‘Knowing Me, Knowing You’: Patients’ Perspectives on Doctors Disclosing Personal Illness

A thesis submitted for the degree of Bachelor of Medical Science with Honours at The University of Otago, Dunedin, New Zealand by Laura R. Bolger

2018
Abstract

There are currently no formal clinical guidelines informing doctors as to whether it is appropriate to disclose their own illness information to patients. The topic of doctor self-illness disclosure (DSID) remains under-researched within current medical literature. Surrounding research concerning doctor self-disclosure in general has presented risks as well as benefits of this behaviour in the clinical setting. This study aimed to address the significant lack of research in this area by investigating patients’ perspectives on DSID within the context of primary care. By addressing this aim, this study has the potential to inform medical professionals and medical students as to what is best practice concerning DSID.

This study explored patients’ perspectives on doctors self-disclosing about their own illness or illness experience to patients. Data was collected through the use of one-on-one semi-structured interviews and subsequently analysed using thematic analysis methods.

The major themes identified from the results centred around emotional reassurance, the doctor-patient relationship, and the doctor’s professional role and responsibilities. The results of this study demonstrated that DSID can have profound effects on patients and the doctor-patient relationship overall. Twelve clinical recommendations for doctors were constructed from the analysis of the results. The purpose of these recommendations is to advise doctors on how to approach DSID in primary care in order to minimise potential harms and emphasise potential benefits of DSID.

Based on these findings, it is recommended for doctors to consider the appropriateness of DSID on a case-by-case basis and acknowledge that it has the potential for both negative and positive effects. This study has also emphasised that there is a legitimate need for DSID to be addressed within medical education.
Acknowledgements

I would like to thank all of the people who have helped me along my journey to completing this thesis. I am incredibly grateful for all of the support that has been given to me throughout this year.

First and foremost, I would like to thank my incredible supervisors, Dr Katherine Hall and Dr Martyn Williamson. I greatly appreciate the guidance and encouragement you have given me throughout this year, I have learnt so much from the both of you.

Thank you to the Otago Medical School for the opportunity to complete this project, this year has allowed me to broaden my knowledge and will undoubtedly make me a better doctor as a result. I would also like to express my appreciation for all of the participants who took part in this study. It has been a privilege to listen to your stories and I thank you all for making this study possible.

Thank you to my amazing sister, Ashley, for constantly reassuring me and bringing me back down to earth when required.

Finally, I would like to dedicate this thesis to my late grandmother, Una Bolger. I would have never made it to this point without you.
Table of Contents

Abstract ........................................................................................................................................ ii
Acknowledgements .................................................................................................................. iii
Table of Contents ....................................................................................................................... iv
List of Abbreviations ................................................................................................................... vi
Chapter 1 Introduction .................................................................................................................. 1
  1.1 Overview of Thesis Structure ............................................................................................... 2
Chapter 2 Literature Review ........................................................................................................ 4
  2.1 Definitions and Prevalence ................................................................................................. 4
  2.2 Ethics and Boundaries ......................................................................................................... 5
  2.3 Doctors’ Perspectives on Self-Disclosure ........................................................................... 7
  2.4 Effectiveness of Self-Disclosure in Clinical Practice ......................................................... 10
  2.5 Doctors as Patients ............................................................................................................. 13
  2.6 Doctor Self-Illness Disclosure ............................................................................................ 19
  2.7 Duty to Warn ..................................................................................................................... 22
  2.8 Summary of Literature Review ......................................................................................... 23
Chapter 3 Methods ..................................................................................................................... 24
  3.1 Ethics Application and Māori Consultation ....................................................................... 24
  3.2 Interview Questions ............................................................................................................ 25
  3.3 Practice Interviews ............................................................................................................ 28
  3.4 Recruitment of Participants .............................................................................................. 29
  3.5 Data Collection and Transcription .................................................................................... 30
  3.6 Member Validation ............................................................................................................. 31
  3.7 Thematic analysis ............................................................................................................... 32
  3.8 Personal Perspective .......................................................................................................... 36
List of Abbreviations

**DSID** – Doctor Self-Illness Disclosure

**EDP** – Emergency Department Provider

**GP** – General Practitioner

**HDC** – The Health and Disability Commissioner

**NZ** – New Zealand

**PCP** – Primary Care Provider

**SD** – Self-Disclosure
Chapter 1 Introduction

This thesis will explore patients’ perspectives on doctor self-illness disclosure (DSID) and how this data contributes to the current literature on this subject.

Communication is an integral part of the doctor-patient relationship, therefore, research investigating doctors’ methods of communicating with patients is an important aspect of medical ethics. Much of the doctor-patient dynamic is occupied by the doctor gathering intimate information about the patient but rarely offering information about themselves. The appropriateness of doctors disclosing personal information to patients has been a contentious issue within medical literature; despite the presence of literature warning of the dangers of self-disclosure (Gabbard & Nadelson, 1995), research has shown that many doctors view it as potentially beneficial to the doctor-patient relationship (Allen & Arroll, 2015).

This study focuses primarily on a specific type of self-disclosure involving doctors disclosing their own personal illness information to patients, referred to throughout this thesis as DSID. Although there is existing research suggesting that DSID could be beneficial to patients (McDaniel et al., 2007), there is a significant lack of literature specifically exploring patients’ perspectives on DSID. Currently, the New Zealand Health and Disability Commissioner (HDC) does not have a stance or recommendation regarding health professionals disclosing their own illness information to patients. The issue of DSID is not explicitly addressed within the Code of Health and Disability Services Consumers’ Rights (1996) or the Health and Disability Commissioner Act (1994). The lack of explicit clinical guidelines concerning the use of DSID emphasises the important need for research in this area.

The central research question of this study is to ask how patients feel about doctors disclosing their own personal illness information to them. Ultimately, the
The purpose of this research is to guide the construction of clinical guidelines concerning the use of DSID in primary care. Therefore, the findings of this study can enable the education of existing doctors and medical students about ethical use of DSID in clinical practice.

1.1 Overview of Thesis Structure

This thesis is separated into multiple chapters in order to fully describe how the study was conducted, portray the study's findings, and describe their consequent implications for medical practice. This opening chapter, chapter one, serves as a prelude to the subsequent chapters by broadly introducing the topic of DSID and demonstrating its importance.

Chapter two summarises the existing research relevant to the topic of DSID in the form of a literature review. This chapter presents various concepts such as the ethical dimensions of the doctor-patient relationship and the use of self-disclosure in clinical practice. By summarising what is already known about the subject of DSID, this chapter emphasises the need for this research and its contribution to existing literature. The context provided by this chapter forms a strong foundation for this thesis and complements the subsequent chapters which explore this study specifically.

The methodological approach of this study is described in chapter three. This chapter begins by recounting the preparatory ethical application and Māori consultation undertaken prior to the commencement of the study. Details about the interview structure and simulated practice interviews are also included. A comprehensive outline of how the data was collected and a description of the data analysis process form the basis of this chapter. An explanation of my own personal perspective as a researcher and its impact upon this study is used to conclude this section.
Chapter four presents the results of this study by describing the main themes identified within the interview data. These themes are wide-ranging and include concepts such as professionalism and the doctor’s role, to objectivity and patient decision-making. This chapter also includes demographic data concerning the participant population including ethnicity, age and rural/urban classification.

The fifth chapter discusses the results described in the previous chapter and identifies the broad overarching ideas extending across the themes. This chapter integrates the findings of this study within existing literature previously discussed in chapter two. This section also includes a discussion of the study's strengths and weaknesses as well as opportunities for further research to help extend the current findings. The results of the study are summarised through the use of a table of clinical recommendations. These recommendations are included within this chapter and help to emphasise the main findings and their translation into clinical practice.

Finally, the sixth chapter concludes this thesis by summarising the main findings and explaining their significance. This chapter describes the take-home messages from this study and demonstrates how they translate into the clinical context.
Chapter 2  Literature Review

The purpose of this chapter is to contextualise the subject of doctor self-illness disclosure (DSID) within current medical literature. This chapter is organised into sub-sections according to each individual topic relevant to DSID. Each sub-section will elaborate on the relevant existing research for each topic to establish how this study fits within past research. This subject is important as there are no formal ethical guidelines for doctors in New Zealand specifically concerning DSID or self-disclosure in general. By summarising the relevant literature, this review will identify areas that require additional research and summarise the current findings.

2.1 Definitions and Prevalence

Doctor self-disclosure (SD) and doctor self-illness disclosure (DSID) both serve as central themes of this thesis, therefore it is important to clearly define what these terms mean. This section will introduce these fundamental concepts and their role within the clinical context.

Doctor SD is a broad phrase used to describe when doctors share information about themselves to patients (Beach et al., 2004a). SD is an over-arching term as it describes the disclosure of any personal information regardless of topic or extent. This information can range from a passing comment about a shared hobby with a patient, to disclosing intimate personal struggles. Instances of doctor SD can vary in terms of intimacy and personal details. ‘Reassurance disclosures’ involve comforting the patient using the doctors’ own similar experience (e.g. “That happens to me too”) (Beach et al., 2004a). ‘Extended narrative disclosures’ describe long explanations of the doctors’ personal experience with limited importance to the patient (Beach et al., 2004a). ‘Reassurance disclosures’ occur most often whereas ‘extended narrative disclosures’ occur the least (Beach et al., 2004a).
One study has shown that doctor SD occurs in 15.4% of routine consultations, (Beach et al., 2004a) and another has reported it occurring in 34% of consultations (McDaniel et al., 2007). These statistics suggest that SD is a relatively common occurrence amongst doctors interacting with patients. Beach et al. (2004b) have reported that the prevalence of SD is similar between surgical and primary care specialties. They have also found that the length of patient visits (primary care and surgical) varied depending on whether SD occurred; visits involving at least one instance of SD were significantly longer than those in which SD did not occur.

As described above, doctor SD includes the sharing of any personal information about the doctor; therefore, specific subjects of disclosure can fit under the umbrella term of SD. For the purposes of this thesis, DSID is defined as a doctor disclosing about their own illness or illness experience to a patient. DSID can involve a past or present illness and can be of any severity or duration. This does not include the doctor sharing health information regarding a family member or friend. There is significantly less literature on the subject of DSID compared with SD in general, and of those papers that do exist, the focus is primarily on the doctor’s experience rather than that of the patient.

2.2 Ethics and Boundaries

The following section will discuss the literature surrounding the boundaries and ethical complexities within the doctor-patient relationship. Ethical boundaries are integral to the doctor patient relationship as it is a unique partnership involving the sharing of intimate and personal information. Despite being intimate by nature, the doctor-patient relationship is built on a foundation of professionalism which should be upheld to prevent ethical boundaries being crossed. By outlining medical research within this subject area, this section will provide a clear foundation before exploring SD and DSID further.
The NZMA ‘Code of Ethics for the New Zealand Medical Profession’ (2014) states that all forms of patient exploitation are unacceptable, however, it does not explicitly outline where the ethical boundaries lie. In the article, ‘Professional Boundaries in the Physician-Patient Relationship’, Gabbard and Nadelson (1995) outline how the confines of professionalism are not clear-cut within the medical context. They argue that forms of ethical misconduct can arise from the difference of power within the doctor-patient relationship and that particular behaviours can be inappropriate in one clinical setting but appropriate, or even necessary, in others. For example, holding a patient’s hand whilst breaking bad news may instil emotional support, however, this same behaviour with another patient may be inappropriate. Although some slight boundary transgressions may be dismissed as harmless and without consequence, they contend that ‘what appear to be trivial violations may in reality be considerably more serious when viewed in the context of a continuum’. For example, a doctor may text a patient from their personal phone to check in on their progress, but this could be misinterpreted by the patient and lead to inappropriate contact. From this existing literature, it is evident that although the doctor may have good intentions, seemingly harmless boundary crossings have the potential to evolve into inappropriate relationships with patients.

Gabbard and Nadelson (1995) warn that inappropriate SD can represent a role-reversal within the doctor-patient relationship that can prove to be problematic and ‘a common starting point on the slippery slope to sexual involvement with a patient’. Other literature, however, has argued that this claim ‘seems unsubstantiated’ based on their research (Beach et al., 2004a). Despite serious claims of potential patient harm, no formal guidelines or ethical codes exist for New Zealand doctors regarding appropriate SD. This suggests that doctors are using their own personal discretion when assessing whether or not SD is appropriate within the clinical context.

As the doctor-patient relationship has evolved from paternalism to a collaborative partnership, doctors have become less formal when interacting with patients
(Bird, 2013). This gradual divergence from formality can impact upon professionalism in clinical practice and may lead to boundary crossings. Boundary crossings are defined as ‘departures from usual professional practice that are not exploitative’, whereas boundary violations involve unethical behaviour that causes harm to the patient. An example of a boundary crossing used by Bird (2013), is a doctor disclosing about a family member’s illness that is similar to that of their patient. This example demonstrates the potentially inappropriate use of SD; however, it is unclear whether SD is the sole cause for a boundary crossing or whether other factors also contribute. Bird (2013) argues that factors impacting upon doctors such as lacking emotional support, illness, isolation, inexperience and stress can contribute towards boundary violations. Ongoing boundary crossings may develop into boundary violations and therefore serious mistreatment of the patient (Galletly, 2004).

This section has highlighted some of the ambiguous aspects of medical ethics whilst placing significant importance on the maintenance of professional boundaries. From the prior literature on this subject, it is evident that the appropriateness of clinical behaviour is somewhat dependant on context and open to doctors’ discretion. This brief summary of clinical ethics and boundaries provides a firm starting point as I begin to explore doctor SD specifically.

2.3 Doctors’ Perspectives on Self-Disclosure

As previously discussed, SD in clinical practice is not a rare occurrence. Despite this, most doctors have not been formally educated on this issue and agree that it should be taught to future doctors-in-training (Allen & Arroll, 2015). Therefore, it is evident that doctors may develop their own preferences as to whether or not to use SD when interacting with patients. To investigate this, this section will detail doctors’ perspectives on SD in clinical practice and their reasoning to support these perspectives.
A 2015 study conducted in New Zealand has reported that, of the sixteen GPs studied, all agreed that doctor SD has the potential to have a positive impact upon the doctor-patient relationship (Allen & Arroll, 2015). Alternately, fourteen of the sixteen GPs acknowledged the possible negative effects of SD when interacting with patients. These findings suggest that although most GPs are aware that SD can have both good and bad implications, some may not appreciate its serious potential to cause harm. This study used a questionnaire to ascertain doctors’ attitudes towards a number of potential advantages and disadvantages associated with the use of SD in clinical practice. Many of the potential disadvantages proved to be divisive amongst the participants involved, demonstrating that doctors are not likely to be united in their perspectives on SD. For example, seven of the sixteen GPs agreed that SD had the potential to skew the doctor-patient relationship, while an equal proportion disagreed (two of the sixteen neither agreed nor disagreed). Other potential disadvantages, such as SD burdening the patient or taking focus away from their needs, also yielded similar results with many of the doctors having opposing viewpoints.

Unlike the potential disadvantages, the section of the questionnaire relating to the potential advantages of SD resulted in a more homogenous response. Of the sixteen GPs studied, all sixteen agreed that SD had the potential to enhance patient support, empathy, trust, mutuality and make it easier for patients to share information with their doctor. In contrast, there were no unanimous viewpoints concerning the potential disadvantages of SD.

This study also addressed the issue of prompted or ‘asked-for’ disclosures, such as a patient directly asking their GP about their personal life. Many of the GPs did not consider this to be a difficult situation to tackle, with some sharing that they can often deflect these questions from patients and steer the consultation back to focusing on the patient. This response is consistent with previous literature emphasising the doctor’s responsibility to ‘solely serve the needs of the patient’ and avoid using the doctor patient relationship for inappropriate gratification (Bird, 2013). Some of the GPs expressed that potentially overt self-disclosures can
be subtly refined into more impersonal statements (Allen & Arroll, 2015), something that has been recommended in past literature on this subject (McDaniel et al., 2007). For example, a GP could express that they have a personal understanding of a patient’s illness without going into depth about this.

One of the main concerns the GPs stated when discussing SD was the potential for it to encourage unprofessional relationships with patients. Whilst discussing this topic, one GP stated the following:

> There can certainly be harm to the doctor, ‘cause [sic] there can be a big blurring of boundaries between the professional relationship that you’ve got with the patient and your personal life. Which is not always a helpful thing (Allen & Arroll, 2015).

This quote highlights that SD can also put the doctor at risk. For example, a patient may become inappropriately invested in their doctor after the doctor has shared details about his or her personal life. Therefore, it is expected that doctors use discretion when sharing personal details with certain patients with a history of potentially inappropriate behaviour.

Some of the doctors that were interviewed used SD to help reassure parents and ease their stress; one GP explained:

> If a mother comes in and she’s absolutely worn out from a sleepless night with a kid with an ear infection, you know, I might say “well yes it’s really difficult isn’t it when kids have ear infections,” you know, being a mother (Allen & Arroll, 2015).

That some doctors feel inclined to use SD when comforting worried parents is supported by prior research which has shown that paediatrician SD increased parent satisfaction in the context of a consultation with a sick child; therefore, demonstrating the positive impact of SD when talking with parents (Holmes, Harrington & Parrish, 2010).

In one way or another, all of the GPs included in the study had patient-centred reasons for using SD in clinical practice and none cited using SD without having a
clear purpose in mind (Allen & Arroll, 2015). This suggests that, although SD involves talking about themselves, their intent is to use SD as a way to benefit the patient. While many of the doctors reported using SD as a tool to show empathy and strengthen their connection with their patients, some also spoke about using it in the context of treatment pathways. Although it could be with good intentions, the potential for SD to involve bias and unethical persuasion towards different treatment options should not be disregarded.

Allen and Arroll (2015) also found that many of the doctors developed personal guidelines as to what was appropriate to disclose to patients and what was not. For example, four of the sixteen GPs were comfortable self-disclosing about personal physical illness and only two were comfortable sharing details about a personal mental illness with a patient. This is significantly lower than those who were comfortable sharing personal details about their family (fourteen of the sixteen GPs studied) or about their physical activities/hobbies (sixteen of the sixteen GPs studied). This suggests that it is not only the SD itself which is important, but the type of information disclosed as well.

This section has demonstrated that there is not a consensus opinion amongst doctors as to how SD should be approached in clinical practice. Despite this, many doctors perceive SD as having both beneficial and detrimental potential when used during clinical consultations with patients.

### 2.4 Effectiveness of Self-Disclosure in Clinical Practice

This section will focus on how SD is used in clinical practice and how it impacts upon the doctor-patient consultation. As previously mentioned, many doctors have a positive view of SD and its potential. This section, however, will outline research investigating the effectiveness of SD within clinical practice as opposed to doctors’ subjective opinions on this topic.
The study, ‘Physician Self-disclosure in Primary Care Visits: Enough About You, What About Me?’ has explored the usefulness of instances of doctor self-disclosure in a primary care setting (McDaniel et al., 2007). This study involved recording doctors’ consultations with standardised actor-patients to investigate the frequency, content, focus, length and timing of doctors’ self-disclosures. Only 4% of the doctor self-disclosures recorded in this study were coded as useful by the researchers; useful was defined as ‘providing education, support, explanation, or acknowledgement, or prompting some indication from the patient that it had been helpful’. Of these useful disclosures, all had involved the doctor disclosing that they had the same illness or condition as the patient. Doctor self-disclosures that were coded as useful had an average length of twenty-six words. Alternately, disclosures coded as not useful had an average of twenty-three words and those that were coded as disruptive had an average of seventy-five words. This suggests that excessively long SD inappropriately disrupted the flow of the consultations. It is important to note that the coding of this data was exclusively performed by the research team and did not include separate input from the standardised actor-patients themselves. This significant limitation of the study highlights the need to focus on patients’ views to establish whether the literature is consistent with their perspective of doctor self-disclosure.

A study investigating SD in the emergency department setting has found a positive relationship between healthcare provider SD and positive patient ratings of the provider’s communication skills and rapport, as well as greater satisfaction with provider communication (Zink et al., 2017). Unlike McDaniel et al. (2007), this study collected survey data from patients after being evaluated by a medical provider rather than solely relying on coding methods by researchers. The medical providers included in this study were doctors as well as physician assistants. Over half of the patients who experienced SD from their provider said they enjoyed it, whilst 7% said they disliked it (Zink et al., 2017). When surveyed about their preferences regarding SD, patients had differing opinions on what they would like to know about an emergency department provider (EDP) compared with a primary-care provider (PCP). Only 7.6% of the patients surveyed reported
that they would like to know about their emergency department provider’s family life, however, 26.3% would like to know this information about their primary care provider. These findings indicate that patients’ interest in the personal life of their health care provider is somewhat dependant on the role of the provider and the type of relationship they have with patients. When asked about disclosure of medical ailments/injuries related to the patient, 34.5% of patients would like to be told by their EDP and 39.6% would like to be told by their PCP. It was found that the two most preferred self-disclosure topics were the provider’s education and whether they had a medical ailment related to the patient.

Beach et al. (2004b) have also investigated the use of self-disclosure by differing classifications of health professionals. They found that, although the frequency of doctor self-disclosure is similar between surgery and primary care, patients who experienced SD by their surgeon were more satisfied than those who experienced SD from their primary care provider. They argued that this finding could be explained by primary care doctors often dealing with patients with chronic health issues and that reassuring self-disclosures may be interpreted as dismissive to the patient. Zink et al. (2017), however, discussed that the majority of the patients studied viewed provider self-disclosure as an attempt to build rapport and strengthen the relationship, whereas only a few perceived it as a demonstration of arrogance. Although the data from this study showed that many patients who experienced SD enjoyed it, ‘those who did not have these conversations did not seem to miss the experience’. This indicates that although many instances of SD were positively received by patients, there may be other methods of communication or behaviour that could serve a similar purpose.

As previously discussed, some doctors use SD as a way to comfort patients and make them feel comfortable in potentially distressing situations. SD can also be used as a method of counselling the patient and acting as a role model. A study conducted by Frank, Breyan and Elon (2000) has demonstrated that doctor SD of their own healthy behaviours can help to motivate patients to adopt similar habits. It is unknown whether this example of a modelling relationship could be useful in
other contexts involving doctor self-disclosure of illness. For example, a doctor could use their own story of illness recovery to encourage and maintain a patient’s adherence with treatment and recommendations. These results add to the potential of SD to be an effective tool when communicating with patients in clinical practice.

This section has illustrated the use of SD within clinical practice and its effectiveness in communicating with patients. This existing literature has demonstrated the negative and positive potential of doctors using SD. This data suggests that there are multiple variables involved that influence the effectiveness of SD and how it is perceived by patients in the clinical setting. These variables include the topic of the disclosure, the specialty of the doctor disclosing and the length of the disclosure.

2.5 Doctors as Patients

Just like the rest of the population, doctors get sick too. For doctors, the duality of being a patient as well as being a doctor involves a complex interconnection of power and vulnerability. Prior literature surrounding this subject has demonstrated that, for many doctors, an experience of a serious illness can be transformative and profoundly impact their clinical practice (Hall, et al., 2018; Opel, 2012). Some doctors acquire a new sense of understanding and empathy for sick patients after experiencing the other side of medicine, while others may gain a new perspective of themselves (Klitzman, 2008). Many doctors are conflicted as to whether to disclose an illness or illness experience to their patients due to concern about how this could impact the doctor-patient relationship (Allen & Arroll, 2015; Fox et al., 2009; Hall et al., 2018; Klitzman & Weiss, 2006; Opel, 2012).

The phenomenon of doctors-as-patients has recently entered public media with an article ‘Heal thyself: meet the doctors living with the conditions they treat’ showing that doctors are not just simply those that treat illness but can be impacted by it as well (Broughton, 2017). The article presented doctors with
illnesses that they medically specialise in, including a dermatologist with rosacea, a psychiatrist with a history of depression, and an oncologist who had survived cancer. All of the doctors featured in the article acknowledged that their illness impacted upon how they interacted with their patients in various ways. Dr David Carbone, an oncologist who overcame lung cancer, expressed how cancer impacted upon his relationship with patients by saying:

I always dealt empathetically with my patients, but until I lived their experience, I don’t think I fully understood it. I survived my cancer, but I still lost part of my lung, had multiple rounds of multi-agent chemotherapy and radiation, thoracic surgery and inadequate pain control – I’ve experienced how bad the side-effects of therapy can feel. I actually enjoy taking these desperate patients and trying to make them comfortable with me as a partner in fighting this disease (Broughton, 2017).

Similarly to Dr Carbone, many doctors develop a deeper understanding of illness, fulfilling the patient role and accepting vulnerability after being unwell. Often doctors feel that they do not need to have experienced illness themselves in order to develop a deep connection with their patients. Despite this, many doctors appreciate just how much their clinical approach changes after walking in a patient’s shoes (Klitzman, 2008).

Dr Linda Gask, a psychiatrist with a history of depression, said the following when asked about how her mental illness had impacted her experience as a doctor:

My own experience of therapy has taught me how important it is to engage your patient . . . I’ve learned to think: “This is a person like me, perhaps with similar kinds of problems to the ones I’ve had. How can I reach out to them and help?” (Broughton, 2017).

This quote demonstrates how experiences of illness and treatment can positively affect doctors’ ability to communicate with patients. By experiencing an illness first-hand, doctors may be able to use this as an opportunity to connect with patients on a deeper level, something that cannot necessarily be learnt from a medical textbook. Dr Gask went on to say that she handled situations of disclosing
her illness carefully and made sure to disclose in a patient-centred manner. Dr Gask said the following when discussing DSID and professional boundaries:

It’s possible to retain a boundary while still offering a glimpse of your humanity and, though that approach isn’t encouraged, some patients told me they really appreciated it. I’ve never felt any need to hide the fact I was seeking help myself, either. I’ve been treated by colleagues and told I could wait in private, away from the waiting room, as if I’d be worried about the risk of being spotted by a patient or colleague who recognised me . . . We really are not being honest with ourselves if we say that we’re against stigma, but we won’t sit and wait with those we treat. I’ve spent years telling people that mental health issues are nothing to be ashamed of, so why would I do otherwise? (Broughton, 2017).

In this quote, Dr Gask highlighted the significant barrier between patients and their doctors and suggested that doctors not only feel a stigma when experiencing illness but could also place it on patients as well. Also, from the same article, Dr Shannon Clark, a fetal medicine specialist who had difficulty conceiving, also thought carefully before mentioning her illness experience to patients. She mentioned that she made sure to fully understand the patient before deciding whether a disclosure would be helpful and appropriate; therefore implying that not every patient will find it useful. As previously mentioned, doctors are not immune from becoming ill, but they are also not immune from carrying biases and judgements of others, including patients. This quote also highlights the potential for DSID to be used as a way to break through the societal stigma regarding illness, however, this has not been explicitly explored amongst the existing literature. For example, a doctor could use DSID of their experience of mental illness to intend to help a patient with a similar condition feel accepted and supported

Psychiatric illness carries a significant amount of stigma currently within today’s society. Mental illness can affect a wide range of individuals of different social classes or perceived levels of success, therefore, doctors are no exception. Mental illness and burnout amongst doctors has been widely reported within existing medical literature as well as in the general media (Bianchi, Bhattacharyya & Meakin, 2016; Marsh, 2016). Many doctors suffer from alcoholism, drug abuse,
depression and suicidality, however, there is still a stigma preventing doctors from addressing their own health (Bianchi et al., 2016). These findings suggest that mental illness amongst medical professionals is still an uncomfortable issue that can be considered taboo. Due to the stigma attached to mental illness, doctors may be reluctant to discuss their own experiences of these illnesses with patients. It can be hypothesized, however, that by disclosing their own experiences of mental illness to patients, doctors could help normalise these conditions and reassure patients that they are not alone. Research exploring patients’ perspectives of DSID of psychiatric conditions does not currently exist, therefore it is unclear whether doctors disclosing illnesses relating to mental health provides any benefit to patients.

It has been shown that some doctors believe that although medicine is an innately high stress profession, other factors also play a part in the evidently high mental illness rates amongst doctors (Bianchi et al., 2016). These reasons include the availability of addictive substances such as morphine and specific personality types being drawn to the medical profession. Due to the nature of medicine, some doctors believed that mental illness could have a greater impact on essential tasks such as clinical reasoning and making difficult decisions as opposed to a physical illness. Doctors have been shown to perceive mental illness as more enduring and having a greater risk of recurrence when compared to physical illness. It is unclear how this perception of mental illness amongst medical professionals may impact their willingness to disclose psychiatric illness with patients as well as colleagues. It is possible that these perceived characteristics may deter doctors from disclosing experiences with mental illness due to fear of judgement as well as others losing confidence in their clinical ability. For example, a patient may be uncomfortable with their doctor disclosing a history of mental illness as they could interpret their doctor as being unfit to practice and unable to provide a sufficient standard of medical care.

The potential for career implications should not be overlooked when exploring doctors’ reasoning regarding the disclosure of personal illness. Past research has
demonstrated that some doctors have felt that they were victims of discrimination, marginalisation and judgement in the workplace as a result of their illness (Klitzman, 2008, p. 128). These findings were also found in cases of illnesses with significant stigma such as psychiatric illness and HIV. For example, some doctors suffering from mental illness felt stigmatised by colleagues who believed that they were at fault for their own health problems. A paediatrician described her experience with stigma against her mental illness by saying: ‘Cancer’s not your fault. You can’t help it. But doctors view mental illness as my own fault. I felt it in conversations about other people: a lessening of respect for the person who had it’ (Klitzman, 2008, p. 134). It has not been fully explored as to whether doctors also fear being blamed for their mental illness if they decide to disclose it to patients.

Fox et al. (2009) have argued that the professional role of doctors, as well as the belief that illness only relates to patients, contributes to problematic attitudes towards illness amongst medical professionals. The article, ‘Illness doesn’t belong to us’ by McEvitt and Morgan (1997) has investigated how doctors view becoming ill. They conducted one-on-one interviews with doctors and doctors-in-training who had recently experienced an illness of one month or greater. Many of the doctors with mental illness lacked awareness that their symptoms may not be as minor as they initially perceived them to be. All of the doctors with psychiatric illness felt a sense of shame, humiliation or fear after being viewed as mentally ill. For example, one doctor said, ‘It felt horrible to be a doctor with an illness. Being a doctor heightened a sense of failure and inadequacy and guilt. Everyone presumes you should be above it and it’s seen as a sort of failure’. This quote highlights the immense pressure on medical professionals to be healthy and exhibit a superhuman image to the outside world, and this is based on a standard they have set for themselves. This suggests that doctors may be apprehensive to disclose their personal experiences of illness with patients and colleagues due to fear of being perceived as inadequate or unfit to fulfil their responsibilities as a doctor. One of the doctors interviewed acknowledged that the competitive nature of medicine was a reason why she hid evidence of her illness from others. Another
issue which arose from the interviews was that doctors felt uncomfortable formally seeing a doctor themselves; some ultimately deciding to diagnose and treat themselves. Those that suffered from mental illness were especially concerned about the confidentiality of their health information if they decided to see a doctor, this has also been demonstrated in more recent literature (Bianchi et al., 2016; Hassan, Ahmed, White & Galbraith, 2009). This is an interesting finding as it suggests that doctors feel ashamed of suffering from psychiatric illness, but whether and how this may impact upon whether doctors decide to disclose mental illness to patients is unknown.

The concept of doctors-as-patients has also been explored within the literature as it relates to the archetype of ‘the wounded healer’ (Daneault, 2008). The archetype of the wounded healer, first described by psychiatrist Carl Jung, demonstrates the value of one’s woundedness in the context of the therapeutic relationship (Zerubavel & Wright, 2012). The concept of the wounded healer has been explored within the field of psychotherapy but less in medicine. The journal article titled, ‘The Dilemma of the Wounded Healer’ by Zerubavel and Wright (2012) has explored the connections between past illness and the healing power these experiences can provide for patients. This is an interesting idea as it could suggest that DSID could provide benefit to patients when recovering from illness, however, there is a lack of research specifically exploring this possibility. The article describes how ‘being wounded in itself does not produce the potential to heal; rather, healing potential is generated through the process of recovery’. This highlights the important distinction between woundedness and impairment. This statement argues that the concept of the wounded healer specifically relates to past illness (i.e. post-recovery), therefore, current or unresolved illness does not hold the same potential for healing. Based on these conclusions, it can be hypothesized that DSID relating to doctors’ current illnesses may be less beneficial than disclosure of those that have been resolved. The concept of the wounded healer describes harnessing the wisdom that comes with illness to heal others; this is different from reopening past wounds when attempting to heal prematurely. It is unclear whether doctors disclosing their experiences of illness
with patients represents this archetype and could therefore help patients to heal from their own ‘wounds’.

This section has highlighted the complexities involved when doctors experience the dual-role of doctor and patient. The existing literature exploring this topic have illustrated the potentially transformative power of illness and how it can impact the way in which doctors interact with their patients. This section has also shown, however, the potential risks doctors face when sharing their illnesses with others. Doctors have a duty to adhere to the ethical principle of non-maleficence and, *prima facie* should not burden the patient with their own health issues that may not be adequately addressed.

### 2.6 Doctor Self-Illness Disclosure

Doctor self-illness disclosure (DSID) has had little focus in recent medical literature. One of the few studies exploring this topic is ‘Disclosures of illness by doctors to their patients: A qualitative study of doctors with HIV and other serious disorders’ by Klitzman and Weiss (2006). This study involved the completion of individual interviews with health professionals who had suffered from serious illnesses. The interviews aimed to explore the issue of DSID from the doctor’s perspective and highlight the various ethical dilemmas DSID encompasses. Many of the health professionals who participated in this study were conflicted as to whether to disclose their illness to their patients as well as the depth of information they should share. The authors described the issue of a patient observing physical signs of illness in their doctor. One of the doctors studied said the following when talking about his experience with cancer: ‘Since my hair was gone, patients were aware of it. I couldn’t hide it. They’d ask how I was, and it deepened the relationship. I didn’t tell every patient. I didn’t want them to worry’.

Continuing their analysis of DSID, Klitzman and Weiss (2006) explored doctors’ reasoning for or against disclosing their illnesses to patients. Some doctors used DSID as an opportunity to provide valuable insight to their patients and believed
that this could help patients with medication adherence and reassure them about treatment options. The paper argued that ‘at times with HIV and other disorders, a doctor’s disclosure could benefit relationships with patients, engendering trust’. It also described the concept of DSID as a web of communicative possibilities between doctors and patients. It was explained that patients may directly ask their doctor about their health, indirectly ask, or not ask at all. Conversely, doctors who are ill could truthfully disclose, decide not to disclose, misrepresent their illness, or directly deny their illness. It was recognised that there are multiple possible consequences of DSID including strengthening the doctor-patient relationship and skewing the doctor-patient relationship.

The stigma carried by some illnesses proved to be an important factor for many doctors when considering DSID (Klitzman & Weiss, 2006). For example, some doctors with HIV even admitted to denying that they were unwell to avoid judgement from others. Interestingly, some even feared negative career implications resulting from DSID; one doctor described this by saying, ‘I would be causing sensationalism in the papers. I don’t think it would be a good for my profession: A bad advertisement’. Some of the doctors were apprehensive to disclose their illness to patients as it felt selfish and unnecessary. For example, one doctor said, ‘… [DSID] seems to take the focus away from why they’re here. Making the focus of a patient’s interaction on how I’m doing just doesn’t seem best’.

Recent research from the New Zealand study, ‘General Practitioners’ Ethical Decision-Making: Does Being a Patient Themselves Make a Difference?’ has shown that GPs have widely varying opinions on the ethics of disclosing personal illness to patients (Hall et al., 2018). This study involved gathering qualitative data from ten GPs who had been patients with a serious illness, and ten who had not, and comparing their responses to multiple clinical case vignettes. Widely differing views on the issue of DSID were found. For example, one GP participant stated that they would ‘Absolutely, all the time [disclose]’, whereas another thought it was ‘really annoying’ when her own GP disclosed their illness to her. Other areas of concern were the usefulness of DSID to the patient, whether it demonstrated
empathy in the doctor-patient relationship and whether it would be appreciated by the patient. This study found that the reasons the GPs had for and against doctor self-illness disclosure were mainly patient-centred and focused on helping the patient. One of the reasons against the use of DSID was that it had the potential to shift the focus of the consultation towards the doctor and away from the patient. Alternately, a belief held by some of the GPs was that DSID could improve the communication and openness in the relationship. Similar results have been found regarding this issue in medical literature in New Zealand and overseas (Allen & Arroll, 2015; Klitzman & Weiss, 2006).

A study titled, 'What happens when doctors are patients? Qualitative study of GPs’ has shown that doctors recognise the benefits as well as the risks of using DSID with patients (Fox et al., 2009). Some of the doctors studied believed that DSID should be considered on an individual basis depending on the patient’s needs. For example, one of the doctors explained this by stating the following:

*I think you have to be wise about who you share things like that with, um, and there are some patients who find it really helpful, it’s really beneficial but there are some people who I know it wouldn’t be terribly wise to open oneself up to in that way because they might actually... not abuse it but just take advantage of it inappropriately. So, I think you must be a bit careful about sharing that sort of information, but for some patients I think it... it is really quite helpful, quite useful* (Fox et al., 2009).

The above quote highlights the case-by-case approach some doctors adopt concerning DSID in order to tailor their communication from patient to patient. This quote implies that doctors may view DSID as beneficial in some cases, whereas unnecessary in others depending on the individual patient.

These studies have focused primarily on doctors’ beliefs and experiences concerning DSID, therefore it is unclear whether patients share this same perspective. The lack of literature exploring patients’ opinions of DSID is significant and emphasises the need for additional research in this area.
2.7 Duty to Warn

DSID has been heavily investigated in the context of potentially fatal, transmissible diseases such as HIV and the duty to warn patients of potential harms (Klitzman & Weiss, 2006). Alternately, voluntary self-disclosure of illnesses which are not as potentially harmful has had a lesser focus. In addition, some illnesses could alter a doctor’s clinical ability in a less obvious sense, such as fatigue and decreased alertness. It is unclear whether these scenarios would, or should, form part of an informed consent process and should be divulged to the patient.

The 1991 case of Hidding V. Williams involved a surgeon failing to disclose his chronic alcohol abuse to his patient prior to performing spinal surgery (Spielman, 1992). The surgery resulted in the patient being unable to control his bowel and bladder, causing him to be incontinent. The court ruled that, by failing to disclose his chronic alcoholism, the surgeon violated the principle of informed consent. Spielman (1992) has detailed the potential consequences of cases such as Hidding V. Williams on medical professionals in the article, ‘Expanding the Boundaries of Informed Consent: Disclosing Alcoholism and HIV Status to Patients’. In this article, she suggested that doctors may be faced with a loss of privacy concerning their personal health information which could lead to negative effects on their medical reputation and livelihood. These negative implications of doctor self-illness disclosure are similar to those detailed by Furrow (1996):

*Why should the professional disclose his status, if he knows it? He may see his practice diminish or disappear as patients spread the word. If a hospital or managed care organization finds out, it may restrict his practice and cut his income (Furrow, 1996).*

Furrow (1996) has also discussed the relevance of informed consent obligations in regard to other possible scenarios such as doctors’ declining performance with age and history of malpractice. He argues that, in some cases, doctor self-illness disclosure can lead to patients drawing inaccurate conclusions of the doctor’s competence and ability to practice medicine. He also presents the argument that the responsibility of screening for impairment lies not exclusively with the doctors
themselves but with their employers as well. This research highlights the complexity of doctor self-illness disclosure and where the line is drawn between the doctor’s privacy and the patient’s right to informed consent. Once again, similarly to the existing research regarding SD, there is a lack of research exploring this concept from the patient’s perspective.

2.8 Summary of Literature Review

This literature review has helped to highlight the significant lack of research exploring doctor SD and DSID specifically. Many of the studies previously mentioned have focused solely on doctors’ views of SD. Of those that have explored the patient perspective, many have done so using quantitative research. Prior research has argued that although SD has the potential to add to the doctor-patient relationship, it may also have profound negative effects that should not be ignored or dismissed. After an exploration of the literature, it is apparent that there is an opportunity for research regarding patients’ perspectives on DSID. The purpose of this study is to help bridge this current gap within current medical ethics literature and inform general practitioners and medical students as to what is best practice regarding DSID. This study will focus primarily on the patient’s perspective using a qualitative research approach to investigate how this issue affects patients and the doctor-patient relationship.
Chapter 3  Methods

The aim of this study is to investigate patients’ perspectives on DSID in both rural and urban settings. To accomplish the objectives of this study, an urban and rural phase of data collection was constructed. The two phases enabled participants’ responses to be compared with those living in a different area, therefore identifying differences between urban and rural communities. I implemented qualitative research methods in the form of one-on-one interviews with urban participants and phone interviews with rural participants to fulfil the aims of this study. The following chapter will outline my procedure for collecting, analysing, and interpreting my data.

3.1  Ethics Application and Māori Consultation

Category A ethical approval from the University of Otago Human Ethics Committee was obtained before the study commenced. A copy of the final approved ethics application can be found in appendix A. All research conducted at The University of Otago involving human participants requires some form of ethical approval to maintain an appropriate standard of research ethics. This study did not recruit participants in their role as consumers of health and disability services, therefore it did not require ethical review from the Health and Disability Ethics Committee. Category A ethical approval is required for all research involving human participants who are not recruited as patients (i.e. not health research). Although this research is related to health care, the study does not directly relate to the participants’ care. Following the initial submission of an ethics application, adjustments to the original proposed research study were mandated before approval could be given.

The primary concerns of the ethics committee were the secure storage of the interview recordings, personal details of the GPs involved and confidentiality of the interview transcripts regarding the professional transcription service.
Following notification of these concerns, procedures were put in place to address these issues in greater detail. A client non-disclosure agreement was obtained from the professional transcription service to ensure that all interview recordings and transcripts would be kept confidential and would not be distributed (Appendix B). A reminder sheet, to be given to participants prior to the commencement of their interviews, was drafted to prevent irrelevant or inappropriate information from being disclosed (Appendix A). This sheet outlined what information was and was not required during the interviews, therefore notifying participants which potentially identifiable details should be omitted from their responses. A clear outline of all possible interview questions was required by the committee before ethical approval could be granted.

The mandated changes were completed to protect the privacy of GPs’ illness information and the security of transcription data. These requirements constrained the interview style, resulting in the interviews following a more structured approach rather than an open-ended style.

A research proposition was also sent for consultation and input from the Ngāi Tahu Research Consultation Committee for Māori Consultation, as required by University policy. Following this, the committee sent a letter of support for the commencement of the study and acknowledged its relevance to Māori health (Appendix C). These tasks began in January of 2018 and approval was obtained by April of 2018.

### 3.2 Interview Questions

The interviews were designed to focus on the interviewees’ experience, thoughts, and feelings about a doctor self-disclosing to them about their own personal illness or illness experience. A draft ‘menu’ of possible interview questions was devised in response to the ethics committee’s concerns about data security and GP privacy. These questions centred on multiple facets of inquiry including: What happened? How did this make them feel? How did this impact upon the doctor-
patient relationship? Did it alter their decision-making in any way? Did they think the disclosure was necessary or helpful? Did they believe the doctor acted appropriately? Each question included in the 'menu' was carefully considered in regard to its purpose and relevance to the central research question.

The questions were framed from a neutral stand-point to minimise the influence they could have on participants’ responses. The majority of the questions were open to a degree or enabled room for further discussion to allow for participants’ complete responses to be explored. Question structure and language was kept simple and focused to minimise confusion. The questions used during each individual interview were tailored according to the interviewee’s initial answers, therefore the order and choice of questions varied across the interviews. By retaining this flexibility in interview structure, I aimed for the interviews to have a natural flow and for participants to feel relaxed and heard. The interview question menu was kept the same between the urban and rural phases to facilitate comparison, save for an additional question of rural interviewees (question 25 in the table 3.1) in order to ascertain how living in a rural community impacted interviewees’ perception of DSID.

I anticipated the interviews would range from 30 to 60 minutes in length.

Table 3.1 Final Question Menu

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>How long ago did the disclosure occur?</td>
</tr>
<tr>
<td>2.</td>
<td>Why was this memorable?</td>
</tr>
<tr>
<td>3.</td>
<td>How did it make you feel at the time? How do you feel about it now?</td>
</tr>
<tr>
<td>4.</td>
<td>Did it influence the consultation for you? If so, how?</td>
</tr>
<tr>
<td>5.</td>
<td>Without letting me know why you were seeing the doctor; did it influence any decisions you had to make? If so, how?</td>
</tr>
<tr>
<td>6.</td>
<td>Looking back, was the disclosure helpful to you in any way? Or was it not helpful?</td>
</tr>
<tr>
<td>7.</td>
<td>Has the disclosure caused you to think differently about your doctor? Positively or negatively?</td>
</tr>
<tr>
<td></td>
<td>Question</td>
</tr>
<tr>
<td>---</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>8.</td>
<td>Do you think it was OK for the doctor to disclose this information to you?</td>
</tr>
<tr>
<td>9.</td>
<td>Do you think all doctors should be able to do this?</td>
</tr>
<tr>
<td>10.</td>
<td>Why do you think the doctor disclosed this information to you?</td>
</tr>
<tr>
<td>11.</td>
<td>Were you told by the doctor that you should keep this information a secret? Do you think a patient should keep this type of information secret?</td>
</tr>
<tr>
<td>12.</td>
<td>Do you think there are any circumstances in which it would ALWAYS be OK for doctors to give health information about themselves to patients?</td>
</tr>
<tr>
<td>13.</td>
<td>Do you think there are any circumstances in which it would NEVER be OK?</td>
</tr>
<tr>
<td>14.</td>
<td>Do you think there are any diseases or illnesses which the doctor had had which would ALWAYS be OK for doctors to give health information about themselves to patients?</td>
</tr>
<tr>
<td>15.</td>
<td>Do you think there are any diseases or illnesses which the doctor had had which it would NEVER be OK?</td>
</tr>
<tr>
<td>16.</td>
<td>Do you think you would have had a different response to the disclosure if the illness was more or less serious?</td>
</tr>
<tr>
<td>17.</td>
<td>When do you think it would be appropriate for a doctor to disclose their illness or illness experiences to a patient?</td>
</tr>
<tr>
<td>18.</td>
<td>Do you think the doctor acted appropriately?</td>
</tr>
<tr>
<td>19.</td>
<td>Do you think doctors should be encouraged to share their illnesses with patients?</td>
</tr>
<tr>
<td>20.</td>
<td>When the disclosure occurred, did you think the doctor was acknowledging or dismissing your concerns?</td>
</tr>
<tr>
<td>21.</td>
<td>Do you think the doctor ‘crossed a line’ when they disclosed this information to you?</td>
</tr>
<tr>
<td>22.</td>
<td>Did the disclosure make you feel closer or more distant to your doctor?</td>
</tr>
<tr>
<td>23.</td>
<td>After the disclosure, did you feel more understood or less understood by your doctor?</td>
</tr>
<tr>
<td>24.</td>
<td>What do you think about doctors disclosing about their mental illness to patients?</td>
</tr>
<tr>
<td>25.</td>
<td>Do you think there would be any differences to your experience if you were living in a city rather than a rural community? (Rural participants only)</td>
</tr>
</tbody>
</table>
3.3 Practice Interviews

I completed two practice interviews with professional actors prior to conducting the actual interviews. The actors were advised to follow fictional scenarios written by my supervisors to prepare me for situations that could arise in the actual interviews. I had no knowledge of the scenarios prior to the interviews. These interviews covered various issues including the following:

- Professional boundaries between researcher and participant, specifically relating to inappropriate sexual advancements and personal safety.
- Managing highly emotional participants (including anger and tearfulness).
- Participants disclosing information that was irrelevant to the study and/or does not fall under the ethically approved categories of data collection.
- Participants inquiring about making a formal complaint regarding their medical care.

The scenarios were based primarily on situations that I anticipated would be challenging for me as well as ideas suggested by my supervisors. These practice interviews, therefore, gave me an opportunity to prepare for any potentially challenging or uncomfortable situations that could arise during the actual interview phase of the study. Full outlines of both interview scenarios can be found in appendix D.

Both of the interviews were supervised by my supervisors to allow me to receive constructive feedback on my performance. The actors were also given the opportunity to share their perspective on what went well and what needed improvement. These interviews allowed the menu of questions to be tested and for any minor adjustments to be made before conducting the actual interviews. Each of the practice interviews and subsequent discussions were completed in approximately 60 minutes.
3.4 Recruitment of Participants

To recruit participants for the urban phase of the study, I displayed a poster advertisement in supermarkets, GP practices, pharmacies and university grounds within Dunedin. The poster advertisement included a brief summary of the aim of the study, inclusion criteria and contact details for Dr. Hall and myself. The inclusion criteria for the urban phase consisted of the following:

- Aged 18 years or older
- Enrolled at a Dunedin general practice
- Fluent in English
- Having had at least one experience with their GP disclosing a personal illness or illness experience when they had an appointment with them

The exclusion criteria consisted of the following:

- Present or past patients of Dr. Katherine Hall or Dr. Martyn Williamson
- Not being fluent in English
- Aged 17 years or younger

Recruitment of participants for the rural phase of the study was conducted primarily through newspaper advertisements in ‘The Southland Times’ and ‘Central Otago News’ newspapers. Participants living within Southland or Central Otago were eligible to take part in a phone interview. Apart from the locational difference, inclusion and exclusion criteria were kept the same for the rural and urban phases of the study.

I used a cell-phone owned by the Department of General Practice and Rural Health for the purposes of recruitment to ensure the privacy of my personal contact details. Once initially contacted by potential participants, I sent them a copy of the participant information sheet (Appendix A) by email or by post. Prospective participants were asked to read the information sheet before deciding whether to
take part in the study. The information sheet detailed the aims of the study, the interview process and how the data would be used to enable participants to make an informed decision. Once participants were happy to continue with the study, and any questions the participants had were answered, an interview time was agreed upon according to their schedule and availability. Participants were made aware that they could change their mind at any time regarding their participation in the study at no disadvantage to themselves.

3.5 Data Collection and Transcription

Data was collected through one-on-one interviews with each participant. Interviews were conducted in a private room within the Department of General Practice and Rural Health or via phone. Interviews were held at varying times depending on the participants’ schedules. Prior to each interview, I explained the purpose of the research and what information I was hoping to gain. Participants were given the opportunity to ask questions or voice concerns prior to the interview process. Participants were asked whether they were comfortable with their interview being recorded before being given a consent form to sign. To meet the ethical obligations relevant to the study, each participant was asked to read a reminder sheet outlining what information was not required for them to share (Appendix A). Participants were not required to share their own medical history as well as information that could identify the GP involved. The gender, age and ethnicity of each participant was recorded for demographic purposes. All participants agreed for their interview to be audio recorded and transcribed. Supermarket vouchers valued at $20.00 were given to all participants in acknowledgement for their time and cooperation.

Interviews were conducted until data saturation had been reached; this was identified as the point at which no new information was gathered from additional interviews (Glaser, Strauss & Strutzel, 1968). Once data saturation was initially suspected, an additional interview was conducted to confirm this.
Each interview was professionally transcribed by ‘Rev Transcription Services’ and later reviewed and amended by myself to correct any mistakes. Each interview transcript was anonymised by removing participants’ names and any potentially identifying information before analysis. In order to protect their identity, all participants were contacted after their interview to agree on a pseudonym to be used in the results and any future publications. Participants were given the opportunity to decide on their own pseudonym if this was preferred.

3.6 Member Validation

Member validation was used as a quality control procedure whilst conducting the research (Braun & Clarke, 2014). This involves cross-checking analysed data with participants to ascertain whether the analysis aligns with the true meaning of the participants’ responses. Braun and Clarke describe this process as:

*Presenting a draft written or oral report of the research, or just of the analysis, to some or all participants, and asking them to comment on the trustworthiness or authenticity of what has been produced (Braun & Clarke, 2014, p. 282).*

To ensure participants’ responses were not misrepresented within the analysis, some participants were provided with a brief summary of their analysed responses to check the validity. Participants were able to communicate any discrepancies between their intended meanings and the analysed data. This process served as a safety measure to prevent misrepresentation of participants’ views and opinions. This process assesses the reliability of qualitative data by determining ‘that the results are credible and dependable, from the point of view of the participants’ (Braun & Clarke, 2014, p. 282).
3.7 Thematic analysis

I decided to use thematic analysis methods when analysing my interview data. As discussed in the previous chapter, the subject matter of this study is not well explored within current medical literature. Due to the lack of extant research in this area, qualitative methods were most appropriate for data collection. This is because qualitative research ‘tends to be theory generating, and inductive (working up from the data)’ (Braun & Clarke, 2014, p. 236). This means that qualitative research often does not aim to prove an existing theory or hypothesis, but instead to generate these ideas in the first place. In the following paragraphs, I will provide reasoning for my decisions regarding data analysis and further detail my approach.

Qualitative research can be distinguished from quantitative research as it primarily uses language rather than numbers as data (Braun & Clarke, 2014). Qualitative methods typically enable rich data to be gathered from participants as opposed to the sometimes-superficial information that can be collected quantitatively. Because of the depth of the data gathered through qualitative methods, a broad sample of participants isn’t always necessary to gain information surrounding a subject.

I used the paper ‘Using Thematic Analysis in Psychology’ to help inform my decision-making regarding methodology (Braun & Clarke, 2006). The authors describe thematic analysis as an accessible and flexible method that can help to provide a rich understanding of the data set. Thematic analysis has been widely used as a tool in qualitative research. It has been argued that ‘thematic analysis should be seen as a foundational method for qualitative analysis’ and therefore is ideal for use by those new to qualitative research such as myself (Braun & Clarke, 2006).

Thematic analysis is defined as ‘a method for identifying, analysing and reporting patterns within data’ (Braun & Clarke, 2006). The process of thematic analysis can
be broken down into steps beginning with engaging with the data set and ending with a written report of the analysis. An overview of how I conducted the analysis is shown in the table below:

Table 3.2 Thematic Analysis Process, as modified from Braun and Clarke, 2006

<table>
<thead>
<tr>
<th></th>
<th>Engaging with the data:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I reviewed the whole data set by reading and re-reading all of the interview transcripts multiple times. This process allowed me to engage with the results and become familiar with the data.</td>
</tr>
<tr>
<td></td>
<td>During this phase of analysis, I highlighted initial areas of interest for further exploration. These areas of interest consisted of quotes which stood out to me for one reason or another and did not necessarily have to align with the overall research question.</td>
</tr>
<tr>
<td></td>
<td>I spent a comparable amount of time on each data item (e.g. each interview transcript) to ensure that I engaged with the data fully.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Coding the data:</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>This phase can be further broken down into preliminary and secondary coding.</td>
</tr>
<tr>
<td></td>
<td>Preliminary coding describes the initial coding process which involves attaching labels to items of interest within the data. During this process, I assigned distinct codes to small sections of dialogue within the transcripts in order to broadly organise the information.</td>
</tr>
<tr>
<td></td>
<td>Secondary coding represents reviewing the data set multiple times to comprehensively code the data so that the information can be easily organised. These additional rounds of coding enabled me to revise the existing codes and make sure all aspects of the data were acknowledged.</td>
</tr>
</tbody>
</table>
3 **Identifying and building themes:**

- After completing the coding process, the data extracts were organised according to their codes and subsequently further organised into themes.
- This was a dynamic process involving drawing up an initial map of how each theme relates to each other.
- I expanded upon the initial themes to gain a clear picture of what each theme represents.
- The themes were later refined and adapted in order to showcase the true essence of the data set as a whole.

4 **Writing a report of the analysis:**

- I gathered supporting coded extracts from the data to support the sub-themes and themes.
- The evidence gathered for each theme helped to form the basis of the written summary of the findings.
- I contextualized the results within the wider medical literature and described the possible implications of the research.

Due to the inherent flexibility of thematic analysis as a methodology, I made sure to follow this systematic and thorough strategy (see table 3.2). Once all interviews were completed and transcribed, I read through all of the transcripts several times to immerse myself in the data. During the early reading process, I recorded any initial items of interest or obvious patterns within the data. Although interesting points that were not directly relevant to the aims of the study were acknowledged, data analysis was primarily guided by the original research question. I tried to spend a similar amount of time reading through each transcript to give each transcript equal attention.
As I continued to review the transcripts, I was able to assign preliminary codes to sections of data. The coding process involved attaching labels to meaningful chunks of the data to enable it to be clearly organised. This process is subjective as I coded the data according to what I personally considered meaningful or significant. This stage of the analysis was guided by the research question, therefore the codes reflected this. Many codes directly related to participants thoughts and feelings regarding their DSID experience. For example, positive and negative opinions towards DSID were coded accordingly as well as participants’ reasoning for these views. These processes were completed multiple times in order to thoroughly code the data and compile data extracts according to their corresponding labels.

The codes used within the data directly guided the process of identifying patterns that were later built into themes. It is notable that there is not a rigid set of rules to determine what qualifies as a theme (Braun & Clarke, 2006). A theme can be defined in a variety of ways, such as the following explanation from Braun and Clarke:

\[
A \text{ theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set (Braun & Clarke, 2006).}
\]

Themes also do not necessarily directly relate to the frequency of that idea within the data; greater importance is placed on whether the theme is perceived as significant in relation to the overall research question.

The task of constructing themes within the collected data was a dynamic process that involved constant shuffling of the codes and patterns before developing the final organisation of themes. I began this process by grouping codes together which shared one or more commonalities; for example, I clustered codes relating to positive and negative responses together as they all related to emotional reactions to DSID. Once I had organised the codes into these logical groups, I could visualize how they could be built up to create broader over-arching ideas that
could potentially become themes. I visualized how the codes, sub-themes and themes related to each other by constructing thematic diagrams. These diagrams followed a ‘tree-like’ structure with codes acting as the foundation or ‘roots’ and merging to create sub-themes and subsequently themes.

Many sections of data could be labelled with multiple codes and therefore contribute to multiple groups. Due to this, I was able to identify horizontal connections between codes and not just vertical connections from codes to sub-themes and themes. I repeated the process of constructing thematic diagrams until I was satisfied that it accurately represented key ideas within the data. I used this framework to organise coded sections of the interview transcripts and therefore guide my written report of the findings.

### 3.8 Personal Perspective

As discussed by Braun and Clarke, the researcher plays an active role in qualitative data analysis instead of just passively presenting the data (Braun & Clarke, 2006). They argue that themes are not ‘discovered’ and don’t simply ‘emerge’ from the data set; instead the researcher creates the themes through their own unique perspective. It is this idea that forms the basis of why acknowledging the researcher’s impact on the analysis is integral to completing a quality thematic analysis. It is important to note that the researcher still has a responsibility to acknowledge the true essence of the data and not manipulate the findings to fit their personal views.

It is important to acknowledge my key role in this study and reflect on how my background and characteristics have shaped this research. This brief explanation of my personal perspective will help to place the following results chapter in context. I am a female university student and completed my third year of my medical degree in 2017. My ethnicity is Pākehā/NZ European, and I have lived in a rural community prior to enrolling at university. I am not completely aware of all of the ways in which my personal characteristics may have influenced the way I
have carried out this research study. Despite this, it is likely that my background played some role in how I interviewed participants, analysed interview data and interpreted the results of the study.

By debriefing with my supervisors during the interview process, I was able to discuss experiences that I found challenging or confronting. These discussions enabled me to acknowledge my personal reactions to the participants and their interview responses. Acknowledging my own thoughts and feelings whilst conducting the research allowed me to own my personal perspective and help me prevent it from inappropriately influencing the findings.
Chapter 4  Results

The following chapter will focus on detailing the results obtained from the interviews as well as presenting a summary of the demographic data of the participants. This chapter will serve as an overview of the findings of the study before contextualising these results in the discussion.

4.1  Participants

A total of fifteen people participated in the study. Of the fifteen participants, twelve lived in an urban area while the remaining three lived in a rural area. Of the three rural participants, only one fully satisfied the inclusion criteria and therefore the remaining rural participants were excluded from the final study and subsequent data analysis.

During the recruitment process, I aimed to have a diverse group of participants across gender, age and ethnicity variables. The participants varied in age from eighteen to sixty-nine and consisted of eight females and five males. The majority of the participants involved in the study were of NZ European/Pākehā descent. Greater diversity regarding ethnicity amongst the participants would have been preferred in order to have a sample that is representative of the NZ population; however, this was limited due to the small number of participants successfully recruited to the study. According to the 2013 census, 74% of New Zealanders self-identified as European while 15% self-identified as Māori (“Major ethnic groups in New Zealand”, 2015). From these statistics, it can be concluded that Māori people were underrepresented in this study.

Recruiting rural participants proved difficult as only a small number (i.e. three) of potential participants showed interest in taking part in the study, and even fewer (i.e. one) satisfied the relevant criteria. Due to this, I was unable to fully explore
how rural participants felt about DSID and whether or not this was comparable to urban participants.

An overview of the participants is shown in table 4.1; all names have been changed in order to preserve participants’ anonymity.

Table 4.1 Demographic Summary of Participants

<table>
<thead>
<tr>
<th>Participant:</th>
<th>Name:</th>
<th>Age:</th>
<th>Gender:</th>
<th>Ethnicity:</th>
<th>Urban/Rural:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Sandra</td>
<td>27</td>
<td>Female</td>
<td>Chinese</td>
<td>Urban</td>
</tr>
<tr>
<td>2</td>
<td>Dena</td>
<td>67</td>
<td>Female</td>
<td>NZ European/Pākehā Māori</td>
<td>Urban</td>
</tr>
<tr>
<td>3</td>
<td>Russell</td>
<td>61</td>
<td>Male</td>
<td>NZ European/Pākehā</td>
<td>Urban</td>
</tr>
<tr>
<td>4</td>
<td>Kristie</td>
<td>18</td>
<td>Female</td>
<td>NZ European/Pākehā</td>
<td>Urban</td>
</tr>
<tr>
<td>5</td>
<td>Adam</td>
<td>52</td>
<td>Male</td>
<td>NZ European/Pākehā</td>
<td>Urban</td>
</tr>
<tr>
<td>6</td>
<td>Peter</td>
<td>69</td>
<td>Male</td>
<td>NZ European/Pākehā</td>
<td>Urban</td>
</tr>
<tr>
<td>7</td>
<td>Lee</td>
<td>19</td>
<td>Male</td>
<td>NZ European/Pākehā</td>
<td>Urban</td>
</tr>
<tr>
<td>8</td>
<td>Tara</td>
<td>30</td>
<td>Female</td>
<td>NZ European/Pākehā</td>
<td>Urban</td>
</tr>
<tr>
<td>9</td>
<td>Lydia</td>
<td>51</td>
<td>Female</td>
<td>NZ European/Pākehā</td>
<td>Urban</td>
</tr>
<tr>
<td>10</td>
<td>Tegan</td>
<td>35</td>
<td>Female</td>
<td>NZ European/Pākehā</td>
<td>Urban</td>
</tr>
<tr>
<td>11</td>
<td>Stephen</td>
<td>57</td>
<td>Male</td>
<td>NZ European/Pākehā</td>
<td>Urban</td>
</tr>
<tr>
<td>12</td>
<td>Renee</td>
<td>35</td>
<td>Female</td>
<td>NZ European/Pākehā</td>
<td>Urban</td>
</tr>
<tr>
<td>13</td>
<td>Lisa</td>
<td>43</td>
<td>Female</td>
<td>NZ European/Pākehā</td>
<td>Rural</td>
</tr>
</tbody>
</table>
4.2 Thematic Analysis

A range of overarching and interlinking themes were built from the coded interview transcripts. These themes spread across a range of topics including the role of patient and doctor, the therapeutic relationship and professionalism. It is important to note that these themes cannot be organised into discrete linear groupings; this is because the themes interact with each other in various ways across the data and do not exist exclusively and independently of each other. Therefore, to present the data according to this structure, the following sections are organised according to the major themes, but each section also encompasses aspects of other themes and sub-themes. Each section is supported with extracts from participant interviews. Any potentially sensitive information about the illnesses disclosed has been redacted from these extracts in order to protect the identity of the doctors involved.

4.2.1 Emotional Reassurance and Support

The majority of the interviews began by asking participants why their experience of DSID was memorable for them. Many of the interviewees were able to discuss their experience of DSID in great detail despite it occurring many years ago. The disclosures varied in recency; the most recent occurring three months previously and the oldest occurring six years ago. The mean recency of the disclosures was two and a half years prior to the interview taking place. This highlights that regardless of the response elicited from the disclosure, the disclosure event was significant to many of the participants in one way or another. Although there were varying responses and opinions regarding their experiences, many of them referenced the emotional significance of the disclosure. This section will focus on the prominent theme of emotional reassurance and support. This theme was interwoven through many of the participants' interviews as it often formed the basis of why they had a positive or negative reaction to the DSID. The theme of
emotional reassurance and support also encapsulates sub-themes relating to emotional vulnerability, empathy and the normalisation of illness.

Some of the participants described themselves as being in a challenging or significant stage in their illness journey when the disclosure occurred, of which they thought their doctor was aware. Therefore, in many of these cases, the doctor used DSID as a way to reassure the patient and validate their emotions. Disclosures of this type have been labelled in past literature as reassurance disclosures (Beach, 2004a). Although many of the participants felt that their doctor acknowledged their emotions in a particularly difficult phase of their illness, this feeling was not unanimous. This diversity amongst the participants’ responses could indicate that, despite good intentions, doctors may not always successfully use DSID to convey emotional support.

One participant, Adam, shared a distressing DSID experience with his doctor while he was in a difficult stage of his illness and struggling to cope. Adam explained that his illness had a significant negative impact on his life at the time, therefore subjecting him to a lot of stress. Due to his situation, Adam was experiencing a low mood at the time when his doctor disclosed a similar experience. The following extract outlines Adam’s initial reaction to the disclosure from his doctor:

Interviewer: So, when the doctor disclosed to you, how did it make you feel at the time?
Adam: Pretty embarrassed
Interviewer: So, why did you feel that way?
Adam: Well, because he basically said that my concerns over my health weren’t that important and that he’d been-
Interviewer: Oh, right
Adam: -through similar concerns, and it was no big deal to have them
Interviewer: So, sort of like, diminishing your experience?
Adam: Yeah
The above passage from Adam’s interview demonstrated that although a doctor may have patient-centred reasoning and good intentions when disclosing their own illness experience, it can be perceived as dismissive to the patient. It is possible that in this example, the doctor intended for the DSID to lift Adam’s spirits and reassure him that he had nothing to be concerned about. Adam’s use of the word ‘embarrassed’ is notable as it suggests that his concerns were brushed-off by his doctor instead of being affirmed and acknowledged.

Adam’s story also implied that the doctor held his own similar illness experience as his central vantage point and failed to recognise that although their situations were similar they are not entirely the same. Even though illness can serve as a transformative experience for doctors, it may also narrow their view of the illness and cause them to put similar cases into a box. This demonstrates the important idea that although a doctor and patient may share a similar illness or illness experience, this does not mean their experiences will be the same. Some participants did bring up the idea that although they generally had a positive experience with DSID, they did sense their doctor did assume they would have similar experiences with illness.

In contrast to other participants describing their experience of DSID as emotionally uplifting and reassuring, Adam described the experience as making him feel hopeless and as if he was “going into a headwind”. From these contrasting perspectives, it is clear that there is not one set approach that will be effective with every patient. Due to his strong negative reaction toward his doctor’s use of DSID, Adam ultimately decided to seek out another GP despite their long relationship. This example demonstrates the significant risks involved when using DSID to comfort patients in a highly emotional or vulnerable state regarding their health.

Despite this negative example, many participants had a positive perception of DSID and its use as a way to comfort patients emotionally. Participants such as Sandra, greatly appreciated their doctor’s disclosure as it aided in settling their
emotions while they were unwell. Sandra recalled her experience of DSID as occurring in an intense time in her life which was made more stressful due to her illness. By sharing a similar experience, the doctor enabled Sandra to understand her illness and her emotional response better. Sandra even described the emotional support provided by her doctor as a form of medicine in itself:

*Actually, the doctor would share her whole experience about way back when she was studying... So, I feel [sic] more connected and supported in that way. Even though it’s not really an instant medication or medicines that made me feel better. But, then it’s still helping me to think about what I should do or, yeah, just a little bit more of connection knowing why or why I will feel that – Sandra (Participant 1)*

These contrasting examples both showcase the crucial emotional component of illness that shouldn’t be overlooked. Sandra’s description of how her mood improved due to her doctor’s simple self-disclosure emphasises the impact communication alone can have on patient’s wellbeing.

Many participants appreciated their doctor’s disclosure as it helped them to feel supported and understood by their doctor. Some participants recognised that their doctor had patient-centred intentions for disclosing and therefore used DSID as a way to establish empathy. For example, Lee believed that his doctor understood the significant impact that illness was having in his life at the time and was prompted to use DSID as a way of providing reassurance.

Lee: I think he might have said it to reassure that once it’s done [treatment], it’s done... as long as you follow these guidelines and it shouldn’t be a problem
Interviewer: Okay, you think he had a purpose in mind. Sort of reassuring you because you’re a little bit anxious and unsure about it?
Lee: Yeah, yeah
Interviewer: Is that right?
Lee: Yeah, we were wanting to know... We were asking a lot of questions
Interviewer: Yeah
Lee: A lot of stuff going on in terms of work, university, so I wanted to be clear. I think that might have been why he did it.

Throughout Lee’s interview, he emphasised how his illness impacted aspects of his life at the time; this included his living situation, physical activity and university studies. Because of this, his doctor shared his experience of a similar illness and successful treatment as a way of putting him at ease. The extract above from the interview outlines Lee’s thoughts regarding his doctor’s intentions for using DSID. In this extract, Lee described how his doctor used DSID as a way to reassure him about treatment options for his illness. Lee believed that his doctor was able to recognise the impact his illness was having on his quality of life and therefore wanted to reassure him that the treatment will help him get back to his usual lifestyle. Lee’s experience serves as an example of how DSID can be used in a patient-centred way to provide support during the treatment phase of their illness.

Similarly to Lee, many participants acknowledged that their doctor had clear patient-centred intentions for using DSID. This meant that a large proportion of the participants believed that their doctor primarily used DSID to provide support rather than shift the focus onto themselves. For example, Tara believed that her doctor recognised that she was struggling to cope with her injury and needed reassurance and support. Tara described her experience in the extract below:

Interviewer: So why do you think she disclosed that information to you?
Tara: I think she could probably tell that I was pretty, sort of, I wouldn’t say depressed about it. But that my injury had been making me feel very, sort of melancholy, about the state of my body and the fact that I’ve been through all these different treatments. Some of it [the treatment] alleviated it a bit at the time. But then, sometimes it seemed to be a bit
worse, and so, I think she just wanted to tell me about her own injury so that I could, yeah, relate to it

Interviewer: Yeah, so you think that sort of came from a place of wanting to help you, through her experience...
Tara: Yeah

In this excerpt, Tara implied that her doctor picked up on her low mood regarding her injury and believed that DSID could give her renewed hope regarding her recovery. She also acknowledged that her doctor used their similar experiences as a way to connect with her and establish empathy. These findings further demonstrate the use of DSID as a method of emotional reassurance for patients.

Despite participants often believing that DSID could provide much needed emotional support and reassurance, some suggested that DSID could be inappropriate in some contexts. As previously mentioned, doctors may feel inclined to use DSID to help patients through a difficult stage in their illness. Some participants believed that DSID should be reserved for use concerning major life-changing illness. One participant, Lydia, discussed this idea in the extract below:

Interviewer: Do you think it makes a difference if it’s [the illness], in subjective terms, more severe or less severe?
Lydia: Yeah, I think so, because I think everyone has various issues in their life and for the doctor to relate some minor thing like “Oh yes, I get eczema too” or “I get allergies” … It’s like, who cares?
Interviewer: Yeah
Lydia: But when it’s like, “Oh my gosh, my life is changing.”
Interviewer: Yeah
Lydia: I think that it can be quite reassuring for the patient. “Well, my life is changing, but it’s not the end” kind of thing. I think it’s just hearing from someone who’s respected and someone
who is still continuing in their work that life isn’t near the end

An interesting point raised by Lydia is the lack of benefit with using DSID for very minor illness. She implied that doctors sharing that they experience common illnesses such as allergies can be irrelevant and of little use to the patient. To support her point, she explained how DSID can be used to reassure patients when experiencing illnesses which have a significant impact on their life. She also suggested that by providing emotional reassurance and empathy, DSID can help to demonstrate how illness doesn’t have to stop one from continuing to live a fulfilling life. From this data, it is clear that the use of DSID in this manner is dependent upon the doctors’ ability to assess their patients’ need for emotional support.

The concept of emotional reassurance and support was well developed within the data and spanned across a range of participants’ responses. The fact that many of the DSID occurrences seemed to be prompted by their patients’ emotional vulnerability is interesting and has multiple implications. This suggests that doctors are inclined to use DSID as a method for conveying reassurance to their patients, however, this does not always mean it is successful.

4.2.2 Normalisation and the Stigma of Illness

A noticeable pattern across the data was the idea of illness normalisation and its relation to stigmatised health conditions. As discussed in the previous section, many participants felt emotionally vulnerable at the time of their doctor's self-disclosure. Some participants felt particularly uncomfortable with carrying the label of their illness and felt that they were ‘abnormal’ because of this; DSID served as a way to affirm to the patients that illness is a normal part of life and doctors experience it as well. For example, Russell shared his experience of struggling to cope with mental illness and the process of recovery. He described
feeling a sense of dissonance compared with social norms relating to his illness by saying:

\[
\text{I suppose it’s really about the notion that at 61 you’re supposed to have your life together and you’re not supposed to suffer these things for such a long period of time – Russell (Participant 3)}
\]

This quote helps to emphasise the prominent impact societal expectations have on illness experience and self-perception. His use of the phrase ‘you’re supposed to have your life together’ highlights his feelings of inadequacy as well as a sense of responsibility and blame. This suggests that Russell perceived his illness as a personal failure, something that is not uncommon regarding mental health conditions. After he shared these feelings with his doctor, the doctor shared his own experience with a similar illness. Russell found the disclosure to be unexpected but had a positive experience overall and even described the event as a ‘privilege’. In the interview passage below, he described how his doctor utilised DSID as a way to break down the stigma of illness and facilitate communication:

Russell: I suppose during the conversation and his self-disclosure, he was to a certain extent normalising the situation
Interviewer: Yeah
Russell: And not making it such an issue and everything. At the same time, he was very, very cognisant of the fact that it was me that was actually involved in the discussion
Interviewer: So, it wasn’t all about him, he was using it to help you?
Russell: Yeah, I think he used it as a fulcrum

This extract serves as an excellent example of how DSID can be used to connect with patients and reduce patients’ feelings of shame concerning their health. This quote is especially prominent as it hints at the delicate balance between potentially dismissive use of DSID and the acknowledgement of patients’ emotions.
In his interview, Russell hinted at the potential for the focus of the conversation to shift to the doctor and their illness experience. Importantly, his doctor made sure to keep the patient as his central priority and use the disclosure for patient-centred reasons. Russell also mentioned that his doctor used DSID ‘as a fulcrum’, a supportive turning point or tool to progress forward with their relationship. ‘Fulcrum’ is formally defined by the Cambridge Dictionary as ‘the main thing or person needed to support something or to make it work or happen’ (Fulcrum, n.d.). Through the use of this word, Russell illustrated the significance of the disclosure and the potential for it to have positive subsequent effects on his relationship with his doctor. Although Russell understood his doctor was using DSID as a tool, he still had a positive experience as it came from a genuine place. In Russell’s case, the DSID arose when he discussed his difficulty with medication adherence.

Interestingly, many participants believed that using DSID with patients suffering from mental illness could be especially beneficial. This was due to participants agreeing that DSID can be effectively used to convey emotional support, normalise illness and prevent patients from feeling alone. Sandra highlighted this idea in the excerpt below:

**Interviewer:** What do you think about doctors disclosing about their mental illness to patients?

**Sandra:** You mean their mental illness?

**Interviewer:** Yeah, so any sort of mental illness as a whole, so it could be depression or bi-polar disorder or anything like that... Do you think doctors should be encouraged to share their mental illness with patients?

**Sandra:** Yes, yeah. Because it's really like my experience, I reckon, the people with mental illness, they need more support or really think people are thinking from their points of view, rather than just giving them really general advice, the advice from the book or the internet... and they can really give good
advice to them, a real one, a practical one rather than just “ah, think positively”, but how and why? I think the ‘how’ is really important, so they can give more specific advice or exactly what they would do...

In this excerpt, Sandra explained how DSID can be especially helpful for use with patients dealing with mental illness. She suggested that these patients need greater emotional support and empathy from medical professionals. She also implied that doctors who have experienced illness first-hand are more qualified to care for patients and give more personalised advice.

Another participant, Dena, felt isolated and alone while dealing with her illness. Her doctor sharing a similar experience enabled her to feel supported and reassured. Dena expressed that she was surprised that her doctor had dealt with a similar illness and therefore realised that she was not alone. Dena described how she appreciated her doctor’s disclosure in the passage below:

**Interviewer:** Ok, and why was this [disclosure] so memorable for you?

**Dena:** I guess it put me at ease a lot, that someone like my doctor had experienced what I was experiencing

**Interviewer:** So, you did actually take a lot from it?

**Dena:** I did yeah, it meant quite a lot to me in a positive way

**Interviewer:** Yeah, yeah, so how did it make you feel at the time?

**Dena:** Well, I thought it was good because it made me sort of realise that I’m not the only one suffering from this particular illness

This section from Dena’s interview shows that her experience with DSID served as a pivotal point whilst coping with her illness. She explained how the disclosure reassured her and helped her to understand that she was not alone. Her interview responses conveyed that she held her doctor in high regard and assumed that they wouldn’t share the same illness experience.
These examples showcase the potential for DSID to be used in a positive way to reduce the stigma of illness. Many participants explained how they were shocked that someone as successful and well regarded as their doctor would suffer from illness as well. This interesting idea demonstrates the prevalent belief that illness doesn't affect those deemed ‘successful’ or in a position of power. Therefore, DSID serves as an opportunity to show patients that no one is immune from experiencing illness and it shouldn’t be seen as a source of shame or embarrassment. This idea and how it relates to the general perception of doctors is further discussed within section 4.2.4.

4.2.3 Connection between Doctor and Patient

The theme of the doctor-patient relationship was often referenced during the interviews in a variety of ways and encompassed many other related ideas within these references. During the interviews, participants were often questioned about whether the DSID changed their relationship with their doctor. Many of the participants shared that they believed DSID greatly impacted their relationship with their doctor, in some cases this was very positive and others it was negative. Some participants did not believe their doctor’s self-disclosure changed their relationship; this was often in cases involving minor illness and with participants who did not convey a strong need for emotional reassurance.

While some did not mind when a doctor decided to disclose as long as it was genuine and relevant, others recommended that a strong doctor-patient relationship should be established prior to disclosure. It is notable that patients did not define a strong doctor-patient relationship as necessarily a long relationship, just in the sense of quality and connection rather than length. For example, Lydia expressed how she believed prior rapport is important before a doctor discloses personal information to their patients:

> And I think if they're telling me that they've had whatever before, they don't know me, they don't know my background. Whereas this
doctor was genuine, and it was coming from a place where he had the whole family in his practice for several years. There was some form of rapport. – Lydia (Participant 9)

In the above quote, Lydia implied that DSID without an established doctor-patient relationship can be premature and not very beneficial to the patient. She suggested that by already having a strong relationship with her doctor, she believed the doctor disclosed with good intentions. This example demonstrates how some patients believed a stable doctor-patient relationship is required for DSID to be appropriate and useful. Conversely, some participants did not mind DSID early in their relationship with their doctor, with some even considering it beneficial to their connection with their doctor. This idea is illustrated in the following extract from Dena’s interview:

Interviewer: Was this early on in your relationship with your doctor?
Dena: Yes, it was quite early on in our relationship
Interviewer: So, what do you think about that? Do you think it was appropriate how early it occurred, or would you have preferred it later?
Dena: No, I’m glad that it occurred in the earlier stage of our relationship
Interviewer: So, it might have been sort of a strengthening, bond-strengthening sort of experience?
Dena: Yeah

Dena believed that it was preferable that her doctor disclosed early in their relationship. Dena expressed that, by occurring at the beginning of their relationship, the disclosure helped her to foster a strong connection with her doctor.

Throughout the interviews, the doctor-patient relationship was presented as a dynamic interaction by some participants. This means that the doctor as well as the patient play a key role in the consultation and adapt to each other. This idea
also connects to the overarching theme of DSID needing to be considered on a case-by-case basis due to multiple doctor and patient factors influencing whether the disclosure would be likely to have a positive effect. This means that there is not a ‘one size fits all’ approach to using DSID effectively with patients.

Whilst interviewing participants, it became obvious that trust and confidence in their doctor’s clinical competence was highly important. Some participants conveyed that they had a deeper trust and appreciation for personal insight from their doctor as opposed to somewhat generic medical advice. This idea had an undertone of shifting the doctor-patient relationship to a more equal power balance in which the doctor is not just instructing the patient on what to do, but actually connecting on a human level that is above and beyond their traditional role. For example, during Lisa’s interview, she explained how she felt more understood by her doctor after they shared their experience of the same illness. She described how her doctor’s personal disclosure actually increased her confidence in her doctor’s clinical ability and made her more trusting of her advice:

Lisa: Sometimes, when I’ve seen a GP about it for the minor problems it causes and a few other things like that, I’ve kind of wondered if they really... being GPs... if they really were quite clued up about it
Interviewer: Right, right
Lisa: It’s something that people still don’t really know what causes it and because this particular GP told me she has it, it gave me confidence in her recommendations and that she really did know what she was talking about

In the extract above, Lisa expressed a feeling of doubt regarding GPs’ depth of clinical knowledge concerning her illness. She explained that after learning her doctor had the same illness, she had increased trust in her ability to treat her. Lisa implied that she greatly valued her doctor’s first-hand knowledge of the illness as
opposed to what is taught in traditional medical education. Lisa also implied that
the DSID helped her to trust her doctor’s clinical recommendations and possibly
improve adherence. This example demonstrates the significant impact DSID can
have on trust and confidence within the doctor patient relationship. This idea was
prominent within the data with other participants having shared a similar
experience to Lisa.

In Lee’s interview, he also referenced the idea that personal insight can be more
valuable than traditional medical advice:

Interviewer: Okay, okay. Do you think professionalism-wise, do you think
it was okay for the doctor to disclose that information to you?
Lee: I have no problem with it. I think that it was quite helpful to
have some insight because there’s what the doctor tells you
anyway in terms of medical practice... Then this is also
something that he has experienced himself
Interviewer: Yeah
Lee: That was quite helpful
Interviewer: You sort of trust the information more if he sort of went
through it himself?
Lee: Mm-hmm (affirmative)
Interviewer: Okay
Lee: I trust a lot what the doctor says anyway, but it is good in
terms of it’s not just what the doctor is telling me
Interviewer: Yeah, yeah
Lee: There is some weight behind it. There’s now weight behind
what the doctor is telling you

In this interview extract, Lee explained that although he trusted the
recommendations of medical professionals, he placed greater confidence in advice
from doctors with personal experience. He suggested that there is a distinction
between information doctors provide because that is their obligation and personal
insight they voluntarily disclose. Lee emphasised the value of DSID by stating that clinical recommendations informed by personal experience of illness have ‘weight behind’ them. By using this language, Lee suggested that clinical recommendations accompanied by DSID can have greater influence and power as compared to medical advice alone. This idea was echoed by other participants including Lydia. She outlined how DSID influenced her perception of her doctor’s clinical competence in the following quote:

*I felt that the doctor understood me a lot more, given that I knew that he had the same diagnosis and I thought he actually knows what I’m going through here, and he can understand and prescribe more appropriately, possibly, who knows? – Lydia (Participant 9)*

It is important to note that not all participants experienced a positive impact on their relationship with their doctor. For example, Adam felt that his DSID experience had a devastating impact on a previously strong relationship with his doctor of many years. He outlined how the disclosure impacted his perception of his doctor in the passage below:

Interviewer: So, looking back, was the disclosure helpful to you in any way?
Adam: No
Interviewer: No?
Adam: Quite the opposite actually
Interviewer: Yeah, yeah
Adam: Actually, I wondered about the trust that we had afterwards
Interviewer: Oh, OK
Adam: And I felt as if I had gone from 100 percent trust of my doctor, down to 50 percent
Interviewer: Oh, really, really ... So, was this early in your relationship with your doctor or had you had this doctor for a while?
Adam: They had been my family doctor for all my life
Interviewer: Really... Oh, OK, Yeah
This example demonstrates the substantial potential for DSID to have a negative impact on the doctor patient relationship. This section from Adam’s interview was especially prominent due to his long history with his doctor and the disclosure’s marked impact on their relationship. Adam interpreted the disclosure from his doctor as a betrayal of trust and felt misunderstood. This implies that trust is integral to the doctor-patient relationship and use of DSID in a dismissive way, like in Adam’s case, can have devastating effects. This example shows that if used inappropriately, DSID can mark an unhealthy change to the doctor-patient relationship where the patient may be hesitant to communicate due to fear of being dismissed. When asked about his doctor’s reasoning for the disclosure, Adam believed that his doctor could have been over-comfortable with him as a patient due to their lengthy relationship. He also believed that the doctor underestimated how the DSID could make him feel and the impact it would have on their relationship in the future.

Another pertinent aspect of this theme was the specific role doctors should fulfil in the doctor-patient relationship. Many participants expressed a sense of discomfort towards the idea of the doctor using DSID for their own personal gain in one way or another, such as venting about their health problems to patients. In Adam’s case, he expressed his disapproval of doctors sharing their health information with patients by suggesting it represents an unhealthy role reversal. The following quote outlines this idea:

Interviewer: So, say if there were any health conditions that you don’t think would be appropriate ever to disclose?
Adam: Well, I don’t really want to hear about my doctor’s health
Interviewer: OK, yeah
Adam: … at all
Interviewer: Yeah
Adam: Because I think, when you go in to see your doctor, it’s because you’re not feeling well, and you want to be the main centre of attention. And you want your concerns to be the top
priority and the main focus. And if the doctor sits there and they start talking to you about, "Well I had this and that and this is what happened to me". It might not be relative, because they might be a different age. Things that affect your health, like income, how's your job going, how's your family, what responsibilities do you have, has anything affected you around your health? And the relativity between your doctor and the patient is not necessarily shared that way, because they're quite different.

In this extract, Adam emphasised the importance of doctors and patients fulfilling their different roles. He suggested that doctors' primary focus should be on the patient and therefore, excessive DSID can be seen as selfish and unhelpful. This idea was supported by multiple other participants with some acknowledging the potential for DSID to inappropriately skew the doctor-patient relationship (e.g. doctor using DSID to gain sympathy and support from patients). The following section from Tegan's interview demonstrates how using patients for intensive emotional support could be exploitative and represents a problematic balance between doctor and patient:

Interviewer: So, do you think you'd have a different response if the disclosure was about something more or less serious?
Tegan: Would probably be concerned if it was more
Interviewer: Yeah, yeah
Tegan: I don't really want to be burdened with someone else's health issues if they're that serious

Tegan implied that patients can be overwhelmed by DSID in cases of severe illness. The use of the word ‘burden’ is prominent in this quote as it shows the potential for harm to the patient and their well-being. This idea was supported by other participants suggesting that the severity of the illness disclosed may influence the appropriateness of the disclosure. This idea may also suggest that
patients can have an adverse reaction to high levels of vulnerability displayed by their doctor. Although many participants greatly appreciated their doctor’s vulnerability, it seemed that for some there was a boundary to this. For example, some participants explained that they would feel sympathy for their doctor if they displayed a great level of negative emotion. This suggests that DSID could move the relationship to a mutual exchange of emotional vulnerability. Although this transformation may seem harmless, there is potential for this to lead to an unhealthy co-dependent relationship.

In addition to this, some shared that they would feel a sense of inappropriate responsibility for their doctor’s emotional state and this could strain the relationship and hinder communication. These results indicate that changes to the typical power structure of the doctor-patient relationship can make some patients uncomfortable therefore influencing how they communicate with their doctor going forward.

### 4.2.4 The Doctor’s Role

A prominent theme which was apparent across many of the responses was the doctor’s role and responsibility within the doctor-patient relationship. This theme also encompassed related ideas including doctor vulnerability and professionalism. Primarily, participants believed that the doctor has an important duty to the patient and their needs. Either directly or in-directly, many participants implied that the doctor held a significant amount of power in the therapeutic relationship and therefore there was a risk of patient exploitation for personal gain. It is unsurprising that participants had a negative response towards doctor’s abusing their privileged position for their own benefit.

Some participants conveyed that they had a fixed schema of what characteristics doctors possess, for example stability, power, influence and professionalism. Many participants demonstrated their perception of what a doctor is or should be through their responses to the interview questions. This was an interesting sub-
theme as it also revealed, to some degree, the impact of societal expectations and stigma placed on medical professionals.

This idea was often highlighted when discussing the topic of doctors disclosing their mental illnesses with patients. This pattern amongst the data helped to demonstrate the perceived characteristics relating to mental illness and how these don’t align with the commonly accepted doctor archetype. One participant even openly expressed that he would not expect doctors to have had a history of mental illness, as shown in the quote below:

_Because it’s unlikely that the doctor’s going to be suffering from, well you don’t know, but you wouldn’t think they’d have mental health problems – Stephen (Participant 11)_

This suggests that the general perceptions of mental illness patients and doctors do not always align. This statement from Stephen was especially salient as it highlights a significant disconnect between the perception of doctors and the reality. Some participants also described a loss of confidence in the doctor’s ability if they had a mental illness, however it seemed that not all mental illnesses were perceived the same. This was further supported by other responses explaining a sense of uneasiness with a doctor having had a mental illness:

**Interviewer:** What do you think about doctors disclosing about mental illness to patients?

**Kristie:** About their own experience?

**Interviewer:** Yeah

**Kristie:** Yeah, I think I’d feel a bit uncomfortable, to be honest. Just because you’re going to someone to sort it out and you kind of want someone stable. I don’t know, it sounds bad because they’re going through their own issues, but you kind of want someone stable and not having a past with it if you know what I mean?
The above quote from Kristie expresses the idea that doctors with a history of mental illness have the potential to be unstable or less qualified to carry out their job. Kristie expressing how ‘it sounds bad’ to have this perception of doctors with mental illness was also noteworthy. Her use of this phrase conveyed feelings of guilt and a sense of self-awareness to how it could be seen as illogical and politically incorrect. There also seemed to be an underlying sense of ownership or fault attached to mental illness, framing it as more of a personal issue than a legitimate illness.

Within the theme of the doctor’s role, fitness to practice and competency was also touched upon by some participants. Similarly to Kristie’s case, other participants also expressed concern over doctors with a history of mental illness being able to fulfil their role as a medical professional. For example, during Lee’s interview, he expressed feelings of doubt and reduced confidence when discussing his perception of doctors with a history of mental illness:

**Interviewer:** Do you have any thoughts on stigmatised illness, such as mental illness or anything like that?

**Lee:** I wouldn’t be particularly reassured if my surgeon or doctor said that they had a mental illness, because they might be cutting me open.

**Interviewer:** Can you tell me a bit more about that? Is that something to do with their competency?

**Lee:** If it’s something like... What kind of mental illness?

**Interviewer:** Do you think there’s a sort of a spectrum in terms of it someone said they had anxiety back when they were at uni or something? Compared to something like bipolar disorder or something like that... do you think there’s a difference?

**Lee:** I would view it from whether it would affect his patients.

This section from Lee’s interview highlights how DSID can potentially reduce patients’ trust in their doctor’s ability to fulfil their professional role. In this
extract, Lee implied that not all mental illnesses are viewed as equal therefore suggesting that some carry greater stigma than others. By expressing his concern regarding surgeons with a history of mental illness, Lee perpetuated the idea that mental illness equates to danger, volatility and untrustworthiness.

One patient, Renee, had a positive experience when her doctor disclosed about a mental illness that they shared. Renee, however, recognised that not all patients may have this reaction:

Interviewer: What do you think in general about doctors disclosing about mental illness to patients?
Renee: I don’t know...
Interviewer: Do you think there’s any sort of...
Renee: I think some people would find it icky and uncomfortable... My doctor told me she suffers from [redacted] and I was OK with that because I suffer from [redacted]. But some patients... they might not feel so trusting or comfortable with their doctor if they knew that, I don’t know, it depends on the relationship.

Interviewer: So, you think that maybe some people might doubt their ability as a doctor or something like that?
Renee: Yeah, they might not... yeah exactly. And it is... it depends on the person. And it depends on the mental illness too because there are lots of different types of mental illnesses. So, you probably want to be careful about who you’re saying it to. I mean I don’t think... we shouldn’t keep it in the dark cause [sic] it happens too long, we should be able to talk about these things. I think when people go to see their doctor, go to see their GP, they like to think they’re somebody who knows it all and whose got it all sorted out and help them with whatever their problem is, rather than being told what the doctor’s problems are.
As demonstrated in the extract above, Renee believed that the issue of doctors disclosing their mental illness to patients was complex and multi-faceted. Consistent with Kristie and Lee, she also believed that DSID regarding mental illness could make patients doubt their doctor’s fitness to practice. She also acknowledged that not all mental illnesses are the same and implied that some may be deemed more socially acceptable. Renee explained how doctors are perceived as living perfect lives and people who have ‘got it all sorted’. She suggested that this unrealistic perception meant that patients could be uncomfortable with some instances of DSID.

Renee further illustrated how doctors are perceived in the following extract:

Interviewer: So, you think that she, in sharing her experience she was sort of normalising it and reducing that stigma?
Renee: Yeah, exactly, like they're making it more real, more human, more like... cause [sic] you always think your doctors are perfect and they've got it all... they've got all their crap together in their house and everything, and they're the ones telling you how to... you know!

In this extract, Renee described how she viewed her doctor, and doctors in general, as ‘perfect’ and aspirational. Because of this unrealistic expectation, Renee found her doctor’s disclosure refreshing and humanising. This was an interesting quote as it showcased the immense pressure placed on health professionals to be super-human. Renee also described how she believed doctors had ‘all their crap together’, therefore qualifying them to counsel patients about their problems. This idea reinforced the belief that for doctors to be able to give advice to patients, they cannot suffer from their own problems.

The way some participants spoke about their experience with DSID highlighted the separation between the role of doctor and patient. Some participants even went as far as to say they wouldn’t expect doctors to suffer from the same illnesses
that everyone else does. This idea was further reinforced when some participants spoke about how it made them feel when ‘someone like their doctor’ shared the same illness. This concept was illustrated by the following extract from Renee’s interview in which she described her reaction to her doctor’s disclosure:

Interviewer: So, when it [the disclosure] did happen, how did you feel at the time?
Renee: Alright, OK cause [sic] at the time my doctor told me she was suffering from [redacted].
Interviewer: OK, right.
Renee: So, at first, I was a little bit surprised because I didn’t think she was the kind of person who suffered from [redacted]. And then at the same time I felt like a little bit closer to her, like she seemed more human to me.

Renee described how she was surprised by her doctor’s disclosure by stating that she did not expect for her doctor to have suffered from the same illness as her. Interestingly, Renee explained how the disclosure helped her to relate better to her doctor, enabling her to see her as a human rather than just a doctor. This implies that doctors have a level of immunity to the illnesses suffered by the general population. These responses from participants emphasise the idea that doctors are often viewed as symbols of perfection and success, therefore DSID of stigmatised illness could interfere with this perception.

Some participants did acknowledge that for doctors to disclose their own illness information to patients, the doctors were taking on a significant risk. These risks included: threat to their personal privacy, negative reaction from patient, negative impact upon doctor-patient relationship and judgement from the patient regarding their clinical competence.
4.2.5 Objectivity and Patient Decision-Making

It was implied amongst some of the interview responses, that doctors have a duty to present medical information in an objective manner as to not inappropriately sway their patients’ choices. This idea is consistent with patients viewing doctors as carrying a high level of influence within the doctor-patient relationship. Although many participants considered the knowledge gained from their doctors’ personal experience as immensely valuable, they also placed importance on presenting information fully and clearly to prevent bias.

This theme was particularly interesting as some participants felt that their doctor could have been more objective in their approach despite still having an overall positive reaction to DSID. This demonstrated that a fine balance exists between sharing personal recommendations with patients and potentially pressuring them into a decision. This risk of inappropriate persuasion could also be increased depending on the patient’s emotional state and maturity. An example of how this theme came across in the interview data is shown below:

Interviewer: So, when the disclosure occurred, do you think that the doctor was acknowledging or dismissing your concerns?
Kristie: I think they were acknowledging the fact that I was quite scared, and I didn't know what to do. I was in a lot of pain, but as I said about the treatment thing, I feel like he was a bit dismissing how I just wanted it gone. I mean obviously I’m glad I didn’t go through the surgery now. And it is a professional opinion, I just kind of wish I had a bit more pros and cons about it instead of just like, “You shouldn’t do this, do this instead because that’s what I did”.

Interviewer: Yeah. So, you think that maybe his experience sort of clouded his view of what your experience is, like, “Oh, you’re exactly like me”, when you might not be?
Kristie: Yeah.
At the time of the disclosure, Kristie was fifteen years old and in a state of desperation regarding her illness. Although she explained that she didn’t necessarily feel persuaded by the DSID, the resulting personal insight changed her mind regarding treatment options. In the extract above, Kristie described how her doctor used his own experience as the basis of his treatment recommendations. Although she was ultimately happy with her treatment decision, Kristie believed that her doctor did not present her options in an objective and balanced manner.

Some participants believed that their doctor’s use of DSID did not influence their decision-making at all. Despite this, many still believed the disclosure was beneficial to them in some way. An example of this is shown below in an extract from Lee’s interview:

Interviewer: Did it influence the consultation for you or any decisions you had to make?
Lee: It did make me feel better, but I’m not sure if it affected my decision. In terms of the decision, I feel like I would have gotten it anyway.
Interviewer: Okay, okay.
Lee: It was already a... I was already sold on the idea if that makes sense?
Interviewer: You don’t think it was necessary for you, but it was helpful?
Lee: Yeah, yeah. It was helpful, in terms of my decision on the surgery... I didn’t have much of a decision anyway.

In the extract above, Lee explained that his decision regarding treatment would have been the same regardless of whether the DSID occurred or not. At the time, Lee felt that he ‘didn’t have much of a decision anyway’ when it came to treatment. Therefore, Lee’s doctor used DSID as a way to reassure him that his seemingly only option was in fact the right one. Lee appreciated his doctor’s insight and explained that it put him at ease when beginning his next stages of recovery.
During Renee’s interview, she described how her doctor’s disclosure gave her valuable insight regarding medication for her illness:

**Interviewer:** So, when it [the disclosure] did happen during the consultation, did it influence the way the consultation went?

**Renee:** Yes, it did. Because at the time, I was umming [sic] and aahing [sic] about it going “oh, I should take [medication]” and she was encouraging me to, but I’d heard a lot of bad stories. And then she opened up and told me how she was on [medication] and, yeah, so she could tell me first-hand what it was like from her experience. It did influence my decision on how things went from there.

**Interviewer:** So, was that sort of a positive influence for you?

**Renee:** Yes, it was.

**Interviewer:** So, you’d say it did influence your decision-making at that time?

**Renee:** Yes, it did.

In the excerpt above, Renee outlined how her doctor’s experience influenced her decision-making regarding treatment. Renee expressed that she saw this experience as a positive influence rather than persuasive. In her case, she was confused as to whether to take a form of medication for her illness as she had ‘heard a lot of bad stories’. Renee’s doctor used this as an opportunity to share her own experience regarding the medication and provided Renee with the clarity she was looking for.

### 4.2.6 Professionalism

The theme of professionalism appeared frequently in the interview data. Participants generally did not see DSID as unprofessional per se, they believed the appropriateness of the disclosure depended primarily on how it was handled. Many participants were not able to list specific health conditions that would be
unprofessional to disclose, with many citing the individual circumstances to be important. Some participants believed ‘embarrassing’ illnesses such as sexually transmitted infections should not be disclosed, therefore suggesting that social norms impact participants’ views of professional conduct. Overall, participants believed that the relevancy of the disclosure to the patient is the key determinant to whether DSID is appropriate. Many believed that as long as the disclosure is relevant and helpful, nothing is off-limits to disclose. This idea is supported by the following extract from Tegan’s interview:

Interviewer: Did you think it was appropriate in your relationship, her sharing that with you?
Tegan: At that point I did because it was something that could affect me, so that was nice knowing someone who had been through it.

Interviewer: Right, right.
Tegan: If I didn’t have that particular condition then...
Interviewer: It wouldn’t be...
Tegan: I probably wouldn’t have wanted to know

The extract above represents an idea that was often touched on by participants. In this example, Tegan explained that in order for DSID to be beneficial to the patient, it should directly relate to the patients’ situation. Conversely, she suggested that disclosing health information that was irrelevant to the patient was not useful and was therefore unprofessional. This idea was also discussed during Tara’s interview:

Tara: I think I’m pretty open to a GP telling me about anything I thought if it was like a mental illness, I think that’d be fine. Physical illness is fine. I mean, I can’t really think of any taboo illnesses that I wouldn’t want my GP telling me that they had

Interviewer: Yeah, yeah. So, you’re comfortable with them, or...
Tara: So long as I also had that complaint.
Interviewer: Oh, okay, yeah.

In Tara’s case, she explained how the particular illness disclosed has little bearing on whether the disclosure was appropriate or professional in her view. She emphasised that as long as the illness was shared by both the patient and the doctor, all illnesses were appropriate to disclose.

The theme of professionalism also related well to the prevalent idea that doctors have a specific role to fulfil and shouldn't stray beyond this. For example, participants often discussed how it was inappropriate for doctors to use DSID as an opportunity to shift the focus of the consultation onto themselves rather than their patients. Because of this, participants expressed that instances of DSID should be kept short and focused:

Interviewer: Did you think it was selfish in any way? Like, talking about themselves? Or do you think he approached it correctly?
Kristie: I think he approached it correctly because he didn't go about it for long. He just kind of... told me how it was the same thing, how he dealt with it. But, he also obviously disclosed it in other appointments where we were discussing treatment options and things like that.

Interviewer: So, it was helpful in those subsequent appointments?
Kristie: Yeah, yeah. I think... He obviously didn’t rant on about it.

In this extract, Kristie explained how her doctor’s disclosure was appropriate as it was concise and patient-focused. She therefore implied that long ‘ranting’ disclosures are unprofessional and inappropriate. These findings further supported the idea that professionalism was deeply rooted in the expectation that doctors must have patients as their top priority.

It was evident amongst some of the interviews that participants felt pressure to align their opinions to what they believed were the ‘rules’ or the consensus opinion. For example, some participants’ opinions on professionalism were
framed by societal expectations and what they believed were the opinions of others. This idea is illustrated in the extract below from Kristie’s interview:

Interviewer: So, so you think overall that it was appropriate for the doctor to disclose that information to you?
Kristie: Yeah, I think it was. I mean, seeing it from a professional, I’m not a professional but trying to see it through, I think it would be considered rather inappropriate just because it’s not professional. And he shouldn’t, well, I’ve heard that it’s not a good idea to disclose your personal life to clients no matter what the profession.

During her interview, Kristie explained how she felt conflicted as to whether her doctor acted professionally by disclosing his own health information. Although she personally appreciated the disclosure and believed it was appropriate, she acknowledged that others may not agree. In the extract above, Kristie describes how she’s ‘heard that it’s not a good idea’ to disclose personal information of any kind to patients or clients. This suggests that societal expectation and traditions regarding professionalism frame our perceptions even if we don’t truly believe them.

4.2.7 The Patient’s Role

The role of the patient was an idea that flowed through many of the interviews. Participants’ views of the patient’s role were noteworthy and, in many cases, signified the cultural changes to medicine that have occurred over time. Participants often referenced the idea that the doctor’s behaviour and approach should adapt to each individual patient. This illustrated participants’ belief that the patient was an active participant in the consultation process and the doctor-patient relationship existed as a partnership.
When discussing the issue of confidentiality, many participants said they would not share their DSID experience around with others to protect their doctor’s privacy. Participants, however, did not believe that it was their obligation to protect the doctor’s information and thought it would be unreasonable to expect this. A large proportion of the participants said they did keep the disclosure private out of respect and said that they would do the same for anyone else regardless of their relationship. An example of how this idea surfaced during the interviews is shown below:

Interviewer: Were you told by the doctor, or did you feel at any point that you `should keep that information a secret that he told you?
Lydia: No.
Interviewer: No?
Lydia: No, it was very matter-of-fact information. If it had been something highly private, I don’t think they would have told it if they thought it had to be kept secret. I don’t think they would disclose it to some patient. Even if there is a rapport, I’m still just a patient.
Interviewer: Yeah, so you don’t think it’s fair to have that burden on the patient that they should keep it a secret at any point?
Lydia: No, if the doctor wants to keep it a secret then the doctor should keep it secret.
Interviewer: Yeah.
Lydia: Why put that onto the patient?

In this excerpt from Lydia’s interview, she highlighted the distinction between the patient and doctor roles. She argued that the doctor should take full responsibility for the information they disclose to patients and that doctors should not hold an expectation of confidentiality. By explaining that she was ‘still just a patient’, Lydia contrasted the theme of patient empowerment which was also prominent throughout the interviews. This dichotomy of ideas showcased that although the doctor patient relationship has progressively moved away from strict traditions,
there were still some boundaries that should not be crossed. Lydia’s response emphasised that no matter how close the doctor-patient relationship becomes, it should still adhere to the normal balance of power and responsibility.

Contrasting to Lydia’s beliefs, another participant spoke about how she felt she had to protect her doctor’s information:

Interviewer: Were you told by the doctor that you should keep this information secret?
Dena: No, she never told me that, but I have. I wouldn’t betray her confidence.

Interviewer: Okay, so you felt that it wouldn’t be right for you to say to anyone else?
Dena: No, I don’t think it would be appropriate at all.

During her interview, Dena expressed how she felt a level of responsibility to keep the doctor’s information confidential. Despite not being explicitly told, she decided to keep the information secret out of respect and loyalty to her doctor. Although Dena’s beliefs regarding confidentiality did not align with many other participants, her responses were prominent as they represent a transformation of the patient’s role. Dena’s experience showed how DSID can cause a shift from the traditional doctor-patient dynamic to a more evenly balanced relationship.

The idea that doctors have a professional duty or obligation to the patient was a theme that underpinned many of the interviews. Unsurprisingly, participants recognised that doctors should primarily have their patient’s best interests in mind and should not conduct themselves in order for personal gain. In the context of DSID, participants identified that it is essential for the doctor to have patient-centred reasons for the disclosure and that it should directly relate to their illness/situation. Therefore, some participants implied that it would be highly inappropriate for the doctor to disclose about an illness that is unrelated to the patient. As shown in the following excerpt, some participants saw the potential for
DSID to be used unethically by shifting the focus to the doctor, therefore wasting patient time and money and potentially harming the patient:

Adam: But, if you’re going through the same condition, providing they let you know about the positive outcome, rather than... I just don’t want to hear them complain to me. I’m the one doing the complaining.

Interviewer: Yeah.

Adam: And I’m paying for it.

Interviewer: No, that’s fair enough.

In this section from Adam’s interview, he recognised the patient’s role as a consumer of a service. He implied that by sharing an illness that is unrelated to the patient, a doctor inappropriately adopted the patient role. Adam also addresses the fact that patients are paying for consultation time, therefore doctors should treat this time as valuable and focus primarily on the patient.

4.2.8 Paradigm Shift in Medicine:

A salient theme within the data was the idea that DSID represented a transformation within the medical profession and health care in general. Some participants, especially older participants, described how medical professionals have changed their approach over time. In some cases, participants contrasted the impersonal nature of the traditional doctor role with the new generations of medical professionals. This theme was primarily rooted in the idea that communication and holistic health care has become more of a priority within medicine. The passage below from Russell’s interview highlighted this theme by showcasing how his DSID experience was somewhat unfamiliar compared to his past interactions with doctors:
Interviewer: So, how did you feel at the time? And then, you were saying that you changed your mind, can you talk a little bit more about that?

Russell: I didn’t really think very much of it at the actual time. It seemed like a logical conversation to have in the context of what we were doing. It was only when I left. I do a daily spiritual exercise, where, at the end of the day I reflect upon my behaviour in life, and the nature of my day. It was only when I sat down there that I felt quite emotional. I realised that the reason was, because someone who would not normally engage in that particular manner had engaged in that particular manner. When I thought about his role in my life, and everything, I thought, “Gosh that’s quite unusual”. I grew up in an era where doctors didn’t do that sort of thing, and they would never consider doing it.

Interviewer: Really?

Russell: Yeah.

Interviewer: So, it was a foreign thing to you?

Russell: Well, no, it was foreign in the sense of my history of, or my experience with General Practitioners, but I’m also very aware that there’s a new wave of medical experts, for want of a better word. I think we’re getting more into that notion of wellness rather than illness.

In this extract, Russell described being surprised by his doctor’s disclosure. From his reaction, Russell implied that DSID did not align with his pre-conceived ideas about the doctor’s role. He suggested that, traditionally, doctors would never stray into such personal territory as an illness disclosure. Although he found this experience surprising, Russell acknowledged that new generations of doctors are moving towards holistic care and away from the strictly biomedical model of health. Russell also directly referenced the idea of a paradigm shift in medicine in the following quote:
I’m very aware that the old guard of stoic, middle-age men is going, and we’re getting a new breed of people who are more in tune with their own experience, and seemingly more empathetic towards their clients – Russell (Participant 3)

The quote above shows the impact that the DSID experience had on Russell and his relationship with his doctor. Russell also explained how the experience was strange and unexpected for him and that this signified a change to how health professionals interact with their patients and approach health and general wellness. This related back to the strong theme of emotional support and reassurance, something that wasn’t such a priority in older forms of medical care. He also acknowledged the doctors’ humanity by implying that their own experiences of illness inevitably shaped how they interact with their patients.

Another participant, Stephen, also referenced a transformation within medical culture in the following quote:

He’s not a real formal doctor if you know what I mean? He’s got a sort of... They’ve got ethics, I know all that. But he hasn’t sort of... I wouldn’t say... he’s not like the old-school where they couldn’t tell you anything unless you were dead. So, it’s changed in that sense – Stephen (Participant 11)

In this quote, Stephen acknowledged that although ethical standards regarding doctors have remained, doctors have moved away from some ‘old-school’ ways of thinking. By explaining how doctors used to have limited communication with patients, he implied that patients are now more involved in their own health-care. This suggested that medical culture had shifted over time to empower patients regarding their care. This idea contrasted the once prevalent approach of viewing patients as passive participants within the therapeutic relationship. These findings relate to the sub-theme of ‘patient as consumer’ referenced by some of the participants, suggesting that the patient-role has evolved over time.
4.3 Summary of Themes

The major themes identified within the data primarily centre around three key ideas. These ideas include the emotional dimension of illness, the doctor-patient relationship, and ethical conduct. The main themes explore these ideas from various angles and connect to subsequent sub-themes and minor concepts. These connections are not strictly linear as many of the themes and sub-themes connect across each other in a web structure as opposed to a hierarchical pyramid.

The impact of DSID was often described by participants as it related to the emotional support it conveyed. This was a key theme within the data which relates to multiple sub-themes and ideas including reassurance, empathy and vulnerability.

Many of the major themes within the data relate to the therapeutic relationship and the roles the doctor and the patient each fulfil. These themes have connections with ideas relating to ethical conduct, balance of responsibility, confidentiality, trust and fitness to practice.

An element which was highlighted within the interviews was the ethical consequences of DSID as it relates to decision-making. This represents a key theme within the data and consists of other sub-themes including objectivity, professionalism and the value of anecdotal evidence.

The themes and sub-themes identified from the interviews demonstrate the complex nature of DSID and its various interconnections with related ethical issues.
Chapter 5  Discussion

This chapter will discuss the overall strengths and weaknesses of this study and their impact on the data. The overall findings will be summarised and integrated within the existing literature. After discussing the findings of this study, the results will be used to construct a set of clinical recommendations regarding the use of DSID in a primary care context. To end this chapter, there will be an overview of the opportunities for further research within this subject area and how they could contribute to the current literature surrounding DSID.

5.1  Strengths of the Study

There are multiple strengths of this study, primarily due to the various quality-control measures and methodological decisions undertaken during data collection and analysis. These strengths helped to ensure the quality of this research, and therefore, the validity and trustworthiness of the results.

One strength of this study was its ability to answer the primary research question: What are patients’ perspectives of DSID? This study aimed to understand patients’ viewpoints and opinions of DSID, therefore, collecting data through individual interviews was the most appropriate method. In-depth interviews facilitate a deeper understanding than would be gained by alternatives such as a questionnaire. According to Braun and Clarke, interviews are ‘best suited to exploring understandings, perceptions and constructions of things that participants have some kind of personal stake in’ (Braun and Clarke, 2014, p. 80). For this study, participants who had at least one prior personal experience of DSID were interviewed about their perception of this experience and their general opinions of DSID. The central research question was able to be sufficiently explored due to the structure of the interview questions. The question menu centred closely on the central aim of the study whilst still enabling the exploration of related topics. This menu was tested by completing multiple practice interviews
with actors in order to predict what data could be collected from participants; this process is described in section 3.3. To facilitate the collection of rich data, open-ended questions formed the basis of the possible interview questions. Existing literature has argued that the use of open questions ‘is the most important guidance for designing effective qualitative interview questions’ (Braun and Clarke, 2014, p. 85).

As previously detailed in section 3.5, the interviews were conducted until data saturation was reached. In order to confirm that this had occurred, an additional interview was completed to ensure that no new data could be collected. Due to this, it can be assumed that the data was sufficiently collected, and additional interviews would not provide any benefit. This serves as a strength of the study as it indicates that data collection was not prematurely ended or inappropriately prolonged.

As described in section 3.8, I made sure to acknowledge my role throughout this research and therefore reduce and hopefully prevent the introduction of bias. By doing this, I was able to accept that I conducted this study through my own personal lens. This means that regardless of how hard I try, I will always have some impact on how the data is collected and analysed. This concept is emphasised in the following quote from Braun and Clarke:

Research is understood as a subjective process; we, as researchers, bring our own histories, values, assumptions, perspectives, politics and mannerisms into the research – and we cannot leave those at the door (Braun and Clarke, 2014, p. 36)

Braun and Clarke (2014) have argued that the act of ‘reflexivity’ is an integral part of conducting effective qualitative research. Reflexivity involves acknowledging the researcher’s role in the research process and accepting, rather than denying, how the researcher unavoidably shapes the research (Braun and Clarke, 2014). This reflective process highlights that it is impossible to complete this type of research objectively; however, by recognising this fact, I am able to better control my impact on the study.
Another strength of this study was the completion of debriefing sessions throughout data collection. I debriefed with my supervisors after particularly challenging interviews or those that elicited a strong personal response from me. This process is a strength as it enabled me to reflect on how I was conducting the interviews and assess whether I was using a consistent approach with each participant. By doing this, I ensured that the interviews were completed in a thorough and uniform manner. Debriefing with my supervisors also gave me an opportunity to acknowledge personal factors that may have impacted upon the way in which I conducted the interviews. This process meant that data collection was completed reliably, therefore maintaining the quality of the research.

One quality-control technique used during the study was to cross-check the interview data with participants, also known as ‘member validation’ (Braun and Clarke, 2014). Whilst analysing the interview transcripts, I decided to contact some of the participants to ensure that I accurately understood their responses. I completed this process in instances when I wasn’t fully sure of what a participant was trying to convey in their responses to the interview questions. This process involved sending selected participants a summary of their analysed responses and giving them the opportunity to give feedback as to whether it accurately represented their perspective. Braun and Clarke argue that this process ‘could be regarded as a qualitative version of reliability’ as it ascertains whether the participants believe the findings accurately reflect their intended meaning (Braun and Clarke, 2014, p. 282). They also state that for research primarily focusing on comprehending participants’ experiences, such as this study, ‘member-checking can be an important way of establishing the credibility and quality of the analysis’ (Braun and Clarke, 2014, p. 283). The completion of this process serves as a strength of this study as it ensured that the responses were not misconstrued and that the findings accurately represent the views of the participants.
5.2 Weaknesses of the Study

This section will discuss the various weaknesses of this study and elaborate on how these impacted the data and its reliability. There were two main weaknesses of this study, both relating to participant recruitment. These limitations mean that the results of the study may not be completely representative of the sample population and potentially restrict the generalisability of the findings.

One weakness of this study was the lack of ethnic diversity amongst the participants. As discussed in section 4.1, the majority of the participants recruited to take part in the study were of NZ European/Pākehā descent. This meant that any potential cultural differences regarding participants’ opinions of DSID could not be effectively explored. This weakness was primarily due to time and financial constraints, meaning that participants were recruited from a restricted geographical area. This limitation serves as an opportunity for further research concerning how cultural background and ethnicity impacts patients’ perceptions of DSID.

Another weakness of this study was the limited representation of rural participants. One of the initial aims of this study was to explore rural and urban participants’ views of DSID. This aim was unable to be fulfilled as there was difficulty recruiting participants from rural areas who also satisfied the inclusion criteria. Due to this limitation, this study was unable to explore rural participants’ experiences enough to assess whether rurality impacted upon patients’ perspectives of DSID.

5.3 Overview and Contextualization of the Findings

This section will highlight the main findings across the key themes of the data and relate these to prior studies. The primary aim of this study was to investigate patients’ perspectives on doctors disclosing personal illness and illness experiences to patients. The findings suggest that there are both significant
benefits and significant risks associated with the use of DSID. Although many participants described their doctor’s disclosure as a significant positive event in their relationship, others did not agree. These contrasting experiences suggest that there is not one ‘right way’ to use DSID that will guarantee a successful outcome, therefore suggesting that multiple variables need to be considered. The following sub-sections will discuss the broad themes within the data and relate these to existing medical literature previously discussed in chapter two.

5.3.1 Emotional Dimension of Illness

Illness should not be approached from a single standpoint as disease can impact upon all aspects of health including physical, mental, social and spiritual well-being. This theme was prominent within the data as many participants acknowledged the impact their physical illness had upon their mental health and emotional well-being. As previously explained in section 4.2.1, participants often spoke about the ways in which their illnesses affected their lives as a whole. For example, Tara described how her injury, as well as a series of unsuccessful treatments, had caused her to feel hopeless and disheartened. Tara’s experience demonstrated that illness is not merely one-dimensional; it inevitably has a ripple-effect across surrounding areas of one’s life. This idea highlights the importance of looking beyond the superficial scope of the traditional medical model and to instead move towards the biopsychosocial model of medicine (Borrrell-Carrio, Suchman and Epstein, 2004). In past literature, McWhinney has critiqued the objective nature of the traditional clinical method (McWhinney, 1986). McWhinney has argued that this method has various limitations and fails to ‘understand the meaning of the illness for the patient or to place it in the context of the patient’s biography or culture’. Due to these shortcomings, he proposed the need for a new clinical method in which doctors appreciate the subjective nature of illness and aim to view illness through the lens of a patient rather than that of a doctor. The findings of this study complement McWhinney’s reasoning by emphasising the importance of understanding how illness affects patients as
individuals beyond the strictly biomedical approach. The multi-faceted nature of illness suggests that treatment should also be multi-faceted. In order to treat all aspects of disease, doctors should not be restricted to a purely biomedical approach and should instead adopt a holistic approach to health-care.

Participants often described how their doctor was prompted to disclose after recognising that they, the patient, needed emotional support. In many cases, participants believed that their doctor used DSID as a tool to establish empathy and provide reassurance. A study by Klitzman and Weiss (2006) supports this finding as it reported that ‘doctors believed that disclosure about their own experiences, particularly about difficult aspects of treatment, could benefit patients, reducing obstacles to adherence’ and reduce general anxieties. Through their DSID experience, some participants were able to release feelings of shame and embarrassment associated with carrying the label of being unwell. This suggests that DSID can be used to help normalise the idea of illness and reduce the social stigma that some illnesses possess.

Despite acknowledging the significant potential for DSID to support patients emotionally, some participants believed that this potential was only applicable to cases of severe illness. This meant that some viewed the disclosure of minor illnesses, such as allergies, as unlikely to provide benefit to the patient and were therefore unnecessary. These results suggest that doctors should reserve the use of DSID for cases of significant illness in which they believe patients need emotional support. A recent study by Allen and Arroll (2015) has shown that some GPs use SD of their own illness experiences or those of family members to convey empathy and provide support to their patients. An example of their findings is shown in the following quote from one of the GPs included in the study:

_A patient of mine has been very distressed with her allergy, you know dermatitis, contact dermatitis from here down and what not and she keeps itching and scratching ... Then I just told her that, you know, I have just recently realised that for over a year I have developed new allergy to the pigment red or magenta (Allen and Arroll, 2015)_
In the above quote, one GP described sharing her own experience of allergies with her patient who was struggling with a similar condition. This is an interesting example as it seemingly contrasts the findings of this study which suggest that patients with minor illnesses were unlikely to appreciate DSID. I believe that this emphasises that the severity of illness is subjective, and therefore, DSID should be reserved for illnesses which the patient perceives as significant or severe. For example, some patients suffering from allergies may not value emotional support in the form of DSID. This may not be true, however, for all patients as each experience of illness is subjective and unique.

Existing literature pertaining to psychotherapy has highlighted how therapists can use their past ‘wounds’ to convey empathy and understanding to patients without necessarily explicitly disclosing past illness or life challenges (Zerubavel and Wright, 2012). I believe that although many participants within this study had an overwhelmingly positive experience of DSID, this was not exclusively due to the disclosure itself but the immense emotional support it conveyed. Due to this, I recommend for doctors to recognise that although DSID presents many potential benefits, these benefits can be achieved through other communicative strategies. For example, doctors could imply that they can relate and empathise with their patient’s experience of illness without necessarily using DSID. This idea has also been recognised in past literature investigating SD within primary-care. McDaniel et al. (2007) have acknowledged that although doctors are likely to have positive intentions regarding DSID, ‘there are other, more reliably helpful ways in which the physician’s personal experience can be called on as a resource to support patients, particularly through the use of empathy, understanding and compassion’.

The findings of this study suggest that doctors should recognise emotional support and reassurance as a legitimate treatment for patients which should be incorporated alongside traditional medical intervention. DSID can be successful in providing emotional support and reassurance, however, care must be taken to avoid excessive disclosure when other methods may be more appropriate (e.g. empathy). Use of DSID must be balanced with alternative methods of providing
emotional support to prevent it from shifting the focus of the consultation onto the doctor. This research also helps to remind doctors of the various ways in which illness can affect patients’ lives beyond the confines of biomedicine.

5.3.2 Perception of Doctors with Illness

Participants often expressed how they valued being able to relate to their doctor through sharing the same illness. Some participants believed that by experiencing illness first-hand, doctors had a deeper medical understanding and could even be more qualified. These findings relate to existing research indicating that doctors ‘believed that their illness experience enhanced their empathy and in some cases was transformative’ (Hall et al., 2018). A study by Hall et al. (2018) has suggested that personal experiences of illness may improve the way in which doctors interact with their patients. It is unclear, however, whether DSID plays an important role in this.

From the interviews, some participants suggested that DSID relating to psychological illness would reduce their confidence in the doctor’s ability. Some participants even expressed that they would feel uncomfortable with these disclosures as it could indicate that their doctor was unstable or unfit to practice. In the article, ‘Must Physicians Reveal Their Wounds?’, Furrow (1996) discussed the legally complex balance between patients’ rights to informed consent and the doctors’ right of privacy regarding their health information. In this article, he suggested that doctors disclosing publicly misunderstood health conditions, such as HIV, could face backlash from patients. This article relates to the current findings of this study that suggest that DSID relating to mental illness could be ultimately detrimental to the doctor-patient relationship by reducing patient trust and confidence. It is important to note that this assumption of incompetence can be completely unfounded, yet it still can significantly damage the doctor-patient relationship. Existing literature has reported that doctors are apprehensive to disclose psychological illnesses to patients (Allen and Arroll, 2015). Other
research has indicated that doctors may be fearful of disclosing stigmatised illnesses such as HIV as it may ‘hurt one’s profession as a whole’ (Klitzman and Weiss, 2006). These interesting findings suggest that doctors should be prepared for these potential risks before deciding to disclose personal illness, especially those that carry stigma.

Conversely, this study also demonstrated that patients can perceive illness as something which can enhance doctors’ clinical ability. This idea has been presented within existing literature concerning the relationship between psychotherapists and clients (Zerubavel and Wright, 2012). For example, Zerubavel and Wright (2012) discussed the concept of wounded healers and argued that ‘many wounded healers view their difficult experiences as having been transformative, leading to profound growth personally and professionally’. This is an interesting idea that emphasises the transformative potential of illness, however, it is unclear whether self-disclosure of these wounds can add any benefit to patients. Zerubavel and Wright (2012) recommend for therapists to ‘discuss woundedness in a nonspecific manner’ by referring to healing from tough times in their lives rather than explicitly describing past struggles. They believe that disclosing more specific details relating to their ‘wounds’ requires great sensitivity and consideration. Similarly to the findings of this study, Zerubavel and Wright (2012) have suggested that patients’ perceptions of therapists with ‘past woundedness’ can be contrasting. For example, some patients may find their therapist’s past issues to be inspiring and relatable, while others may not appreciate this personal information at all. These contrasting possibilities further emphasise the important skill of being ‘in tune’ with the patient.

These contrasting scenarios illustrate the unpredictable nature of patients’ reactions to DSID; something that has been discussed within existing medical literature (Klitzman and Weiss, 2006). Before deciding to disclose their own illness information to patients, doctors should be aware of both the positive and negative ways in which patients can react to DSID. These findings emphasise that DSID does possess significant risks as well as potential benefits; therefore, it is
unlikely that it will always elicit a positive response from patients. Based on this research, I argue that doctors should reserve the use of DSID for instances in which they believe it will be well-received and beneficial to the patient. Recommendations for doctors concerning effective use of DSID are summarised later in this chapter within section 5.4.

5.3.3 Impact upon the Doctor-Patient Dynamic

The interview findings suggested that DSID can have a profound impact on the doctor-patient relationship. Many participants described how their experience of DSID marked a pivotal point in their relationship with their doctor, with some explaining how it helped to establish a strong bond between them. Despite these findings, this idea has been contested in the existing literature. McDaniel et al. (2007) have argued that there is little evidence to suggest that doctors self-disclosing personal information to patients helps to strengthen the doctor-patient relationship. The findings of my research challenge the conclusions of McDaniel et al. (2007) and suggest that DSID has the potential to strengthen the doctor-patient relationship. Many participants greatly appreciated their doctor’s disclosure and felt a greater connection with their doctor as a result.

McDaniel et al. (2007) have also warned that ‘sharing strong beliefs or emotions without understanding the patient’s perspective seems risky’, suggesting that the doctor may shift the consultation to focus on their own needs rather than the patient’s needs. It should be acknowledged that DSID does present various risks if not handled sensitively. Doctors may prematurely disclose to a patient without adequately understanding their point of view; doctors should be aware of this risk and its consequences for the doctor-patient relationship. Adam’s experience, detailed in section 4.2.1, illustrates this risk and shows the circumstances in which DSID can be perceived as dismissive or invalidating. Based on this research, it is advised that doctors should be aware that DSID has the potential to be considered condescending or competitive by patients. Because of this, it is important for
doctors to actively acknowledge the patient’s feelings and concerns when using DSID and avoid using it to shift the focus of the consultation onto themselves.

The potential for the doctor-patient relationship to evolve into an inappropriate friendship as a result of DSID was not prominent within the data. This could suggest that patients may be naïve to the legitimate risks subtle boundary transgressions can present to the doctor-patient relationship, however, this is still unclear. A few participants did acknowledge that doctors could misuse DSID in order to reverse the therapeutic relationship and adopt the patient role. This idea has been explored in existing medical literature in the context of SD, often warning doctors against forming a co-dependent relationship with patients (Gabbard & Nadelson, 1995).

Past research regarding the use of SD in general has identified instances of doctors using it as a way to gain emotional support from patients (McDaniel et al., 2007). In this study, the majority of participants believed that their doctor had patient-centred reasoning for their disclosure and did not perceive it as exploitative. I argue, however, that a fine-line exists between appropriate and potentially exploitative DSID. Some participants believed that doctors disclosing illnesses of great severity could be emotionally burdensome to patients, especially when patients are already struggling to cope with their own health concerns. These findings suggest that doctors should refrain from disclosing illnesses that are extremely severe or traumatic as this could overwhelm patients and cause them to carry excessive concern for their doctor. These findings also highlight doctors’ important responsibility to maintain their own health before attempting to help others. McDaniel et al. (2007) have suggested that some instances of self-disclosure can ‘make patients feel pressured to provide caring and support to a distressed physician’. Research in this area has also argued that patients ‘may find sharing health concerns extremely difficult if the physician is perceived as needy or vulnerable’ (Gabbard & Nadelson, 1995). Doctors should be aware that DSID has the potential to inappropriately upend the doctor-patient dynamic and cause the patient to feel uncomfortable or as if they need to fulfil the doctor-role.
Doctors who feel inclined to use DSID to elicit emotional support from patients should recognise that patients are likely to find this inappropriate and take the time to reflect on their own health care needs. It is important to note, however, that doctors may not be conscious that they are using DSID in a manipulative manner to gain emotional reassurance from patients. This further emphasises the need for doctors to practice good self-care and reflection to recognise when they need to access support through the appropriate channels.

Participants had strong feelings regarding the role of the doctor and the role of the patient within the doctor-patient relationship. Many believed that doctors' top priority should be the health and wellbeing of their patients, therefore implying that they should have patient-centred reasons guiding their behaviour. Participants strongly believed that doctors should have patient-centred reasoning for using DSID and therefore avoid using it for their own personal gain. Gabbard and Nadelson (1995) presented this idea within the literature by stating that ‘an essential element of the physician's role is the notion that what is best for the patient must be the physician's first priority’. Participants strongly aligned with this belief and agreed that doctors should only disclose illness information which directly relates to the patient’s situation. From these results, it can be concluded that doctors should reserve DSID for instances in which it is likely to provide valuable insight for the patient regarding their illness experience. This idea has been discussed amongst existing literature concerning the psychotherapist-client relationship and self-disclosure. For example, it has been argued that ‘therapists need to examine their motivations, making sure that the disclosure is made for the benefit of the client, rather than to meet the therapist’s own needs’ (Zerubavel and Wright, 2012). Although these recommendations are specifically concerning self-disclosure within psychotherapy, this research suggests that they are transferable to the doctor-patient relationship in general practice.

Gabbard and Nadelson (1995) have also argued that regardless of whether SD results in serious clinical misconduct, it is still inappropriate as ‘it is a misuse of the patient to satisfy one’s own needs for comfort or sympathy’, Interestingly, past
research has shown that when doctors disclose about themselves to patients, it is often focused on themselves rather than the patient (McDaniel et al., 2007). Quantitative research investigating doctors’ use of self-disclosure in the clinical context has shown that they are usually spontaneous in nature; meaning that the disclosures are rarely prompted by direct questioning from the patient and are instead often spontaneously initiated by the doctor (Beach et al., 2004a).

A few participants acknowledged that DSID could potentially shift the consultation away from the patient and therefore waste valuable consultation time. This belief has also been shared by GPs in existing literature exploring doctors’ attitudes towards SD (Allen and Arroll, 2015, Hall et al. 2018). Some participants implied that a disclosure does not have to be lengthy in order to be impactful. These findings suggest that doctors should keep disclosures short and focused. This idea has been explored within existing literature investigating types of self-disclosure. For example, Beach et al. (2004a) have addressed how extended narrative disclosures, defined as ‘a lengthy description of physician’s personal experience that has seemingly little relevance’ to the patient, can be perceived as disruptive to the consultation. This existing research, as well as my current findings, imply that doctors should avoid going into excessive detail when using DSID as it can distract from the purpose of the consultation.

The results of this study have also demonstrated that it is possible for DSID to alter the doctor-patient relationship and cause patients to carry an unnecessary sense of responsibility. An example of this was when Dena felt as if she owed her doctor confidentiality concerning the illness information they disclosed. Although this slight change to the therapeutic relationship can seem harmless, it can be argued that this effect alone shows the exploitative potential of DSID. It is notable that even though her doctor did not explicitly ask her to keep the disclosure a secret, Dena still felt that this was her responsibility. In contrast to this, many participants believed that doctors hold complete responsibility for any personal information they disclose to their patients. Within the context of psychotherapy, it has been emphasised that therapists should not disclose any information that they
would ‘not want known within the professional context (e.g. among colleagues, supervisors)’ (Bloomgarden and Mennuti, 2009 as cited in Zerubavel and Wright, 2012). Based on this research, I recommend that doctors should not disclose any information about themselves to patients that they would be uncomfortable with the patient sharing with others. Even though doctors are required to keep their patients’ personal information confidential, this is not reciprocal. GPs should expect the same level of privacy when disclosing information to their patients as if they told someone outside of work.

5.3.4 Impact upon Decision-Making

During the interviews, many participants described how their doctor used DSID to reassure them about treatment options. This was often greatly appreciated by participants. Some participants, however, did recognise how this could be problematic by suggesting it could unethically impact upon patient decision-making and their doctor’s clinical judgement.

Inappropriately influencing patient decision-making is undoubtedly a risk when doctors decide to disclose their illnesses to patients, regardless of their intentions. There is a risk that doctors may assume that their own illness experience is the same as their patients. This idea is significant as it presents the possibility of compromised clinical judgement that could directly impact the health outcomes of patients. Prior research has warned of an increased ‘chance of a misdiagnosis if the physician does not distinguish the patient’s clinical situation from his or her own (e.g., assuming a benign explanation for symptoms based on his/her own outcome)’ (McDaniel et al., 2007). I agree with this existing research regarding the potentially harmful impact DSID can have on patients’ decision-making. Kristie’s experience of DSID (detailed in section 4.2.5) served as an example of how doctors can project their own history of illness onto the patient, therefore assuming they will share a similar experience when they may not. These findings highlight the importance of doctors acknowledging that illness is a subjective experience.
Conversely, Lee’s experience (detailed in section 4.2.5) showed that DSID can still have a positive impact on patients without directly influencing or guiding treatment decision-making.

The results of this study demonstrate how doctors should recognise that not all cases of an illness may present the same. If they decide to disclose their own illness to patients, it would be wise for doctors to explain that this is their own personal experience and that no two cases are likely to be exactly the same. Doctors should acknowledge that DSID can greatly benefit patients struggling with the treatment phase of their illness; however, it should not be used to inappropriately sway patients toward a particular treatment decision or course of action. In order for DSID to be used wisely in the context of patient decision-making, doctors should make sure to still present all information clearly and without inappropriate persuasion. I still argue, however, that doctors can provide valuable insight to patients through DSID to help them gain clarity and confidence whilst making important treatment decisions regarding their care.

5.4 Clinical Recommendations

A key element of the findings is the idea that DSID as a behaviour is not inherently ‘good’ or ‘bad’ but having both negative and positive potential. The results of this study suggest that DSID should be considered on a case-by-case basis due to the multiple factors that could influence its success in the clinical context. Therefore, there is not a ‘one size fits all’ guide to the successful use of DSID. In order for DSID to be used appropriately, doctors need to act intuitively and be highly aware of their patients’ emotions and cues.

Although the majority of participants had a generally positive and helpful experience with DSID, many did not agree that doctors should be ‘encouraged’ to share their illnesses with patients. Many participants instead suggested that DSID should be reserved for specific instances that are appropriate and genuine (i.e. based on patient-centred reasoning). This is different from the obvious cases
including HIV and communicable diseases that may put the patient at an increased risk of harm and therefore require appropriate notification.

The results of this study have multiple implications on future medical practice and education. This study has demonstrated that DSID is an important issue due to its potential to have a significant impact on patients and how they interact with their doctors. As discussed in chapter two, there is a lack of clear ethical guidelines advising clinicians on how they should approach DSID. This implies that doctors may be unaware of the impact DSID can have on patients and its consequences in clinical practice. Although there is a significant lack of research concerning DSID, these findings can contribute towards the construction of a clinical framework to advise doctors on best practice regarding the use of DSID in primary care.

The range of data collected from the individual interviews provided a solid foundation for clinical guidelines regarding DSID. Although the participants’ opinions were not homogenous, general recommendations for the use of DSID could be constructed. These recommendations are summarised in the table below:

<table>
<thead>
<tr>
<th></th>
<th>Clinical Recommendations for DSID</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Doctors should not expect patients to keep their disclosed health information confidential.</td>
</tr>
<tr>
<td>2</td>
<td>The disclosure should be directly related to the patient and their situation.</td>
</tr>
<tr>
<td>3</td>
<td>Extended disclosures are unprofessional and can waste consultation time.</td>
</tr>
<tr>
<td>4</td>
<td>Doctors should not use DSID as an opportunity to gain emotional support from patients.</td>
</tr>
<tr>
<td>5</td>
<td>Doctors should have clear patient-centred reasoning before disclosing illness information to patients (i.e. not use DSID for personal gain or ulterior motives).</td>
</tr>
<tr>
<td>6</td>
<td>Doctors need to be mindful of emotionally vulnerable patients who may be overwhelmed by a personal disclosure.</td>
</tr>
</tbody>
</table>
Empathy and reassurance can be conveyed to patients without using DSID (i.e. DSID is not necessary to achieve this per se).

Doctors should not assume the patients’ illness experience is identical to their own.

Doctors should not use DSID to invalidate the symptoms or feelings of a patient.

DSID should not be used to inappropriately influence patients’ decision-making.

DSID should not shift the focus of the consultation from the patient onto the doctor.

DSID of very minor illness may not be of benefit to the patient, however, the severity of illness should be considered from the patients’ point of view.

5.5 Opportunities for Further Research

This study has demonstrated how patients perceive DSID and their opinions regarding its use in clinical practice. This study helped to address a considerable lack of research concerning DSID within existing literature, therefore providing the foundation for further research on this topic. Due to this study’s inductive approach, the resulting findings present opportunities for the exploration of theories relating to the use of DSID.

As discussed in section 4.2.3, some participants had increased trust in their doctor’s clinical judgement after their DSID experience. This suggests that patients may place a great level of importance and value on doctors’ personal experience and anecdotal recommendations and therefore, could be more likely to follow them. This concept emphasises an opportunity for further research in exploring how DSID impacts upon medication adherence. For example, some participants believed that their doctor had a greater understanding of their illness due to their
personal experience and could provide more accurate medical advice (e.g., prescription decisions). It is unclear whether patients have greater medication adherence after a doctor uses DSID when discussing treatments. Such research would complement the findings of this study and help evaluate potential clinical uses of DSID as a communication technique and assess whether they are of benefit to patients. The findings of a distinction between patients’ perceptions of doctors’ anecdotal advice compared to advice based on their clinical education was notable. This concept needs to be explored further to fully understand its clinical implications. Research investigating how patients respond to DSID-based advice compared to traditional medical recommendations would help to shed light on the potential implications of these findings.

Further research investigating how patients view doctors with stigmatised illnesses could help to expand the findings of this study. Patient assumptions regarding doctors’ fitness to practice after or with mental illness warrant further research. Within the findings, this concept often centred around the assumption that doctors suffering from mental illness may not be as qualified as ‘healthy’ doctors. Future research exploring patients’ perceptions of doctors with stigmatised illness would help to clarify these findings further. This research could also help to identify potential adjustments to the current fitness to practice criteria for health professionals. In the case of this study, these findings related to the idea that some illnesses aren’t compatible with the traditional expectation of what a doctor should be. Therefore, it can be hypothesised that illnesses such as diabetes (type 2), alcoholism and obesity could elicit a similar response from patients.

Unfortunately, due to logistical issues, the intended rural phase of this study could not be sufficiently completed. Additional research exploring how rural patients perceived DSID could help to strengthen the results of this study.

The results of this study demonstrated that most participants believed it was unreasonable for doctors to expect patients to keep information disclosed via
DSID confidential. This was an interesting finding as it highlighted the unequal balance between doctors and patients concerning confidentiality of information. Research exploring doctors’ perspectives on this issue could help to clarify the ethical complexities involved and investigate how this aspect of confidentiality should be approached within the therapeutic relationship.
Chapter 6 Conclusion

This final chapter will summarise the main findings of this study and describe the conclusions that can be drawn from the results as well as their relevance to clinical practice.

This study has fulfilled the aim of exploring patients’ perspectives on DSID within the context of primary care. The findings of this study demonstrate that DSID has the potential to significantly benefit the patient as well as the doctor-patient relationship. This study has emphasised that DSID is neither good nor bad, but instead carries significant positive and negative potential. A short instance of DSID alone may be perceived as insignificant by some, however, the findings of this study emphasise that the consequent effects of DSID can be profound and wide-ranging. DSID can reassure patients that they are not alone in their illness and even those that are highly regarded in society, such as doctors, are not immune.

The impact DSID can have on patients is significant, even if the disclosure is short in length. As eloquently expressed by Lydia, one of the participants, an effective disclosure can be as simple as conveying that ‘I, too, suffer’. For many patients, the idea that their doctor suffers from a similar condition is in itself emotionally healing; lengthy or heavily detailed disclosures, therefore, are not necessary to express this simple but powerful message.

DSID is a complex issue that is influenced by multiple doctor- and patient-based factors. This study has demonstrated that patients can have widely varying opinions of DSID and preferences for their doctor’s behaviour. Something that many patients agreed on, however, was the need for DSID to be directly related to the patient and for doctors to have patient-centred reasoning for the disclosure.

DSID can be used as a way to help patients gain clarity and insight regarding possible treatment options or courses of action. It is important, however, for doctors to tread carefully when disclosing personal recommendations as to not
inappropriately influence patient decision-making. Illness is a subjective experience that is unique to the individual, therefore, doctors should take care not to enable their own illness experiences to narrow their clinical judgement and make inappropriate generalisations.

Emotional support can be successfully conveyed through the use of DSID, although other methods are likely to have similar effects. This study has shown the prominent benefit DSID can have on patients in terms of empathy and reassurance. Despite its positive potential, it should be acknowledged that DSID may not be appreciated by all patients. Care should be taken when treating patients who are emotionally vulnerable as a personal disclosure may be inappropriate and consequently damage the doctor-patient relationship.

The variation within the findings of this study emphasise the need for doctors to be in tune with their patients in order to tailor their clinical approach accordingly. Based on this research, it is advised that doctors act intuitively when assessing whether or not DSID is appropriate and beneficial to the patient.

The data obtained from this study is important as it helps to address a prominent lack of literature concerning DSID and illuminates a relatively unexplored area of medical ethics. The few studies that have explored DSID have primarily focused on doctors’ perspectives on this issue rather than those of patients. The fundamental purpose of this study is to gain understanding of how patients perceive DSID, therefore, enabling the education of doctors and medical students on this subject. The knowledge gained from this study will allow medical professionals to view DSID through the eyes of a patient. Medicine, at its core, is about caring for patients and their health needs. By focusing primarily on the patients' perspective, this study contributes valuable insight into how doctors should handle DSID in order to provide the best possible care for patients.
References


Bianchi, E., Bhattacharyya, M., & Meakin, R. (2016). Exploring senior doctors’ beliefs and attitudes regarding mental illness within the medical profession: a qualitative study. BMJ Open, 6(9), e012598. doi: 10.1136/bmjopen-2016-012598


Code of Health and Disability Consumers’ Rights (1996)


Furrow, B. (1996). Must Physicians Reveal Their Wounds?. *Cambridge Quarterly Of Healthcare Ethics, 5*(02), 204. doi: 10.1017/s0963180100006940


Health and Disability Commissioner Act (1994)


Appendices
APPENDIX A

University of Otago Ethics Committee Application Reference Number 018/015

UNIVERSITY OF OTAGO HUMAN ETHICS COMMITTEE
APPLICATION FORM: CATEGORY A

Form updated: October 2017

1. University of Otago staff members responsible for project:
   Dr Katherine Hall
   Dr Martyn Williamson

2. Department/School:
   General Practice and Rural Health, Dunedin School of Medicine

3. Contact details of staff members responsible:
   katherine.hall@otago.ac.nz / 03 479 5408 / 027 664 0044
   martyn.williamson@otago.ac.nz

4. Title of project:
   ‘Knowing Me, Knowing You’: The Ethics of Doctor’s Self-Disclosing about Personal Illness to Patients

5. Indicate project type and names of other investigators and students:
   Staff Co-investigators:  
   Names: Katherine Hall, Martyn Williamson

   Student Researchers:  
   Names: Laura Bolger
   Level of Study (PhD, Masters, Hons): BMedSc (Hons)

   External Researchers:
   Names:
   Institute/Company:

6. Is this a repeated class teaching activity?
NO

If YES and this application is to continue a previously approved repeated class teaching activity, provide Reference Number:

N/A

7. **Fast-Track procedure**

Do you request fast-track consideration?

YES

If YES, provide a robust justification on the need for urgency:

This is a re-submission following a deferred assessment from a previous submission. Ms Bolger is requiring to complete this research in a prompt manner in order to meet her requirements for the degree of BMedSc(Hons).

8. **When will recruitment and data collection commence?**

April 2018

What is the planned conclusion date of the study?

November 2018

9. **Funding of project**

Is the project to be funded by an external grant?

NO

If YES, specify who is funding the project:

N/A

If commercial use will be made of the data, will potential participants be made aware of this before they agree to participate? If not, explain:

No commercial use will be made of the data. This information will be provided in the participant information form.

10. **Will researchers be travelling overseas in order to conduct the research?**

NO
If YES is permission, or ethical approval, required to conduct the research in the country or countries to be visited?

N/A

11. **Brief description in lay terms of the purpose of the project:**

The purpose of this project is to investigate patients’ perspectives on the ethics of doctors disclosing about their own personal illness and illness experiences to patients in both rural and urban settings. The data gathered from this qualitative research will be used to define further quantitative research in this area (a separate ethics application will be made for this). The purpose of both phases of research is to 1. Define the ethics of doctors’ self-disclosure on the doctor-patient relationship, 2. Analyse the subsequent impact on patient decision-making and 3. Inform General Practitioners (GPs) and medical students as to the best practice surrounding this issue.

12. **Aim and description of project:**

This study aims to investigate patients’ views surrounding doctors disclosing their (i.e. the doctor’s) own illnesses (such as diagnoses) and illness experiences (such as what being in hospital is like) to patients and how this ultimately impacts upon the doctor-patient relationship and patient decision-making. There is very minimal research on this topic focusing on patients’ perspectives, therefore this information will be invaluable to help inform doctors as well as medical students on the best, safest and most ethically correct clinical practice regarding self-disclosure. This research is also an opportunity to study the differences between rural and urban communities. Living and working as a GP in a rural area can present added complexities as there are more difficulties in overlapping personal and professional lives. Rural medical practice is a significant part of New Zealand health care and any subsequent ethical framework needs to be cognisant of this dimension.

Previous research from the study, “General Practitioners’ Ethical Decision-Making: Does Being a Patient Themselves Make a Difference?”, led by Dr. Katherine Hall, has shown that GPs have widely varying opinions on the ethics of disclosing personal illness to patients (1). This study involved gathering qualitative data from ten GPs who had been patients with a serious illness, and ten who had not, and comparing their responses to four clinical case vignettes. Widely differing views on the issue of disclosing their illnesses to patients were found. One GP participant stated that they would “Absolutely, all the time [disclose]”,
whereas another thought it was “really annoying” when her own GP disclosed their illness to her. Areas of concern were the usefulness of self-disclosure to the patient and whether it demonstrated empathy in the doctor-patient relationship, and if this would be appreciated by the patient. One of the reasons against the use of self-disclosure included that it could move the focus of the consultation toward the doctor rather than the patient. Alternately, a belief held by some of the GPs was that doctor self-disclosure could improve the communication and openness in the relationship.

The published literature on this subject is very limited. One study has shown that doctor self-disclosure occurs in 15.4% of routine consultations, (2) and another has reported it occurring in 34% of consultations (3). The latter study also noted that doctor self-disclosure is rarely prompted by direct questioning from the patient and often results in the consultation shifting focus from the patient’s concerns to the topic of the doctor’s disclosure. Self-disclosure can be seen as manipulative and even a ‘common starting point down the slippery slope toward a sexual relationship with a patient’ (2). Several types of disclosure have been noted.

Reassurance disclosures involve comforting the patient using the doctor’s own similar experience (e.g. “That happens to me too”). Extended narrative disclosures describe long explanations of the doctors’ personal experience with limited importance to the patient.

Instances of doctor self-disclosure vary in terms of intimacy and personal details; ‘reassurance disclosures’ occur most often whereas ‘extended narrative disclosures’ occur the least (2). It has been theorised that doctors’ self-disclosing personal illness to their patients can strain the relationship and cause the doctor to be ‘perceived as needy and vulnerable’ (4). Research has also indicated that patient satisfaction varies depending on whether a doctor self-discloses during a surgical consultation compared with a primary care consultation, although frequency of physician self-disclosure between surgical and primary care specialties is similar (5). The focus of these papers was a description of current practice and doctor self-disclosure in general. The previous literature does not explore what should be happening, informed by the patients’ perspectives.

Apart from our own previous research (1), there has been only one paper published on this area in New Zealand (6). This showed that 6 of the 16 GPs interviewed were comfortable self-disclosing about personal physical illness and only 4 were comfortable sharing details about a personal mental illness with a patient. This is significantly lower than those who were
comfortable sharing personal details about their family (14 of the 16 GPs studied) or about their physical activities/hobbies (16 of the 16 GPs studied).

This prior research has explored doctors’ self-disclosure but has not focused on the issue with regard to personal illness and the patients’ perspectives. The illness experiences of medical professionals have recently entered public media with an article ‘Heal thyself: meet the doctors living with the conditions they treat’ showing that doctors are not just simply those that treat illness but can be impacted by it as well (7). The knowledge gained from this study will fill a significant gap in the literature concerning how patients view doctors who self-disclose their own illness or illness experiences to them. This study is different from existing studies in this area as it focusses on the patient rather than the doctor whilst also placing an emphasis on the comparison between rural and urban contexts. Doctor self-illness disclosure describes a doctor sharing information about their own (i.e. the doctor’s) illness to their patients. Therefore, this does not include a doctor sharing identifiable details about other patients or even the doctor’s own family members’ illnesses as this is already prohibited in New Zealand privacy laws. There are no laws in New Zealand prohibiting doctors from disclosing about their personal illness to their patients. New Zealand doctors have expressed a need for more comprehensive training in medical ethics generally and, specifically to this particular issue, one stated: ‘I think definitely if I was starting out now I would like to have some [self-disclosure] guidelines’; another expressed that ‘it’s important to teach round this topic [self-disclosure] cause [sic] it just saves young doctors wading into mistakes and finding out the hard way’ (6). The main outcome of our study will be the construction of an ethical framework for appropriate self-disclosure for doctors, which will be reported to the New Zealand Medical Council (they have already indicated that they wish to receive the outcomes of this study) and the Royal New Zealand College of General Practitioners, as well as submission to an appropriate, international, peer-reviewed journal. In addition, the results will be disseminated to the relevant convenors of the Medical School Teaching Modules for both undergraduate and postgraduate teaching.

This study will involve conducting of structured interviews with participants from rural and urban areas (Dunedin, Alexandra and surrounding areas) to discuss their experience with doctors self-disclosing about their personal illness to them. The aim of these interviews is to understand the patient’s perspective on this issue and to see how this impacted upon their relationship with their doctor. The interviews will be based on a menu of predetermined
questions; which questions are drawn from this pool will be determined by the flow of the
interview to allow for the fulsome telling of the patient’s story whilst still covering specific
areas of questioning. All questions within the menu may or may not be asked depending on
how the interview progresses, however no additional questions external to this menu will be
asked. We are not collecting any information about the information that the doctor disclosed,
the patient’s health information or identifying details of the doctor, but analysing the reaction
of the patient to that disclosure.

References:


13. Researcher/instructor experience and qualifications in this research area:

**Katherine Hall (Primary Supervisor):**

Dr Hall holds the MBBS degree in medicine as well as two research degrees: a BSc(Med) in Immunology and a PhD in ethics and patient decision-making. She is a Senior Lecturer within the Department of General Practice and Rural Health, DSM, a Fellow of the Royal New Zealand College of General Practitioners and has eighteen published peer-reviewed papers. She was the primary supervisor for the preceding, original research which led to the creation of this BMedSc project.

**Martyn Williamson (Secondary Supervisor):**

Dr Williamson gained his medical degree from the University of Newcastle in the UK and currently works as a rural GP. He is an academic within the Department of General Practice and Rural Health with experience conducting qualitative research. Dr Williamson also teaches the ‘Ethics in General Practice’ postgraduate paper alongside Dr Hall.

**Laura Bolger (Student Researcher):**

Ms Bolger is a medical student at the Dunedin School of Medicine and is undertaking this BMedSc (Hons) in 2018 before entering her 4th year of her Mb ChB next year. She has a strong interest in medical ethics, especially in the context of the doctor-patient relationship.

14. **Participants**

**14(a) Population from which participants are drawn:**

The participants will be adults who have had an experience with a doctor self-disclosing about their own personal illness or illness experience to them. Participants will be drawn from Dunedin, and Central Otago to ensure both rural and urban participants are represented.

**14(b) Inclusion and exclusion criteria:**

With regards to the inclusion criteria, all participants must:

- Be 18 years or older
- Have had at least one experience with a doctor self-disclosing about their own personal illness or illness experience to the patient in the course of a GP consultation paid by the patient
University of Otago Ethics Committee Application Reference Number 018/015

- Be enrolled at a GP practice in Dunedin or Central Otago
- Be comfortable sharing thoughts and opinions
- Be comfortable and fluent in speaking English

With regards to the exclusion criteria:

- Former and/or current patients of Dr Katherine Hall
  - Former and/or current patients of Dr Martyn Williamson

14(c) Estimated number of participants:

Participants will be recruited until research saturation occurs or until a maximum of 20 is reached.

14(d) Age range of participants:

The age-range of participants will be 18 years and older (adult population). There is no upper limit in age, provided the participant is deemed competent to give informed consent and participate.

14(e) Method of recruitment:

Participants will be recruited through advertisements in local newspapers, supermarkets and shopping areas in both Alexandra, Cromwell and Dunedin (and surrounding areas).

14(f) Will any form of compensation be offered to participants for taking part in the research?

A $20 supermarket voucher will be offered to participants for taking part in the research.

15. Methods and Procedures:

Qualitative research methods will be used for this project and information will be gathered by conducting individual one-on-one interviews. Qualitative methods are the most suitable for gathering data in these conditions of very limited previous research, as they will allow for the best collection of data in situations of great uncertainty (1). Participants will not be asked or required to name or identify the doctor in any way. They will not be asked or required to reveal the content of that disclosure, nor the reasons for why the patient was attending the practice on that occasion or any other health information of the patient. A reminder sheet
outlining what information is and isn’t required will be handed to participants to read before
the interview begins. In the event that the participants begin talking about the GPs personally,
the interview will be stopped, they will be reminded of what information is not required and
the interview will be restarted. The questions used during each individual interview will be
drawn from a predetermined menu of questions; which questions are chosen will depend on
the participant’s response and the way in which the interview flows. Not all the questions on
the menu will necessarily be asked, depending on the individual participant’s circumstances
and responses, however, no additional questions to the menu will be asked. Data collection
will occur until data saturation is reached. Dr Hall’s previous experience of conducting a
summer student project in this area suggests that data saturation is likely to occur within 10 to
20 interviews.

The Menu of Questions re. Disclosure will be:

Menu of Questions re Disclosure: (questions will not be necessarily all asked, or be in the order as
listed)

1. How long ago did the disclosure occur?
2. Why was this memorable for you?
3. How did it make you feel at the time? How do you feel about it now?
4. Did it influence the consultation for you? If so, how?
5. Without letting me know why you were seeing the doctor did it influence any decisions you
had to make? If so, how.
6. Looking back, was the disclosure helpful to you in any way? Or was it not helpful?
7. Has the disclosure caused you to think differently about your doctor? Positively or
negatively?
8. Do you think it was OK for the doctor to disclose this information to you?
9. Do you think all doctors should be able to do this?
10. Why do you think the doctor disclosed this information to you?
11. Were you told by the doctor that you should keep the information secret? Do you think a
patient should keep this type of information secret?
12. Do you think there are any circumstances in which it would ALWAYS be OK for doctors to give
health information about themselves to patients?
13. Do you think there are any circumstances in which it would NEVER be OK?
14. Do you think there are any diseases or illnesses which the doctor had had which would ALWAYS be OK for doctors to give health information about themselves to patients?
15. Do you think there are any diseases or illnesses which the doctor had had which it would NEVER be OK?
16. Do you think you would have had a different response to the disclosure if the illness was more or less serious?
17. When do you think it would be appropriate for a doctor to disclose their illness or illness experiences to a patient?
18. Do you think the doctor acted appropriately?
19. Do you think doctors should be encouraged to share their illnesses with patients?
20. When the disclosure occurred, did you think the doctor was acknowledging or dismissing your concerns?
21. Do you think the doctor ‘crossed a line’ when they disclosed this information to you?
22. Did the disclosure make you feel closer or more distant to your doctor?
23. After the disclosure, did you feel more understood or less understood by your doctor?
24. What do you think about doctors disclosing about their mental illness to patients?

Ms Bolger will be conducting the interviews. Ms Bolger is unfamiliar with the GP community and therefore is very unlikely to be able to identify specific GPs from the participants’ interview responses to the above questions. Ms Bolger is yet to have completed her clinical attachments in General Practice and Rural Medicine and as no in-depth knowledge of the General Practitioner community. She is very unlikely to recognize a GP even if a participant inadvertently gave unasked-for identifying details. After each interview she will complete a debriefing session with both Doctors Hall and Williamson after each individual interview. This will allow a safe place and method for Ms Bolger to explore any issues that were raised for her or the interviewee in a safe and confidential manner. These sessions will also enable the discussion of any possible changes to the way the interviews are conducted, necessary feedback to participants, and to ensure no additional data collection will be performed once data saturation has been reached.

Data will be collected in equal (or near equal assuming saturation is reached at the same rate) numbers from both urban and rural participants to investigate similarities and differences between these two groups. We aim to gather information from as diverse a range of participants as possible to enable the data to be representative of the New Zealand patient
population and therefore applicable to clinical practice. Recordings of the interviews will be made and then professionally transcribed to enable them to be further analysed using thematic analysis. The transcripts from the individual interviews will be coded using the ATLAS computer program. The thematic analysis of the data will be undertaken by Ms Bolger with cross-validation with Dr Hall and Dr Williamson. Further cross-validation will be completed by interviewing the participants a second time to ensure the thematic analysis adequately caught their intended meanings.

References:

16. Compliance with The Privacy Act 1993 and the Health Information Privacy Code 1994 imposes strict requirements concerning the collection, use and disclosure of personal information. The questions below allow the Committee to assess compliance.

16(a) Are you collecting and storing personal information (e.g. name, contact details, designation, position etc.) directly from the individual concerned that could identify the individual?

YES

16(b) Are you collecting information about individuals from another source?

NO

If YES, explain:

N/A

16(c) Collecting Personal Information:

- Will you be collecting personal information (e.g. name, contact details, position, company, anything that could identify the individual)?
  
  YES

- Will you inform participants of the purpose for which you are collecting the information and the uses you propose to make of it?
  
  YES

- Will you inform participants of who will receive the information?
YES

• Will you inform participants of the consequences, if any, of not supplying the information?

YES

• Will you inform participants of their rights of access to and correction of personal information?

YES

If you are NOT informing them of the points above, please explain why:

N/A

16(d) Outline your data storage, security procedures and length of time data will be kept:

The audio from the interviews with participants will be gathered using audio recording equipment. The raw audio data will be sent to a professional transcription service to be transcribed. There is a current confidentiality agreement in place with service and details are attached separately to this ethics application. No record is kept by this service. The interview transcripts will be stored as computer files as well as physical copies in secure storage. Once the transcription has been completed, the audio-recordings will be returned on a USB-stick as a password protected file (the password emailed separately) by a sign-only courier delivery to the relevant participants if they would like them. Otherwise the recordings will be destroyed.

Any data that is in digital form will be securely stored on the researchers’ computers within the Department of General Practice and Rural Health, Dunedin School of Medicine and/or shared via the standard University secure networks. These computers are password protected and will be shut down/locked when not in use within the researchers’ offices.

Any paper copies of data and audio recordings/transcripts will be held in a locked cabinet within the department which will only be accessible by the researchers. All data will be stored for a minimum of five years and possibly up to ten years before being destroyed in a secure manner.
The transcripts of the sessions will be securely destroyed by the primary supervisor and research assistant. The transcription service will not retain any transcripts or audio files from the interviews after the transcription of the data.

16(c) Who will have access to personal information, under what conditions, and subject to what safeguards? If you are obtaining information from another source, include details of how this will be accessed and include written permission if appropriate. Will participants have access to the information they have provided?

The people who will have access to personal information are:

- Dr Katherine Hall (Primary Supervisor), for supervision purposes. This includes access to the raw data.
- Dr Martyn Williamson (Secondary Supervisor), for supervision purposes. This includes access to the raw data.
- Ms Laura Bolger (Student Researcher), for work on the project. This includes access to the raw data.
- Participants will have access to any personal information they provide at any time. Verbal requests will be sufficient to initiate access. Participants will be informed about the storage, sharing and collection of their personal information in the information sheet before they choose to take part in the study.

16(f) Do you intend to publish any personal information they have provided?

YES

If YES, specify in what form you intend to do this:

The transcripts of the interviews with participants will form part of the published study. All personal details will be anonymised. Real names of the participants will not be published, and pseudonyms will be used. Other information including age, ethnicity, rural/urban classification and answers to interview questions may be published, however, every attempt will be made to preserve the anonymity of the participants involved. Participants will be sent a copy of any material of theirs (including quotes, general comments, etc.) for approval prior to publication. They will also be given a copy of the
article and/or presentation if they would like one. The results of the study will form the basis of a thesis written by Laura Belger (student researcher) to fulfil the requirements of her Bachelor of Medical Science (Honours) qualification.

16(g) **How will you disseminate and feedback the project results at the end of the research? Please describe your plans with respect to feedback to participants as well as any public dissemination plans, e.g. in journals and conferences.**

A main potential output of the study will be a completed journal article that we aim to be published in a reputable medical journal. The New Zealand Medical Council and the Royal New Zealand College of General Practitioners will be notified of the results. The findings will also be sent to the relevant convenors of the Otago Medical School Teaching Modules for both undergraduate and postgraduate teaching. Participants will be asked to provide their email address so that if they would like to be sent a copy of any published material from the study and/or the results of the study.

16(h) **Do you propose to collect demographic information to describe your sample? For example: gender, age, ethnicity, education level, etc.**

YES

16(i) **Have you, or will you, undertake Māori consultation? Choose one of the options below, and delete the option that does not apply:**

YES We have already undertaken consultation. We have forwarded the positive response of the Ngai Tahu Research Committee to you prior to this re-application.

17. **Does the research or teaching project involve any form of deception?**

NO

18. **Please describe the ethical issues that might arise from the proposed research and how they are to be addressed.**

- Informed consent.

It is important that the participants do not feel obligated to take part in the research project at any stage and understand that they can withdraw at any time without any negative consequences to themselves. This ethical issue will be addressed by
University of Otago Ethics Committee Application Reference Number 018/015

providing sufficient and extensive information to all participants and notifying them of their rights before they take part in any form of data collection

- **Anonymity of participants:**

  Personal information (i.e. name, age and ethnicity) will be obtained in the recruitment phase of the research study but every attempt will be made to remove or anonymise any personal identifying information from the published study. Any personal information will only be known to the immediate research team (Dr Hall, Dr Williamson and Ms Belger). Written permission from participants will be sought before any personal information or responses (including anonymised material) are published.

- **Storage of information:**

  There will be adequate consideration for the security of the information if needing to be stored on researchers' personal computers to work on the project outside of their office.

- **Participant well-being:**

  Participant welfare is of utmost concern to the researchers. The researchers will strictly adhere to the principles of consent, including full information, freedom from coercion and necessary competency. Every participant will receive a copy to keep of the information sheet and consent form. Participants are free to withdraw at any time throughout the course of the research and they are not required to provide any reasons for this withdrawal unless they so choose. No coercion will be applied to enrol or continue in the study; if the subject matter causes significant distress to the participant they will be withdrawn even if the participant was willing to continue. Similarly, if researchers have good reason to doubt the competency of the participant to consent then they will be withdrawn from the study by the researchers, unilaterally if necessary.

- **Anonymity of GPs:**

  To prevent the GPs involved in the disclosure being identified, participants will not be asked to provide any specific details about the disclosure itself. Participants will only be asked questions pertaining to their response and implications of the disclosure rather than the illness disclosed, personal details of
the GP or any other identifying information. Ms Bolger (student researcher) will conduct the interviews as she is unfamiliar with the GP community and therefore less likely to recognise specific doctors from the participants’ responses. A reminder sheet outlining what information is and isn’t required will be handed to participants to read before the interview begins. In the event that the participants begin talking about the GPs personally, the interview will be stopped, they will be reminded of what information is not required and the interview will be restarted.

19. *Applicant’s Signature: ............................... Name (please print): ........................................

Date: ........................

*The signatory should be the staff member detailed at Question 1.

20. Departmental approval: I have read this application and believe it to be valid research and ethically sound. I approve the research design. The Research proposed in this application is compatible with the University of Otago policies and I give my consent for the application to be forwarded to the University of Otago Human Ethics Committee with my recommendation that it be approved.

Signature of **Head of Department: .................................................. Name of HOD (please print): ..................................................

Date: ..........................
‘Knowing Me, Knowing You’: The Ethics of Doctor’s-Self
Disclosing about Personal Illness to Patients

INFORMATION SHEET FOR PARTICIPANTS

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you and are very thankful for your involvement. If you decide not to take part, there will be no disadvantage to you and we thank you for considering our request.

What is the aim of the project?
There is some research showing that doctors have varying opinions on whether it is appropriate to talk to their patients about their own illness experience, however, there is a lack of research investigating what patients think about this issue.

The aim of this project is to better understand patients’ thoughts and feelings towards doctors who disclose their own (i.e. the doctor’s) illnesses and/or illness experiences to them. This study will also involve comparing the responses from patients from urban and rural communities to see if there are any differences. This research will be used to help inform doctors and medical students about how to approach this issue when treating patients in the future. This project is being undertaken as part of the requirements for Laura Bolger’s Bachelor of Medical Science with Honours.

Who is being sought to take part in the project?
We are looking for participants who:

- Are 18 years old or older
- Have had at least one experience with a doctor self-disclosing about their own personal illness or illness experience in the course of a GP consultation that you paid for
- Are enrolled in a Dunedin or Central Otago GP practice
University of Otago Ethics Committee Application Reference Number 018/015

- Are comfortable sharing their thoughts and opinions about this (you are not required to name the doctor or identify him/her in any way)
- Are comfortable speaking English

What will I be asked to do?
Should you agree to take part in this project, you will be asked to take part in a structured one-on-one interview with a researcher from the Department of General Practice and Rural Health, Dunedin School of Medicine. You will also be asked to provide your age, gender, rural/urban classification and ethnicity.

The interview will involve being asked to share your experience with a doctor self-disclosing about their illness and how this made you feel. The audio from the interviews will be recorded so that they can be transcribed and later analysed. The questions used during the interview will be drawn from a menu of prepared questions and will depend on the way in which the interview flows. All of the questions on the menu may not be used, however, no questions outside of this menu will be asked. The questions you could be asked are:

1. How long ago did the disclosure occur?
2. Why was this memorable for you?
3. How did it make you feel at the time? How do you feel about it now?
4. Did it influence the consultation for you? If so, how?
5. Without letting me know why you were seeing the doctor did it influence any decisions you had to make? If so, how.
6. Looking back, was the disclosure helpful to you in any way? Or was it not helpful?
7. Has the disclosure caused you to think differently about your doctor? Positively or negatively?
8. Do you think it was OK for the doctor to disclose this information to you?
9. Do you think all doctors should be able to do this?
10. Why do you think the doctor disclosed this information to you?
11. Were you told by the doctor that you should keep the information secret? Do you think a patient should keep this type of information secret?
12. Do you think there are any circumstances in which it would ALWAYS be OK for doctors to give health information about themselves to patients?

13. Do you think there are any circumstances in which it would NEVER be OK?

14. Do you think there are any diseases or illnesses which the doctor had had which would ALWAYS be OK for doctors to give health information about themselves to patients?

15. Do you think there are any diseases or illnesses which the doctor had had which it would NEVER be OK?

16. Do you think you would have had a different response to the disclosure if the illness was more or less serious?

17. When do you think it would be appropriate for a doctor to disclosure their illness or illness experiences to a patient?

18. Do you think the doctor acted appropriately?

19. Do you think doctors should be encouraged to share their illnesses with patients?

20. When the disclosure occurred, did you think the doctor was acknowledging or dismissing your concerns?

21. Do you think the doctor 'crossed a line' when they disclosed this information to you?

22. Did the disclosure make you feel closer or more distant to your doctor?

23. After the disclosure, did you feel more understood or less understood by your doctor?

24. What do you think about doctors disclosing about their mental illness to patients?

You will not be asked to identify or share details about the GP personally, details of the illness or illness experience disclosed or why you went to see the GP in the first place. You will be handed a reminder sheet prior to the actual interview outlining what information we would like, and what we don’t want to know about. If necessary, the interview will be stopped, you will be reminded about what isn’t required and the interview will be restarted. If the line of questioning does develop in any a way that you feel hesitant or uncomfortable, you are reminded of your right to decline to answer any particular question(s) and also that you may withdraw from the project at any stage without any disadvantage to yourself of any kind.
These interviews are likely to take approximately 30 minutes to 1 hour to complete and will take place at a time that suits both the researcher and the interviewee. The interviews will take place in a private interview room in the Department of General Practice and Rural Health, Dunedin School of Medicine, mutually agreed upon location, or via the phone or computer e.g. Skype or Zoom, depending on your wishes. It is important to know that there are no right or wrong answers to the questions asked during the interview process and there will be no pressure to share any details if it makes you uncomfortable.

How will the information I provide be used and who will see it?

The interview you take part in will be audiotaped so that your verbal responses can be professionally transcribed prior to being analysed. This ‘raw’ data will only be handled by the immediate research team and the professional transcribers. The immediate research team includes Dr Katherine Hall (supervisor), Dr Martyn Williamson (supervisor) and Laura Bolger (student researcher).

Any personal information held on the participants (such as contact details and the audio-recordings) will be destroyed at the completion of the research (this includes publication). Only the anonymised transcripts, in both written and digital form, will be kept. The data collected will be securely stored in such a way that only the people mentioned above will be able to gain access to it. The audio recordings obtained from your interview will be loaded onto a USB and returned to you by a signed courier delivery. Data obtained as a result of the research will be retained for at least 5 years in secure storage. The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve your anonymity. It will also be available to the New Zealand Medical Council and the Royal New Zealand College of General Practitioners. You will have an opportunity to review what anonymised information is being used of yours prior to publication.

If I agree to take part, can I change my mind or withdraw from the project?

You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind. If you choose to do so, the audio-recordings of your interview(s) can be returned to you if desired. Otherwise they will be destroyed at the end of the research.

What should I do if I would like to find out more or take part in the project?
University of Otago Ethics Committee Application Reference Number 018/015

If you have any questions about our project, either now or in the future, please feel free to contact either:

Laura Bolger  
Department of General Practice and Rural Health  
bolla901@student.otago.ac.nz

Dr Katherine Hall  
Department of General Practice and Rural Health  
katherine.hall@otago.ac.nz

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph. +643 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.
CONSENT FORM FOR PARTICIPANTS

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

1. My participation in the project is entirely voluntary;

2. I am free to withdraw from the project at any time.

3. Personal identifying information contained within the audio recordings will be destroyed at the conclusion of the project but any other data on which the results of the project depend will be retained in secure storage for at least five years;

4. The results of the project are intended to be published in a medical journal and given to the New Zealand Medical Council and the Royal New Zealand College of General Practitioners. They will be available in the University of Otago Library (Dunedin, New Zealand). The results of the project will also form the basis of a thesis written by Laura Bolger to fulﬁl the requirements of her Bachelor of Medical Science (Honours) qualification. Every attempt will be made to preserve my anonymity – no personal details will be used, or only used in an anonymised form. I will be given the opportunity to review any of my information prior to it being disseminated if I so wish.

I agree to take part in this project.
University of Otago Ethics Committee Application Reference Number 018/015

(Signature of participant)  (Date)

(Printed Name)

Name of person taking consent

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research, you may contact the Committee through the Human Ethics Committee Administrator (ph +643 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.
‘Knowing Me, Knowing You’: The Ethics of Doctor’s-Self Disclosing about Personal Illness to Patients

Has your General Practitioner/Family Doctor ever told you about an illness (or illness experience) that they themselves have had whilst you were having an appointment with them? If so, we would like to talk with you please! We would like to better understand patients’ thoughts and feelings when GPs share their own illness experience with patients. This research will be used to help teach doctors and medical students the ethical issues about doing this when treating patients. This study will involve a confidential 30 to 60-minute interview where you will be free to share your experience. A $20 New World supermarket voucher will be provided as compensation for your time.

We are looking for participants who:

- Are 18yrs or older
- Have had at least one experience with your General Practitioner/Family Doctor telling you about their own personal illness or illness experience when you had an appointment with them.
- Are enrolled at a Dunedin or Central Otago GP practice
- Are comfortable sharing your thoughts and opinions
- Are comfortable and fluent in speaking English

If you are interested or would like to know more, please contact either:

Laura Bolger
Department of General Practice and Rural Health
Phone: 0275680295
Email: bolla901@student.otago.ac.nz

Dr Katherine Hall
Department of General Practice and Rural Health
Email: katherine.hall@otago.ac.nz

[This project has been reviewed and approved by the University of Otago Human Ethics Committee. Reference: 018/015]
Reminder Sheet:

The focus of this interview is to understand your response to doctor self-illness disclosure and whether this altered your relationship with your GP. We will not be asking you for personal details or identifying information about the GP involved. We will not be asking you for any health information or about why you were seeing the doctor.

What we DO want to know:

- Your thoughts and feelings about the doctor’s self-disclosure
- How the disclosure affected you and your decision-making
- How you think generally doctors should behave about giving out information to patients about their own illnesses and illness experiences

What we DON’T want to know:

- Personal details about the GP
- Details about the illness specifically
- Any other identifying information about the GP
- Why you went to see the GP in the first place, or any of your health information

*If the interview begins to include details which we don’t think are appropriate for us to know about, we will pause the interview, and you will be reminded of these guidelines, before restarting the interview again.*
APPENDIX B

CLIENT NON-DISCLOSURE AGREEMENT

This CLIENT NON-DISCLOSURE AGREEMENT, effective as of the date last set forth below (this "Agreement"), between the undersigned actual or potential client ("Client") and Rev.com, Inc. ("Rev.com") is made to confirm the understanding and agreement of the parties hereto with respect to certain proprietary information being provided to Rev.com for the purpose of performing translation, transcription and other document related services (the "Rev.com Services"). In consideration for the mutual agreements contained herein and the other provisions of this Agreement, the parties hereto agree as follows:

1. Scope of Confidential Information

1.1. "Confidential Information" means, subject to the exceptions set forth in Section 1.2 hereof, any documents or other text supplied by Client to Rev.com for the purpose of performing the Rev.com Services.

1.2. Confidential Information does not include information that: (i) was available to Rev.com prior to disclosure of such information by Client and free of any confidentiality obligation in favor of Client known to Rev.com at the time of disclosure; (ii) is made available to Rev.com from a third party not known by Rev.com at the time of such availability to be subject to a confidentiality obligation in favor of Client; (iii) is made available to third parties by Client without restriction on the disclosure of such information; (iv) is or becomes available to the public other than as a result of disclosure by Rev.com prohibited by this Agreement; or (v) is developed independently by Rev.com or Rev.com's directors, officers, members, partners, employees, consultants, contractors, agents, representatives or affiliated entities (collectively, "Associated Persons").

2. Use and Disclosure of Confidential Information

2.1. Rev.com will keep secret and will not disclose to anyone any of the Confidential Information, other than furnishing the Confidential Information to Associated Persons; provided that such Associated Persons are bound by agreements respecting confidential information. Rev.com will not use any of the Confidential Information for any purpose other than performing the Rev.com Services on Client's behalf. Rev.com will use reasonable care and adequate measures to protect the security of the Confidential Information and to attempt to prevent any Confidential Information from being disclosed or otherwise made available to unauthorized persons or used in violation of the foregoing.

2.2. Notwithstanding anything to the contrary herein, Rev.com is free to make, and this Agreement does not restrict, disclosure of any Confidential Information in a judicial, legislative or administrative investigation or proceeding or to a government or other regulatory agency, provided that, if permitted by law, Rev.com provides to Client prior notice of the intended disclosure and permits Client to intervene therein to protect its interests in the Confidential Information, and cooperate and assist Client in seeking to obtain such protection.

3. Certain Rights and Limitations

3.1. All Confidential Information will remain the property of Client.

3.2. This Agreement imposes no obligations on either party to purchase, sell, license, transfer or otherwise transact in any products, services or technology.

4. Termination

4.1. Upon Client's written request, Rev.com agrees to use good faith efforts to return promptly to Client any Confidential Information that is in writing and in the possession of Rev.com and to certify the return or destruction of all Confidential Information; provided that Rev.com may retain a summary description of Confidential Information for archival purposes.

4.2. The rights and obligations of the parties hereto contained in Sections 2 (Use and Disclosure of Confidential Information) (subject to Section 2.1), 3 (Certain Rights and Limitations), 4 (Termination), and 5 (Miscellaneous) will survive the return of any tangible embodiments of Confidential Information and any termination of this Agreement.

5. Miscellaneous

5.1. Client and Rev.com are independent contractors and will so represent themselves in all regards. Nothing in this Agreement will be construed to make either party the agent or legal representative of the other or to make the parties partners or joint venturers, and neither party may bind the other in any way. This Agreement will be governed by and construed in accordance with the laws of the State of California governing such agreements, without regard to conflicts-of-law principles. The sole and exclusive jurisdiction and venue for any litigation arising out of this Agreement shall be an appropriate federal or state court located in the State of California, and the parties agree not to raise, and waive, any objections or defenses based upon venue or forum non conveniens. This Agreement (together with any agreement for the Rev.com Services) contains the complete and
exclusive agreement of the parties with respect to the
subject matter hereof and supersedes all prior
agreements and understandings with respect thereto,
whether written or oral, express or implied. If any
provision of this Agreement is held invalid, illegal or
unenforceable by a court of competent jurisdiction,
such will not affect any other provision of this
Agreement, which will remain in full force and effect.
No amendment or alteration of the terms of this
Agreement will be effective unless made in writing and
executed by both parties hereto. A failure or delay in
exercising any right in respect to this Agreement will not
be presumed to operate as a waiver, and a single or
partial exercise of any right will not be presumed to
preclude any subsequent or further exercise of that
right or the exercise of any other right. Any modification
or waiver of any provision of this Agreement will not be
effective unless made in writing. Any such waiver will
be effective only in the specific instance and for the
purpose given.

IN WITNESS WHEREOF, the parties have caused this Agreement to be executed below by their duly
authorized signatories.

CLIENT

Print Name: __________________________

By: __________________________

Name: __________________________

Title: __________________________

Date: __________________________

Address for notices to Client: __________________________

REV.COM, INC.

By: __________________________

Name: Abid Mohsin

Title: VP Sales and Marketing

Date: __________________________

Address for notices to Rev.com, Inc.: 251 Kearny St. FL 8

San Francisco, CA 94108
APPENDIX C

NGÄI TAHU RESEARCH CONSULTATION COMMITTEE
TE KOMITI RAKAHOU KI KAI TAHU

Wednesday, 14 February 2018.

Dr Katherine Hall,
Dunedin School of Medicine - General Practice and Rural Health,
DUNEDIN.

Tēnā Koe Dr Katherine Hall,

Knowing Me, Knowing You: The Ethics of Doctors’ Self-Disclosing About Personal Illness to Patients.

The Ngāi Tahu Research Consultation Committee (the committee) met on Tuesday, 13 February 2018 to discuss your research proposition.

By way of introduction, this response from The Committee is provided as part of the Memorandum of Understanding between Te Rimatora o Ngāi Tahu and the University. In the statement of principles of the memorandum it states “Ngāi Tahu acknowledges that the consultation process outlined in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago”. As such, this response is not “approval” or “mandate” for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee base consultation on that defined by Justice Meecham:

“Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based: listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal.”

The Committee considers the research to be of importance to Māori health.

As this study involves human participants, the Committee strongly encourage that ethnicity data be collected as part of the research project as a right to express their self-identity. That is the questions on self-identified ethnicity and descent, these questions are contained in the latest census.

The Committee encourages contact with Associate Professor Joanne Baxter regarding this study.

The Committee suggests dissemination of the research findings to Māori health organisations regarding this study.

The Ngāi Tahu Research Consultation Committee has membership from:
Te Rimatora o Otago Incorporated
Kāti Huirapa Rūnanga ki Pokiokoi
Te Rimatora o Moeraki
NGĀI TAHU RESEARCH CONSULTATION COMMITTEE
Te Komiti Rakahau ki Kai Tahu

We wish you every success in your research and the committee also requests a copy of the research findings.

This letter of suggestion, recommendation and advice is current for an 18 month period from Tuesday, 13 February 2018 to 13 August 2019.

Nāhaku noa, nā

Mark Brunton
Kaiwhakahaere Rangahau Māori
Research Manager Māori
Research Division
Te Whare Wānanga o Otago
Ph: +64 3 479 8738
Email: mark.brunton@otago.ac.nz
Web: www.otago.ac.nz

The Ngāi Tahu Research Consultation Committee has membership from:

Te Rūnanga o Ōtautahi Incorporated
Kāti Huirapa Rūnanga ki Pokaiwhero
Te Rūnanga o Moeraki
APPENDIX D

Practice Interview Instructions for Actor

The two scenarios are:

**Scenario One (this can be played by a male or female actor called Jo)**

You are Jo, a 40-year-old person with a family history of Barrett’s oesophagitis. This is a condition that can run in families. It gives people recurrent severe heartburn and can also predispose them to oesophageal cancer. The standard treatment for this is to take acid reducing medication and have regular gastroscopies to check that cancer hasn’t developed.

When you saw your GP three years ago, although your father had had Barrett’s oesophagitis, you haven’t had any symptoms to suggest that you had it. You were getting to the age though when your father did first develop symptoms. You asked your GP if you should have a gastroscopy to check. Your GP (who is a male 55-year-old doctor) told you at the time that gastroscopies are horrible. He should know, he had one. The sedation didn’t work properly, and he can remember coughing and gagging and feeling horrible about it. The way he describes it completely put you off it, and after all, you weren’t getting any symptoms were you?

About two years later (i.e. one year ago), however, you did start to develop acid reflux and get indigestion. Because you were worried that you might have to have a gastroscopy (given what you had been told), you put off going to the GP for 6 months, by which time the symptoms were really bad, and you had started to lose weight because so many foods set it off. When you did see the GP, the GP obviously got worried and sent you off for a gastroscopy. You aren’t quite sure, but you think the GP hadn’t remembered the relevant family history as you reminded him about this at this consultation.
You went and had a gastroscopy about 6 weeks after seeing the GP (about 10.5 months ago). At the gastroscopy it was found you didn’t have Barret’s oesophagitis, but you did have a nasty oesophageal ulcer which was pre-malignant. You were very lucky it was caught in time – another few months and it would have developed into cancer. You are now on regular yearly gastroscopy monitoring.

**You as Jo**

Jo is happy to participate although you do have a bit of a secret agenda (see later). You come across jolly and talkative, but you are nervous, and this makes you too talkative. Laura needs to put you at ease and then you settle down and hear what she is asking you better. If she does this well and makes you feel respected, you can either stop the scenario and say that is great but probably best to make a mental note to compliment her at the end so she can get underway without too many interruptions. If the way she is to get you on track is upsetting you or making you feel disrespected, you do need to stop and say this. Then Martyn and I can give suggestions as to what to try. Once things are settled and underway your next challenge is to impart to Laura without being too specific. You shouldn’t mention any specific diagnoses or conditions, or any specific procedures. You can say something runs in your family and you went to see the Dr and because you weren’t getting any symptoms they didn’t think you needed any investigations. The one you were thinking you might need, the doctor told you they had had it, that it was awful… etc, etc. But being human details do slip out. You mention Barrett’s oesophagitis and Laura should stop and explain the ‘rules of the interview again’. If she doesn’t you keep on mentioning explicit medical details until she does. Again, if how she stops and re-starts the interview makes you uncomfortable call Time-out and explain why.

Finally, though, your ‘secret agenda’. You would like to get a de facto second opinion about whether the GP was remiss at not referring you when you first raised the issue of having a gastroscopy 3 years ago, and whether you should put
in a complaint (but you don't know to whom or to where). You let Laura get through the interview but when she is obviously finishing up you insert this into the conversation. Laura should give you some options about what you could do to pursue your complaint but otherwise she should remain neutral and not give any actual opinion about whether the GP was right or wrong in their course of action. Try to push her into voicing an opinion and see how staunch she can be! You can get angry (not about her, but about the situation) and see how she copes. After all, you could have died. Then she should finish the conversation in a way that leaves you content even though you didn't get all your questions answered.

Scenario Two (again this can be played by either a male or female actor, preferably one who is a parent in real-life - and you need to be able to cry, shed visible tears and be very grief stricken)

You are Chris, a mid-30s year old parent. Five years ago (and actually its very close to the anniversary today when you are being interviewed), a terrible tragedy struck. You were walking your first born 5-year-old child Molly home from school when she saw a beautiful cat across the road. She suddenly ran across the road to pat the cat and got hit by a car right in front of you and was killed. It was a parent’s nightmare come true. Usually you hold her hand when walking, but she had been telling you she was a big girl now she was at school and didn’t need to be ‘babied’. She had been skipping happily in front of you but was out of arm’s reach when she darted across the road. Of course, you were utterly devastated. Three months after her funeral you were at a very low ebb. You began to get chest pains and thought you were getting chest pains, so you went to your GP. Prior to this you had only seen him/her (GP to be same sex please to aid identification with their experience) for coughs, colds and taking your child Molly for vaccinations.

Your GP ascertained that the chest pains weren’t coming from your heart but that you were suffering from severe grief. By the way your GP handled the consultation you started to open up to them in a way you never thought you possibly could to a doctor and relative stranger. You started seeing the GP for counselling each week,
and on the third occasion you asked the GP why they seemed to understand your grief and how to help them so well when so many friends and family seem unable to reach you. That was when your GP told you that many years ago they, too, lost a daughter in tragic circumstances. She had died as a nine-month-old baby from cot death. The GP had had a terrible time recovering from this as they felt as a doctor they should have been able to prevent this. That is why he/she has understood your guilt and how it affected you and your grief so well, and why were able to reach you.

You now feel this is really important for Laura to know. You want her to know you feel the fact the GP had also lost a child made an incredibly important difference. In fact, without the counselling from the GP you think you may well have committed suicide. As it was, the relationship with Molly’s father did end after her death as the dad never could fully forgive you. Whilst sad about this, you have forgiven Molly’s father understanding that this represents his limitations. But you still haven’t had another relationship since then, the clock is ticking, and you would really like another family.

You as Chris

This is really personal stuff, so you are quiet and hesitant to begin. Laura needs to work at making you feel comfortable. You might want to check something out about the research – e.g. who else is going to know about what you tell her. You want to tell her, you are even evangelical about it, but you don’t want the whole world to know it was YOU exactly and then overload your Facebook and Twitter-feed with sanctimonious comments. So, she needs to negotiate the way through this concern to your satisfaction before you really unfold the tale. If you aren’t satisfied call Time-Out. At some stage, you need to start sobbing quietly and apologetically, but to keep this up. Laura needs to make you feel comfortable crying and if this doesn’t happen you need to call Time-Out, so we can discuss this as a group. Once she has made you feel comfortable you can sniff a bit and dab the eyes and be deeply mournful. You do cheer up though and wax lyrical about how
wonderful the GP has been, even making this slightly over-the-top in the effusion of praise. Because...

...as you are telling this you are thinking how nice doctors are and how nice it would be to be back in another relationship and here is this lovely, obviously kind and caring medical student who might be a bit young for you, but you are wondering just possibly, maybe you could get together after this interview and see if....?? (You never had any sort of impropriety with the GP but that was because you knew they were VERY married. But the whole experience has left you with a particular emotional vulnerability, which you can act on without thinking things through very well.)

So, when the interview is winding up you have a go at chatting Laura up and seeing if you could get together, ‘just’ for a cup of coffee either immediately afterwards, or maybe next week, or maybe...? Just maybe, something more? (If you are the same gender you can explain you are gay now since Molly’s husband left you, and you are quite happy to get pregnant by artificial insemination, but you want a loving partner around for the future child/children). Call Time-Out if you feel Laura doesn’t respectfully but firmly decline (she has to do both!).