et al.[129], Weber's ideas about lifestyle have long been used to promote a healthy lifestyle and personal choices. However, Cockrham et al. argue that Weber asserts that a person's ability to enjoy a specific lifestyle is related to their economic status[129] or to their chances, according Cockerham's theory of Health lifestyle[130].

Thirdly, the disconnect and priority differences between healthcare providers and healthcare bureaucrats can also be understood using Weber's thoughts about rationality. As I discussed in Chapter 2, Weber distinguishes between two types of rationality: formal or substantive. Formal rationality refers to the "purposeful calculation of the most efficient means and procedures to realize goals"[131]. The substantive rationality, on the other hand, refers to the performance of activities that is directed, influenced, or motivated by factors other than efficiency, including ethics, politics, and values[131]. In the healthcare system, healthcare bureaucrats adopt formal rationality to deliver and organize health services efficiently[132,133], whereas healthcare providers adopt more substantive rationality by considering ethical and emotional factors in their services[132,133]. This differentiation between the two groups' rationality can explain priority differences and the disconnect between the two groups.

3.6 Conclusion

Patient experience can be affected by a diverse range of factors. These factors may be related to healthcare providers, healthcare systems, healthcare politics, the patient, and the social context of the patient. Under the biomedical model of healthcare, these factors receive varying attention and consideration depending on their relationships with health outcomes of the patient and the ability of the healthcare system to control these factors (i.e., healthcare system boundaries). This ability, and thus the resultant patient experience, are determined by the design of the healthcare system as a welfare system, the separation between healthcare and social care, the scope of healthcare professional practices, and the healthcare budget. This means that some factors and aspects of patient experience may be ignored by health care providers or administrators, such as patient expectations, patient satisfaction, patient's socioeconomic status, wait time, and provider burnout. Moreover, there are two main aspects of the healthcare system that affect this ability, and thus they always receive more attention from healthcare administrators: and these are healthcare system efficiency and cost containment. While these two aspects of the system are paramount for its functioning, focusing only on them may lead to inadequate healthcare service coverage that disproportionally impacts people of low socioeconomic status in Ontario, threatening their healthcare continuity and health outcomes.

Lastly, there may be a disconnect between healthcare providers and administrators, which manifests in healthcare providers' limited participation in health policymaking and dissatisfaction with several health policy interventions in Ontario. While it would be naïve to expect that the fundamental differences between the two groups can diminish, it is inevitable that health policymakers regularly collect healthcare providers' feedback on all health policy interventions. This feedback, in my opinion, can help policymakers understand the impact of their policies on the healthcare system's ability to fulfill the health needs of people.

3.7 Limitations and Implications for Future Research

There are some limitations to this study. Firstly, as I have explained in the theoretical perspective (Chapter 2), there are three social groups in the healthcare system, the healthcare providers, the healthcare administrators, and the patients. This study focused on the first two groups and excluded the patient group. Nevertheless, further research is required to explore the perspectives of patients on the different factors that affect patient experience, some of which have been identified in this study. There was also an imbalance between the number of participating healthcare providers and administrators, which might have caused a bias towards the views of the providers. However, the study findings regarding the perspectives of the two groups on patient experience are consistent with existing knowledge, as presented in the discussion section. Nevertheless, further research can help clarify the views of healthcare administrators.

Secondly, the study utilized one method of inquiry, which is the interview method. However, a policy analysis can complement the study findings. A policy evaluation study should review and explore health policies, and the policies of the professional healthcare regulatory authorities (i.e., the colleges) in Ontario to identify how these policies shape the views of healthcare providers and healthcare administrators and affect healthcare experiences.

3.8 Research Quality

The quality of this study can be demonstrated using the trustworthiness criteria developed by Lincoln and Guba[134,135]. These criteria are credibility, transferability, dependability, and confirmability. The credibility of the research represents its rigor[136] and the adequacy of interpretation[136]. This study followed well-established methods of participant recruitment, interviews, and data analysis. The study was guided by a conceptual framework that was initially developed and published in a peer-reviewed journal[2]. This framework guided the interpretation of the results.

Transferability refers to the applicability of research results and conclusions to other contexts. It can be achieved through a detailed description (i.e., thick description) research context, participants, and processes[135,136]. Qualitative research recognizes the importance of the social context on the explored phenomena[137], and therefore the findings of qualitative studies are context-bound[134]. This study explored several social and political factors in the healthcare context in Ontario, including conflict of interest and power relations among healthcare stakeholders. While I do believe that the power dynamics in the healthcare system in most Western countries are quite similar, I advise all researchers to verify the applicability of the findings in similar or different contexts.

Dependability denotes the reliability of the research process[138]. The research process in this study was reviewed by two colleagues and by the research ethics board. The process is also fully documented in this paper.

Lastly, confirmability refers to the objectivity of researcher[136]. While I have strived to be objective in my data analysis, I concur with Lincoln and Guba[134] that complete objectivity cannot be achieved in qualitative research. In this study, my beliefs, values, and perspectives on the phenomenon under study may have affected the research questions, study design, framing of the interview questions, analysis of the data, and interpretation of the findings.

Forward to Chapter 4

In the first study in this dissertation (Chapter 3), I explored the perspectives of healthcare providers and administrators on patient experience and the factors that affect this experience, including the provider-related factors, the patient-related factors, and the healthcare system-related factors.

In this study, I explore the perspectives of healthcare providers and administrators on patient stories on social media and whether they can be used for evaluating the healthcare experiences of patients. I also explore how patient experience is evaluated in the healthcare system in Ontario because if the patient experience is rarely evaluated, asking healthcare providers about using patient stories for patient experience evaluation is meaningless.

This study consisted of interviewing healthcare providers and administrators regarding the utility of patient stories on social media. All study participants were aware of several social media platforms that collect patient stories. Nevertheless, I informed the interviewees about the Care Opinion platform in the UK and how it is used by the patients and providers to talk about healthcare experiences.

CHAPTER 4

The Perspectives of Healthcare Providers on Patient Stories on Social Media

Purpose: There has been a growing use of social media by patients to share their healthcare experiences and produce information that can be useful to other patients seeking healthcare services. These stories may help healthcare providers identify aspects of healthcare that can be improved. However, faced with the inherent risks of social media, the healthcare system has adopted restrictive and protective policies to control the use of social media by healthcare providers. Nevertheless, these policies may impact benefit from patient stories. This study explores the perspectives of healthcare providers and administrators on patient stories on social media and whether they can be used for evaluating the healthcare experiences.

Study Design: This study is an exploratory qualitative research study. Data were collected between April 2018 and May 2019. Twenty-one semi-structured interviews were conducted with healthcare providers and administrators in Ontario. Inductive and data-driven used thematic analysis to analyze the data.

Findings: Several barriers prevent healthcare providers from realizing the benefits of social media, including the professional healthcare standards and codes of conduct, the time and effort required to process these stories, and the significant number of stories on social media, which also increase the time needed to process these stories.

Originality/value: The study suggests that cultural changes in the healthcare system can be required to foster the use of social media for healthcare quality improvement and enable the development of a safe patient-provider communication environment that facilitates the exchange of constructive feedback between the two parties without the fear of legal consequences, breaches of patient privacy, or violation of professional codes of conduct.

4.1 Introduction

Social media refers to internet-based applications that enable people to communicate, interact, publish, and exchange all types and formats of information[1]. Social media has given people the tools to produce knowledge individually and collaboratively[2] and express and exchange their opinions on every aspect of their lives[3]. It has also enabled them to mobilize to achieve fundamental political and social changes in many countries.

In the healthcare context, social media has been used for many purposes. Public health organizations such as the ministries of health use social media to disseminate timely information about health risks and healthy behaviour and to monitor public posts to identify public health risks. For example, Twitter data has been used for health surveillance to track diseases spatially and temporarily[4]. Social media has also been used by healthcare professionals for knowledge exchange, news dissemination, and health promotion[5]. Laypeople have used social media to post and share different types of information, including health information, health news, illness experiences[6], and personal perspectives on health and health lifestyle[7].

While some of this laypeople-produced health information can be of low quality[7,8], there has been a growing use of social media by patients to share their healthcare experiences and produce information that can be useful to other patients[9,10]. In March 2020, Hao Dai Fu (www.haodf.com), a Chinese website, contained 4,024,818 patient reviews for doctors across China[11]. A survey study, in 2012, explored the benefits of using physician rating websites by the US population for choosing healthcare providers and found that 40% of the US people believed that these websites are “somewhat important,” and 19% believed that they are “very important”[12]. Patient stories can also help other physicians to identify aspects in healthcare that can be improved[13]. In this study, I explore the perspectives of healthcare providers in Ontario on the use of social media by patients to describe and share their healthcare experiences.

4.2 Background

Social media has produced a ground-breaking shift in customer-business relationships. Before the evolution of social media, customers or service users were treated as audiences or passive targets of marketing and public-relation campaigns[14]. Also, customers provided feedback and expressed their opinions through provider-controlled means such as customer-support offices or customer satisfaction surveys. Social media, however, changed customer-business relationships and boosted the emergence of active customers who can express their views and post different types of stories about businesses and service providers at any time. They can also start campaigns in favour of or against certain products[14]. With the change of customer-business relationships, a new phenomenon has emerged, which is the electronic word of mouth (eWOM), and it refers to the online sharing of knowledge and experiences with products among actual and potential customers who are mostly anonymous[15].

In the healthcare system, the term "healthcare experience" has been used to denote the relationship between the patient and the healthcare system. Healthcare experience refers to the interactions of a patient with the healthcare system members, including the nurses, physicians, and staff, and the resultant emotional and behavioural effects of these interactions on patients[16], including patient satisfaction, patient commitment to health, and patient adherence to treatment plans[17].

The attention to patient experience has been part of healthcare quality improvement and healthcare quality research[16,18,19]. Qualitative and quantitative research methods have been used to explore patient experience and examine the different factors that impact it. To date, survey methods have dominated[20,21]. Surveys enable healthcare providers to focus on specific dimensions of patient experience and ignore others. Common patient experience dimensions that are frequently measured include access to health services, communication with staff, quality of service, shared decision-making, and patient satisfaction[22–24].

Social media also provides a means for patients to post stories about their illness and healthcare experience. Two types of social media platforms host patient stories: the dedicated platforms, which are only operated to collecting patient stories and facilitating patient-provider communication such as the Care Opinion platform, and the undedicated platforms such as Facebook, which are open to diverse type of stories.

Patient stories on social media can have some advantages. They are available in large volumes, which reduces the data collection costs, and they also represent recent healthcare encounters. These stories shed light on issues in healthcare that are not always exposed by traditional patient experience surveys, including the patient's lived experience of illness, emotional and financial burdens of illness, and patient satisfaction[13,25]; therefore, they may have a high potential for healthcare quality improvement[25,26]. They can also help other patients learn about the quality of services in specific healthcare settings[13]. Seal et al.[27] compared illness narratives collected through patient interviews to those collected from online discussion forums and argued that online patient stories contain more in-depth descriptions of the daily lived experience of illness, and they can also contain experience sharing and empathy with other patients, which may not always be present in interview narratives[27].

Despite the vast expansion of social media and the potential benefits that it can bring to people and organizations, there has been a dark side for social media, which has not been fully explored by researchers[28], and it denotes the risks it has brought to people and organizations[28–31].

At the individual level, breaches to privacy have become a significant risk[32]. Other individual risks include stress, wasting of time, and accidental violation of workplace and organization policies[32,33]. Reputational risks have become a major risk for organizations; these include negative product reviews by clients, and leaks of information about business performance, business relations, product issues, or workplace politics[34–37]. Reputational risks can also affect individuals. Controversial posts by a person, critiques by peers or clients and leaks of private information can all cause reputation damages to people[38], which can lead to social and financial problems to them.

Faced with these risks, many organizations and professional associations in the business sector and healthcare have adopted restrictive and protective social media policies to control the social media related behaviours of their employees or members and implementing disciplinary measures for violating these policies[29]. In Ontario, social media policies adopted by regulatory authorities and healthcare institutions focus on three goals: protection of privacy, protection of professional boundaries, and protection of professional image[39,40].

4.2.1 Purpose of the Study

This study aims to explore the perspectives of healthcare providers and administrators in Ontario regarding the utility of patient stories on social media and focuses in particular on the following questions:

1- How is the healthcare experience evaluated?

2- What are the benefits and harms of patient stories on social media for patients and healthcare providers?
3- Can these stories be used for evaluating the healthcare experiences of patients?
4- What is the quality of these stories?

4.3 Methods

This study is an exploratory qualitative research study. Data were collected between April 2018 and May 2019. Twenty-one semi-structured interviews were conducted with a purposively selected sample of family physicians (n=3), specialized physicians (n=1), optometrists (n=2), physiotherapists (n=1), nurses (n=6), nurse practitioners (n=1), psychiatrists (n=1), dietitians (n=2), healthcare quality managers (n=2) and policymakers (n=2) in Ontario.

Purposive sampling[41] was chosen in order to recruit participants with the experience needed to shed light on the different dimensions of the patient experience. Knowing that healthcare professionals can have different perspectives with regard to patient experience, we wanted to recruit participants from different healthcare professions in order to get more diversified views. I used an interview guide (Appendix 4.A) that was developed based on the four research questions cited above. Before the study, I had no a priori perspectives on the use of patient stories on social media and the factors that affect this use. Therefore, I framed broad research questions about this phenomenon, and I also informed the interviewees about the Care Opinion platform in the UK and how it is used by the patients and providers to talk about healthcare experiences. I also explored any emerging topics by asking relevant follow-up questions. The average interview time was 50 minutes.

4.3.1 Ethics Approval

This study received the ethics approval (ORE #22793) from the University of Waterloo's Research Ethics Board.

4.3.2 Data Analysis

I have used thematic analysis to analyze the data. Data analysis was mainly inductive and data-driven[42], and it included iteratively reading, categorizing, and coding the data to identify main categories and prominent themes[43]. I did not use an a priori coding scheme, but let themes emerge inductively from the data. I used Nvivo version 12 for data analysis.

4.4 Results

In this section, I present the themes that emerged from the data analysis. The themes are grouped into two sub-sections: patient experience evaluation and patient stories on social media.

4.4.1 Patient Experience Evaluation

Four themes represent how and how frequently patient experiences are being measured.

Methods of Evaluation

Some participants stated that they use patient satisfaction surveys and questionnaires in their practices. Others depend on focus groups, patient relations departments, advisory committees that include patients and families, social media, or feedback from other healthcare providers. Others stated that they do not formally evaluate patient satisfaction, but they use indirect indicators, such as patient comments, online reviews, and comments from other physicians. Participants also believed that patient experience surveys require extensive efforts to collect and analyze the data and are therefore considered burdensome.

Participant #4, a family physician, stated that they use patient satisfaction surveys, despite their limited value, and try to understand patient expectations and identify issues that can be improved in their healthcare practice:

> “Our family health team uses patient satisfaction surveys. We also ask for suggestions or comments on a regular basis, and we also ask about specific experiences. Even though patient satisfaction surveys are generally positive, I don’t think that we take them far more than what it is because you will never satisfy 100% of people ever.”

Participant #17, a nurse, was concerned with the efforts required from healthcare providers to benefit from patient feedback:

> “I think that gathering information from patients is always good to improve the quality of care. However, with all those tools that have been used, are we asking healthcare providers to do this on top of what they have been asked, especially with the increasing demand for healthcare?”

Frequency of Evaluation

Some participants stated that they do evaluate the patient experience in their practices frequently, while others stated that they do not.

Participant #17, a registered nurse, said:

> “Time is the biggest barrier. I don’t have time to sit and ask the patient how we can improve the care that has been delivered, which I think is an important question before discharge, but we don’t have time for that. We barely have the time to ask the medical or health-related questions.”

The Reliability of Evaluation

Study participants were skeptical about the reliability of patient experience evaluation because it generally shows an unrealistic high level of patient satisfaction. Also, because this evaluation may not be anonymous, patients may fear to talk about negative issues.

Participant #21, a registered nurse, questioned the reliability of satisfaction questionnaires and stated that these questionnaires do not touch on critical issues :

> “I know that usually, our patient satisfaction ratio is 69%, but what does that mean? I don’t know because it all depends on how you ask the questions. You can avoid really sensitive questions. So, it is asking what you want to hear back, and yet you don’t get 90%.”

Participant #13, a nurse, said:

> “I am always surprised to see how high the satisfaction rate is. Maybe, they could have an outside or third-party organization doing that by using anonymous surveys, so it is not at the site, and no one can identify the participants.”

Meaningfulness of Evaluation

This theme refers to the perceived value of patient experience evaluation. Many participants were skeptical about the value of evaluating patient experience and patient satisfaction because it does not yield the kind of detailed information that can be acted upon by healthcare providers. However, some participants believed that the mail-out surveys may be more accurate than onsite questionnaires, even if they do not provide actionable results.

Participant #13, a policymaker, said:

> “I am not a huge fan of those overall experience metrics because you don’t know what to do with them.”

Participant #17, a nurse, said:

> “They have had a voluntary questionnaire, so the patients can use them if they want to acknowledge the efforts of a specific provider or staff to improve patient experience. I am not sure how many patients will actually do that, and I am also not sure how well it is utilized, or if it causes any changes, or if any outcomes come from it.”

4.4.2 Patient Stories on Social Media

Six themes reflect several aspects of patient stories on social media. They provide answers to the second, third, and fourth research questions in this study.

The Benefits of Patient Stories on Social Media

Some study participants believed that patient stories can be useful to patients and providers. Patient stories enable the sharing of healthcare experiences among patients and help them select healthcare providers and healthcare settings.

Participant #8, a quality manager, said:

> “I think it is a great thing if it, [social media], allows other patients to read the stories about specific healthcare settings if they need this information before visiting those settings, so that would be excellent because at our hospital we certainly don’t publish anything that comes through our patients’ relation office for other patients to read.”

Patient stories may also help healthcare providers understand the experience of their patients.

Participant #12, a registered nurse, said:

> “Patients might not accurately answer the surveys, and if you use social media to look at the stories so sure that would be one way of finding out some of the issues in people’s experience because sometimes people let go of everything or they will say whatever they think on social media, whereas in a questionnaire they may not be apt to be as vocal.”

Social Media Harms

This theme refers to possible harm to healthcare providers caused by patient stories. Some study participants expressed their concerns about the misuse of social media by people intending to damage the reputation of healthcare providers.

Participant #4, a family doctor, said:

> “I think it is good for people to be able to express their views. However, people can also sometimes be destructive in comments because comments can get very personal. If somebody has an agenda to try hurting some healthcare providers or institutions, then that is a platform where you could potentially misuse.”

Barriers to Using Social Media by Healthcare Providers

Study participants identified three barriers to using social media by healthcare providers, and these are the healthcare professional standards set by healthcare regulatory authorities, the time and effort required to process these stories, and the significant number of stories on social media, which also increase the time needed to process these stories.

Professional standards set many restrictions on healthcare providers’ interaction with patients on social media and assert the importance of patient privacy.

Participant #14, a specialist, said:

> “I have some concerns about it, because I am at the losing side, because I cannot mention names, and I cannot comment on posts objectively, because if I want to comment honestly, then patients can be easily identified. Even if patients mention my name, I cannot respond because that is against confidentiality agreement. I won’t be concerned about the credibility of these posts if I am allowed to respond.”

Reading and exploring patient stories require extra time from healthcare providers on top of their healthcare workload.

Participant #3, a physician, said:

> “It will be challenging to family doctors that are working out there in the trenches; they are so busy keeping their heads above water seeing their patients; they don’t have time to read

> <u>the data or to contemplate how they are going to make changes</u> because they are just way too busy.”

Some participants were concerned about the significant number of patient stories on social media, which can be difficult to explore:

Participant #8, a quality manager, said:

> “I think patient narratives are powerful, we do that a little bit in the patient relations office, so I do like it. <u>But my caution around it is the capacity to be able to read or digest these stories</u>.”

Barriers to Using Social Media by Patients

Although study participants do not represent the patient population, they have identified two possible barriers to patient’s access to and use of social media. Firstly, patients may fear the undesired consequences of posting stories about their healthcare experiences, including damaging relationships with healthcare providers and the impact this can have on them and their families.

Participant #7, a quality manager, said:

> “If the patients are getting inadequate care, they will probably <u>won’t report</u> it, especially during the period of care because <u>they will be worried about the reaction of the care providers</u>, and <u>this reaction could be very serious</u> and could have negative consequences for the patient and their families.”

Secondly, patients may have lower expectations of a positive change in healthcare experiences because, in Ontario, patients cannot always select their healthcare providers due to shortages in the healthcare workforce.

Participant #18, an optometrist, said:

> “I worry about the patient’s perspective of those comments. They might help a patient find a practitioner that could meet their expectations. <u>But at the same time, one of the things in Ontario is that we don’t have the luxury of choosing our physicians, so there is no room for that</u>.”

Enablers of Using Social Media by Healthcare Providers and Administrators

Study participants identified three factors that enable the use of social media by healthcare providers for improving the healthcare experiences of the patients. These factors are a policy change, a cultural change, and the development of a trusted social media platform dedicated to collecting patient stories.

A change in the policies that govern the professional conduct of healthcare providers and the professional relations between the provider and the patient may be required to create a safe environment for the healthcare providers and the patients to communicate without fear of litigation or disciplinary action.

Participant #15, a family doctor, said:

> “It is not only about the privacy law, I think it is the legal system that tells you not to respond because you don’t know whether this patient is going to file a law suit, and you don’t want to say anything to the patient that would possibly incriminate you or incriminate somebody else. If these platforms would be used for quality improvement and if there are policy changes that would support that, then I think they will provide tremendous benefits.”

Study participants believed that a change to the culture of the healthcare system may be required to accept patient feedback about their experiences. One participant believed it is important to accept that the healthcare system is error-prone and that we need to build a learning healthcare system. One way to do this is to accept the feedback from patients provided through social media.

Participant #16, a policymaker,

> “I think we need a little bit of a cultural change, trying to get people comfortable with giving and receiving feedback like that. We also need to have some guidance on how to interpret those comments.”

Quality of Patient Stories on Social Media

Several aspects of information quality were described by study participants. These are credibility, representativeness, coverage, and objectivity.

The credibility of stories refers to their perceived truthfulness. Many participants believed that the credibility of patient stories should be checked. Other participants believed that if the credibility of patient stories can be verified, these stories can be useful for other patients and healthcare providers.

Participant #17, a registered nurse, said

> "We know that social media tends to embellish a lot of things positively or negatively. So, I think I would take it with a grain of salt. So, I don't think it is highly credible. But I would never discredit it."

Participant #15, a family physician, believed that if the credibility of patient stories can be verified, then these stories can be useful for other patients and healthcare providers.

> "I think the challenge is how you distinguish real vs unreal patients that are able to post on social media, but if that can be addressed, and you know that these are actual visits that have occurred by actual patients, then I think it can add value to the public because they can know; for example; the clinics that have high satisfaction rates; and it can also add value to the clinics because they can themselves use that data to see where things can be improved."

Representativeness denotes how much these stories reflect the views of the patient population. Study participants believed that often patient stories capture extreme cases only in terms of patient satisfaction or dissatisfaction. These stories may not represent all patient groups such as the elderly population, who may not be comfortable using social media and communication devices, or Aboriginal peoples in the northern communities in Canada, who may not have internet access.

Participant #19, an optometrist, said:

> "I think these platforms often capture the extremes, patients who are either very satisfied or dissatisfied. I wonder what it does with the people in the middle, so these platforms may be flawed with the same thing as the other [measurement] instruments."

Coverage represents the depth and breadth of the stories. Study participants were skeptical about the ability of the stories to reflect a complete picture of healthcare quality and the factors that can affect patient experience, including healthcare processes, medical protocols, and healthcare outcomes.

Participant #21, a registered nurse, said:

> “Patients don’t rate the outcomes, and if you look at the reviews, they will not rate the outcomes, they will rate the wait time, which is beyond our control, how soon a patient gets into the room, how soon they will be seen by nurses and doctors, the patient just sees pieces of our work.”

The objectivity of patient stories refers to the distinction between patients’ subjective experiences and what providers consider objective reality. Many participants were concerned that patient stories represent only the perceptions of the patients about their healthcare experiences. Because these perceptions are influenced by subjective factors and by lack of medical knowledge, they may not capture other important dimensions of healthcare.

Participant #10, a registered nurse, said:

> “It may be one-sided to get the patient’s view about what is happening while there are two sides to the story. Don’t forget that if someone from the public is posting their stories from a healthcare perspective, they don’t have the knowledge of, maybe, the medical conditions and the treatment they are getting and so their perspective is going to be different than the healthcare provider's perspective.”

Because of concerns about the quality of patient stories, some participants were skeptical about the value of these stories:

Participant #3, a family doctor, said:

> “I think that you have to take any information like that and reflect on whether it provides you with enough evidence that you need to change the way how you are doing things. So, I think that it can help to stimulate thoughts, but does it lead to a change? I am not sure.”

4.5 Discussion

This study aimed at exploring the perspectives of healthcare providers and administrators in Ontario on the use of patient stories for evaluating the healthcare experiences of the patients. The results can be summarized as follows.

How Is Healthcare Experience Evaluated?

The findings suggest that patient satisfaction surveys and questionnaires are the main methods used to evaluate healthcare experiences in Ontario. These findings are consistent with the patient experience literature[20,21,44]. The Ministry of Health and many hospitals and primary care practices in Ontario use mainly patient experience surveys[44]. However, the literature is scant concerning the systematic use of surveys for healthcare quality improvement.

The data also show that healthcare providers and administrators are skeptical about the value and validity of patient experience and patient satisfaction surveys. These findings confirm existing knowledge in this field. Surveys, in general, are subject to social desirability and non-response biases. The social desirability bias is also widespread in attitudinal and interview surveys[45]. It results from the inclination of respondents to give socially acceptable answers to survey questions even if those answers are not true[46]. This bias is common in patient satisfaction surveys, which generally report higher patient satisfaction than the reality (i.e., positively skewed)[47–49]. Nonresponse bias occurs when there are significant differences between respondents and non-respondents in the survey sample, which can lead to biased survey results[50]. Evidence suggests that many dissatisfied patients refuse to participate in patient experience surveys, which causes a positive skew in survey results[47–49,51]. Additionally, many patient experience surveys do not provide meaningful information to clinicians and hospital boards, and the uptake of patient experience survey results is generally weak[47,52,53]. Many factors are behind this weak uptake. First, within the healthcare system, there may be disagreement between healthcare providers and administrators on the goals and priorities of healthcare and the importance of patient experience to achieve these goals[47,52,54]. There is also considerable disagreement on the components of patient experience and whether it consists only of healthcare experiences or both healthcare and illness experiences of the patients[17,55,56]. The former describes patient experience within the healthcare system. The latter, on the other hand, describes the emotional, financial, and social burdens of illness on patients and their families[17]. Secondly, to protect the privacy of the patients, the healthcare system imposes many restrictions on collecting and using patient experience data. These restrictions limit researchers' ability to link survey data to health outcomes and prevent them from producing actionable guidelines for healthcare quality improvement[53]. Thirdly, the depth and breadth of patient experience measures play a crucial role in the usefulness of those measures. Patient satisfaction measures have been criticized for being "simplistic," and lacking a practical value for healthcare quality improvement[47,49,57]. On the other hand, more specific patient experience measures that are linked to specific aspects of healthcare quality or healthcare processes, including timeliness of care and effectiveness of communication, can be more meaningful to healthcare providers and administrators than simple measures of satisfaction[49,57–60]. Fourth, collecting and analyzing patient experience feedback requires time and skills[60], both of which exceed the capacity of providers who are already busy with a heavy healthcare workload[55].

What Are the Benefits and Harms of Patient Stories on Social Media?

Consistent with the literature, the study data suggest that patient stories help patients share their healthcare experiences. Indeed, these stories have been identified as useful to other patients seeking healthcare[9,13]. However, the literature is scarce regarding people's motivations to share their experiences on social media[61]. Providers have diverse opinions on this; however; as not all believed that patient stories provide valuable information about healthcare experiences and healthcare quality. However, several non-empirical studies[13,25,26] and empirical ones[62–65] suggest that these stories are useful for quality improvement. These discrepancies can be due to the fact that patient stories on social media is a fairly new phenomenon that has not been recognized by healthcare regulators and in the biomedical literature. Additionally, the providers' concerns of credibility and objectivity of the stories can also affect their overall perception of this phenomenon.

The study findings show that patient stories can also be harmful to the reputation of providers if misused by patients. Reputational damage is a significant risk of social media[28]. Many professional associations, for example, the American Medical Association, encourage its members to monitor their online presence to make sure that no negative reviews about them are posted on social media[66]. However, in the healthcare context, this risk has not been fully explored by researchers in terms of prevalence, credibility of the reputation-damaging posts, and the motivations of the posters.

Can Social Media Be Used to Evaluate Healthcare Experiences?

The study findings suggest that several barriers prevent healthcare providers from realizing the benefits of social media. These barriers are the professional healthcare standards and codes of conduct that restrict patient-provider communication and relations, the time and effort required to process these stories, and the significant number of stories on social media, which also increase the time needed to process these stories. These findings are consistent with existing knowledge in this field. Healthcare professional standards in Canada and the USA proscribe healthcare professionals from establishing any personal relationships with patients, including online relationships. These standards give priority to patient privacy and call on healthcare professionals to avoid exchanging most kinds of information online unless it occurs through controlled and protected platforms[39,67]. Also, benefiting from patient stories requires considerable time and effort from providers. Patient stories can be quite long and involved. However, because of the heavy workload, there is a little chance that the providers can make these efforts. While the literature is scant regarding workload and professionals' burnout in Ontario, patient wait times may be a good proxy for the workload. The wait time indicators in primary healthcare in Ontario in 2017, including the same or next day appointment, and seeing a specialist are poor in comparison to most OECD countries[68]. There is also a shortage in the healthcare workforce in Canada and the USA[69].

Patients may also be discouraged from posting stories on social media. Study findings suggest that patients may fear undesired consequences for talking about their healthcare experiences on social media. These consequences include impairment of patient-provider relationships and the discontinuity of healthcare services. Also, patients may have lower expectations of a positive change in the healthcare system that may result from their stories. Although the literature is scant regrading the dynamics of patient stories and patient-provider relationships on social media, these findings are consistent with what is known about patient satisfaction surveys and the factors that can reduce their credibility[47,49].

Additionally, study findings show that in the healthcare context, policy and cultural changes are required to enable the use of social media by healthcare professionals. In business and governmental sectors, the adoption of social media has been a challenging endeavor that requires changes to organizations' communication policies, customer relationships, and organizational culture[70–72]. However, in the Canadian healthcare context, healthcare regulatory authorities have adopted restrictive social media policies to control the social media behaviours of healthcare professionals and to identify consequences for violating these policies[29]. Thus, further research is required to explore the aspects of policy and cultural changes required to foster the use of social media for healthcare quality improvement. Another enabler is the use of a social media platform that is dedicated to collecting patient stories such as the Care Opinion platform. Such a platform employs techniques for authenticating the stories and protecting the privacy of the patients, which increases its credibility and the credibility of stories, and encourages healthcare providers to respond to them.

What Is the Quality of Patient Stories on Social Media?

The study findings show that providers may be concerned about the quality of patient stories on social media. Providers believe that the credibility of the stories should be checked and that these stories may not be objective nor representative to all patients. The literature is scarce regarding assessments of the quality of patient stories on social media. A few studies suggest that social media platforms are subject to selection bias, because these platforms can be used by specific sociodemographic segments of users, and therefore, the stories may not accurately represent the patient population[25,73].

However, a similar phenomenon, although in a different domain, has been amply described. This phenomenon is the electronic word of mouth (eWOM) phenomenon, which I have described in the background section. Although the context of healthcare is different from the business context in terms of the needs of consumers (i.e., the patients) and type of relationship between service providers and consumers, the motivations of people to share their expertise can be similar. Positive eWOM posts can have a significant positive impact on product sales[74]. eWOM posts can also help companies understand the perceived usefulness of their products and any issues that require improvement[74]. While the anonymity of the posters may reduce the credibility of the eWOM, other factors can improve it, including the credibility of social media platforms, the reputation of posters, and how satisfied other people are with the eWOM[15,75]. However, a study by Hu et al.[76] analyzed more than 4,000,000 product reviews on Amazon.com and concluded that the reviews were skewed, mainly reflecting the views of people who were either very satisfied or very dissatisfied[76]. Nevertheless, further research is needed to explore the quality of patient stories on social media and the factors that affect it.

4.6 Interpreting the Results in Light of the Theoretical Perspective

In chapter 2, I discussed Max Weber's conflict theory. This theory helps understand many themes that emerged in this study.

First, the Weberian thoughts about social groups and social conflict can shed light on power relations in the healthcare system. For Weber, power, economic capabilities, and social status create social groups that have different goals and interests. The social stratification and the goals and interests of the dominant groups are preserved by the creation and nurturing of certain norms, values, and beliefs that direct the actions of the members of these groups. The study findings show that healthcare providers and administrators, which are the dominant groups in the healthcare systems do not see practical value in evaluating patient experience because patient experience surveys do not yield reliable, valid, or meaningful data that may be acted on. The same has been said about patient stories, which, according to study participants, suffer from issues in their credibility, representativeness, coverage, and objectivity. It can be concluded that the dominant groups in the healthcare system believe that not only patient experience evaluation methods and the data they produce suffer from quality issues but also the patients themselves are less capable of objectively and accurately judge the different aspects of their healthcare experiences because they lack adequate background.

Secondly, the study findings show that professional healthcare standards and codes of conduct restrict patient-provider communication and relations. As presented and discussed in chapter 5, the codes of conduct represent the social norms that, according to Weber, enable the social groups (i.e., the healthcare professions) to control the behaviour of their members to protect the status and interests of these groups[77–79].

4.7 Conclusion

In this study, I have explored the perspectives of healthcare providers and administrators in Ontario on the methods used to evaluate the patient experience and the utility of patient stories on social media. Data show that patient satisfaction surveys and questionnaires are the main methods used in the healthcare system in Ontario, and that patient stories on social media can be a source of information that can be used for understanding healthcare experiences. However, there are structural barriers behind listening to the voice of the patient, irrespective of the media used for this purpose, including onsite questionnaires, surveys, or social media. The first barrier is providers' concerns about the quality of patients' feedback, which can be subject to several biases, including selection and non-response biases. The second barrier is the patient privacy protection policies that govern how patient experience data is collected and restrict linking this data to health outcomes, which can impede quality improvement. These policies also restrict patient-provider communication and relations on social media. The third barrier is the time and effort required to collect and analyze patient feedback, which can add more burdens on healthcare providers who are already busy and burnout responding to the healthcare needs of people. The fourth barrier is the patients' hesitancy to provide feedback about their healthcare experiences. This hesitancy may be because of fearing undesired consequences that can affect their relationships with healthcare providers and impact the care they receive, or it may be related to patients' hopelessness of any changes in the quality of healthcare. The findings suggest that policy and cultural changes may be required to foster the use of social media for healthcare quality improvement and enable the development of a safe patient-provider communication environment that facilitates the exchange of constructive feedback between the two parties without the fear of legal consequences or privacy breaches. Additionally, the phenomenon of patient stories on social media has not been well explored by researchers and therefore, further research may be able to shed light on the different elements of this phenomenon, including the perspectives of patients, the quality of data, and the technical systems that need to be developed to collect and analyze the data.

4.8 Limitations

There was an imbalance between the number of participating healthcare providers and administrators, which might have caused a bias towards the views of the providers. However, the study findings regarding the perspectives of the two groups on patient experience evaluation and social media are consistent with existing knowledge, as presented in the discussion section. Nevertheless, further research can help clarify the views of healthcare administrators.

4.9 Research Quality

Since this study used the data collected in the study described in (Chapter 3), the reader can review my discussion in section 3.8.

Forward to Chapter 5

In Chapter 4, I describe an empirical study I conducted where I interviewed healthcare providers and administrators. The study participants expressed their concerns about the possible undesirable consequences of using health social media as a platform to evaluate the patient experience. Those undesired consequences are primarily related to the health system policies that control how healthcare professionals can or are able to react to those stories.

Healthcare is a highly regulated sector. In Ontario, there are 29 regulated healthcare professions, and each healthcare profession is regulated by a college. Colleges are the licensing bodies, and they set the practice standards and codes of conduct, and they can take disciplinary actions against their members. Many of these colleges have created social media policies to control the interaction of their members on social media. Other colleges have not created standalone social media policies; instead, they have used guidelines and position statements. These materials are the focus of this study.

In this study, I analyze the social media policies of the healthcare regulatory authorities in Ontario and explore how these policies encourage or discourage the use of social media by healthcare providers to assess patient stories and identify points for improvement in healthcare quality. These policies include social media policies, guidelines, and position statements of the healthcare regulatory authorities (i.e., the professional colleges). I also analyze codes of conduct and professional standards that govern the healthcare professions in Ontario.

CHAPTER 5

How Healthcare Regulatory Bodies in Ontario Control the Risks of Social Media: A Policy Review

Purpose: Patients have been using social media to post stories about their experiences with healthcare providers. These stories provide information about the quality of healthcare services, which can be useful for both patients and providers. To benefit from these stories, providers need to interact with patients through social media platforms. In this study, I analyze the social media policies of the healthcare regulatory authorities, which are the regulating and licensing bodies in Ontario, and I explore how these policies encourage or discourage the use of social media by healthcare providers.

Study Design: The study uses document analysis and qualitative content analysis to analyze social media policies and guidelines of some healthcare colleges in Ontario issued between 2013 and 2019. I followed a deductive approach to content analysis by using an existing theoretical framework to develop a coding frame.

Findings: In the healthcare system in Ontario, social media is perceived as a source of risks to the healthcare professions and professionals, and therefore, policies are developed to mitigate those risks. Healthcare regulators emphasize that the codes of conduct and the professional standards of healthcare extend to social media, despite the distinct context of social media. The study found no systematic recognition of patient stories on social media as a source of information that requires the attention of healthcare professionals.

Originality/value: The study identifies potential unintended and demotivating effects of the social media policies of healthcare regulators on healthcare professionals' abilities to use social media as a means to collect patient stories.

5.1 Introduction

Social media refers to the internet-based applications that enable people to communicate, interact, publish, and exchange all types and formats of information, including text, pictures, audio, and video[1]. Social media platforms provide several interaction capabilities that leverage information technology, including instant communication, live broadcasting of events, emotional expressions, sharing of information, voting, and game playing. These interaction capabilities continuously evolve following the rapid changes and developments in the information and communication technology field, and this makes conceptualizing social media a difficult task[2,3]. Although the definition of social media should be broad, context-based, and technology sensitive[3], there are two common features by all social media platforms: the ability of the user to create different types of content, and the ability of other members in the platform to view, comment on, or vote on this content[2].

In healthcare, social media has been used by healthcare professionals for knowledge exchange, news dissemination, health promotion, and public health surveillance[4,5]. For example, Promed (www.promedmail.org) is a network of epidemiologists and public health experts who share the latest news about disease incidence around the world. Another example is Sermo (www.sermo.com), which is a global network of physicians, which includes around 800,000 members, who can share case studies and ask questions about medicine-related topics. The last example is the Care Opinion platform (www.careopinion.org.uk), which is used to collect patient stories in the UK. The platform also enables healthcare providers to review and respond to patients' stories about the quality of services in their practices.

Patients, on the other hand, use social media to gain health knowledge, share their illness experiences, healthcare experiences, and news on health and illness outbreaks, and to get social or emotional support[4–8]. Patient stories on social media help other patients get information about healthcare services and healthcare quality. These stories shed light on issues in healthcare that are not exposed by traditional patient experience surveys[9,10]. Many of these stories describe recent patient encounters with healthcare, and they are also available in large volumes and do not require a substantial investment from healthcare providers and policymakers to collect them, which increases their potential for healthcare quality improvement[10,11]. There are many social media platforms dedicated to patient stories. Patients use these platforms to share their stories about specific doctors or healthcare settings. For example, RateMDs (www.ratemds.com), established in 2004, enables people to post and rate their healthcare providers. As of February 2020, it contains 2.6 million reviews for 1.7 million healthcare providers, and these reviews have been read by 161 million persons[12]. Another example is Hao Dai Fu (www.haodf.com), a Chinese website, which contains, as of March 2020, 4,024,818 patient reviews for doctors across China[13]. In terms of the role of these websites in informing patients' healthcare decisions, a 2012 study found that 40% of the US population believed that physician rating websites are "somewhat important," and 19% believed that these websites are "very important" when choosing their physician[14]. Patient stories can also help physicians to identify aspects in healthcare that can be improved[9]. However, despite the growing number of research studies that aim at analyzing online patient stories, the literature is scant on studies on how to systematically integrate this data into healthcare quality improvement efforts, and how healthcare providers can interact with patients who post these stories without any undesired consequences for both parties.

Additionally, social media has posed several risks, including breaches to privacy and reputational damage, which, depending on the context, may affect social media users, ordinary people, professionals, employees, and organizations. In order to mitigate social media risks, business and governmental organizations, and the professional regulatory authorities such as professional colleges develop policies and guidelines to control the behaviour of their members on social media.

In this study, I analyze the social media policies of the healthcare regulatory authorities in Ontario and explore how these policies encourage or discourage the use of social media by healthcare professionals to collect patient stories and identify points for improvement in healthcare quality.

5.2 Background

I did a literature review on social media risks, and I identified several types of risks for people and organizations.

5.2.1 The Risks of Social Media

A risk is the likelihood and consequences of a deviation from an expected outcome or objective[15]. There are four types of identified risks related to social media: general, professional, organizational, and platform-related risks[16,17]. These risks are represented in Figure 5.1, and they are discussed below.

First, the general risks: These are common risks that threaten all social media users, and they include possible wasting of a person's time, breach of a person's privacy, and the psychological harms that may be caused by negative feedback from other people[18]. Another general risk is the low information quality, which is related to the clarity of the information posted on social media and its appropriateness to the target audience[19]. Low information quality can lead to misinterpretation when the purpose and the context of information are not clear[20]. Using short sentences, abbreviations, short text, or expressions that are not meaningful to the audience reduces the quality of information and may cause miscommunication[19].

Second, the professional risks: These refer to the negative impacts of social media on employees or autonomous professionals such as physicians. Accusations on social media that a person has violated organizational policies or professional codes of conduct may result in disciplinary actions by professional colleges, associations, or employers[21]. A breach of client privacy is another professional risk. Privacy refers to a person's freedom from any intrusion, observation, or attention of others directed towards a person's body, ideas, information, or properties[22]. In professional contexts, a breach of client privacy may occur as a result of a disclosure of clients' private information by an entrusted person such as an employee or a physician[23,24].

Third, organizational risks: These refer to undesired outcomes of social media for organizations, such as damage to their reputation and legal liabilities[17,25,26]. Some posts on social media can have negative consequences for an organization's reputation, including information leaks by employees, negative product reviews, and stories about workplace conflicts[27,28].

Fourthly, the platform-related risks: These are technical risks related to social media platform operations, including information processing and information security, which determine the platform's technical ability to protect user accounts and personal information from unwanted or malicious access[17,23,24].

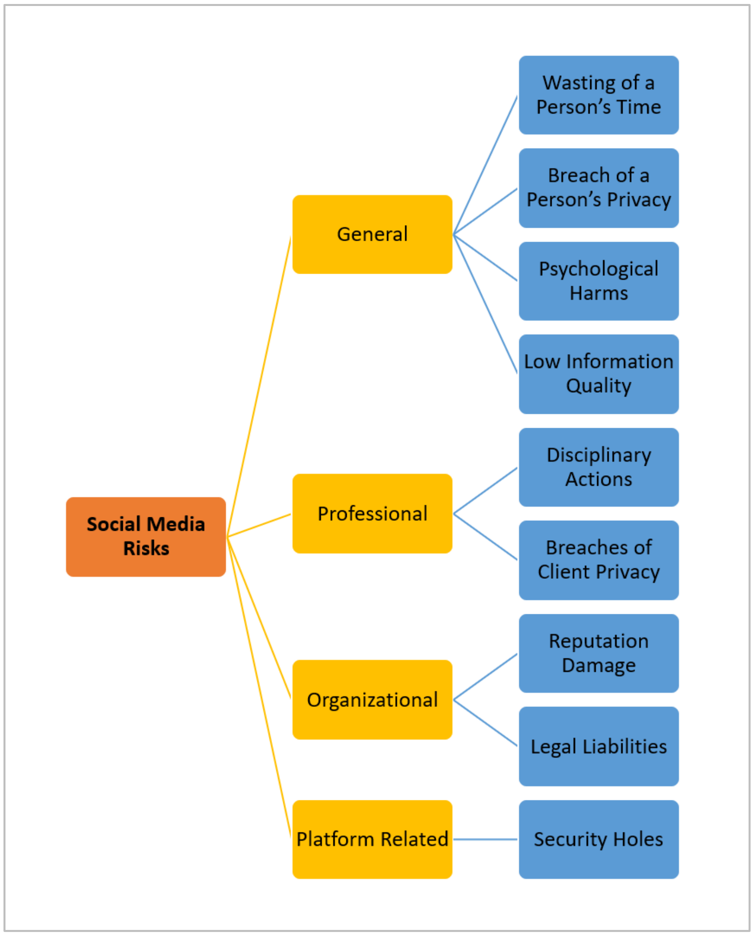


Figure 5.1: Social Media Risks

5.2.2 Social Media Risks in Healthcare

In the healthcare domain, professional and organizational social media risks may occur. These risks are represented in Figure 5.2.

Professional risks are breaches of patient privacy and confidentiality, crossing the professional boundary, potential conflicts of interest, distortion of professional image, misinterpretation of health information by laypeople, and violating healthcare ethics and professional practice standards by healthcare professionals[29]. These risks are discussed below.

Breaches of patient privacy and confidentiality

Confidentiality is an ethical principle in medicine and research, and it refers to an obligation to safeguard a person's private information by those who are allowed to access it[22,30]. In 2018, a nurse in a children's hospital in Texas, USA, was fired because she described the case of a child who had measles on Facebook. The hospital believed that the nurse had violated the HIPAA law that protects the privacy of patients in the US[31]. In Ontario, the confidentiality of patient information is one of the principles that govern the practice of healthcare[32,33], and in 2004, the Personal Health Information Protection Act became a law to which all healthcare professionals are legally bound[32].

Crossing professional boundaries

Professional boundaries define the acceptable and unacceptable actions of healthcare professionals not only at work but also in their personal lives[34]. They demarcate the limits of the relationship between healthcare professionals and patients[35]. In this relationship, healthcare professionals are entrusted by patients and the healthcare system to provide the necessary healthcare services to the patients. As a result, they are granted limited access to some of the private spaces of patients. This limited access is contingent on the necessity of healthcare services and on not causing harm to patients. However, when this access is unjustified or harmful, it becomes a boundary-crossing, and depending on its frequency, intensity, and consequences, it can become a boundary violation[36]. Trust and power differences underpin the relationship between patients and healthcare professionals, and most intentional boundary crossings stem from the misuse of power or trust by healthcare professionals[35,37,38]. The most prominent form of boundary violation is the sexual exploitation of patients, and therefore, protecting patients from any forms of sexual exploitation by healthcare professionals underpins the considerable attention to professional boundaries in healthcare[36].

Conflicts of interest

In the conflict of interest situations, healthcare professionals have personal interests that affect their professional views and decisions[39]. Examples include accepting gifts from patients, soliciting business for a relative of the healthcare professional, or referring a patient to a specific provider where there are some financial advantages to the referring professional (i.e., “kickbacks”). Additionally, most healthcare regulators provide guidelines on specific situations where a conflict of interest may exist, including commercial advertising, research studies, and accepting grants from the industry. In social media, a conflict of interest arises in situations where a healthcare provider directly or indirectly advertises, promotes, or endorses a product or service of a third party.

Distortion of the professional image of the healthcare professional

Roberts[40] defines the professional image as: "the aggregate of key constituents' (i.e., clients, bosses, superiors, subordinates, and colleagues) perceptions of one's competence and character."[40] A social media post by a healthcare professional may contain comments, pictures, audio and video materials, links to websites, and attachments. Any of these materials can be misinterpreted, controversial, inappropriate, or inaccurate, at least from the perspective of some people on social media, and can, therefore, negatively affect the professional image of the respective healthcare professional and the organization to which they belong[41,42].

Misinterpretation of health information on social media by laypeople

This risk is a challenge for healthcare professionals [43]. In all types of the media, the effectiveness of health communication depends on several factors related to the producer of the health information (i.e., the healthcare professional) and the receiver of this information (i.e., the patient or the layperson)[44]. These factors include the layperson's health literacy and cognitive needs, and the presentation of the information[44]. Many health-related websites include complex information that is difficult to understand by laypeople[45], or that is not valid outside specific geographic or demographic contexts[46].

Violating ethical and professional standards by healthcare professionals

A negative consequence of social media on professionals in all sectors is that it renders the line between what is personal and what is professional indistinct and blurry[26]. Therefore, a controversial post of healthcare professionals on their personal social media account may result in negative professional consequences. For example, in 2015, a registered nurse in Saskatchewan, Canada, posted comments on Facebook and Twitter criticizing healthcare services provided to her grandfather in a healthcare setting. The nurse questioned the competence of the staff in the specific healthcare setting, which she explicitly named. The nurse also made comments questioning the empathy of the practitioners in one of the healthcare professions. The nurse's online behaviour was found to be an act of professional and off-duty misconduct by the Saskatchewan Registered Nurses' Association (SRNA). A Saskatchewan court upheld the decision of the SRNA. According to the decision, the nurse caused damage to the nursing profession and other nurses, and while the SRNA acknowledged the nurse's right to freedom of expression, SRNA asserted that the nurse should abide by the SRNA's code of ethics and policies[47].

Any of the social media risks for healthcare professionals, discussed above, can have a damaging impact on the reputation of the related organizations such as hospitals, family practices, or other healthcare settings. These risks may also damage the reputation of the respective medical professions, such as nursing, medicine, and dietetics[48–50].

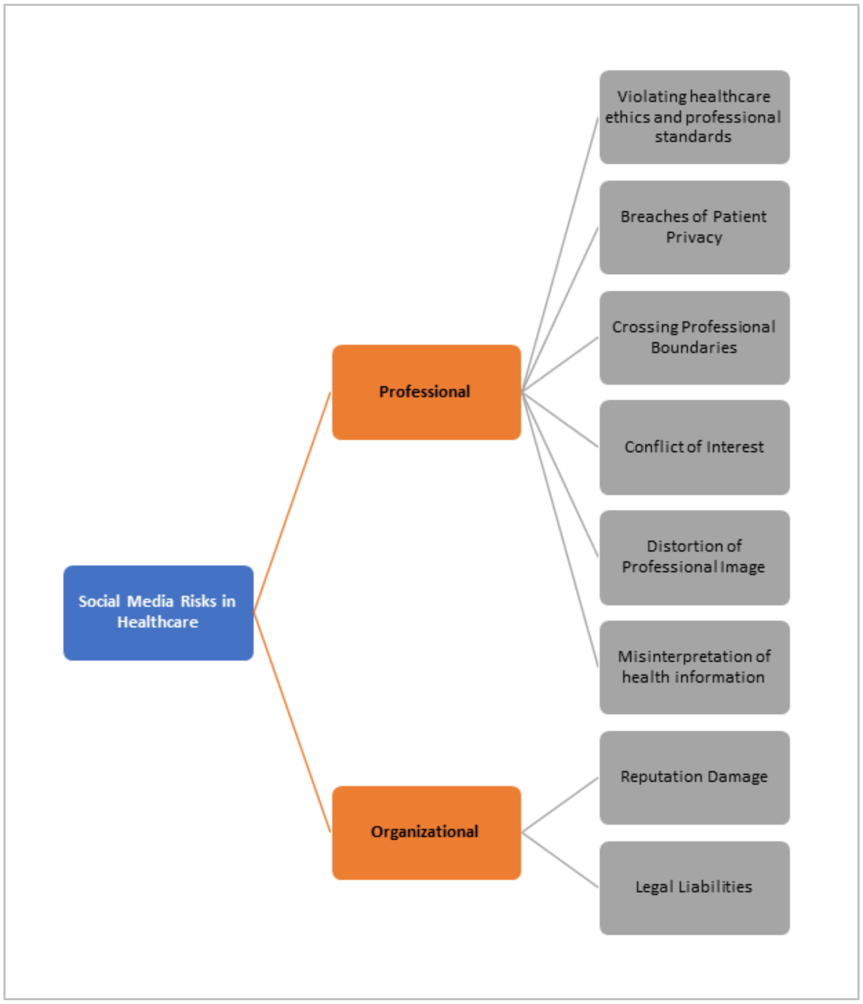


Figure 5.2: Social Media Risks in Healthcare

5.2.3 How Organizations Responded to Social Media

In business and professional organizations, social media policies govern the use of social media by employees and define employee's privacy boundary and employer's rights, and they set workplace rules and organizational expectations. These policies are legally binding, and they have been used by the judicial systems in cases involving breaches of employee's privacy, workplace rule violations, and professional standard violations[26]. Therefore, organizational social media policies play a vital role in controlling, enabling, or disabling activities that organization members can do on social media.

Due to the lack of legal guidelines on the use of social media, many of these policies have been overly protective and risk-averse, and they may have overlooked potential benefits of social media, such as professional knowledge sharing, client education, and marketing intelligence (i.e., understanding the characteristics and needs of clients)[51,52]. Kaganer et al.[53] use social representations theory to explore how organizations have responded to “end-user driven technologies,” such as social media, whose spread and use are driven by the end-users more than a rational adoption by organizations[53]. Social representations are “systems of values, ideas, and practices” that help group members communicate and behave[54]. The theory of social representations states that when group members face a threat or an unfamiliar situation, they cope with it by first trying to link it or anchor it to existing social representations. Anchoring enables group members to classify this unfamiliar situation and assign attributes or meanings to it, and, as a result, makes it more understandable[54,55]. Group members also construct new social representations in a process called objectification, in which people develop ideas and create meanings about the unfamiliar situation[53,54]. The researchers analyzed randomly selected corporate policies on social media from organizations from different sectors, including healthcare, government, and technology. These policies govern the use and adoption of social media by its employees. Kaganer et al. argue that, in the early days of social media, most organizations had a short time to develop social media policies because of the vast increase in the number of users of social media and the continuous development of social media platforms that bring new interaction capabilities to the users. Therefore, those policies reflect a limited understanding of decision-makers in those organizations about the new technology and do not represent a strategic endeavour to utilize social media for the achievement of strategic goals. The researchers found that decision-makers have favoured anchoring more than objectification, and they used existing social representations to understand social media and its risks and to design policies to control its use and mitigate its risks.

Decision-makers have conceptualized social media as a communication medium and therefore linked social media to existing communication policies. As a consequence, social media policies illuminate fundamental organizational communication guidelines and risk mitigation tactics, including behaving professionally, providing authentic information, and protecting information confidentiality[53].

On the other hand, organizations have struggled with one unfamiliar risk, which is the misrepresentations of an organization by wrongly attributing personal and inappropriate posts of employees to it. To mitigate this risk, organizations stress protecting organizational reputation by asking employees to label their posts as personal opinions. Organizations also highlight a critical social media issue, which is the blurred boundaries between people's personal and professional spaces.

Lastly, to mitigate any unforeseen or unknown risks, organizations use two strategies. They ask employees to respect all the professional codes, which not only guide employees' professional behaviour but also include disciplinary actions for misconduct. When employees are not sure on how to interact in any conditions, organizations ask those employees to consult with other employees to find a solution[53].

5.2.4 Development of Social Media Policies in Ontario's Healthcare System

Healthcare regulatory authorities control the use of social media by healthcare professionals through developing guidelines, practice standards, and learning materials to remind healthcare professionals about the ethical principles of their professions and to sensitize them to the potential consequences of patient privacy breaches and violations of professional standards on social media. Additionally, many healthcare organizations, such as hospitals and family practices, create social media policies to guide the proper use of social media by its staff, including physicians, nurses, and resident students[16,50,51].

In Ontario, healthcare professions, such as medicine, dentistry, pharmacy, and psychotherapy, are self-regulated under the Regulated Health Professions Act, 1991, and other related acts such as the Medicine Act, 1991, and the Dietetics Act, 1991. Each profession is governed by a college, which is responsible for setting practice standards, policies, and codes of conduct, and licensing the workforce in the respective profession. Additionally, most healthcare organizations, including hospitals, public health units, and family practices, develop workplace policies that also guide the delivery of health services. Social media policies are developed at both the college and the organizational levels. However, while the college policies are publicly available, most organizational policies are internal documents and cannot be accessed by the public.

Creating a historical timeline for social media policies in the healthcare system in Ontario can be difficult because of the scarcity of data on this topic. However, based on the publicly available policies that are published online, we can draw a timeline that starts in 2011 by the creation of the social media policy of the Canadian Medical Association[49]. In 2013, several colleges created social media policies and guidelines. The College of Physicians and Surgeons of Ontario issued a position statement on Social Media titled " Social Media - Appropriate Use by Physicians"[56]. The College of Nurses of Ontario developed a learning video titled "Social Media: Reflect before you post."[57] Additionally, also in 2013, seven healthcare colleges in Ontario, including the College of Occupational Therapists, The College of Respiratory Therapists, The College of Dietitians, and The College of Optometrists, developed a learning module titled, "Pause Before You Post," that aims at increasing the awareness of healthcare professionals about the risks of using social media[58].

5.2.5 Purpose of the Study

The study reviews social media policies in the healthcare system in Ontario to identify the goals of these policies, the acceptable use of social media by healthcare professionals, and the common risks, if any, and risk mitigation strategies of using social media. The study also explores whether these policies support the use of patient stories by healthcare professionals for healthcare quality improvement.

It is essential to mention that this study focuses only on social media as an online open environment that all people can access and use to interact with each other. Nevertheless, there are other online platforms that are used in telemedicine, which provide controlled access and secure communication for physicians and patients. These platforms are not technically considered social media, and they are not explored in this study.

5.3 Study Design

This study employed qualitative document analysis, following the approach described by Coffey[59], whereby a document is defined as:

> "any material that provides information on a given social phenomenon and which exists independently of the researcher's actions and is produced by individuals or institutions for purposes other than social research."[60]

Documents include newspapers, legislative acts, autobiographies, emails, social media posts, court orders, organizational policies, and minutes of meetings. They are produced for a specific purpose and specific beneficiaries, and their production and consumption comply with specific social, political, or technical constructs, and therefore, they provide traces of the social practices[59]. They may capture significant events or the daily life of individuals and institutions, which may become of interest to other people, such as researchers, authors, or decision-makers, in other times[59,60]. The documents in this study are social media policies in the healthcare system in Ontario.

The document analysis method is defined by Coffey[59] as:

> "A document analysis is an approach in which documents are analyzed for what they are and for what they are used to accomplish. This means paying attention to the knowledge that documents 'contain' about a setting, but also examining their role and place in settings, the cultural values attached to them, their distinctive types, and forms. It should seek to locate documents within their social as well as textual context."[59]

Document analysis explores the context and content of the document. Qualitative research is context-sensitive[61], and researchers strive to understand the social context where phenomena occur, and the data is produced. Because documents can be of different formats (e.g., audio recordings, texts, or video), the document analysis method only provides a high-level approach to document analysis. In this paper, most of the documents are textual documents, or they provide a readable content such as the learning modules; therefore, I used qualitative content analysis, as explained in the data analysis section below.

5.3.1 Data Collection Method

I have collected social media policies and guidelines of some healthcare colleges, which are the regulating and licensing bodies of healthcare in Ontario. The data collection method consisted of several steps.

Firstly, I selected a set of healthcare regulatory authorities and healthcare service delivery organizations in Ontario, based on feedback that I received during a previous study that I conducted in 2018 and 2019, and it consisted of interviewing 21 healthcare providers in Ontario, which is reported in Chapter 4. Secondly, I explored how to acquire the required documents for each organization. All healthcare regulators have websites where they publish all their policies. As for healthcare service-delivery organizations such as hospitals and public health units, most social media policies are internal policies that are not available for public use. I, therefore, contacted a few of these organizations and included policies of those who accepted my request (Ottawa Hospital and the North Bay Parry Sound District Health Unit). I have also included two non-regulatory organizations: the Canadian Medical Protective Association and the Canadian Medical Association. The former provides consulting and advisory services for physicians in cases of litigation. The latter is the labour union of physicians. Thirdly, the documents collected include policies, standards, and learning materials. I included any document that has been explicitly labelled as a social media policy, social media guidelines, or social media position statement. I also included any document that I discerned was important for understanding the content of the included documents, such as codes of conduct and professional standards. Fourthly, I did not set a limit for the number of documents to collect; however, during data analysis, I reached a stage where I felt that I captured all the common themes in these documents, and I had collected enough data to answer my research questions, and therefore, I was comfortable to stop data collection.

The participating organizations and the included documents are listed in Table 5.1.

Table 5.1: Documents Collected in the Study

	Organization	**Document Name**	**Document Type**	**Publishing Date**
1.	The College of Dietitians of Ontario	Professional Communications Online and on Social Media[42]	Practice Guidelines	2016
2.	The College of Dietitians of Ontario	Boundary Guidelines for Professional Therapeutic RD-Client Relationships[62]	Practice Guidelines	2017
3.	The College of Dietitians of Ontario	Social Media and Dietetic Practice[41]	Practice Guidelines	2013
4.	The College of Dietitians of Ontario and other colleges	Pause Before You Post — A Learning Module[58]	Learning Video	2013
5.	College of Nurses of Ontario	Social Media Use: Common Expectations for Nurses[63]	Position Statement	2016

6.	College of Nurses of Ontario	Social Media: Reflect Before You Post[57]	Learning Video	2013
7.	College of Nurses of Ontario	Should you accept a patient’s friend request on social media?[64]	Practice Guidelines	2019
8.	College of Nurses of Ontario	Code of Conduct[38]	Policy	2019
9.	College of Nurses of Ontario	Professional Standards[65]	Professional Standards	2018
10.	College of Nurses of Ontario	Confidentiality and Privacy — Personal Health Information[33]	Practice Standard	2019
11.	College of Nurses of Ontario	Ethics[66]	Practice Standard	2019
12.	College of Physicians and Surgeons of Ontario	Social Media — Appropriate Use by Physicians[56]	Position Statement	2013
13.	College of Physicians and Surgeons of Ontario	Confidentiality of Personal Health Information[67]	Policy	2006
14.	College of Physicians and Surgeons of Ontario	The Practice Guide — Medical Professionalism and College Policies[32]	Practice Guidelines	2007
15.	College of Physicians and Surgeons of Ontario	Maintaining Appropriate Boundaries and Preventing Sexual Abuse[37]	Policy	2018
16.	College of Optometrists of Ontario	Guidelines for the Appropriate Use of Social Media by Optometrists[68]	Practice Guidelines	2013
17.	The Ottawa Hospital	Social Media[69]	Policy	2013
18.	The Ottawa Hospital	Guidelines for Social Media Participation[70]	Guidelines	2017
19.	The Canadian Medical Protective Association	Social media: The opportunities, the realities[46]	Guidelines	2014
20.	The Canadian Medical Protective Association	Top 10 tips for using social media in professional practice[71]	Guidelines	2014
21.	The Canadian Medical Protective Association	Online physician reviews: How to manage your virtual presence, and real reputation[72]	Guidelines	2019
22.	Canadian Medical Association	Social media and Canadian physicians: Issues and rules of engagement[49]	Policy	2011
23.	North Bay Parry Sound District Health Unit	Social Media[73]	Policy	2017

5.3.2 Data Analysis

To explore the content of the policies, I have used a qualitative content analysis method, following the methods of Elo et al.[74] and Mayring[75]. Qualitative content analysis is a systematic exploration of the collected data or documents, and it enables the researcher to explore the manifest features and meanings in the documents[76].

In this study, I followed a deductive approach[74,75] to content analysis by using an existing theoretical framework, which is the honeycomb framework[52,77], to develop a coding frame that I have used for coding and categorizing the content. The honeycomb framework defines the areas of use, benefits, and risks of social media in organizational contexts, and it helps organizations develop strategies and policies that enable them to use, manage, and monitor social media to maximize its benefits and minimize its risks[52,77]. The framework defines several types of interactions that may occur on social media, including sharing of information, communication, and building relationships. These interactions occur among an organization's clients or employees, and therefore they may have significant positive or negative impacts on organizations[52,77].

In my analysis, I read the documents several times to be able to understand the different meanings in them, and I coded the different parts of data using the appropriate codes. Because most of these documents contain guidelines, they are well-organized and highly structured. This made reading and understanding them straightforward. I did the coding manually by using a categorization matrix, which enables the researcher to categorize the units of analysis and represent theme distribution in the documents[74].

5.4 Results

In this section, I present the results of the document analysis. The subsections correspond to the research questions.

5.4.1 The Goals of Social Media Policies

In this study, I found that the social media policies that have been analyzed can have one or more of the following goals: to set the code of conduct, to define risk mitigation strategies, to present operational guidelines, and to educate healthcare professionals.

A code of conduct policy aims at reminding healthcare professionals of the code of conduct, professionalism, and legal obligations to be respected online. A risk mitigation policy aims to identify strategies that can reduce the personal, professional, and organizational risks of using social media by healthcare professionals. Because most healthcare professionals are independent professionals, organizational risks refer to damaging the reputation of the whole profession, as I have explained in the background section. An operational policy describes how to manage the social media pages of organizations or the online presence of healthcare professionals. An educational document aims at informing healthcare professionals about the use of social media, and the legal and professional obligations of healthcare professionals when using it.

The goals of the analyzed documents are presented in Table 5.2. We can see that all of the analyzed policies have two main goals: to remind healthcare professionals of the professional codes of conduct and to provide them with risk mitigation strategies. For example, the social media e-learning module of the College of Dietitians of Ontario states the following:

> "This learning module will enhance your awareness of the benefits and risks of social media use in healthcare. Applying sound principles from professional standards of practice and related legislations when you are on social media will help ensure risk management strategies are in place, and professional reputations and relationships are maintained."[58]

The College of Physicians and Surgeons of Ontario states the following:

> "The College's position is that physicians are expected to comply with all of their existing professional expectations, including those set out in relevant legislation, codes of ethics, and College policies when engaging in the use of social media platforms and technologies."[56]

The Ottawa Hospital (TOH) states the following:

> "Improper internet and social media use expose TOH to risks that may include virus attacks, compromise of network systems and services, privacy issues, legal litigation, and damage to reputation. Users should be responsible and productive and protect the interests of TOH. Management reserves the right to take administrative and/or disciplinary action where there is a contravention of this policy."[69]

Table 5.2: Social Media Policies' Goals

	Organization	**Organization type**	**Document Name**	**Main Goals**
1.	The College of Dietitians of Ontario	Regulatory	Professional Communications Online and on Social Media[42]	Code of conduct, Risk mitigation
2.	The College of Dietitians of Ontario	Regulatory	Social Media and Dietetic Practice[41]	Code of conduct, Risk Mitigation
3.	The College of Dietitians of Ontario and other colleges	Regulatory	Pause Before You Post — A Learning Module[58]	Education, Code of conduct, Risk Mitigation

4.	College of Nurses of Ontario	Regulatory	Social Media Use: Common Expectations for Nurses[63]	Code of conduct, Risk Mitigation
5.	College of Nurses of Ontario	Regulatory	Social Media: Reflect Before You Post[57]	Education, Code of conduct, Risk Mitigation
6.	College of Nurses of Ontario	Regulatory	Should you accept a patient's friend request on social media?[64]	Code of conduct, Risk Mitigation
7.	College of Physicians and Surgeons of Ontario	Regulatory	Social Media — Appropriate Use by Physicians[56]	Code of conduct, Risk Mitigation
8.	College of Optometrists of Ontario	Regulatory	Guidelines for the Appropriate Use of Social Media by Optometrists[68]	Code of conduct, Risk Mitigation
9.	Ottawa Hospital	Healthcare Provision, Regulatory	Social Media[69]	Code of conduct, Risk Mitigation, Operational
10.	Ottawa Hospital	Healthcare Provision, Regulatory	Guidelines for Social Media Participation[70]	Code of conduct, Risk Mitigation
11.	The Canadian Medical Protective Association	Advisory, Non-Regulatory	Social media: The opportunities, the realities[46]	Education, Risk Mitigation
12.	The Canadian Medical Protective Association	Advisory, Non-Regulatory	Top 10 tips for using social media in professional practice[71]	Education, Risk Mitigation
13.	The Canadian Medical Protective Association	Advisory, Non-Regulatory	Online physician reviews: How to manage your virtual presence, and real reputation[72]	Education, Risk Mitigation, Operational
14.	Canadian Medical Association	Advisory, Non-Regulatory	Social media and Canadian physicians: Issues and rules of engagement[49]	Education, Risk Mitigation
15.	North Bay Parry Sound District Health Unit	Healthcare Provision, Regulatory	Social Media[73]	Code of conduct, Risk Mitigation, Operational

5.4.2 Areas of Use of Social Media by Healthcare Providers

The documents reviewed identified several possible areas of use of social media. These areas of use are presented in Table 5.3.

Some healthcare professionals and healthcare organizations such as public health units in Ontario use social media for health promotion, dissemination of public health information, and educating the public. Social media can also be used by healthcare professionals to share best practices and knowledge. The College of Dietitians of Ontario permits the use of social media for promoting a dietitian's services[41,42].

Some of the organizations in the study do not prevent communicating with patients on social media, provided that such communication does not evolve into a therapeutic relationship[46]. The

College of Dietitians of Ontario asserts that informed consent should precede such communication[42]. However, all these organizations assert that healthcare professionals must abide by the laws and regulations when using social media, including the Personal Health Information Protection Act (PHIPA) in Ontario, and the professional codes of conduct and practice standards of each profession.

Table 5.3: Areas of Use of Social Media

	Organizations*							
Area of Use	College of Dietitians of Ontario	College of Nurses of Ontario	College of Physicians and Surgeons of Ontario	College of Optometrists of Ontario	North Bay Parry Sound District Health Unit	Ottawa Hospital	The Canadian Medical Protective Association	Canadian Medical Association
Public education and health promotion	X	X	X	X	X	X	X	X
Disseminating timely health information to simulate public discussion and trigger action	X	X			X	X	X	X
Interprofessional dialogue and collegiality	X	X	X	X	X	X	X	
Communicate with patients or patients' family members.	X					X	X	X
Communicate with members of the public		X			X	X	X	X
Marketing of professional services.	X							
Conducting Research						X		

* The X sign denotes that the specific area of use has been permitted by the specific organization.

5.4.3 The Risks of Using Social Media by Healthcare Providers

The organizations in the study recognize several potential risks that healthcare professionals should pay attention to in order to avoid any undesired consequences when they use social media. These risks (Table 5.4) can be general, professional, organizational, or platform-related risks, which have been defined in the background section in this paper. However, I present here the professional and organizational risks identified in the analyzed documents.

Table 5.4: The Risks of Using Social Media

		Organizations*							
Risk	**Risk Type**	College of Dietitians of Ontario	College of Nurses of Ontario	College of Physicians and Surgeons of Ontario	College of Optometrists of Ontario	North Bay Parry Sound District Health Unit	Ottawa Hospital	The Canadian Medical Protective Association	Canadian Medical Association
Breaches of client privacy and confidentiality	Professional	X	X	X	X	X	X	X	X
Crossing the professional boundary	Professional	X	X	X	X			X	X
Damaging the organization or group reputation	Organizational	X		X		X	X	X	
Distortion of a professional image.	Professional	X		X					X
Information security issues	Platform/Technical	X	X				X		X
Misinterpretation of information by laypeople	General risks	X						X	X
The potential conflict of interest	Professional	X		X	X				
Miscommunication	General risks	X			X				
The inaccuracy of health information	General risks					X		X	

* The X sign denotes that the specific risk has been identified by the specific organization.

5.4.3.1 Breaches of Client or Patient Privacy

All the organizations in the study have position statements or guidelines that set the expectations of those organizations regarding how healthcare professionals should behave on social media.

Protecting the privacy of patients is the first expectation that should be met by healthcare professionals. The College of Physicians and Surgeons of Ontario asserts that a physician's behaviour on social media is subject to the same professional obligations of the real-life practice:

> "Legal and professional expectations that govern medical practice are set out in the College's Practice Guide, policies, and relevant legislation. These obligations are not unique to social media, but apply to medical practice in general, and must be met by all physicians, [including] compliance with all legal and professional obligations to maintain patient privacy and confidentiality."[56]

Many actions can be considered breaches of privacy, including posting identifiable information about a particular patient without prior consent, posting information about a particular case that can enable the identification of a particular patient, and using the Internet to find information about a particular patient[42].

5.4.3.2 Crossing Professional Boundaries

All organizations under the study assert that using personal social media accounts by healthcare professionals to connect with patients violates professional boundaries because such a connection would lead to a dual relationship between the two parties (i.e., a professional and personal relationship). Furthermore, most of these organizations, including the College of Nurses of Ontario, caution healthcare professionals against crossing professional boundaries even when using their professional social media accounts:

> "By connecting on or corresponding over your personal social media account, you are crossing the boundary where the professional therapeutic nurse-client relationship changes to unprofessional and personal. [Additionally,] when using a professional social media account, you must ensure you are not violating patient privacy and confidentiality or crossing the therapeutic nurse-client boundary."[64]

The College of Dietitians also asserts that dietitians should not connect with any client on a personal social media account:

> “Accepting a client as a ‘friend’ on Facebook (or other personal social networking sites) would be considered a boundary crossing. Specifically, this would fall under the category of dual relationships, as this proposed friendship has the potential to interfere with the client-RD professional relationship. A client who is a “friend” of an RD under their personal profile would be privy to messages, photos, and other personal information that may compromise the dynamics of the professional relationship.”[41]

5.4.3.3 Conflict of Interest on Social Media

In a conflict of interest situations, healthcare professionals do not prioritize the interests of their clients. The College of Dietitians of Ontario, College of Nurses of Ontario, and the College of Optometrists of Ontario consider providing healthcare in these situations to be an act of professional misconduct[39,78].

The College of Dietitians of Ontario argues that even client testimonials on social media may lead healthcare providers to a conflict of interest[41].

The College of Physicians and Surgeons emphasizes that physicians should avoid situations of conflict of interest in social media[56]. Conflicts of interest not only compromise the interest of the patients but also can damage the reputation of the profession:

> “Any conflicts of interest must be properly managed so as not to compromise the patient’s best interests or be avoided. Physicians should guard against compromising their duty to their patients by pursuing personal advantage, whether financial or otherwise, at the expense of the patient. <u>Physicians should also be aware of the possibility of damage to the reputation of the profession by the appearance of a conflict</u>, <u>even though an actual conflict may not exist</u>, and avoid creating such a perception.“[32]

5.4.3.4 Distortion of Professional Image of the Healthcare Professionals

Distortion of the professional image of the healthcare professional is another risk of social media.

The College of Physicians and Surgeons of Ontario advises physicians not only to refrain from posting “unprofessional content” but also to make sure that social media do not have unprofessional posts about them by other people[56]. The College of Dietitians of Ontario asserts that dietitians should maintain their professionalism in their personal social media:

> "To maintain professionalism, be cautious about what you or others post on your professional and personal social networks. Always maintain a respectful and professional image, even on your personal social media. Your personal status updates and photos, even if marked private, can be shared and distributed to a wider public by someone in your network. What you do in your personal life can impact your professional life, too."[42]

5.4.3.5 Damaging the Organization or Profession's Reputation

Most of the organizations in the study describe the potential impact of the behaviour of healthcare professionals, on their professional and personal social media, on the reputation of the profession as a whole as well as that of the respective organization. For example, the College of Physicians and Surgeons of Ontario links individual physician's reputation to the profession's reputation and asks physicians to protect both reputations by refraining from posting unprofessional content on social media[56].

Healthcare professionals who interact on social media using their personal accounts may also be held accountable for their posts on social media if they can be identified by the audience as healthcare professionals or as employees at a specific healthcare organization. For example, the Social media policy of the Ottawa Hospital asserts the accountability of staff for their social media posts:

> "Social media users are responsible for all communications using their personal social media accounts when referring to the Ottawa Hospital or representing themselves as the Ottawa Hospital staff members. Users with the Ottawa Hospital listed as their place of employment should keep in mind that their actions reflect on the Hospital."[69]

The North Bay Parry Sound District Health Unit requires that staff members use a disclaimer that declares that the social media posts of any staff member do not represent the health unit if they identify themselves as healthcare professionals.

5.4.4 Social Media Risk Mitigation Guidelines

Several guidelines have been suggested by the organizations in the study to mitigate or reduce the risks of using social media. These guidelines are presented in Table 5.5. Many guidelines are shared among all the organizations: protecting patient privacy and confidentiality of patient information, and behaving professionally and respectfully by not posting, sharing, or liking disrespectful content and by respecting all people online. Respectful online conduct also requires not publishing or sharing offensive, defamatory, insulting, bullying posts. Other common guidelines are keeping professional boundaries between the healthcare professional and the patient, and respecting all the relevant laws and professional regulations, including healthcare-specific laws such as the Personal Health Information Protection Act (PHIPA), and the copyrights laws.

The College of Physicians and Surgeons of Ontario and the College of Optometrists of Ontario explicitly recommend not providing clinical advice to patients online. On the other hand, the College of Dietitians does not prevent dietitians from providing general dietetic advice to their clients but recommends that in cases where the clients ask for more specific advice, it should be provided in a practice setting[42]. This college also recommends including a "disclaimer statement" on social media posts that reminds the clients that online health advice is limited and does not replace professional advice provided in healthcare settings[42].

Because all healthcare professionals must abide by the Personal Health Information Protection Act (PHIPA) of Ontario, all the organizations in the study agree on the significance of protecting the privacy of the patients online. Under PHIPA, the collection, use, and disposal of a person's health information are forbidden without their consent[79]. In this study, the College of Dietitians of Ontario, the College of Nurses of Ontario, and the Ottawa hospital ask their healthcare professionals to request informed consent from patients or clients before publishing any patient-specific content online, including photos and testimonials. Additionally, the College of Dietitians of Ontario asks dietitians to also obtain informed consent before communicating with a client online[41,42]. Many of the organizations in the study also assert the importance of posting accurate and current health information on social media.

Additionally, the Canadian medical association (CMA) and Canadian Medical Protective Association advise physicians to indicate to their audience that any health information posted by those physicians is relevant in the Canadian context only as stated in the CMA social media policy:

> "Physicians who use blogs or other social media sites to discuss health-related issues may want to include a reference to the Canadian context in which the information is provided. This will help mitigate the risks of non-Canadians heeding advice that may not be

appropriate or relevant. Publishing information on blogs or other social media platforms may result in legal actions being brought outside of Canada."[46]

Table 5.5: Social Media Risk Mitigation Guidelines

	Organizations*							
Risk Mitigation	The College of Dietitians of Ontario	College of Nurses of Ontario	College of Physicians and Surgeons of Ontario	College of Optometrists of Ontario	North Bay Parry Sound District Health Unit	Ottawa Hospital	The Canadian Medical Protective Association	Canadian Medical Association
Protecting the privacy and confidentiality of client's or patient's information by not sharing it online	X	X	X	X	X	X	X	X
Professional and respectful online conduct	X	X	X	X	X	X	X	X
Respect the laws and regulations, including PHIPPA, advertising, conflict of interest, defamation, copyright, and plagiarism.	X	X	X	X	X	X	X	X
Protect the privacy of the healthcare professional (own privacy)	X	X	X			X	X	X
Keeping professional boundaries	X	X	X	X			X	X
Understand the social media platform's technical features and policies, including privacy and information sharing policies.	X	X	X	X		X	X	X
Compliance with collegiate and organizational	X	X			X	X	X	X

policies and guidelines								
Accurate, current, and authentic health information	X			X	X	X	X	X
Reflect on the potential consequences of your posts on social media before posting.	X	X			X	X	X	
Refrain from providing clinical advice to patients through social media.	X		X	X			X	X
Provide a disclaimer statement and a user policy on social media pages	X				X	X	X	X
Not accepting friend requests from a client on personal accounts	X	X	X	X			X	
Respect the privacy of workplace by avoiding discussing workplace issues online	X	X		X		X		
Monitoring and updating when possible the online presence of the healthcare professionals	X		X	X			X	
Obtain informed consent before publishing any client health information	X	X		X			X	
Obtain informed consent before publishing client information such	X	X		X			X	

as photographs and testimonials								
Know the benefits and risks of social media. Have the skills and judgment to use it appropriately and ethically.		X				X	X	X
Protect self reputation and the reputation of the profession or the organization			X		X	X	X	
Use different accounts for personal and professional activities and connect with clients through your professional account only	X	X					X	
Always provide credit and links back to original sources when sharing information.	X						X	X
Refrain from seeking out the patient information online without consent	X		X	X				
Clear, professional, and audience-appropriate communications.	X			X				X
Understand and set the expectations of people on your social network		X					X	
Create a social media management policy for your							X	X

professional social media								
Obtain informed consent before communicating with the clients online	X							
Do not use social media for personal matters when you are at work.		X						
Carefully identify your employment and affiliation with others.						X		

* The X sign denotes that the specific risk mitigation guideline has been mentioned by the specific organization.

5.4.5 Social Media Policies and Patient Stories

In this section, I review the perspectives of the organizations in the study on patient stories posted on social media.

Our document analysis has not revealed any systematic recognition of patient stories on social media as a source of information that requires the attention of healthcare professionals. Some organizations under the study recommend that healthcare professionals remain vigilant about their online presence, which consists of all the online interactions of healthcare professionals, including their personal posts, blogs, pictures, as well as posts by other people about them. However, no guidelines have been provided to address patients' posts about their experiences within the healthcare system or with healthcare professionals.

The training video provided by The College of Nurses provides five scenarios related to social media that can be faced by nurses, and what the appropriate behaviour is in line with the college policies, and these scenarios are "a friend request by a patient," joining a professional network of nurses, using social media to complain about job conditions, using social media for health promotion, and posting pictures on social media. However, the video does not mention anything about a patient complaining about a negative experience within the healthcare system[57].

The College of Physicians and Surgeons of Ontario advises physicians to actively monitor their "internet presence" and strive to remove any unprofessional content about them[56].

The College of Dietitians of Ontario recommends that dietitians stay vigilant to patient stories and strive to remove these stories if they contain inaccurate information:

> “RDs should strive to be aware of comments posted about their practice. Where information is inaccurate, misleading, fraudulent, or defamatory, RDs should contact the third party’s website administrator to request a correction or deletion.”[41]

The College of Optometrists of Ontario does recognize the importance of patient stories on social media. However, no guidelines have been provided to collect these stories:

> “online story-telling by patients or clients and health professionals has been identified as a rich experience, it provides insight into the patient or client's perspective which can inform quality improvement initiatives, and client-centered behaviours and principles and allows for reflections on the quality of care and service provided.”[68]

However, the Canadian Medical Protective Association (CMPA) provides a different and less risk-averse perspective than the other organizations under study. In a document published in 2019, CMPA recognizes that while some online patient comments may be ranting, unfounded, or defamatory; others may include constructive criticism and suggestions for improvement[72]. According to CMPA, physicians can benefit from the “wisdom of the crowd” on social media[72], or the collective intelligence, as referred to in the Internet and social media literature, and it denotes the intelligence that develops in the internet-based and interconnected environments where people interact and generate content and knowledge independently, collaboratively, or competitively[80]. CMPA advises physicians to be mindful regarding patient comments on social media and look for common ideas in those comments, which can expose certain aspects of patient experience that need improvement[72].

5.5 Discussion

In this study, I review and analyze social media policies and guidelines related to the use of social media by healthcare professionals in select healthcare professions, including nursing and medicine. In this section, I review the study findings in light of the available literature.

5.5.1 Benefits and Risks of Using Social Media by Healthcare Professionals

Our study identified commonalities among social media policies in the healthcare system in Ontario, in terms of social media uses, risks, and risk mitigation strategies. These policies govern the use of social media by healthcare professionals. The study findings are consistent with current knowledge on using social media in healthcare[4,29,81], the risks of this use[29,50,82], and risk mitigation strategies[48,50,82,83].

Healthcare professionals may use social media for health education and promotion, disseminating timely health information in case of medical emergencies or endemics, and interprofessional dialogue and collegiality among healthcare professionals. On the other hand, these uses are associated with risks, which are the breaching of a patient or client privacy, crossing the professional-client boundaries, damaging the reputation of the organization or profession, and distortion of professional image. Several strategies can be used to mitigate these risks, and consist of protecting patient privacy, professional conduct online, and respecting all the laws and regulations related to healthcare. Other strategies include understanding the technical features of the social media platform in general and privacy-related settings in particular, keeping professional boundaries between the healthcare professional the patient, and protecting the privacy of the healthcare professionals.

Drawing on the study of Kaganer et al.[53], which is presented in the background section, this study's data lead us to suggest that healthcare organizations and regulators have used existing social representations to develop their social media policies. For these organizations, social media is a source of risks to the healthcare professions and healthcare professionals, and policies are developed to mitigate these risks. Organizations, therefore, emphasize that the codes of conduct and the professional standards of healthcare extend to social media, despite the distinct context of social media. Accordingly, social media risks are risks of violating the codes of conduct or practice standards. These findings suggest that social media policies of healthcare organizations and regulators are important constructs that enable these entities to control the use of social media by healthcare professionals.

5.5.2 Patient Stories on Social Media

As I have discussed in the results section, many healthcare organizations in Ontario have not considered social media to be a technological platform with capabilities that can be exploited to improve healthcare quality and patient experience. Instead, social media has been dealt with cautiously with suspicion, and the fears of privacy breaches and reputational damages have overwhelmed the positions of most organizations regarding social media. The risk mitigation guidelines suggested by the healthcare organizations call for minimizing the interaction between healthcare professionals and patients on social media. Also, in such policies, professionals are advised to actively monitor their online presence to make sure that the public's comments are contained and addressed. These policies are similar to the policies adopted by healthcare regulators in the USA[48,82] and the UK[84–86]. These policies may be more protective than progressive because they focus more on protecting healthcare professionals and their professions than on actively promoting means and practices through which patient comments can be used to improve the delivery of healthcare. By focusing on the possible legal consequences of the interaction between the patient and the healthcare professional on social media, these policies may impede the uptake of social media by healthcare professionals[87].

However, there are several non-empirical studies[9–11] and empirical ones[88–91] that suggest that these stories can reveal issues in healthcare that are not always exposed by traditional patient experience surveys, and they can provide evidence for healthcare quality improvement. These stories can also contain detailed descriptions of patients' illness experiences and the burdens of disease, which may not be captured by traditional surveys or interviews[92]. There is also one notable example that has been operating since 2005, which is the Care Opinion platform (www.careopinion.org.uk). This platform collects patient stories in the UK, and in September 2019, it contained 367,573 stories, 73% of which received a response from healthcare providers, despite the restricted social media policies in the healthcare system in the UK. This platform shows that there are ways to respond to patient stories and respecting professional standards and applicable laws.

Therefore, as I discussed in Chapter 4, policy and cultural changes may be required to foster the use of social media for healthcare quality improvement and enable the development of a safe patient-provider communication environment. Such an environment can facilitate the exchange of constructive feedback between the two parties without the fear of legal consequences or privacy breaches. Healthcare regulatory authorities in Ontario are invited to evaluate their social media policies and guidelines and assess the risks and potential benefits of social media to make sure that while asserting the risks that may threaten both patients and healthcare providers, no opportunities for listening to patients and improving the quality of healthcare are lost. There also needs to be a change in the healthcare providers' perception of the value of patient feedback and patient stories. Achieving this change requires educating the providers and advocacy from patient support organization.

5.5.3 Interpreting the Results in Light of the Theoretical Perspective

In chapter 2, I discussed Max Weber's conflict theory. This theory helps understand many themes that emerged in this study. Weber recognized the evolution of the profession in the West and distinguished between a profession and an occupation[93] by identifying several factors that characterize the profession, including the power to control the delivery of its services, a body of knowledge that is collected and maintained systematically, systematic training, specialization, and a unique life style[93]. The profession's power is, according to Weber, a legal-rational power[94]. Healthcare professions have two types of authorities, according to Starr[95]: a social authority to control the delivery of its services and practices of their members (i.e., the healthcare professionals), and cultural authority to define what health and illness are and how to treat illness[95]. For Weber, power, economic capabilities, and social status, create social groups, such as the professional groups, which have different goals and interests. The social stratification and the goals and interests of these groups are preserved by the creation and nurturing of certain norms, values, and beliefs that direct the actions of the members of these groups. The findings of this study show that the codes of conduct, practice guidelines, and social media policies are social constructs that enable the different healthcare professions to protect their distinctive identity. The study's findings show that these healthcare professions are overtly distinguishing themselves as closed social groups by using and emphasising the professional image, the shared reputation, and the professional boundaries. As I discussed in Chapter 2, the social groups bring socioeconomic benefits to their members, and these groups protect their interests by creating norms and values and by taking disciplinary actions against any disobedient members. This was also clear in the study findings. Many of the analyzed policies focused on the possible legal consequences of the interaction between the patient and the healthcare professional on social media. Although all of these policies are meant to protect both the patients and the healthcare providers, they are also social constructs that aim to protect socioeconomic interests.

5.6 Conclusion

This study analyzed a selection of social media policies and guidelines in the healthcare system in Ontario. Those policies have been developed by healthcare professional regulatory authorities (i.e., the professional colleges), and healthcare organizations (i.e., hospitals and public health units). The study revealed three key concerns of social media policies in healthcare: protection of privacy, protection of professional boundaries, and protection of professional image. The study used existing evidence to show that similarly to some other types of organizations, healthcare organizations perceived social media as an innovation that brings several risks to organizations, including wasting of employee's time, breaching of client privacy, information security issues, and damaging the reputation of organizations. Therefore, these organizations responded to social media by using existing social representations, which are systems of values, ideas, and practices in the healthcare system that govern professional practices. These social representations include patient privacy protection, the professional boundaries between healthcare professionals and the patients, and the professional image.

The study argues that healthcare organizations, frightened by the inherent risks of social media and influenced by the lack of a large body of legal evidence, might have ignored the potential benefits of using social media as a source of patient stories that can provide credible information about patient experience with healthcare.

5.7 Limitations and Implication for Future Research

In this study, I have focused on the documentary materials in the form of policies and guidelines to explore the position of healthcare regulatory organizations concerning the use of social media by healthcare professionals. However, these documents do not fully reveal or reflect the attitudes and beliefs of decision-makers in these organizations. A policy evaluation would complement this study by analyzing the perspectives of the policy actors, including policymakers, healthcare professionals, and interest groups[96].

Secondly, while there are 29 healthcare professional regulatory authorities in Ontario, I have only explored the social media policies of four of them, and this is because my initial scan of the available materials revealed that most of these organizations share the same ideas about social media. However, further research on some of the other regulatory organizations may be able to expose different and unique aspects of social media policies than what I have exposed in this study.

Thirdly, I have included two healthcare provision organizations: a hospital and a public health unit. However, there are tens of hospitals and public health units in Ontario, and policymakers in these organizations may have unique positions about social media. Therefore, also, further research is required in this regard.

Forward to Chapter 6

In the previous three studies in this dissertation, I explore several elements in the phenomenon of patient stories on social media: the concept of patient experience; the perspectives of healthcare providers and administrators regarding patient experience and patient stories on social media; the benefits and risks of patient stories; and the sociopolitical context that impacts the use of patient stories by healthcare providers for improving the quality of healthcare. However, these studies are premised on the assumption that patient stories, which are available in large volumes, can provide useful information about patient experiences.

Additionally, these studies show that there are several factors that can discourage healthcare providers from utilizing patient story platforms. The first study (Chapter 3) shows that healthcare providers prioritize health outcomes over other outcomes of healthcare, such as patient satisfaction. The first study also shows that providers in Ontario may face burnout because of the increasing workload. This burnout can prevent providers from utilizing patient stories on social media. The second study (Chapter 4) shows that healthcare providers have concerns about the validity, credibility, and usefulness of patient stories, and about potential negative consequences on the providers' reputation. The existence of these concerns suggests that online patient stories platforms are ignored or discredited by healthcare providers and administrators. The third study (Chapter 5) shows that social media policies and professional standards in the healthcare system in Ontario are risk-averse, and they reflect the concerns of healthcare regulators about social media risks on healthcare professions and professionals.

In this study, I explore the content of patient stories and the provider response pattern on the Care Opinion Platform, which is a social media platform dedicated to collecting patient stories in the UK.

Because the focus of this thesis is on dedicated social media platforms, which can only be used to post patients stories, and because there are no dedicated social media platforms in Ontario or Canada, I had to use a platform like Care Opinion, which operates in a cultural and social environment that is very close to the Canadian environment and covers a publicly funded healthcare system that is also similar to the Canadian healthcare system.

The study does not evaluate the technical quality of the platform in terms of information security, speed, or design. Instead, it focuses on exploring the types of stories that are posted on this platform and how meaningful these stories are for healthcare providers and administrators. I hypothesize that providers would only respond to the stories that describe issues in healthcare that are meaningful to them. Understanding the response pattern can help understand the utility of these stories.

To analyze the stories, I use two approaches. First, I use topic modelling, which is a text-mining methodology, to explore the aspects of patient experience that these stories describe. Second, I use logistic regression to identify the story topics that were most likely to garner responses from providers.

With this study, I complete my exploration of the socio-technical system or the patient stories on social media. This exploration covered the actors (Chapters 3 and 4), the sociopolitical context (Chapter 5), and the meaningfulness of the system (Chapter 6).

CHAPTER 6

Using Text Mining to Analyze Patient Stories on Social Media

Purpose: Patients have used social media to describe their healthcare experiences. Several social media platforms, such as the Care Opinion platform, host large volumes of patient stories. However, there are several factors that may discourage healthcare providers from utilizing patient story platforms, including the priorities of healthcare providers, the healthcare workload, the concerns of the providers about validity and credibility of the stories, the social media policies and professional standards, and the meaningfulness of the stories. This study analyzes patient stories on the Care Opinion platform to explore the elements of healthcare experience described in these stories and the characteristics of the stories that receive responses from healthcare providers.

Study Design: 367,573 patient stories were collected from the Care Opinion platform. The stories were posted between September 2005 to September 2019. Topic modelling (Latent Dirichlet Allocation), sentiment analysis, and logistic regression were used for data analysis.

Findings: Sixteen topics were identified in these stories. These topics can be grouped into five categories: communication, quality of clinical services, quality of non-clinical services, human aspects of healthcare experiences, and patient satisfaction. Stories that describe healthcare experience of a family member, or reflect patient thankfulness, gratitude, or satisfaction with communication are associated with a high likelihood of receiving a provider's response; however; the sentiment score of a story, which was used as a proxy for patient satisfaction, was not associated with a provider's response.

Originality/value: The study provides insights into the content of patient stories. It proposes a novel method to analyze the factors that affect the likelihood of receiving a response from the healthcare providers. The study findings suggest that these stories are not general social media

posts; rather, they describe aspects of healthcare experiences that have varying importance to the providers, and therefore, these stories have a varying likelihood of receiving a response.

6.1 Introduction

Social media refers to internet-based applications that enable people to communicate, interact, publish, and exchange all types and formats of information, including text, pictures, audio, and video[1]. Since the beginning of the social media revolution, in the 1990s, billions of people have been using it for various human activities, including education, entertainment, social networking, marketing, healthcare, news broadcasting, and people discussions[2,3]. Patients use social media to exchange their health knowledge, share their illness and healthcare experiences, and get social or emotional support[4–6].

The diversified usage of social media has produced large volumes of data (i.e., big data), consisting of textual posts, pictures, and audio and video materials. Analysis and extraction of useful information from this huge and continuously growing body of data have been challenging[7]; however, it has fostered the development and use of research methods and machine learning algorithms and tools that can be used to analyze this data and understand its dynamics. Text mining refers to the use of computational algorithms (e.g., machine learning) for analyzing unstructured text data, and it has been used to analyze social media in different domains such as business, politics, and healthcare[8]. In healthcare, text mining has been used in event-based public health surveillance, pharmacovigilance, health behaviour monitoring, and exploring illness experiences[9]. In this study, I use text mining to analyze patient stories, which are the social media posts that describe experiences with healthcare.

Healthcare experience refers to the interactions of a patient with healthcare providers, including nurses, physicians, and staff, and the resultant perceptions and behavioural and emotional effects[10]. Patient stories on social media describe several aspects of healthcare experiences, including quality of healthcare services and communication with healthcare staff, and they reflect the level of satisfaction the patients have with these experiences[11]. These stories can also shed light on healthcare issues that may not be captured by patient experience surveys, which are the dominant method used in the healthcare system for assessing patient experience[12–14]. Patients use two types of social media platforms to post these stories: the general platforms and specialized platforms. The general social media platforms host diverse types of posts and are not dedicated to patient stories; these include Facebook, Twitter, and Reddit. Specialized social media platforms are fully dedicated to collecting patient stories and facilitating patient-provider communication regarding these stories. An example of these platforms is Hao Dai Fu, a Chinese website (www.haodf.com), which in March 2020, contained 4,024,818 patient reviews for doctors across China[15]. Another example is the Care Opinion platform (www.careopinion.org.uk), on which I will focus in this study.

6.2 Background

6.2.1 Patient Healthcare Experience

A patient's healthcare experience describes patient interactions with healthcare providers throughout a service encounter, starting from seeking a health service, to receiving it, and ending with fulfillment of a patient's health needs. Zakkar[16] developed a framework that classifies the elements of patient experience into determinants and manifestations. The framework is represented in Figure 6.1.

The determinants are the factors that affect this experience, and they are patient's expectations, the burdens of illness, the quality of healthcare, the healthcare system's responsiveness to patients' needs, and the politics in the healthcare system. The determinants related to healthcare quality receive larger attention from healthcare providers than the other elements[16]. Several factors affect healthcare quality and, consequently, healthcare experiences, including patient safety, the effectiveness of care, timeliness of services, quality of communication between the patient and the healthcare team, patient's comfort, the level of respect that a patient receives for their values and preferences, and the empathy and support that a patient receives from the healthcare team[17]. The determinants of a healthcare experience can result in emotional and behavioural outcomes on the patient that are called manifestations of healthcare experience, and they include patient satisfaction and patient engagement[16]. Patient satisfaction is a sentimental judgment by the patients regarding the achievement of specific patient goals during their healthcare experiences[18]. Patient engagement is a behavioural reaction of the patients that results from healthcare experience and materializes into various levels of commitment to their health and well-being[18].

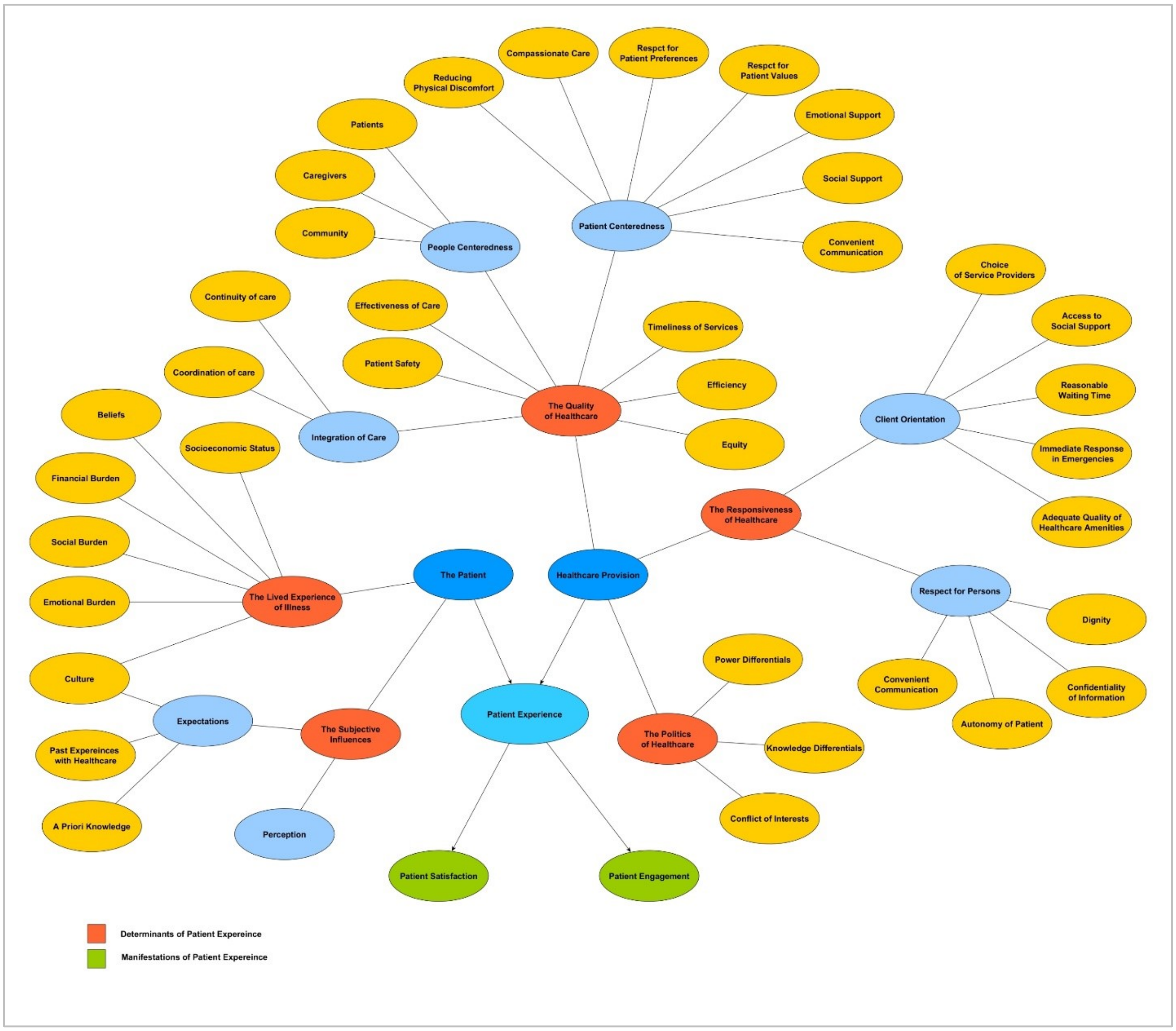


Figure 6.1: Patient Experience Determinants and Manifestations[16]

6.2.2 Care Opinion Platform

The Care Opinion platform has been operating since 2005. It enables patients to post stories about their experiences with the UK healthcare system. The patient should identify the name of the healthcare settings, such as family practices or hospitals, where their experience took place. Patients can give titles to their stories and put some tags to describe good and alarming elements in their healthcare experiences. The story is examined by a moderator before being published to make sure that it does not contain defamatory content. The moderator assigns some tags to the story, which represent the type of healthcare services described, such as diabetes care or family medicine. The moderator also assigns a criticality score to the story, which represents the urgency of the story. The platform enables healthcare providers to review the stories about them and respond to patients. All the stories and the responses are published on the platform's website, and they can be read by other patients and the public. In December 2019, the platform contained 63,537 members who posted 367,573 stories, of which 73% had received responses from the respective healthcare providers. The platform does not use any computer software to process and analyze the content of the stories.

6.2.3 Text Mining

Text mining refers to the use of computational algorithms (i.e., machine learning) for analyzing unstructured text data. These algorithms transfer the data into a numerical format suitable for statistical and linguistic analyses[8]. Text mining is used to perform several types of functions, including document classification, document clustering, information retrieval, and web mining[8]. It also utilizes natural language processing (NLP) techniques to perform these functions. In this study, I used two text mining techniques: topic modelling and sentiment analysis.

Topic modelling denotes a group of unsupervised machine learning methods that identify themes in a collection of documents or a corpus by analyzing co-occurrence of words in it and identifying prominent topics in the corpus and prominent words in each topic[7,19]. It utilizes several NLP methods to transform textual data, which is inherently unstructured, into a structured quantifiable form onto which statistical analyses may be applied[20]. A key characteristic of topic modelling is that it does not use any form of pre-classification or a human annotation of the documents. Therefore, it has been used to analyze high-volume data sources such as social media data, genetic sequences, and digitized library collections where such annotation is impractical[21,22]. Topic modelling has also been used in healthcare research. For example, Myneni et al.[23] use topic modelling to analyze discussions on QuitNet, which is an online social network for smoking cessation[23]. Kim et al.[24] use topic modelling and sentiment analysis to analyze 4,581,181 tweets and 14,818 news articles on the Ebola epidemic[24].

One topic modelling method that is widely used is the Latent Dirichlet Allocation (LDA). This method assumes that in a corpus of text, there is a set of topics, and each topic is a distribution of words where each word has a probability in this distribution. Also, each document in the corpus can be associated with any topic from the set of topics but with varying probabilities[21]. LDA has been used to analyze smoking-related posts on social media and to explore people's experiences and attitudes towards smoking harms and cessation[25]. LDA was also used to analyze millions of posts on a Swedish social media platform and explore representations of Muslim immigrants on social media[7].

Sentiment analysis is a text mining technique that can be used to analyze the polarity or valence of textual data[26]. According to the Oxford dictionary, the sentiment is "A view of or attitude toward a situation or event."[27] Sentiment analysis can be done using several approaches. Machine learning approaches develop models that can be trained to classify documents based on their sentiment[28]. The lexicon-based approaches use a dictionary with a set of words that have a distinct sentiment. Each word is assigned a positive or negative sentiment score, depending on whether the word carries a positive or negative sentiment. The sentiment scores of the words in a document can be used to analyze and compute a document's sentiment score, which provides an approximation of its overall sentiment[29]. Sentiment analysis has been used by researchers to analyze online product reviews, social media posts, and polls[20,26].

6.2.4 Purpose of the Study

The purpose of this study is to analyze patient stories on the Care Opinion Platform. The study is guided by three research questions:

1. What elements of healthcare experience do these stories describe?
2. What are the characteristics of the stories that receive responses from healthcare providers?
3. Does the satisfaction level expressed in these stories affect the likelihood of receiving a provider response?

6.3 Methods

6.3.1 Data Collection

I collected 367,573 patient stories from the Care Opinion platform. The stories were posted between September 2005 to September 2019, and they are all in English. The average size of the story is 66 words ($\sigma = 60$). I developed a web scraper to download these stories from the platform website. The stories are anonymized; however, patients use usernames to post their stories. A story has associated meta-data, including a title, the date of posting, the name of the healthcare setting described in it, the number of provider's responses to the story, and the patient and moderator tags.

6.3.2 Data Analysis

Our data analysis process was fully automated. I developed several computer programs for doing all analyses and data processing. I used Python (version 3.7) as a programming language, along with a set of Python libraries, including Gensim (version 3.8.1)[30], NLTK (version 3.4.5), Statsmodels (version 0.11.0), and vaderSentiment (version 3.2.1). I employed several methods in my data analysis, as described below.

6.3.2.1 Data Analysis for Answering the First Research Question

To answer the first research question, which is "what elements of healthcare experience do patient stories describe," I conducted LDA topic modelling using the full corpus of n= 367,573 stories, each of which is considered a separate document.

The topic modelling process comprises several steps. The first step is data pre-processing, where I do stopword removal, part of speech tagging, and lemmatization[31,32]. The second step consists of building the document-term matrix for the corpus. I did unigram and bigram tokenization. However, I controlled the tokenization process so that only the dominant bigram phrases are used. This ensures that the total number of terms in the document-term matrix remains small and reduces the processing time.

The third step consists of performing topic modelling. Several parameters can be configured to control the modelling process, including the document-topic density (i.e., alpha), which controls the per-document topic probabilities[33]; the topic term density (i.e., beta), which controls the per-topic term probabilities[33]; and the expected number of topics. Given the small size of each story, I estimated that a story would represent only a few topics, and therefore, I set alpha to 0.01. As for the beta parameter, I set it to its default value in Gensim, which is 1/number of topics. To select the ideal number of topics, I conducted a topic number detection experiment, by creating 69 models, corresponding to a range of topic numbers from 2 to 70 topics, and I assessed the quality of the models using the UCI model quality indicator. This indicator is premised on the idea that in order for a topic to be meaningful for humans, its word set should include words that are found to occur together in human-generated articles such as Wikipedia articles[34,35]. This indicator scores each topic by calculating the logs of probabilities of the co-occurrence of the topic's words in a corpus of Wikipedia articles[34]. The indicator is considered close to the human judgment of the meaningfulness of topics[36]. The topic number detection experiment identified the number 16 as the ideal topic number, as represented in Figure 6.2.

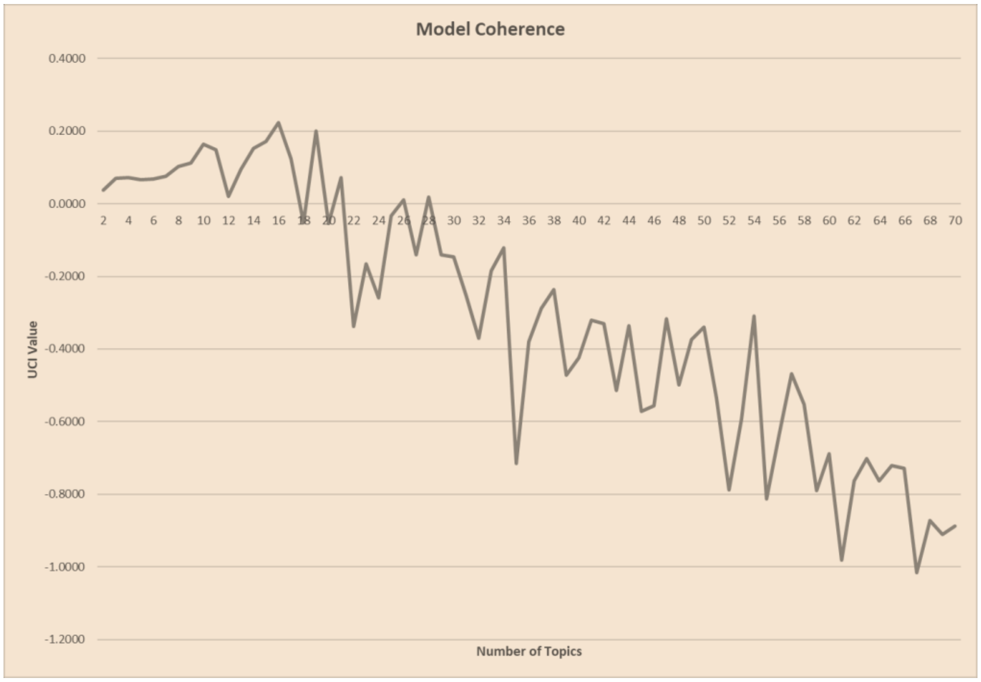


Figure 6.2: Model Quality Experiment

The fourth step is to identify the generated topics. LDA topic modelling produces a topic-term matrix, which contains the probabilities of the terms in each topic. Researchers can analyze the terms that have the highest probabilities within each topic to interpret it. I analyzed the topic-term matrix, and then coded or labelled each topic based on the main themes represented in the topic's set of terms. To create the topic labels, I used the patient experience determinants and manifestations framework developed by Zakkar[16], which I have presented in the background section.

To improve the quality of the labels, I also examined the document-topic matrix, which is another output of the modelling process. This matrix shows the prominent topics comprising each document. Reading some of the documents where a topic is the most prominent one, and comparing that with the topic's set of terms enabled me to produce meaningful labels. I also wanted the topic labels to reflect the dominant sentiment in each topic if there is a dominant sentiment. To achieve this goal, I calculated the sentiment scores for all the documents where a topic is the most prominent topic, and I counted the number of documents with positive and negative sentiments to gauge the dominant sentiment in the majority of documents (i.e., more than 85% of documents) as presented in Table 6.8 in the Results section. This technique helped me coining descriptive and sentiment aware labels.

6.3.2.2 Data Analysis for Answering the Second and Third Research Questions

To answer the second and third research questions, which are "what are characteristics of the stories that receive responses from healthcare providers?" and "does the satisfaction level of the patient, expressed in these stories affect the likelihood of receiving a provider response?" I used logistic regression. The method was used to analyze how the presence of one or more of the topics identified in a story is associated with the probability of receiving a response from healthcare providers, which is the desired outcome in this study. This analysis method is explained in the next section.

Logistic Regression Modelling Using Topic Probabilities

For each document, LDA generates a document-topic probability distribution, which defines the probabilities that a document represents each topic. These probabilities have been used for developing predictive models and classifiers in several text-mining research studies.

Nguyen et al.[37] use LDA topic probabilities and sentiment information to analyze social media posts of persons with Autism spectrum disorder (ASD). The study uses logistic regression to create a classifier that can recognize whether a post is written by a person with ASD[37]. Wang et al.[38] use LDA topic probabilities to identify fake online product reviews on Yelp (www.yelp.com). The study employs logistic regression and other machine learning modelling methods[38]. Parimi et al.[39] use LDA topic probabilities and logistic regression to model the interests of the users of Live Journal (www.livejournal.com), which is a social media platform. The study creates a model that can predict whether any two members are possibly friends. The model enables the platform to make friendship suggestions to its members[39]. Sarkar et al.[40] use LDA topic probabilities and the Classification and Regression Tree method to analyze thousands of occupational accident reports. The study developed a model that can predict the type of accident that may occur based on several variables[40]. Bhan et al.[41] use LDA topic probabilities, logistic regression, and other modelling methods to create classifiers that can detect sarcastic comments in Twitter[41]. Wang et al[42] use topic probabilities and GLM modelling to analyze Twitter data and predict the likelihood of criminal events[42].

Transforming Topic Probabilities into Topic Weights

Because LDA topic probabilities add up to 1, they represent compositional data. This type of data requires special treatment before applying statistical analyses because, for each observation, the data elements are not free to vary since they represent parts of a constant whole[43], which leads to erroneous correlations among data elements[44]. Several types of logarithmic transformation have been developed to treat this data before using statistical analyses[44]. However, these transformations make interpreting the results of the statistical analyses a complex task[43].

In this study, I have designed and used a transformation method that suits the type of data in the study, where each observation (i.e., a story) is a set of words. I transformed the data by multiplying the topic probabilities of each document by the number of unique words in this document. This multiplication produces topic weights, which are used for logistic regression modelling. This transformation method is further explained in Appendix 6.A.

The Model Variables

In addition to topic weights, I also used story sentiment as a proxy indicator for the level of patient satisfaction; therefore, I added the sentiment score to the explanatory variables list, to examine the association of story sentiment with the desired outcome. This score is derived from rule-based sentiment analysis, as explained in the background section of this paper.

Thus, there were 17 explanatory variables for each document: the weights of each of the 16 topics, and a sentiment score, which ranges from -1 to 1. The dependent variable is the "Responded To" binary variable, where "1" indicates the story received a response, and "0" indicates no response. Table 6.1 shows a part of the document-topic matrix.

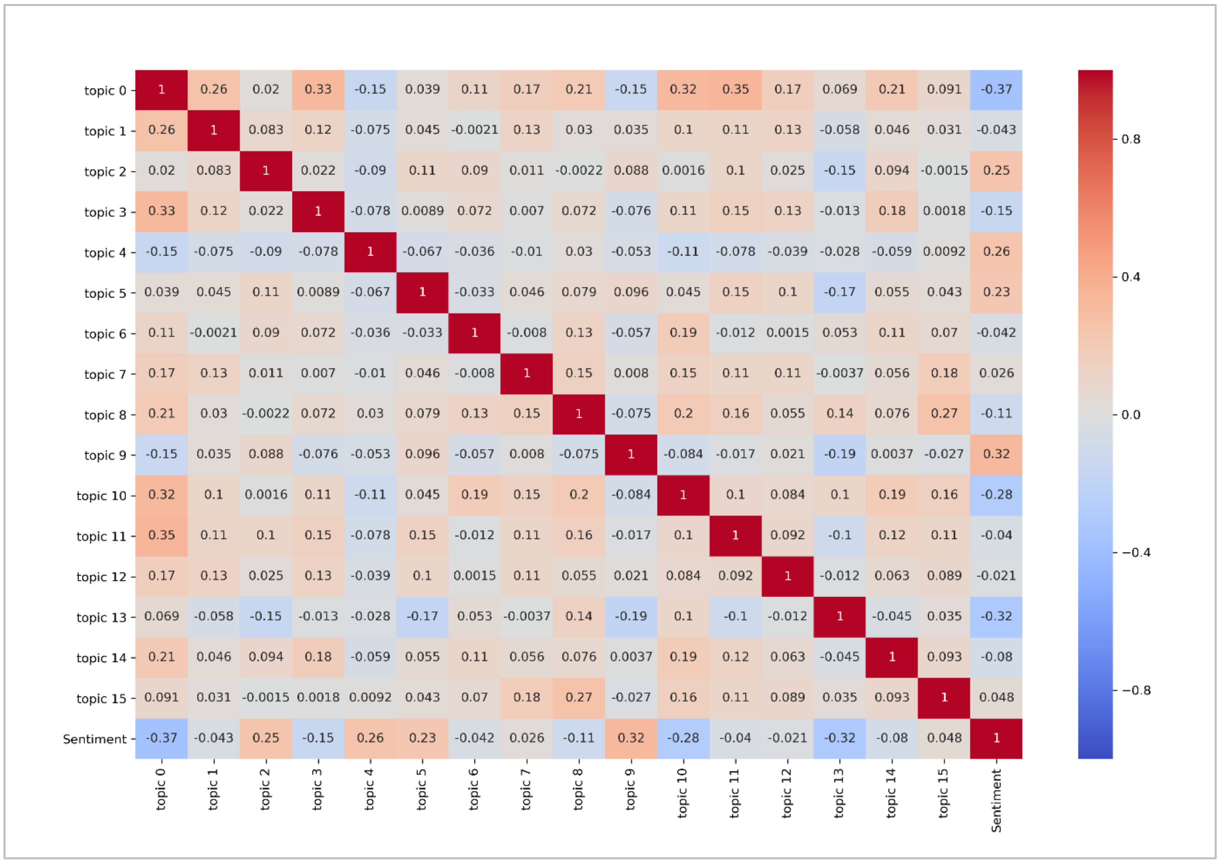
Table 6.1: Document-Topic Matrix

Document	Responded To	topic 0	topic 1	topic 2	topic 3	topic 4	topic 5	topic 6	topic 7	topic 8	Sentiment
0	0	0.0090	0.0090	19.0142	0.0090	0.0090	0.0090	0.0090	0.0090	0.0090	0.7117
1	0	12.1077	4.0633	1.4756	6.6204	0.0087	0.0087	1.7312	18.3057	0.0087	0.6403
2	0	0.0078	3.2917	0.0078	12.7631	4.8377	0.0078	0.0078	0.0078	0.0078	-0.6003
3	0	3.3736	0.0087	0.0087	0.0087	0.0087	0.0087	0.0087	0.0087	0.0087	0.2406

4	0	1.1696	0.0126	4.0978	0.0126	0.0126	0.0126	0.0126	0.0126	0.0126	0.8801
5	1	0.0130	0.0130	0.0130	0.0130	2.6872	0.0130	0.0130	3.8311	0.0130	0.4391
6	0	15.8926	0.0089	2.4147	6.3117	0.0089	0.0089	0.0089	20.8833	0.0089	-0.5271
7	0	0.0110	0.0110	0.0110	3.8456	1.2175	0.0110	0.0110	0.0110	6.4327	0.3591
8	1	1.2578	0.0085	0.0085	0.0085	0.0085	0.0085	0.0085	0.0085	0.0085	-0.3353
9	0	0.0147	0.0147	11.7794	0.0147	0.0147	0.0147	0.0147	0.0147	0.0147	0.6288
10	0	6.8792	0.0119	0.0119	2.8946	0.0119	0.0119	0.0119	5.4598	16.6107	-0.8572
11	0	0.0097	0.0097	0.0097	0.0097	0.0097	0.0097	0.0097	0.0097	0.0097	0.6249
12	0	0.0096	0.0096	17.1493	0.0096	0.0096	1.8231	4.9017	6.0104	0.0096	0.4117
13	1	23.0925	0.0094	0.0094	11.8907	0.0094	0.0094	0.0094	6.9779	0.0094	0.1403

To prepare the data for logistic regression, I checked for multicollinearity among the explanatory variables. Multicollinearity refers to correlations among explanatory variables[45]. Strong correlations reduce model quality and may lead to problematic predictions[46]. I assessed multicollinearity by creating the correlation matrix (Figure 6.3), which did not reveal strong correlations, and all Pearson r values were in the range [-0.37, 0.35]. I also calculated the variance inflation factor (VIF) for each explanatory variable, which represents the effect of the correlations among the explanatory variables on the variance of the coefficient of the respective variable[46]. For logistic regression models, the VIF of any explanatory variable should not be greater than 2.5[45]. The analysis showed that all the VIF values were less than 2 (Table 6.2).

To understand the association between the topic weights of a story, the sentiment of a story, and the probability of receiving a provider response, I conducted univariate, bivariate, and multiple logistic regression analyses.



	topic 0	topic 1	topic 2	topic 3	topic 4	topic 5	topic 6	topic 7	topic 8	topic 9	topic 10	topic 11	topic 12	topic 13	topic 14	topic 15	Sentiment
topic 0	1	0.26	0.02	0.33	-0.15	0.039	0.11	0.17	0.21	-0.15	0.32	0.35	0.17	0.069	0.21	0.091	-0.37
topic 1	0.26	1	0.083	0.12	-0.075	0.045	-0.0021	0.13	0.03	0.035	0.1	0.11	0.13	-0.058	0.046	0.031	-0.043
topic 2	0.02	0.083	1	0.022	-0.09	0.11	0.09	0.011	-0.0022	0.088	0.0016	0.1	0.025	-0.15	0.094	-0.0015	0.25
topic 3	0.33	0.12	0.022	1	-0.078	0.0089	0.072	0.007	0.072	-0.076	0.11	0.15	0.13	-0.013	0.18	0.0018	-0.15
topic 4	-0.15	-0.075	-0.09	-0.078	1	-0.067	-0.036	-0.01	0.03	-0.053	-0.11	-0.078	-0.039	-0.028	-0.059	0.0092	0.26
topic 5	0.039	0.045	0.11	0.0089	-0.067	1	-0.033	0.046	0.079	0.096	0.045	0.15	0.1	-0.17	0.055	0.043	0.23
topic 6	0.11	-0.0021	0.09	0.072	-0.036	-0.033	1	-0.008	0.13	-0.057	0.19	-0.012	0.0015	0.053	0.11	0.07	-0.042
topic 7	0.17	0.13	0.011	0.007	-0.01	0.046	-0.008	1	0.15	0.008	0.15	0.11	0.11	-0.0037	0.056	0.18	0.026
topic 8	0.21	0.03	-0.0022	0.072	0.03	0.079	0.13	0.15	1	-0.075	0.2	0.16	0.055	0.14	0.076	0.27	-0.11
topic 9	-0.15	0.035	0.088	-0.076	-0.053	0.096	-0.057	0.008	-0.075	1	-0.084	-0.017	0.021	-0.19	0.0037	-0.027	0.32
topic 10	0.32	0.1	0.0016	0.11	-0.11	0.045	0.19	0.15	0.2	-0.084	1	0.1	0.084	0.1	0.19	0.16	-0.28
topic 11	0.35	0.11	0.1	0.15	-0.078	0.15	-0.012	0.11	0.16	-0.017	0.1	1	0.092	-0.1	0.12	0.11	-0.04
topic 12	0.17	0.13	0.025	0.13	-0.039	0.1	0.0015	0.11	0.055	0.021	0.084	0.092	1	-0.012	0.063	0.089	-0.021
topic 13	0.069	-0.058	-0.15	-0.013	-0.028	-0.17	0.053	-0.0037	0.14	-0.19	0.1	-0.1	-0.012	1	-0.045	0.035	-0.32
topic 14	0.21	0.046	0.094	0.18	-0.059	0.055	0.11	0.056	0.076	0.0037	0.19	0.12	0.063	-0.045	1	0.093	-0.08
topic 15	0.091	0.031	-0.0015	0.0018	0.0092	0.043	0.07	0.18	0.27	-0.027	0.16	0.11	0.089	0.035	0.093	1	0.048
Sentiment	-0.37	-0.043	0.25	-0.15	0.26	0.23	-0.042	0.026	-0.11	0.32	-0.28	-0.04	-0.021	-0.32	-0.08	0.048	1

Figure 6.3: Correlation Matrix

Table 6.2: Explanatory Variables' VIF

Explanatory Variable	**VIF**
topic 0	1.653976
topic 1	1.111090
topic 2	1.146985
topic 3	1.156454
topic 4	1.156026
topic 5	1.143546
topic 6	1.080060
topic 7	1.103663
topic 8	1.196625
topic 9	1.165205
topic 10	1.266492
topic 11	1.212310
topic 12	1.065534

topic 13	1.189807
topic 14	1.107645
topic 15	1.140986
Sentiment	1.778160

6.4 Results

As I have explained in the data analysis section, I conducted LDA topic modelling and logistic regression to answer the research questions.

6.4.1 What Elements of Healthcare Experience Do Patient Stories Talk About?

The topic modelling revealed 16 topics. In Table 6.3, I provide descriptive labels, brief descriptions, and categories for these topics, which are intended to help the reader understand the differences among these topics. Some of the topics are given more than one category to increase their specificity.

Table 6.3: Topic Labels and Descriptions

	Topic Label	What the Story Describes	Category	Topic Sentiment
Topic 0	Patient Requesting Information	Patients requesting information about their health conditions and treatment.	Communication	Positive or Negative
Topic 1	Maternity Care	Healthcare experiences related to pregnancy and birth.	Quality of non-clinical services	Positive or Negative
Topic 2	Patient Satisfaction with Staff Communication	Satisfactory communication with the healthcare team.	Communication, Patient Satisfaction	Positive
Topic 3	Wait Time in the Healthcare Setting	A patient's view about the wait time in the healthcare setting.	Quality of non-clinical services	Positive or Negative
Topic 4	Patient Expressing Satisfactory Encounter with the Staff	An empathetic and respectful encounter of the patient with the healthcare team.	Human Aspects of Healthcare Experience, Patient Satisfaction	Positive
Topic 5	Patient Expressing Gratitude	Patients' gratitude towards the healthcare team and satisfaction with the health outcomes of their healthcare experience.	Patient Satisfaction	Positive
Topic 6	Timing of the Appointment	A patient's view regarding the appropriateness of the healthcare appointment to a patient's conditions.	Quality of non-clinical services	Positive or Negative
Topic 7	Healthcare Experience of a patient	Healthcare experiences.	Quality of non-clinical services	Positive and Negative

Topic 8	Health Service Availability and Accessibility	Health needs and service availability.	Quality of non-clinical services	Positive and Negative
Topic 9	Patient Thanking the Staff	General thankfulness to the healthcare team.	Patient Satisfaction	Positive
Topic 10	Patient's Description of Treatment	Patient's impression about the received clinical treatment.	Clinical Quality of Services	Positive or Negative
Topic 11	Cleanness of the Healthcare Setting	The cleanness of the healthcare setting.	Quality of non-clinical services	Positive or Negative
Topic 12	A Patient Experience Described by a Family Member	A patient story is told by a family member and identifies several elements of the quality of service.	Quality of non-clinical services	Positive and Negative
Topic 13	Patient's Making of an Appointment	A patient's view on elements of appointment process such as talking to a staff member, or referral.	Quality of non-clinical services	Positive or Negative
Topic 14	Musculoskeletal Health Conditions	Healthcare experiences related to accidents and injuries and the need for physiotherapy.	Quality of non-clinical services	Positive or Negative
Topic 15	Car Parking	Issues related to car parking in a healthcare setting.	Quality of non-clinical services	Positive or Negative

Our topic categorization distinguishes between two types of healthcare quality: quality of non-clinical service and clinical quality. The quality of non-clinical healthcare services (topics 1, 3, 6, 7, 11, 12, 13, 14, 15) refers to patient perspective on healthcare quality, and it includes service elements that can be observed and understood by a patient such as cleanness of the setting, communication with staff members, and the wait time[47]. On the other hand, the clinical quality (topic 10) denotes health service effectiveness for diagnosing diseases and achieving good health outcomes[47], and it is associated with healthcare provider's expertise, medical equipment, and medicines used in treatment. The communication category (topics 0, and 2) refers to the communication between patients and the healthcare team. The patient satisfaction category (topics 2, 4, 5, and 9) represents a patient's subjective evaluation of the healthcare experience or some elements of this experience. Lastly, the human aspects of healthcare experiences category (topic 4) describes how the healthcare team interacts with the patient respectfully and with empathy.

Table 6.4 represents part of the topic-term matrix with the top 25 terms for each topic. However, my full topic-term matrix contained 70 words per topic.

Table 6.4: The Topic-Term Matrix

	Topic Label	The top 25 terms (features)
Topic 0	Patient Requesting Information	Tell, say, ask, would, go, could, come, get, back, leave, know, take, nurse, even, give, want, call, need, speak, still, hospital, day, home, put, when, find
Topic 1	Maternity Care	Pain, baby, midwife, give, birth, partner, experience, relief, feel, care, day, week, first, pregnancy, night, labour, pregnant, due, scan, time, make, hospital, help, hour, support, can't
Topic 2	Patient Satisfaction with Staff Communication	Feel, make, staff, procedure, nurse, ease, thank, operation, explain, experience, put, surgery, friendly, go, would, surgeon, day, well, team, take, care, professional, time, hospital, whole, lovely
Topic 3	Wait Time in the Healthcare Setting	Wait, see, hour, doctor, take, blood, nurse, minute, time, test, call, arrive, go, room, check, come, long, morning, could, sit, give, triage, send, receptionist, back, get
Topic 4	Patient Expressing Satisfactory Encounter with the Staff	Surgery, staff, always, doctor, helpful, friendly, good, reception, service, nurse, recommend, year, see, professional, receptionist, excellent, polite, find, great, care, happy, efficient, patient, very, visit, really
Topic 5	Patient Expressing Gratitude	care, staff, treat, receive, thank, team, time, nurse, hospital, respect, family, admit, day, excellent, treatment, home, mother, ward, give, take, support, husband, kindness, dignity, outstanding, stay
Topic 6	Timing of the Appointment	appointment, clinic, see, treatment, consultant, hospital, time, refer, receive, attend, follow, eye, give, test, referral, result, wait, visit, week, letter, department, explain, would, consultation, arrange, scan
Topic 7	Healthcare Experience of a patient	feel, doctor, time, make, help, really, get, see, good, know, people, need, never, thing, work, always, think, go, want, say, take, year, much, listen, come
Topic 8	Health Service Availability and Accessibility	patient, practice, staff, medical, care, experience, issue, reception, review, feel, make, however, need, service, would, concern, deal, seem, health, member, register, provide, information, rude, lack, many
Topic 9	Patient Thanking the Staff	thank, staff, care, would, much, team, enough, say, amazing, receive, like, treatment, service, nurse, wonderful, hospital, excellent, help, praise, work, great, well, look, fantastic, first, give
Topic 10	Patient's Description of Treatment	doctor, medication, year, month, surgery, week, pain, take, problem, test, see, result, condition, blood, give, suffer, send, day, last, symptom, treatment, due, prescription, tell, ago
Topic 11	Cleanness of Healthcare Setting	staff, patient, hospital, ward, bed, room, food, clean, day, stay, good, unhelpful, night, could, time, nurse, toilet, use, drink, seem, admit, place, area, need, discharge, care
Topic 12	A Patient Experience Described by a Family Member	daughter, son, child, old, mum, year, parent, young, school, ailment, mother, play, bring, family, start_finish, poorly, age, month, girl, green, love, brace, little, grandmother
Topic 13	Patient's Making of an Appointment	appointment, surgery, call, get, phone, time, doctor, day, tell, book, receptionist, week, see, try, need, wait, make, practice, work, ring, system, would, never, answer, say, service
Topic 14	Musculoskeletal Health Conditions	pain, foot, physio, injury, leg, practitioner, knee, fall, ray, break, arm, walk, wound, fracture, exercise, shoulder, hip, ankle, hand, head, dress, physiotherapist, dressing, painful, back, right
Topic 15	Car Parking	service, practice, use, support, help, find, provide, work, able, need, group, year, access, offer, would, family, session, new, health, parking, good, knowledgeable, local, well, also, advice

6.4.1.1 Topic Distribution Over Stories

I calculated the distribution of topics over the stories by counting the topic with the highest probability for each story. The distribution is presented in Table 6.5.

Table 6.5: Topic Distribution Over Stories

Topic	Topic Label	Category	Total Stories	Total Stories %
topic 13	Patient's Making of an Appointment	Quality of non-clinical services	52737	14.35%
topic 0	Patient Requesting Information	Communication	43882	11.94%
topic 2	Patient Satisfaction with Staff Communication	Communication, Patient Satisfaction	42659	11.61%
topic 5	Patient Expressing Gratitude	Patient Satisfaction	40322	10.97%
topic 7	Healthcare Experience of a patient	Quality of non-clinical services	31857	8.67%
topic 4	Patient Expressing Satisfactory Encounter with the Staff	Human Aspects of Healthcare Experience, Patient Satisfaction	27979	7.61%
topic 9	Patient Thanking the Staff	Patient Satisfaction	24016	6.53%
topic 3	Wait Time in the Healthcare Setting	Quality of non-clinical services	23586	6.42%
topic 10	Patient's Description of Treatment	Clinical Quality of Services	20123	5.47%
topic 8	Health Service Availability and Accessibility	Quality of non-clinical services	17793	4.84%
topic 6	Timing of the Appointment	Quality of non-clinical services	13525	3.68%
topic 11	Cleanness of Healthcare Setting	Quality of non-clinical services	12547	3.41%
topic 15	Car Parking	Quality of non-clinical services	8320	2.26%
topic 1	Maternity Care	Quality of non-clinical services	7696	2.09%
topic 14	Musculoskeletal Health Conditions	Quality of non-clinical services	426	0.12%
topic 12	A Patient Experience Described by a Family Member	Quality of non-clinical services	105	0.03%

Table 6.6 represents a summary of Table 6.5, and it shows the percentage of stories corresponding to each topic category. Because a topic can belong to multiple categories, these figures do not add up to 100%. We can see that 45% of the stories talked about issues related to the quality of non-clinical services. Interestingly, we can see that one-third of the stories describe patient satisfaction topics, which are topics 2, 4, 5, and 9, and they all represent satisfactory experience, as I discussed above.

Table 6.6: Category Distribution Over Stories

Category	Number of Stories %
Quality of non-clinical services	45.87%
Patient Satisfaction	36.72%
Communication	23.54%
Human Aspects of Healthcare Experience	7.61%
Clinical Quality of Services	5.47%

6.4.1.2 Sentiment Analysis

As I explained in the background, because these stories are strongly related to health, illness, and patient's needs, sentiments are expected to be clear in these stories. We present sentiment score frequencies at the corpus level and at the topic level.

The analysis of the sentiment scores of the stories at the corpus level is presented in Table 6.7. We can see that 71% of the stories reflect positive sentiment. However, these ratios may not be advantageous to reveal more specific issues in the patient experience because the topics varies in their distribution over the corpus as evident in Table 6.5, which shows, for example, that topic 0 is prominent in 14.35% of the stories whereas topic 1 is prominent in 2.09% of the stories. Therefore, the aggregate picture presented in Table 6.7 may not be very useful.

Table 6.7: Story Sentiment Distribution in the whole corpus

	Total Stories	Percentage
Stories with a Positive Sentiment Score	262796	71%
Stories with a Negative Sentiment Score	101476	28%
Stories with a Neutral Sentiment Score	3301	1%

On the other hand, it can be more useful for quality improvement purposes to analyze the sentiment distribution at the topic level (Table 6.8). We can see that only some of the topics represent a dominant sentiment on more than 85% of the stories where a topic is the most prominent one, and these are topics 2, 4, 5, and 9. The remaining twelve topics do not reflect a dominant sentiment.

Also, we can see that for some topics, the stories with negative sentiments are more than those with positive sentiments. These topics are topic 0, topic 10, and topic 13, and they are highlighted in green.

Table 6.8: Topic Sentiment distribution

Topic	Topic Label	Average Sentiment	Stories with Positive Sentiment %	Stories with Neutral Sentiment %	Stories with Negative Sentiment %	Topic Sentiment
topic 0	Patient Requesting Information	-0.202	37.80%	0.70%	61.50%	More than 55% negative
topic 10	Patient's Description of Treatment	-0.118	42.40%	1.00%	56.70%	More than 55% negative
topic 13	Patient's Making of an Appointment	-0.086	42.40%	2.40%	55.20%	More than 55% negative
topic 14	Musculoskeletal Health Conditions	0.113	57.70%	1.90%	40.40%	20%-40% negative
topic 8	Health Service Availability and Accessibility	0.252	63.30%	0.70%	36.00%	20%-40% negative
topic 3	Wait Time in the Healthcare Setting	0.273	64.60%	1.60%	33.80%	20%-40% negative
topic 11	Cleanness of Healthcare Setting	0.42	73.30%	0.70%	26.00%	20%-40% negative
topic 6	Timing of the Appointment	0.473	76.80%	2.20%	21.00%	20%-40% negative
topic 1	Maternity Care	0.581	80.40%	0.30%	19.20%	14%-19% negative
topic 7	Healthcare Experience of a patient	0.561	81.10%	0.50%	18.40%	14%-19% negative
topic 15	Car Parking	0.605	84.10%	1.40%	14.50%	14%-19% negative
topic 12	A Patient Experience Described by a Family Member	0.537	80.00%	5.70%	14.30%	14%-19% negative
topic 5	Patient Expressing Gratitude	0.83	95.30%	0.20%	4.50%	Less than 5% negative
topic 2	Patient Satisfaction with Staff Communication	0.853	96.50%	0.20%	3.30%	Less than 5% negative
topic 4	Patient Expressing Satisfactory Encounter with the Staff	0.806	96.50%	0.40%	3.10%	Less than 5% negative
topic 9	Patient Thanking the Staff	0.837	97.00%	0.40%	2.60%	Less than 5% negative

6.4.1.3 Visualization of Topic Distribution and Sentiment

Figure 6.4 represents a visualization of topic distribution and sentiment presented in table 6.8. In the figure, we have four groups of topics. First are the topics in green (topics 0, 13, and 10). These topics have more negative sentiment than a positive one in more than 55% of their stories. Second are the topics in yellow (topics 3, 8, 6, 11, and 14). These topics have negative sentiment in 20% to 40% of their stories. Third are the topics in blue (topics 5, 2, 4, and 9). These topics have positive sentiment in more than 85% of their stories, and they represent satisfactory experience. Fourth are the topics in aqua (topics 7, 15, 1, and 12). The stories in these topics do not reveal a dominant sentiment. Nevertheless, they represent aspects of healthcare quality and the patient experience that may be important for healthcare providers.

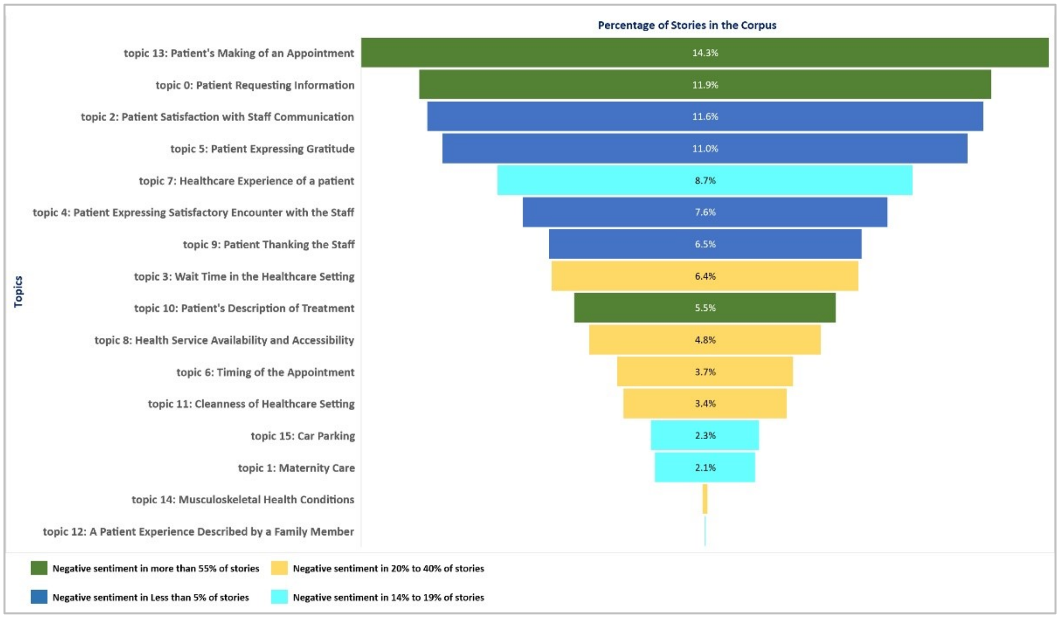


Figure 6.4: Topic Distribution Over Stories

6.4.2 What Are the Stories That Receive Responses from Healthcare Providers?

I did logistic regression modelling to examine how the existence of any of the topics, revealed through the topic modelling, along with the sentiment, affects the probability of the story receiving a response from healthcare providers. I created univariate, bivariate, and multiple logistic regression models.

As I explained in the data analysis section, each of the topic variables represents the topic weight, which is the probability that a patient story represents the respective topic multiplied by the length of this story. Depending on the sign of the corresponding (β) parameter, an increase in this weight can have a positive or negative impact on the probability of a story receiving a provider response. To interpret the model's β-parameters in these models, I calculated the corresponding odds ratio for all the variables. These odds ratios represent the change in the odds of receiving a response corresponding to a one-unit change in each explanatory variable if all other variables are held constant. As I discuss in Appendix 6.A, achieving one-unit or multiple unit changes in the topic weights can be done by adding words to the stories that are relevant to the respective topic.

6.4.2.1 The Univariate Logistic Regression

The univariate logistic regression results are presented in Table 6.9. All the independent variables are significant for predicting the probability of receiving a provider's response.

The odds ratios of topics 12, 9, 14, 5, 2, 1, 6, 3, 0, 11, 7, and the sentiment scores show that a unit-change in any of these topics is associated with an increase in the likelihood of receiving a response. This increase ranges from 14% for the sentiment score, to 0.3% for topic 7. Notably, the sentiment score has the highest odds ratio. The small size of the odds ratios may be because of the nature of the independent variables or the topic weights, which represents topic probabilities that are inherently small. In fact, the average topic probability of any topic in all the stories is 0.06. Therefore, the small odds ratios can mean a relatively significant change in the topic weights.

As I explain in the data analysis section, the sentiment score ranges between -1 and +1, with the positive scores representing patient satisfaction, and the negative scores representing patient dissatisfaction. As a result, these scores will have a different impact in the univariate models. Consequently, the positive scores would be associated with a high chance of receiving a response, whereas; the negative scores would be associated with a reduced or very low chance of receiving a response.

We can also see that three topics can have a negative impact on the likelihood of receiving a response, and these are topics 8, 13, and 4. A unit-change in any of these topics is associated with a decrease in the likelihood of receiving a response. This decrease ranges from 0.3% for topic 10, to 4.6% for topic 4.

Table 6.9: Univariate Logistic Regression

Dependent Variable for all models: "Responded To"		**LLR for all models:** 0.000			
Independent Variable	**Topic Label**	**coef (β)**	**P>|z|**	**(β) CI**	**Odds Ratio***
Sentiment		0.1307	0.000	[0.121, 0.141]	1.140
topic 12	A Patient Experience Described by a Family Member	0.0696	0.000	[0.063, 0.077]	1.072
topic 9	Patient Thanking the Staff	0.0414	0.000	[0.039, 0.044]	1.042
topic 14	Musculoskeletal Health Conditions	0.0394	0.000	[0.034, 0.044]	1.040

topic 5	Patient Expressing Gratitude	0.0322	0.000	[0.031, 0.033]	1.033
topic 2	Patient Satisfaction with Staff Communication	0.0317	0.000	[0.030, 0.033]	1.032
topic 1	Maternity Care	0.0234	0.000	[0.022, 0.025]	1.024
topic 6	Timing of the Appointment	0.0204	0.000	[0.018, 0.022]	1.021
topic 3	Wait Time in the Healthcare Setting	0.0139	0.000	[0.013, 0.015]	1.014
topic 0	Patient Requesting Information	0.0053	0.000	[0.005, 0.006]	1.005
topic 11	Cleanness of Healthcare Setting	0.0039	0.000	[0.002, 0.005]	1.004
topic 7	Healthcare Experience of a Patient	0.0034	0.000	[0.002, 0.005]	1.003
topic 10	Patient's Description of Treatment	-0.0029	0.000	[-0.004, -0.002]	0.997
topic 15	Patient Requesting Information	-0.0047	0.000	[-0.007, -0.003]	0.995
topic 8	Health Service Availability and Accessibility	-0.0109	0.000	[-0.012, -0.010]	0.989
topic 13	Patient's Making of an Appointment	-0.0231	0.000	[-0.024,-0.022]	0.977
topic 4	Patient Expressing Satisfactory Encounter with the Staff	-0.0475	0.000	[-0.049, -0.046]	0.954

* The table is sorted based on the odds ratios.

6.4.2.2 The Bivariate Logistic Regression

The bivariate logistic regression results are presented in Table 6.10. We can see that in all models, except model 11, the sentiment and the respective topic are significant for predicting the probability of receiving a provider's response. However, in the bivariate model 11, topic 10 is insignificant.

After controlling for the sentiment score, the odds ratios of the independent variables topics 12, 9, 14, 5, 2, 1, 6, 3, 0, 11, and 7 show that a unit-change in any of these topics is associated with an increase in the likelihood of receiving a response.

In all the bivariate models, the odds ratios corresponding to the sentiment score are higher than those of the corresponding topics, and they also show that a one-unit positive change in the sentiment score is associated with an increase in the likelihood of receiving a response. This increase ranges from 23% to 5%. This increase may be because a one-unit change in sentiment score may reflect a change the sentiment from negative to neutral to positive, which may reflect a profound change in the purpose of the story from dissatisfaction to satisfaction. Also, and consistently with the univariate analysis results, positive sentiment scores are associated with a high chance of receiving a response, whereas negative sentiment scores are associated with a reduced chance of receiving a response.

Lastly, four topics have a negative impact on the likelihood of receiving a response, and these are topics 8, 13, 4, and 15. These results are consistent with the univariate logistic regression analysis of the respective variables presented in Table 6.9 above.

Table 6.10: Bivariate Logistic Regression Models

Bivariate Model 1				
Dependent Variable: "Responded To"	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 0 (Patient Requesting Information)	0.0104	0.000	1.01	[0.010, 0.011]
Sentiment	0.1855	0.000	1.20	[0.175, 0.196]
Bivariate Model 2				
Dependent Variable: "Responded To"	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 1 (Maternity Care)	0.0247	0.000	1.03	[0.023, 0.027]
Sentiment	0.1383	0.000	1.15	[0.128, 0.148]
Bivariate Model 3				
Dependent Variable: "Responded To"	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 2 (Patient Satisfaction with Staff Communication)	0.0297	0.000	1.03	[0.028, 0.031]
Sentiment	0.0681	0.000	1.07	[0.058, 0.078]
Bivariate Model 4				
Dependent Variable: "Responded To"	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 3 (Wait Time in the Healthcare Setting)	0.0168	0.000	1.02	[0.015, 0.018]
Sentiment	0.1512	0.000	1.16	[0.141, 0.161]
Bivariate Model 5				
Dependent Variable: "Responded To"	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 4 (Patient Expressing Satisfactory Encounter with Staff)	-0.0587	0.000	0.94	[-0.061, -0.057]
Sentiment	0.2095	0.000	1.23	[0.199, 0.220]
Bivariate Model 6				
Dependent Variable: "Responded To"	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 5 (Patient Expressing Gratitude)	0.0301	0.000	1.03	[0.029, 0.031]
Sentiment	0.0746	0.000	1.08	[0.064, 0.085]
Bivariate Model 7				
Dependent Variable: "Responded To"	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 6 (Timing of the Appointment)	0.0214	0.000	1.02	[0.019, 0.023]
Sentiment	0.1357	0.000	1.15	[0.126, 0.146]

Bivariate Model 8				
Dependent Variable: “Responded To”	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 7 (Healthcare Experience of a patient)	0.003	0.000	1.003	[0.002, 0.004]
Sentiment	0.1301	0.000	1.14	[0.120, 0.140]
Bivariate Model 9				
Dependent Variable: “Responded To”	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 8 (Health Service availability and accessibility)	-0.0093	0.000	0.99	[-0.010, -0.008]
Sentiment	0.1214	0.000	1.13	[0.111, 0.132]
Bivariate Model 10				
Dependent Variable: “Responded To”	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 9 (Patient Thanking the Staff)	0.0363	0.000	1.04	[0.034, 0.039]
Sentiment	0.0749	0.000	1.08	[0.064, 0.085]
Bivariate Model 11				
Dependent Variable: “Responded To”	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 10 (Patient's Description of Treatment)	0.0011	0.044	1.001	[0.00003, 0.002]
Sentiment	0.1338	0.000	1.14	[0.123, 144]
Bivariate Model 12				
Dependent Variable: “Responded To”	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 11 (Cleanness of Healthcare Setting)	0.0047	0.000	1.005	[0.003, 0.006]
Sentiment	0.1321	0.000	1.14	[0.122, 0.142]
Bivariate Model 13				
Dependent Variable: “Responded To”	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 12 (A patient experience described by a family member)	0.0714	0.000	1.07	[0.064, 0.079]
Sentiment	0.1331	0.000	1.14	[0.123, 0.143]
Bivariate Model 14				
Dependent Variable: “Responded To”	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 13 (Patient's Making of an Appointment)	-0.0219	0.000	0.98	[-0.023, -0.021]
Sentiment	0.045	0.000	1.05	[0.034, 0.056]
Bivariate Model 15				
Dependent Variable: “Responded To”	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 14 (Musculoskeletal Health Conditions)	0.0445	0.000	1.05	[0.040, 0.049]
Sentiment	0.1383	0.000	1.15	[0.128, 0.148]
Bivariate Model 16				

Dependent Variable: “Responded To”	LLR p-value: 0.000			
Independent Variables	**coef (β)**	**P>|z|**	**Odds Ratio**	**(β) CI**
topic 15 (Car Parking)	-0.006	0.000	0.99	[-0.008, -0.004]
Sentiment	0.1322	0.000	1.14	[0.122, 0.142]

6.4.2.3 The Multiple Logistic Regression

I created a multiple logistic regression model with the 16 topics and the sentiment score as independent variables. The results are presented in Table 6.11, and they show that two explanatory variables are statistically insignificant: topic 15 and the sentiment score.

The insignificance of the sentiment score in the full model is inconsistent with the bivariate logistic regression models in which this variable is significant. This result may be due to the confounding effects of the other independent variables.

Table 6.11: Multiple Logistic Regression Results

Dep. Variable: “Responded To”	Log-Likelihood: -2.0670e+05
No. Observations: 367573	LL-Null: -2.1192e+05
Df Residuals: 367555	LLR p-value: 0.000
Df Model: 17	Pseudo R-squared: 0.025
	AIC: 413438.6110
	Roc AUC : 0.614

Independent Variable	coef (β)	std err	z	P>|z|	(β) CI	
topic 0	0.0047	0	9.534	0.000	0.004	0.006
topic 1	0.0116	0.001	12.163	0.000	0.01	0.013
topic 2	0.0207	0.001	30.39	0.000	0.019	0.022
topic 3	0.0096	0.001	13.493	0.000	0.008	0.011
topic 4	-0.0393	0.001	-35.646	0.000	-0.041	-0.037
topic 5	0.0244	0.001	34.845	0.000	0.023	0.026
topic 6	0.0222	0.001	21.912	0.000	0.02	0.024
topic 7	0.0032	0.001	5.11	0.000	0.002	0.004
topic 8	-0.0093	0.001	-13.829	0.000	-0.011	-0.008
topic 9	0.0247	0.001	20.411	0.000	0.022	0.027
topic 10	-0.0077	0.001	-12.432	0.000	-0.009	-0.007
topic 11	-0.0119	0.001	-14.926	0.000	-0.013	-0.01
topic 12	0.037	0.004	9.918	0.000	0.03	0.044
topic 13	-0.0161	0	-35.006	0.000	-0.017	-0.015
topic 14	0.0081	0.003	3.1	0.002	0.003	0.013
topic 15	-0.0013	0.001	-1.201	0.23	-0.003	0.001

Sentiment	0.0069	0.007	0.991	0.322	-0.007	0.021
intercept	0.9298	0.008	119.611	0	0.915	0.945

Table 6.12 represents the reduced logistic regression model.

Table 6.12: The Reduced Logistic Regression Model

Dep. Variable: “Responded To”	Log-Likelihood: -2.0670e+05
No. Observations: 367573	LL-Null: -2.1192e+05
Df Residuals: 367557	LLR p-value: 0.000
Df Model: 15	Pseudo R-squared: 0.025
	AIC: 413436.7626
	Roc AUC : 0.614

Independent Variable	coef (β)	std err	z	P>|z|	(β) CI	
topic 0	0.0045	0.0005	9.6459	0.000	0.0036	0.0055
topic 1	0.0116	0.001	12.1736	0.000	0.0097	0.0134
topic 2	0.0208	0.0007	31.6358	0.000	0.0195	0.0221
topic 3	0.0097	0.0007	13.5216	0.000	0.0083	0.0111
topic 4	-0.039	0.001	-37.2434	0.000	-0.041	-0.0369
topic 5	0.0245	0.0007	35.9193	0.000	0.0232	0.0258
topic 6	0.0222	0.001	21.9728	0.000	0.0202	0.0242
topic 7	0.0032	0.0006	5.1241	0.000	0.002	0.0044
topic 8	-0.0095	0.0007	-14.4741	0.000	-0.0107	-0.0082
topic 9	0.025	0.0012	21.4322	0.000	0.0228	0.0273
topic 10	-0.0079	0.0006	-12.9965	0.000	-0.0091	-0.0067
topic 11	-0.0119	0.0008	-14.9888	0.000	-0.0135	-0.0104
topic 12	0.0368	0.0037	9.8745	0.000	0.0295	0.0441
topic 13	-0.0162	0.0004	-36.0196	0.000	-0.0171	-0.0153
topic 14	0.0079	0.0026	3.0108	0.0026	0.0028	0.013
intercept	0.9305	0.0076	122.3587	0.000	0.9156	0.9454

To interpret model parameters in Table 6.12, I calculated the corresponding odds ratio for all the variables (Table 6.13). These odds ratios correspond to a one-unit change in the respective variable. Comparing these odds ratios with each other can help us answer the second research question, which is “what are the stories that are most likely to receive responses from healthcare providers?”.

Table 6.13: Model Parameter Interpretation

Explanatory Variable	Description	Parameter (β)	Odds Ratio*
topic 12	A Patient Experience Described by a Family Member	0.0368	1.037
topic 9	Patient Thanking the Staff	0.025	1.025
topic 5	Patient Expressing Gratitude	0.0245	1.025
topic 6	Timing of the Appointment	0.0222	1.022
topic 2	Patient Satisfaction with Staff Communication	0.0208	1.021
topic 1	Maternity Care	0.0116	1.012
topic 3	Wait Time in the healthcare setting	0.0097	1.010
topic 14	Musculoskeletal Health Conditions	0.0079	1.008
topic 0	Patient Requesting Information	0.0045	1.005
topic 7	Healthcare Experience of a patient	0.0032	1.003
topic 10	Patient's Description of Treatment	-0.0079	0.992
topic 8	Health Service Availability and Accessibility	-0.0095	0.991
topic 11	Cleanness of Healthcare Setting	-0.0119	0.988
topic 13	Patient's Making of an Appointment	-0.0162	0.984
topic 4	Patient Expressing Satisfactory Encounter with the Staff	-0.039	0.962

* The table is sorted based on the odds ratios.

Based on Table 6.13, we see that topic 12 is a strong predictor for receiving a provider's response. This topic represents patient stories that are told by family members and identify several elements of the quality of service. Other topics describe certain elements of service quality and may be associated with receiving a response from the healthcare providers. These are topics, 6, 2, 3, and 0, which describe the timing of appointment, communication with the staff, and wait time in the healthcare setting.

On the other hand, there are two topics that also describe elements of health service quality, but they may be associated with a decrease in the likelihood of receiving a provider's response, and these are topics 8, 13, which describe health service availability, and the making of a health service appointment. These two elements of quality are generally beyond the control of healthcare providers, and therefore, the providers may not be able to provide a satisfactory response to patients.

Topic 11, which describes the cleanness of the healthcare setting, is also associated with a decrease in the likelihood of receiving a provider's response, and this weak likelihood of response is difficult to explain given the importance of the cleanness of healthcare settings.

Lastly, topic 10, which describes the clinical quality, may be associated with a reduced likelihood of receiving a response. This topic represents what the patient feels about the clinical treatment that they received, and therefore, it should be important to healthcare providers and administrators. However, commenting on stories of this topic is discouraged by most healthcare regulatory authorities because it may require revealing some private patient information, which is forbidden by patient privacy laws in UK[48–50] and most other countries.

6.5 Discussion

In this study, I analyzed 367,573 patient stories that were posted on the Care Opinion platform. The stories describe healthcare experiences from the perspective of patients in the UK. Using LDA topic modelling, the study identified 16 topics in these stories. These topics can be grouped into five categories: communication, quality of clinical services, quality of non-clinical services, human aspects of healthcare experiences, and patient satisfaction. The topics represent different aspects of the healthcare experience that are important to patients.

The study findings show that patients have used the Care Opinion platform to express their satisfaction with their healthcare experiences and the quality of non-clinical services. However, some patients have also expressed their dissatisfaction regarding some service elements that are, from a healthcare quality perspective, critical to achieving health outcomes.

As presented in figure 6.4, the visualization of the topics and the sentiment of the relevant stories can reveal important issues about some elements of healthcare quality in the UK, which are considered in healthcare quality literature pivotal for achieving health care quality[51]. The figure shows that there are four groups of topics. The first group has more negative sentiment than a positive one in more than 55% of its stories. One topic in this group is topic 10, which represents stories that describe the clinical quality of services. I argue that because more than 55% of these stories reflect negative sentiment about issues related to clinical quality, these stories should be significant to healthcare providers and administrators. Another topic in this group is topic 0, which represents requesting of information by patients about their health conditions. Adequate communication is an essential element of healthcare quality and patient experience. Issues related to communication may also be important to healthcare providers and administrators. The second group has negative sentiment in 20% to 40% of its stories. This group includes topics 3, 6, and 11, which represent wait time in the healthcare setting, the timing of the appointment, and cleanness of the healthcare setting. These three topics represent essential elements of healthcare quality. This group also includes topic 8, which represents health service availability and accessibility, both of which are essential goals for healthcare systems. Issues related to service availability can be very important for policymakers. The third group includes topics 5, 2, 4, and 9, which represent satisfactory experience because they have positive sentiment in more than 85% of their stories. The fourth group includes topics 7, 15, 1, and 12, which represent aspects of healthcare quality and a patient experience that can be important for healthcare providers, despite that they do not reflect a dominant sentiment.

The identified topics are also described in current healthcare quality literature. For example, a systematic review and meta-synthesis study by Graham et al.[52] explored qualitative research studies published between 1997 to 2017. The reviewed studies explore the patient experience of adult patients in emergency departments in Sweden, Canada, the USA, the UK, and other countries. The review identified five types of patient needs that should be fulfilled by healthcare providers to create an ideal patient experience. These types are communication needs, emotional needs, care needs, waiting needs, physical and environmental needs[52]. The communication needs comprise a patient's need for good, respectful, and empathetic interpersonal communication and interaction with healthcare providers. Patients also need accurate and understandable information about their health conditions and the required healthcare services. The emotional needs are the need for reducing patients' uncertainty about their health conditions and recognizing patients' illness experiences and suffering by healthcare providers. The care needs represent patients' needs for competent and effective care that can solve their health issues and reduce their health concerns. Waiting needs represent patients' needs for timely services and convenient waiting rooms. Patients also need to be informed about the expected wait time before receiving healthcare services. The physical and environmental needs refer to patients' basic needs for a clean and comfortable healthcare setting that can also protect their privacy[52]. The identified 16 topics in my study are consistent with the five types of patient needs identified in Graham et al.'s study[52].

Additionally, the16 topics underpin several healthcare initiatives that aim to improve the quality of healthcare and patient experiences, such as healthcare quality control[10,17,53,54], patient-centredness[17,53], people-centred health services[55,56], or healthcare responsiveness[57,58]. These topics are also explored in many healthcare surveys, including those developed by NHS England[51], the Agency for Healthcare Research and Quality in the USA[59,60], Picker Institute[61], and Health Quality Ontario[62].

One of the prominent healthcare quality initiatives is the quality initiative of the Institute of Medicine in the USA[17], which defines six aims for healthcare quality improvement: patient safety, effective and evidence-based care, patient-centeredness, timeliness of services, efficiency, and health equity[17]. The patient-centeredness goal focuses on improving patient experience[17]. Patient centredness is very common in the healthcare literature. It focuses on providing ideal healthcare experience to the patient[17], and it identifies a set of factors that positively affect the patient experience. These factors are respecting patient's values, preferences, and needs, coordination and integration of healthcare services, appropriate communication between the patient and medical staff, the physical comfort of patients, the level of compassion in the care provided to patients, and the social support available to patients[17]. The identified 16 topics concur well with the six aims for quality, as represented in Table 6.14.

Table 6.14: Alignment of the Topics with the Six Aims for Quality

	Topic Label	Topic Category	Six Aims for Quality
Topic 0	Patient Requesting Information	Communication	Patient centeredness: Appropriate communication
Topic 1	Maternity Care	Quality of non-clinical services	Patient centeredness
Topic 2	Patient Satisfaction with Staff Communication	Communication, Patient Satisfaction	Patient centeredness: Appropriate communication
Topic 3	Wait Time in the Healthcare Setting	Quality of non-clinical services	Timeliness of services
Topic 4	Patient Expressing Satisfactory Encounter with the Staff	Human Aspects of Healthcare Experience, Patient Satisfaction	Patient centeredness: Compassionate care
Topic 5	Patient Expressing Gratitude	Patient Satisfaction	Patient centeredness
Topic 6	Timing of the Appointment	Quality of non-clinical services	Timeliness of services
Topic 7	Healthcare Experience of a patient	Quality of non-clinical services	Patient centeredness
Topic 8	Health Service Availability and Accessibility	Quality of non-clinical services	Health equity
Topic 9	Patient Thanking the Staff	Patient Satisfaction	Patient centeredness
Topic 10	Patient's Description of Treatment	Clinical Quality of Services	Patient safety, Effectiveness of care
Topic 11	Cleanness of the Healthcare Setting	Quality of non-clinical services	Patient centeredness
Topic 12	A Patient Experience Described by a Family Member	Quality of non-clinical services	Patient centeredness

Topic 13	Patient's Making of an Appointment	Quality of non-clinical services	Patient centeredness, Timeliness of services
Topic 14	Musculoskeletal Health Conditions	Quality of non-clinical services	Patient centeredness
Topic 15	Car Parking	Quality of non-clinical services	Patient centeredness

To identify the stories that receive responses from healthcare providers, I used logistic regression modelling to analyze the impact of story topics and the story sentiment on the likelihood of the story receiving a response from the healthcare provider. I did univariate, bivariate, and multiple logistic regression modelling. I found that the story topics have a varying impact on this likelihood.

In the full logistic regression model, I found that stories that describe the healthcare experience of a family member or reflect patient thankfulness, gratitude, or satisfaction with communication are associated with a higher likelihood of receiving a provider's response. I also found that stories that describe specific healthcare quality elements such as the wait time or talk about healthcare quality of maternity care or musculoskeletal health conditions are also associated with good chances of receiving a provider's response. These findings reinforce existing knowledge in healthcare quality field, which suggests that in order for patient experience measures to be meaningful and useful for healthcare providers and administrators, they should describe specific patient experience elements that may affect health outcomes, including patient safety, timeliness of the healthcare services, communication, and the wait time[58,63–66].

On the other hand, I found that stories that describe health service availability and access, making of a health service appointment, or the cleanness of healthcare settings are associated with a reduced chance of receiving a response. Health service availability is generally not under the control of healthcare providers; rather, it is controlled by policymakers, so providers may not be able to provide meaningful responses to these stories. Making health service appointments can be inconvenient for some patients due to the workload in the healthcare setting, which is also out of the control of healthcare providers. However, explaining why stories that describe issues related to the cleanness of healthcare settings have a low chance of receiving a provider response may require further research.

Lastly, I found that stories that describe treatments or clinical quality have a low chance of receiving a provider's response. This finding is consistent with healthcare standards and social media policies in the healthcare system, which strictly forbid discussing issues related to clinical quality on social media because this discussion may require revealing patient's private information, and it can be used by the patients for litigation purposes[50,67–70].

The impact of the story sentiment and the dynamics of the provider's response are discussed in the next sections.

6.5.1 The Story Sentiment

In the background section, I explained why I used the story sentiment as a proxy for patient satisfaction in the logistic regression models. Notably, the sentiment score has the highest odds ratios in the univariate logistic regression model and in the bivariate models. Because sentiment score ranges between -1 and +1, positive sentiment scores, which represent patient satisfaction, are associated with a high chance of receiving a response; whereas; negative sentiment scores, which represent patient dissatisfaction, are associated with a reduced or very low chance of receiving a response. In the full multiple model, however, the sentiment score was insignificant.

The impact of a negative sentiment of a story on the likelihood of receiving a response ranges from a negative impact, according to the univariate and bivariate logistic regression models, to no impact, according to the full model. However, the results of the full model may be more consistent with existing knowledge in the healthcare quality field. They are also consistent with the results of the second empirical study in this dissertation (Chapter 4) that show that for some healthcare providers, patient satisfaction is not essential for achieving a good quality of care and good health outcomes, and therefore the story sentiment has no impact on the likelihood of receiving a provider response.

Patient satisfaction represents a controversial element in healthcare quality literature. Under the biomedical model of healthcare, patient satisfaction is depicted as a subjective, simplistic, and unreliable measure of healthcare quality[58,64,71], and therefore, patient satisfaction and dissatisfaction receive little attention in the healthcare system. Nevertheless, since patients are necessarily service receivers or customers, sentiments are expected to be clear in the patient stories[11,72]. Because of the voluntary and open nature of social media, it is likely that patients use the social media platform subjectively to express their satisfaction or dissatisfaction with their healthcare experiences.

6.5.2 The Meaningfulness of Patient Stories in Care Opinion Platform

The different analyses performed in this study enable me to demonstrate the meaningfulness of patient stories in the Care Opinion Platform.

First, in the results section, I show that LDA topic modelling revealed that the analyzed stories reflect a variety of topics that are related to patient experience (Table 6.5). Secondly, using sentiment analysis, I also show that the stories reflect a clear sentiment, and as presented in Table 6.7, only 1% of the stories do not reflect a clear sentiment. Thirdly, because the Care Opinion Platform is moderated, it highly unlikely that the stories include defamatory content that would require a response from the respective healthcare provider. On the contrary, the moderator ensures that only the stories that describe healthcare experiences are published and made available to the public and to healthcare providers. Given the fact the providers do not respond to all the stories, we believe that they only respond to stories that are meaningful to them. Therefore, these stories are meaningful to the providers because they describe some aspects of patient experience, they reflect a varying level of sentiment, and they are associated with a varying probability of receiving a provider's response.

6.5.3 The Dynamics of the Provider Response

Because the phenomenon of patient stories on social media is an emerging one, the literature is scant on relevant research in general, and the dynamics of healthcare provider's interaction and responses to these stories in particular.

Nevertheless, with the emergence of social media, a similar phenomenon has evolved in the business domain, which is the electronic word of mouth (eWOM), which refers to the online sharing of knowledge and experiences with products among actual and potential customers, through social media posts and blogs[11,73]. eWOM posts are outcomes of customers' emotional reactions to their experiences with the products[11]. These emotional reactions result in various levels of satisfaction or dissatisfaction that are represented by the eWOM posts[11]. A few empirical research studies[74,75] analyze millions of customer product reviews on websites such as Amazon.com, Hotels.com, and Tripadvisor.com, and show that the relationship between company's responses to online product reviews and the resultant outcomes is complex[74,75]. These studies suggest that responding to negative customer reviews can lead to more negative but constructive reviews from other customers, which can have a positive impact on the company in the long run[74,75]. On the other hand, responding to positive reviews may be perceived by other customers as promotional and exploitive, which can provoke negative reviews from these customers. Building on the findings of these studies and my study, I believe that healthcare providers should respond to patient stories that reflect patient dissatisfaction if these stories are specific, and describe issues in healthcare quality that can be managed or improved by the providers.

6.6 Conclusion

Since the emergence of social media, patients have used it to post stories about their healthcare experiences. These stories describe different aspects of these experiences, including health conditions, healthcare quality, communication between patients and providers, and health outcomes. Through these stories, patients can express their satisfaction or dissatisfaction with their healthcare experiences in general or with specific elements of these experiences. The study shows that these stories can reveal important issues in healthcare clinical quality, service availability and accessibility, and quality of non-clinical services, and therefore, they can be important to healthcare providers and administrators.

The findings of this study show that more than 73% of patient stories do receive providers' responses, depending on the topics of these stories. The findings carry practical implications for patients that use social media platform as a means to describe their healthcare experiences. Posting a story by a family member increases the likelihood of receiving a response from healthcare providers. A story by a family member may be perceived by healthcare providers as being more objective, and this may encourage the providers to respond. However, patients that have some concerns regarding the clinical quality or treatments should not post their stories on social media because the likelihood of receiving a response is low because of the healthcare provider's fear of violating patient privacy laws. These patients should communicate their concerns to healthcare managers or regulatory authorities. Nevertheless, further research is required to understand the dynamics of the healthcare provider's interaction and responses to patient stories.

Text mining methods, such as LDA topic modelling, are inherently quantitative methods that enable researchers and healthcare providers to analyze and benefit from the large volumes of patient stories available on social media to explore the healthcare experiences of patients and identify critical issues in these experiences.

Lastly, social media platforms that are dedicated to collecting patient stories such as the Care Opinion platform may be considered more credible by healthcare providers and administrators than the general social media platforms such as Facebook. The credibility of the platform increases the credibility of the stories and encourages healthcare providers to respond to them.

6.7 Limitations

In this study, I have used LDA topic modelling to analyze patient stories. LDA uses quantitative analyses to identify prominent topics within the textual data by calculating topic-term and document-topic distributions. However, in LDA methodology, the researcher has to assign descriptive labels to these topics. Label-assignment is an interpretive process. I strived to improve the accuracy of the labels, and I used an existing theoretical framework. However, the labels may also reflect my personal perspectives and understanding of the healthcare experience phenomenon.

Secondly, the research questions of this study did not require analyzing the content of the provider responses. As I explain in section 6.5.2, the meaningfulness of the stories can be demonstrated by analyzing their content and by examining the provider’s response pattern. However, analyzing the content of the response can also expose how meaningful a story is.

Lastly, for sentiment analysis, I have used a rule-based method, which estimates sentiment scores based on specific vocabulary. Although the accuracy of this method is good, using methods that are based on machine learning, such as supervised or semi-supervised classifiers that are trained on an annotated corpus of text that resembles patient stories, can provide more accurate results.

CHAPTER 7

Conclusion

7.1 Preamble

This thesis focuses on the phenomenon of patient stories on social media. In these stories, patients describe their illness and healthcare experiences. The thesis has an overarching question, which is: "What is the utility of patient stories on social media for healthcare quality improvement." The thesis is guided by a theoretical perspective comprised of two theoretical lenses.

First, I use the socio-technical systems theory to conceptualize social media as a socio-technical system for collecting patient stories and facilitating the communication between patients and healthcare providers about these stories. In this system, I explore the following elements: the users, the healthcare regulatory authorities that set the policies that govern the healthcare professionals and practices, and the technical system. In this phenomenon, there are two groups of users: the first group are the patients, and the second group are the healthcare providers and administrators. The thesis focuses on healthcare providers and administrators because they are responsible for improving healthcare quality.

Second, I use critical health sociology to understand the power relations among the actors and the sociopolitical context of the system. Specifically, I explore how the biomedical model in healthcare enables and empowers healthcare providers to focus on specific aspects of patient experience and ignore other equally important aspects. I also explore how, in the current design of the healthcare system and the separation of responsibilities, healthcare administrators may adopt health policy interventions that can have unintended consequences on patient experience.

In this final chapter, I attempt to answer the dissertation's overarching research question by reviewing the scope and contribution of each study in this dissertation towards answering this question. I also draw some conclusions and implications regarding patient experience and healthcare quality improvement.

7.2 Dissertation Studies and Findings

I conducted four empirical studies. Two of these studies included interviewing healthcare providers and administrators, one study included document analysis, and one study included text mining.

In the first study, I interviewed a group of healthcare providers and administrators in Ontario to understand their perspectives regarding the factors that affect the patient experience.

The findings of this study suggest four ways through which beliefs, power and priority differences, and conflict of interests between the two dominant groups in the healthcare system in Ontario (healthcare providers and the healthcare administrators), can amplify the burden of disease and compromise people's healthcare experiences.

The first way is the selective consideration of specific aspects of the healthcare experience, which means that factors such as quality of communication between patients and providers and timeliness of the healthcare services receive more attention than other factors, such as patient's socioeconomic status, patient expectations, and patient satisfaction. It also means that healthcare providers and administrators may look at some elements in patient stories and ignore others. The second way is the adoption of policies that promote the responsibility of people for their health and health behaviours while ignoring the quality problems of healthcare[1] and patients' socioeconomic barriers that prevent the patients from seeking healthcare, buying drugs, following-up services, or adopting a healthy lifestyle[2,3]. The third way is cutting healthcare budgets and laying off healthcare staff, which can lead to an increase in wait time for the patients, an increase in workload and burnout for the providers, and cancellation of essential healthcare services, which prevents vulnerable people from receiving the care that they need[4–9]. The frontline burnout may be common in the healthcare system in Ontario, and it may threaten patient safety and prevent healthcare providers from paying attention to many aspects of healthcare experiences. Pandemics, cutting healthcare budgets and laying off healthcare staff, can increase the wait time for the patients and the workload for the available medical staff, and can lead to frontline burnout. The frontline burnout can also negatively affect the already selective consideration of healthcare providers for healthcare experiences. The fourth way is controlling and regulating the medical professions' scope of practices, licensing procedures, and the size of the healthcare workforce, which can have unintended consequences on the healthcare system's ability to respond to the health needs of the population and can increase the workload of the healthcare providers.

The findings of this study lead me to my first conclusion: in the healthcare system in Ontario, several factors can prevent healthcare providers and administrators from paying adequate attention to patient experience and to collecting information about it, either through surveys or from social media.

This study implies that health policymakers and healthcare regulatory authorities should assess the impact of healthcare policies, regulations, and professional standards on patient experience.

In the second study, I explore the perspectives of healthcare providers and administrators on patient stories on social media and whether these stories can be used for evaluating the healthcare experiences of patients.

The study findings show that surveys and questionnaires are the main methods used to evaluate healthcare experiences in Ontario. However, the findings also show that healthcare providers and administrators are skeptical about the value and validity of these instruments. Many of these surveys may not provide meaningful information to healthcare providers and administrators because they may be positively or negatively biased, and they do not expose specific issues in healthcare quality.

The study also shows that providers may also be concerned about damages to their reputation that may be caused by patient stories if misused by patients. They may also be concerned about the quality of the stories. Providers believe that the credibility of the stories should be checked and that these stories may not be objective nor representative to all patients. Nevertheless, the study shows that a policy change, a cultural change, and the development of a trusted social media platform dedicated to collecting patient stories are factors that can enable the use of social media in the healthcare system.

The findings of this study lead me to my second conclusion: For both possible sources of information about healthcare experience— surveys and patient stories— information quality issues and other risks can reduce the value of these sources from the perspective of healthcare providers and administrators.

Subjectivity and social desirability bias are inherent limitations in attitudinal and interview surveys[10] and the electronic word of mouth posts[11]. However, as I present in this study, many organizations in the business sector have benefited from online customer reviews of their products and services; despite the issues mentioned above. These reviews can help organizations understand the usefulness of their products and the issues that require improvement[12].

The findings of this study highlight the need for further research to develop methods that can help healthcare providers assess the quality of patient stories.

In the third study, I explore how the social media policies of healthcare regulatory authorities in Ontario encourage or discourage the use of social media by healthcare providers to collect patient stories and identify points for improvement in healthcare quality.

The study shows that in the healthcare system in Ontario, social media is perceived as a source of risk to healthcare professions and professionals, and therefore, policies are developed to mitigate these risks. However, healthcare organizations, frightened by the inherent risks of social media and influenced by the lack of a large body of legal evidence, may ignore the potential benefits of patient stories on social media.

The findings of this study lead me to my third conclusion: current social media policies in the healthcare system in Ontario may have unintended and demotivating effects on the abilities of healthcare professionals to use social media as a means to collect patient stories and use them to understand healthcare experiences of the patients.

In the fourth study, I explore the usefulness of a patient story social media platform by evaluating the Care Opinion Platform, which is dedicated to collecting patient stories in the UK. The study does not evaluate the technical quality of the platform in terms of information security, speed, or design. Instead, it analyzes the content of the stories in the platform to understand the aspects of patient experiences described in these stories and assess whether the stories are meaningful to the providers and administrators.

The study findings show that patients in the UK have used the Care Opinion platform to express their satisfaction with their healthcare experiences and the quality of non-clinical services. However, some patients have also expressed their dissatisfaction regarding some service elements that are, from a healthcare quality perspective, critical to achieving health outcomes.

The study findings show that patient stories can reveal essential issues in healthcare clinical quality, service availability, and accessibility, and therefore, they can be important to healthcare providers and administrators. The findings show that these stories are not just general social media posts; instead, they describe aspects of healthcare experiences that are consistent with existing knowledge in the healthcare quality field. These findings suggest that patient story platforms can be helpful and useful for both the patients and the providers.

The findings show that 73% of the stories posted receive responses from healthcare providers. The study analyzes whether healthcare providers respond to these stories and shows that certain aspects of patient experience are more relevant to providers in terms of prompting responses. The study suggests that providers' response patterns are likely related to the meaningfulness of the stories. The study shows that stories describing specific healthcare quality elements such as the wait time or talk about the quality of maternity care or musculoskeletal health conditions are meaningful to the providers and are, therefore, associated with good chances of receiving a provider's response. These findings show that the Care Opinion platform or similar platforms can be useful sources of information about healthcare experiences and can provide an authentic medium for patient-provider communication.

Furthermore, the Care Opinion platform operates in the UK, whose healthcare system has strict social media policies[13–15] that are similar to those in Ontario. However, these policies have not impeded the use of this platform by healthcare providers and healthcare administrators to communicate with patients and respond to their stories.

The study findings lead me to my fourth conclusion: social media policies in the healthcare system in Ontario cannot alone explain the hesitancy of healthcare providers and administrators to interact with patients on social media and benefit from patient stories, and there can be other barriers. As I discuss in the second study above, these barriers may be information quality and the other risks of social media that can reduce the value of patient stories from the perspective of healthcare providers and administrators.

7.3 The Utility of Patient Stories

Based on the findings of this thesis, we can identify five types of barriers that impede the use of patient stories on social media for quality improvement. The first of these are the beliefs and priorities of healthcare providers that focus on health outcomes and weight the different elements of patient experience based on their contribution to these outcomes. In the same vein, the focus of healthcare administrators on healthcare system efficiency also means that they pay less attention to the patient experience.

The second type of barriers are organizational barriers, which are the social media policies of the healthcare regulatory authorities and the professional healthcare standards and codes of conduct that restrict patient-provider communication. The third type of barriers are those related to the time and effort required to process these stories. These stories exist in large volumes, and although there are information processing methods, including text mining and natural language processing that can facilitate the processing of these stories, these methods have not been widely adopted in healthcare[16]. Therefore, healthcare providers and administrators may need to process these stories manually, which may be a very daunting task. As the first study shows, the workload in the healthcare system in Ontario is high, and provider burnout is common. Thus, the providers and administrators may not have the time to explore these stories or use them. The fourth type of barriers are related to the quality of patient stories. Healthcare providers may be concerned about the credibility, objectivity, and representativeness of these stories. The fifth type of barriers are related to healthcare providers' concerns about the risks that may accompany the use of social media, including the provider's reputation damage and patient privacy violation. Consideration of these barriers leads me to my fifth conclusion: In the current healthcare system in Ontario, it is unlikely that a social media platform dedicated to collecting patient stories will be considered useful by healthcare providers and administrators.

However, and as I have presented in the third study, social media has been a user-driven technology, and in most domains, the needs and online behaviour of the people have inspired the development of social media more than the strategic directions and rational adoption of organizations[17]. Therefore, it is possible that in the future, there will be a social media platform for collecting patient stories in Ontario. If such a platform becomes available, I believe that it is important to explore the data that will be provided through this platform using the methods that were used in the fourth empirical study (Chapter 6) or other methods to understand the different aspects of patient experience in Ontario as reflected in this data.

However, the integration of such a platform with existing quality improvement processes in the healthcare system should be evidence-informed. Without the availability of evidence for the usefulness of this platform from the perspective of healthcare providers, such integration will be weak. Hence, further research is required to assess the relationships of using patient stories platforms and the accepted healthcare quality indicators. Platform developers and operators should also provide evidence for the technical quality of their platforms in terms of privacy protection and information security.

7.4 Contributions

This thesis makes several contributions to patient experience and health social media fields. Firstly, the first study develops a conceptual framework that provides two perspectives to analyze patient experience: the biomedical and the sociopolitical perspectives. Under each perspective, the framework identifies a set of factors that can affect the patient experience. The framework is supported by qualitative data collected by interviewing healthcare providers and administrators in Ontario, and it is also supported by existing literature, which makes it useful for different purposes, including research purposes in academia, and quality improvement in healthcare settings.

Secondly, the second study critically explores patient experience evaluation and sheds light on fundamental quality issues that may affect patient experience surveys and patient stories on social media. The study findings can help researchers, healthcare providers, and healthcare administrators understand the limitations of existing patient experience evaluation methods and develop new ones.

Thirdly, the third study may be one of a few studies that analyze the social media policies of healthcare regulatory authorities in Ontario. It identifies social media benefits, risks, and risk mitigation guidelines that are described in these policies. The analysis and conclusions made in the study can help healthcare organizations develop their social media policies, and it can help social media developers understand the concerns of healthcare regulators and healthcare professionals.

Fourthly, the fourth study may be one of a few studies that analyze patient stories on social media using text analytics. It proposes novel approaches that employ statistical methods, text analytics, and natural language processing to analyze the content of the stories, assess patient satisfaction levels in these stories, and model the factors that affect the likelihood of receiving a response from the healthcare providers. These approaches can be used by researchers and social media platform operators to analyze the large volumes of patient stories in their platforms.

Fifthly, the thesis critically analyzes the phenomenon of patient stories on social media and provides insights into the area of use, benefits, risks, and adoption barriers and enablers. The findings in the thesis can help healthcare regulators and policymakers understand this phenomenon and make informed decisions about adopting it in the healthcare system.

Lastly, in times of fundamental healthcare system changes such as policy reforms, or public health emergencies such as the Coronavirus pandemic, healthcare providers and administrators may not have the capacity to assess the healthcare experiences of the patients. However, this thesis shows that social media can be a means for patients to voice their concerns, satisfaction, or dissatisfaction with their healthcare experiences.

7.5 Implications for Future Research

I have discussed the implications for future research in each study separately. Nevertheless, in this final chapter, it is vital to summarize these implications. In the patient experience field, further research is required to expand and enrich our understanding of healthcare providers, administrators, policymakers, patients, and healthcare regulations. First, it is essential to further understand the perspective of healthcare providers, administrators and policymakers on patient experience and patient stories by building on the findings of the first, second, and third studies in this dissertation (Chapters 3, 4, and 5). These findings can inform the development of a survey instrument that can be used to validate and generalize them. Second, it is equally important to understand the perspective of patients regarding the ideal patient experience. In Canada, patients have diversified cultural backgrounds, and many of them may have healthcare experiences in other countries; therefore, they may have very diversified perspectives in this regard, which warrants further research. Third, in this thesis, I utilized the interview method to explore the perspectives of healthcare providers and administrators. However, as discussed in the theoretical perspective in Chapter 2, these perspectives may be influenced and shaped by the policies of healthcare regulators. Therefore, policy evaluation studies are needed to explore these policies. Fourth, the phenomenon of patient stories on social media is relatively new and has not been well explored by researchers. Therefore, further research may be able to shed light on the different elements of this phenomenon, including the perspectives of stakeholders, the quality of data, and the technical systems that need to be developed to collect and analyze the data.

7.6 Implications for Policy and Practice

There are several policy implications that can be identified based on the findings of the empirical studies in this dissertation.

First, I discussed in the first empirical study (Chapter 3) how the ideologies and policies of healthcare providers and healthcare administrators can amplify the burden of disease and compromise people's health and healthcare experiences in several ways, including cutting healthcare budgets and controlling and regulating the medical professions' scope of practices. Cutting healthcare budgets and laying off healthcare staff can increase the wait time for the patients and the workload for the medical staff leading to frontline burnout, and it may threaten patient safety. Budget cuts can also result in the cancellation of essential healthcare services, which can prevent vulnerable people from some vital healthcare services. Therefore, health policymakers should evaluate the impact of their policy interventions on people's health and health equity. Controlling and regulating the medical professions' scope of practices, licensing procedures, and the size of the healthcare workforce may have unintended consequences on the healthcare system's ability to respond to the health needs of the population and can increase the workload of the healthcare providers. Therefore, health policymakers and healthcare colleges in Ontario should regularly evaluate and update the scopes of professional practices to make sure that the healthcare workforce is fully utilized.

Secondly, in the second and third empirical studies (Chapter 4 and 5) I discussed how policy and cultural changes may be required to foster the use of social media for healthcare quality improvement and enable the development of a safe patient-provider communication. Healthcare regulatory authorities in Ontario are invited to evaluate their social media policies and guidelines and assess the risks and potential benefits of social media to make sure that while asserting the risks that may threaten patients and healthcare providers, no opportunities for listening to patients and improving the quality of healthcare are lost. There also needs to be a change in the healthcare providers' perception of the value of patient feedback and patient stories. Achieving this change requires educating the providers and advocacy from patient support organizations.

References

References of Chapter 1

1. Zakkar M. Patient experience: determinants and manifestations. *Int J Heal Gov* 2019; 24: 143–154.

2. Shale S. Patient experience as an indicator of clinical quality in emergency care. *Clin Gov An Int J* 2013; 18: 285–292.

3. Agency for Healthcare Research and Quality. *What Is Patient Experience?* Rockville, https://www.ahrq.gov/cahps/about-cahps/patient-experience/index.html (2017, accessed 15 May 2018).

4. Experience. *Oxford Dictionaries*, https://www.lexico.com/en/definition/experience (2020).

5. Press I. *Patient satisfaction: Understanding and managing the experience of care*. Chicago: Health Administration Press, 2006.

6. Papanicolas I. International Frameworks for Health System Comparison1. In: Papanicolas I, Smith PC (eds) *Health System Performance Comparison: An Agenda for Policy, Information and Research*. Berkshire: Open University Press, 2013, pp. 31–74.

7. Manary MP, Boulding W, Staelin R, et al. The patient experience and health outcomes. *N Engl J Med* 2013; 368: 201–203.

8. Berwick DM, Nolan TW, Whittington J. The Triple Aim: Care, Health, And Cost. *Health Aff* 2008; 27: 759–769.

9. Ministry of Health and Long-Term Care. Patients first: action plan for health care, http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_patientsfirst.pdf (2015, accessed 20 September 2017).

10. World Health Organization. Framework on integrated, people-centred health services. Report by the Secretariat. *WHO, Geneva. Retrieved from www.who.int/servicedeliverysafety/areas/people-centred-care/en/on*; 18.

11. Weldring T, Smith SMS. Article Commentary: Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs). *Heal Serv insights* 2013; 6: HSI-S11093.

12. Ziebland S, Coulter A. Introduction. In: Ziebland S, Coulter A, Calabrese JD, et al. (eds) *Understanding and using health experiences: improving patient care*. Oxford: Oxford University Press, 2013, pp. 1–5.

13. Kaplan AM. Social Media, Definition, and History BT - Encyclopedia of Social Network Analysis and Mining. In: Alhajj R, Rokne J (eds). New York, NY: Springer New York, pp. 2662–2665.

14. Mayer MA, Fernández-Luque L, Leis A. Big Data For Health Through Social Media. In: *Participatory Health Through Social Media*. Elsevier, 2016, pp. 67–82.

15. McCay-Peet L, Quan-Haase A. What is Social Media and What Questions Can Social Media Research Help Us Answer? In: *The SAGE handbook of social media research methods*. 55 City Road: SAGE Publications Ltd. Epub ahead of print 2017. DOI: 10.4135/9781473983847.

16. RateMds. Doctor Reviews and Ratings - Find a Doctor at RateMDs, https://www.ratemds.com/on/toronto/ (2020, accessed 8 February 2020).

17. Zakkar M, Sedig K. Interactive visualization of public health indicators to support policymaking: An exploratory study. *Online J Public Health Inform* 2017; 9: e190–e190.

18. Eisenberg L. Disease and illness Distinctions between professional and popular ideas of sickness. *Cult Med Psychiatry* 1977; 1: 9–23.

19. LaVela SL, Gallan A. Evaluation and measurement of patient experience. *Patient Exp J* 2014; 1: 28–36.

20. Alford RR. *Health care politics: Ideological and interest group barriers to reform*. University of Chicago Press, 1975.

21. Coulter A. Understanding the experience of illness and treatment. In: Ziebland S, Coulter A, Calabrese JD, et al. (eds) *Understanding and Using Health Experiences: Improving patient care*. Oxford: Oxford University Press, 2013, pp. 6–15.

22. Starr P. *The social transformation of American medicine*. 1st ed. New York: Basic Books, 1982.

23. Engel GL. The need for a new medical model: a challenge for biomedicine. *Science (80-)* 1977; 196: 129 LP – 136.

24. Wade DT, Halligan PW. Do biomedical models of illness make for good healthcare systems? *BMJ* 2004; 329: 1398 LP – 1401.

25. Laing A, Hogg G. Political exhortation, patient expectation and professional execution: Perspectives on the consumerization of health care. *Br J Manag* 2002; 13: 173–188.

26. Alharbi TSJ, Carlström E, Ekman I, et al. Experiences of person-centred care-patients' perceptions: qualitative study. *BMC Nurs* 2014; 13: 28.

27. Greenhalgh T, Snow R, Ryan S, et al. Six 'biases' against patients and carers in evidence-based medicine. *BMC Med* 2015; 13: 200.

28. Kleinman A, Benson P. Anthropology in the clinic: the problem of cultural competency and how to fix it. *PLoS Med* 2006; 3: e294.

29. Kleinman A. *The illness narratives: suffering, healing, and the human condition.* New York: Basic books, 1988.

30. Greaves F, Ramirez-Cano D, Millett C, et al. Harnessing the cloud of patient experience: using social media to detect poor quality healthcare. *BMJ Qual Saf* 2013; 22: 251–255.

31. Schlesinger M, Grob R, Shaller D, et al. Taking patients' narratives about clinicians from anecdote to science. *N Engl J Med*.

32. Flott KM, Graham C, Darzi A, et al. Can we use patient-reported feedback to drive change? The challenges of using patient-reported feedback and how they might be addressed. *BMJ Qual Saf* 2017; 26: 502–507.

33. Sitzia J, Wood N. Patient satisfaction: a review of issues and concepts. *Soc Sci Med* 1997; 45: 1829–1843.

34. Zinckernagel L, Schneekloth N, Zwisler A-DO, et al. How to measure experiences of healthcare quality in Denmark among patients with heart disease? The development and

psychometric evaluation of a patient-reported instrument. *BMJ Open* 2017; 7: e016234.

35. Jerant A, Fenton JJ, Kravitz RL, et al. Association of clinician denial of patient requests with patient satisfaction. *JAMA Intern Med* 2018; 178: 85–91.

36. Bleich SN, Özaltin E, Murray CJL. How does satisfaction with the health-care system relate to patient experience? *Bull World Health Organ* 2009; 87: 271–278.

37. Bowling A. *Research methods in health: investigating health and health services*. McGraw-Hill Education (UK), 2014.

38. Ziebland S, Coulter A, Calabrese JD, et al. Understanding and using health experiences: improving patient care. OUP Oxford, 2013.

39. Tipper B. A scan of existing and planned surveys of patient/client or caregiver experiences, https://www.changefoundation.ca/site/wp-content/uploads/2016/05/ExperienceSurveyReview-Tipper.pdf (2010, accessed 9 January 2019).

40. Health Quality Ontario. *Primary Care Patient Experience Survey*. Toronto, http://www.hqontario.ca/Portals/0/documents/qi/primary-care/primary-care-patient-experience-survey-en.pdf (2015).

41. Agency for Healthcare Research and Quality. CAHPS Clinician & Group Survey, https://www.ahrq.gov/cahps/surveys-guidance/cg/index.html (2016, accessed 2 October 2017).

42. Picker Institute. Questionnaire - Patient experiences of compassionate care, http://www.picker.org/tools-resources/toolkits/ (2017, accessed 2 October 2017).

43. Jenkinson C, Fitzpatric R. Patient reported outcome. In: *Understanding and using health experiences: improving patient care*. OUP Oxford, 2013.

44. Mokkink LB, Terwee CB, Patrick DL, et al. The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *J Clin Epidemiol* 2010; 63: 737–745.

45. Busse R. Understanding satisfaction, responsiveness and experience with the health

system. In: Papanicolas I, Smith PC (eds) *Health System Performance Comparison: An Agenda for Policy, Information and Research*. Berkshire: Open University Press, England, 2013, pp. 255–280.

46. Alwin DF, Krosnick JA. The reliability of survey attitude measurement: The influence of question and respondent attributes. *Sociol Methods Res* 1991; 20: 139–181.

47. Norris AE, Matsuda Y, Altares Sarik D, et al. Implementation Quality: Implications for Intervention and Translational Science. *J Nurs Scholarsh*.

48. Papoutsi C, Reed JE, Marston C, et al. Patient and public views about the security and privacy of Electronic Health Records (EHRs) in the UK: results from a mixed methods study. *BMC Med Inform Decis Mak* 2015; 15: 86.

49. Spencer K, Sanders C, Whitley EA, et al. Patient perspectives on sharing anonymized personal health data using a digital system for dynamic consent and research feedback: a qualitative study. *J Med Internet Res*; 18.

50. World Health Organization. *The world health report 2000: health systems: improving performance*. Geneva: World Health Organization, 2000.

51. Canadian Institutes of Health Research, Canada NS and ERC of, Social Sciences and Humanities Research Council of Canada. *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.* 2014.

52. British Medical Association. Bridging the Gap Between Theory and Practice: The BMA’s Approach to Medical Ethics. *Medical Ethics Today The BMA’s Handbook of Ethics and Law* 2012; 1–19.

53. Biggs H. *Healthcare research ethics and law: regulation, review and responsibility*. Routledge-Cavendish, 2009.

54. Ryan S. Engagement and inclusivity in researching patients’ experiences. In: *Understanding and Using Health Experiences: Improving Patient Care.* Oxford University Press, 2013, pp. 127–137.

55. Valentine NB, de Silva A, Kawabata K, et al. Health system responsiveness: concepts,

domains and operationalization. In: Murray CJL, Evans DB (eds) *Health systems performance assessment: debates, methods and empiricism*. Geneva: World Health Organization, 2003, pp. 573–596.

56. Aday LA, Cornelius LJ. *Designing and conducting health surveys: a comprehensive guide*. San Francisco: John Wiley & Sons, 2006.

57. Dillman DA, Smyth JD, Christian LM. *Internet, phone, mail, and mixed-mode surveys: the tailored design method*. 4th ed. Hoboken,: John Wiley & Sons, 2014.

58. Graham C, Woods P. Patient experience surveys. In: Ziebland S, Coulter A, Calabrese JD, et al. (eds) *Understanding and Using Health Experiences: Improving patient care*. Oxford: Oxford University Press, 2013, pp. 81–93.

59. Streiner DL, Norman GR, Cairney J. *Health measurement scales: a practical guide to their development and use*. Oxford: Oxford University Press, USA, 2015.

60. Perneger T V, Chamot E, Bovier PA. Nonresponse bias in a survey of patient perceptions of hospital care. *Med Care* 2005; 43: 374–380.

61. Lavrakas PJ. Nonresponse. *Encyclopedia of survey research methods*. Epub ahead of print 2008. DOI: https://dx.doi.org/10.4135/9781412963947.n339.

62. Davern M. Nonresponse rates are a problematic indicator of nonresponse bias in survey research. *Health Serv Res* 2013; 48: 905–912.

63. Halbesleben JRB, Whitman M V. Evaluating survey quality in health services research: a decision framework for assessing nonresponse bias. *Health Serv Res* 2013; 48: 913–930.

64. Canadian Institutes of Health Research. Knowledge Translation, http://www.cihr-irsc.gc.ca/e/29529.html (2018, accessed 3 February 2019).

65. Robert G, Cornwell J. Rethinking policy approaches to measuring and improving patient experience.

66. Coulter A, Locock L, Ziebland S, et al. Collecting data on patient experience is not enough: they must be used to improve care. *BMJ Br Med J* 2014; 348: g2225.

67. Beattie M, Murphy DJ, Atherton I, et al. Instruments to measure patient experience of

healthcare quality in hospitals: a systematic review. *Syst Rev* 2015; 4: 97.

68. Wong ST, Johnston S, Burge F, et al. Measuring Patient Experiences: Is It Meaningful and Actionable? *Healthc Pap* 2017; 17: 22–29.

69. Gleeson H, Calderon A, Swami V, et al. Systematic review of approaches to using patient experience data for quality improvement in healthcare settings. *BMJ Open* 2016; 6: e011907.

70. Khankeh H, Ranjbar M, Khorasani-Zavareh D, et al. Challenges in conducting qualitative research in health: A conceptual paper. *Iran J Nurs Midwifery Res* 2015; 20: 635–641.

71. Kvale S. Ten standard Objections to Qualitative Research Interviews. *J Phenomenol Psychol* 1994; 25: 147–173.

72. Dickson-Swift V, James EL, Kippen S, et al. Doing sensitive research: what challenges do qualitative researchers face? *Qual Res* 2007; 7: 327–353.

73. Salmons J. Using Social Media in Data Collection: Designing Studies with the Qualitative E-Research Framework. In: Sloan L, Quan-Haase A (eds) *The SAGE Handbook of Social Media Research Methods*. 55 City Road, London: SAGE Publications Ltd, 2017, pp. 177–196.

74. Quan-Haase A, Sloan L. Introduction to the handbook of social media research methods: goals, challenges and innovations. In: Quan-Haase A, Sloan L (eds) *The SAGE Handbook of Social Media Research Methods*. 55 City Road, London: SAGE Publications London, 2017, pp. 1–9.

75. Hagg E, Dahinten VS, Currie LM. The emerging use of social media for health-related purposes in low and middle-income countries: A scoping review. *Int J Med Inform* 2018; 115: 92–105.

76. Hamm MP, Chisholm A, Shulhan J, et al. Social media use among patients and caregivers: a scoping review. *BMJ Open* 2013; 3: e002819.

77. Lin H-C, Chang C-M. What motivates health information exchange in social media? The roles of the social cognitive theory and perceived interactivity. *Inf Manag*.

78. Thackeray R, Crookston BT, West JH. Correlates of health-related social media use among adults. *J Med Internet Res*; 15.

79. Haodf. Home Page. *www.haodf.com*, www.haodf.com (accessed 4 March 2020).

80. Hanauer DA, Zheng K, Singer DC, et al. Public Awareness, Perception, and Use of Online Physician Rating Sites. *JAMA* 2014; 311: 734–735.

81. Liu X, Chen H. A research framework for pharmacovigilance in health social media: identification and evaluation of patient adverse drug event reports. *J Biomed Inform* 2015; 58: 268–279.

82. World Health Organization. *Novel Coronavirus (2019-nCoV) Situation Report - 13*. Geneva, https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200202-sitrep-13-ncov-v3.pdf (2020).

83. Juran J. How To Think About Quality. In: Juran, Joseph M.Godfrey AB, Hoogstoel RE, Schilling EG (eds) *Juran's Quality Handbook*. McGraw-Hill, 1999.

84. McNab AL, Ladd DA. Information quality: the importance of context and trade-offs. In: *System Sciences (HICSS), 2014 47th Hawaii International Conference on*. IEEE, 2014, pp. 3525–3532.

85. Stvilia B, Twidale MB, Smith LC, et al. Information quality work organization in Wikipedia. *J Am Soc Inf Sci Technol* 2008; 59: 983–1001.

86. Floridi L, Illari P. *The philosophy of information quality*. Springer, 2014.

87. Metzger MJ. Making sense of credibility on the Web: Models for evaluating online information and recommendations for future research. *J Am Soc Inf Sci Technol* 2007; 58: 2078–2091.

88. Syed-Abdul S, Gabarron E, Lau AYS, et al. An introduction to participatory health through social media. In: *Participatory Health Through Social Media*. Elsevier, 2016, pp. 1–9.

89. Welch V, Petkovic J, Pardo JP, et al. Interactive social media interventions to promote health equity: an overview of reviews. *Heal Promot chronic Dis Prev Canada Res policy*

Pract 2016; 36: 63.

90. McDonald L, Malcolm B, Ramagopalan S, et al. Real-world data and the patient perspective: the PROmise of social media? *BMC Med* 2019; 17: 11.

91. Seale C, Charteris-Black J, MacFarlane A, et al. Interviews and Internet Forums: A Comparison of Two Sources of Qualitative Data. *Qual Health Res* 2009; 20: 595–606.

92. Paul MJ, Sarker A, Brownstein JS, et al. Social media mining for public health monitoring and surveillance. In: *Biocomputing 2016: Proceedings of the Pacific Symposium*. World Scientific, 2016, pp. 468–479.

93. Cole J, Watkins C, Kleine D. Health advice from internet discussion forums: how bad is dangerous? *J Med Internet Res*; 18.

94. Griffiths A, Leaver MP. Wisdom of patients: predicting the quality of care using aggregated patient feedback. *BMJ Qual Saf* 2017; 27: 110–118.

95. Lambert KM, Barry P, Stokes G. Risk management and legal issues with the use of social media in the healthcare setting. *J Healthc Risk Manag* 2012; 31: 41–47.

96. Pillow MT, Hopson L, Bond M, et al. Social media guidelines and best practices: recommendations from the Council of Residency Directors Social Media Task Force. *West J Emerg Med* 2014; 15: 26–30.

97. Hyman JL, Luks HJ, Sechrest R. Online Professional Networks for Physicians: Risk Management. *Clin Orthop Relat Res* 2012; 470: 1386–1392.

98. Gholami-Kordkheili F, Wild V, Strech D. The impact of social media on medical professionalism: a systematic qualitative review of challenges and opportunities. *J Med Internet Res* 2013; 15: e184–e184.

99. The Council on Ethical and Judicial Affairs. *Professionalism in the Use of Social Media*. Chicago, https://www.ama-assn.org/sites/ama-assn.org/files/corp/media-browser/public/about-ama/councils/Council Reports/council-on-ethics-and-judicial-affairs/i10-ceja-professionalism-use-social-media.pdf (2010).

100. Canadian Medical Association. *Social media and Canadian physicians: Issues and rules*

of engagement. Ottawa, https://policybase.cma.ca/documents/policypdf/PD12-03.pdf (2011).

101. Speed E, Davison C, Gunnell C. The anonymity paradox in patient engagement: reputation, risk and web-based public feedback. *Med Humanit* 2016; 42: 135 LP – 140.

102. Martin GP, McKee L, Dixon-Woods M. Beyond metrics? Utilizing 'soft intelligence' for healthcare quality and safety. *Soc Sci Med* 2015; 142: 19–26.

103. Menon A V. Do online reviews diminish physician authority? The case of cosmetic surgery in the U.S. *Soc Sci Med* 2017; 181: 1–8.

104. Patel S, Cain R, Neailey K, et al. General Practitioners' Concerns About Online Patient Feedback: Findings From a Descriptive Exploratory Qualitative Study in England. *J Med Internet Res* 2015; 17: e276.

105. Raconteur. Future of Data 2019, https://www.raconteur.net/future-data-2019 (2019, accessed 19 April 2020).

106. DOMO. Data Never Sleeps 6.0, https://www.domo.com/learn/data-never-sleeps-6 (2018, accessed 19 April 2020).

107. Blei DM. Probabilistic Topic Models. *Commun ACM* 2012; 55: 77–84.

108. Chen C, Ren J. Forum latent Dirichlet allocation for user interest discovery. *Knowledge-Based Syst* 2017; 126: 1–7.

109. Weiss SM, Indurkhya N, Zhang T. *Fundamentals of predictive text mining*. Springer, 2015.

110. Liddy ED. Natural Language Processing. In: *Encyclopedia of Library and Information Science*. Marcel Decker, Inc, 2001.

111. Indurkhya N, Damerau FJ. *Handbook of natural language processing*. CRC Press, 2010.

112. Miner G, Elder IV J, Fast A, et al. *Practical text mining and statistical analysis for non-structured text data applications*. Academic Press, 2012.

113. Manning CD, Raghavan P, Schutze H. *An introduction to information retrieval*.

Cambridge: Cambridge University Press, 2008.

114. Velasco E, Agheneza T, Denecke K, et al. Social media and Internet-Based data in global systems for public health surveillance: A systematic review. *Milbank Q* 2014; 92: 7–33.

115. Paul MJ, Dredze M. You are what you tweet: Analyzing twitter for public health. In: *Fifth International AAAI Conference on Weblogs and Social Media*. 2011.

116. Fernandez-Luque L, Karlsen R, Bonander J. Review of extracting information from the Social Web for health personalization. *J Med Internet Res*; 13.

117. Myneni S, Cobb NK, Cohen T. Finding meaning in social media: content-based social network analysis of QuitNet to identify new opportunities for health promotion. In: *MedInfo*. 2013, pp. 807–811.

118. Chen AT, Zhu S-H, Conway M. What online communities can tell us about electronic cigarettes and hookah use: a study using text mining and visualization techniques. *J Med Internet Res*; 17.

119. Huang J, Kornfield R, Szczypka G, et al. A cross-sectional examination of marketing of electronic cigarettes on Twitter. *Tob Control* 2014; 23: iii26–iii30.

120. Gonzalez-Hernandez G, Sarker A, O'Connor K, et al. Capturing the patient's perspective: a review of advances in natural language processing of health-related text. *Yearb Med Inform* 2017; 26: 214–227.

121. Doing-Harris K, Mowery DL, Daniels C, et al. Understanding patient satisfaction with received healthcare services: a natural language processing approach. In: *AMIA Annual Symposium Proceedings*. American Medical Informatics Association, 2016, p. 524.

122. Varanasi P, Tanniru M. Seeking intelligence from patient experience using text mining: Analysis of emergency department data. *Inf Syst Manag* 2015; 32: 220–228.

123. Eaneff S, Wang V, Hanger M, et al. Patient perspectives on neuromyelitis optica spectrum disorders: data from the PatientsLikeMe online community. *Mult Scler Relat Disord* 2017; 17: 116–122.

124. Frost J, Okun S, Vaughan T, et al. Patient-reported outcomes as a source of evidence in

off-label prescribing: analysis of data from PatientsLikeMe. *J Med Internet Res*; 13.

125. Ru B, Harris K, Yao L. A content analysis of patient-reported medication outcomes on social media. In: *2015 IEEE International Conference on Data Mining Workshop (ICDMW)*. IEEE, 2015, pp. 472–479.

126. Deng L, Liu Y. A Joint Introduction to Natural Language Processing and to Deep Learning BT - Deep Learning in Natural Language Processing. In: Deng L, Liu Y (eds). Singapore: Springer Singapore, pp. 1–22.

127. Che W, Zhang Y. Deep Learning in Lexical Analysis and Parsing BT - Deep Learning in Natural Language Processing. In: Deng L, Liu Y (eds). Singapore: Springer Singapore, pp. 79–116.

128. Celikyilmaz A, Deng L, Hakkani-Tür D. Deep Learning in Spoken and Text-Based Dialog Systems BT - Deep Learning in Natural Language Processing. In: Deng L, Liu Y (eds). Singapore: Springer Singapore, pp. 49–78.

129. Liu K, Feng Y. Deep Learning in Question Answering BT - Deep Learning in Natural Language Processing. In: Deng L, Liu Y (eds). Singapore: Springer Singapore, pp. 185–217.

130. Tang D, Zhang M. Deep Learning in Sentiment Analysis BT - Deep Learning in Natural Language Processing. In: Deng L, Liu Y (eds). Singapore: Springer Singapore, pp. 219–253.

131. Li Y, Yang T. Word Embedding for Understanding Natural Language: A Survey BT - Guide to Big Data Applications. In: Srinivasan S (ed). Cham: Springer International Publishing, pp. 83–104.

132. Lane H, Howard C, Hapke HM. *Natural language processing in action : understanding, analyzing, and generating text with Python*. Shelter Island: Manning, 2019.

133. Liu J, Chang W-C, Wu Y, et al. Deep Learning for Extreme Multi-Label Text Classification. In: *Proceedings of the 40th International ACM SIGIR Conference on Research and Development in Information Retrieval*. New York, NY, USA: Association for Computing Machinery, pp. 115–124.

134. Chatterjee A, Gupta U, Chinnakotla MK, et al. Understanding Emotions in Text Using Deep Learning and Big Data. *Comput Human Behav* 2019; 93: 309–317.

135. Yousefi-Azar M, Hamey L. Text summarization using unsupervised deep learning. *Expert Syst Appl* 2017; 68: 93–105.

136. Xue D, Wu L, Hong Z, et al. Deep learning-based personality recognition from text posts of online social networks. *Appl Intell* 2018; 48: 4232–4246.

137. Chen MC, Ball RL, Yang L, et al. Deep Learning to Classify Radiology Free-Text Reports. *Radiology* 2017; 286: 845–852.

138. Jiang Z, Li L, Huang D, et al. Training word embeddings for deep learning in biomedical text mining tasks. In: *2015 IEEE International Conference on Bioinformatics and Biomedicine (BIBM)*. 2015, pp. 625–628.

139. National Institute For Health And Care Excellence. *Evidence standards framework for digital health technologies*. London: National Institute For Health And Care Excellence, https://www.nice.org.uk/about/what-we-do/our-programmes/evidence-standards-framework-for-digital-health-technologies (2018, accessed 2 March 2019).

140. Emmert M, Sauter L, Jablonski L, et al. Do Physicians Respond to Web-Based Patient Ratings? An Analysis of Physicians' Responses to More Than One Million Web-Based Ratings Over a Six-Year Period. *J Med Internet Res* 2017; 19: e275.

141. Viviani M, Pasi G. Credibility in social media: opinions, news, and health information—a survey. *Wiley Interdiscip Rev Data Min Knowl Discov* 2017; 7: e1209.

References of Chapter 2

1. Collins CS, Stockton CM. The central role of theory in qualitative research. *Int J Qual Methods* 2018; 17: 1609406918797475.

2. Grant C, Osanloo A. Understanding, selecting, and integrating a theoretical framework in dissertation research: Creating the blueprint for your "house". *Adm issues J Connect Educ Pract Res* 2016; 4: 7.

3. Creswell JW. *Qualitative inquiry and research design: Choosing among five approaches*. Sage publications, 2007.

4. Ballinger C. Demonstrating Rigour and Quality? In: Finlay L, Ballinger C (eds) *Qualitative research for allied health professionals: challenging choices*. John Wiley & Sons, 2006, pp. 235–246.

5. Guba EG, Lincoln YS. Competing paradigms in qualitative research. In: Denzin NK, Lincoln YS (eds) *Handbook of qualitative research*. Sage, Thousand Oaks, CA, 1994, pp. 105–117.

6. Creswell JW. *Research design: Qualitative, quantitative, and mixed methods approaches*. Sage publications, 2013.

7. Fletcher AJ. Applying critical realism in qualitative research: methodology meets method. *Int J Soc Res Methodol* 2017; 20: 181–194.

8. Madill A, Jordan A, Shirley C. Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *Br J Psychol* 2000; 91: 1–20.

9. Lincoln YS, Guba EG. *Naturalistic inquiry*. Beverly Hills, Calif.: Sage Publications, 1985.

10. Zakkar M. Patient experience: determinants and manifestations. *Int J Heal Gov* 2019; 24: 143–154.

11. Mumford E. New treatments or old remedies: is business process reengineering really socio-technical design? *J Strateg Inf Syst* 1994; 3: 313–326.

12. Baxter G, Sommerville I. Socio-technical systems: From design methods to systems engineering. *Interact Comput* 2011; 23: 4–17.

13. Abdelnour-Nocera J, Clemmensen T. Theorizing About Socio-Technical Approaches to HCI. In: Barricelli BR, Roto V, Clemmensen T, et al. (eds) *Human Work Interaction Design. Designing Engaging Automation*. Cham: Springer International Publishing, 2019, pp. 242–262.

14. Andrea JH. Socio-technical systems theory as a diagnostic tool for examining underutilization of wiki technology. *Learn Organ* 2014; 21: 48–68.

15. Mumford E. The story of socio-technical design: reflections on its successes, failures and potential. *Inf Syst J* 2006; 16: 317–342.

16. Dixon D. Pattern languages for CMC design. In: *Handbook of research on socio-technical design and social networking systems*. IGI Global, 2009, pp. 402–415.

17. Geels FW. From sectoral systems of innovation to socio-technical systems: Insights about dynamics and change from sociology and institutional theory. *Res Policy* 2004; 33: 897–920.

18. Link B. Social Conditions as Fundamental Causes of Health Inequalities. In: Bird CE, Conrad P, Fremont AM, et al. (eds) *Handbook of medical sociology*. Nashville: Vanderbilt University Press, 2013, pp. 3–17.

19. Weitz R. *The sociology of health, illness, and health care : a critical approach*. 4th ed. Belmont: Thomson Wadsworth, 2007.

20. Coburn D, Willis E. The medical profession: knowledge, power and autonomy. In: Albrecht GL, Fitzpatrick R, Scrimshaw SC (eds) *Handbook of social studies in health and medicine*. London: SAGE Publications Ltd, 2000, pp. 377–393.

21. Kleinman A. *The illness narratives: suffering, healing, and the human condition.* New York: Basic books, 1988.

22. Solar O, Irwin A. *A conceptual framework for action on the social determinants of health*. Geneva: World Health Organization, https://www.who.int/sdhconference/resources/ConceptualframeworkforactiononSDH_eng.pdf (2010).

23. Engel GL. The need for a new medical model: a challenge for biomedicine. *Science (80-)* 1977; 196: 129 LP – 136.

24. Brinkerhoff DB, White LK, Ortega ST, et al. *Essentials of sociology*. Belmont, CA: Wadsworth/Cengage Learning, 2011.

25. Giddens A, Duneier M, Appelbaum RP, et al. *Introduction to sociology*. 11th ed. New York, NY: W. W. norton & company, 2018.

26. Weber M, Tribe K. *Economy and society. a new translation*. 2019.

27. Dillon M. *Introduction to sociological theory.* 2nd ed. Chichester: John Wiley & Sons Ltd, 2014.

28. Turner BS. Outline of a Theory of Human Rights. *Sociology* 1993; 27: 489–512.

29. Allan K. *The social lens : an invitation to social and sociological theory*. 2014.

30. Swidler A. Cultural Power and Social Movements. In: Johnston H, Klandermans B (eds) *Social movements and culture*. Minneapolis: Univ. of Minnesota Press, 1995.

31. Swidler A. Culture in Action: Symbols and Strategies. *Am Sociol Rev* 1986; 51: 273–286.

32. Ritzer G. Professionalization, Bureaucratization and Rationalization: The Views of Max Weber. *Soc Forces* 1975; 53: 627–634.

33. den Berg A van, Janoski T. Conflict Theories in Political Sociology. In: Hicks AM, Schwartz MA, Alford RR, et al. (eds) *The Handbook of Political Sociology: States, Civil Societies, and Globalization*. Cambridge: Cambridge University Press, pp. 72–95.

34. Dobratz BA, Waldner LK, Buzzell T. *Power, politics, and society : an introduction to political sociology*. 1st ed. Abingdon: Routledge, 2012.

35. Cockerham WC. Max Weber: bureaucracy, formal rationality and the modern hospital. In: Collyer F (ed) *The Palgrave handbook of social theory in health, illness and medicine*. Springer, 2015, pp. 124–138.

36. Alford RR. *Health care politics: Ideological and interest group barriers to reform*. University of Chicago Press, 1975.

37. Tajfel H. Social psychology of intergroup relations. *Annu Rev Psychol* 1982; 33: 1–39.

38. Calnan M. Eliot Freidson: Sociological Narratives of Professionalism and Modern Medicine. In: Collyer F (ed) *The Palgrave Handbook of Social Theory in Health, Illness and Medicine*. London: Palgrave Macmillan UK, pp. 287–305.

39. Derber C, Schwartz WA, Magrass YR. *Power in the highest degree : professionals and the rise of a new Mandarin order*. 1st ed. New York; Oxford: Oxford University Press,

1990.

40. Barker KK. The Social Construction of Illness. In: Bird CE, Conrad P, Fremont AM, et al. (eds) *Handbook of medical sociology*. Nashville: Vanderbilt University Press, 2010, pp. 147–162.

41. Zola IK. Culture and Symptoms--An Analysis of Patient's Presenting Complaints. *Am Sociol Rev* 1966; 31: 615–630.

References of Chapter 3

1. Ministry of Health and Long-Term Care. Patients first: action plan for health care, http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_patientsfirst.pdf (2015, accessed 20 September 2017).

2. Zakkar M. Patient experience: determinants and manifestations. *Int J Heal Gov* 2019; 24: 143–154.

3. Shale S. Patient experience as an indicator of clinical quality in emergency care. *Clin Gov An Int J* 2013; 18: 285–292.

4. Agency for Healthcare Research and Quality. *What Is Patient Experience?* Rockville, https://www.ahrq.gov/cahps/about-cahps/patient-experience/index.html (2017, accessed 15 May 2018).

5. Press I. *Patient satisfaction: Understanding and managing the experience of care*. Chicago: Health Administration Press, 2006.

6. Ziebland S, Coulter A. Introduction. In: Ziebland S, Coulter A, Calabrese JD, et al. (eds) *Understanding and using health experiences: improving patient care*. Oxford: Oxford University Press, 2013, pp. 1–5.

7. Greenhalgh T, Snow R, Ryan S, et al. Six 'biases' against patients and carers in evidence-based medicine. *BMC Med* 2015; 13: 200.

8. Eaton S, Collins A, Coulter A, et al. Putting patients first. *BMJ* 2012; 344: e2006.

9. Institute of Medicine. *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: Institute of Medicine, 2001.

10. Papanicolas I. International Frameworks for Health System Comparison1. In: Papanicolas I, Smith PC (eds) *Health System Performance Comparison: An Agenda for Policy, Information and Research*. Berkshire: Open University Press, 2013, pp. 31–74.

11. Manary MP, Boulding W, Staelin R, et al. The patient experience and health outcomes. *N Engl J Med* 2013; 368: 201–203.

12. Donabedian A. *An introduction to quality assurance in health care*. New York: Oxford University Press, 2002.

13. National Academies of Sciences and Medicine E. *Crossing the Global Quality Chasm: Improving Health Care Worldwide*. Washington, DC: The National Academies Press. Epub ahead of print 2018. DOI: 10.17226/25152.

14. Coulter A. Understanding the experience of illness and treatment. In: Ziebland S, Coulter A, Calabrese JD, et al. (eds) *Understanding and Using Health Experiences: Improving patient care*. Oxford: Oxford University Press, 2013, pp. 6–15.

15. Kleinman A. *The illness narratives: suffering, healing, and the human condition.* New York: Basic books, 1988.

16. Sheard L, Peacock R, Marsh C, et al. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study. *Heal Expect* 2018; 22: 46–53.

17. Robert G, Cornwell J. Rethinking policy approaches to measuring and improving patient experience.

18. Graham C, Woods P. Patient experience surveys. In: Ziebland S, Coulter A, Calabrese JD, et al. (eds) *Understanding and Using Health Experiences: Improving patient care*. Oxford: Oxford University Press, 2013, pp. 81–93.

19. The Ministry of Health and Long-Term Care. Ontario Health agency, https://www.ontario.ca/page/ontario-health-agency (2019, accessed 31 July 2019).

20. Ontario Health Coalition. Mounting Health Care Cuts, https://www.ontariohealthcoalition.ca/index.php/mounting-health-care-cuts/ (2019, accessed 31 July 2019).

21. Ontario Nurses Association. ONA Launches New Ad Campaign, https://www.ona.org/news-posts/ona-launches-new-ad-campaign/ (2019, accessed 31 July 2019).

22. Gray J. Ontario to lay off more than 400 people at health agencies. *The Glob and Mail*, 19 June 2019, https://www.theglobeandmail.com/canada/article-ford-government-to-lay-off-more-than-400-people-at-ontario-health-care/ (19 June 2019).

23. Ontario Medical Association. OMA and its section of public health physicians call on the provincial government to maintain core programs in public health units, https://www.oma.org/sections/news-events/news-room/all-news-releases/oma-and-its-section-of-public-health-physicians-call-on-the-provincial-government-to-maintain-core-programs-in-public-health-units/ (2019, accessed 31 July 2019).

24. Ontario Medical Association. OMA Welcomes Premier’s Council Recommendations, https://www.oma.org/sections/news-events/news-room/all-news-releases/oma-welcomes-premiers-council-recommendations-to-improve-health-care-and-end-hallway-medicine/ (2019, accessed 31 July 2019).

25. World Health Organization. *World Health Report, 2010: health systems financing the path to universal coverage.* Geneva: World Health Organization, 2010.

26. Karanikolos M, Kentikelenis A. Health inequalities after austerity in Greece. *Int J Equity Health* 2016; 15: 83.

27. Stuckler D, Reeves A, Loopstra R, et al. Austerity and health: the impact in the UK and Europe. *Eur J Public Health* 2017; 27: 18–21.

28. Keramidou I, Triantafyllopoulos L. The impact of the financial crisis and austerity policies on the service quality of public hospitals in Greece. *Health Policy (New York)* 2018; 122: 352–358.

29. Wenzl M, Naci H, Mossialos E. Health policy in times of austerity—A conceptual

framework for evaluating effects of policy on efficiency and equity illustrated with examples from Europe since 2008. *Health Policy (New York)* 2017; 121: 947–954.

30. Cervero-Liceras F, McKee M, Legido-Quigley H. The effects of the financial crisis and austerity measures on the Spanish health care system: A qualitative analysis of health professionals' perceptions in the region of Valencia. *Health Policy (New York)* 2015; 119: 100–106.

31. Engel GL. The need for a new medical model: a challenge for biomedicine. *Science (80-)* 1977; 196: 129 LP – 136.

32. Wade DT, Halligan PW. Do biomedical models of illness make for good healthcare systems? *BMJ* 2004; 329: 1398 LP – 1401.

33. Weitz R. *The sociology of health, illness, and health care : a critical approach*. 4th ed. Belmont: Thomson Wadsworth, 2007.

34. Dobratz BA, Waldner LK, Buzzell T. *Power, politics, and society : an introduction to political sociology*. 1st ed. Abingdon: Routledge, 2012.

35. Starr P. *The social transformation of American medicine*. 1st ed. New York: Basic Books, 1982.

36. Gross DA, Zyzanski SJ, Borawski EA, et al. Patient satisfaction with time spent with their physician. 1998; 47: 133+.

37. Wilson IB, Kaplan S. Physician-patient communication in HIV disease: the importance of patient, physician, and visit characteristics. *J Acquir Immune Defic Syndr* 2000; 25: 417–425.

38. Kleinman A, Benson P. Anthropology in the clinic: the problem of cultural competency and how to fix it. *PLoS Med* 2006; 3: e294.

39. College of Physicians and Surgeons Of Ontario. *The Practice Guide - Medical Professionalism and College Policies*. Toronto, https://www.cpso.on.ca/Physicians/Policies-Guidance/Practice-Guide (2007).

40. LaVela SL, Gallan A. Evaluation and measurement of patient experience. *Patient Exp J*

2014; 1: 28–36.

41. Gill L, White L. A critical review of patient satisfaction. *Leadersh Heal Serv* 2009; 22: 8–19.

42. World Health Organization. Framework on integrated, people-centred health services. Report by the Secretariat. *WHO, Geneva. Retrieved from www.who.int/servicedeliverysafety/areas/people-centred-care/en/on*; 18.

43. Valentine NB, de Silva A, Kawabata K, et al. Health system responsiveness: concepts, domains and operationalization. In: Murray CJL, Evans DB (eds) *Health systems performance assessment: debates, methods and empiricism*. Geneva: World Health Organization, 2003, pp. 573–596.

44. Busse R. Understanding satisfaction, responsiveness and experience with the health system. In: Papanicolas I, Smith PC (eds) *Health System Performance Comparison: An Agenda for Policy, Information and Research*. Berkshire: Open University Press, England, 2013, pp. 255–280.

45. World Health Organization. *The world health report 2000: health systems: improving performance*. Geneva: World Health Organization, 2000.

46. Scott CEH, Bugler KE, Clement ND, et al. Patient expectations of arthroplasty of the hip and knee. *J Bone Joint Surg Br* 2012; 94-B: 974–981.

47. Kalauokalani D, Cherkin DC, Sherman KJ, et al. Lessons from a Trial of Acupuncture and Massage for Low Back Pain: Patient Expectations and Treatment Effects. *Spine (Phila Pa 1976)*; 26, https://journals.lww.com/spinejournal/Fulltext/2001/07010/Lessons_from_a_Trial_of_Acupuncture_and_Massage.5.aspx (2001).

48. Linde K, Witt CM, Streng A, et al. The impact of patient expectations on outcomes in four randomized controlled trials of acupuncture in patients with chronic pain. *Pain* 2007; 128: 264–271.

49. Ross CK, Frommelt G, Hazelwood L, et al. The Role of Expectations In Patient Satisfaction With Medical Care. *J Health Care Mark* 1987; 7: 16–26.

50. Bjertnaes OA, Sjetne IS, Iversen HH. Overall patient satisfaction with hospitals: effects of patient-reported experiences and fulfilment of expectations. *BMJ Qual &amp; Saf* 2012; 21: 39 LP – 46.

51. Laing A. Meeting patient expectations: healthcare professionals and service re-engineering. *Heal Serv Manag Res* 2002; 15: 165–172.

52. Institute of Medicine. *Health Literacy: A Prescription to End Confusion*. Washington, DC: The National Academies Press. Epub ahead of print 2004. DOI: 10.17226/10883.

53. Berkman ND, Sheridan SL, Donahue KE, et al. Low Health Literacy and Health Outcomes: An Updated Systematic Review. *Ann Intern Med* 2011; 155: 97–107.

54. Parker RM, Ratzan SC, Lurie N. Health Literacy: A Policy Challenge For Advancing High-Quality Health Care. *Health Aff* 2003; 22: 147–153.

55. Wynia MK, Osborn CY. Health Literacy and Communication Quality in Health Care Organizations. *J Health Commun* 2010; 15: 102–115.

56. Sudore RL, Mehta KM, Simonsick EM, et al. Limited Literacy in Older People and Disparities in Health and Healthcare Access. *J Am Geriatr Soc* 2006; 54: 770–776.

57. Nettleton S, Bunton R. Sociological critiques of health promotion. In: Bunton R, Nettleton S, Burrows R (eds) *The sociology of health promotion : critical analyses of consumption, lifestyle, and risk*. London; New York: Routledge, 2005.

58. Willis K, Smith A, Stenning A. Introduction: Social justice and neoliberalism. In: Smith A, Stenning A, Willis K (eds) *Social justice and neoliberalism: Global perspectives*. London and New York: Zed Books, 2008, pp. 1–15.

59. Power E. Fat children, failed (future) consumer-citizens and mothers' duties in neoliberal consumer society. In: Polzer J, Power E (eds) *Neoliberal governance and health: Duties, risks, and vulnerabilities*. Montreal & / Kingston: McGill-Queen's Press, 2016, pp. 43–57.

60. McGregor S. Neoliberalism and health care. *Int J Consum Stud* 2001; 25: 82–89.

61. Coburn D. Income inequality, social cohesion and the health status of populations: the role of neo-liberalism. *Soc Sci Med* 2000; 51: 135–146.

62. Polzer J, Power E. Introduction: The governance of health in neoliberal societies. In: Polzer J, Power E (eds) *Neoliberal governance and health: Duties, risks and vulnerabilities*. Montreal & / Kingston: McGill-Queen's Press, 2016, pp. 3–42.

63. Mirella Y. Revisiting Drucker's theory. *J Manag Hist* 2009; 15: 452–466.

64. Montgomerie J. The Pursuit of (Past) Happiness? Middle-class Indebtedness and American Financialisation. *New Polit Econ* 2009; 14: 1–24.

65. Jung T. Citizens, co-producers, customers, clients, captives? A critical review of consumerism and public services. *Public Manag Rev* 2010; 12: 439–446.

66. Wolff RD. Ideological State Apparatuses, Consumerism, and U.S. Capitalism: Lessons for the Left. *Rethink Marx* 2005; 17: 223–235.

67. Chapman AR. *Global health, human rights, and the challenge of neoliberal policies*. 1st ed. Cambridge: Cambridge University Press, 2016.

68. British Medical Association. Bridging the Gap Between Theory and Practice: The BMA's Approach to Medical Ethics. *Medical Ethics Today The BMA's Handbook of Ethics and Law* 2012; 1–19.

69. College of Nurses of Ontario. *Ethics*. Toronto, https://www.cno.org/globalassets/docs/prac/41034_ethics.pdf (2019).

70. Institute of Medicine. *To Err Is Human: Building a Safer Health System*. Washington, DC: The National Academies Press. Epub ahead of print 2000. DOI: 10.17226/9728.

71. National Academy of Medicine, ational Academies of Sciences, Engineering and M. *Taking Action Against Clinician Burnout: A Systems Approach to Professional Well-Being*. Washington, DC: The National Academies Press. Epub ahead of print 2019. DOI: 10.17226/25521.

72. Shanafelt TD, Boone S, Tan L, et al. Burnout and Satisfaction With Work-Life Balance Among US Physicians Relative to the General US PopulationBurnout and Satisfaction With Work-Life Balance. *JAMA Intern Med* 2012; 172: 1377–1385.

73. Dyrbye L, Shanafelt T, Sinsky C. Burnout among health care professionals: a call to

explore and address this underrecognized threat to safe, high-quality care. *NAM Perspectives*. Epub ahead of print 2017. DOI: 10.31478/201707b.

74. Bressi C, Manenti S, Porcellana M, et al. Haemato-oncology and burnout: an Italian survey. *Br J Cancer* 2008; 98: 1046.

75. Newell JM, Macneil G. Professional burnout, vicarious trauma, secondary traumatic stress, and compassion fatigue: A review of theoretical terms, risk factors, and preventive methods for clinicians and researchers. *Best Pr Ment Heal* 2010; 6: 57–68.

76. National Academy of Medicine, National Academies of Sciences, Engineering and M. *Taking Action Against Clinician Burnout: A Systems Approach to Professional Well-Being*. Washington, DC: The National Academies Press. Epub ahead of print 2019. DOI: 10.17226/25521.

77. Germov J. Imagining Health Problems as Social Issues. In: Germov J (ed) *Second Opinion: An Introduction to Health Sociology*. Victoria, Australia: Oxford University Press, 2014.

78. Bambra C, Fox D, Scott-Samuel A. Towards a politics of health. *Health Promot Int* 2005; 20: 187–193.

79. Waring J, Allen D, Braithwaite J, et al. Healthcare quality and safety: a review of policy, practice and research. In: Allen D, Braithwaite J, Sandall J, et al. (eds) *The Sociology of Healthcare Safety and Quality*. Malden: Wiley Online Library, 2016, pp. 18–35.

80. Tritter JQ. Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world. *Heal Expect* 2009; 12: 275–287.

81. Alford RR. *Health care politics: Ideological and interest group barriers to reform*. University of Chicago Press, 1975.

82. Hunter DJ. *The health debate*. 1st ed. Bristol: Policy Press, 2008.

83. Cooke H. Changing discourses of blame in nursing and healthcare. In: Holmes D, Rudge T, Perron A (eds) *(Re) Thinking Violence in Health Care Settings*. Surrey: Routledge, 2012, pp. 47–66.

84. Denis J-L, van Gestel N. Medical doctors in healthcare leadership: theoretical and practical challenges. *BMC Health Serv Res* 2016; 16: 158.

85. Derber C, Schwartz WA, Magrass YR. *Power in the highest degree : professionals and the rise of a new Mandarin order*. 1st ed. New York; Oxford: Oxford University Press, 1990.

86. Lohr KN, Eleazer K, Mauskopf J. Health policy issues and applications for evidence-based medicine and clinical practice guidelines. *Health Policy (New York)* 1998; 46: 1–19.

87. Ansell C, Sørensen E, Torfing J. Improving policy implementation through collaborative policymaking. *Policy & Politics*; 45: 467–486.

88. Dopson S, Locock L, Gabbay J, et al. Evidence-Based Medicine and the Implementation Gap. *Health (Irvine Calif)* 2003; 7: 311–330.

89. Dower C, Moore J, Langelier M. It Is Time To Restructure Health Professions Scope-Of-Practice Regulations To Remove Barriers To Care. *Health Aff* 2013; 32: 1971–1976.

90. Hilliard JW, Johnson ME. State practice acts of licensed health professions: Scope of practice. *DePaul J Health Care Law* 2004; 8: 237–261.

91. Solar O, Irwin A. *A conceptual framework for action on the social determinants of health*. Geneva: World Health Organization, https://www.who.int/sdhconference/resources/ConceptualframeworkforactiononSDH_eng.pdf (2010).

92. Braveman P, Egerter S, Williams DR. The social determinants of health: coming of age. *Annu Rev Public Health* 2011; 32: 381–398.

93. Baker EH. Socioeconomic Status, Definition. *The Wiley Blackwell Encyclopedia of Health, Illness, Behavior, and Society* 2014; 2210–2214.

94. Reutter L, Kushner KE. 'Health equity through action on the social determinants of health': taking up the challenge in nursing. *Nurs Inq* 2010; 17: 269–280.

95. Roberts MJ, Hsiao W, Herman P, et al. *Getting health reform right : a guide to improving performance and equity*. New York: Oxford University Press, 2004.

96. Creswell JW. *Qualitative inquiry and research design: Choosing among five approaches*. Sage publications, 2007.

97. Creswell JW. *Research design: Qualitative, quantitative, and mixed methods approaches*. Sage publications, 2013.

98. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nurs Health Sci* 2013; 15: 398–405.

99. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.

100. Bauer MW. Classical content analysis: A review. In: Bauer MW, Gaskell G (eds) *Qualitative researching with text, image and sound*. London: SAGE Publications Ltd, 2000, pp. 131–151.

101. World Health Organization. *Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services*. Geneva: World Health Organization, 2018.

102. Petek Šter M, Švab I, Živčec Kalan G. Factors related to consultation time: Experience in Slovenia. *Scand J Prim Health Care* 2008; 26: 29–34.

103. Zinckernagel L, Schneekloth N, Zwisler A-DO, et al. How to measure experiences of healthcare quality in Denmark among patients with heart disease? The development and psychometric evaluation of a patient-reported instrument. *BMJ Open* 2017; 7: e016234.

104. Jerant A, Fenton JJ, Kravitz RL, et al. Association of clinician denial of patient requests with patient satisfaction. *JAMA Intern Med* 2018; 178: 85–91.

105. Farley H, Enguidanos ER, Coletti CM, et al. Patient satisfaction surveys and quality of care: an information paper. *Ann Emerg Med* 2014; 64: 351–357.

106. Kennedy GD, Tevis SE, Kent KC. Is there a relationship between patient satisfaction and favorable outcomes? *Ann Surg* 2014; 260: 592–600.

107. Lyu H, Wick EC, Housman M, et al. Patient satisfaction as a possible indicator of quality

surgical care. *JAMA Surg* 2013; 148: 362–367.

108. Ishikawa H, Yano E. Patient health literacy and participation in the health-care process. *Heal Expect* 2008; 11: 113–122.

109. Brown S, Shoveller J, Chabot C, et al. Risk, resistance and the neoliberal agenda: young people, health and well-being in the UK, Canada and Australia. *Health Risk Soc* 2013; 15: 333–346.

110. Teghtsoonian K. Depression and mental health in neoliberal times: A critical analysis of policy and discourse. *Soc Sci Med* 2009; 69: 28–35.

111. Alexander SA, Coveney J. A critical discourse analysis of Canadian and Australian public health recommendations promoting physical activity to children. *Heal Sociol Rev* 2013; 22: 353–364.

112. Canadian Institute for Health Information. International Comparisons — Access to Care. *OECD Interactive Tool*, https://www.cihi.ca/en/oecd-interactive-tool-international-comparisons-access-to-care (2019, accessed 26 November 2019).

113. Canadian Institure for Health Information. International Comparisons — Patient Safety. *OECD Interactive Tool*, https://www.cihi.ca/en/oecd-interactive-tool-international-comparisons-patient-safety (2019, accessed 26 November 2019).

114. Weissman JS, Rothschild JM, Bendavid E, et al. Hospital Workload and Adverse Events. *Med Care* 2007; 45: 448–455.

115. Montgomery VL. Effect of fatigue, workload, and environment on patient safety in the pediatric intensive care unit. *Pediatr Crit Care Med* 2007; 8: S11–S16.

116. Tummers L, Bekkers V, Steijn B. Policy Alienation of Public Professionals. *Public Manag Rev* 2009; 11: 685–706.

117. Marchildon GP, Hutchison B. Primary care in Ontario, Canada: New proposals after 15 years of reform. *Health Policy (New York)* 2016; 120: 732–738.

118. Tjepkema M, Wilkins R, Long A. Cause-specific mortality by education in Canada: a 16-year follow-up study. *Heal Reports* 2012; 23: 23–32.

119. Greenwood M, de Leeuw S, Lindsay N. Challenges in health equity for Indigenous peoples in Canada. *Lancet* 2018; 391: 1645–1648.

120. Tjepkema M, Wilkins R, Long A. Cause-specific mortality by income adequacy in Canada: A 16-year follow-up study. *Heal Reports* 2013; 24: 14–22.

121. Mitra D, Shaw A, Tjepkema M, et al. Social determinants of lung cancer incidence in Canada: a 13-year prospective study. *Heal Reports* 2015; 26: 12–20.

122. Matheson FI, LaFreniere MC, White HL, et al. Influence of neighborhood deprivation, gender and ethno-racial origin on smoking behavior of Canadian youth. *Prev Med (Baltim)* 2011; 52: 376–380.

123. Oliver LN, Hayes M V. Effects of neighbourhood income on reported body mass index: an eight year longitudinal study of Canadian children. *BMC Public Health* 2008; 8: 16.

124. Matheson FI, Moineddin R, Dunn JR, et al. Urban neighborhoods, chronic stress, gender and depression. *Soc Sci Med* 2006; 63: 2604–2616.

125. Gayle A. Sulik AE-K. No longer a patient: The social construction of the medical consumer. In: Astrid E-K, Chambré SM, Goldner M (eds) *Patients, Consumers and Civil Society*. Emerald Group Publishing Limited, pp. 3–28.

126. Veinot T. Power to the Patient? A Critical Examination of Patient Empowerment Discourses. In: Harris R, Wathen N, Wyatt S (eds) *Configuring Health Consumers: Health Work and the Imperative of Personal Responsibility*. London: Palgrave Macmillan UK, pp. 30–41.

127. Calnan M. Eliot Freidson: Sociological Narratives of Professionalism and Modern Medicine. In: Collyer F (ed) *The Palgrave Handbook of Social Theory in Health, Illness and Medicine*. London: Palgrave Macmillan UK, pp. 287–305.

128. Coburn D, Willis E. The medical profession: knowledge, power and autonomy. In: Albrecht GL, Fitzpatrick R, Scrimshaw SC (eds) *Handbook of social studies in health and medicine*. London: SAGE Publications Ltd, 2000, pp. 377–393.

129. Cockerham WC, Rütten A, Abel T. CONCEPTUALIZING CONTEMPORARY

HEALTH LIFESTYLES: *Sociol Q* 1997; 38: 321–342.

130. Cockerham WC. Health Lifestyle Theory and the Convergence of Agency and Structure. *J Health Soc Behav* 2005; 46: 51–67.

131. Weber M, Tribe K. *Economy and society. a new translation*. 2019.

132. Ritzer G. Professionalization, Bureaucratization and Rationalization: The Views of Max Weber. *Soc Forces* 1975; 53: 627–634.

133. Cockerham WC. Max Weber: bureaucracy, formal rationality and the modern hospital. In: Collyer F (ed) *The Palgrave handbook of social theory in health, illness and medicine*. Springer, 2015, pp. 124–138.

134. Lincoln YS, Guba EG. *Naturalistic inquiry*. Beverly Hills, Calif.: Sage Publications, 1985.

135. Ballinger C. Demonstrating Rigour and Quality? In: Finlay L, Ballinger C (eds) *Qualitative research for allied health professionals: challenging choices*. John Wiley & Sons, 2006, pp. 235–246.

136. Ravenek MJ, Rudman DL. Bridging conceptions of quality in moments of qualitative research. *Int J Qual Methods* 2013; 12: 436–456.

137. Guba EG, Lincoln YS. Competing paradigms in qualitative research. In: Denzin NK, Lincoln YS (eds) *Handbook of qualitative research*. Sage, Thousand Oaks, CA, 1994, pp. 105–117.

138. Finlay L. Mapping methodology. In: Finlay L, Ballinger C (eds) *Qualitative research for allied health professionals: challenging choices*. John Wiley & Sons, 2006, pp. 9–29.

References of Chapter 4

1. Kaplan AM. Social Media, Definition, and History BT - Encyclopedia of Social Network Analysis and Mining. In: Alhajj R, Rokne J (eds). New York, NY: Springer New York, pp. 2662–2665.

2. Saxton GD, Anker AE. The Aggregate Effects of Decentralized Knowledge Production:

Financial Bloggers and Information Asymmetries in the Stock Market. *J Commun* 2013; 63: 1054–1069.

3. Valentini C. Is using social media "good" for the public relations profession? A critical reflection. *Public Relat Rev* 2015; 41: 170–177.

4. Paul MJ, Dredze M. You are what you tweet: Analyzing twitter for public health. In: *Fifth International AAAI Conference on Weblogs and Social Media*. 2011.

5. Hagg E, Dahinten VS, Currie LM. The emerging use of social media for health-related purposes in low and middle-income countries: A scoping review. *Int J Med Inform* 2018; 115: 92–105.

6. Al-Busaidi IS, Anderson TJ, Alamri Y. Qualitative analysis of Parkinson's disease information on social media: the case of YouTube^{TM}. *EPMA J* 2017; 8: 273–277.

7. Syed-Abdul S, Fernandez-Luque L, Jian W-S, et al. Misleading Health-Related Information Promoted Through Video-Based Social Media: Anorexia on YouTube. *J Med Internet Res* 2013; 15: e30.

8. Welch V, Petkovic J, Pardo JP, et al. Interactive social media interventions to promote health equity: an overview of reviews. *Heal Promot chronic Dis Prev Canada Res policy Pract* 2016; 36: 63.

9. Hamm MP, Chisholm A, Shulhan J, et al. Social media use among patients and caregivers: a scoping review. *BMJ Open* 2013; 3: e002819.

10. Myneni S, Cobb NK, Cohen T. Finding meaning in social media: content-based social network analysis of QuitNet to identify new opportunities for health promotion. In: *MedInfo*. 2013, pp. 807–811.

11. Haodf. Home Page. *www.haodf.com*, www.haodf.com (accessed 4 March 2020).

12. Hanauer DA, Zheng K, Singer DC, et al. Public Awareness, Perception, and Use of Online Physician Rating Sites. *JAMA* 2014; 311: 734–735.

13. Schlesinger M, Grob R, Shaller D, et al. Taking patients' narratives about clinicians from anecdote to science. *N Engl J Med*.

14. Plowman KD, Wakefield RI, Winchel B. Digital publics: Tracking and reaching them. *Public Relat Rev* 2015; 41: 272–277.

15. Lee M, Youn S. Electronic word of mouth (eWOM). *Int J Advert* 2009; 28: 473–499.

16. Agency for Healthcare Research and Quality. *What Is Patient Experience?* Rockville, https://www.ahrq.gov/cahps/about-cahps/patient-experience/index.html (2017, accessed 15 May 2018).

17. Zakkar M. Patient experience: determinants and manifestations. *Int J Heal Gov* 2019; 24: 143–154.

18. Papanicolas I. International Frameworks for Health System Comparison1. In: Papanicolas I, Smith PC (eds) *Health System Performance Comparison: An Agenda for Policy, Information and Research*. Berkshire: Open University Press, 2013, pp. 31–74.

19. Manary MP, Boulding W, Staelin R, et al. The patient experience and health outcomes. *N Engl J Med* 2013; 368: 201–203.

20. Weldring T, Smith SMS. Article Commentary: Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs). *Heal Serv insights* 2013; 6: HSI-S11093.

21. Ziebland S, Coulter A. Introduction. In: Ziebland S, Coulter A, Calabrese JD, et al. (eds) *Understanding and using health experiences: improving patient care*. Oxford: Oxford University Press, 2013, pp. 1–5.

22. Health Quality Ontario. *Primary Care Patient Experience Survey*. Toronto, http://www.hqontario.ca/Portals/0/documents/qi/primary-care/primary-care-patient-experience-survey-en.pdf (2015).

23. Agency for Healthcare Research and Quality. CAHPS Clinician & Group Survey, https://www.ahrq.gov/cahps/surveys-guidance/cg/index.html (2016, accessed 2 October 2017).

24. Picker Institute. Questionnaire - Patient experiences of compassionate care, http://www.picker.org/tools-resources/toolkits/ (2017, accessed 2 October 2017).

25. Greaves F, Ramirez-Cano D, Millett C, et al. Harnessing the cloud of patient experience:

using social media to detect poor quality healthcare. *BMJ Qual Saf* 2013; 22: 251–255.

26. Liu X, Chen H. A research framework for pharmacovigilance in health social media: identification and evaluation of patient adverse drug event reports. *J Biomed Inform* 2015; 58: 268–279.

27. Seale C, Charteris-Black J, MacFarlane A, et al. Interviews and Internet Forums: A Comparison of Two Sources of Qualitative Data. *Qual Health Res* 2009; 20: 595–606.

28. Baccarella C V, Wagner TF, Kietzmann JH, et al. Social media? It's serious! Understanding the dark side of social media. *Eur Manag J* 2018; 36: 431–438.

29. Kaganer EA, Vaast E. Responding to the (almost) unknown: Social representations and corporate policies of social media. In: *ICIS*. 2010, p. 163.

30. Pillow MT, Hopson L, Bond M, et al. Social media guidelines and best practices: recommendations from the Council of Residency Directors Social Media Task Force. *West J Emerg Med* 2014; 15: 26–30.

31. Gholami-Kordkheili F, Wild V, Strech D. The impact of social media on medical professionalism: a systematic qualitative review of challenges and opportunities. *J Med Internet Res* 2013; 15: e184–e184.

32. Khan GF, Swar B, Lee SK. Social Media Risks and Benefits: A Public Sector Perspective. *Soc Sci Comput Rev* 2014; 32: 606–627.

33. Chretien KC, Tuck MG. Online professionalism: A synthetic review. *Int Rev Psychiatry* 2015; 27: 106–117.

34. Pekka A. Social media, reputation risk and ambient publicity management. *Strateg Leadersh* 2010; 38: 43–49.

35. Sánchez Abril P, Levin A, Del Riego A. Blurred Boundaries: Social Media Privacy and the Twenty-First-Century Employee. *Am Bus Law J* 2012; 49: 63–124.

36. Van Looy A. *Social media management*. Springer International Publishing, 2016.

37. Rokka J, Karlsson K, Tienari J. Balancing acts: Managing employees and reputation in social media. *J Mark Manag* 2014; 30: 802–827.

38. Studwell R. The Notion and Practice of Reputation and Professional Identity in Social Networking: From K-12 through Law School . *Kansas J Law Public Policy*; 225–272.

39. College of Physicians and Surgeons Of Ontario. Social Media — Appropriate Use by Physicians, https://www.cpso.on.ca/Physicians/Policies-Guidance/Statements-Positions/Social-Media-Appropriate-Use-by-Physicians (2013).

40. International Nurse Regulators Collaborative. *Social Media Use: Common Expectations for Nurses*, http://www.cno.org/globalassets/docs/prac/incr-social-media-use-common-expectations-for-nurses.pdf (2016).

41. Creswell JW. *Qualitative inquiry and research design: Choosing among five approaches*. Sage publications, 2007.

42. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.

43. Creswell JW. *Research design: Qualitative, quantitative, and mixed methods approaches*. Sage publications, 2013.

44. Health Quality Ontario. *Ontario Patient Experience Measurement Strategy*. Toronto, https://www.hqontario.ca/Portals/0/documents/system-performance/patient-experience-measurement-strategy-1608-en.pdf (2016).

45. Aday LA, Cornelius LJ. *Designing and conducting health surveys: a comprehensive guide*. San Francisco: John Wiley & Sons, 2006.

46. Dillman DA, Smyth JD, Christian LM. *Internet, phone, mail, and mixed-mode surveys: the tailored design method*. 4th ed. Hoboken,: John Wiley & Sons, 2014.

47. Graham C, Woods P. Patient experience surveys. In: Ziebland S, Coulter A, Calabrese JD, et al. (eds) *Understanding and Using Health Experiences: Improving patient care*. Oxford: Oxford University Press, 2013, pp. 81–93.

48. Streiner DL, Norman GR, Cairney J. *Health measurement scales: a practical guide to their development and use*. Oxford: Oxford University Press, USA, 2015.

49. Sitzia J, Wood N. Patient satisfaction: a review of issues and concepts. *Soc Sci Med* 1997;

45: 1829–1843.

50. Lavrakas PJ. Nonresponse. *Encyclopedia of survey research methods*. Epub ahead of print 2008. DOI: https://dx.doi.org/10.4135/9781412963947.n339.

51. Perneger T V, Chamot E, Bovier PA. Nonresponse bias in a survey of patient perceptions of hospital care. *Med Care* 2005; 43: 374–380.

52. Robert G, Cornwell J. Rethinking policy approaches to measuring and improving patient experience.

53. Flott KM, Graham C, Darzi A, et al. Can we use patient-reported feedback to drive change? The challenges of using patient-reported feedback and how they might be addressed. *BMJ Qual Saf* 2017; 26: 502–507.

54. Sheard L, Peacock R, Marsh C, et al. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study. *Heal Expect* 2018; 22: 46–53.

55. Coulter A. Understanding the experience of illness and treatment. In: Ziebland S, Coulter A, Calabrese JD, et al. (eds) *Understanding and Using Health Experiences: Improving patient care*. Oxford: Oxford University Press, 2013, pp. 6–15.

56. Kleinman A. *The illness narratives: suffering, healing, and the human condition.* New York: Basic books, 1988.

57. Valentine NB, de Silva A, Kawabata K, et al. Health system responsiveness: concepts, domains and operationalization. In: Murray CJL, Evans DB (eds) *Health systems performance assessment: debates, methods and empiricism*. Geneva: World Health Organization, 2003, pp. 573–596.

58. Beattie M, Murphy DJ, Atherton I, et al. Instruments to measure patient experience of healthcare quality in hospitals: a systematic review. *Syst Rev* 2015; 4: 97.

59. Wong ST, Johnston S, Burge F, et al. Measuring Patient Experiences: Is It Meaningful and Actionable? *Healthc Pap* 2017; 17: 22–29.

60. Gleeson H, Calderon A, Swami V, et al. Systematic review of approaches to using patient

experience data for quality improvement in healthcare settings. *BMJ Open* 2016; 6: e011907.

61. Thackeray R, Crookston BT, West JH. Correlates of health-related social media use among adults. *J Med Internet Res*; 15.

62. Griffiths A, Leaver MP. Wisdom of patients: predicting the quality of care using aggregated patient feedback. *BMJ Qual Saf* 2017; 27: 110–118.

63. Eaneff S, Wang V, Hanger M, et al. Patient perspectives on neuromyelitis optica spectrum disorders: data from the PatientsLikeMe online community. *Mult Scler Relat Disord* 2017; 17: 116–122.

64. Frost J, Okun S, Vaughan T, et al. Patient-reported outcomes as a source of evidence in off-label prescribing: analysis of data from PatientsLikeMe. *J Med Internet Res*; 13.

65. Ru B, Harris K, Yao L. A content analysis of patient-reported medication outcomes on social media. In: *2015 IEEE International Conference on Data Mining Workshop (ICDMW)*. IEEE, 2015, pp. 472–479.

66. The Council on Ethical and Judicial Affairs. *Professionalism in the Use of Social Media*. Chicago, https://www.ama-assn.org/sites/ama-assn.org/files/corp/media-browser/public/about-ama/councils/Council Reports/council-on-ethics-and-judicial-affairs/i10-ceja-professionalism-use-social-media.pdf (2010).

67. Ethics and Professionalism Committee. *Social Media and Electronic Communications*. Euless, http://www.fsmb.org/siteassets/advocacy/policies/social-media-and-electronic-communications.pdf (2019).

68. Canadian Institute for Health Information. International Comparisons — Access to Care. *OECD Interactive Tool*, https://www.cihi.ca/en/oecd-interactive-tool-international-comparisons-access-to-care (2019, accessed 26 November 2019).

69. Fyfe T, Akins R, Cheifetz C, et al. Regional Medical Campuses in Canada and the United States: A Systematic Review. *J Reg Med Campuses*; 1.

70. Mergel I. *Social media in the public sector: A guide to participation, collaboration and*

transparency in the networked world. San Francisco: John Wiley & Sons, 2013.

71. Kuikka M, Äkkinen M. Determining the challenges of organizational social media adoption and use. In: *ECIS*. 2011, p. 248.

72. Sharif MHM, Troshani I, Davidson R. Public Sector Adoption of Social Media. *J Comput Inf Syst* 2015; 55: 53–61.

73. McDonald L, Malcolm B, Ramagopalan S, et al. Real-world data and the patient perspective: the PROmise of social media? *BMC Med* 2019; 17: 11.

74. Kim AJ, Johnson KKP. Power of consumers using social media: Examining the influences of brand-related user-generated content on Facebook. *Comput Human Behav* 2016; 58: 98–108.

75. Shan Y. How credible are online product reviews? The effects of self-generated and system-generated cues on source credibility evaluation. *Comput Human Behav* 2016; 55: 633–641.

76. Hu N, Pavlou PA, Zhang JJ. Why do online product reviews have a J-shaped distribution? Overcoming biases in online word-of-mouth communication. *Commun ACM* 2009; 52: 144–147.

77. Swidler A. Cultural Power and Social Movements. In: Johnston H, Klandermans B (eds) *Social movements and culture*. Minneapolis: Univ. of Minnesota Press, 1995.

78. Swidler A. Culture in Action: Symbols and Strategies. *Am Sociol Rev* 1986; 51: 273–286.

79. Ritzer G. Professionalization, Bureaucratization and Rationalization: The Views of Max Weber. *Soc Forces* 1975; 53: 627–634.

References of Chapter 5

1. Kaplan AM. Social Media, Definition, and History BT - Encyclopedia of Social Network Analysis and Mining. In: Alhajj R, Rokne J (eds). New York, NY: Springer New York, pp. 2662–2665.

2. McCay-Peet L, Quan-Haase A. What is Social Media and What Questions Can Social Media Research Help Us Answer? In: *The SAGE handbook of social media research methods*. 55 City Road: SAGE Publications Ltd. Epub ahead of print 2017. DOI: 10.4135/9781473983847.

3. Papacharissi Z. We Have Always Been Social. *Soc Media + Soc*; 1. Epub ahead of print 1 April 2015. DOI: 10.1177/2056305115581185.

4. Hagg E, Dahinten VS, Currie LM. The emerging use of social media for health-related purposes in low and middle-income countries: A scoping review. *Int J Med Inform* 2018; 115: 92–105.

5. Antheunis ML, Tates K, Nieboer TE. Patients' and health professionals' use of social media in health care: Motives, barriers and expectations. *Patient Educ Couns* 2013; 92: 426–431.

6. Hamm MP, Chisholm A, Shulhan J, et al. Social media use among patients and caregivers: a scoping review. *BMJ Open* 2013; 3: e002819.

7. Smailhodzic E, Hooijsma W, Boonstra A, et al. Social media use in healthcare: A systematic review of effects on patients and on their relationship with healthcare professionals. *BMC Health Serv Res* 2016; 16: 442.

8. Moorhead SA, Hazlett DE, Harrison L, et al. A New Dimension of Health Care: Systematic Review of the Uses, Benefits, and Limitations of Social Media for Health Communication. *J Med Internet Res* 2013; 15: e85.

9. Schlesinger M, Grob R, Shaller D, et al. Taking patients' narratives about clinicians from anecdote to science. *N Engl J Med*.

10. Greaves F, Ramirez-Cano D, Millett C, et al. Harnessing the cloud of patient experience: using social media to detect poor quality healthcare. *BMJ Qual Saf* 2013; 22: 251–255.

11. Liu X, Chen H. A research framework for pharmacovigilance in health social media: identification and evaluation of patient adverse drug event reports. *J Biomed Inform* 2015; 58: 268–279.

12. RateMds. Doctor Reviews and Ratings - Find a Doctor at RateMDs, https://www.ratemds.com/on/toronto/ (2020, accessed 8 February 2020).

13. Haodf. Home Page. *www.haodf.com*, www.haodf.com (accessed 4 March 2020).

14. Hanauer DA, Zheng K, Singer DC, et al. Public Awareness, Perception, and Use of Online Physician Rating Sites. *JAMA* 2014; 311: 734–735.

15. Cooper DF, Grey S, Raymond G, et al. *Project risk management guidelines : managing risk in large projects and complex procurements*. West Sussex, England: John Wiley & Sons Ltd, 2005.

16. Pillow MT, Hopson L, Bond M, et al. Social media guidelines and best practices: recommendations from the Council of Residency Directors Social Media Task Force. *West J Emerg Med* 2014; 15: 26–30.

17. Braun R, Esswein W. Towards a Conceptualization of Corporate Risks in Online Social Networks: A Literature Based Overview of Risks. In: *2013 17th IEEE International Enterprise Distributed Object Computing Conference*. 2013, pp. 267–274.

18. Khan GF, Swar B, Lee SK. Social Media Risks and Benefits: A Public Sector Perspective. *Soc Sci Comput Rev* 2014; 32: 606–627.

19. LDCP Social Media & Technology Team. *Social Media Toolkit for Ontario Public Health Units*, https://www.publichealthontario.ca/-/media/documents/ldcp-social-media-toolkit.pdf?la=en (2014).

20. Zakkar M, Sedig K. Interactive visualization of public health indicators to support policymaking: An exploratory study. *Online J Public Health Inform* 2017; 9: e190–e190.

21. Chretien KC, Tuck MG. Online professionalism: A synthetic review. *Int Rev Psychiatry* 2015; 27: 106–117.

22. Canadian Institutes of Health Research, Canada NS and ERC of, Social Sciences and Humanities Research Council of Canada. *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.* 2014.

23. Barth S, de Jong MDT, Junger M, et al. Putting the privacy paradox to the test: Online

privacy and security behaviors among users with technical knowledge, privacy awareness, and financial resources. *Telemat Informatics* 2019; 41: 55–69.

24. Zangerle E, Specht G. 'Sorry, I Was Hacked': A Classification of Compromised Twitter Accounts. In: *Proceedings of the 29th Annual ACM Symposium on Applied Computing*. New York, NY, USA: ACM, pp. 587–593.

25. Pekka A. Social media, reputation risk and ambient publicity management. *Strateg Leadersh* 2010; 38: 43–49.

26. Sánchez Abril P, Levin A, Del Riego A. Blurred Boundaries: Social Media Privacy and the Twenty-First-Century Employee. *Am Bus Law J* 2012; 49: 63–124.

27. Van Looy A. *Social media management*. Springer International Publishing, 2016.

28. Rokka J, Karlsson K, Tienari J. Balancing acts: Managing employees and reputation in social media. *J Mark Manag* 2014; 30: 802–827.

29. Gholami-Kordkheili F, Wild V, Strech D. The impact of social media on medical professionalism: a systematic qualitative review of challenges and opportunities. *J Med Internet Res* 2013; 15: e184–e184.

30. British Medical Association. Bridging the Gap Between Theory and Practice: The BMA's Approach to Medical Ethics. *Medical Ethics Today The BMA's Handbook of Ethics and Law* 2012; 1–19.

31. HIPAA Journal. Texas Nurse Fired for Social Media HIPAA Violation. *HIPAA Journal*, 2018, https://www.hipaajournal.com/texas-nurse-fired-for-social-media-hipaa-violation/ (2018).

32. College of Physicians and Surgeons Of Ontario. *The Practice Guide - Medical Professionalism and College Policies*. Toronto, https://www.cpso.on.ca/Physicians/Policies-Guidance/Practice-Guide (2007).

33. College of Nurses of Ontario. Confidentiality and Privacy — Personal Health Information, http://www.cno.org/globalassets/docs/prac/41069_privacy.pdf (2019, accessed 6 September 2019).

34. Doel M, Allmark P, Conway P, et al. Professional Boundaries: Crossing a Line or Entering the Shadows? *Br J Soc Work* 2010; 40: 1866–1889.

35. Gabbard GO, Nadelson C. Professional Boundaries in the Physician-Patient Relationship. *JAMA* 1995; 273: 1445–1449.

36. Peternelj-Taylor CA, Yonge O. Exploring Boundaries in the Nurse-Client Relationship: Professional Roles and Responsibilities. *Perspect Psychiatr Care* 2003; 39: 55–66.

37. College of Physicians and Surgeons of Ontario. *Maintaining Appropriate Boundaries and Preventing Sexual Abuse*. Toronto, https://www.cpso.on.ca/Physicians/Policies-Guidance/Policies/Maintaining-Appropriate-Boundaries-and-Preventing (2018).

38. College of Nurses of Ontario. *Code of Conduct*. Toronto, http://www.cno.org/globalassets/docs/prac/49040_code-of-conduct.pdf (2019).

39. Steinecke R. *The Jurisprudence Handbook for Dietitians in Ontario*. Toronto, https://www.collegeofdietitians.org/resources/publications-cdo/jurisprudence-handbook-for-dietitians-in-ontario-(.aspx (2015).

40. Roberts LM. Changing Faces: Professional Image Construction in Diverse Organizational Settings. *Acad Manag Rev* 2005; 30: 685–711.

41. Cohen D. *Social Media and Dietetic Practice*. Toronto, https://www.collegeofdietitians.org/resources/professional-practice/social-media/social-media-and-dietetic-practice-(2013).aspx (2013).

42. Chatalalsingh C. *Professional Communications Online and on Social Media*. Toronto, https://www.collegeofdietitians.org/resources/professional-practice/social-media/professionalcommunications.aspx (2016).

43. Wong CA, Merchant RM, Moreno MA. Using social media to engage adolescents and young adults with their health. *Healthcare* 2014; 2: 220–224.

44. Mandana V. The impact of health communication on health-related decision making: A review of evidence. *Health Educ* 2007; 107: 27–41.

45. Nguyen A, Mosadeghi S, Almario C V. Persistent digital divide in access to and use of the

Internet as a resource for health information: Results from a California population-based study. *Int J Med Inform* 2017; 103: 49–54.

46. The Canadian Medical Protective Association. *Social media: The opportunities, the realities*. Ottawa, https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2014/social-media-the-opportunities-the-realities (2014).

47. Maciura J, Wade A. How Off-Duty Use of Social Media May Lead to Professional Discipline. *J Nurs Regul* 2019; 9: 31–33.

48. The Council on Ethical and Judicial Affairs. *Professionalism in the Use of Social Media*. Chicago, https://www.ama-assn.org/sites/ama-assn.org/files/corp/media-browser/public/about-ama/councils/Council Reports/council-on-ethics-and-judicial-affairs/i10-ceja-professionalism-use-social-media.pdf (2010).

49. Canadian Medical Association. *Social media and Canadian physicians: Issues and rules of engagement*. Ottawa, https://policybase.cma.ca/documents/policypdf/PD12-03.pdf (2011).

50. Lambert KM, Barry P, Stokes G. Risk management and legal issues with the use of social media in the healthcare setting. *J Healthc Risk Manag* 2012; 31: 41–47.

51. Hyman JL, Luks HJ, Sechrest R. Online Professional Networks for Physicians: Risk Management. *Clin Orthop Relat Res* 2012; 470: 1386–1392.

52. Kietzmann JH, Hermkens K, McCarthy IP, et al. Social media? Get serious! Understanding the functional building blocks of social media. *Bus Horiz* 2011; 54: 241–251.

53. Kaganer EA, Vaast E. Responding to the (almost) unknown: Social representations and corporate policies of social media. In: *ICIS*. 2010, p. 163.

54. Wagner W, Duveen G, Farr R, et al. Theory and Method of Social Representations. *Asian J Soc Psychol* 1999; 2: 95–125.

55. Moscovici S. Notes towards a description of Social Representations. *Eur J Soc Psychol* 1988; 18: 211–250.

56. College of Physicians and Surgeons Of Ontario. Social Media — Appropriate Use by Physicians, https://www.cpso.on.ca/Physicians/Policies-Guidance/Statements-Positions/Social-Media-Appropriate-Use-by-Physicians (2013).

57. College of Nurses of Ontario. Social Media: Reflect Before You Post, http://www.cno.org/en/learn-about-standards-guidelines/educational-tools/webcasts/social-media-reflect-before-you-post/ (2013, accessed 8 September 2019).

58. The College of Dietitians of Ontario. Pause Before You Post — A Learning Module, https://www.collegeofdietitians.org/resources/pages/pause-before-you-post.aspx (2013, accessed 9 September 2019).

59. Coffey A. Analysing Documents. In: Uwe Flick (ed) *The SAGE Handbook of Qualitative Data Analysis*. London: SAGE Publications Ltd, 2014. Epub ahead of print 2014. DOI: 10.4135/9781446282243.

60. Corbetta P. Social Research: Theory, Methods and Techniques. Epub ahead of print 2003. DOI: 10.4135/9781849209922.

61. Patton MQ. *Qualitative Research & Evaluation Methods*. 4th ed. Thousand Oaks: SAGE Publications, Inc, 2014.

62. College of Dietitians of Ontario. *Boundary Guidelines for Professional Therapeutic RD-Client Relationships*. Toronto, https://www.collegeofdietitians.org/resources/standards/boundaryguidelinesfinal-website-version.aspx (2017).

63. International Nurse Regulators Collaborative. *Social Media Use: Common Expectations for Nurses*, http://www.cno.org/globalassets/docs/prac/incr-social-media-use-common-expectations-for-nurses.pdf (2016).

64. College of Nurses of Ontario. Should you accept a patient’s friend request on social media?, http://www.cno.org/en/learn-about-standards-guidelines/magazines-newsletters/the-standard/april-2019/Should-you-accept-a-patient-friend-request-on-social-media/ (2019, accessed 6 September 2019).

65. College of Nurses of Ontario. *Professional Standards*. Toronto,

http://www.cno.org/globalassets/docs/prac/41006_profstds.pdf (2018).

66. College of Nurses of Ontario. *Ethics*. Toronto, https://www.cno.org/globalassets/docs/prac/41034_ethics.pdf (2019).

67. College of Physicians and Surgeons of Ontario. *Confidentiality of Personal Health Information*. Toronto, https://www.cpso.on.ca/admin/CPSO/media/Documents/physician/polices-and-guidance/policies/confidentiality-personal-health-information.pdf (2006).

68. College of Optometrists of Ontario. Guidelines for the Appropriate Use of Social Media by Optometrists, https://www.collegeoptom.on.ca/resources/news/180-guidelines-for-the-appropriate-use-of-social-media-by-optometrists/ (2013, accessed 9 September 2019).

69. Ottawa Hospital. *Social Media*. Ottawa, https://www.ottawahospital.on.ca/en/documents/2017/01/social-media-policy-en.pdf (2013).

70. Ottawa Hospital. *Guidelines for Social Media Participation*. Ottawa, https://www.ottawahospital.on.ca/en/documents/2017/01/guidelines-for-social-media-en-final.pdf/ (2017).

71. The Canadian Medical Protective Association. *Top 10 tips for using social media in professional practice*. Ottawa, https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2014/top-10-tips-for-using-social-media-in-professional-practice (2014).

72. The Canadian Medical Protective Association. *Online physician reviews: How to manage your virtual presence, and real reputation*. Ottawa, https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2019/online-physician-reviews-how-to-manage-your-virtual-presence-and-real-reputation (2019).

73. Faulkner J. *Social Media*. North Bay, https://www.myhealthunit.ca/en/about-us/resources/Policies-/Personnel-Policies/Social-Media---B-P-010.pdf (2017).

74. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs* 2008; 62: 107–115.

75. Mayring P. Qualitative content analysis. In: Flick U, Kardorff E von, Steinke I (eds) *A*

companion to qualitative research. London: SAGE publications, 2004, pp. 266–269.

76. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nurs Health Sci* 2013; 15: 398–405.

77. Baccarella C V, Wagner TF, Kietzmann JH, et al. Social media? It's serious! Understanding the dark side of social media. *Eur Manag J* 2018; 36: 431–438.

78. College of Nurses of Ontario. *Professional Conduct*. Toronto, https://www.cno.org/globalassets/docs/ih/42007_misconduct.pdf (2019).

79. Government of Ontario. Personal Health Information Protection Act. Sched. A, s. 29., Canada, https://www.ontario.ca/laws/statute/04p03 (2004).

80. Schoder D, Gloor PA, Metaxas PT. Social Media and Collective Intelligence—Ongoing and Future Research Streams. *KI - Künstliche Intelligenz* 2013; 27: 9–15.

81. Grajales III FJ, Sheps S, Ho K, et al. Social Media: A Review and Tutorial of Applications in Medicine and Health Care. *J Med Internet Res* 2014; 16: e13.

82. Ethics and Professionalism Committee. *Social Media and Electronic Communications*. Euless, http://www.fsmb.org/siteassets/advocacy/policies/social-media-and-electronic-communications.pdf (2019).

83. Ventola CL. Social media and health care professionals: benefits, risks, and best practices. *P T* 2014; 39: 491–520.

84. General Medical Council. Doctors' use of social media, https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/doctors-use-of-social-media (2013).

85. British Medical Association. Social media Practical guidance and best practice, https://www.bma.org.uk/-/media/files/pdfs/employment advice/ethics/social media guidance final.pdf (2018).

86. British Medical Association. Social media, ethics and professionalism - BMA guidance, https://www.bma.org.uk/advice/employment/ethics/social-media-guidance-for-doctors (2018).

87. Andersen KN, Medaglia R, Henriksen HZ. Social media in public health care: Impact domain propositions. *Gov Inf Q* 2012; 29: 462–469.

88. Griffiths A, Leaver MP. Wisdom of patients: predicting the quality of care using aggregated patient feedback. *BMJ Qual Saf* 2017; 27: 110–118.

89. Eaneff S, Wang V, Hanger M, et al. Patient perspectives on neuromyelitis optica spectrum disorders: data from the PatientsLikeMe online community. *Mult Scler Relat Disord* 2017; 17: 116–122.

90. Frost J, Okun S, Vaughan T, et al. Patient-reported outcomes as a source of evidence in off-label prescribing: analysis of data from PatientsLikeMe. *J Med Internet Res*; 13.

91. Ru B, Harris K, Yao L. A content analysis of patient-reported medication outcomes on social media. In: *2015 IEEE International Conference on Data Mining Workshop (ICDMW)*. IEEE, 2015, pp. 472–479.

92. Seale C, Charteris-Black J, MacFarlane A, et al. Interviews and Internet Forums: A Comparison of Two Sources of Qualitative Data. *Qual Health Res* 2009; 20: 595–606.

93. Ritzer G. Professionalization, Bureaucratization and Rationalization: The Views of Max Weber. *Soc Forces* 1975; 53: 627–634.

94. Turner BS. Outline of a Theory of Human Rights. *Sociology* 1993; 27: 489–512.

95. Starr P. *The social transformation of American medicine*. 1st ed. New York: Basic Books, 1982.

96. Buse K, Mays N, Walt G. *Making health policy*. McGraw-Hill Education (UK), 2012.

References of Chapter 6

1. Kaplan AM. Social Media, Definition, and History BT - Encyclopedia of Social Network Analysis and Mining. In: Alhajj R, Rokne J (eds). New York, NY: Springer New York, pp. 2662–2665.

2. Mayer MA, Fernández-Luque L, Leis A. Big Data For Health Through Social Media. In:

Participatory Health Through Social Media. Elsevier, 2016, pp. 67–82.

3. McCay-Peet L, Quan-Haase A. What is Social Media and What Questions Can Social Media Research Help Us Answer? In: *The SAGE handbook of social media research methods*. 55 City Road: SAGE Publications Ltd. Epub ahead of print 2017. DOI: 10.4135/9781473983847.

4. Antheunis ML, Tates K, Nieboer TE. Patients' and health professionals' use of social media in health care: Motives, barriers and expectations. *Patient Educ Couns* 2013; 92: 426–431.

5. Hagg E, Dahinten VS, Currie LM. The emerging use of social media for health-related purposes in low and middle-income countries: A scoping review. *Int J Med Inform* 2018; 115: 92–105.

6. Hamm MP, Chisholm A, Shulhan J, et al. Social media use among patients and caregivers: a scoping review. *BMJ Open* 2013; 3: e002819.

7. Törnberg A, Törnberg P. Muslims in social media discourse: Combining topic modeling and critical discourse analysis. *Discourse, Context Media* 2016; 13: 132–142.

8. Miner G, Elder IV J, Fast A, et al. *Practical text mining and statistical analysis for non-structured text data applications*. Academic Press, 2012.

9. Velasco E, Agheneza T, Denecke K, et al. Social media and Internet-Based data in global systems for public health surveillance: A systematic review. *Milbank Q* 2014; 92: 7–33.

10. Agency for Healthcare Research and Quality. *What Is Patient Experience?* Rockville, https://www.ahrq.gov/cahps/about-cahps/patient-experience/index.html (2017, accessed 15 May 2018).

11. Kietzmann J, Canhoto A. Bittersweet! Understanding and Managing Electronic Word of Mouth. *J Public Aff* 2013; 13: 146–159.

12. Schlesinger M, Grob R, Shaller D, et al. Taking patients' narratives about clinicians from anecdote to science. *N Engl J Med*.

13. Greaves F, Ramirez-Cano D, Millett C, et al. Harnessing the cloud of patient experience:

using social media to detect poor quality healthcare. *BMJ Qual Saf* 2013; 22: 251–255.

14. Liu X, Chen H. A research framework for pharmacovigilance in health social media: identification and evaluation of patient adverse drug event reports. *J Biomed Inform* 2015; 58: 268–279.

15. Haodf. Home Page. *www.haodf.com*, www.haodf.com (accessed 4 March 2020).

16. Zakkar M. Patient experience: determinants and manifestations. *Int J Heal Gov* 2019; 24: 143–154.

17. Institute of Medicine. *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: Institute of Medicine, 2001.

18. LaVela SL, Gallan A. Evaluation and measurement of patient experience. *Patient Exp J* 2014; 1: 28–36.

19. Jurafsky D, Martin JH. *Speech and language processing*. draft (3rd. Previosuly published by Pearson., https://web.stanford.edu/~jurafsky/slp3/ (2018).

20. Lane H, Howard C, Hapke HM. *Natural language processing in action : understanding, analyzing, and generating text with Python*. Shelter Island: Manning, 2019.

21. Blei DM. Probabilistic Topic Models. *Commun ACM* 2012; 55: 77–84.

22. Chen C, Ren J. Forum latent Dirichlet allocation for user interest discovery. *Knowledge-Based Syst* 2017; 126: 1–7.

23. Myneni S, Cobb NK, Cohen T. Finding meaning in social media: content-based social network analysis of QuitNet to identify new opportunities for health promotion. In: *MedInfo*. 2013, pp. 807–811.

24. Kim EH-J, Jeong YK, Kim Y, et al. Topic-based content and sentiment analysis of Ebola virus on Twitter and in the news. *J Inf Sci* 2015; 42: 763–781.

25. Chen AT, Zhu S-H, Conway M. What online communities can tell us about electronic cigarettes and hookah use: a study using text mining and visualization techniques. *J Med Internet Res*; 17.

26. Pang B, Lee L. Opinion Mining and Sentiment Analysis. *Found Trends® Inf Retr* 2008; 2: 1–135.

27. Oxford Dictionaries. Sentiment. *Lexico*, https://www.lexico.com/definition/sentiment (2020).

28. Piryani R, Gupta V, Singh VK, et al. A Linguistic Rule-Based Approach for Aspect-Level Sentiment Analysis of Movie Reviews BT - Advances in Computer and Computational Sciences. In: Bhatia SK, Mishra KK, Tiwari S, et al. (eds). Singapore: Springer Singapore, 2017, pp. 201–209.

29. Hutto CJ, Gilbert E. Vader: A parsimonious rule-based model for sentiment analysis of social media text. In: *Eighth international AAAI conference on weblogs and social media*. 2014.

30. Rehurek R, Sojka P. Software Framework for Topic Modelling with Large Corpora. In: *Proceedings of the LREC 2010 Workshop on New Challenges for NLP Frameworks*. Valletta, Malta: ELRA, 2010, pp. 45–50.

31. Manning CD, Raghavan P, Schutze H. *An introduction to information retrieval*. Cambridge: Cambridge University Press, 2008.

32. Sarkar D. *Text analytics with Python: a practitioner's guide to natural language processing*. Berkeley: Apress, 2019.

33. Srivastava AN, Sahami M. *Text mining: Classification, clustering, and applications*. New York: Chapman and Hall/CRC, 2009.

34. Newman D, Lau JH, Grieser K, et al. Automatic Evaluation of Topic Coherence. In: *Human Language Technologies: The 2010 Annual Conference of the North American Chapter of the Association for Computational Linguistics*. USA: Association for Computational Linguistics, 2010, pp. 100–108.

35. Aletras N, Stevenson M. Evaluating topic coherence using distributional semantics. In: *Proceedings of the 10th International Conference on Computational Semantics (IWCS 2013)–Long Papers*. 2013, pp. 13–22.

36. Röder M, Both A, Hinneburg A. Exploring the Space of Topic Coherence Measures. In: *Proceedings of the Eighth ACM International Conference on Web Search and Data Mining*. New York, NY, USA: Association for Computing Machinery, pp. 399–408.

37. Nguyen T, Duong T, Venkatesh S, et al. Autism Blogs: Expressed Emotion, Language Styles and Concerns in Personal and Community Settings. *IEEE Trans Affect Comput* 2015; 6: 312–323.

38. Wang X, Zhang X, Jiang C, et al. Identification of fake reviews using semantic and behavioral features. In: *2018 4th International Conference on Information Management (ICIM)*. 2018, pp. 92–97.

39. Parimi R, Caragea D. Predicting Friendship Links in Social Networks Using a Topic Modeling Approach BT - Advances in Knowledge Discovery and Data Mining. In: Huang JZ, Cao L, Srivastava J (eds). Berlin, Heidelberg: Springer Berlin Heidelberg, 2011, pp. 75–86.

40. Sarkar S, Patel A, Madaan S, et al. Prediction of occupational accidents using decision tree approach. In: *2016 IEEE Annual India Conference (INDICON)*. 2016, pp. 1–6.

41. Bhan N, D'silva M. Sarcasmometer using sentiment analysis and topic modeling. In: *2017 International Conference on Advances in Computing, Communication and Control (ICAC3)*. 2017, pp. 1–7.

42. Wang X, Gerber MS, Brown DE. Automatic Crime Prediction Using Events Extracted from Twitter Posts BT - Social Computing, Behavioral - Cultural Modeling and Prediction. In: Yang SJ, Greenberg AM, Endsley M (eds). Berlin, Heidelberg: Springer Berlin Heidelberg, 2012, pp. 231–238.

43. Pawlowsky-Glahn V, Egozcue JJ. Compositional data and their analysis: an introduction. *Geol Soc London, Spec Publ* 2006; 264: 1–10.

44. Smith PF, Renner RM, Haslett SJ. Compositional data in neuroscience: If you've got it, log it! *J Neurosci Methods* 2016; 271: 154–159.

45. Midi H, Sarkar SK, Rana S. Collinearity diagnostics of binary logistic regression model. *J Interdiscip Math* 2010; 13: 253–267.

46. Montgomery DC, Peck EA, Vining GG. *Introduction to linear regression analysis*. 5th ed. New Jersey: John Wiley & Sons, 2012.

47. Roberts MJ, Hsiao W, Herman P, et al. *Getting health reform right : a guide to improving performance and equity*. New York: Oxford University Press, 2004.

48. European Union. The General Data Protection Regulation, https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=OJ:L:2016:119:FULL&from=EN (2016).

49. United Kingdom Government. Data Protection Act, http://www.legislation.gov.uk/ukpga/2018/12/contents/enacted (2018).

50. Johnson B. Social media and attributed digital content policy, https://www.england.nhs.uk/wp-content/uploads/2018/04/social-media-policy.pdf (2017).

51. Clinical Programmes and Patient Insight Analytical Unit. *Statement of Methodology for the Overall Patient Experience Scores (Statistics*, https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2018/11/Methods-statement_2018Nov_Update.pdf (2018).

52. Graham B, Endacott R, Smith JE, et al. 'They do not care how much you know until they know how much you care': a qualitative meta-synthesis of patient experience in the emergency department. *Emerg Med J* 2019; 36: 355 LP – 363.

53. National Academies of Sciences and Medicine E. *Crossing the Global Quality Chasm: Improving Health Care Worldwide*. Washington, DC: The National Academies Press. Epub ahead of print 2018. DOI: 10.17226/25152.

54. Donabedian A. *An introduction to quality assurance in health care*. New York: Oxford University Press, 2002.

55. World Health Organization. Framework on integrated, people-centred health services. Report by the Secretariat. *WHO, Geneva. Retrieved from www.who.int/servicedeliverysafety/areas/people-centred-care/en/on*; 18.

56. World Health Organization. *Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health*

services. Geneva: World Health Organization, 2018.

57. World Health Organization. *The world health report 2000: health systems: improving performance*. Geneva: World Health Organization, 2000.

58. Valentine NB, de Silva A, Kawabata K, et al. Health system responsiveness: concepts, domains and operationalization. In: Murray CJL, Evans DB (eds) *Health systems performance assessment: debates, methods and empiricism*. Geneva: World Health Organization, 2003, pp. 573–596.

59. Agency for Healthcare Research and Quality. CAHPS Clinician & Group Survey, https://www.ahrq.gov/cahps/surveys-guidance/cg/index.html (2016, accessed 2 October 2017).

60. The Centers for Medicare & Medicaid Services. CAHPS for Hospital, http://www.hcahpsonline.org/en/survey-instruments/ (2017, accessed 2 October 2017).

61. Picker Institute. Questionnaire - Patient experiences of compassionate care, http://www.picker.org/tools-resources/toolkits/ (2017, accessed 2 October 2017).

62. Health Quality Ontario. *Primary Care Patient Experience Survey*. Toronto, http://www.hqontario.ca/Portals/0/documents/qi/primary-care/primary-care-patient-experience-survey-en.pdf (2015).

63. Beattie M, Murphy DJ, Atherton I, et al. Instruments to measure patient experience of healthcare quality in hospitals: a systematic review. *Syst Rev* 2015; 4: 97.

64. Sitzia J, Wood N. Patient satisfaction: a review of issues and concepts. *Soc Sci Med* 1997; 45: 1829–1843.

65. Wong ST, Johnston S, Burge F, et al. Measuring Patient Experiences: Is It Meaningful and Actionable? *Healthc Pap* 2017; 17: 22–29.

66. Gleeson H, Calderon A, Swami V, et al. Systematic review of approaches to using patient experience data for quality improvement in healthcare settings. *BMJ Open* 2016; 6: e011907.

67. College of Physicians and Surgeons of Ontario. *Confidentiality of Personal Health*

Information. Toronto, https://www.cpso.on.ca/admin/CPSO/media/Documents/physician/polices-and-guidance/policies/confidentiality-personal-health-information.pdf (2006).

68. College of Physicians and Surgeons Of Ontario. Social Media — Appropriate Use by Physicians, https://www.cpso.on.ca/Physicians/Policies-Guidance/Statements-Positions/Social-Media-Appropriate-Use-by-Physicians (2013).

69. College of Nurses of Ontario. Social Media: Reflect Before You Post, http://www.cno.org/en/learn-about-standards-guidelines/educational-tools/webcasts/social-media-reflect-before-you-post/ (2013, accessed 8 September 2019).

70. The Council on Ethical and Judicial Affairs. *Professionalism in the Use of Social Media*. Chicago, https://www.ama-assn.org/sites/ama-assn.org/files/corp/media-browser/public/about-ama/councils/Council Reports/council-on-ethics-and-judicial-affairs/i10-ceja-professionalism-use-social-media.pdf (2010).

71. Graham C, Woods P. Patient experience surveys. In: Ziebland S, Coulter A, Calabrese JD, et al. (eds) *Understanding and Using Health Experiences: Improving patient care*. Oxford: Oxford University Press, 2013, pp. 81–93.

72. Press I. *Patient satisfaction: Understanding and managing the experience of care*. Chicago: Health Administration Press, 2006.

73. Lee M, Youn S. Electronic word of mouth (eWOM). *Int J Advert* 2009; 28: 473–499.

74. Chevalier JA, Dover Y, Mayzlin D. Channels of Impact: User Reviews When Quality Is Dynamic and Managers Respond. *Mark Sci* 2018; 37: 688–709.

75. Wang Y, Chaudhry A. When and how Managers' Responses to Online Reviews Affect Subsequent Reviews. *J Mark Res* 2018; 55: 163–177.

References of Chapter 7

1. Gayle A. Sulik AE-K. No longer a patient: The social construction of the medical consumer. In: Astrid E-K, Chambré SM, Goldner M (eds) *Patients, Consumers and Civil*

Society. Emerald Group Publishing Limited, pp. 3–28.

2. Veinot T. Power to the Patient? A Critical Examination of Patient Empowerment Discourses. In: Harris R, Wathen N, Wyatt S (eds) *Configuring Health Consumers: Health Work and the Imperative of Personal Responsibility*. London: Palgrave Macmillan UK, pp. 30–41.
3. Power E. Fat children, failed (future) consumer-citizens and mothers' duties in neoliberal consumer society. In: Polzer J, Power E (eds) *Neoliberal governance and health: Duties, risks, and vulnerabilities*. Montreal & / Kingston: McGill-Queen's Press, 2016, pp. 43–57.
4. World Health Organization. *World Health Report, 2010: health systems financing the path to universal coverage.* Geneva: World Health Organization, 2010.
5. Karanikolos M, Kentikelenis A. Health inequalities after austerity in Greece. *Int J Equity Health* 2016; 15: 83.
6. Stuckler D, Reeves A, Loopstra R, et al. Austerity and health: the impact in the UK and Europe. *Eur J Public Health* 2017; 27: 18–21.
7. Keramidou I, Triantafyllopoulos L. The impact of the financial crisis and austerity policies on the service quality of public hospitals in Greece. *Health Policy (New York)* 2018; 122: 352–358.
8. Wenzl M, Naci H, Mossialos E. Health policy in times of austerity—A conceptual framework for evaluating effects of policy on efficiency and equity illustrated with examples from Europe since 2008. *Health Policy (New York)* 2017; 121: 947–954.
9. Cervero-Liceras F, McKee M, Legido-Quigley H. The effects of the financial crisis and austerity measures on the Spanish health care system: A qualitative analysis of health professionals' perceptions in the region of Valencia. *Health Policy (New York)* 2015; 119: 100–106.
10. Aday LA, Cornelius LJ. *Designing and conducting health surveys: a comprehensive guide*. San Francisco: John Wiley & Sons, 2006.
11. Hu N, Pavlou PA, Zhang JJ. Why do online product reviews have a J-shaped distribution?

Overcoming biases in online word-of-mouth communication. *Commun ACM* 2009; 52: 144–147.

12. Kim AJ, Johnson KKP. Power of consumers using social media: Examining the influences of brand-related user-generated content on Facebook. *Comput Human Behav* 2016; 58: 98–108.

13. General Medical Council. Doctors' use of social media, https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/doctors-use-of-social-media (2013).

14. British Medical Association. Social media Practical guidance and best practice, https://www.bma.org.uk/-/media/files/pdfs/employment advice/ethics/social media guidance final.pdf (2018).

15. British Medical Association. Social media, ethics and professionalism - BMA guidance, https://www.bma.org.uk/advice/employment/ethics/social-media-guidance-for-doctors (2018).

16. Schaeffer C, Booton L, Halleck J, et al. Big Data Management in US Hospitals: Benefits and Barriers. *Health Care Manag (Frederick)*; 36, https://journals.lww.com/healthcaremanagerjournal/Fulltext/2017/01000/Big_Data_Management_in_US_Hospitals__Benefits_and.12.aspx (2017).

17. Kaganer EA, Vaast E. Responding to the (almost) unknown: Social representations and corporate policies of social media. In: *ICIS*. 2010, p. 163.

Appendixes

Appendix 1.A Definitions

In this section, I provide definitions for the key concepts used in this dissertation.

Illness and Disease

There are two different terms that are related to a patient's state of being ill, and these are: illness and disease.

Illness refers to "experiences of discontinuities in states of being and in social function."[1] It is a lived experience of a patient that includes various levels of suffering, and it is influenced by a patient's subjective factors and culture[2].

A disease is a biomedical concept that refers to "abnormalities in the function and/or structure of body organs and systems"[1]. These abnormalities are defined within the scientific paradigm of modern medicine and can only be measured by healthcare professionals[3].

Patient Experience

In the healthcare quality literature, the term patient experience usually refers to healthcare experience. The patient experience with healthcare has been defined by the Agency for Healthcare Research and Quality in the USA (AHRQ):

> "*Patient experience encompasses the range of interactions that patients have with the health care system, including their care from health plans, and from doctors, nurses, and staff in hospitals, physician practices, and other health care facilities*" [4].

Patient Stories

In this thesis, the term "patient stories" refers to patients posts on social media platforms that describe their healthcare experiences. Social media platforms could be general-purpose platforms such as Facebook and Twitter, or healthcare-related platforms such as RateMD and Care Opinion Platforms.

Healthcare Providers

This term refers to all healthcare professionals who provide medical or clinical services to patients, including nurses and physicians.

Healthcare Administrators

This term refers to personnel in the healthcare system who are responsible for non-clinical services in the system. Administrators include policymakers and quality managers.

Healthcare Team

This term refers to both healthcare providers and administrators. It reflects the fact that within the complex healthcare system, healthcare service provision requires the efforts and cooperation of both parties.

Healthcare Quality

Quality of healthcare is "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge." [5 (p. 4)]

Social Media

Social media refers to the internet-based applications that enable people to communicate, interact, publish, and exchange all types and formats of information, including text, pictures, audio, and video[6]. Social media platforms provide several interaction capabilities that leverage information technology, including instant communication, live broadcasting of events, emotional expressions, sharing of information, voting, and game playing. These interaction capabilities continuously evolve following the rapid changes and developments in the information and communication technology field, and this makes conceptualizing social media a difficult task[7,8]. Although the definition of social media definition should be broad, context-based, and technology sensitive[8], there are two common features among all social media platforms: the ability of the user to create different types of content, and the ability of other members in the platform to view, comment on, or vote on this content[7].

Appendix 3.A : Interview Guide

Study: Perspectives of Primary Healthcare Providers and Healthcare Administrators on Patient Experience in Ontario: A Qualitative Exploratory Study

Interview Guide

General Introduction

In 2015, the Ministry of Health and Long-Term Care in Ontario announced the Patient First Action Plan, which later became the Patient First Act, the goal of which is to improve patient experience with healthcare and create a healthcare system that is responsive to patient needs (MoHLTC, 2015).

The Agency for Healthcare Research and Quality in the USA (AHRQ) provides the following **definition for patient experience**:

> Patient experience encompasses the range of interactions that patients have with the health care system, including their care from health plans, and from doctors, nurses, and staff in hospitals, physician practices, and other health care facilities (Agency for Healthcare Research and Quality, 2017).

Patient experience results in perceptions and responses, which are affected by the degree of conformity between the expectations of the patient about the different aspects of healthcare and the reality of those aspects(Press, 2006).

Health system responsiveness:

> The ability of the health system to meet the population's legitimate expectations regarding their interaction with the health system, apart from expectations for improvements in health or wealth.

The population's legitimate expectations were defined in terms of international human rights, norms and professional ethics, including treating people with dignity and understanding their cultural concerns.

1. Background Questions

Question 1: Tell me about your work, previous work

2. Patient Expectations

Question 2:
During their interaction with health system, what do you think people’s legitimate expectations are, apart from health improvement? Or stated differently, what do you think your patient expects from you and from your staff?

Question 3:

Doesn’t this mean that there are illegitimate expectations? What are they?

Question 4:
Do you think that sometimes there might be a disconformity between patient and physician expectation?

3. Experience with Illness

Question 5:
According to Press (2006), the patient expects that doctor pays attention to the patient’s explanatory model. However, many doctors see no point in negotiating the explanatory model with their patients, and this leads to patient dissatisfaction. Do you agree? why?

Question 6:
Do you discuss your patients’ explanatory models with them?

Question 7:
Do you think patient’s expectations should be limited to health improvement only; and all other factors that are known to affect “satisfaction” are not important for the physician to pay attention to?

4. Patient Experience with Healthcare

Question 8:
In your opinion, what are the most important factors that affect patient experience with healthcare provided in your practice?

Question 9:
From your perspective, what is patient experience?

Question 10:
What is the relation between patient experience and patient safety?

Question 11:
Do you think the socioeconomic status impacts patient experience?

Question 12:
Do you think patient experience can be prioritized in such a complex healthcare system and the increasing demand for healthcare?

Question 13:
Which of the factors that affect patient experience are controllable by you?

Question 14:
Have we explored the requirements to put the patient first? Or how are we going to make the patient first?

Question 15:
A study conducted by Laing and Hogg (2002) argues that the focus on patient experience reflects a trend towards “consumerization of healthcare” and that nurses and physicians might perceive this

consumerization as a challenge and a distraction to healthcare delivery, because their main goal is to improve health outcomes rather than satisfying patients' needs. Do you agree with that? Why?

Question 16
Do you think that, in Canada, we are moving towards consumerization of healthcare?

Question 17 (Anthropology)
There are two different descriptions/definitions of sickness:

- Disease can be defined as biomedicine's definition of sickness and the physical impact and manifestation of sickness.
- Illness can be defined as the patient's definition and view of sickness and the social and emotional effect and manifestations of sickness.

According to Eisenberg (1977), "patients suffer illnesses; physicians diagnose and treat diseases." Press (2006) suggest that "By recognizing and responding to the illness,
providers can go beyond the usual service issues to significantly enhance the patient's experience of care."

Should family doctors treat patient's illness? if no, why? if yes; how?

Question 18 (Measurement):
According to LaVela and Gallan (2014), patient satisfaction might not be a valid indicator for the patient experience, because of three reasons:

1- The patient lacks an adequate scientific expertise to understand every aspect of the healthcare services, and therefore, the patient could misunderstand or misinterpret some parts of the health service delivery process, which could result in patient dissatisfaction.
2- The disconformity between patient's explanatory model and his/her actual health status that is evaluated by you. This disconformity could result in patient dissatisfaction.
3- The third reason is that patient satisfaction is highly affected by the fulfillment of patients' immediate desires, for instance, the receipt of a specific medication, regardless of its benefit.

Do you agree? Why?
What do you think a better measure for patient experience?

Question 19
Do you think that there are other reasons for the unreliability of patient satisfaction?

Question 20:
If you want to evaluate the experience of your patients, or a group of them, what would be your preferred method to do that?
Question 21:
What do you think about the following instruments to evaluate the patient experience?

1- A questionnaire that is given to the patient upon the end of his visit to the family doctor.
2- A questionnaire that is mailed to the patient within a month of his visit to the family doctor.
3- A website where the patient can rate his/her family doctor and maybe he can write a short comment to describe his/her experience.

5. Healthcare Politics

Question 22:
Politics denotes the expression of stakeholders' power and conflicts, and the strategies used to resolve those conflicts (Bambra et al., 2005). In the healthcare system, power differentials exist between healthcare providers, including physicians, nurses, and quality managers. Power differentials also exist between healthcare providers and patients (Allen et al., 2016).

Do you think that politics within healthcare organizations affect patient experience?

Question 23:
Do you think that there might be a knowledge differential between healthcare providers and healthcare quality managers, which might affect patient experience?

6. Healthcare Quality

Quality of healthcare is "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge." (Lohr, 1990) (p. 4) Good healthcare quality has a positive impact on health outcomes, patient satisfaction, and patient experience (Agency for Healthcare Research and Quality, 2017).

In 2001, the seminal work of the Institute of Medicine in the USA, Crossing the Quality Chasm, identified six aims for healthcare quality: patient safety, the effectiveness of care, patient-centeredness, timeliness of services, efficiency, and equity (Institute of Medicine, 2001).

Question 24:
Would you please describe the relationship between healthcare quality and patient experience?

Question 25:
Would you please describe the relationship between healthcare quality and patient satisfaction?

Question 26:
Do you think if the patients have the "practical" capability to select their healthcare providers, those providers might pay more attention to patient experience?

Question 27:
What are the actions that can be taken by the providers to improve patient satisfaction?

Appendix 4.A : Interview Guide

Study Title: The Perspectives of Healthcare Providers on Patient Stories on Social Media

Interview Guide

General Introduction

In 2015, the Ministry of Health and Long-Term Care in Ontario announced the Patient First Action Plan, which later became the Patient First Act, the goal of which is to improve patient experience with healthcare and create a healthcare system that is responsive to patient needs (MoHLTC, 2015).

The Agency for Healthcare Research and Quality in the USA (AHRQ) provides the following definition for patient experience:

> Patient experience encompasses the range of interactions that patients have with the health care system, including their care from health plans, and from doctors, nurses, and staff in hospitals, physician practices, and other health care facilities (Agency for Healthcare Research and Quality, 2017).

Patient experience results in perceptions and responses, which are affected by the degree of conformity between the expectations of the patient about the different aspects of healthcare and the reality of those aspects(Press, 2006).

1. Background Questions

Question 1 - Tell me about your work.

2. Patient Experience with Healthcare

Question 2:

In your opinion, what are the most important factors that affect patient experience with healthcare provided in your practice?

Question 3:

From your perspective, what is patient experience?

Question 4:

What is the relation between patient experience and healthcare quality?

Question 5:

Which of the factors that affect patient experience are controllable by you?

3. Evaluation of Patient Experience

Question 6:

According to LaVela and Gallan (2014), patient satisfaction might not be a valid indicator for the patient experience, because of three reasons:

4- The patient lacks an adequate scientific expertise to understand every aspect of the healthcare services, and therefore, the patient could misunderstand or misinterpret some parts of the health service delivery process, which could result in patient dissatisfaction.
5- The disconformity between patient's explanatory model and his/her actual health status that is evaluated by you. This disconformity could result in patient dissatisfaction.
6- The third reason is that patient satisfaction is highly affected by the fulfillment of patients' immediate desires, for instance, the receipt of a specific medication, regardless of its benefit.

Do you agree? Why?

What do you think a better measure for patient experience is?

Question 7

Do you think that there are other reasons for the unreliability of patient satisfaction?

4. Evaluation and Social Media

Question 8:

If you want to evaluate the experience of your patients, or a group of them, what would be your preferred method to do that?

Question 9

Are their any systematic steps that you take to evaluate the experience of your patients?

Question 10

What do you think about the following instruments to evaluate the patient experience?

4- A questionnaire that is given to the patient upon the end of his visit to the family doctor.
5- A questionnaire that is mailed to the patient within a month of his visit to the family doctor.
6- A website where the patient can rate his/her family doctor and maybe he can write a short comment to describe his/her experience.

Question 11 (Social Media):

Many people have been using social media to talk about their experience with healthcare. The UK healthcare system is using a platform to collect patient stories.

Do you think the data available on social media in the form of posts and comments about their experience with healthcare is a credible source which can be used by healthcare providers for quality improvement?

Credibility here means accuracy, relevance, and honesty of the people submitting these posts.

Question 12

Do you think healthcare providers can use patients' posts on social media to explore the experience of those patients?

Question 13 (Social Media, Measurement):

Taking into consideration the fact that most patient experience surveys are positively skewed, do you think that social media provides a more naturalistic means for the patients to talk about their experience and identify issues in healthcare quality that cannot be exposed in the normal "closed-ended" surveys?

Question 14

Do you think a website to collect patient stories would be a legitimate tool to collect information about patient stories?

Question 15

Many people have been using social media to talk about their experience with healthcare. For example, Reddit, Care Opinion, Yahoo QA platform.

However, there are many barriers or challenges that hinder the use and benefiting from these media to improve healthcare:

1. Lack of demographic identification data
2. Lack of temporal, and geographical dimensions

However, platforms like Care Opinions have overcome those barriers.

Do you think there is a potential in such platform to help improve healthcare?

Question 16:

Do you think health social media is worth investigating by researchers? like finding a way to extract meaningful information from it?

Question 17 (Social Media, Quality):

What do you think the main Issues on Social media data?

Question 18 (Social Media in Canada):

Do you think we can use Social Media platforms to collect credible patient stories in Canada? What obstacles do you think might impede such an effort?

Question 19

In your organization, or in your practice do you have a policy for interacting with patients on social media, or maybe some guidelines from your college or association regarding this issue?

Question 20

Do hospitals in Ontario have specific policies regarding social media?

Question 21

Do you think that healthcare providers are free to respond to patient posts on social media regarding healthcare experiences?

Appendix 6.A : Topic Weights

In this study, the topic probabilities of each story, which were produced by our LDA model, represent compositional data, and therefore, we had to transform the data in order to use logistic regression modelling. We did the transformation by multiplying a topic probability by the length of the document (i.e., number of unique words). Because the coef (β) in the logistic regression model is the log odds ratio corresponding to a one-unit change in the topic weight, it is important to understand how this one-unit change could be achieved.

Let TP be the topic probability, and DL be the story length.

Topic Weight (W) = TP x DL.

A one-unit change in W = (TPxDL) +1.

Algebraically, (TPxDL) +1 = TP (DL+1/TP) , and because TP is < 1, its reciprocal is > 1. Therefore, a one-unit change in W can be achieved by adding a number of words that equals the reciprocal of the corresponding topic probabilities. However, because the topic probability is not known to the story writer, this might be impractical.

Nevertheless, for the topics that have a positive impact on the probability of receiving a provider response, increasing a topic weight is desirable and this can be achieved, according to the formula W = (TPxDL), by adding more relevant words that could increase both the topic probability and the document length.

Curriculum Vitae

Education

- **Master's Degree** in health information science, University of Western Ontario, Canada 2016
- **Master's Degree** in business administration (MBA), New York Institute of Technology, UAE 2006
- **Bachelor's Degree** in Dentistry, Damascus University, Syria 1994

Research Affiliations

- Expert Researcher at the Local Health Integration Network, Waterloo, Ontario, Canada 2017- 2019
- Researcher at Global Health Lab, University of Waterloo, Canada 2017- Present
- Researcher at the Insight Lab, University of Western Ontario, Canada 2014- 2016

University Teaching Certifications

- University Teaching Certificate, University of Western Ontario 2017
- Teaching Assistant Training, University of Waterloo 2017
- Advanced Teaching Program, University of Western Ontario 2015
- Teaching Assistant Training, University of Western Ontario 2014

Professional Certifications

- Manager of Quality CMQ Certificate, American Society for Quality 2010
- Project Manager Professional PMP Certificate, Project Management Institute 2009

Information Technology Certifications

- Oracle Master JAVA Enterprise Architect, Oracle 2012
- Certified Software Engineer (PSP), Carnegie Mellon University 2011
- Oracle Certified Expert in Java EE Web Services, Oracle 2012
- Java Web Development Certificate, Sun Microsystems 2002
- Java Programming Certificate, Sun Microsystems 2001

Work Experience

- **Teaching Assistant,** University of Waterloo, Waterloo, ON September 2016 – Present
- **Research Assistant,** University of Western Ontario, London, ON January 2015 – April 2015
- **Teaching Assistant,** University of Western Ontario, London, ON September 2014 – June 2016
- **Director/Board Member,** Hemophilia Ontario, Toronto, ON March 2013 – September 2014
- **Director/Board Member,** *Over 55 Inc*, London, Ontario, Canada Feb 2013 – September 2014
- **Managing Partner**, RELEMIT IT Solutions, India and UAE Nov 2010 – May 2012

- **Project Manager**, Ministry of Culture, Youth & Community Development, UAE Jul 2008 – Oct 2010
- **Project Manager,** Tejari B2B LLC, Dubai, UAE Jul 2007 – Jun 2008
- **Product Manager**, The Electronic Village, Abu Dhabi, UAE Jun 2002 – Jul 2007

Contractual Work Experience

Consultant, The International Criminal Court, The Hague, Netherlands Mar 2006

Computer Programmer, The World Health Organization, Geneva, Switzerland Feb 2005 – Sep 2005

Consultant, ESCWA/ United Nations, Beirut, Lebanon Jun 2003

Consultant, UNESCO, Beirut, Lebanon Sep 2003

Publications

1. Zakkar, M. (2019). Patient Experience Determinants and Manifestations. *International Journal of Health Governance Healthcare Systems.*
2. Zakkar, M., & Sedig, K. (2017). Using Information Visualization to Represent Health Indicators and Support Health Policymaking. *Online Journal of Public Health Informatics*.

Conferences Presentations

- The 17th Annual Human Factors Engineering Inter-University Workshop (IUW), Waterloo, ON, December 2016.
- 23rd Canadian Conference on Global Health, Ottawa, ON, October 2017.
- Canadian Association for Health Service and Policy Research, Halifax, NS, May 2019.

Professional Membership

- The Project Management Institute, USA, member since 2008.
- The American Society for Quality, member since 2010.
- The Canadian Society for International Health, member since 2017.