
Hope and Fear: Consumers, Psychiatric Medications and the Therapeutic Relationship

A Report Prepared by

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for

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Table of Contents

Introduction	5
Chapter 1: Accessing Mental Health Care	10
1. <i>Accessing medical help</i>	10
2. <i>Seeking help in crisis</i>	11
3. <i>Positive experiences and gratitude</i>	13
4. <i>“Cut loose”</i>	14
5. <i>“Abusing the system”</i>	15
6. <i>Critical views</i>	15
7. <i>System better now</i>	17
Chapter 2: Diagnosis and Acceptance	18
1. <i>Did your physician explain your diagnosis?</i>	18
2. <i>Agreement with diagnosis?</i>	19
3. <i>Agree you need psychiatric medications?</i>	20
Chapter 3: Elements of the Therapeutic Relationship	22
1. <i>Views on the physician</i>	22
2. <i>Role of case manager</i>	25
3. <i>Experiences with teams</i>	26
4. <i>Continuity of care</i>	27
5. <i>Duration of visits</i>	29
6. <i>Time for questions</i>	31
Chapter 4: Sources of Information	33
1. <i>Learning more</i>	33
2. <i>Accessing Sources</i>	35
3. <i>Evaluating the information</i>	35
Chapter 5: Experience with Side Effects	37
1. <i>Side effects and risks</i>	37
2. <i>Reactions to side effects</i>	37
3. <i>Concerns about adverse effects and toxicity</i>	39
4. <i>Discussing with physician about the medications’ risks</i>	40
5. <i>Would you take medications if aware of all the risks?</i>	42
Chapter 6: Trial and Error	44

Cont.

Table of Contents

Chapter 7: Ambivalence about Psychiatric Medications.....	47
1. <i>Too much emphasis on medication?.....</i>	<i>47</i>
2. <i>Conflicted feelings</i>	<i>48</i>
3. <i>Aversion to taking medication.....</i>	<i>49</i>
4. <i>Fear of dependency.....</i>	<i>49</i>
5. <i>Appreciating and getting better on medications</i>	<i>50</i>
6. <i>Meds may help prevent suicide</i>	<i>51</i>
7. <i>Stabilizing</i>	<i>51</i>
8. <i>Dulling Effect.....</i>	<i>52</i>
Chapter 8: Alternatives to Being on Psychiatric Medications	53
Chapter 9: Whose Decision Is It?	57
1. <i>Involvement in decisions</i>	<i>57</i>
2. <i>Who manages the medication</i>	<i>58</i>
3. <i>Consumers' competence.....</i>	<i>59</i>
4. <i>Being proactive.....</i>	<i>60</i>
5. <i>Medication negotiations.....</i>	<i>62</i>
6. <i>In times of crisis.....</i>	<i>65</i>
7. <i>Feeling Excluded.....</i>	<i>66</i>
Chapter 10: Trust in Physician	67
1. <i>Degrees of trust.....</i>	<i>67</i>
2. <i>What builds trust?.....</i>	<i>68</i>
3. <i>What makes consumers lose trust?</i>	<i>69</i>
Chapter 11: Consumer-Physician Partnership?.....	71
1. <i>In the beginning.....</i>	<i>71</i>
2. <i>Equal partners?</i>	<i>71</i>
3. <i>Not "on par".....</i>	<i>72</i>
4. <i>Communication and listening</i>	<i>73</i>
5. <i>Treated with respect.....</i>	<i>74</i>
6. <i>Openness and honesty.....</i>	<i>75</i>
7. <i>Individual's responsibility in partnership.....</i>	<i>76</i>
8. <i>Positive on relationship.....</i>	<i>77</i>
9. <i>Crisis in the therapeutic relationship</i>	<i>77</i>
10. <i>Changing physicians</i>	<i>78</i>
11. <i>"Magic Wand"</i>	<i>79</i>

Cont.

Table of Contents

Chapter 12: Adherence, Fear and Lack of Options.....	81
1. <i>Being adherent</i>	81
2. <i>Feeling pressured into take medications</i>	82
3. <i>Experimenting with medications/Going "cold turkey"</i>	83
4. <i>Individual histories</i>	84
5. <i>Experimenting without telling physician</i>	85
6. <i>Fear of getting worse when stopping or changing medications</i>	87
7. <i>Withdrawal effects promote adherence</i>	88
8. <i>"Cold turkey" a bad idea</i>	88
9. <i>Fear of hospitalization</i>	89
10. <i>Fears of being "on" or "off" medication</i>	91
11. <i>Lack of options/being stuck</i>	92
Chapter 13: Philosophical Outlook	94
1. <i>Stigma</i>	94
2. <i>Acceptance and resignation</i>	96
3. <i>Quality of life</i>	84
4. <i>Hope and optimism</i>	99
Summary	102
Discussion.....	106
Appendices	109

Introduction

Background and Purpose of the Study

“Consumers for Knowledge Exchange and Research (CONKER) of Mental Illness”¹ is comprised of mental health service providers, service recipients, and researchers. Its members are committed to conducting research into topics deemed important by consumers.² Potential topics of interest for research were identified by consumer focus groups in early 2007. Ranked high was the issue of psychiatric medications, which was later developed into the present study focus. Representation of the consumer point of view was also ensured at all research levels in terms of advisory, consultative, executive and participatory capacities: consumers were critically involved in the CONKER steering committee, in volunteering to participate in the study, in collecting the data, and in presenting the findings.

This study explores the role psychiatric medication plays in the lives of mental health consumers, and, in particular, how this experience of taking medication is affected by the relationship with the prescribing physician. Rather than concentrating exclusively on issues of adherence/non-adherence to medication regimens, as other studies have done, our goal was to unveil the complex lived experiences of consumers, their attitudes, beliefs, and behaviour as they pertain to medications and the therapeutic relationship. It is hoped that the study findings will add to the knowledge base and understanding of participants’ experiences, empower consumers and raise practitioners’ awareness so as to promote increased collaboration in the treatment process.

Methodology

We decided to adopt a qualitative approach as this was particularly acceptable for this project’s goal of exploring the subjective meaning of psychiatric medications for consumers in their daily lives. It was also felt that individual and group interviews were methods best suited to give voice to consumers. Specifically, semi-structured interviews were chosen to allow consumers to tell their story in their own words and thus enable researchers to collect rich, in-depth information about participants’ personal reality of living with a mental illness, taking psychiatric medications and being treated by a physician.

We conducted a series of 15 one-on-one interviews with consumers. Additionally, in a second phase of the study, we invited interview participants back for group discussions which were informed by preliminary research findings and would provide an additional opportunity for consumers to participate in the research enterprise and offer an opportunity to check the validity and accuracy of our data and interpretations.

Developing the interview questions

A series of open-ended interview questions were developed by the research team that addressed many and varied aspects of the role of medications and the interactions between consumers and their physicians. Discussion also generated potential additional probes to be utilized in order to gain greater depth in the interviews. Question-asking was conceived as an iterative process, in that supplementary questions were generated and redesigned during the interviews and throughout the series to retain flexibility and elicit the most meaningful responses. (Appendix A) In keeping with researchers’ determination to ensure consumer involvement in each aspect of the project, the proposed interview questions were then presented to and amended by members of the Vancouver Coastal Health Consumer Initiative Fund Committee, a group of consumers that hold leadership positions within Vancouver Community Mental Health Services.

¹ Formerly known as Vancouver Coastal Research Centre for Mental Wellness (VCRCMW)

² For the purpose of this study, the term “consumer” is used to denote individuals who have at some point received psychiatric services, particularly so in having been prescribed psychiatric medications. This criterion was used in determining eligibility for volunteer participants. We recognize that this terminology is not universally satisfying.

Ethics Approval

Institutional review board approval was obtained from the University of British Columbia and Vancouver Coastal Health.

Ethics and Confidentiality

The design of the interviewee recruitment process guaranteed the completely voluntary nature of consumer participation in this study. Data obtained was kept strictly confidential. For the purpose of this report, to allow for greater ability to distinguish and compare the individual contributions, pseudonyms were used as identifiers. Group contributions always remained anonymous.

Consent

No data was collected prior to full written and informed consent being obtained from each participant for both the individual and the group interviews. (Appendices B & C)

Participant recruitment process

In order to recruit participants in this study, a purposive sampling strategy was pursued. A recruitment poster, combined with a description of the research project, was distributed to Vancouver Coastal Health psychiatric outpatient programs and to non-profit agencies (Kettle, Coast, MPA, Lookout and Triage) that provide services to psychiatric patients within Vancouver. The posters were placed on a consumer listserv and on public bulletin boards to inform consumers about the interviews. (Appendix D). A small honorarium was offered per interview session.

Within few days, there was a very high level of interest in participating in the study. As a result, the first 15 respondents who had contacted the researchers and/or could be reached again were enlisted to be interviewed. Then the recruitment process was stopped; many potential candidates had to be turned away. Mental health team clients dominated the group of volunteers as they seemed to have been the first to become alerted to the study and its search for participants.

Consumers self-identified as adults who had been given prescriptions for psychiatric medications either currently or previously for a period of at least 6 months. Researchers were in contact with each participant prior to the interview and the group discussion to ascertain eligibility and explain the nature and purpose of the research.

Characteristics of the Participants

Participants were a heterogeneous group in terms of gender, age, diagnosis, duration of treatment, and current care providers. The ten women and five men ranged in estimated age between mid-20s and early 60s; the majority were middle-aged. All participants were in professional care at the time of the interview. Nine participants were Vancouver Community Mental Health Services' mental health team clients (11 had at some point been team clients). Three participants were followed by their general practitioner, one participant saw a private psychiatrist, one interviewee was a client at a hospital outpatient clinic, and one participant was no longer seen by a physician but by a counsellor at the Centre for Concurrent Disorders.

In the interviews, we did deliberately not ask for the diagnosis to be named. Rather, we considered it of interest if the consumers themselves identified their diagnosis and the purpose of their medications. However, all participants offered this information and many named some of their past and present medications. This group of consumers identified with the following diagnoses: bipolar disorder, borderline personality disorder, (paranoid) schizophrenia, schizoaffective disorder, generalized/ social anxiety disorder, depression, obsessive compulsive disorder, and posttraumatic stress disorder. In some instances concurrent disorders were mentioned. Interestingly, this list represents most major psychiatric illnesses. At the time of the interview, 13 out of the 15 participants stated that they were presently being prescribed and taking psychotropic medications.

Possible volunteer bias and sample limitations

In light of several circumstances, the application of some volunteer bias in this sample was inevitable; this group of participants may not have been representative of the consumer community at large. For example, we may well regard this group as consisting of mostly "seasoned" consumers: 11 out of 15 participants had been in treatment for their mental health concerns with service providers for 10 years or longer (with a range of between 3 and 40 years.) They had had varied experiences with many physicians: only 7 participants had been in treatment by the same physician for more than 5 years (with a range of between 1.5 months and 17 years).

Also, a number of participants were "insiders": at least 4 consumers were apparently very actively involved in the local mental health community: there were references to sitting on committees, volunteering at the teams, having trained as mental health workers, being advocates or peer support workers, leading self-help groups, organizing recreation programs for consumers, or working in group homes. In addition, other volunteers, too, mentioned that they were attending workshops and symposia, forums, talks and info sessions and had been participating in other studies.

Due to their extensive mental health treatment and their proactive behaviour as mental health consumers, these participants may thus have had some particular experiences, views and skills that others with a mental illness did not necessarily share.

Concerning additional sampling bias, consumers who volunteered to be interviewed for this study were probably more comfortable to talk about medications and their relationship with their doctor than those who did not volunteer to participate. Moreover, we may assume that volunteers were not in crisis or did not feel too ill to undergo a potentially strenuous question-and-answer process with an unknown interviewer. At the same time, the honoraria offered for the interviews may have been a factor in motivating some consumers, perhaps particularly those with very limited income, to volunteer for this study.

Other limitations of the study

As with every research endeavour, there are a number of other potential limitations to this project, its findings and conclusions.

- In assessing the results of this study, we are bound to consider the nature of the group of participants, both in terms of the non-random nature of the sample and its chosen size. Recruitment by other methods and a smaller or larger sample may have influenced the findings.
- Participants had been receiving psychiatric services in the Vancouver area, many through the Vancouver Community Mental Health Service outpatient clinics. Experiences with other providers of mental health care and other mental health systems, in Canada and elsewhere, may well be different.
- Non-English speakers were excluded.
- The sample happened to be more "middle-aged" and less "young adult." This age factor may have impacted on experiences with and attitudes toward medication and physicians, for example in that the more mature participants for the most part had been in treatment and with the same physician longer and thus may have been more accepting of their illness and medication regimen.
- This sample may not have adequately captured the most disadvantaged population, such as residents of the Downtown Eastside, which may have in part been related to difficulties in being in contact with persons without phones or e-mail.
- The "demand characteristics" of the setting for both individual and group interviews – a psychiatric outpatient clinic – may have in some way influenced the responses.

Moreover, the fact that the study was based solely on individual and group interviews had its own implications for our findings.

- Reactive bias may have been in effect as the interviewer might have inadvertently given clues about what the participants “should” be talking about.
- The nature of the questions asked and the manner in which they were asked may have constrained some of the answers that we found. However, the semi-structured nature of the interviews, with their open-ended questions, and the open forum of the group discussions did allow participants to pursue issues of particular interest to them, so that the findings reported here often exceeded the scope of the original questions and probes.
- We recognize that any interview is a socially constructed product and its ability to reflect the “true” authentic experiences of the participant can be challenged.
- In another aspect, there are limitations of the exclusively self-reported nature of the data in this study. For instance, self-reports – both in psychiatric practice and in research - may fail to reflect adequately the extent to which consumers do or do not take their medication as prescribed by their physician. But the purpose of the study was to explore and try to understand the subjective meaning and management of psychiatric medications for consumers in their daily lives and all participant contributions were thus taken at face value.

Interviews – additional information

Participants were debriefed both prior and at the closure of each interview. They were apprised that an interview could be upsetting and that they could take a break or discontinue at any time without repercussions. At the end of each interview they were asked if they had anything to add and how this interview experience had been for them. All participants, including those who had temporarily become tearful during the interview, wanted to complete the process and proclaimed that it had been a positive experience.

All interviews were undertaken by only one of the authors to ensure consistency. The interviewer asked a series of 10 main questions, supplemented by a range of additional potential probes to be used at the interviewer’s discretion. Interviews lasted between 40-90 minutes. With permission, narratives were audio-taped and transcribed verbatim for data accuracy.

Focus groups – additional information

At the end of the individual interviews, participants were asked whether they would be willing to participate in future group discussions for which all indicated an interest. Again, small honoraria were offered. This secondary recruitment process resulted in 9 out of 15 volunteers (4 and 5 consumers respectively) participating in two focus groups.

These meetings provided an opportunity for participants to comment on and validate a number of preliminary study findings, which researchers shared with all volunteers prior and during the group meetings. Group participants also seemed eager to exchange views on other issues of immediate interest to them, such as stigma and both positive and frustrating personal experiences with the mental health system. The meetings were audio-taped and salient themes recorded on flipcharts. The data were then transcribed, analyzed thematically and incorporated in the report.

The interviews and group discussions generated very rich data about volunteers’ thoughts, beliefs, attitudes, opinions and behaviours surrounding the complex role of medications and the therapeutic relationship. These data collection methods gave participants a chance to elaborate on issues close to their heart. Not infrequently, contributions made transcended the realm of the questions asked, such as with “trial and error,” “fear of being ‘cut loose’ from the mental health system,” or “stigma.”

Analysis

Individual and group interviews produced some 400 pages of transcribed text. Starting from familiarization with the raw transcripts, a thematic analysis approach, using a constant

comparison method, was adopted. Data were analyzed and assembled according to emerging subjects by hand; no computer data coding programs were used.

Themes and key words or phrases were extracted from the transcripts and compared. Researchers were particularly alert to discovering patterns and commonalities as well as noteworthy differences within and across participants' responses. The result was the organization, description and analysis of participants' contributions under a number of main themes and a wide array of subordinate topics, all addressing aspects of participants' personal reality of being a consumer, their experiences with taking medications and their relationship with their mental health providers.

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Chapter 1: Access to Mental Health Care

1. Accessing medical help

Participants recalled varying experiences when asked about whether they found it “difficult to find good medical help” for their mental health concerns. Participants commented on the fact that in the metropolis of Vancouver today it could be a challenge to access psychiatric help (Sarah 11³⁴) and even to find a general practitioner (Focus Group 2, 12). There were walk-in clinics, but it was found difficult to establish a relationship with a physician there. (Focus Group 1, 10) This group of consumers also briefly debated the shortage of psychiatric beds and of doctors and nurses and how consumers (including those in prison) needed be properly cared for. (Focus Groups 1, 12, Carole 18)

Other service issues identified were long outpatient clinic waiting lists, delay in diagnosis and gaining access to mental health teams, not being referred to a specialist in a timely manner, high staff turnover, or concurrent disorders not being recognized. Experience led to a perception that there was simply a “lack of resources.” (Anna 16)

Others felt challenged to get good care.

- **“In my experience...Yeah, it has been. Part of what we were talking a little bit about the changing of the staff, the doctors and the case manager, and sticking within the tried and true aspect, I find that very difficult...” (Alex 3)**
- **(difficult to get good help?)“Yes, yes definitely.” (Patty 3)**

Some participants had faced problems with being accepted as clients by a mental health team.

- **(difficult to get good medical help?)“Well, yeah...because there is a process, you had to be referred and the person who refers you had to really believe you need it because like it’s hard to get in here especially a person not having family or connection.” (Thomas 2)**

One respondent came to Vancouver from rural B.C. in search of specialized help and had encountered obstacles.

- **“I didn’t have a psychiatrist when I came down from the north so I was looking for one and I went to a team and they gave me a book “Bringing up Emotions Anonymous’ and that didn’t help and then I was in a revolving door at XYZ, the Psychiatric Assessment Unit at XYZ and they got tired...well it’s just one day they thought that, you know with the progress I was doing going downhill all the time and I wouldn’t be alive, so they actually called the team and they told them that they have to take me and that’s how I go into the system and that was 1999/2000. Two years after I moved down here I got into a team.” (Sarah 1)**

By contrast, one participant came to Vancouver from another province and faced no problems in accessing care through a mental health team.

- **“I came right off the Greyhound, had 2 weeks of medication and I found a psychiatrist, no problem. (Carole 2).**

³ We have used pseudonyms in order to protect the privacy of our participants.

⁴ Numbers in brackets refer to the page location of the quote or reference in the individual transcript of interviews and focus groups.

It could be difficult to accept help within the paradigm of the mental health system.

- **“...there was moments when I felt it was difficult to get what I needed partly because something didn’t quite fit in terms of my own values and the way that I saw the world and the way that psychiatry seems to see the world so that was a little bit of a difficulty but in the end I was able to find a kind of compromise in terms of what attitude I needed to have in order to work with a psychiatrist.’ (Carl 1/2)**

One participant was disappointed that he could not see the psychiatrist who had seen him at emergency and who the participant very much respected, on a regular basis. “The accessibility wasn’t there.” (William 7). He remained on the medication regimen determined by the specialist, with his prescriptions renewed by his GP and appeared so disillusioned that he now hesitated to seek access to treatment by another mental health caregiver. (William 8)

Finding appropriate care was seen as even more difficult in small towns in B.C. One participant shared about her experience with physicians there:

- **“They’re less knowledgeable and they’re less compassionate. I mean even down here in the 90s or beginning of 2000 they weren’t very nice ...”...“It’s too bad that we can only live in Vancouver to get this health system...we are very blessed to be here...”(Focus Group 2, 11)**

2. Seeking help in crisis

Access to appropriate care could go amiss in the most precarious situations. Given the ubiquity of suicidal ideation and real risk among persons with a mental illness, an adequate and timely intervention seemed to be key. Participants turned to find professional help when realizing their own level of risk, but had different experiences with the health care system.

Participants sought or accepted psychiatric help when they felt in extreme crisis and desperately needed help.

- **“I was suicide prone...I turned to the team because I didn’t want to commit suicide.” (Thomas 1)**
- **“I only seek help typically when I am on the floor, and I’m gonna commit suicide. ...I am very proud person. I usually suck it up until I reach the end of the road and say “I’m gonna kill myself,” you know, at that point and seek help...”(William 18.3)**
- **“I was really really suicidal and depressed for a while. I tried to kill myself, I tried once before.” (Rhonda 7, 13, 21)**
- **“I was suicidal all the time before [medications]. I was suicidal; before I started the Lithium actually.”(Anna 11)**
- **“I was hospitalized quite a bit in the first 5 or 6 years ...because I had suicidal ideation.” (Alex 4)**

But one consumer had also tried to avoid treatment when at risk:

- **“Because I’ve been suicidal and I’ve gone, like, when I’ve attempted, I’ve not gotten help and hid to facilitate death.” (Alex 15)**

One participant felt that optimal care, including referral to specialists, was provided by her doctor:

- **“(difficult to get good medical help?) “No, not at all. I have a really excellent doctor. She makes referrals to a counselor and to a psychiatrist because at one point I**

actually became suicidal and she referred me. I find it easy to have access to good medical care for this particular issue, yes.” (Angela 1)

One participant mentioned suicide repeatedly, including in the context of his physician not taking his risk seriously. He stated that without the medication he would be suicidal again, and that it was only when he felt at risk again would he seek out help. But he found he could not count on his family doctor.

- **“...but I also did mention suicide – I said the subject’s come up lately, what was his [GP’s] reaction – ‘aah, it’ll be okay,’ that was it – ‘you’ll be okay, here, you’re a bright guy...’” (William 12)**

Another at-risk participant had had a similar experience of being placated by her general practitioner:

- **(difficult to find professional help?) “Oh, extremely, I waited, I went to my GP for I can’t tell you how long, and I’d say to her, I was on this antidepressant that wasn’t working and I said I wished I was dead...She’d say “Oh, you shouldn’t feel like that.” So finally she put me on a waiting list and it took another year of my life to get to XYZ hospital...It would have really helped if they had sent me to a psychiatrist earlier.”...”So it turned out to be 3 years or something of just hell.” (Anna 1, 15)**

Mental illness could remain unrecognized despite repeated expression of suicidal ideation.

- **“I don’t know if she [the GP] didn’t have the expertise or there wasn’t even a waiting list she could put me on, she just didn’t seem to want to, like she just thought I was normally like that...” (Focus Group 1, 10)**

These experiences reflected the challenges encountered when trying to get help in times of greatest need.

One participant reviewed the process of being caught in the team’s safety net:

- **“...I reached such a bad rock bottom. I mean it served a purpose at the time when I was with the psychiatrist because I just walked in there one day absolutely in crisis and I didn’t know what to do, and so I kind of ended up ...it got me out of a hole.” (Rhonda 4)**

After leaving the team, this participant experienced another crisis, but this time, based on a history of substance abuse, went to see a counselor specializing in concurrent disorders.

It could be a personal struggle to reach out and seek assistance when in crisis.

- **“It’s not easy to seek help because you don’t want to because that’s anxious in itself.” (William 3)**

Still, help was sought in a “preservation response”. (Focus Group 1, 18).

- **“I think it’s almost like a cry for help, they know, you know ‘cus they’re not stable they know that they need something that something is wrong.” (Focus Group 1, 18)**

Some consumers debated that in crisis the support system, (family, doctor) needed to take over and support the patient (even through certification) as this may save their life. Another consumer recommended the development of a detailed personal crisis plan ahead of time to be shared with one’s support system. (Focus Group 2)

3. Positive experiences and gratitude

Some participants noted that their experiences with the mental health system had been overwhelmingly positive.

- **“I really haven’t had a bad experience so I mean my faith is in the medical experience.” (Carole 9)**

This participant was also amazed that her team physician took 1.5 hours to inquire about medical history, life situation and family background, leaving her wondering why “you always hear on the news there’s not enough time and how bad our system is...” (Carole 5)

With over 20 years experience in the mental health system, another participant concluded:

- **“I feel that I’ve been able to create a reasonably good life for myself in the mental health service.” (Alex 4)**

One participant felt that her experience with the system had been “for the most part positive” and remarked on the apparent availability of resources. (Rhonda 19)

Holding some critical views about the system, did not prevent one consumer from still appreciating the system as a whole:

- **...”It’s relative, too, the fact that we have this system in place, I’m very grateful for it. There have been many times I have been in poverty and I haven’t been able to afford meds so that is highly valuable, so it’s relative, too. There is a lot of positive things in the fact that the system is there the way that it is but I appreciate the desire to want to improve it.” (Carl 13, 14)**

Other consumers also expressed outright gratitude for help received. They felt grateful for the psychiatric treatment, their physician, their therapist, their counselor, and their medications. Mental health care was not always taken for granted.

- **“[Care by a team psychiatrist] served its purpose and for that I was grateful, it picked me out of a hole and stabilized me for a time.” (Rhonda 13)**
- **“So I’m grateful for that.” [seeing a counselor on a weekly basis] (Rhonda 6)**
- **“I am grateful for both my psychiatrist, but mostly my therapist....So I’m very grateful for that service that was offered.” (Carl 13)**
- **“I am grateful that there’s medication.” (Angela 11)**
- **“Well I am grateful that [the physician] takes an interest in me and I feel more now that somebody cares that my medications are right.” (Carole 6)**

Consumers even credited their psychiatrist with saving their life.

- **“At the time, my psychiatrist, she was in times of crisis [part of the support network], I guess, especially at the beginning, she probably saved my life.” (Rhonda 18)**

Another participant had been hospitalized for lithium toxicity (Wendy 9) and her present psychiatrist took over her care. After many years of treatment, she retained a grateful attitude.

- **“I feel a big gratitude because we share the same religion and I think I owe everything to her and it’s more than a friend. For me it’s like somebody saved my life, I feel indebted to her.” (Wendy 5)**

4. “Cut loose”

In a number of circumstances, participants had the perception that they would lose access to professional support if they became “too well” or if they were no longer taking their medication and thus no longer fit the team’s mandate.

Some participants worried about/experienced being ‘cut loose’ from the mental health system if their health improved too much...

- **“I keep thinking that if I get too well, I won’t be able to see her.” (Anna 5)**
- **“If I get too well then what is going to happen, she might be thinking in her head like “why is she still coming here, she seems okay this week.” (Focus Group 1, 8)**
- **“Well I was but I can’t see him anymore because I’m not ill enough to see him ... Well, that was the sense I got.” (William 5)**
- **“That’s been a challenge to me now that I’m going back to work is how to access resources that are going to help me maintain rather than ok, you go to work now so you’re obviously well enough that you don’t need that.” (Rhonda 2)**

...or if they resisted or discontinued medication intake.

- **(If go off medications completely) “...at that point basically they would decide to wash their hands of the relationship probably because of my ability and they let me loose in the world.” (Carl 7)**
- **“Well, if I don’t take the meds then I don’t have a team that’s the reality, right. That’s it the reality if I’m not on the meds then the team has no purpose in my life...I need the support of a team.” (Sarah 6)**
- **“I felt that there was this ultimatum at the end when I said I didn’t want to be on it [medication] anymore. And it was ok then you can’t come here anymore.” (Rhonda 15)**
- **“...but I don’t even think you could go there unless you were getting prescriptions, could you?” (Anna 17)**

One participant shared that he was now considered well enough to “graduate” from the team and chose to be seen by a general practitioner in the future. (Focus Group 1, 9)

The policies of the teams differed starkly from the experiences made by one participant with her general practitioner.

- **“I weaned myself off AD’s [antidepressants] gradually. When I told her she was ok with it. We still have a good relationship.” (Focus Group 2)**

Whereas a fellow consumer pointed out:

- **“That would be completely different if you are with a team. If you’re not on pills, you can’t be with the team.” (Focus Group 2)**

In one of the focus groups, discussion turned to consumers finally becoming comfortable in the therapeutic relationship and maybe even becoming too dependent on this support.

- **“Well. It’s hard, it’s a really hard feeling you have an empathetic relationship, a valuable relationship, it’s hard to you know even if you are doing better and even if you could move on you know it’s hard to leave that behind because it’s been so valuable, and I think we kind of trap ourselves in that.” (Focus Group 1, 13)**

The discussion group debated the different care given to consumers who seemed to be doing well and the fear of having psychiatric services withdrawn. For example, one participant claimed that some consumers appear to make themselves seem more disabled than they really were.

- **“They lie about their illness so that they can stay in the team...they don’t want to lose the team.” (Focus Group 2, 2)**

Participants spoke from personal experience about the mental health system turning its back on those who seemed to be doing well. One consumer related that some mental health organizations in Vancouver tended to dismiss those clients who were viewed as “high functioning” while in a similar vein another participant felt that “high functioning” clients were ignored at the teams because they appeared as stable and as not requiring crisis intervention. (Focus Group 2, 3)

Also, the group considered whether consumers should be encouraged to “move on” or whether such an expectation was not based on the assumption “that there is a cure” for mental illness. (Focus Group 1, 13)

5. “Abusing the system”

Some participants could face the distress that came with their health care professionals believing that they might be “abusing” the system.

- **“So I can understand that point where you know abusing the system, okay, where you’re a revolving door, you phone your nurse 1,000 times a day, you say you’re going to slash your wrists, I mean that’s the way but I don’t do that.” (Sarah 3)**

This consumer recalled how she “od’ed a lot on meds” and that she in the past “used to abuse the system” (Sarah 3/4, 10) She insists that she is not doing this any more, but allowed that due to her past behaviour her psychiatrist might now be “a little cautious.” (Sarah 10)

Another participant found herself in the situation where she had to contact her new team for prescription renewal and encountered some cautious attitudes. She resented such suspicions and emphasized that she wanted to build up a relationship with the team based on openness and trust, “so they know you and trust you.” “I’m not abusing or trying to get extra medication for whatever reason.” (Carole 11)

6. Critical views

This group of consumers had varied experiences with accessing professional help for their mental health concerns. Some variables leading to good or bad service seemed to depend on the individual case, illness, and circumstances. In a number of situations, access to care seemed suboptimal and some more critical voices were raised about the system.

Among the negative issues cited were high staff turnover (Angela 19, Anna, Sarah), delays at emergency care (Carole), GP not realizing severity of illness and delaying in making referrals (Anna 1, 15, William 12, Thomas 17), lack of access to emergency housing (Alex), people “falling through the cracks” of the services (Anna 2, Carole), psychiatrist of choice not being accessible (William), fear of being forced into treatment (Thomas), failure to make the right diagnosis (William) or to prescribe an acceptable regimen (Louise), shortage of medical support system/lack of services (Anna 2), lack of patient empowerment (Alex), professionals not being helpful enough (William, Patty), absence of free counseling (Angela 18), or poor communication

(Sarah) and lack of integration of care between GP, psychiatrist, counselor and case manager (Rhonda 18, Sarah) .

Wishing for a democratic, inclusive, recovery-oriented consultation system, one participant advocated for “less of a paternal relationship with the medical system.” (Alex 21)

Spending many years without appropriate treatment, one participant recalled:

- **“Well a few regular doctors got it only was ...they never prescribed me anything right or referred me [to a psychiatrist] right...” (Thomas 17)**

For another participant, care received was disappointing.

- **“I’m not a real positive person on health care professionals. Why? I’ve seen a lot of them and whether it’s my own doing or theirs I never really thought that there was substantive gains made.”...“So I’m not gonna say that they were 100% to blame, but I still feel that they being professionals they should have kind of been a little more helpful.” (William 2)**

Not being able to receive appropriate, effective care made some participants feel like not only had they “wasted years”, but also that in the meantime their health had deteriorated and became “harder to treat.” One consumer blamed her GP for not placing her on the hospital waiting list much earlier and having kept on treating her with an ineffective antidepressant.

- **“I wasted years not only that you get sicker. You get more and more withdrawn and more and more harder to treat.” (Anna 2)**

For another participant, 40 years of incorrectly treated illness left him frustrated and pessimistic, thinking there now was a “fat chance” for successful treatment. .

- **“Once there set in stone you become rewired...In my case I was 8, I’m 48 now that’s 40 years of conditioning...” (William 8)**

This consumer felt “cheated” by having seen eight or nine professionals over the years with no apparent benefit to him.

- **“I am at a point in my life where I feel I have wasted a lot of years...I feel cheated, I feel I’ve been ripped off and I don’t want to spend any more time...”(William 8)**

A personally positive experience with the psychiatrist and the health care system did not prevent one consumer viewing the system as flawed, especially when it came to vulnerable populations in the Downtown Eastside and the penitentiary, but also when seeking care for a teenaged family member.

- **“We’re not helping people with mental illness. We wait too long and by the time people have an episode that’s too long, there’s a build-up...people shouldn’t have to suffer... People fall through the cracks.” (Carole 18)**

For another consumer, the home situation was crucial for well-being and recovery, but he felt that this aspect was often left neglected in the treatment process...

- **“I had a very difficult home situation and I had deteriorated so much that I really should have been considered for emergency housing in the SIL program, but I never got that.” (Alex 7)**

...which made him feel like ultimately he had not been ideally cared for. (Alex 7/8)

7. System better now

Some participants agreed that “the system is changing for the better,” (Focus Group 2) in terms of recognizing and treating mental illness. One participant wished that the awareness of mental illness had been at its present level when he grew up or first needed treatment 18 years ago (William 19) . Changes in newer psychiatric medications also contributed to consumers’ perception of the mental health system improving. As one participant explained:

- **“...The side effects, I remember they are not as bad as they used to be...I mean I was on Haldol and Trazadone ...horrible meds.” (Sarah 5, 13)**

Other participants also appreciated changes happening in the system:

- **“I think things have changed. Typically more so with younger people coming through the system, their perception, their expectations of meds I’ve seen a change...what the limitations are, side effects would be mentioned today, whereas they never were...” (William 20/21)**
- **“I think it’s changed somewhat in the last 4 or 5 years. I see a change where it’s more open to discussion rather than just saying the problem and then nodding and going away, and then making a decision and coming back. There is more of a dialogue.” (Alex 5)**
- **(do you feel things have become better or have they become worse in the system?) “Well actually I think it’s better...” (Thomas 18)**
- **“But I think like it’s better now than like when I went with my mom to see her psychiatrist, and I think it’s a lot better now, they are not just writing prescriptions out...” (Focus Group 1, 7)**

Participants underwent a myriad of positive and negative experiences with reaching out to medical professionals and receiving psychiatric services. Often the search for mental health care was precipitated by a crisis situation and then it could be particularly frustrating when mental health services were difficult to access. In some instances, consumers were feeling left for years without optimal care. At the same time, they could be concerned that they could be cut off from care if they no longer fit the services’ mandate. While there was gratitude for treatment received and belief in the “system” and medications overall improving in more recent years, psychiatric care was often still seen in a critical light.

Chapter 2: Diagnosis and Acceptance

In order to establish if participants felt informed about their illness and their medications, we asked during the interviews whether participants presently were on medications, whether they knew what the medications were for, and whether their doctor had explained the diagnosis to them.

Participants usually knew the name of their diagnosis and which medications they were on, though for some the nature of the diagnosis was not entirely clear and the purpose of the medication could be confusing.

1. Did your doctor explain your diagnosis?

A number of participants affirmed that their physician had explained their diagnosis to them.

- **“Totally, well yes.”...“They thought I was depressed at first...then Dr. XYZ said it was Bipolar II.” (Anna 2)**
- **“Oh yes, schizophrenia.” (Mark 1)**
- **“Clinical depression.” (Angela 1)**
- **“...he thought that I had Schizoaffective...and then my doctor at Riverview thought that I had Schizophrenia, so I never really got the chance to ask him why the difference. They’re closely related.” (Louise 3)**
- **“Um yeah I think so in the beginning when I was at XYZ hospital. Dr. XYZ tried to explain to me that I was schizoaffective, and that it has mania and delusions, and also manic and depressed, and also delusions and stuff like that. He told me that.”(Patty 3)**
- **“Yes, they said I had Borderline.” (Sarah 2)**

Some participants did not always believe in the accurateness of their diagnosis, though.

- **“I was misdiagnosed there.” (William 2)**
- **“No, I don’t think so. It’s just that I’m not willing to try to go off it [the medication] and see how that is...” (Anna 3)**

After 40 years at treatment, one consumer declared that neither diagnosis nor medications were really made plain to him.

- **“No nothing has ever been clear from the beginning you know, even as a child.” (Jack 2)**

Another consumer bluntly answered that she was uncertain about both diagnosis and treatment.

- **“No...I don’t know even about my medications.” (Wendy 3/4)**

One participant knew the purpose of her medications, but was unsure about the more recent development of her illness.

- **“No, I don’t think I am really informed because my illness is getting better but I am not too sure what the diagnosis is now...[the doctor] doesn’t know for sure where I am at right now and we really haven’t talked about it...maybe I’m looking at a whole different diagnosis.” (Sarah 3)**

Consumers could feel a lack of certainty and thought that their doctor also could be unsure about the nature of their illness.

- **“I really don’t know if it’s bipolar or schizoaffective. It just depends on the doctor.” (Patty 3)**
- **“...but you know the other thing is, they don’t know. Nobody’s 100% sure how much or to what degree I suffer from depression. They don’t know whether 100% sure or not if I suffer from bipolar.”(Jack 4)**

Realizing that labeling was maybe not the point, one participant still wished to know so that he could assess his own progress and the use of medications:

- **“Well, I know that’s is a very individual illness even tough there are symptoms that are common to people with schizophrenia...So that doesn’t really worry me a lot whether it’s schizophrenia or psychotic depression...Although I would like to know because it plays a role in the types of medications I receive and the types of medications I receive can affect my daily life as far as some of the side effects and things like that are concerned.” (Alex 4)**

2. Agreement with diagnosis?

One participant was very much in agreement with the diagnosis made by his last psychiatrist, whom he credits as finally having made the right diagnosis after many years of suboptimal care.

- **“Absolutely. It sure seems pretty plain to me now.” (William 3)**
- **“I believe that I was accurately diagnosed a year and a half ago.” (William 2)**

The majority of participants seemed in agreement with their diagnosis...

- **“Yes.” (Angela 3)**
- **“I don’t know.” (Patty 3)**
- **“Schizoaffective definitely.” (Louise 3)**
- **“I definitely believe, yeah.” (Carole 2)**
- **“Um it really, it made so much sense. It made a lot of sense. A lot of things suddenly fit together...yeah, I’d say for the most part.” (Rhonda 2)**

...though some initially had gone through a period of denial of having a mental illness.

- **(you didn’t understand you had a mental illness?) “Exactly. I knew I had but I didn’t want to believe it, so I figured I didn’t.” (Louise 17)**
- **“A lot of times people told me I was probably bipolar but I didn’t want to believe it.” (Focus Group 1, 7)**
- **“I have a hard time thinking of myself as disabled...I still have issues with the whole thing, and medications is part of that thing.”...”In the past I’ve had a greater sense of disdain for mental illness and even though I’ve been seeing doctors and on medication I never really considered myself having a, sounds strange, having a mental illness.”(William 17, 3, 16))**
- **“Oh yeah, at first I didn’t – when I was first hospitalized I didn’t think I had a mental problem but it took me like a month and a half to finally figure out that I did.” (Mark 1)**
- **“Well first of all I was in denial. A lot of people said to me they thought I was bipolar but I thought it skipped a generation and I used to feel that because my parents were bipolar I picked up their actions...a lot of nurses and doctor would say to me ‘oh you’re bipolar’ I would say ‘no I’m not’...” (Carole 11, 7)**

She wished that her illness had been recognized much earlier:

- **“If they [at work] had seen that there was something wrong I could have been treated and I could have kept that job...I was used to such a good lifestyle...there is that loss that can never be replaced...It was over 10 years and I still think if someone had seen it, if someone has diagnosed me I wouldn't have lost everything.” (Carole 17/18)**

One participant did accept it when a proper diagnosis was made, but experienced it like a “slap in the face” when she became ill and had to go on disability benefits. (Focus Group 1, 11)

Participants could be left wishing that they had been diagnosed earlier in their life, which may have helped avoid some of the devastating effects of the mental illness.

- **“I've been sick all my adult life, probably since childhood really...” (Thomas 17)**

3. Agree you need psychiatric medications?

Some participants were particularly accepting of their illnesses and willingly took their psychotropic medication, which they felt let them get on with life and without which they feared they would be institutionalized. (Louise 4, Mark 2) Another participant had no problem embracing her psychiatric medications the same way she did her other medications. (Carole) For others, medications definitely fulfilled a function. (William 9)

- **“I generally do usually think that I need them, I do think I need them.” (Patty 15)**
- **“Today I absolutely agree. I would never stop. In the past I did not feel comfortable taking medication because and this would be true even to a certain extent today, I have a hard time thinking of myself as disabled...” (William 16)**
- **“I'm afraid I have to agree...if I'm not on meds I don't think I have much of a life left.” (Thomas 3)**
- **“Oh yeah, I have from the first visit I was diagnosed. I haven't stopped taking them.” (Carole 2)**
- **“I find ultimately you just have to live with it...” (Alex 9)**
- ***(Right, right, so it's really something that you accept that you have to do that in your life and that you have to stick with regimen if you want to have the positive effects of the medication?) “Yeah, yes.” (Sarah 15)***

In one instance, however, a participant felt that he was stuck with the same regimen without much reconsideration if he really still needed it.

- **“It has been many many years that I have been on that medication and they were very reluctant to change my medication.” (Focus Group 1, 4)**

Asked whether they felt comfortable filling their prescriptions, the feeling was not always unequivocal.

- **“Absolutely, absolutely.” (William 9)**
- ***(comfortable or conflicted?)* Oh, very. I let it [the pill vial] sit there...it's radioactive to me. That's how it feels to me. I take that, something's going to feel different and I don't really know what and I'm here by myself.” (Anna 10)**
- **“I was apprehensive at first...maybe a bit skeptical, a little bit scared of side effects and things. Then there was a point when I was kind of happy about it, because it was going alright, I guess. And then, ups and downs, things change in life and medications change also and I didn't really like it.” (Rhonda 13)**
- **“Yes, yes, why not.” (Wendy 21)**
- **“I have never felt completely comfortable taking it...some things not sit right...”(Carl 9)**

These participants overall knew their exact diagnosis and the purpose of their medications. Yet, some of them had gone through periods when the nature of their illness and a need for drugs had not always been entirely clear or acceptable. Since the majority of interviewees had been in psychiatric care for many years, however, the level of their acceptance of being given a diagnosis of a mental illness and of the role of psychotropic drugs in their lives may have been comparatively high. Some were left wishing that they had been diagnosed in a more timely manner in order to avoid the worst consequences of their mental illness.

Chapter 3: Elements of the Therapeutic Relationship

Study participants had had varied experiences with and opinions about their physician and of the role their case manager played in the therapeutic experience. They appreciated a longer relationship that allowed for the building of trust and understanding and generally felt that the duration of doctor's visits was satisfying and provided them with sufficient opportunity to ask questions.

1. Views on the physician

On the whole, participants spoke in positive, sometimes enthusiastic terms about their physician. For example, one consumer appreciated his psychiatrist in many different ways...

- **“He remembers the stuff that we talked about before to a T.” (Mark 3)**
- **“He’s awesome, he takes his patients for dinners and movies. A few years ago he took us all on a cruise, and so my relationship with my psychiatrist is very good. He’s the best, the best there is.” (Mark 1)**
- **“He’s the most positive person in the world. He’s just phenomenal.” (Mark 2)**
- **“He doesn’t just talk about medications...he really cares about you.” (Mark 8)**

...and he concluded that:

- **“I am very lucky to have him as a psychiatrist.” (Mark 4)**

Other participants also appreciated when their doctor listened attentively, was empathetic, showed respect, demonstrated knowledge, took an interest in their quality of life, and applied talk therapy.

- **“She’s a nice woman and she cares... I really like her.”(Anna 4)**
- **“I’m very happy right now...he’s very knowledgeable.”(Carole 4)**
- **“He’s the best GP that I have ever had...” (Jack 3)**
- **“I have a really excellent doctor.” (Angela 1)**
- **“Yes, I manage well. She’s not pushy or bossy or anything.”(Tina 25)**
- **“I like my doctor, but, I like my doctor just fine...” (Focus Group 2, 8)**
- **“I consider him a friend.”(Thomas 3)**
- **“He respects me as a client and I respect him as a doctor.”(Louise 4)**

One participant could not praise her physician enough.

- **“Oh, satisfactory. Very. I love her so much”... “We are like friends, you know.” (Wendy 5, 2)**

And another consumer also spoke highly of his doctor.

- **“That’s right. Somebody that actually cares and likes being who they are and what they do and how they help other people and he’s a wonderful person, period, doctor or not.” (Jack 14)**

Many participants were definite that their doctor was part of their support system.

- **“Yes.” (Alex)**
- **“Yes.” (Mark 5)**
- **“Yes, a big part.” (Anna 7)**

- **“Yes, a huge part.” (Angela 5)**
- **“Yes, of yeah, definitely.” (Louise)**
- **“Yeah, definitely.” (Carl)**
- **“Medically, most important person [other things I have other support].“ (Tina)**
- **“My counselor, very much part of my support network. At the time, my psychiatrist, she was in times of crisis, I guess, especially at the beginning. She probably saved my life, I didn’t have a support network...So she was the support network, the nurse especially.” (Rhonda 18)**
- **“I would say that she’s a support person.” (Patty 9)**

At the same time, there were some more negative voices. One participant described his brief visits with the team psychiatrist:

- **“My current psychiatrist, it’s almost utilitarian, really very practical and pragmatic very quick....they come and they’re really there to prescribe my medications, to update or to make an adjustment, maybe do some small answer stuff and then to take off.” (Carl 3,4)**

This participant admitted “I have some views which are somewhat critical.” (Carl 5)

Some participants felt that their physician’s treatment had not been successful.

- **“I was always sort of at odds with him about my meds because they weren’t good and I was afraid to try new ones.” (Louise 1)**
- **“I had a doctor for about three years....he wasn’t very good. He didn’t really help me.” (Patty 2)**

For one consumer, an apparent lack of a treatment plan or treatment consistency, poor communication, or conflict about the medication regimen were also causes for complaint.

- **“...They don’t study their notes properly...should be keeping a closer eye on what those meds have been, and so it’s not like going from day 1 again...”(Patty 11)**
- **“Well, maybe treat them with more respect and dignity in that they know what they’ve lived through with their experiences and just give them more understanding and try to listen more and try to come up with a treatment plan, and not just pills, pills, pills,” (Patty 23)**

Negative experiences could lead to extreme emotions about the physician:

- **“Oh yeah, I hated XYZ Mental Health Team.” (Mark 4)**
- **“Like XYZ hospital I really hated that doctor.” (Patty 10).**

Some consumers were looking for “warmth” and “comfort” in their relationship with the physician and were disappointed when it was “all business.”

- **“It’s pretty practical and utilitarian, it’s really fact based. I wouldn’t say it’s really warm. He’s a nice guy...”(Carl 4)**
- **“It’s just usually a business meeting...”(Thomas 6)**
- **“I was looking for more, more comfort, maybe, that kind of thing. Whereas it was all business and was all medication.”(Rhonda 10)**
- **“But I feel in the beginning she was treating me very nice trying to help me and the social worker also were very nice but now I feel I am only a client of her. I feel like I am only for business I feel like she doesn’t pay attention to me.” (Focus Group 2, 13)**

Some participants recognized the limits of empathy, stressing that their psychiatrist could not possibly know what it was really like to be mentally ill and on psychiatric medications.

- **“No no no the psychiatrists haven’t taken the pills. The psychiatrists have never taken the pills. If they had taken the pills they would know, okay. They have not a clue okay, how potent or how destructive and everything it is okay.”(Thomas 10)**
- **“Because I said “you can’t really know what this is like” and [the psychiatrist] said “No, I can’t.” ...“I just want to hear ‘it must feel terrible to feel this way’.” (Anna 6, 5)**
- **“They just see it from their perspective, or you know, seeing so many sick people every day...I don’t think that they have that much empathy for it.”(Patty 6)**

For consumers, personal experience could rate higher than making treatment decisions “from a book.”

- **“I’d like to have asked her if she was Bipolar. Seriously, I guess I’d like to know if she had any personal experience than just professional from the outside, prescribing medications from a book kind of thing.” (Rhonda 12)**
- **“In one incidence...I found that a little bit too much reliance on the book rather than what I was saying, as far as medications is concerned.” (Alex 13)**

A lack of personal experience was not necessarily seen as disqualifying the physician however....

- **“Just because the doctor hasn’t taken the medications doesn’t mean they can’t treat the illness. Although in other areas, you may need a different person, with a mental health experience to help you.” (Focus Group 1)**

...though appropriate help could sometimes rather come from fellow consumers.

- **“There are some things that only people [like peer support workers] who have been through the illness can help you out.”(Focus Group 1, 7)**

At times, participants saw the psychiatrist too focused on prescribing as opposed to counselling.

- **“There is not very much counseling, that’s the thing...they just push pills. That’s all they do. All they do is write a prescription and ask you how you’re doing and it lasts about 5 minutes.” (Patty 5)**
- **“With my psychiatrist before I basically told her I felt like she was a drug-pusher and I didn’t appreciate it.” (Rhonda 7)**
- **“...but mostly, the main thing, there’s only one hour, is all I get is about medication.” (Anna 4)**

In some cases, the physician could be seen in the context of an outdated “old school” ways of thinking and treating.

For instance, a young psychiatrist was seen in a positive light.

- **“She is not one of those old school psychiatrists.” (Anna 4).**

Another consumer had had negative experiences with his family doctor.

- **“My doctor is an older doctor ...his point of view is somewhat maybe from the 70’s you know he’s not positive on medications... I don’t feel too comfortable with him.”...“He’s older, he has his mind set...” (William 1, 8)**

Similarly critical of her physician was another participant.

- **“He’s from the old school, he hasn’t stepped up to the new school yet.” (Sarah 7)**

2. Role of the case manager

Team nurses/case managers/therapists played an integral role in the care provided by the psychiatric outpatient clinics. There appeared to be a division of labour between the doctor and the nurse, with the latter being more available to talk to, seeing clients more often and for longer periods of time, plus being accessible by phone. Seeing the nurse was often the first contact point for consumers seeking help at the team. (Rhonda 19) Nurses were contacted in times of crisis or when there was a need to make an earlier doctor’s appointment or deal with medication issues like renewal.

Participants saw their nurse weekly, bi-weekly, “once in a while” or just together with the psychiatrist. Clients sometimes also saw nurses informally when they dropped into the clinic. The case manager could be considered a friend, play the role of a facilitator and help clients solve problems and work on goals. In this way, case managers could be instrumental in the recovery process. Some participants felt that if case managers were given the opportunity to address the more stressful problems of daily living with a mental illness, then doctors would have an easier time and the consumer, the team and the budget would benefit.(Focus Group 2)

Several team clients spoke very positively about their case manager and differentiated between their closer relationship with the nurse as opposed to the physician. For example, one participant found her relationship with the nurse praiseworthy in multiple ways:

- **“She’s really good at talking, you know, and really good at figuring out where we’re going.” (Sarah 3)**
- **“My nurse is the best...I gotta nurse now that is really good.”...“like I call her only in cases of emergency or whatever and we seem to be able to talk it out.” (Sarah 3, 10/11)**
- ***(It’s like in a hierarchy?)* “My nurse isn’t, but he is, yes.” (Sarah 9)**
- **“I like my nurse, she’s cool.” (Sarah 9)**
- **“Well I think the way my needs are being met, not probably by the psychiatrist but by the nurse.” (Sarah 12)**

Others also felt that their case manager was crucial in their care and met important needs.

- **“The therapist in that respect is the person that has been the most helpful at the team, very helpful, more than the psychiatrist...If it was just my psychiatrist I would be very unhappy with the relationship. The fact that the therapist is there makes a huge difference for me.” (Carl 4)**
- **“I probably had a personal relationship with [the nurse] because I saw her obviously more often...The psychiatrist was there to monitor my medication.” (Rhonda 19)**
- **“...for an appointment I see the doctor every three months, but sometimes if I have difficulty I phone my social worker, my nurse and she can just explain me by phone or give me direction by phone and everything will smooth out.” (Wendy 2)**
- ***(Is there a closer relationship with the case manager then?)* Yes, exactly. Because she’s there every day...I hope she doesn’t retire.” (Louise 2, 16)**

In the group, it was clear:

- **“Every patient needs a case manager.” (Focus Group 2)**

Being considered less as a part of the therapeutic hierarchy seemed to make the nurse more approachable. A nurse was seen as being less powerful than the psychiatrist since she could not make major decisions and also as having less expertise on medications.

- **“But for any of the big decisions like when I can get into respite care or whatever I have to go through the psychiatrist.” (Sarah 4)**
- **“And then if I need to, like I have a burning question, I’ll ask my case manager, but she always directs me to the doctor because she knows that he’s the expert on in.” (Louise 4)**

Meeting the physician and the case manager together could be reassuring to consumers.

- **“I like to see them both, just the nurse alone means I’m not getting full care.” (Focus Group 1)**

For one participant, interpersonal relations with the physician and the case manager were cultivated, e.g. through socializing. (Wendy 10)

At times, however, some participants had felt unsupported in their recovery by their nurse.

- **[Had requested a change in case manager] “...because the first case manager treats you like a patient, and kind of holds you down...I felt she didn’t want me to get better.” (Tina 26/27)**
- **“The case manager made a huge difference in my daughter’s life but only after she transferred away from a case manager where there was a poor relationship.” (Focus Group 2)**
- **“She thinks I’m doing fine. If I contact her with a problem, that’s the only time she ever contacts me, right. Whereas a worker should be someone that sits and talks with you, and you know, tries to work out things with you.” (Patty 7)**

Too much reliance on the case manager could also be considered as possibly detrimental:

- **“Yeah, it depends on the individual and the day sometimes. I’m hesitant, too because I don’t want to have too much of an emotional relationship with my case manager, they’re not my friend, and they’re not my constant support. I try to be more independent than that and rely on myself and my natural supports, my friends and my family, and things like that. I almost see that as disabling in a way.” (Alex 12)**

3. Experience with teams

Nine out of the 15 interview participants were at present clients of Vancouver Community Mental Health Services psychiatric outpatient clinics and another two were former team clients.

Physicians and nurses were seen as working “together as partners.” (Wendy 2), though in at least one case the consumer suspected that the psychiatrist, nurse and GP were not necessarily talking to each other and found that ideally there should be more of a dialogue, even a “One stop shopping” for one’s entire health care. (Sarah 14) Similarly, another participant was in favour of more integration between the different health professionals and the prescribed medications. (Rhonda 18)

Participants’ experiences were shaped by their relationship with the treating physician, the nurse, and support staff.

- **“...each team is different. Each team has their own little, nice people, not nice people, some people are really nice, some support staff isn’t really nice. And I think that’s the same as a big company, too, I mean you have some people that are moving forward and some people that should have gone a long time ago. (Sarah 12)**

The team could also be viewed in a very positive light.

- **“The people in my team are terrific. I mean the quality at Riverview was that much higher, but for a mental health team outside in the world, they’re amazing.” (Louise 17)**

For some participants, the team experience was somewhat unpredictable.

- **“It depends on your team and it depends on your nurse. (Sarah 2)**
- **“...depending on how proactive they are in including the consumer’s wishes and desires and outcomes in that process.” (Alex 12)**

One participant contrasted the experience with one team, which seemed to operate on crisis mode and where visits at times lasted a mere 4 minutes to her care at another team, where the atmosphere was “calm and peaceful” and visits lasted some 30 minutes. She therefore came to the conclusion “It depends where you are.” (Carole 3)

4. Continuity of care

Participants had for different periods been diagnosed/treated for a mental disorder, ranging from the past 3 to 40 years (11 out of 15 had been in treatment for over 10 years). One participant had been admitted to a psychiatric hospital when he was 10 years old. Participants had been treated by the same current caregiver (in 14 cases a physician) for the last 1.5 months to 13 years (7 out of 15 participants had been seeing the same doctor for 5 or more years). One participant had been with the same team well over 20 years, while another consumer had for some 17 years known her physician, who had now been treating her for a mental disorder for the past 10 years.

Mental health team clients or hospital outpatient clinic clients usually could not choose their health professionals. Rather they were at the receiving end of a high staff turnover, which often left them confused, skeptical as to the quality of care, and regretting that they could not establish more long-term, trusting relationships. At the same time, participants sounded resigned that the system just worked that way.

As one participant explained, over the past 20 years he had been passed from team physician to physician and from nurse to nurse.

- **“The first time was my choice, the first time. But then the rest the decision was just who was assigned to me and how long they stayed and things like that.”...“It wasn’t out of choice that I went through many other psychiatrists before, it was because they would come and go...the same with the case managers.” (Alex 2)**

Similarly, another participant recalled, “I’ve seen quite a few psychiatrists at different times” and that his “moving through the system” was not due to his own choice (Carl 1).

A number of participants lamented the turnover of nurses (Louise, Carole) which made it hard to form reliable relationships.

- **“I’ve had four different psych nurses in the last six years at the team so it’s just building that trust...it’s been difficult that way for trusting.” (Focus Group 2, 6)**

High staff turnover in the mental health system was regretted. (Angela 19), though one team client perceived physicians and nurses staying on longer in recent years and he now appreciated having been seen by the same physician for the past 8 years. (Alex) Continuity of care was seen as crucial in building relationships where trust and respect was mutual.

- **“Having the same nurse and psychiatrist just so they know you and trust you.”... “That continuity is very important,” (Carole 11)** for example when it was time to renew prescriptions.

Continuity of care was so appreciated and deemed important that it could be rated higher than intermittent problems with the physician. One participant shared:

- **“I’ve been through like 8 years with him...he knows me...arguing is part of a relationship...I don’t want to change my psychiatrist.” (Focus Group 2, 7)**

At the hospital outpatient clinic, staff turnover was also high. One participant recorded having seen “many many different psychiatrists,” which made her feel objectified and unconnected.

- **“...they kept on switching me. I felt like I was in a zoo or something, they’d be learning from me but I didn’t feel connected to anybody. I never had a thread running through it...” (Anna 1)**

This participant was already glad that she was now seeing the same psychiatrist for the past year “so I can kind of get safer with her, you know, get more comfortable.” (Anna 2)

Another participant also had had “lots of different psychiatrists” both in hospital and in the community and agreed that she had not had a chance to establish a long-term relationship. (Patty 1) “I’ve just got a new one. I’ve only had her for about a month and a half.” Things would have been easier if “maybe having one psychiatrist the whole time.” (Patty 22)

- **(You feel you’ve been passed on from doctor to the next one without there being any continuity?) “Yeah, definitely.” (Patty 23)**

One participant said she cried when finding out that her caregiver’s tenure was ending.

- **“I’m so upset I’m going to have kind of start all over again with a different person.” (Rhonda 4)**

Staff turnover was particularly difficult at times of crisis with medications.

- **“...at the same time I was going through many changes in case managers.” (Alex 6)**

In light of high staff turnover, one participant stressed the importance of family, which is a “huge resource” and “in there for the long haul.” (Angela 19)

Over the course of their illness, participants had received treatment by many different physicians and case managers both in the community and during hospitalizations. Given the long-term nature of mental illness and the importance of interpersonal interaction between consumers and their care providers, high staff turnover was perceived as particularly regrettable. Continuity of care was seen by consumers as key to forming trusting, dependable relationships with their mental health professionals.

5. Duration of visits

Receiving good medical help and building a relationship with one's physician/team could be considered as intrinsically linked to the nature of the therapeutic encounter and how much time consumers actually spent interacting with their doctor. Yet, consumers' experiences and satisfaction with their visits did not follow a simple pattern.

The frequency and duration of visits with their physician as reported by participants ranged widely, lasting anywhere from between 4-30 minutes every 3 months to 1 hour every week. It seemed common that team physicians saw their clients every three months for a 5-15 minute visit. Longer, more frequent visits could occur in crisis or at beginning of the treatment and later be tapered, though that was not a consistent pattern. One participant reported having first seen her doctor every 1-2 weeks and the nurse every week, later every 6 weeks but also when needed, as often decided by the nurse. (Rhonda 10) Other team clients had been followed by their physician every 3 months, for 10-30 minutes, with the nurse being available on an informal basis or once a week; and another team client spoke of 30 minutes a month. In one instance, a participant recalled having seen her team psychiatrist for 4 minutes, commenting in hindsight "I was very lucky because I was stable." (Carole 3)

Consumers did not always feel that they were seen often or given a long time, speaking of the visits lasting "only" so much time or that visits "don't last long".

- **"I only see him every 2 to 3 months, but if I need to see him before that, then my nurse will arrange." (Sarah 3)**
- **"If I'm going through a difficult time then I'll probably see her once a month. But usually I see her once every 3 months and the case manager once a month... (Do you have a long session?) "No, not even when things are going not well, usually things are going well, the longest that I would see the psychiatrist is about half an hour." (Alex 2)**
- **"It's not very long that she works, every time, she, our appointment it's only 15 minutes, 20 minutes...that's all." (Wendy 6)**

In another case, the physician was seen as determining the limited visit time.

- **"Sometimes it is a bit short; like he limits it usually to about half-an-hour" (Louise 5)**

Another team client saw her GP physician every 3 months and was very happy with the duration of these visits.

- **"And it's nice to know that at the XYZ team where I have that 1/2 hour if I want to discuss something I have enough time." (Carole 4)**

One participant saw her counselor once a week for one hour. General practitioners' visiting time varied also, with the frequency ranging from 15 to 45 minutes every 2-3 weeks to once a year. One participant saw his private psychiatrist every two weeks for about one hour. (Mark 3) One client remarked about her GP "And she makes time, you don't get the sense that she wants you out of there in 5 minutes or so." (Angela 4)

Satisfaction with the duration of doctors' visits did not necessarily depend only on the length of time spend together, but on how the consumer valued the quality of the encounter and how the consumer's needs were met.

For example, one participant was seeing a resident at the hospital outpatient clinic for one hour on a weekly basis, but that did feel far from sufficient.

- **“...but mostly, the main thing, there’s only an hour, is all I get is about medication.”... “I don’t have a psychiatrist that I go to at an office, which would be the ideal thing. Someone I could go to and see as many times as I wanted to, ideally.” ... “I’d like to have more time, yeah.” (Anna 4,5)**

For other consumers visits were too brief and unsatisfactory, feeling like they were given the brush off.

- **“(The time that you have with the psychiatrist, sometimes it’s only 5-10 minutes, it’s not very satisfying then?) “No, it isn’t. It’s definitely not.” (Patty 23)**
- **“I feel like now like I am not treated like a guinea pig but feel like in 10 minutes she want...She has more and more patients and she doesn’t have time for me, it is a little disappointing because I feel like. It’s a kind of business like she doesn’t have concern about whatever I say...” (Focus Group 2, 13)**

One participant was frustrated but also took partial ownership about how her sessions with the team psychiatrist usually went.

- **“I admit I was quite quiet on many occasions. I didn’t really have much to say. But then again, maybe that’s part of the illness and the doctor should be trying to help you through that.” (Patty 23)**

Much depended on what the consumer expected from a visit. For example, if the visit was seen just as “routine”, with no pressing issues arising, short and infrequent visits could still be considered as adequate. Short visits could be interpreted by the consumers as a signal that the physician believed they were stable and did not need more time.

- **“I don’t see him that much and when I do it’s very quick because I’m doing well, it’s I’d say 5-10 minutes. (Carl 8)**

Another team client related that she saw the psychiatrist

- **“once a month or every 2 months. It was once a month for the past year and a half or so, and then now he’s saying I can go down to less.” (Louise 2)**

One participant felt that her doctor set the pace based on an assessment of how she was doing.

- **“All depends on her, if she says I’m okay. I remember when I am feeling bad she looked after me maybe longer but she can tell that I am doing fine, just a routine check-up...there’s no problem.” (Wendy 7)**

Other participants were affirmative when asked whether the duration of the visits was satisfactory.

- **“Yes, I have all the time I want.”(Jack 3)(30-45 minutes every few weeks)**
- **“Oh yes.” (Mark 3) (1 hour every two weeks and more often if needed)**
- **“Yeah.” (Louise 5) (30 minutes every 1-2 months)**
- **“Absolutely.” (William 6) (15 minutes with psychiatrist, “ as little as possible” with GP)**
- **“Yes.” (Angela) who can also phone the GP and be called back.**
- **“Yeah, enough time. I don’t think there’s anything more that I need to discuss.” (Carole 4) (30 minutes every 3 months).**

However, the nature and speed of the doctor’s visit did not necessarily lend itself to a quality encounter. One participant wondered whether the psychiatrist was under pressure to “spend such little time” (Carl 9) and just go through “a formula of questions.” (Carl 4) He felt fortunate with being able to supplement this care with hour long visits with his therapist at the team.

For one team client, the scope of her doctor's visits was very limited, leaving her frustrated.

- **(Visit long enough?) "No, because in like 15 minutes...he's up and gone and I'm like, okay." (Sarah 4)**

The degree of satisfaction did not only depend on how often and how long the doctor actually saw the consumer and on the quality of the encounter. It was also important whether or not the consumer felt that the physician would be available when the need arose. For example, an earlier visit could be arranged with the team psychiatrist through the case manager.

- **"I could see her more..." (Tina 5)**
- **"Oh, if I want to see him sooner, he's left the door open." ... "if I have a problem or there is a crisis in my family that I needed to talk to him yeah I can phone up and make an appointment." (Carole 7)**

Another consumer also felt that he could request an earlier appointment when he felt he needed to see his psychiatrist. (Mark)

6. Time for questions

Once being seen by a physician for a mental health issue, there was the challenge of making the most out of the therapeutic encounter. In a focus group participants wondered whether there was merit in preparing oneself, perhaps even in writing, for the doctor's visit in order to keep some kind of overview, as it could be hard to focus in the session and "then it's over." (Focus Group 1, 6)

Given the diversity in frequency and duration of visits with their physician, we asked participants whether they had enough opportunity and encouragement to pose their own questions. This group of consumers was overwhelmingly firm that their provider made time for their questions, which was appreciated.

- **"Oh yes, Yes I have all the time I want." (Jack 3)**
- **"Oh, of course, yes." (Mark 3)**
- **"Yes, I think so, I think." (Alex 7)**
- **"Yes, always." (Louise 5)**
- **"Yes...If I have more things to ask, they don't kick you out. They want you to finish." (Tina 6)**
- **"Oh yeah, definitely, which is nice..."(Carole 4)**
- **"Yeah..." (Carl 4)**
- **"Yeah, sure." (Thomas 4)**
- **"Yeah." (Rhonda 5)**

Time for questions could again be a matter of perception, i.e. it seemed important to consumers to know that there would be time for questions if they had any. However, a challenge could lie in consumers being able to articulate any questions or emotions they might have within the limitations of the - often brief - therapeutic encounter. One participant illustrated how a physician might need to probe deeper.

- **"They do. Like if you have questions, they'll answer them and everything, but they don't really go out of their way to see how you're doing, spending more time and trying to get at the bottom of how you're feeling and stuff like that, you know." (Patty 6)**

On the whole, participants related a fairly positive experience with and attitude toward their mental health professionals. Physicians were often held in high regard and considered important pillars of the consumer's support system even though their ability to empathize with their patients could be seen as limited. Close and trusting relationships were often developed with the case manager. High staff turnover at the teams and at the hospital was particularly regretted.

The frequency and duration of doctor's visits were often accepted as sufficient and opportunities to ask questions were appreciated. At the same time, when the therapeutic encounter took the shape of a very brief, "utilitarian" business meeting, with the physician only focusing on prescribing and monitoring medications, participants could feel disenchanting.

Chapter 4: Sources of information

1. Learning more

Study participants stated resolutely that they could ask their physician questions. However, the physician definitely did no longer hold the exclusive domain about medical knowledge. Participants admitted that in addition to the team they were using a variety of resources to inform themselves about their illnesses and their psychiatric medications, such as the pharmacy, the Internet, the media, fellow consumers, books, the library, the Diagnostic and Statistical Manual of Mental Disorders (DSM), the Compendium of Pharmaceuticals and Specialities (CPS), educational events, symposia, forums, support groups, and other sources.

Consumers could be confronted with differing information about their medications and their illness and feel challenged to make sense of it all. Some of this data came to them without great effort, such as what their doctor volunteered or answered for them, or in the form of the pharmacy monograph; other information they sought out actively.

The physician was still an important, respected source of information. One participant related:

- **“From my psychiatrist...he knows everything...he’s like an encyclopedia.” (Mark 2)**

But this consumer did not rely on his physician alone and rather also looked up his medication on the Internet. Armed with the new information he obtained there he used it to negotiate with his doctor about a higher doses of his medication. (Mark)

For one participant, her physician was a logical source should she ever feel the need for more information.

- **“Well I feel that if I have something to ask him or I want to know about my illness or more about my meds that he definitely would give me info or where to look.” (Carole 5, 3)**

However, not always was the information flow from the professionals to the consumer satisfying.

- **“I found my doctors and case managers very hesitant to talking about the diagnosis and the symptoms and the medications and their effect...” (Alex 5)**

Also, another participant discovered the need to request more information from the doctor about the purpose of the medication, who then at least explained it to him “better than in the beginning.” (Jack 2) Still the situation was frustrating:

- **“It’s lax the information. No, they don’t explain what it’s for they only explain what the dosage is and when to take it...the pharmacy isn’t going to go into detail...”(Jack 2)**

Left to speculate about their disorder, participants could find themselves taking their own initiative and make it their own goal to find out the characteristics of their mental illness.

- **“They never really did explain the diagnosis. I learned about my diagnosis by taking courses in college.” (Alex 3)**
- **“Well. You see, I researched it, I researched the diagnosis...I really studied it a lot, you know Bipolar just it fit me like a glove.” (Thomas 2)**
- **“I did a lot of my own research because initially when I was working in Richmond with somebody there was really not much of an explanation. It was very simple but it did not satisfy me.” (Carl 12)**

Multiple sources were sometimes accessed in order to obtain answers to their questions.

- **“Usually the team or internet or XYZ psych outpatient.” (Sarah 2)**

One participant found the pharmacy monographs accompanying the medications useful. (Thomas 3) Information could sometimes come through the case manager rather than the physician, or if problems arose they could be talked about with the pharmacist, stated one participant. (Alex 5)

Absence of factual information could sometimes yield to confusing hearsay. One consumer referred to “somebody else told me” about the purpose and risks of one of his prescribed drugs, or “other people...or on TV” providing information about medications, leaving him uncertain about their accuracy: “I don’t know if it’s true or not.” (Jack 11)

Fellow consumers could be seen as a valuable source of information about mental illness, medication, and the mental health system in general.

- **“There is a whole grapevine out there with consumers...like what did you think of this one, what did you think of that one...And that and there’s a whole grapevine of people that I am involved with, yeah, because they are all sort of on the same wave length...” (Sarah 13)**

One participant stressed the value of self-help groups and educational speakers, which could be accessed in a friendly, sociable and supportive environment, making it the “most comfortable place to gain information to help.” (Alex 5)

Another participant explained how she tried to keep up with information about her medications, which she found confusing as there were “different families of medications.” “So I can only do research afterwards, I can’t do research beforehand”, i.e. before the medication had already been prescribed. (Tina 12)

Not all consumers may have felt the desire or need to conduct their own research into their medications and illnesses. Indeed, as one consumer stated, she seemed to feel that it was simply up to her to follow her physician’s instructions even though she had no real understanding of the nature of her regimen.

- **“No, I just take it. I just take the medication because I am seeing the doctor and he said you have to take this every evening.” (Wendy 5)**

One participant criticized that patients themselves were too ignorant about their medication regimen and rather placed all their confidence in the physician.

- **“I think that a lot of times people don’t have a lot of information about what they’re taking and they just trust a doctor or a physician without really knowing what they’re taking, and I think that can be kind of scary...” (Rhonda 3)**

Thus, consumers’ attitudes toward medical information varied as did their perception of the information flow in the therapeutic encounter. Some participants were inquisitive and sought out different sources of information about their illness and their medications, while others relied on their physician to share knowledge if deemed necessary.

2. Accessing sources

One issue in accessing information could be if the language used in the sources was indeed easy to follow for the consumer. One participant pointed out her special position:

- **“Well for me because I have been around the system for a while that I could understand it. I teach at UBC ...So I mean I have been blessed with learning all this information to kind of peer instruction, so I guess I’m one the lucky ones. When I first got sick it was really hard for me to understand this and if I have to look at the system today for new people coming and I would say it’s not as rough as what it was...” (Sarah)**

One participant stated that it was easier for her to stay abreast of medical information, especially the more technical language, because of her university training. (Angela) For others, the information could be quite medical and confusing. (Louise 4)

Apparently, it was common for participants to utilize the Internet in order to access information about their illnesses and the medications prescribed to them. They looked up the indication for certain drugs, side effects or medication dosages. (Mark, Sarah, Carole, Rhonda, Patty)

- **“I read a lot about psychiatric medications on the Internet.” (Angela 2)**
- **“I don’t know where to get the information other than just by myself on the Internet.” (Anna 4)**

This participant also preferred the privacy of the Internet and shied away from associating with groups of other persons with mental illness because of fear of stigma. (Anna 3)

With sufficient effort, the Internet could produce detailed, satisfying medical information

- **“Oh, from the Internet mostly, the Internet really because you can get like the case studies and the percentages and everything.” (Thomas 3)**

For another respondent, there was no shortage of information, but she disapproved of being left to do her own research on the Internet and felt that her research did not absolve physicians from their responsibilities:

- **“[I] go on the Internet and look up different pills, my mom gives me a lot of info and I also go to workshops and they give me info. So I’ve got a lot of info about mental illness...yeah, it’s usually pretty helpful I think...I don’t always have time to read it all.” (Patty 4)**
- **“They should be trying to come up with a treatment plan for you, you know, writing it down. What can we do to help you, you know? Instead of us consumers going out and finding information on our own on the Internet. We shouldn’t be doing that.” (Patty 23)**

3. Evaluating the information

Confidence placed in the health professionals could be very high and some participants turned to their physician in order to clarify information they had obtained elsewhere.

- **“The big thing was that somebody told me Lithium causes kidney diseases, but I asked my doctor and he’s very good about medications and he told me the whole story”...”My doctor is very, very good with meds so I usually ask him. And then if I**

need to, like I have a burning question, I'll ask my case manager, but she always directs me to the doctor because she knows that he's the expert on it." (Louise 4)

In another case, the physician successfully assuaged the fears that troubled one consumer after she had looked up her medication in the library.

- **"For instance, I went to her with the paper on Effexor, she explained to me the dosage and everything, and she reassured me not to worry. I got a satisfying answer, instead of worry what's up, I just bring it up." (Tina 8)**

As one participant pointed out, diverse origins of information required him to do his own interpretation of the sources and their data.

- **"Different places including the doctor and the Internet. It's a variety of sources. I'm open-minded but I try to be discerning." (Carl 3)**

The Internet could be leading to a wealth of data, which could be difficult to interpret and assess and simply be overwhelming.

- **"[Internet] is a sticky one, because there is so much out there and whether or not it's actually true or valid, so you have to proceed with caution with that." (Rhonda 3)**
- **"I hesitate to go to the Internet because every site tells you something different..."(Louise 4)**
- **"And I go on the Internet and I'm left to my own devices." ..."the information could be too much." (Anna 8, 3)**

Reading up on the Internet could be scary.

- **"When you read the Internet about Haldol, it makes it sound really bad." (Louise 1)**

Understanding the nature of mental illnesses and the pros and cons of psychotropic medications could require in-depth, detailed information – data that was still accessible to the lay person. Some consumers were more passive and trusted their physician to both be "very, very good with meds" and provide explanations to the client on a per need basis, while others were dissatisfied with health professionals not going into enough detail about their prescribed medications. Other participants were more proactive and sought more knowledge, accessing a range of sources including books, educational events or the World Wide Web, which also could empower them during medication discussions with their doctor.

The Internet may be increasingly playing the role of an important and instantaneous resource, which moreover could be accessed from the privacy of one's own home. Yet, the abundant data produced by Internet searches could often be difficult to sift through and assess. Some consumers turned to their physician for clarification and reassurance when the new knowledge found through other sources was confusing or disconcerting. Therefore, the issue may not lie so much in a lack of medical information but in consumers conducting a discerning interpretation and evaluation.

Chapter 5: Experience with Side Effects

Participants reported the burden of a wide range of adverse effects experienced while taking psychiatric medication. Side effects were identified as probably the most frustrating aspects of being on psychotropic medication. (Alex 17) Participants named many different effects, including weight gain, loss of energy, or dry mouth. Some had even suffered the serious risk of Lithium toxicity. Still, consumers' reactions to such effects and risks varied. Some were feeling resigned, or in denial, or others were very attentive and confronted their physician with their experiences, though they often did not always find an open ear for their complaints.

1. Side effects and risks

Commonly, participants had been subjected to considerable weight gain (some participants specified weight gain from 30 – 50 pounds), (Louise 7, Sarah 5, Mark 10, Carole 8, Thomas 12, Patty, Rhonda 8). One consumer found her metabolism now so difficult to understand, that she called weight gain the “worst” frustrating part of being on psychotropic drugs. (Louise 12).

One adverse effect also repeatedly noted was a “dulling” effect, a “flattening” of emotions (see also Chapter 7) Participants also felt that medication made them sluggish, took away their energy (Tina 17, Mark 11), and caused somnolence or drowsiness. (Carole, Louise 2, Patty) As one consumer suggested about psychotropic drugs:

- **“Well no, the medication you know, like they never really stimulate a patient to like you know go out there and do something or you know accomplish something or achieve things, in fact the meds tends to make the opposite, it encourages laziness and being overweight and stuff like that, it’s just terrible.” (Thomas 12)**

Other participants felt that their concentration and memory were negatively affected. (Patty 10, Louise 2)

- **“Seroquel ...made me stupid, really stupid.” (Anna 3)**

Reported were also a range of other sensations and adverse effects: restlessness and pacing (Alex), Tardive Dyskinesia (TD) or twitching (Alex, Louise, Thomas), shaking (Rhonda 8, Carl), sweating (William 13), speech impediments (Louise 12), dry mouth (Alex 16, Carole, William 13, Angela 5, Patty 9), stomach upset (Tina 10), muscle stiffness (Louise, Alex), loss of libido (Carl, Angela), dizziness (Alex 16), pain (Alex, Louise 15), high cholesterol (Sarah 5), fatty liver (Sarah 5), and diabetes (Sarah 5) Two participants had experienced toxicity due to Lithium effect (Patty 5, Wendy 9)

2. Reaction to side effects

One participant first stated that he did not experience any side effects, then later admitted to considerable weight gain (Mark 10) and having less energy. (Mark 11) However, he accepted the effects, such as feeling sluggish.

- **“I don’t worry about it – I bus everywhere.” (Mark)**

Others also acquiesced in the negative consequences of the medication intake as a “trade off.”

- **“I find ultimately you have to live with it.” (*Is that what the psychiatrist says?*) “I don’t think she says it that way, but because there aren’t changes that’s how I**

- feel.” (Alex 9) *(You’re just saying that it’s a necessary evil in terms of taking the medication?)* “Yeah, yeah.” (Alex 9)
- **“For me that was a choice....I am aware [of side effects] and to me that’s a trade off.” (Angela 6)**
 - **“..some things you have to put up with...wouldn’t stop me from taking my meds.” (Carole 8)**
 - **“...a lot of problems of restlessness and pacing, but I’m comfortable taking meds. I don’t have an anti-medication stance, but whether it’s working for me, I feel that it is.” (Alex 4)**

One experienced consumer felt that over the years medications had become more effective, i.e. that lower doses were prescribed which led to a reduction of these side effects and risks, (Alex 4/5) while another participant also felt that the side effects were not as bad as they used to be on the “horrible meds.” (Sarah 5, 13)

Another participant felt he was sufficiently in control of his medications and felt less worried about adverse effects:

- **“No, because I won’t let him overdose me.” (Thomas 7)**

This consumer had in the past felt “terrible with the Epival,” had advocated for a change in medication and even did his own research on a new drug. (Thomas 7). In such cases, when the adverse effects were very severe, physicians sometimes reduced the dosage or changed the medication. (Rhonda 9)

- **“I guess after the stomach upset I was concerned that I had to switch. But I was seeing them once a week, so right away they could do something.” (Tina 10)**
- **“Sometimes I trip over my words more than I used to or I just insert the wrong word. Dr XYZ said he wants to lower the Loxapine so that it frees up my tongue a bit more...”(Louise)**

Ultimately, however, consumers could find themselves as being left to deal with their medications’ side effects on their own, especially if their physician did not believe in the occurrence of the adverse effect experienced, which was apparently not uncommon. For example, participants related that one psychiatrist did not believe that Gabapentin could cause Tardive Dyskinesia (Thomas 7) or that other physicians doubted the consumers as the side effects they reported were not listed in medical reference books.

- **“I was trying Seroquel and I was experiencing something that wasn’t listed in the DSM⁵ as a side effect and then it couldn’t be that the medication was causing it....That’s been part of my argument, that I have to go home and deal with that. So I would appreciate you recognizing that I’m experiencing it and I wasn’t experiencing it before...”(Alex 12, 13)**
- **“I was having certain symptoms I thought because of medication and she said it doesn’t say that in the DSM so you can’t say that. (Focus Group 1, 16)**

However, one participant said that things have improved now since mutual understanding with the psychiatrist had made progress: the doctor now respected that she was indeed more sensitive to certain side effects. (Focus Group 1, 16) Some other consumers also concluded that they experienced harsher side effects because they were “more sensitive.” (Anna 9, Louise1, Patty 5) In one case, the physician learned to have greater regard for the experiences of one consumer who was sure to “know my body really really well.”

⁵ Consumers may actually be referring to the Compendium of Pharmaceuticals and Specialties (CPS).

- **“...so we worked out now you know this better respect mutual respect like before she would think I was being histrionic...”(Focus Group 1, 15)**

Reporting side effects and being respected for it could be linked to a sense of trust between physician and patient. One participant was certain that her physician would respect her reporting any side effects and explore their occurrence.

- **“She would investigate that with me.” (Angela 6)**

In order to combat side effects, participants felt motivated to “double their exercises” and engage in “Why Weight” Programs in order to produce a better quality of life. (Sarah 5/8, Carole 8, Louise12) As one participant conceded, there were many severe side effects but she could not see any alternatives to taking medications.

- **“Side effects are huge, are a big thing, but if I don’t take them I get into hearing voices.” (Sarah 6, 13)**

Experience of medications’ severe effects could prompt participants to discontinue their regimen. (See also Chapter 12) As one participant recalls her frightening experience:

- **“... feeling strange in my body, not thinking straight, all the bad nightmares, being physically in pain...muscles all stiff...that’s another reason why I went off my meds.” (Louise 14/15)**

3. Concerns about adverse effects and toxicity

Despite experiencing side effects and being afraid of possible risks and toxicity, participants on the whole stated that they were still taking their medications.

- **“I keep taking my medication even though some of the side effects like the weight gain that hurt.” (Carole 8)**

This participant first refused to be concerned, but then admitted to a worry about possible dementia as she grows older, which she had heard about at a recent symposium. (Carole 9, 11) Other consumers were also concerned, though long-term effects were hard to assess.

- **“Well ever so often I hear about a side effect that might be long-term and I go “Oh, that’s not so good” but so far...” (Louise 4)**
- **“I have concerns about newer medications and their long-term effects but I still would not give up...”(William)**
- **“I have had doubts...about the real possibility of toxicity of the drugs over the long term.” (Carl 3, 10)**

Some participants who downplayed the experience of or the concern about side effects, tended to be participants who were generally very positive about the medication and their physician. When asked whether they were concerned:

- **“No.” (Jack 5)**
- **“Don’t have any...no, not really, it’s pretty smooth.” “I don’t worry about it.” (Mark 5)**
- **“There are barely any side effects, a bit of a twitch sometimes, that’s it.”...“not really because mostly I function like I did before I got sick”...“I think he [the physician] is more concerned about side effects than I am” (Louise 7)**

One participant worried about Tardive Dyskinesia, after having had one bad experience with limbs shaking. (Alex 17)

Some risks of psychiatric medications were apparently talked about on the consumer grapevine.

- **“It was also someone has told me that if you take Seroquel you can get diabetes.” (Jack 11)**

Another participant also worried about a hazardous interaction between psychotropic drugs and diabetes, fearing that pills could make diabetes worse and that at the same time diabetes could trigger an episode. (Focus Group 2)

A number of participants admitted to their concerns.

- **“Oh yes.” [naming severe side effects] (Sarah 5)**
- **“Very much, yeah. That’s why, one of the reasons I’m resistant to it would be side effects...” (Rhonda 8)**
- **“Oh yeah, oh yeah....Like my kidneys and well, I didn’t want to go on Lithium for that...” (Anna 7)**

One consumer had become alerted to the risk of liver damage if she was drinking at the same time as taking medication. (Rhonda 8) One participant had come away from a team information session with news of side effects, fear of addiction, and worry that taking medication could take 5-10 years off her life span. (Focus Group 2, 5) Her daughter also looked up her medications on the Internet and shared her concerns about possible side effects which the mother may already be experiencing. (Focus Group 2, 4)

Concerns about possible risks and side effects could require courage in order to take a new medication.

- **“To me it’s like a loaded gun. I go to the pharmacy, I pick that up, and I think “Oh no, not another one.” So it sits there for a while until I have the courage to try it.” (Anna 11)**

Concerns about side effects could lead to action, ranging from stopping to take the medication to consumers doing their own research.

- **“Whenever I’m going on a drug, I put it in the Internet and I put the drug name and then the side effects...” (Anna 8)**

4. Discussing with physician about the medications’ risks

In the interviews, we asked participants whether they and their doctor had deliberately discussed the (potential) side effects and risks of their medications. Participants’ answers reflected that such frank discussions were sometimes missing from the therapeutic relationship and that they themselves did not always feel comfortable bringing up the subject.

- **(Did you tell your physician when you experienced side effects?) “Yeah...” (How did he react?) “We know better otherwise a nice guy, we know better guy, we’ve had 12 years of college so guy comes out here and says impossible...there is no TD on Gabapentin and there is, small, but there is.” (Thomas 7)**
- **(Do you tell your psychiatrist about experiencing your side effects?) “No, we don’t really talk about that, no.” (So you don’t know how he or she would react?) No. I’m not sure. Probably they’d say, oh yeah, that’s part of it.” (Patty 10)**

- **“Not in great detail, but sufficiently enough yes. “(Jack 4) “They don’t always tell you necessarily about the side effects.” (Do you think they should?) “Yes.” (Jack 11)**
- **“No, but I just look them up.” (Sarah 5)**

For one participant, there was trust that side effects concerns or experience could be openly discussed with her doctor. (Angela 6) For example, she and her physician talked about the drawbacks and the benefits of pharmaceuticals products versus herbal solutions. (Angela 5)

One participant did not necessarily want to engage in conversations about the medications.

- **“Yeah, he would but I told him I don’t want to know.” (Carole 7)**

Physicians could inform patients about risks and benefits as they saw fit.

- **“Well, not anymore because I guess I’m compliant, but when I was noncompliant he would always try to sell up the potential benefits, but he was good, he would always warn me about the side effects...even when he saw that I was resisting all the meds because of the potential effects, he still told me about them.”(Louise 7)**
- **“Well, no...”(Thomas 6)**
- **“Not too much because I haven’t had too many changes. “(has been on main medication longer than seeing the same psychiatrist). (Alex 8)**
- **“Yeah” (Mark 5) yet later: “I don’t really get side effects, so I don’t really like talk to him about that.” (Mark 6)**
- **“No, not too much. A little bit. If you asked them what’s the side effects and stuff.” (But they wouldn’t volunteer?) “Well, not particularly, no, I don’t think so.” (Patty 9)**

In one therapeutic relationship, the consumer was encouraged to educate herself about the medications and illnesses:

- **“He’ll explain it from his point of view and then he’ll say to me: “You do your own research if you want.” (Louise 8)**

One participant figured that doctors did not necessarily want to discuss medication side effects and risks.

- **“I guess that’s the scheme with the thing, they don’t want to let you know too much information.” (Tina 11)**

Physicians did not always respect consumers’ concerns about adverse effects.

- **“She wouldn’t pay attention when I would say, I’m not taking that, because I read about it the side effects and they far outweigh...” (Focus Group 1, 3)**

Some participants were openly interested in learning about risks and asked their physician.

- **“Yes, there were some of those points covered and I would typically ask certain questions if they weren’t.” ...”It’s always something that I would either bring up or be curious to know if there are side effects.” (William 10, 12).**

For one interviewee, discussion of side effects was paramount for finally finding the right medication.

- **“Yes, we sure did, because I decided I had to change many times, the med, before I got to this one, the other ones make me sick.” (Tina 11)**

This consumer did her own research and confronted her psychiatrist with a list of the medication's possible side effects. (Tina 11) For another participant his own research also prompted discussion with the physician.

- **“Yeah, I guess in the past and also from some of the reading I have done.” (Carl 6)**

Sometimes, the physician seemed more focused on benefits rather than forewarning about drawbacks.

- **“More the benefits than the risks or the side effects. I found the risks and the side effects were discussed as they came out like the shaking and the weight gain...” (Rhonda 8)**

It apparently took courage to force the issue with the care provider. For example, when planning to confront her psychiatrist with concerns about side effects and risks, one consumer decided to take her daughter with her for moral support. (Focus Group 2, 4)

Considering the many potential diverse and serious adverse consequences of taking psychotropic medications, discussions about side effects and risks did not seem to command much attention in the therapeutic encounter. Physicians seemed at times reluctant to engage in such debates, perhaps because they feared that discussion of risks could negatively affect patients' motivation to take the drugs. At the same time, consumers' attitudes ranged from curiosity about what side effects they had to expect to hesitation of learning about severe risks for fear of becoming disheartened.

5. Would you take medication if aware of all the risks?

Exploring the issue further, participants were asked whether they thought they would not take their medications if made aware of all the possible side effects and risks.

For one participant, the attitude toward medication had dramatically changed over time, after intense treatment and the identification of an effective regimen.

- **“Well, at this point probably not. Not in the same way before it would have, before I was at Riverview. I would have not taken any meds I would have just said “Forget it.” I don't want any dry mouth ...But now I guess I see the meds in a different light.” (Louise 7)**

Another participant pondered whether giving consumers “too much” information about risks could undermine trust in the medication and the physician.

- **“Maybe... [read pamphlets etc.] Most of the side effects didn't seem all that serious. Yeah, it's a tricky one because it's all to do with medication compliance. If you tell people too much bad things then they're going to just not listen to the good things. I suppose. There's definitely a danger of that.” (Rhonda 8)**

Still, more knowledge about medication did not necessarily mean more choice about actually taking the medications.

- **“It would make it harder to take but then I don't know what other options I have.” (Carl 6)**
- **“Well, no because you know getting psychiatric treatment is a life and death matter for me...less or worse options you know...that's the only reason I ever accepted treatment.” (Thomas 7)**

As long as adverse effects did not seem life-threatening, such as posing a danger to his heart, one participant counted on the vigilance of his doctor while he himself remained philosophical about risks:

- **“I don’t think so, I don’t think so. I think I have a pretty good understanding that pretty much any med has a certain amount of risk dependency on you...I think I can appreciate that, but that wouldn’t necessarily happen to me and that they would watch for it.” (Alex)**
- **(risk of TD) “So I really watch that with my doctor.” (Alex 5)**

Another participant was scared of leaning about all possible dangers and was inclined to let this influence her acceptance of a new medication.

- **”Well, we go through the risks, but she knows that she can only go down a certain number and then I tell her to stop because I’d never do any of them if you told me every risks.”(Anna 7)**

Being exposed to information about risks could also be received differently when the consumer was in crisis, could be resistant to the very idea of psychiatric medications, and had not (yet) developed a trusting relationship with their psychiatrist.

- **“At the beginning when I was very ill, if she told me the side effect, I probably won’t take it...But now it’s okay, she mentioned that the side effects would go away after a while... (So maybe you wouldn’t want to take it if you knew that there were those many side effects?) “Probably not.” (Tina 9, 11)**

In sum, these recipients of psychiatric medication reported experiencing a wide range of side effects and risks, including weight gain, low energy, emotional “dulling”, tardive dyskinesia, dry mouth, somnolence or Lithium toxicity. Also, diabetes was associated with the effect of prescribed drugs. Some consumers seemed less afflicted and thus expressed little concern about adverse effects; others sounded more resigned to accept side effects and risks, at times figuring that they simply were more “sensitive”, for which they sought respect and understanding by their physician.

Not every physician seemed to make it a point of discussing (potential) side effects and risks with their patients, and not every consumer wanted to know about all possible ramifications – perhaps due to fear of being disheartened. Some service providers may have been aware of consumers doing their own research (such as on the Internet) and in at least one case actively encouraged the patient to do so. Ultimately, recipients and service providers may have been sharing in the belief that side effects simply had to be accepted as a “trade off” to the benefits of medications. Nevertheless, feeling at risk, fighting against adverse effects, and being concerned about long-term risks contributed to participants having mixed feelings about medications and to their perception that even when their physical health was jeopardized, they had to accept pharmacological treatment and both its obvious and hidden downsides.

Chapter 6: Trial and Error

Participants were aware that pharmacological treatment of their mental illness could often turn out to be a “trial and error” process. As they experienced, especially in the beginning of the therapeutic relationship, but sometimes for years on end, different medications were being tested in an attempt to reduce adverse effects and to optimize results. In the course of complex medication histories, participants could sometimes feel like “guinea pigs” or remain afraid of what effect the next medication on trial would have on them.

This was how one consumer described the lengthy process of searching for a suitable antidepressant:

- **“We changed, it was switch, switch, switch for a while till we got this one...”(Tina 9/10)**

Another participant reported her frustrating experience:

- **“They try all these different kinds of medications, some made me sick, on some I was too high, made me all jittery...This had been going on for years...”(Anna 2)**

Inadvertently, consumers could find themselves feeling like subjects of medication trials. A participant who generally was positive about her treatment and her physician recalled about initial treatment challenges:

- **“The first medications they put me on I don’t remember the names but they weren’t the right ones and I was almost comatose I was slow and stuff but he changed me after.” (Carole 2)**
- **“That’s one thing which I find with psychiatric medication you have to play around and I feel like sometimes I was like a guinea pig until the doctor got me to the right amount.” (Carole 13)**

Similarly, a consumer shared “in the beginning I was like a guinea pig.” (Focus Group 2, 13) Another participant, speaking of frequently having been prescribed changing medications in the past, recalled her sister saying “Your doctor is treating you like a guinea pig,” which “offended” her since she was placing her trust in her psychiatrist. (Wendy 8)

Participants could sound accepting and even resigned about frequently changing medication regimens as well as having to be on a “cocktail” (Anna 9) of psychotropic drugs.

- **“I’ve been on a lot of different medications.”(Jack 14)**
- **“There is no medication that I haven’t been on, so you’ll have a wealth of information from me.” (Anna 1)**
- **“...and then I was on the other things, like mood stabilizing, antipsychotic, all this business...” (Rhonda 9)**

One participant emphasized that continuity of care was needed in order to arrive at an effective treatment.

- **“My cocktail works, it took years to get to that. You need continuity.” (Focus Group 2)**

Another participant reviewed past experience with the prescription of psychiatric drugs and concluded that there was better, less experimental treatment today.

- **“In the earlier days it was more hit and miss, it was more try this, try that – oh, there’s a new medication...I think things have changed.” (William 20)**

It required a great amount of trust in the physician on the part of consumers when medications were being changed frequently over several years.

- **“So you have to trust them a certain amount you know to take a certain amount of medication and get well enough. It’s hard you know – years and years of trial and error.” (Focus Group 1, 16)**

A certain amount of skepticism was retained as participants reflected upon their changing treatment. As one consumer explained:

- **“Doctors themselves they don’t know exactly what the medication is going to do exactly...a lot of time you got to take it for what: two to six weeks, you know what I mean?”(Jack 2)**
- **“They don’t know whether or not it is going to help you, it may help you. So take this drug at this amount, you know, everyday, they don’t know. They don’t know what’s going to make you better, if it’s going to make you better, if it’s going to make any difference at all, or if it’s going to end up making you worse. They don’t know unless they try it out on you and it’s a crapshoot most of the time, it’s a roll of the dice.” (Jack 13)**

And similarly, another participant voiced her opinion, however with a higher degree of acceptance of the trial and error process simply being inevitable where psychiatric medications were concerned.

- **“...meds are a total crapshoot and if one thing doesn’t work you try another... people in the mental health system have to be willing...to experiment.” (Angela 19)**

One participant commented that her psychiatrist had been experimenting with different medication while seeking more information about the specific nature of her disorder. “So I kind of felt it was like a test to help her diagnose me.” (Rhonda 9). She pondered the nature of the prescribing process.

- **“Well, she put me on Prozac for a week and I went “who”, I went kind of crazy and then she took me off that and put me on a bunch of other things and then it’s a question of balance, right...” (Rhonda 4)**
- **“...It is trial and error. People don’t really know, I mean they kind of know what it’s going to do to you, but they don’t exactly know, the amount and everything. And I don’t like that about it, the kind of trial and error.” (Rhonda 20)**

Consumers could be left with the impression that medications were almost prescribed at random.

- **“Maybe it’s a quick fix...Because they don’t know should we give him Wellbutrin or should we put him on Paxil for depression or whatever...” (Jack 6/7)**

Frustration and loss of confidence in the professional could ensue.

- **“I want to trust that they know. I realize they don’t. She doesn’t even pretend to, in a way. She doesn’t pretend to know that this combination will do the trick...They have a guess.” (Anna 12)**
- **“For me, it’s like they don’t know what they’re doing.” (Rhonda 20)**
- **“I’m kind of a success story, but, ah, really they never get it right, you know, they never get it right.” (Thomas 9)**

Still, consumers appeared resigned to prescribed psychotropic drugs being by their very nature unpredictable and the physician simply not knowing for sure. In one case, the physician was blamed for negative experiences with the medication regimen but apparently not openly criticized.

- **”Yeah, I had a rough time the first time, because they did try me on several medications and I held him responsible. I said ‘it’s your fault,’ not to his face but that’s what I thought.” (Louise 4)**

Having been subjected to trial and error over the course of many years, one frustrated participant was left longing for certainty of treatment, for a magic formula for her.

- **“That it’s so haphazard. If only they had a blood test, could give me something that would zero right in on my brain chemistry.” (Anna 11)**
- **“Well, it would be nice if it was specific though – like if there was an insulin for me, where I was better. If it wasn’t this iffy kind of thing, trying to get the combination just right.” (Anna 9)**

This consumer explained her view that while the process remained hit or miss, a physician with a longer experience might be more confident to try out different medications in search of the right combination.

- **“They have a guess....But with some I think... [they] would have a better shot just by being able to try...just by experience...Yes, how to juggle that’s right. To play with it.” (Anna 13)**

On the whole, participants seemed resigned to the fact that treatment often meant being on a cocktail of different psychotropic medication in order to treat mental health concerns and that it was difficult to combine the drugs for optimal effect. (Angela 7)

- **“It’s a hard balance between not enough meds and enough to keep you under control.” (Patty 6)**

While the present regimen might not seem satisfying, there also could be fear about ever changing medications and their unwanted effects.

- **“If they could tell me that this cocktail was going to do it. But every time they add something something happens to me, something that usually I don’t like.” (Anna 9)**
- **“I don’t really want to switch because it’s scary...it’s like a status quo...I’m not getting better and I don’t what the answer is...and I don’t push it [i.e. medication change] because I’m scared.” (Anna 5)**

Being subject to a process of “hit and miss” in pharmacological treatment, these participants often could feel frustrated. Still, they seemed to acquiesce in the treatment process inevitably being one in which the physician needed to “play around” in search of the right “cocktail.” This experience may be contributing to consumers’ ambivalence about their regimen and to a conclusion that while the prescription process could be unsatisfactory and even scary, they wanted to believe in the physician’s expertise and felt that they had little choice but to trust their physician.

Chapter 7: Ambivalence about Psychiatric Medications

Participants frequently were ambivalent about psychiatric medications. They spoke about “double-edged” feelings: on one hand, there were negative experiences such as adverse effects or worries about long-term risks, the “hit and miss” of pharmacological treatment plus a sense that drugs were overrated and that physicians “pushed pills” without necessarily making consumers feel much better. They could feel uncomfortable or quite opposed to taking drugs and were afraid of becoming addicted. On the other hand, participants described how medications were “extremely important” and appreciated, how they were stabilizing their health and may be helping to reduce suicidal ideation.

1. Too much emphasis on medications?

We asked whether participants felt that their physician and the medical system, in treating mental illness, placed too much emphasis on the prescribing of medications.

Some participants felt that in their own experience the benefits of medications were not overestimated.

- **“I don’t think there’s too much, I think many more people could be helped if they were on medications.”(Angela 14).**
- **“Oh no, I’m fine. I think medication is extremely important, extremely important.” (Mark 10)**
- **“Medications are just sort of, that’s it, there is no comparison. They are so good, they’ve been so successful in my life.” (Louise 13)**

For some there was definitely too much emphasis on prescribing drugs.

- **“Oh sure, oh yeah.” (Anna 12)**
- **“Yes, I do.” (Thomas 13)**
- **“Yeah, definitely. They are taught in medical school that pills are the answer and it’s not always true, sometimes vitamins are better.” (Patty 16)**

Other participants felt that pills were used as a “quick fix”, a simplified attempt to control a complex health problem.

- **“Maybe it’s the quick fix.” (Jack 6)**
- **“Oh yeah, well I’m certain of that.” (Thomas 12)**
- **“I think it’s a simplistic solution, pinpoint a problem in a way that might be better solved dealing with the whole person...” (Carl 10)**

For others, there was no universal answer.

- **“I think for other people, but I don’t have too much medication...No, I’ve just heard other people’s horror stories.” (Tina 18)**
- **“Depends on where you are in your recovery.” (Sarah 6)**
- **“I think that it really depends on, you cannot generalize that statement because it depends on what the problem is with the individual as to whether the focus should be on, other than medication, a combination of medication and others ...” (William 14)**

One participant felt that while there often was a tendency to over-prescribe, medications were definitely indicated in severe cases.

- **“I think prescriptions are handed out really, really quickly, in my experience, without that much looking into it ...I think there is a big emphasis in society about pills fixing ills ... And for some people I understand that like that’s the only way that they can possibly function in the world, when people are so ill that they really, they have to take medication.” (Rhonda 3, 15)**

Another consumer similarly felt that while medications were needed, too many medications were prescribed and in too high doses.

- **“I think that a lot of patients are over-prescribed they need the pills...half of what they are getting, medication might get them to be able to recover from treatment.” (Thomas 4)**

Psychiatrists’ prescription practices, their “pushing pills,” were seen in a critical view.

- **“I don’t know what made me turn against her...like she was a drug pusher on me.” (Rhonda 14)**
- **“Yeah, definitely for sure. They really push the pills. They don’t do much counselling at all.” (Patty 16)**

One participant was frustrated because when he had presented to his physician with a surge of depression, “he gave me a bigger bottle of pills.” (Focus Group 2, 3)

At the same time, experiences could run against a quick and simple “pills fixing ills” process: another participant recalled that the initial intake at the team had taken a lot of time “not just like you have a headache, we’ll give you Aspirin type of thing.” (Tina 18)

Consumers wondered whether liability issues, i.e. “They are responsible for us so they keep you on meds,” played a role in modern psychiatric care and its prescribing practices. (Focus Group 2)

2. Conflicted feelings

Once a prescription had been issued, consumers could have mixed feelings about being on psychiatric medications, particularly due to concerns about side effects and toxicity but also because consumers could feel embarrassed about being on psychotropic drugs. .

- **“I have never felt completely comfortable taking it. I still have conflicted feelings, I have always had them. It’s a strange trap that I’m in, that’s why I call it a pharmacon.”(a term for a poison and a medicine at the same time)(Carl 13)**
- **“I have had doubts and not just in the sense of if I feel great I think I’m okay I’m going to later have a relapse but in terms of number 1 not really trusting, feeling a lot of doubt about the real possibility of toxicity of the drugs over the long-term.”(Carl 3)**
- **“It’s a very, very kind of double-edged kind of feeling. I felt grateful that it was giving me some kind of stability, I felt shame that I had to be on it...” (Rhonda 13)**
- **“Well I would say it’s better now in some ways...I think in some ways I think it’s a little better, but not better in a lot of ways because of the side effects of having to take pills and sleeping a lot, and you know there’s problems with any time in your life, really.” (Patty 15)**

For one consumer, the situation was unclear. On one hand she felt:

- **“Yes, I am on the right track with the meds. But I wouldn’t mind coming off of them if there was some other way of doing it because that would really help my physical health.” (Sarah 13)**

Yet on the other hand she was unsure whether she was really better on medication than without them.

- **“See, I don’t know about that. I don’t know I probably haven’t had the chance to explore that part, other than cold turkeying it a couple of times and that was not a good situation.” (Sarah 6)**

Some participants said medications did not always seem to be working or really making them feel better.

- **“Yeah you take them but you don’t know if they’re working.” (Jack 7)**
- **“I haven’t been getting better this whole time. This is the whole problem...I’ve been just stagnating getting worse”... Well, I don’t think they are doing a very good job of helping me to feel better. I mean, I don’t really feel better.” (Patty 9, 15)**

And yet, that same participant, who in the past had rejected her regimen, now stated that she needed to continue taking her psychiatric medications:

- **“In general, though, I think the medication is better to take than not to take.” (Patty 10)**

Another consumer stated that her condition was not really improved, yet her health was so fragile that she and her physician were reluctant to make any changes to the present medication regimen.

- **“...It’s not great, this is not working...I don’t really want to switch because it’s scary...so we both just let it go, it’s like a status quo. I’m not getting better and I don’t know what the answer is.” (Anna 5)**

3. Aversion to taking medications

Some participants categorically stated their dislike of taking the medications, though they could feel that the drugs were helping and that their illness was at the root of the problem.

- **“I don’t like it.” (Jack 4)**
- **“I don’t like it,” though “It’s helping though” and that she “Don’t like medicine in general.”(Tina 15, 17)**
- **“I really don’t like it, I wish that I could be off them.” (Patty 14)**
- **“Well, I hate it. But I hate being mentally ill, too.” (Anna 10)**

4. Fear of dependency

Part of participants’ negative feelings about medications was caused by the fear that they could become addicted to them. (Focus Group 2)

- **“Well now that I’ve been on it I can’t stop taking them because then they make me nauseous.” (Jack 6)**
- **“Yeah, it was cold turkey and it was really bad. I couldn’t sleep or anything because I was addicted to the pills, so.” (Patty 17)**
- **“And that’s another reason why I’m resistant to medication in general I guess, is because it is another drug and it is another substance and it’s something you can get dependent on and you can abuse.” (Rhonda 16)**

- **“She [the pharmacist] knows if I get more of that pill that I would get addicted and I would not get it off anymore for the rest of my life.” (Focus Group 2, 5)**

5. Appreciating and getting better on medications

Conversely, despite such ambivalent feelings, many participants appreciated their medication and even those consumers who had serious concerns about taking psychotropic drugs could often see tangible benefits and were motivated to follow the regimen.

- **“I love my meds” ...“They’re so good...they’ve been so successful in my life.”(Louise 11, 13)... “Well how good it makes me feel. I can do whatever I want basically.” (Louise 14)**
- **“...what I’ve seen in my own life and in my daughter’s life is that they make a tremendous difference in the quality of life or even in being able to live...I am grateful that there is medication so when we need it it’s there.” (Angela 11)**
- **“I’m more than happy to take my meds, you know, if I had a magic wand I’d be taking more.” (Mark 12)**
- **“So I feel kind of better now on the whole...” (Anna 2)**
- **“Yes, yeah, because I was so down and out.” (Tina 16)**
- **“They are the best meds I have been on.” (Sarah 3)**
- **“So under my medication I’m okay, otherwise I don’t think I be fine...I am completely stable.” (Wendy 2) “Yes, they make me feel better otherwise I don’t have to take it but what can I do?” (Wendy 13)... “One reason to take the medication is I am doing fine.” (Wendy 14)**
- **“I am happy, I love what they are doing for me.” (Focus Group 1, 8)**
- **“It’s working for me right now I can function, I can hold down a part-time job when I want to, I have my friends, I have everything going well so why would I stop taking them.” ...“I definitely wouldn’t ever stop...because I felt so much better I know it worked.” (Carole 1, 16, 7)**
- **“I wouldn’t be able to survive, if I didn’t my medications I would definitely end up back on the street and lose everything..” (Focus Group 1, 8)**
- **“...for me I am happy, I love what they are doing for me...” (Focus Group 1, 8)**
- **“Yeah, really you know, a lot better ...”(Jack 12)**
- **“At this point I feel I’m in a good place.” (Carl 1)**
- **“I’m comfortable with taking medications. I don’t have like an anti-medication stance, but whether it’s working for me. I feel that it is.”(Alex 4)**
- **“I’m in a recovery mode in my mental and physical health because of my psychiatric treatment.” (Thomas 8)**

One participant who had reservations with respect to modern prescribing practices also admitted:

- **“I have to confess that I am much more physically healthy and my life works because I took the pills.” (Focus Group 2, 8)**

Agreement with one’s regimen could be clear, albeit given reluctantly.

- **“I’m afraid I have to agree, yes. Really, because I only wanted to fix that depression/poverty cycle that’s all I wanted but like I realize now that if I am not on medication I don’t think I would have much of a life left.”(Thomas 3)**

6. Medications may help to prevent suicidal ideation

The taking of psychiatric medication could be perceived as a matter of alleviating the risk of suicide though that was not mistaken for producing high quality of life and real trust in the drugs.

- **“Today it allows me to function at a better level than without but I have concerns about newer medications and their long-term effects but I still wouldn’t give it up because if I did I would probably be somewhere where I wouldn’t want to be as in suicide...” (William 9)**
- **“I don’t think it’s given me quality of life. I think it’s just taken away that “oomph” that I would have to actually throw myself off a bridge or something which isn’t living.”...“Oh no, I’m not convinced at all. I just feel like...I’m not suicidal but that’s not really enough.” (Anna 11)**

7. Stability and functioning

One common benefit cited by participants was that medication seemed to help “stabilize” them, keeping them “calm” or “on level” and letting them “function.”

- **“Yes because they keep me kind of level.” (Sarah 5)**
- **“Oh yeah, definitely. I’ve seen where I’m at without my meds and where I am now, there is no comparison.”...“I’m almost completely symptom-free now.” (Louise 2, 12, 18)**
- **“I’m completely stable.” (Wendy 2)**
- **“I feel they keep me calm. I look at the medications as a blessing...they keep me calm they’re keeping me in a place where I can function.” (Carole 13)**
- **“But it served its purpose and for that I was grateful, it picked me up out of a hole and it stabilized me for a time.” (Rhonda 7, 13)**
- **“That’s when I take the medication and that’s when the medication kinda calms me down to where I can actually function and make decisions and get up in the morning and go to work and take care of my son.” (Angela 10)**
- **“And then I finally went on it [Lithium] and it actually did help. It did seem to stabilize me.” (Anna 3)**

As the flipside of this desire to keep consumers “stable,” participants found that the physician or the team could be reluctant to try new or different treatment “because they tend to want to stay with the tried and true” (Alex 2). Health professionals would want to avoid any “risk-taking,” such as changes in medications.

- **“They thought maybe he’s going to develop problems, and it’s gonna get worse and maybe there will be other complications.” (Focus Groups 1, 4)**

At times, achieving “stability” was juxtaposed with real improvement in the consumer’s condition and was seen in the context of health professionals setting their own priorities.

- **“...they’re more interested in keeping you calm, and keeping you level, and keeping you out of hospital...That’s all they want to do is stabilize you, they don’t want to improve your situation really.”(Patty 7, 12)**

8. Dulling effect

Achieving stability was not always seen as producing the most optimal results and rather could be seen as coming at a significant price to quality of life for participants.

For example, some participants felt that the medication “flattened” and “dulled” their emotions.

- **“...it flattened out. I used to be more of a vibrant, even my cousin who knows me quite well, we’re the closest two cousins, she said you used to be so flamboyant and outgoing, but it’s different...” (Carole 7)**
- **“My creativity and everything was dulled. Like I was leveled out but I was too level, and that wasn’t really of concern for her because it was more important to her to stabilize me.” (Rhonda 10)**
- **“She gave me some Seroquel to calm me down a bit more. Well, that made me completely stupid, really stupid. Not just a little bit stupid but where I was like a cow. I just couldn’t even think.”(Anna 3)**
- **“I just want to be stable, but without being...slow. Apparently you get those two things together.” (Anna 14)**

As one participant observed, medications could change her personality.

- **“And I don’t like it. I want my edge back, but on the other hand, maybe I was a bit too edgy. I’d like to be myself again.” (Anna 3)**

This group of consumers often described the role of medications in their lives in positive terms and many appreciated tangible benefits such as symptom alleviation, improved functioning, greater control over their life, and generally making them “feel better.” For some the importance of medications in treating mental illness remained unquestioned. However, some participants could find themselves torn about medications and took them with deeply conflicted feelings. Positive experiences and views were at times juxtaposed with ambivalent attitudes: participants expressed concerns about the strong emphasis on medication in modern psychiatric care, suspected drugs to work as “medicine and poison” and worried about long-term risks, were averse to taking medications on principle, and held a fear of growing dependency on the drugs. Consequences of being on psychiatric medication such as the noted changes to a consumer’s personality reflected that even achieving “stability” had a flipside and that it in itself did not necessarily mean that the best health outcomes had been attained.

Chapter 8: Alternatives to Psychiatric Medications

A number of participants described ambivalent feelings about taking psychotropic medications and, though conflicted, often did not seem to see other options for dealing with their serious mental health concerns than to accept pharmacological therapy. However, intermittently, some participants raised the question of alternative or complementary treatment or how to safely discontinue all medication intake.

Apparently not wanting to again take medication management into their own hands and go “cold turkey,” some participants wondered if they could be “weaned off” their drugs, though they found that they could not necessarily count on the support of their physician for such an initiative.

- **“If I could go to XYZ, which is like a treatment facility and they could wean me off all the pills and then slowly introduce one pill at a time. And she [the psychiatrist] said it’s not a good idea because the psychiatrist there does his own thing and he’s not going to listen to what she has to say about it” ...”but I think it would be interesting if I did go to XYZ and got weaned off all the pills. And then saw like how I would behave, you know, that might be interesting to see whether I could be okay without the pills.” (Patty 8, 10)**

This consumer was inspired by the example of her mother and her brother, who both suffered from mental illness yet did well without medication (Patty 9). Another participant also wondered about coming off medication and still being “safe”.

- **“...If I knew or if I was in a safe place for like a month or six weeks in coming off the meds and going into an alternative place where I could be safe for that length of time then I would try to get off the meds...”(Broached that with your psychiatrist?) “No, I haven’t done that one yet because I don’t think there is any place in the system where you can do that.” ...”But I wouldn’t mind coming off of them if there was some other way of doing it because that would really help my physical health.” (Sarah 6,13)**

Alternative treatment was contemplated, yet could be shrouded in uncertainty.

- **“If there was another way of doing it I would. I would want to be doing it in more of a holistic way, I wouldn’t mind getting into more of an alternative medicines you know I wouldn’t mind doing that but to come off the meds and to do something that I’m not too sure, I can’t do that.” (Sarah 5)**
- **“I want to feel better but I just don’t know that that’s possible without medication.” (Anna 15)**

Telling her physician that she was determined to come off all medications, one participant had initiated a controlled titration process.

- **“[The psychiatrist] drew up a very short plan to titrate down but at least it was a plan and it was done with her guidance.” (Rhonda 17)**

She had come off her medications completely and now saw a counselor for her concurrent disorder. Based on her experience, this consumer was critical of the exclusive role of psychotropic drugs in treating mental illness:

- **“I think chemicals in your body play a big part and there’s lots of ways you can do that better or worse, not necessarily just through medications.” (Rhonda 7)**

“Talk therapy” was sometimes seen as an alternative or as a treatment option complementary to the prescription of psychotropic medications. One participant had first:

- **“...been to psychotherapists and psychologists. I just didn’t want to go on any kind of medications.” (Anna)**

However, she became frustrated with psychotherapy while pursuing the “very elusive” goal of once again experiencing “success” in her life. (Anna 9)

- **“...I already had had all the therapy, I mean, I can always use talk therapy...I have some of these tools, but my brain chemistry just doesn’t help me.”(Anna 9)**

Now she appreciated that her psychiatrist, in addition to prescribing medications,

- **“tries the cognitive behavioural therapy, which is great. She’s always trying to turn my thinking around, or my acting, so I can act myself into a better way of thinking or feeling. She’s always recommending books, and that kind of thing. So, I mean, she’s great. She’s sort of new for that. She’s not one of those old school psychiatrists.” (Anna 17/18, 4)**

Still, this participant very reluctantly took her medications and wondered whether she could access care by a psychiatrist who did not “just prescribe” and whether there were perhaps more treatment options than she had been aware of.

Cost could sometimes play a factor in pursuing non-pharmaceutical treatments.

- **“I mean, all psychiatrists do is prescribe...Because the government doesn’t pay the psychologists so I thought that was the deal, ‘you’d better write a ‘script or you’re not...’” (Anna 17).**

The fact that private psychotherapists are not covered by the regular medical services plan was regretted and one participant, who had experienced both types of treatment, advocated free counseling.

- **“A lot of people can’t [access counseling] and there’s a lot of suffering out there and it could be better.” (Angela 18)**

One consumer praised “talk therapy” as less invasive than medications

- **“Things like CBT (cognitive behavioural therapy) I think have real value. I just think it’s a less intrusive form of controlling the things that are going on within you.” (Rhonda 2/3)**

Yet at the same time this participant held the belief that medications had their place and a right “balance” needed to be found.

- **“I think you need to learn other ways to cope with your life. It’s natural to feel immense sadness when a bad thing happens, you know, things like that. I’m not totally adverse to it [medication] in general, because it does serve a value with others, with people that are otherwise not functioning safely with themselves or other people. It’s finding a balance, right?” (Rhonda 15)**

Psychiatric medications and psychotherapy could be seen as best working in tandem.

- **“You can’t replace medication. I think you need to have both.” (Angela 13)**

Another treatment alternative to psychiatric medications was sought in herbal remedies. One participant called herself a “great believer in herbs” and was able to talk to her physician about herbal solutions such as St. John’s Wort. (Angela 5, 7) In the experience of another participant who had also been “all into herbs and stuff, that herbal cures,” somebody also had recommended St. John’s Wort, yet he found those to be “deadly herbs.” (Thomas 9)

Being adherent to doctor’s orders could prevent consumers from trying out remedies like St. John’s Wort.

- **“I can’t, I have to listen to my doctor before I start stuff so I never try.” (Focus Group 2, 4/5)**

“Vitamin therapy” was also contemplated. One participant had at one point rejected psychiatric drugs and rather wanted to go the “non-medication route:”

- **“Well, my mum wanted me to try vitamin therapy, but nobody was willing to help her out with that...” (Louise 13)**

Another recipient of psychiatric medications had also wondered about the benefits of vitamin therapy as offered by a doctor in Victoria, but concluded that he “probably couldn’t afford it anyways.” (Carl 6)

For severe illness, or in a crisis situation, the conventional pharmacological treatment could be seen as the last resort. As this participant explained:

- **“They tried to recommend me to a couple of non-medication programs and in the end...I was turned down for all of them probably because I was in such rough shape.” (Louise 6)**

Some participants praised the benefits of recreation and rehabilitation programs, in which they were actively involved.

- **“I’m very pro-rehab and for I guess about 14 years they’ve given me help, so I believe that. That’s the magic of the missing ingredient lots of times.” (Alex 21)**
- **“Rehabilitation and recreation programs can be very effective and therapeutic.” (Thomas 13)**

Alternative help was sometimes sought in combination with psychiatric medications. As one participant acknowledged,

- **“I decided to seek help outside of the psychiatric system (e.g. Shaman).” (Carl 2)**

But he still maintained that he kept on adhering to his medication regimen.

According to one participant, a combination of non-pharmaceutical strategies and cautiously administered medications was recommended.

- **“From my point of view with therapeutic and social support and half the medication there would be a lot more recovery today.” (Focus Group 2, 9)**

One consumer stressed the importance of self-care (especially nutrition) in order to maintain good health. (Carl 13)

A participant believed in the benefits of her medication but also derived strength from her religious practice.

- **“Well for me I have a Christian background and the medications can only do so much, the rest for me is my spiritual values...It’s a combination of both and I wouldn’t give up either one.” (Carole 14)**

Participants could be frustrated with the conventional pharmaceutical therapy, but found themselves at a loss as to how to go about seeking out “holistic” alternatives.

- **“Maybe try some holistic thing. But I just couldn’t do it on my own.”... “XYZ went on this holistic thing and it seems to be she’s okay, relatively speaking. But I think that it’d be quite rare.”(Anna 3, 14)**
- **“I would want to get into doing it in more of a holistic way.” (Sarah 5)**

Some participants had at some point contemplated alternative medicine or wished for a “holistic way” for treating their illness. Some had tried the “non-medication route” and one participant seemed to have been able to successfully switch from medications to counseling. Those keen on pursuing alternative ways, could not necessarily depend on the help of their physician in exploring more unconventional methods or how to come off medication, and they seemed to be at a loss as to how to proceed when they were left “on my own.” Most participants in this study eventually found themselves taking medications to control their symptoms, though they at times chose to complement the drug intake with other therapies and practices. For these consumers, it apparently could be frustrating, unrealistic, difficult – and too expensive - to negotiate and rely exclusively on non-pharmacological treatment options.

Chapter 9: Whose Decision Is It?

When exploring how consumers perceived the role of medication in their lives and the nature of the therapeutic relationship, it seemed important to ask whether or not the consumer felt involved in medication decision-making. Participants expressed mixed views about medical decision-making and their role in it. Several did feel involved, while others saw themselves excluded from the decision-making process. Consumers described feeling comfortable in making suggestions to their doctor, in engaging in medication negotiations and generally in trying to be proactive in their care. Yet, they also pondered whether consumers are always, particularly in times of crisis, competent to make their own rational decisions. Some felt they had to accept that they may not always be “in control.”

1. Involvement in decisions

A number of participants answered in the affirmative when asked whether their doctor involved them in decisions about medication.

- **“Yes. (Angela 13)**
- **“He involves me.” (Carl 7)**
- **“Yes.” (Tina 5)**
- **“Yes, I have an input with my GP, I do...” (Jack 10)**
- **“Well, overall in my experience with doctors, I have...” (Alex 10)**

Feeling “involved” could take different shapes. For one participant, having things explained felt satisfying.

- **“So yeah, he does involve me that way. If he wants to change my medication he tells me and why.” (Carole 9)**

In one interview, the dichotomy between following doctor’s orders on one hand, and still retaining a sense of personal agency on the other hand was reflected.

- ***(And do you think it should be that way that even psychiatric patients get to have a say as to what they are taking and what they’re not taking?)***
“No, well I can’t say that because even I have to get that – they absolutely have to or they’re going to jail or they’re going to a psych ward or they’re going to Riverview if they don’t take the medication even if it has lots of side effects.” Yet he was adamant that **“A person who is in treatment can make right decisions for themselves right...”** and when asked if the decision to take the medication was made by him or the doctor, he replied **“Nono, it’s my decision.” (Thomas 17, 15/16)**

Some participants felt they were being involved in decision-making and given options provided that the physician believed them to be able to make informed choices.

- **“I think that they see that I’m pretty balanced, that I’m also pretty self-aware that I can make an intelligent decision and I’m not going to be rash. They ask me, so what do you think? What do you want to do?” (Carl 7)**
- **“...but I’m choosing. I’m saying I’m going to go with this but I also recognize that the psychiatrists they have certain knowledge. I think I start feeling I don’t like the sound of this because I wonder about its safety long term.” (Carl 13)**
- **“...and then recently he said “You look at the side effects, you look at the benefits, you look at what these meds are doing to you, and you decide how you want to proceed.”...”So he gives me a choice.” (Louise 8)**

The physician could be seen as having the ultimate responsibility, however.

- **“They have to make the decision, the right decision.” (Tina 8)**
- **“She, I think. She is the boss and she has to decide....She’s the one she’s under control of my medication...” (Wendy 10, 2)**

One consumer recalled her decision to seek help, the psychiatrist’s role and her trust in the doctor’s expertise and how she transferred control to her doctor.

- **“...It’s up to me I guess...I was looking for a psychiatrist, it’s not the psychiatrist that is the rule of me and once that I was asking her help she is the one that has the decision to whatever she has to do with me because she has more knowledge on the patient right, because she can look at me, my behaviour and then whatever she’s knowledge. She has so many years that she can prescribe the medication.” (Wendy 17) ,**

Medication decision-making created a challenge in that participants might feel that they had some control yet ultimately needed to defer to the physician who had the last say. Consumers making decisions about their treatment could occur within a certain leeway of what the professionals might be regarding as safe or “wise.”

- **“I think if I were to make decisions they weren’t feeling okay with they would probably say you know what we don’t think that it is a wise decision so we would have to talk but it’s never gotten to that point.” (Carl 7/8)**
- **“Nono. I am not shoved around I’m not shoved around at all okay. I can make my own decisions there but I don’t think that he would go along with the decision to drop the pills and I’ve never made that decision now that I’ve got something that I’m comfortable with...” (Thomas 8)**

One participant elaborated that consumers are bringing their own experience with their psychiatric disability and past medications to the therapeutic encounter and that decisions should be collaborative.

- **“It should be a joint decision because you’ve lived through what you lived through and you know a lot about your meds, and they also know quite a bit about them as well, and they have the history. So it should be a joint process of figuring out what meds to take.” (Patty 22)**

2. Who manages the medication?

In response to the question “Who manages your medications, who is in charge?” participants’ answers also varied. Some felt that the doctor was and should definitely be in charge.

- **“Well, no it’s not up to me, I didn’t – it’s the doctor that has prescribed, another person that has suggested, it’s not me do you know what I mean?” (Jack 9)**
- **“Good God, no, I’m way beyond that...I’m not in a position to be a doctor, to make the calls.”(William 16)**

Others opined that they had – or should have – control and responsibility over their medication and were motivated by positive effects of their regimen.

- **“I am.” (Tina 23)**
- **(Up to you to manage?) Oh yeah.” (Sarah 10)**
- **“I should have complete control.” (Mark 17).**
- **“It’s up to me I guess.” (Wendy 17)**

- **“Oh no, it’s up to me. Oh absolutely, it’s up to me. If I decided I wasn’t going to take it, I mean I wouldn’t but luckily because I’m taking it there is a rational part that says ‘Remember that? Remember when you were in bed everyday?’” (Anna 14)**

Another participant explained the working relationship with her physician, who seemed respectful of her ability to manage the medication.

- **“My doctor and I have an understanding that I am pretty well educated whether or not I need the medication and also the dose...I can gauge when I need it and how much of it based on previous experience. But I would still probably consult my doctor about it.” (Angela 2,17)**

Control over medication intake was not always an issue for another participant, who saw decisions as shared within the trusted team.

- **“Well, for me, I like to have a lot of doctor’s input. And case manager’s as well. Just because both of mine are so experienced and I know they are really good. So if in their experience, someone in my situation should probably at least be taking a certain amount of meds, then I’ll go with it. I don’t need to feel like I’m in ultimate control of my meds.”...*(Is that because you have their trust?)* “I think so. And I also trust my meds as well.” (Louise 16)**

3. Consumers’ competence

Taking another angle to the issue, participants were asked whether they felt that their own competence about their health was being respected in the therapeutic relationship. Some answered in the affirmative.

- **“Oh, I think so...” (Carole 10)**
- **“Yes, she does...she knows that I am aware and health conscious and I think she takes me seriously and gives me credit for that.” (Angela 9)**
- **“He also respects me for being honest whether or not it’s my best decision at that time or whatever it was, right. I do not lie to my GP.” (Jack 10)**
- **“Yes, definitely. He recognizes that I’m the one who makes choices and decisions and who recognizes what goes on in my own life. So he’s very respectful that way.” (Louise 9)**

Yet there also was some hesitation. One consumer felt “Sometimes yes, sometimes not” (Alex 12) and other participants were also unsure whether or not their competence was being recognized (Anna 9, Patty 12).

- **“He should by now, whether or not he admits it, I don’t know.” (Sarah 8)**

One participant wondered whether she had always shown herself deserving of her physician’s respect for her decisions.

- **“I think there were times when I perhaps didn’t demonstrate that to her, so maybe that would have coloured her opinion of that. I don’t know if she did. Maybe she would say differently.” (Rhonda 11)**

4. Being proactive

Some interviewees wanted to be proactive participants in their treatment. They seemed to believe that in order to become empowered and influence the treatment process, they needed to become both knowledgeable and courageous enough to ask questions, make suggestions and generally stand up for their rights. However, to assert oneself could be difficult as “it takes a certain amount of wellness.” (Focus Group 1, 16)

One consumer stressed the importance of building a relationship with the doctor, that one needed to “be a participant in taking the medication,” (Alex 10) and that this process could be empowering for the consumer. He explained that this, however, took some effort:

- **“...my concern to have my part in that dialogue to make sure that I’m included without trying to guess what they are talking about.” (Alex 8)**
- **“I think you have to be an informed consumer. I think you need to sort of make sure they know your history and make sure they know your concerns...If you don’t ask you’re probably not going to have a chance of getting it. So I feel that I’ve worked to have a part in that.” (Alex 10)**

This participant had, for example, repeatedly skillfully negotiated to avoid treatment in hospital.

- **“...They didn’t hospitalize me or say that they were going to hospitalize me at that one time, because I have in the past in different situations talked my way out of it.”(Alex 13)**

Another participant also felt that he needed to stand up for his rights,

- **“...as people who are too passive and submissive get you know walked over.” (Thomas 5)**

One participant credited this present study with giving her new hope that there may be alternatives to how her psychiatric treatment had been progressing so far.

- **“...you’ve kind of gelled a lot for me, where I realize how conflicted I am about it and I’m going to talk to my doctor on Thursday when I see her, and see what she thinks. I mean, all psychiatrists do is prescribe...it gels for me about there are options, perhaps. I don’t know that, but I can probably search for them.” (Anna 17)**

She almost blamed herself for delayed psychiatric treatment but recognized that in severe illness it was difficult to become empowered and fight for access to appropriate mental health care.

- **“She [the GP] was not good. I have just felt like I’ve fallen through the cracks. I don’t know whether I wasn’t proactive enough myself or ...but if you’re not well, it’s really hard to go home and fight for yourself.” (Anna 15)**

This consumer was in a quandary between looking out for her own interests, trusting the physician, and being loyal as a patient. She found:

- **“how hard it is when you’re not well to be your own advocate. Because that’s the last thing you want to do, is to struggle or to confront someone...,” (Anna 16)**

which was perhaps a reason why she had previously remained with a general practitioner who had hesitated to refer her to psychiatric care and who did not seem to take her illness and her suicidal ideation seriously. At the time of the interview, this consumer shared how she also had doubts about the expertise of her young doctor at the hospital outpatient clinic, yet was reluctant to ask for a second opinion as she did not want to hurt her doctor’s feelings.

- **“I’d like the senior psychiatrist to take another look at me”...but “I feel this loyalty”... “I really like her.”...”So I just feel that would be like a slap in the face...” (Anna 6/7)**

Another participant also found that the mental illness itself could hold one back from being proactive even when the therapeutic relationship was dissatisfying:

- **(consider changing doctors?) “Well, that would be stressful, wouldn’t it. That would have me being proactive and it goes against my illness, it’s a battle...”(William 18)**

This participant reproached himself for his reluctance to actively seek help.

- **“In a way I blame myself. I’m sure if I was proactive and if I spent the effort – and this has been said by my wife – on my own illness the ways I do other things, then I would be much better.”(William 20)**

At the same time, the language used during the interviews responses points to some participants being active and taking charge in some situations. For instance, one participant spoke of “I had negotiated” a lower medication dose which “made me feel better having that role in my care.” (Alex 11), and in terms of the medication regimen “I’ve kind of initiated that” (Alex 16) and “I have that influence with her [the physician].” (Alex 9)

Participants could know their own minds when it comes to medications. For example:

- **“It’s usually me wanting to increase the medication.” (Mark 6)**
- **“I didn’t want to be on medications anymore.” (Rhonda 1).**
- **“Initially I was taking Lithium but I made a change...” (Carl 3)**
- **“I can make my own decisions...It was my decision.” (Thomas 8)**
- **“I decided I had to change many times, the meds before we got to this one.” (Tina 9)**

Several participants answered in the affirmative when asked whether they could make their own suggestions about their treatment.

- **“Yes, I can make a suggestion.” (Jack 14)**
- **“Yeah.” (Mark 8)**
- **“Anytime, yes.” (Angela 8)**
- **“Yes.” (Louise 9)**
- **“I think I could bring up my suggestions.” (Tina 14)**

Seeing the same psychiatrist for over 8 years could help forge a relationship that gave a measure of control to this consumer:

- **“I don’t have to explain things as much, if I want her to do something or try something...” (Alex 2)**

As exemplified in one case, there was a flipside to sharing in medication decision-making as it could challenge the consumer to take responsibility and make choices for which they may not have been sufficiently prepared. Offered to reduce the doses of her antidepressant after many years of stability, this consumer was feeling uncertain and hesitated to make a decision (Tina 14), as she was afraid of suffering a relapse and being hospitalized.

- **“It’s something hard to decide...Would be easier if they decided for you, gave you a guarantee.” (Tina 23)**

Struggles with partaking in medication decisions, adhering to doctor's orders, or making their own changes were connected with issues of power and control. For example, one participant criticized his fellow consumers for being too submissive:

- **“Psychiatric patients they are so insecure if they change their medication it really just frightens them to death.”(Thomas 11)**

One participant indeed stated that she was afraid to push for a change with her medication regimen even though she was not happy with how she felt. (Anna 10) Another participant was worried about losing control and what life after medication would look like.

- **“I guess I am just really uncertain of, you know, I got to control, everything is control on this side and then if I give up those medications well what's on this hand to counteract it...” (Sarah 5)**

Changing his own regimen gave this consumer a sense of empowerment:

- ***(What happened when not taking it as prescribed?)* “Nothing dramatic. I guess it kind of made me think to myself: ‘Well, maybe I’m not as tied to the meds as had been indicated by my psychiatrist and case manager.’...it just kind of made me feel a little bit better that I wasn’t so dependent on them.” (Alex 20)**

Goal-setting could produce a sense of control over the treatment process. One participant related:

- **“I started bringing up my own goals and it made me feel empowered.” (Focus Group 1, 6)**

Being given a measure of responsibility could be viewed as success.

- **“I am far along in my recovery that the team gives me some responsibility.” (Focus Group 2)**

5. Medication negotiations

Some consumers tried to navigate the parameters of their medication regimen to meet some of their direct needs. Participants engaged in negotiating processes with their physician in a number of ways. For example, some participants successfully suggested to their physician that they rather take the majority of their medications in the evening as they had experienced side effects like somnolence when taking them in the morning. Being able to make such a change was important to consumers.

- **“...She’s willing to allow me to persuade her, and I have. I have that influence with her on medication.....she’s very open to allowing me to make those decisions.” (Alex 9/10)**
- **“I don’t want to take meds in the morning anymore and he changed them. So that was good.” (Louise 14)**
- **“So I’ll ask the doctor if I can just take them at night, because I think it would be better if I took everything at night. I’m used to that, right?” (Patty 19)**

Also, reducing dosages was many participants’ concern and presented a matter for discussion in the therapeutic encounter.

- **“Yes, there’s time I would say I’d like to reduce at this point or I say I think I’m fine where I’m at.” (Carl 7)**
- **“Yes. Oh yeah. I guess because the treatment right now we’re looking at is decreasing the meds...he said ‘You choose.’” (Louise 8)**
- **“Oh yeah, I can tell him I’d like to reduce this, I can increase that, hm.” (Mark)**
- **“Usually they listen to what you’re saying. If you say I want to lower my meds, which I did say, then they do it. They pretty much do listen. They listen to what you’re saying and they do what you’re suggesting.”(Patty 11)**
- **“...But as long as I can cut down on my medication I’ll be more happy.” (Wendy 18)**
- **“If I choose, she’ll taper off.” (Tina)**
- **“I want to bargain with my doctor ...I want to try to cut down my...I want to try to take less.” (Focus Group 2, 6)**

One participant was offered to go off Seroquel, but she was content with her present regimen and did not want to jeopardize her stability. (Focus Group 1, 5)

Negotiations about medications could take courage. One participant took her mother with her for moral support when she planned to negotiate a reduction of medication. (Patty 4)

Consumers could be alert and gauge when it was an opportune time to ask for medication reduction. One participant had requested a cut of Clonazepam some time ago to which the physician consented. (Wendy 10) Now she contemplated when it would be a good time to try to negotiate another reduction. (Wendy 14)

We heard more about the desire to decrease medication doses than we did about requests for increased medication.(Mark 6) This may reflect a perception that less medications was preferable and that reducing medication intake would alleviate the occurrence of adverse effects and reduce risks.

One participant advocated a lower dosage in order to avoid severe side effects.

- **“I like the middle there okay. I want half the dosage they’re planning on using eh because I don’t want TD, the shakes and stuff like that...” (Focus Group 2, 8)**

Prescribing medications as a PRN per need basis was one way for physicians and consumers to respond to temporary deteriorations in symptoms while shifting more control over to the consumer. PRN prescriptions assumed a certain level of trust on both sides.

- **“At this point there’s the whole PRN thing where I’m feeling not ok I can take a little bit more, I can take a little bit less, but that’s been ok’d by the psychiatrist and at this point I feel ok making minor adjustments but it’s usually something that I tell the doctor about.” (Carl 12)**

In one case, there were ongoing discussions about medication intake. One participant was keen on increasing his medication dosages. He had been denied his request for an additional PRN of Clonazepam, which he considered a “magic pill” (Mark 16) for his paranoia. He said he respected his physician’s authority and concern that even more medications could turn him into “a zombie.” (Mark 5, 6, 18), yet he tried his own self-dosing until the psychiatrist intervened and he himself was concerned that after he had increased his dosage there were pills missing at the end of his blister pack. In another instance, however, he was successful. Having researched the various benefits for his condition and the maximum daily dosage of Prozac on the Internet, this participant used the leverage of this new knowledge and negotiated an increase in the antidepressant’s dosage. (Mark 9) At another occasion, the physician agreed with the participant to try out half the dosage of a nighttime medication during the day for the purpose of controlling severe anxiety. The effect was so strongly sedating that the consumer willingly abandoned this manner of trying

to alleviate symptoms. (Mark 17) In this fashion the physician was retaining some control as opposed to the consumer experimenting on his own.

Another participant fought hard to be given a prescription for Seroquel as a PRN medication for acute psychotic episodes.

- **“...we had a big fight over it, eventually he gave it to me but we had a big fight, big fight...” (Sarah 7)**

One consumer recalled:

- **“Yeah, yes, I was negotiating with her with the medication.” (Wendy 9)**

She had refused to resort to her PRN medication even though encouraged to take it by her psychiatrist. “She want to force me to take it but in one year I didn’t take it.” This consumer only decided in favour of the medication when she encountered stress-related problems when trying to go back to school. (Wendy 2, 19)

For one consumer, her antidepressant itself functioned as a PRN, available when needed. “I am given the option of altering the dose if necessary.” (Focus Group 2)

One participant recalled having negotiated with the psychiatrist about his Ativan intake, but did not always get his way. “So, it depends.” (Alex 11) He had had various experiences in negotiating with different physicians and at different stages of his treatment.

- **“...it worked out for my benefit...not only stopping the medication but for having that sort of leeway in the process. I find that much more with this particular doctor, whereas I’ve never found that in the past so much. It was black and white before.” (Alex 8)**

In another instance, the psychiatrist agreed to a reduction of Seroquel, which the consumer hoped would ameliorate her metabolism and decrease weight gain. (Louise 10)

Disagreement about medication could last for years. For example, one participant could be persistent in minimizing medication intake and argue that she had been stable for a long time.

- **“I was fighting over this little pill and that means fighting for four years.” (Focus Group 2, 4)**

Eventually, the physician consented, until the consumer faced a stressful challenge, then both sides agreed that the medication should be reintroduced. (Focus Group 2, 5)

One participant successfully negotiated with the new psychiatrist about reducing the Epival dosage and generally commented on how she had to enlighten changing doctors about which medications worked for her.

- **“Ah well, it’s never quite right, so I always have to negotiate with the doctors how the meds are going...” (Patty 17, 3)**

Fear of recurring symptoms made another participant cautious about medication changes.

- **“I’m happy with it the way it is....because I don’t want to go through that period of having a few delusions or a few hallucinations...I think Dr. XYZ wants to lower my meds...We’ll see, I’ll talk to him about it next time, see what he says.” (Louise 15)**

Not every consumer initiative gained the physician's approval. One participant argued with her psychiatrist about prescribing respite care, and his refusal to do so left her to "deal with stuff at home on my own" and feeling confirmed that she was "not on par" with the psychiatrist, and that he was not there to meet her needs (Sarah 3, 4,13)

Treatment of mental health symptoms was not necessarily pharmaceutical, according to the participants' preferences that were openly discussed and shared with the physician.

- **"My doctor actually promotes a healthy lifestyle and that's why she gave me the option of trying exercise to see if that would deal with my anxiety...I have a good relationship with her so we can negotiate whether to combat anxiety with medications." (Focus Group 2, 6,10)**
- **"My preference would be not to take medication and my doctor knows that my preference would always be to minimize medication intake." (Angela 7)**

7. In times of crisis

In severe crisis, often at the beginning of the therapeutic relationship, participants could be accepting that their decision-making capacity was severely compromised. Handing over control to the physician could be seen as necessary...

- ***(Were there times when you think you just were not competent enough yourself to make any rational decisions about what was going to happen to you?) "Oh definitely, especially at first." (Carl 14)***

...or was even legislated. Participants spoke about certification ensuing when a person with a mental illness seems to pose danger to self or others, leaving the consumer no choice about treatment. (Focus Group 1, 18) Issues of decision-making power within the therapeutic relationship, self-determination and consumer competence were considered.

- **"Well, I don't know but collaboration, it's like people, sick people, don't know that they're sick"...especially if you are manic." (Focus Group 1, 17)**
- **"...I think what you need to look at is the range of mental illnesses and the range of functionality or ability or you know whether somebody is really at a high level functioning or right at the bottom end and how in times of severe illness when somebody has a serious illness like schizophrenia or so, that person may not want medication, should they be in charge of that? At this very ill stage they can't make the decision..." (Angela 20)**
- **"So me personally I would like to have the choice of whether or not I choose to be on med, I guess, would be the short answer." ... "Do I think I should have that choice? I guess up to a point, yes. But I have to understand that there are times when people go too far off at either end and maybe that choice for your own sake has to be taken out of their hands until, they're back in the space where they can make that decision. But then are you ever really in a space where you're going to make that decision wisely? I don't know." (Rhonda 8, 18)**

Further probing revealed another participant holding a similar point of view.

- ***(So when you're talking about the bottomless pit, and you're there and you're depressed, right, you can't see the light, do you feel that in that situation the doctor has to take over and deal with the medications and so on?) "Yeah." (Tina 26)***
- ***(And only when you're better can you become more involved, is that what you're saying?) "Yeah." (Tina 26)***

Participants discussed how they could prepare themselves for a time of crisis in order to keep some control and provide for backup support. The design of a “crisis plan” to be created ahead of time and be shared with one’s support system was recommended. (Focus Group 2)

8. Feeling excluded

While medication negotiations and involvement in treatment decisions were not necessarily taken for granted, some participants were sensitive to feeling that they were altogether excluded from the decision-making process. Feeling uninvolved in decision-making could be disconcerting. For example, one participant shared that he was confused and scared when medication was suddenly increased.

- **“...I’m left out of the picture and I feel pretty dismal because my meds were upped and what did I do?...Not being involved in the process is a scary thing, because ultimately once you have been to Riverview, you have this tremendous fear of everything going wrong.”(Alex 12)**

Sometimes there seemed to be no room for negotiation or shared decision-making.

- **“I do find sometimes that I am not always included in the decision-making. Sometimes it’s between the case manager and the doctor, separate from me.” (Alex 6)**
- **“So this last time around, I felt it was very rigid. They had a plan and I didn’t necessarily agree with it and there was no room for maneuvering in that plan.” (Rhonda 18)**
- **“Well, not in the hospital. Like XYZ hospital I really hated that doctor and I just felt like he was making his own decisions and not really listening to me at all.” (Patty 10)**

Some participants thus were well aware of the occasions when their physician did or did not involve them in medication decision-making and to feel excluded could be disconcerting. Others could sound accepting of the fact that in severe circumstances they may be rendered powerless and their competency to engage in treatment decisions could be severely compromised. Being involved in the treatment process and generally being “proactive” and “empowered” was seen as desirable, but could seem very difficult to achieve when one was acutely suffering from a mental illness. Some consumers nonetheless almost tended to blame themselves for not accessing and receiving more optimal mental health care. Not uncommonly, however, participants negotiated various minor and major aspects of their medication regimen with their physician. When “bargaining” with their doctor about the prescribing and taking of psychiatric medications, they were seeking to minimize drug intake, to be able to decide themselves about taking PRN medications, to take medications at night when they would not experience such severe side effects, or to increase dosages in order to control symptoms.

Chapter 10: Trust in the physician

1. Degrees of Trust

Whether faced with confusing data about illnesses and medications and being confronted with side effects and worries about risks, whether experiencing a “hit and miss” treatment and having doubts about the benefits of their treatment, whether feeling conflicted about being on medications and finding themselves not part of the decision-making process, or whether realizing that in crisis their competency was compromised - trust was crucial to the consumer-physician encounter. When we asked “Do you trust your doctor to make the right decisions about your health?” a sense of trust seemed to prevail: in the making of medical decisions, participants tended to put their confidence into their doctor, particularly when they were starting to feel better.

- **“Oh definitely. Well, I figure the medical board ...I mean he studied to be general...and then he went on to psychiatry so I mean obviously you have to pass and he teaches at the university so he must be competent.” (Carole 9)**
- **“For the most part, yeah.”... “Yes.” (Jack 3,10)**
- **“Yes for sure.” (Angela 7)**
- **“Without a doubt, without a doubt. Yes.” (William 10)**
- **“Yeah...He’s very, very good.” (Louise 7)**
- **“Oh yeah.” (Mark 6)**
- **“I trust her. I don’t have to go back to the hospital in 10 years, now even I am a happy person.” (Wendy 8)**
- **“To a great percentage.” (Alex 10)**

As a rule participants did not challenge medical expertise. There could, however, be hesitation in always giving one’s full trust...

- **“Well, ah most of the time, okay, most of the time.” (Thomas 8)**
- **“No, I’m not sure, as much as I really like her, with that part about the medication.” (Anna 6)**
- **“I’m not a doctor so one only is able to listen to what somebody else tells you and that doesn’t necessarily mean it’s always the right thing.” (Jack 7)**

...especially when recognizing that physicians were working within a certain paradigm and did not take a lot of time in the encounter.

- **“I think I trust him to be able to take what he has learned within his field of knowledge to be able to make the best decisions and I do think that he does have my interests in mind, I do give him credit for that even though he is sometimes really rushing.” (Carl 7)**

Trust in medications prescribed did not necessarily extend to full trust being given about all aspects of mental health care:

- **“(trust your doctor with health decisions?) “My psychiatrist? In one way yes when it comes to the meds because they are the best meds I’ve been on, but in another way of communication and in another way of getting my needs met when I’m in a crisis mode or when I just need time out, or whatever – no, I don’t think he’s there.”(Sarah 4)**

As one participant pointed out, consumers often did not have sufficient data about their medication, but took them in good trust. (Rhonda 3)

Participants' willingness to explore medications and follow their doctor's suggestions seemed to increase when the therapeutic relationship was good and characterized by trust.

- **“Yeah, for sure, definitely. How you trust is huge. Trusting someone makes you far more likely to listen to their suggestions and try their ideas.” (Rhonda 20)**
- **“I felt definitely more of a connection; I'm more comfortable, more trusting, most willing to do what the latest guy that I was seeing suggested without a doubt.” (William 11)**
- **“You were told by someone who is supposed to have your best interests at heart, correct? Now what if the patient supposed to do...could he decline or are they supposed to be trusting and willing...I am a little trusting and willing, a little more willing than trusting...”...“Yes, that's only because if I had another doctor told me to take any kind of medication – no – I wouldn't do it because there is no trust there.” (Jack 7)**

Trust in the doctor created trust in medication and vice versa.

- ***(So you trust the professionals and the medications together?)* “Exactly.” (Louise 16)**

Trusting did not necessarily come easy. Participants could remain skeptical about the physician's knowledge as much as they really wanted to trust and were aware of the limits of their own expertise.

- **“...I'm not in a position to be a doctor to make the calls. Realistically I need to follow a professional but then again I need to feel that there is some kind of trust too and belief that he knows at least as much as I do.” (William 17)**
- **“...I want to trust that they know. I realize they don't. [My psychiatrist] doesn't even pretend to, in a way. She doesn't pretend to know that this combination will do the trick...They have a guess.” (Anna 12)**

Clients wanted to trust their doctor, especially when they were reaching out in crisis.

- **“I did at first because I was so desperate, and it did help gradually.” (Rhonda 9)**
- **“Yeah, well I trusted him because I think to this day that he's one of the most talented people or aware people that I've ever seen and I was in crisis so you tend to, when I am at a certain point – reach out. And inherently in reaching out I guess there is a certain amount of trust expressed just in reaching out.” (William 10)**

2. What builds trust?

The development of trust in the therapeutic relationship was facilitated by various factors, such as the consumer's belief that the physician was competent and wanted to provide good care, a general confidence in the medical system and an experience that trust in the relationship was mutual.

- **“I guess she has my best interest.” (Tina 24)**

Another participant was impressed and reassured by the fact that her team psychiatrist had taken his time at the intake interview, reviewing all family and medical history. (Carole 5, 6) Feeling that her physician had enough time to address all care issues affirmed her trust.

- **“I feel more confident that he's more interested and the thing is he has the time.” (Carole 6)**

The physician's education served to elicit automatic confidence for some interviewees.

- **"Definitely the doctor. I don't have the expertise, he's got the medical degree." (Carole 16)**
- **"...I also recognize that the psychiatrists they have certain knowledge....(Carl 13)**

The physician's treatment of other health concerns also helped build trust. Trust in mental health care could be influenced by good experiences with the medical system as a whole.

- **"I just always had a really good experience with medical...my faith is in the medical experience." (Carole 9)**
- **"He's got a lot done for me (like laser surgery)." (Jack 3)**

Upon being asked what would make her more trusting in the relationship, a participant pondered:

- **"Um, just more of a sharing attitude. Or what different meds are available and what they all do and doing a medication review...it would be nice if they asked you more about your life." (Patty 11)**

And it helped to build mutual trust when the physician also demonstrated confidence in the consumer not abusing their medications.

- **"He just issued me a script for a year...Yes, five months ago, so that's the relationship that I have with my doctor, you know, it's a trusting relationship." (Jack 6)**

As one participant stated, there needed to be trust from both sides of the therapeutic relationship.

- **"Well, it's mutual, it's interdependent." (Alex 23)**

Mutual trust characterized also another relationship, where the physician was offering different treatment options and could be sure that the consumer would not make any rash decisions but rather check back with her doctor. (Focus Group 2, 6)

3. What makes consumers lose trust?

Sometimes a client could "lose faith" in the doctor or in the medication, especially when experiencing many side effects or their health not seeming to improve.

- **"I've lost faith in my psychiatrist, just my situation not improving and lots of side effects and very difficult to get through my day and I just go and see them..." (Alex 8)**
- **"And I felt like she just nailed a lot of things on the head that gave me kind of trust and respect for her in the beginning and then I guess I lost faith in the meds because it wasn't ... it was helping but it was kind of flatlining. You know, and I just didn't really like that..." (Rhonda 20).**

One participant recalls his childhood experiences in the psychiatric hospital and how it shaped his views:

- **"Then after that I trusted no one and basically respect no one. Because when the trust wasn't there there was basically no respect, you know, and then things went downhill from there..." (Jack 5)**

General doubts about psychiatric prescription practices could prevail.

- **“Nonono, they are wrong, because you know there’s lots of people out there in that waiting room who are going to get the wrong medication from them. I’m sure of it.” (Thomas 15)**

Another consumer seemed to have experienced a certain loss of trust when her physician told her “one day you will not have to take any medication and you will feel fine,” after having told her daughter just the contrary. This participant suspected “She is lying to me.” (Focus Group 2, 4/10)

In summary, participants showed a clear need and willingness to trust their doctor on an interpersonal level and with respect to competency and care. Specifically, participants wanted to believe that the right medications were prescribed, that they were being helped, and that their physician had the expert medical knowledge, training and authority to do so. Willingness to be subjected to treatment was often based on trust in the physician, and trust was intertwined with respect. Some experiences in the therapeutic relationship were more conducive to creating trust, while other episodes such as poor health or troubling side effects could lead consumers to “lose faith.”

Chapter 11: Consumer-Physician Partnership?

Within the scope of the interviews and the group discussions, participants did not overtly state demands for more “shared decision-making” or more “partnership” with their physician. Still, when we asked whether or not participants felt like an “equal partner” with their doctor, answers reflected a range of finely differentiated views and experiences.

1. In the beginning

In the beginning of the therapeutic relationship, when they could find themselves in severe crisis, participants often felt powerless, excluded from decision-making, deprived from choices, and almost forced to accept psychiatric medications and treatment.

- **“In the beginning, it was talk down. I was almost told you have to take it. I can’t remember because I was quite out of it, so that’s my impression anyway - that I have to take it, to get out of this mess.” (Tina 12)**
- **“Back in the beginning, I didn’t feel like an equal partner just because I felt like I was having meds forced upon me.” (Louise 7)**
- **“Initially there wasn’t really dialogue between us.” (Rhonda 9)**
- **“At first, yeah (*saying you need to take this medication?*) but then I couldn’t even think, at first pretty much it was you have to go on the meds there was no choice.” (Carl 12)**
- **“At the beginning there wasn’t that [mutual respect], I didn’t trust him, I didn’t like him...” (Louise 4/5)**

2. Equal partners

Some participants considered themselves as “equal” with their doctor who involved them in decision-making. Partnership could manifest itself in the physician being “democratic” and inviting the client to have a say in their care.

- **“Yes, equal with her. With Dr. XYZ it’s top down, but not with her...She’s democratic and I like that about her.” (Anna 8)**
- **“Yes, for sure.” (Angela 5)**
- **“At times I have...” (Alex 10)**
- **“Now I feel much more like an equal partner. We discuss the medications and it’s like a partnership.” (Louise 7)**
- **“I think that they see that I’m pretty balanced, that I’m also pretty self-aware that I can make an intelligent decision and I’m not going to be rash. They ask me, so what do you think? What do you want to do?” (Carl 7)**
- **“Following the regimen, yes, until ‘we’ decide otherwise. It’s not him, it’s ‘we’. It’s not my doctor period. It’s ‘we’.” (Jack 10)**
- **“I was feeling anxious...and I saw my doctor and she said well do you want to go back on meds and I did ...I have a really good relationship with her so we can negotiate.” (Focus Group 2)**
- **“Support lots of support will make you feel like an equal partner for sure...”(Focus Group 2, 12)**

3. Not “on par”

In what might be considered as a ‘best case scenario,’ physician and consumer were engaged in a therapeutic relationship that was founded on mutual trust and respect and formed the basis for

unison decisions. Other times, however, participants felt that they were not “on par” but rather were at a disadvantage in the therapeutic encounter where the physician was “up there” and they were “down here.” One consumer described her experience with the power asymmetry:

- **“Like when I was in the hospital. Dr. XYZ it felt like he was this god above me making all the decisions, but I just got really frustrated and I said I want a new psychiatrist...because I couldn’t stand the way he was up there and I was down here.” (Patty 8)**
- ***(Feel like equal partner?)* “No not Dr. XYZ. He really thinks like he knows all the answers. Like if you try to talk to him about what you’re thinking or feeling, he just brushes you off.” (Patty 8)**

Another participant also described a situation where there was a clear hierarchy with the physician talking down to her and decisions being made by the physician:

- **“I’m not like, he’s up here and I’m down here, on an equal...” (Sarah 8/9)**
- ***(You find it’s like a hierarchy?)* “Yes I think so, yeah. My nurse isn’t but he is, yes.” (Sarah 9)**
- **“No, I’m not on par with it.” (Sarah 12/13)**

This consumer had also described poor communication with her physician in addition to an unequal relationship. Asked how that made her feel, she admitted. “Not good, not good.” (Sarah 9)

Another participant recalled her physician’s initial attitude of superiority.

- **“It used to be very standoffish, at the beginning, when I was first treated by him. But after I got out of Riverview it all changed.” (Louise 5)**

Participants recognized a power imbalance between them and their doctor, which they may have interpreted as being created by the difference of medical expertise. However, physicians were respected for their specialized knowledge and it was often accepted that they took charge.

- **“I don’t have any knowledge about medicine, so I guess I depend on her, her knowledge. A lot.” (Tina 11)**
- **“Well he has the advantage that he’s educated, I really don’t think I’m on an equal basis, no I don’t feel equal. His education...” (Carole 9)**
- **“They seem like they are more in charge of it, though, like they seem to know more about it.” (Patty 12)**
- **“When I was at the psychiatrist, she was obviously a lot more informed than I was because that’s her job and she knew, and so there wasn’t really, initially there wasn’t really dialogue between us of my options. No, no it was more like she was the one in charge and she knew what I needed and she would prescribe me...” (Rhonda 9)**
- **‘He’s got knowledge that I don’t have, some understanding that I don’t have, and I respect that.’ (Carl 7)**
- **“...I respect him as a doctor, and I respect his opinion, and his suggestions, the info he gives me...” (Louise 4)**

One participant felt that she did not have the doctor’s expertise but also was not motivated to try to catch up on this knowledge.

- **“To me it’s, there is no equal partnership...I mean you can go on the Internet and I mean and read all you want but I’m not interested.” (Focus Group 1, 15)**

In one participant's view, a doctor's expertise was seen as possibly more important than an equal partnership.

- **“There is something to be said for the top down. I don't want someone telling me what to do, but I sure like when someone's sure. I can really appreciate it.” (Anna 8)**

Talking in the group, some participants found that “equal partnership” was maybe not a realistic expectation: as physicians were specially trained, there was always going to be an imbalance of knowledge and education. Rather, consumers may not need the same information, but just good information in order to make decisions. With informed consent and a session where the right questions were asked by both physician and consumer, a form of partnership could still be created. (Focus Group 1, 14)

4. Communication and listening

Communication between consumers and their physician was considered an important component of the therapeutic relationship and sometimes seen in need of improvement. Consumers took note if their health professionals seemed to be listening to them.

One participant found the interaction to be very satisfying (Wendy 6) and another consumer voiced his impression that compared to earlier times there was now more “dialogue” in the relationship with the team. (Alex 5) Good, satisfying communication was considered as also depending on participants feeling understood in terms of the life situation they experienced.

Some participants felt that their physician had a good understanding of their situation. (Jack 3/4)

- **“Oh yeah, he knows. I tell him in great detail and he totally understands.”(Mark 4)**
- **“On a one-to-one basis, yes.” (Alex 7)**
- **“She knows me very well.” (Wendy 7)**
- **“Yes, definitely. He helped me out in a lot of ways.” (Louise 6)**
- **“Of yeah, he's always asking me is there anything else we can do for you.” (Carole 5)**

Interpersonal interaction did, however, not always guarantee that decision-making was shared.

- **(*Good communication?*) “Yes, but I do find sometimes that I'm not always included in decision-making.”(Alex 6)**

Overall, participants maintained that they were listened to by their physician or counselor, and that communication was good.

- **“Oh yeah oh yeah – he's the most positive person in the world – he's just phenomenal.” (Mark 2)**
- **“Yeah, they do, they listen to what you're saying about what the drugs are doing to your body.”(Patty 13)**
- **“Very good communication.” (Wendy 6)**
- **“Absolutely.” (William 6)**
- **“Yeah, he hears them.” (Thomas 4)**
- **“Yes...” (Alex 7)**
- **“I think he respects me and he listens, he is a good listener.” (Carl 5)**
- **“Yeah, I think he listens actively (Rhonda 6)**
- **“So I guess she listened to me in that respect of how I was feeling.” (Rhonda 12)**
- **“The new one, she seems okay. She listens. It seems like she listens pretty good.” (Patty 5)**

Listening was seen as important, even if the relationship otherwise did not seem satisfactory.

- **“It wasn’t that bad. Like he would listen to what you said, but he was hard to understand. Like he didn’t really have any practical suggestions to, you know, make my life better.” (Patty 8)**

Communication between client and the team was not always satisfying, though it could improve over time. One participant had experienced a lack of reciprocity in the therapeutic encounter in the past.

- **“But I found my doctors and case managers very hesitant in talking about the diagnosis and the symptoms and the medications and their effects, and I think it’s changed somewhat in the past 4 or 5 years. I see a change where it’s more open to discussion rather than just saying the problem and then nodding and going away and then making a decision and coming back. There is more of a dialogue.” (Alex 5)**

Another participant described a breakdown in communication with her psychiatrist:

- **“And then with all the arguments we have I don’t even want to talk to him actually...it’s just like, okay sign the meds for another three months, you know.” (Sarah 9)**
- ***(Is it like a prescription sheet relationship?)* “That’s it, yes. That’s it yup.” (Sarah 9)**
- **“With my psychiatrist I think it’s just communication again, listening to me and actually hearing, instead of just assuming.” (Sarah 12)**
- **“Sometimes it can be rocky, can be really rocky.” ... “...him and I just don’t see eye to eye sometimes ...” (Sarah 3)**
- **“Oh, I do but he doesn’t listen, I don’t think.” (Sarah 8)**

5. Treated with respect

Many participants stated they felt treated with respect by their physician or counselor. Participants described respect as manifesting itself in behaviour such as nonjudgmental listening, encouraging the consumer to talk, having regard for their opinions and experiences, or explaining medications without seeming to “talk down” to the client.

- **“I think he does listen to me. He has respect for my tenacity and what I’m trying to do and the progress that I’ve made.” (Rhonda 8)**
- **“Oh yeah, he lets you talk, he lets you say whatever you want and he won’t judge you.” (Mark)**
- **“I do feel he does listen and he respects my opinion...”...“I don’t think that either my doctor or my therapist are talking down to me that way.” (Carl 8, 5)**
- **“He respects me for being honest.” (Jack)**
- ***(Do you feel treated with respect?)* “Yes, I do.” (Anna 6)**
- **“I think so...sometimes.” (Sarah 4)**
- **“Yes, yes.” (William 7)**
- **“He respects me as a client...” ...“He doesn’t baby me. He doesn’t talk down to me. Like he’s a very intelligent man and he’ll just come right out and say things, he doesn’t try to dumb it down or anything...So that makes me feel good.” (Louise 4,6)**
- **“It’s a two-way kind of engagement with him. He doesn’t just tell you, you know. So I think that he has respect for that.” (Rhonda 8)**

- **“I talk more...I talk more about how I feel and things that are relevant to me. And I feel a lot more comfortable in getting...well, I’ve always found comfortable in feedback, but getting direction more comfortable with getting direction.” (Alex 7)**

Respect also meant to be treated like a person, not just a patient, which could be part of the therapeutic relationship developing over time.

- **“It’s good to have a psychiatrist who actually cares, who is not just there to listen about medication but to actually talk to you and not to treat you like a patient, he treats you like a person.” (Mark 19)**
- **“I don’t think he’s patronizing me, I think he treats me as a person...” (Thomas 5)**
- **“No, as a whole person.” (Wendy 8)**

One participant stated:

- **“I think he respect me and listens...” yet still feels treated like “A patient.” (Carl 5)**

Another participant also was not satisfied.

- **“(feeling respected) Umm, I guess so, I guess they do. I don’t know. I’m not sure...I think they are treating me more as a patient because if they were treating me as a whole person they would have more group therapies...” (Patty 7)**

Respectfulness for the consumer could be perceived as having grown over time.

- **“I’m sure at the beginning I felt like a patient. And now, a little bit more like a person.” (Tina 7)**

It helped when the therapeutic relationship had already lasted many years and mutual rapport had been built.

- **“My GP takes me seriously, I do research but then she’ll also study it. I’ve had the same GP for 17 years.” (Focus Group 2)**

As one participant related, a lack of respect and due consideration by the physician could also be experienced. For example, when a student came to sit in at the visit with the psychiatrist, this consumer felt “objectified” as they were talking “as if I wasn’t there.” (Focus Group 1, 8)

Other consumers concluded that persons with a mental illness were simply not fully respected. “They assume you’re neurotic, so it’s easy to discount you.” (Focus Group 1)

6. Openness and honesty

When asked, some participants felt that “openness and honesty” indeed characterized the relationship with their physician.

- **“I’ve been telling him the truth because it’s kind of stupid to sit around for 30 years and tell lies to your psychiatrist.” ...”No I’m not holding anything back from him, no I don’t hold anything back...”(Thomas 5,6)**
- **“Yes, definitely.” (Louise 6)**
- **“Yes. And I’ve told them that I try to tell them, like when I was drinking and things like that, I say ‘as much as I can tell you...’” (Alex 7)**
- **“Oh definitely yeah he knows...” (Carole 6)**

Some consumers, however, stated that they themselves were holding back at times as they were unsure how their opinions would be received.

- **“More closed. Yeah.” (Patty 7)**
- **(would like a senior psychiatrist’s opinion but does not dare to say so) “So I guess it’s not open that way. I hold back.” (Anna 6)**
- **“With my psychiatrist, no...limited openness and limited honesty within its own range. I don’t think he’s being dishonest or not open...I have some views which are somewhat critical and also some views that I know he would really discount, so it makes me not really want to touch on it so is that being honest or how open is that?” (Carl 5)**

One participant hesitated to feel certain whether honesty in the relationship was mutual.

- **“I think so. At least I am.” (Tina 8)**

7. Individual responsibility in the relationship

One participant emphasized that consumers had to accept responsibility for their own life and at the same time needed to work towards building a relationship with their mental health professionals who could also reflect back when they were making progress.

- **“...I think it should be up to the individual. I’m not militant about it, I’m not saying people should stop taking their meds or I should stop taking my meds. But the ultimate consequence and responsibility over your own life is your own, but the reality of life is that we need to be in partnership with professionals sometimes. When you have a mental illness, that’s the reality of mental illness, there needs to be a partnership. Even if you’re not taking medication, I think there needs to be someone to talk to and make sure yourself, for your own reasons, that you’re doing good...because that generates health.” (Alex 20)**

Making an effort to form a good relationship with one’s psychiatrist and developing trust was deemed important.

- **“...always listening to your psychiatrist’s directions, trust in your psychiatrist and form a good relationship...”(Wendy 20)**
- **“The biggest part of seeing a psychiatrist is building the relationship.” (Alex 10)**
- **“I think what I valued from my time with the psychiatrist I had was that we did establish a relationship.”(Rhonda 3)**

The relationship with the physician was compared to other professional relationships:

- **“...the relationship isn’t so different than any other type of professional relationship. Like you go to your lawyer, you expect someone to be forthright and to be honest and to be sincere and to be nurturing and to be caring. It’s no different...”(Alex 22)**

8. Positive on the relationship

Upon being asked to generally describe their relationship with their physician, several participants were very satisfied, some even claiming that they had formed a kind of friendship.

- **“Good working relationship.” (Alex 6)**

- **“It’s okay.”... “Yes, I manage well. She’s not pushy or bossy or anything.” (Tina 5, 25)**
- **“Excellent.” (Jack 3)**
- **“I consider him a friend.” Yet also “It’s usually a business meeting.” (Thomas 3,6)**
- **“A very trusting and a very honest relationship.” (Angela 4)**
- **“I’m really impressed with Dr. XYZ...yeah, the doctor I have now I’m very happy with...with both doctors I had.” (Carole 4)**
- **“So I have a really good rapport with him and you know he really cares...” (Focus Group 1, 5)**
- **“Our relationship is pretty nice...But I see her everyday walking because she is at the team and we say “hi”, she’s very friendly and we are like friends you know.” (Wendy 5, 2)**

One participant credited the team and the quality of the relationship with helping to get over alcohol and smoking issues.

- **“In part that was their help, that they were there because we had that relationship...” (Alex 11/12)**

9. Crisis in the therapeutic relationship

In some interviews, participants were asked whether they had ever experienced a real crisis in their relationship with their physician. Participants responded that they rarely experienced an overt confrontation, perhaps as they chose not to take up an issue. Yet, dispute did occur and some participants had been outspoken about how they had not been in agreement with the treatment.

- **“No.” (Tina 8)**
- **“Not really, there has been potential for it but I chose not to butt heads.” (Carl 5)**
- **“Well, no, because like hey I know when to suck up, okay, and when to fold and that’s how I managed to avoid the maximum treatment.” But then this participant recalled having had a “really big beef” with his psychiatrist about him being prescribed a high dosis of a new medication.(Thomas 6)**
- **“Well, he’s really pigheaded, I’m really pigheaded and we just don’t see eye to eye...and then he started raising his voice and I started raising my voice and then he says “well, you’re just using the system...” (Sarah 4)**
- **“Definitely, when I was not taking my meds, hallucinating, delusional, and everything, manic. He said ‘Take these meds’ and I said ‘No, I want to go the non-medication route.’” (Louise 6)**
- **“With my psychiatrist before, I basically told her I felt she was a drug pusher and don’t appreciate it. So we kind of we probably...I don’t know, I think she got frustrated, we both got frustrated with each other.” (Rhonda 7)**

10. Changing physicians

In certain circumstances, when the consumer felt too much at odds with their physician, they contemplated and sometimes followed through with a change of physician, though access to psychiatric specialists and even GPs was experienced as increasingly problematic. (Focus Group 2) For example, at least 3 out of 15 study participants had at one point discontinued seeing their team physician and sought help elsewhere.

One participant left the team with a lot of frustration.

- **“I went to the XYZ Mental Health and the psychiatrist there was just a, excuse my language, an asshole basically.” (Mark 1)**

Care received could be considered very critically and prompt a change of caregivers.

- **“...it seemed like they did not know what they were talking about...It seemed to me like they were rookies. They just didn’t grasp like the whole mental illness factor so my mom was cool enough to send me to a private psychiatrist so I have quit the team and I have been seeing my psychiatrist now for about three or four years and it’s been the best thing I’ve done because my psychiatrist is really really cool.” (Focus Group 2, 3)**

Another consumer made a choice when feeling frustrated after seeing the team psychiatrist for three years.

- **“He wasn’t very good. He didn’t really help me.” (Patty 2)**

She changed to a team in a different municipality for a while, then came back to the same team for practical reasons but now saw a different physician. (Patty 2)

In another instance, the team’s care discontinued when the participant decided to go off her medication. This participant indicated that it may have been her family’s anti-medication attitude that influenced her in her decision.

- **“...my boyfriend never liked me being on Seroquel” ... “my family didn’t want me to [go back on medications] because they didn’t believe in it.” ...”I felt I had to hide it.” (Rhonda 5, 7,13)**

In reviewing her decision in the interview, she became very emotional.

- **“But I don’t know, maybe in retrospect I was wrong and maybe she [the team psychiatrist] was right, it’s hard to say, right.”...”maybe I should have listened to her and she knew better and I am sad that our relationship ended kind of badly.” (Rhonda 9, 10)**

This participant later had second thoughts about ending the therapeutic relationship, especially when she experienced another episode and found herself kind of helpless and without professional care.

- **“I was without any kind of anything for a while and I really fucked up badly...I was so close to going back on medication, because I was absolutely desperate and I didn’t know what else to do.” (Rhonda 4, 7)**

Other participants were, in different ways, hesitant to take charge of their treatment by making changes in care providers.

- **“(considered changing doctors?) Well, that would be stressful, wouldn’t it. That would have me being proactive and it goes against my illness, it’s a battle...” (William 18)**

In one case, changing from the team to another psychiatrist was contemplated, then reconsidered.

- **“...then I realized that I was in so much of a better situation with the public aspect of medical services because he would put me on very high dosages of medication.” (Alex 6)**

Starting with a new caregiver could be seen as too daunting even when the relationship with the current physician was experienced as dissatisfying.

- **“If I start over again I’ll have to tell my story all over again...(Focus Group 2, 7)**
- **(Have you tried to change psychiatrists?) “No, I don’t want to do that, no, I would have to start all over again and I don’t think I’m well enough to do that. It’s harsh to come into a new team, and a new psychiatrist, a new this a new that, and I know that there’s a complaint process that one can do to get...”(Sarah 11)**

Therefore, this participant made a deliberate choice to stay with the present team in order to retain a continuity of care and the services of her case manager.

- **“Well I think the way my needs are being met, not probably by the psychiatrist but by the nurse, only because I can be proactive...I mean it just depends on where you’re at. (Sarah 12)**

Awareness of the difficulty in accessing other psychiatric care seemed at least to play part of her decision.

- **“Well, psychiatrists aren’t that available either...when you’re in the real world without the team it’s up to a year or two years before you can see a psychiatrist and then they won’t take you on anyways so there is no point in going that route...”(Sarah 11)**

Group participants also realized that it could be hard to leave a therapeutic relationship and that it took time to establish a trusting relationship. (Focus Group 1)

11. “Magic Wand”

In the interviews, participants were given a virtual “magic wand” and invited to affect what they most wanted to change in their relationship with their physician. Some were content with the present state of affairs, while others revealed a spectrum of ideas for improvement.

Some participants desired no changes to the therapeutic relationship.

- **“Excellent...It’s fine the way it is, no need to change anything.” (Jack 12)**
- **“No, it’s pretty good. If the magic wand was doing on me, it would be no medication.” (Tina 15)**
- **“I don’t see anything I am not happy about my psychiatrist.” (Wendy 11)**

For one participant access to effective, trustworthy mental health care was paramount.

- **“...What I wished for today would be some contact with a professional that I felt was beneficial to me.” (William 18)**

One consumer's experience at Riverview hospital had been so positive, that her main concern now was how she could access this care again if faced by another crisis:

- **“... how would I be able to get back directly, if I were to get sick again, from the team directly back to Riverview...to skip out the XYZ step that I found so useless both times.” (Louise 10)**

Better communication, i.e. more of a mutual exchange rather than a one-sided interview, was also identified.

- **“More conversational rather than me speaking and having it acknowledged or a few words spoken. An interaction back and forth with the case manager and the psychiatrist. More of a conversation.” (Alex 14)**
- **“Communication.”(less of a hierarchy where)“he’s up there and I’m down here.” (Sarah 8/9)**

One participant would have actually liked to change the whole medical system’s paradigm and rather promote a more preventative, holistic approach to health care as opposed to the present “allopathy.” (Carl 8)

Another consumer wished that the relationship with the team psychiatrist had not “just been about medications,” (Rhonda 12) which ultimately had let her to reject all psychotropic drugs and thus lost access to psychiatric care.

More staff continuity and availability in order to establish trust and to provide accessibility to care were desired by other participants, (Angela 10, Carole 11) as was a reduction of medication, more life skill discussions and the provision of more easily accessible information. (Patty 13)

Another participant wished she could be more honest with her psychiatrist, more open about her critical views on the treatment.

- **“I’d like to be able to say to her “this isn’t working, we have to do something.” And every week I go in and I’m going to say that and I don’t say it.” (Anna 10)**

One participant wanted more medication and in higher dosages in order to control symptoms.

- **“I’d probably increase everything if I had the magic wand.” (Mark 9)**

Consumers and their mental health professionals were challenged to forge satisfying therapeutic relationships, characterized by mutual openness, honesty, and good communication, where consumers felt respected and listened to. Some were apparently completely satisfied with the nature of their relationship with their physician, while others had varied ideas about how they could find greater satisfaction in the therapeutic relationship and improve their lives.

Some consumers saw themselves treated like “equal partners,” while for others feeling “on par” could remain a somewhat idealized concept as they were always faced by an asymmetry of power and knowledge in the relationship with their physician. In some cases, the physician’s attitude could be perceived as more “top down”, especially in the beginning of the treatment, though it could then improve over time. In some instances, disagreement about treatment could lead to crisis situations, though participants could also deliberately choose to not openly express their dissatisfaction and avoid overt conflict. Changing one’s physician or completely disengaging from psychiatric care was sometimes contemplated and not necessarily actually done lightheartedly, as finding a new caregiver could be recognized as a problematic and daunting process.

Chapter 12: Adherence, Fear and Lack of Options

Participants described a range of negative emotions associated with taking psychiatric medications, including worry about their health worsening, apprehension of adverse effects and risks, fear of hospitalization, and concern about drug dependency. Therefore, the question arose whether they still took their medications as prescribed by their physician. We learned that the temptation to make unilateral decisions about their medication could be strong. Yet, behaviour around medication management was marked by fear of the consequences of not being adherent, thus leaving some consumers feeling like they were “stuck,” like they had no real options but to follow the prescribed regimen.

1. Being adherent

In the interviews, we raised the questions whether participants were always taking their medications “as prescribed” and if they had ever “experimented” with their medications as many patients with a chronic illness do, i.e. taken less or more than what was prescribed. All interviewees currently seen by a physician and being prescribed psychiatric medication stated – some adamantly – that they were now adherent to their medication regimen (i.e. 13 out of 15 participants were on medications; one participant was no longer on medication; another respondent self-administered her medication and was at present not taking it).

- **“I always took it, no questions asked, I always took it.” (Mark 15)**
- **“Yes, I did, just the right amount.” (Wendy 14)**
- **“At this point I am complaint.” ...“Yes, ...Pretty much, all those 13 years now I have taken what they said...” ...“99.9% of the time I have taken the meds as agreed with the doctor.” (Carl 13, 11, 12)**
- **[since going cold turkey] “I’ve pretty much taken them all the time.” (Patty 17).**
- **“For the most part I would try to follow it exactly as it was prescribed...I would always try to take it as it was prescribed.” (Rhonda 15)**
- **“I’ve never stopped taking them. I would not stop taking them, my meds, ever no...” (Carole 2)**
- One consumer stated that he was taking his medication, but not at the assigned time in order to **“have a life.” (Thomas 13)**
- **(Experiment?) “Never tried and wouldn’t contemplate it.” ...“I may have forgotten once or twice.” (Tina 20, 19)**
- **“Today I would absolutely agree ...“As per the recommended dosage or frequency. Yes unless if I don’t take it there’s a reason...”(self-medication with street drugs and alcohol)(William 3,14)**
- **(Experiment?) “I don’t do that.” (Louise 13)**
- One participant was less certain. She responded with **“Hmm, hmm ...Yes”.** (Sarah 6) but later was firm. **(Experiment?) “No.” (Sarah 12)**
- **(Experiment?) “No.” (Anna 12)**

Several participants declared that they were not tempted to make unilateral changes:

- **“No...I don’t want to take more. And I haven’t experimented with taking less, because it’s one capsule...I never tried. No, because I have the choice to taper down, so I don’t need to do it on my own.” (Tina 22, 23)**
- **“I won’t do it any more...It was just because I was young.”(Wendy 17)**
- **“No, I do now, but the first episode that I had, after what I didn’t care what the doctor said, I could do whatever I wanted to.” (Louise13) (Experimenting?) “No, I’m happy with it the way it is.” (Louise 15)**
- **“I don’t know if you can overdose on these meds or get high or whatever ‘cause I’ve never been interested in that.” (Carole 10)**

- **“I would never stop...I wouldn't think of stopping.”... “No no, I think I may have in the past but very slightly I'm not that type of person. Rarely would I make my own decisions.”(William 9, 16)**

One participant had the advice for fellow consumer to watch their impulse to abruptly stop taking their medications. (Rhonda 19) and another interviewee similarly recommended “To be compliant and get through the worst part.” (Tina 25)

One participant was firm that he would never go off his regimen, but rather would want more medications, (Mark 9) while another consumer was basically adherent, but allowed himself some liberties with self-dosing.

- **“Oh no, I am really comfortable okay, where I am and it's really been positive to my life.”...“I take more in a crisis.” (Thomas 14)**

A participant who had had experiences with stopping drug intake all of a sudden (going “cold turkey”) as well as overdosing, vigorously negated any plans to do so now or in the future:

- **“No, well at one point I used to OD [overdose] a lot on meds, I don't do that anymore.” (Sarah 10)**
- **“No, I wouldn't want to experiment with that, no no, I wouldn't want to do that...too dangerous, I've cold-turkeyed a couple of times before and it wasn't nice.” (Sarah 13)**

One consumer specified her own definition of “taking medications as prescribed.”

- **“Oh, yeah, well sometimes I haven't taken them at all. If it's like an add on, like 'here, take more of this.' Sometimes I just don't want to do it. But I would never take them any other way than it's been suggested.” (Anna 12)**

Most participants also maintained that following their medication regimen in itself did not pose any significant problems and were aware that a firm routine was important. Most had their own system, utilizing the pharmacy's blister pack or their own dispensing containers for more complicated regimens.

2. Feeling pressured into taking medications?

Being adherent may not be a matter of free choice. Some participants described various scenarios with taking medication under duress. They had felt coerced, especially “in the beginning” of their severe illness, but felt they had to trust their physician in order to get better.

- **“Because there have been people who have pressured me to take medication and I haven't.”(Alex 17)**
- **“I can't remember in the beginning I was almost told you have to take it...that I have to take it to get out of this mess.” Yet she later qualified “I don't think she pressured so much as she emphasized that this will help you get better and everything.” (Tina 9, 20)**
- **“Oh well yes, everyone of us do okay, but hey that's okay.” (Thomas 14)**
- **“I felt like there was this ultimatum at the end, when I said I didn't want to be on it anymore.” (Nicola)**
- **“Yeah I have. Yeah I have. But we have to trust sometimes, I'm not sure when.” (Anna 12)**
- **“Back in the beginning, I didn't feel like an equal partner just because I felt I was having meds forced upon me.” (Louise 7)**

- **“No, the only time I was pressured was in the States, if I didn’t take them then I would end up back in jail.” (Carole 15)**

One consumer experienced coercion in hospital, where the physician made the granting of a weekend pass dependent upon her taking a particular medication. (Patty 13) Another participant had gone through a phase where she refused to give in to pressure until she herself thought she could benefit from the medication when encountering problems. Consequently, her psychiatrist impressed upon her a warning not to stop any medication without checking with her first. (Wendy 19)

Some participants apparently experienced no external pressure.

- **“Never, never.” (Mark)**
- **“No.” (except some social pressure from wife) (William 15)**
- **“No no, I don’t feel that they’re trying to.” (Alex 16)**
- **“Nono.” (Angela 15)**

3. Experimenting with medications/Going “cold turkey”

Despite their assurances of being adherent, many participants admitted to having made unilateral changes in the past. Reasons for stopping to take their medication or rejecting all or part of the regimen could be varied and it could happen deliberately or on impulse: one strong motivator for altering their own medication dosage was in response to concerns about risks and the experience of unwanted side effects. Moreover, consumers could reject their particular regimen outright, they could feel better and not see the need for the medication, or they simply wanted to find out what it would be like to live without being medicated. Experimenting in almost all cases took the form of minimizing intake of taking none at all, and only rarely consisted of taking more or overdosing.

- **“I wanted to stop taking it, I wanted to try it without medication, I wanted to try life without medication...I would see how it would feel.” (Jack 9)**
- **“I was feeling pretty good.” (William 16)**
- **“I stopped Seroquel on my own accord.”...“I didn’t want to be on medication anymore.” (Rhonda 14, 1)**
- **[Cold turkeying it due to “horrible meds”] “I think it was...I just not being in the right frame of mind.” (Sarah 5 & 13)**
- **“So I kept thinking that I’d get really bad side effects ...So in the end I went off my meds, thinking that maybe I wouldn’t need them any more.” ...“The stupid side effects, like feeling strange in my body, not thinking straight...” (Louise 1, 15)**
- **(has not picked up prescription from pharmacy after looking it up on Internet and thinking) “I’m never taking that.” (Anna 15)**
- **“Yes, and those side effects may have been the thing that made me make a decision as to I’m not taking them any longer which I did when I was younger.” (William 13)**
- **“No, well that’s why I didn’t take Lithium for a long time. Not only was it the stigma of the Lithium, but all of the side effects.” (Anna 8)**

These consumers admitted having made unilateral regimen modifications more often in the earlier stages of their treatment or when they were younger. Perhaps, after many years of treatment and even having experienced the serious effects of sudden withdrawal when they had stopped on their own, they may now have become more accepting of their medications and more motivated to follow their doctor’s instructions.

4. Individual histories

Participants' biographies as shared with the interviewer reflected their mixed experiences and attitudes toward medication. Through various interview questions, it became apparent that it was relatively uncommon for consumers to always have been taking medications exactly as prescribed. They could take actions such as missing their doses, treating a medication as a PRN, suddenly stopping to take all medication or overdosing. Some participants also admitted to self-medicating with street drugs and alcohol.

For one participant, who after 13 years of treatment viewed psychiatric care somewhat critically, taking medication was not a problem. He also appreciated being able to have a PRN at his disposal in order to make "minor adjustments." This participant had experienced immediate withdrawal effects when omitting his medication due to oversight or running out. He also feared that stopping medication could precipitate a relapse. "99.9% of the time I have taken the meds as agreed with the doctor." (Carl 12)

One participant had for 40 years had experiences with the mental health system. He was somewhat uncertain about his diagnosis and the medications prescribed but very much trusted his physician. Still, he had stopped medication intake suddenly as he wanted "to try life without medication." However, he felt physically very sick when he did so, and consequently he now felt very dependent on the drugs and took them as prescribed. (Jack)

During 27 years of treatment, regular depot injections of medication contributed to another participant's adherence over the long-term. He also followed doctor's orders in order to avoid hospitalization. This consumer did, however, stop one oral medication in the past without telling the team, keeping quiet about it to prove that he was doing well without the drug. (Alex)

One participant stopped medication "when I was younger". Typically "I would take it for two weeks and say no way I'm not taking it anymore." (William 9) This happened usually when "I was feeling pretty good". This consumer also self-medicated with medications, street drugs and alcohol during the past 18 years, but "today, no, I wouldn't think of stopping medication." (William 3)

Another participant, in treatment for over a decade, accepted his diagnosis and the need for a medication that he himself had researched thoroughly. He was generally adherent yet apt to "take more in crisis." (Thomas 14) He also unilaterally decided to take his medications in the evening in order to minimize side effects.

Taking overdoses of Ativan had repeatedly taken one participant to the hospital. During 6 years of psychiatric care, he had also experimented with higher dose of Clonazepam and daytime Clozapine but was deterred from doing so by his psychiatrist. This consumer would have liked to be on higher doses of all his medications and considered himself as completely adherent. "No questions asked, I always took it." (Mark 15)

Side effect concerns and experiences and general resistance to the idea of psychotropic medications had led another participant to go "cold turkey" in over 3 years of treatment, when she thought "maybe I wouldn't need them any more," and also had felt that the medications were "forced upon" her. (Louise 7) Consequently, she became very ill and was hospitalized. She credited doctors at Riverview hospital with having identified effective medications and on her new regimen she was very positive ("I love my meds") and adherent. (Louise)

One participant was very adamant about being adherent since her diagnosis, stressing that she had never strayed from the medication regimen in five years of psychiatric treatment. She related that it was the example of her mother, who had been non-adherent and thus was repeatedly hospitalized, who served as a warning to always take her medications as prescribed. Feeling very well on medication and appreciating her psychiatric care, she saw no reason not to take her medications and would not risk going off. (Carole).

Another respondent had gone “cold turkey” a number of times during the past 11 years, prompted by side effects or not being in the “right frame of mind”, but concedes now that this was not a “good idea,” “not nice” or even “dangerous” and also could lead to hospitalization. She had also had experiences with overdosing. She praised her present medication regimen and stated that now she would consult with her physician before making any changes. (Sarah)

One participant’s behaviour around medications varied as she was ambivalent about her regimen and her psychiatrist’s expertise. She had received psychiatric care for some 13 years. She stated that she took her medications as prescribed, but then also elaborated how she had on occasion decided not to take new medications or higher dosages mainly due to concern about risks and side effects. On one occasion she decided to stop Prozac and experienced severe withdrawal effects, leaving her worried about how difficult it would be to come off Lithium or other medications. (Anna)

One consumer stated that she had been adherent, but also self-medicated with street drugs and alcohol over the past 10 years. She was conflicted about pharmaceutical therapies, and upon her request her psychiatrist guided her in titrating most of her medications. Eventually, however, she discontinued Seroquel on her own accord because she did not want to be on any medications any more, also due to fear of becoming addicted and experiencing side effects like emotional “dulling.” (Rhonda)

Fear of returning to the hospital made another consumer stick with the regimen (for the past 11 years on the same medication), but now she was anxious about her psychiatrist’s suggestion of tapering her pills. (Tina)

One participant had been in treatment over 30 years and confessed that she had overdosed early on in her illness because she wanted “to feel happy”, but “I won’t do it anymore...that was just because I was young.” (Wendy 17) More recently she had for some years resisted to taking one particular medication despite being encouraged to do so by her physician, though she acknowledged that she should better follow the regimen. (Wendy)

Now stating that she is adherent, one participant did go “cold turkey” early on in her treatment as, she said, she was not yet used to the medications. Also, she confessed that she did “hate Risperidone,” had in the past, during the past 4 years of treatment, stopped taken it on her own and was promptly hospitalized. (Patty).

Another consumer shared that she was confident about administering her antidepressant as she saw fit, gauging herself whether to take it and in what dosage, and this with full knowledge of her physician who had been treating her for mental health concerns for the past 10 years. On one occasion she did stop medication suddenly and experienced severe withdrawal effects and now took care to taper off gradually. (Angela)

5. Experimenting without telling the physician

Another related question shedding light on the nature of the therapeutic relationship was whether participants told their doctor about experimenting with their medications or whether they felt that they had to conceal from their physician the modifications they made to their regimens.

Some consumers stated that they would inform their physician of any (planned) changes.

- **“At this point I feel okay making minor adjustments but it’s usually something that I tell the doctor about.” (Carl 12)**
- **“Yes, I would do that with consulting my psychiatrist.” (Sarah 12)**

- **“Not without telling the doctor that was what I was going to do.” (William 16)**

One participant had told her psychiatrist that she planned on stopping the hated Risperidone, which had made her feel “like a zombie.” He warned her that she would “end up in hospital,” and so she did, which motivated her to abstain from making any more unilateral changes. (Patty 18, 19) .

- **“I usually listen to the doctor. Usually they’ve got good reasons why they don’t want me to do it, you know.” (Patty 21)**

One consumer decided to wait telling his doctor until he was back on his regimen.

- **Well, I probably didn’t tell him until after I went back on it.” (Jack 9)**

Another participant had felt compelled to keep secret about her not taking a particular drug.

- **“I keep it quiet, I didn’t even tell her, not even to my mother.” (Wendy 16)**

One participant also had not made it public to his team that he had discontinued taking one of his medications and rather let them assume that he was completely adherent.

- **“...the way it worked is they didn’t ask me and they just assumed I was taking it...” (Focus Groups 1, 3)**

By contrast, one consumer made it clear to her psychiatrist that she was going off the medications:

- **“And he was not happy but he didn’t stop me, and then I got much more ill than I was in the first place. I spent about a month, I think, at XYZ hospital.” (Louise 1)**

In another instance, a consumer stated:

- **“I weaned myself off ADs [antidepressants] gradually. When I told her she was ok with it. We still have a good relationship.” (Focus Groups 2)**

Apprehension about possible withdrawal effects moved one participant to consult her physician about stopping drug intake, but eventually she took medication management into her own hands:

- **“That’s what I did with the Seroquel....With the other stuff, no, I was frightened with what might happen if I did that.”(Rhonda 16)**

Upon learning from his patient that he had experimented with his medications, one psychiatrist apparently resorted to threats of cutting the prescription if abuse continued to occur: The participant shared:

- **“I did once [tell him], he said wow taking three Clonazepam is a lot, he says if you continuously do that we are going to stop it altogether. So that was an incentive to not take more than I should because he’ll take it right off my prescription.”(Mark 17)**

At the same time, learning that their patient had made unilateral decision around prescription medications, could make the physician suspicious and undermine trust.

- **“No we, at one time I used to OD [overdose] a lot of meds...so maybe that’s one way that the psychiatrist is being a little cautious.” [e.g. to prescribe PRN medications] (Sarah 10)**

Consumers correctly assumed the team's negative reaction to them experimenting.

- **"I felt if I told them no I am not taking this medication then I would have lost their confidence." (Focus Group 1, 4)**
- **"No, but I did [tell them], and I suffered the consequences. Some of the anger and the suspicion as to whether I was an individual who would be the one to stop taking it and not tell them," (So that raised suspicions among the medical professionals?) "Yeah, yeah. "(Alex 20)**

6. Fear of getting worse if changing or stopping medications

Despite all misgivings and uncertainties about psychiatric drugs, even after having very real concerns about potential risks and experience of severe adverse effects, a number of participants voiced that it was even more "scary" or "dangerous" when *not* taking the medication as prescribed, that they could end up in "that dark place" and that it would be "worse." Often it was outright "fear" that motivated them to adhere to their regimen.

- **[If she does not take her medications] "I could go back to that dark place in a minute." (Anna 14)**
- **"If I don't take it then I cannot sleep and then it will be worse, so right so what can I [do]?" (Wendy 4)**
- **"Probably both hope and fear, I guess." (Rhonda 15)**
- **"... if you don't take the medication at the same time everyday and things like that, my life is ...I start to run off the rails fast."(Thomas 11)**
- **"If I don't take them, I'll get screwed up, go down the tubes." (Focus Group 2)**
- **"Oh my god, oh when I'm not on my meds, it's very scary." (Louise 13)**
- **"It's mainly a fear that I'll get really sicker or that my head will get really delusional." (Patty 18)**
- **"Before, when I didn't take the medication I was homeless, I was doing erratic things, being arrested in the States. I could have been worse, out of hand, I could have ended up dead. But taking the medication has been a real good thing for me." (Carole 14)**
- **"That I want to function and I don't want to be a vegetable and I don't want to be zombie. I'm largely self-motivated because I know what I'm like without it." (Angela 15)**
- **"Fear...Apparently if you go off Lithium it's brutal, so I mean I'm scared. ...So fear is what keeps me going. Not only what I feel, like I already feel bad on it, if I went off of it, just the physical symptoms alone and the emotional rollercoaster that I'd be on. So altogether it's just not good, any way I look at it." (Anna 13)**
- **"No, I wouldn't want to experiment with that, no no I wouldn't do that...too dangerous, I've cold turkeyed a couple of times before and it was not nice." (Sarah 13)**

As one consumer described his dilemma:

- **"I don't completely trust what they're doing but then I'm not sure if I go off them that I'll be okay." (Carl 12)**
- **"'cause I know if I don't [take medications] I'm going to feel shitty and also just a great fear that if I completely go off them I'm going to have another nervous breakdown and feeling like I have no other option." (Carl 12)**
- **"I also don't want to be rash and I don't want to make a mistake because there is a possibility that I would have a relapse...feel a little bit kind of stuck."(Carl 3) "It's almost fear that's keeping me in."(Carl 19)**

These participants, some of who had stated their aversion to medications and who felt adverse effects and worried about risk, clearly at the same time found themselves experiencing fear of what would be their fate if they discontinued or made (again) a major unilateral change in their medication regimen.

7. Withdrawal effects promote adherence

As many participants described, sometimes they had missed a dose of medication for a few days or even longer, either on purpose, by mistake, or because they ran out of pills.

- **“If I miss the meds I get nightmares, it’s like clockwork...It’s pretty scary...”(Mark 15)**
- **“So I miss a day or two and I start to feel these withdrawal symptoms and that is terrible.” (Carl 9/10)**
- **“And the particular medication that I’m on now, if I forget it one day, wow, I am so outta...my mind is not right, I don’t feel right and so I never wanted to get off it, I would have to decrease it gradually over a long period of time. The effects of just one day are unbelievable. I mean I am on a relatively high dose...”(William 9)**
- **“But I remember telling her about – I had this physical sensation you know going off it, you know I said it almost feels like there’s lightening – some jolts of lightening going through the back of you head and it’s really weird...may have been a time when I went off without tapering it off when I just sort of stopped...” (Angela 12, 17) and in a remarkably similar language**
- **“Fear. I remember when I went off Prozac. I felt like I had electric shocks in my head...I thought what would it be like...(to stop other medications)” (Anna 13)**
- **“I just got really sick. Slowly but surely, the delusions and hallucinations all came back.” (Louise 15)**
- **“...I didn’t take them for a few days and I got really worse and ended up in hospital, so it was pretty bad...I couldn’t sleep or anything because I was addicted to the pills.” (Patty 17)**
- **“...by about day five I got really sick...and went back on it.” (did this a couple of times) “I get ill, I get too sick. If you stop Seroquel you get physically sick, it takes a long time before you start to get mentally sick.” (Jack 9)**
- **“I experimented but the sensations were unpleasant so I didn’t want to do that anymore.” (Focus Group 2)**

The severe withdrawal effects so immediately experienced could impress upon consumers a need to stay adherent or at least to taper down slowly.

8. “Cold turkey” a bad idea

The thought – and in some cases the actual attempt - of suddenly stopping their medication intake, without guidance by their physician, filled some participants with worry about relapse and institutionalization and could be considered as irrational or “foolish.”

- **“Do I do that now? No, I don’t think it’s wise.” (William 16)**
- **“Oh no, oh no. Oh no that’d be foolish. No, I can’t imagine that. No, because I already feel bad...” (Anna 14)**
- **“I know this is common that people think they’re ok they’re like oh I’m just going off medication and then they have a relapse. I know that happens. It’s kind of complicated.” (Carl 13)**

- **“Well, it occurs to me but the rational part of my brain tells me that’s kind of stupid. My rationale is even if I don’t need the medications, I need medical supervision to come off.” (Alex 19)**
- **“Oh god no, if I did I would end up in Riverview.” (Mark 16)**

9. Fear of hospitalization

Whether due to a major episode or the effects of going “cold turkey” or overdosing, several participants reportedly had hospital experiences. A deep fear of being hospitalized and staying in the psychiatric ward or being admitted to Riverview psychiatric hospital was reflected in several outspoken comments by participants, who thus could be motivated to follow their medication regimen. No one wanted to “end up” in institutional care.

As the case of one participant exemplified, fear could be a strong motivator for being adherent to the medication regimen. She said:

- **“That’s the education they give you at the hospital. You don’t take that, you’ll end up coming back here.” (Tina 21)**
- ***(So that’s something that motivates you to take your medication, because you don’t want to end up in hospital?)* “That plays a large part, anyways.” (Tina 21)**

This consumer remained afraid of suffering a relapse when her physician gave her the option to reduce her dosage.

- **“Because if you stop then maybe you have to go to the hospital again and lose all my effort, right?” (Tina 23)**

One participant was inclined to increase his dosage in order to stabilize himself and avoid hospitalization.

- **“Take more in crisis ...so they don’t take me to XYZ and give me the full treatment.” (Thomas 14)**

For one consumer, following the team’s instructions and taking his medication as prescribed was definitely preferable to being certified and institutionalized.

- **“Because I actually had been someone who took my medications, went to my case manager, saw my doctor, went to a program, because I had to. There was no choice. It was either that or be hospitalized, and that was committed.”(Alex 11)**

Another participant had seen her mother not taking her medication and subsequently being hospitalized repeatedly and was determined that she herself would stay out of hospital. Hospitalization was associated with “losing everything.”

- **“I’m glad to take my meds because I don’t want to be hospitalized, I don’t want to lose my furniture, I don’t want to get shock treatment and all these other things involved.” (Carole 5)...“...the benefits outweigh that I won’t be hospitalized. I’ve only been hospitalized when I was first diagnosed, and I take my meds and I haven’t been hospitalized.” (Carole 8)**
- **“And then if I wasn’t doing well then there was Crease Clinic and then that was a lot of things, no social life, no work life, you lose your home...”(Alex 11)**

One participant was “just terrified” at the thought of “someone saying” that she should receive shock treatment like her mother did and as she had seen in the movie “One Flew Over the Cuckoo’s Nest” and “that’s the one thing why I won’t go off my medications.” (Focus Groups 1,

17) There could be fear of “falling apart” and needing hospitalization when faced with future major life losses. (Focus Group 1, 9)

Another consumer was firm in linking adhering to the medication regimen to avoiding hospitalization.

- **“I know I won’t be institutionalized, I won’t.” (Mark 16)**

Having taken an Ativan overdose a number of times in order to control anxiety, he was now determined to stop doing so:

- **“...basically just not wanting to go to the hospital again.” (Mark 14)**

The fear of hospitalization was widely shared.

- **“But of course there is fear of going...to Crease Clinic, thinking going back to square one and starting all over again and losing a lot of your skills...” (Alex 23)**

Institutionalization was seen as resulting from making extreme unilateral medication changes, especially stopping the regimen. One participant insisted:

- **“... they [psychiatric patients] have to [take medication] or they are going to jail or they’re going to the psych ward or they’re going to Riverview if they don’t take the meds even if it has lots of side effects.” (Thomas 16)**

Many concerns around the adverse effects of the drugs had caused another consumer to go off her medications, which led to hospitalization.

- **“...they’re just terrible, terrible meds so I kinda went “I’m not taking this stuff” and I ended up in the psychiatric ward, so I guess it wasn’t too good, and those were the old meds, really harsh ones.” (Sarah 13)**

Non-adherence to one’s medication regimen was considered as running the risk of “ending up” in Riverview.

- **(need medications?) “Oh 100%. If I didn’t [take medication] I’d be in Riverview. Which is a place that I don’t want to go to. My mom’s mom, my grandmother she was there yeah.” (go cold turkey?) “Oh God, no, if I did I would end up in Riverview.” (Mark 2, 11, 15/16)**

Another participant also affirmed that she needed to stay on medications.

- **“Oh yes, otherwise I could end up in Riverview being as badly off as I was.” (Louise 4)**

The Riverview hospital experience apparently left one participant scarred for life.

- **“Not being included in the [decision-making] process is a scary thing because ultimately, once you’ve been to Riverview, you have this tremendous fear of everything going wrong. Not that Riverview or Crease Clinic was a totally bad experience for me, it’s just that it’s so removed from everyday life and what you work for everyday to improve your life ...and to be taken from that and then have to start over at square one is kind of scary, scary thing...”(Alex 12)**

By contrast, one participant described a completely positive experience. Originally, she was scared when taken by ambulance from XYZ hospital to Riverview (Louise 11)

- **“I was transferred to Riverview. Best thing that ever happened, because they found these meds for me.”...“...my opinion of psychiatrists changed when I got into Riverview and I met some just phenomenal doctors.”... “I got out of Riverview it all changed.” (especially her relationship with her physician and her medications) (Louise 1/2, 5)**

By contrast, not being hospitalized could also signify successful recovery to the consumer. As one participant shared:

- **“I am quite good. For the past 15 years I am very good. I haven’t been to the hospital.” (Focus Group 2, 12/13)**

10. Fears of being “on” or “off” medications

Psychiatric medications played a significant role in the lives of consumers and could be the cause for emotional turmoil, most notably characterized by a feeling of fear. Some participants could be afraid of the negative effects when taking their medications and at the same time worried about the ramifications of not being adherent.

For example, when being “on” psychotropic medications, some participants were anxious whether they could become mentally and physically addicted to these potent drugs. (Jack, Rhonda, Patty) Also, those who were being treated for a mental health issue were exposed to the fear of stigma. (Rhonda, Louise, Carole)

Taking medications filled some participants with alarm about potential and actual adverse effects or risks (Sarah, Louise, Anna), and toxicity (Carl, Patty), especially over the long-term. (William, Carl). Even when a particular regimen was unsatisfying, consumers could be scared of making/proposing changes and possibly facing another set of new side effects and risks. (Anna)

Associated with stopping to take one’s medication or making unilateral changes, were many fears: the experience of lapsing in one’s medication intake, even just a day or two, led to apprehension of the severe withdrawal effects that can ensue. (Jack, William, Anna, Carl) Participants also expressed fear of recurring symptoms (Wendy, Anna, Louise) or even relapse (Carl, Mark). Dread of (re)hospitalization was common. (Sarah, Thomas, Alex, Carl, Carole, Tina, Mark) A frightening uncertainty of what might happen if they went off medications on their own accord (Rhonda, Anna) was also related. Fear of going “out of control” (Wendy, Sarah) was generated at the thought of going off one’s regimen, as was fear of refusing treatment and thus remaining in severe crisis (Louise, Tina, Carl) or “ending up on the street and lose everything.” (Carole).

Some participants were torn by the idea of reducing their dosages even at the suggestion of their doctor, since the physician could not give them “guarantee” that they would still be alright, (Tina, Louise) Some respondents were afraid of admitting to their doctor that they were experimenting with their regimen as this may lead to repercussions. (Mark, Wendy, Alex) Consumers felt that if they went off their medication without medical supervision they would not be “safe.”(Patty, Sarah, Alex).

Other strong negative emotions transpiring from the interviews and focus groups with respect to psychiatric medication and the therapeutic relationship were trepidations of being disloyal to their psychiatrist if requesting a second opinion (Anna), or fear of trying to change physicians. (Sarah, Alex) Fear of being “cut loose” from medical support if the consumer did not fit the team’s mandate by getting too well (Anna, Rhonda, Carl) or by discontinuing to take medications (Sarah, Rhonda) was also noteworthy.

Thus, being “on” or “off” medications during a mental illness was frequently the cause of fear. Some consumers were very concerned about both taking their medications and of not being adherent, leaving them a conflicted situation. It is thus easy to understand how consumers were motivated to stay on their regimen while at the same time having been seriously tempted to make their own medication decisions in the course of their illness.

11. Lack of options/feeling “stuck”

Caught between trying to be adherent, the temptation to self-dose, worry about the drawbacks of the drugs, and the fear of getting much worse when not taking the medications and even being institutionalized, consumers could feel trapped, seeing no viable alternatives. We heard that some participants felt “stuck”, that they saw “no options,” no choice but to follow the regimen - a seemingly intense experience that is reflected in the extreme language used (hell, evil, life/death, kill me).

- **“I don’t know what other option I have...I’m not 100% confident in being able to completely go off my medication then the possibility of having another breakdown is too painful.”...“So I really feel a little bit kind of stuck.” (Carl 6, 3)**
- **“Well, I have to, I have to stay on them if I stop taking them I get sick so you know what’s the lesser of two evils?” (Jack 6)**
- **“Well no because you know getting psychiatric treatment is a life/death matter for me you know this is a life and death matter, less or worse options you know, okay ...like that’s the only reason that I ever accepted treatment.” (Thomas 7)**
- **“...the side effects are a huge thing, the side effects are huge – but if I don’t take them – then I get into hearing voices, voices, so you know what’s the best of two evils. I don’t know.” (Sarah 6)**

One participant described her dilemma:

- **“I don’t push it [medication change] because I’m scared. I’ve read up, I don’t know what options there are for me, really it doesn’t seem like there’s many options for me.”...“I’ve just kind of just gone along for all this time. I just haven’t felt like I’ve ever had any other options. I felt so afraid if I go off them, it’s like the sky has fallen completely.”... “So I’m kind of stuck.” (Anna 5, 18, 3)**
- **“It’s just that I’m not willing to try to go off it and see how that is, because it wasn’t so great before either. So it’s like hell if I do and hell if I don’t.” (Anna 3)** and later, after once again having looked up a medication on the Internet,
- **“And I think, well, what’s it worth, and I can get out of bed? Am I going to spend the rest of my life in bed or should I take the medicine that may kill me.” (Anna 8)**

One participant became very emotional when talking about having to take medication:

- **“What happens if I don’t take it? I will be out of control again...I have to take it, there’s no other choice, there’s no other choice for me.” (Wendy 8, 15)**

While the power to *prescribe* rested with the physician and the motivation to follow doctor’s orders could be strong, participants sometimes had exercised their personal agency in challenging the treatment and making their own decision with respect to the actual *taking* of their psychiatric medications. Many consumers indeed admitted that in the course of their illness they had made unilateral changes to their regimen and some had even decided to go “cold turkey.”

Conversely, there were many indications and assurances that consumers felt they needed to be adherent and that they did not want risking any (more) experiments with their medication, being

afraid of withdrawal effects, return of symptoms, relapse and even of a dreaded hospitalization. These consumers may not have been making a positive choice in favour of pharmacological treatment, but rather were motivated by fear and by a sense that they had no real options, no other choices than to take the prescribed medications or suffer severe consequences. Skeptical views and negative experiences with drugs were juxtaposed with fears of bearing the full brunt of a mental illness that was being left untreated by psychotropic medications.

Yet, within this study's small sample of consumers there were also those who explained that they had arrived at a different solution for themselves after having experienced mental health issues and having been exposed to psychotropic medications. One participant had resolved to administer her antidepressant as she saw fit and made her own decisions about timing, frequency and dosage, apparently doing so with full knowledge and acceptance by her physician. Another interviewee had come to reject all psychiatric drugs and was now in the process of receiving professional care without medications. All other respondents were adamant that they at present time took their medications as prescribed by their physician.

Chapter 13: Philosophical Outlook

Participants developed their own philosophical stances to their life of receiving pharmacological treatment and their status as mental health consumers. It was difficult for them to come to terms with the widespread stigma of receiving psychiatric services. Participants could become resigned to their illness and accept that their quality of life was, though improved by medication, not as high as they would wish for. Eventually, there was cautious hope that being on medications was not a life sentence and that some day one would once again be “normal.”

1. Stigma

Exploring “stigma” was not a focus of this study. However, the way in which the taking of psychiatric medications was linked to the stigma of mental illness, was an important and troubling issue for some consumers and spurred discussion.

For instance, one participant had experienced the stigma of both mental illness and homelessness first hand. Explaining that she herself just treated her mental illness like she does her other chronic ailments and felt that she had nothing to feel ashamed of, this participant acknowledged that she lost friendships when she had been frank about her mental illness. (Focus Group 1, 19)

Other voices chimed in:

- **[As found when a survey was done] “...most people ... said they [persons with a mental illness] were dangerous, unpredictable...yeah, and I have found that most of the groups that I have been in if nobody knew that I have a mental illness, I’d just be quirky, eccentric you know but all of a sudden it’s like crazy...you know, I really hate that...” (Focus Groups 1, 14)**
- **“...the idea of being on psychiatric medications kinda stigmatizes... I mean I think there is a lot of stigma around it...”(Angela 11)**
- **“Whole stigma of having Borderline Personality Disorder is a terrible stigma, it’s just a horrible stigma.” (Sarah 4)**

Participants felt that the media, which had recently again reported about a criminal offender having been given a diagnosis of mental illness, contributed to an extremely negative public image of persons with a psychiatric diagnosis. (Focus Group 1, 14) Consumers tried to understand the emotions behind stigma:

- **”And that’s scary, it scares people and they react because they are scared.” (Focus Group 1, 17)**

One consumer even found her dealings with the pharmacy influenced by stigma, as – she felt – her picking up psychotropic medications was not handled with the appropriate discretion and respect and that the pharmacy team members were judging her. (Carole 12) She became very emotional when relating how, contrary to her experience with breast cancer, “nobody is there for you,” (Carole 11) and that the severely disabling effects of living with a diagnosis of bipolar disorder were not respected.

- **“There’s more sympathy for my cousin in the wheelchair than me with my mental illness.” (Carole 17)**

This participant was prepared to do her share, for example through participation in research and public education events, to help change social attitudes. (Carole 17 & 19) She tried not to internalize the stigma, though she was not indifferent to people’s negative reactions:

- **“I don’t figure myself as crazy. I have a mental illness, I also have a thyroid illness. I have acid reflux, those are all illnesses....” (Carole 16)**
- **“When I meet people, I’m very honest and I tell them I’m bipolar and you can tell people’s reaction is still hurtful. (Carole 11)**

Other persons with a mental illness were afraid of stigma and let it influence their behaviour even when it worked to their disadvantage. For example, one consumer stated that she did not wish to associate with other clubs or groups of consumers.

- **“Because I find that, for me, there is still such a stigma about it that I don’t want to go to groups or people with other afflictions.” (Anna 3)**

However, this meant that she could not share with fellow consumers about relevant information about medications and mental illness and was rather left “by myself on the Internet.” (Anna 4)

Some consumers tried to hide their mental illness for fear of discrimination. One participant, concerned about stigma in her schooling and career (Louise 18), stopped disclosing her illness and was afraid that knowledge about her illness would come back to haunt her at her workplace.

- **“...I’m afraid I wouldn’t get work. It’s all about reputation I guess.” (Louise 17)**

One participant pointed out that if co-workers found out about a colleague suffering from mental illness, they would subject that person to stigma and discrimination. “That’s the real world.” (Thomas 12)

Others also confessed keeping quiet about being on psychiatric medications.

- **“Very few people, unless I was close to them, knew I was taking it. It wasn’t something I came out with very quickly.” (Rhonda 3)**
- **“Only really really really close friends know about myself.” (Mark 4)**
- **“No one else knows I’m taking it because no one else knows I’m sick.” (William 15)**

As one consumer related, stigma was “really bad” in Chinese families, which had dismissed her as “she’s crazy.” (Tina 28)

According to other participants, nobody was immune to having preconceived notions about mental illness, including both the clients and providers of mental health services. (Focus Group 1, 20)

- **“[I] learned at a symposium that the worst stigma comes from people who work in the mental health professions.” (Louise 18)**
- **“I think there is [stigma], both by consumers and professionals and the public, there is.” (Alex 15)**

Fearing stigma could be connected to not wanting to accept one’s diagnosis as being disabled and having to take psychiatric medications.

- **“There is even to this day a certain stigma...I still have issues with the whole thing and medications is part of that thing.” (William 16)**
- **“Umm...it sort of sends the message, it’s kind of like you’re not good enough without medication. You’re flawed...” (Angela 11)**

Not telling family and friends could indicate that consumers themselves had problems coming to terms with their mental illness.

- **“...if I don’t feel comfortable acknowledging it myself and my family doesn’t know then have I accepted it, I guess not...” (William 17)**

For consumers, it could be hard to accept their illness and the constant need to take medications.

- **“...the act of taking medications is and of itself a reminder, whether you consciously are aware of it or not.” (William 17)**
- **“So it reminds me all day that I’m different.” (Anna 10)**
- **“[I] felt shame that I had to be on it or was on it.” (Rhonda 13).**
- **“...I go there and it depresses me because I’m sitting around with people who are mentally ill and I think “I’m not really,” but there I am.” (Anna 3/4)**
- **“Oh, I fought so hard not to go on Lithium. I struggled with that. To me, that was like the final thing that said “you’re really mentally ill, here’s some Lithium for you.” (Anna 3)**

Thus, the stigma of mental illness troubled participants in a number of ways: they were afraid of people’s reaction to learning about their mental illness and about their medication, they considered the very real possibility of actual discrimination, and, perhaps most importantly, they could have internalized the stigma and view the medication as a constant unwanted reminder that they were mentally ill.

2. Acceptance and resignation

Some participants found their own compromise with their life as recipients of mental health care while others sounded more resigned and disillusioned about the limits of what the available treatment could do for them. Many participants struggled with coming to terms with both illness and treatment.

For example, service by the mental health service providers was taken with a grain of salt. “Some teams are just better than others,” (Sarah 11) concluded one participant, who had described her relationship with the team physician as “rocky” but really appreciated her case manager. Another consumer did not want to rely on the team alone in seeking help and recognized that the system clearly had its limits, which he had learned to accept:

- **“I decided to seek help outside of the psychiatric system (consulted a shaman e.g.)... In the end my approach tends to be a bit more complementary and I haven’t said no to the psychiatric help and work that I’ve been doing, the therapeutic work that I’ve been doing at the team but I also don’t take it to be the whole ball of wax.” (Carl 2)**
- **“..in a way I think it really helped me out at one point when I realized what I needed to have toward the relationship and not to expect more than it’s going to give and to just see what I see as its limitations and be ok with that.” (Carl 5)**

Another participant also felt that his expectations of the relationship with the team should better not be too high. He remained philosophical about his treatment.

- **“You can’t have like, the perfect doctor and perfect case manager and things like that. I’m not expecting that.” (Alex 14)**
- **“No, I don’t feel they’re responsible for the illness or the fact that I have to take medication and things like that. It’s not their responsibility.” (Alex 16)**

Similarly, expectations of the potency and effects of medications were also seen as needing to be realistic.

- **“No, I don’t think there is a perfect pill, some things you have to put up with...” (Carole 8)**

One consumer expressed a resigned pessimism that the effectiveness of both medications and psychotherapy were both very limited and unlikely to generate “normality.”

- **“There’s limitation to what medication can do. There’s limitation to what therapy can do and if anybody believes that either/ or in conjunction with themselves, the patients should be aware that they’re never going to be what normal is.” (William 22)**

With respect to the role of medications in the life of a consumer, the following quotes reflect different degrees of acceptance and resignation. Some consumers seemed unperturbed about their regimen...

- **“It doesn’t bother me too much.” (Alex 15)**
- **“I’m more than happy to take my meds.” ...“To stick with the meds? Yeah, it’s okay, it’s not a problem, I’ll stick with the meds. I probably need them my whole life.” (Mark 12, 15)**

...whereas another participant became very emotional when speaking about the apparent lack of treatment options.

- **“I...there is nothing I can do, I have to take [medication] for the rest of my life.” (Wendy 4)**

In the group, extremely negative inferences were also drawn from being ill. Being mentally ill and taking medications was regarded as a ‘life sentence.’

- **“If you’re bipolar, you’re stuck with it, you can’t get better and just have to take your meds.” (Focus Group 1)**
- **“Being on meds the rest of your life means you’re disabled for life.” (Focus Group 1)**

Being prescribed psychiatric medications and being designated as “mentally disabled” or as a “consumer” could be upsetting and hard to accept.

- **“Lots of times my strongest feeling about it is being actually burdened by being a consumer or that designation. Rather than it being something positive, it seems to be something more disabling than anything else at times.” (Alex 13)**
- **“...it’s kinda crutch for me...it takes away from my self-image as being not in need of help.” (Angela 11)**

As one consumer lamented about mental illness having held him back in life, that there had been many “wasted years”.

- **“I’m 48, I could’ve done a lot of things with my life. I’m very frustrated.” (William 19)**

Still, he resisted the label of “mental disability.”

- **“I have a hard time thinking of myself as ‘disabled.’” (William 3)**

Other participants found reassurance in an analogy between their mental illness and its pharmacological treatment and other medical conditions like diabetes or high blood pressure and

to medications like insulin. (Anna) Making such a comparison had apparently been suggested to them by medical professionals.

- **"I guess I see the meds in a different light...Much more positive. Much more along the lines that they were encouraging me at the beginning, see like diabetes with Insulin or headache with Tylenol." (Louise 7)**

Regarding psychiatric medications in that light, however, also seemed to leave no alternative to taking the medications. As one participant explained:

- **"What other choice do you have? It's just like diabetes or high blood pressure, people have to take medication." (Tina 15)**

3. Quality of life

Participants were asked how they would rate their quality of life since they were taking psychiatric medication, whether the quality of life was better now. They often stated that they noticed a positive effect, that medications had enabled them "to live," though there also was room for improvement.

- **"Of course a better quality now it's not the same a person on medication than a person after taking medication, I think it's not the same. I know I have a good quality of life..."(Wendy 13)**
- **"From the time I was ill? Yeah, big difference. I can get around – Now I can drive, before, I couldn't. I didn't know what I was doing; I could be reversing when I should be going forward. I wasn't allowed to drive. ...I was really out of it...Compared to when I was well? Before I got sick? I still think it's just 50, 60 at the most. It was very hard to function before." (Tina 17)**
- **"Out of 100% being zero feeling like crap and 100 excellent, I'd say 70." (Mark 12)**
- **"10 being high I would say 9." (Carole 14)**
- **(Is there a big difference?) "Certainly, currently certainly on the medication I'm on now, yes." (William 13)**
- **"[Medication] make a tremendous difference in the quality of life or even in being able to live." (Angela 11)**
- **"Much better, much better than I thought I could. Much better, in most ways. I mean, there are still things that I want to attain that would make it better." (Alex 18).** For this participant it was hard to make a comparison with pre-medication time, it was **"so long ago."(Alex 17)**
- **"Much better, much better." (Thomas 12)**
- **"... for the past year and a half I've been very stable and very very well." (Louise 5).**

A comparison could be difficult to make when the consumer had always been medicated since falling ill.

- **"I don't know what it would be like if I didn't take them. Before I took them I was ok. So that's kind of impossible to answer." (Carl 10)**

Having come off all prescription medications and now being engaged in psychotherapy, one participant described her mixed recovery:

- **"...now I have a better idea of what my goals are than I did at the time when I was on meds or when I was sick of meds. I wasn't seeing the psychiatrist. The last year has, it's been really rough, terrible in lots of ways, but it's given me a shape to focus a lot more strongly about what it is I do want to achieve." (Rhonda 21)**

- **“...it’s a ride...or maybe it’s a journey...”** she wondered, now experiencing more feelings without the dulling effect of the medications. (Rhonda 14)

Another consumer was adamant about her bad situation of being ill and taking psychiatric medications.

- **“Oh, it’s terrible, it’s terrible. Honest to God, it has never been worse. No, it’s terrible, I just can’t begin to tell you. It’s very frustrating.”**(Anna 11)

Long illness, albeit treated, could lead to resignation and pessimism about a lack of quality of life.

- **“Life has not been pleasant... life has not been fun...It’s not worth whatever I’ve been able to obtain so far. I would just as soon be content and happy but realistically I have no comparison of what that is.”** (William 4/5).

The adverse effects of psychotropic medications were also experienced as directly impacting on enjoyment of life.

- **“...because of all the weight that people are gaining because of the meds, and then it’s not a good quality of life you know?”**(Sarah 8)
- **“...if you tell them ‘oh, I’m sleeping about 16 hours,’ they know that the quality of life is not that great, right. I mean nobody wants to be sleeping the whole time.”** (Patty 13)

Medications in themselves could be considered as necessary but not as a panacea for treating mental illness:

- **“I think it gives me the basis to feel better. I don’t think they make me feel better. I think it’s a lot of work. I think that’s the work part. I think they give me the basis to work to make myself better.”** (Alex 17)
- **“This particular medication...has allowed me to function better and have a better quality of life, but not as good as I want it to be.”** **“The quality of life is enhanced, are they the be all and end all – no. Have they allowed me to get where I want to go – no.”** but **“Well, currently I need them.** (William 13, 14)

4. Hope and Optimism

Being diagnosed with a mental illness and being prescribed psychotropic medications could be perceived as a ‘life sentence.’ It could be hard for consumers not to lose hope. Some participants retained trust that medication could play a positive role in their recovery while others perceived medication as holding them back.

One participant, who presently was very content and positive about her care and her regimen but had in the past rejected medications, had become a strong believer in the power of “the right medications.” However, she acknowledged that there was ample evidence to the contrary and that her experience was not the norm:

- **“I guess I would offer out the hope that there is a medication out there for you that gives you minimal side effects, that will allow you to function and have a good social life and work life, that sort of thing...if that’s what you want. Allow you to be symptom-free, for the most part, even if...like for me I’m just about completely symptom-free now. So I would hope that that’s possible for everyone, but from my experience most people never achieve that.”** (Louise 18)
- **“I don’t know what the magic formula is to make it happen for everybody” ...“so I know I’m the minority.” ...“I’m very lucky.”** (Louise 13, 11)

- **“I have to think that because I’m going into the field. ...There is no reason why a person with a mental illness can’t go out there and do whatever they really want to do, if they can find the right meds. That’s the key, I think.” (Louise 19)**

In the group, it was also suggested that successful pharmacological treatment might provide the basis for a positive perspective on leading a fulfilled life:

- **“Hope might be being on the medication and having a life and being able to function and to have a social life and have a work life and to me that’s all pretty well...it depends on ...what you mean by hopeful.” (Focus Group 1, 10)**

Some participants tried to maintain a cautious optimism and to believe in recovery and hope. For example, one consumer, after many years of various and frustrating treatments, still hoped that eventually there could be medication that would really help her. (Anna) Another participant looked at the medications as a blessing and was convinced that better times would come for her.

- **“I’m going to be down for awhile but I’m not going to be down forever.” (Carole 12)**

One reason for following a medication regimen was that participants hoped the medications would help them to regain their health and give them control over their life.

- **(*motivated to take medications*) “To be more socially competent, to not have paranoia, to be sociable without being scared...” (Mark 14)**

Consumers could be looking toward their health professionals to give them hope and encouragement through the hard times. One physician had suggested the long view to her patient:

- **“...each year a little better. So she kind of told me, just be patient.” (Tina 18)**

And one participant suggested

- **“...if somebody could still manage to give that [depressed] client hope that would be a wonderful thing,” yet at the same time she admitted that “I think one thing that is really difficult is to give people hope.” (Angela 19)**

One consumer found that mental health professionals neither conveyed much hope nor did they seem to pursue a goal of reducing or even eliminating the need for medications.

- **“They have more of an attitude like you’re going to be sick for the rest of your life, you know. That’s what I think. They don’t really look to get you off pills or anything like that. They just want to do is stabilize you. They don’t want to improve your situation really.” (Patty 12)**

Considering possible future strides in medical research and care, one consumer wondered about an inevitability of pharmacological treatment for mental health concerns.

- **“...not a lot of research has been done...on whether people have to take the medications all their lives...maybe there is a point where we can stop taking medication...” (Alex 15)**

Another participant had been motivated to take her medication by hope, which was however coupled with fear of feeling worse without the drugs.

- **“Probably both hope and fear, I guess.” (Rhonda 15)**

As one consumer concluded, taking the medication could be based on a sense of fatalism combined with a cautious hope.

- **“The best I think you realistically can hope for is, be on meds and hope for the best.” (William 22)**

The ability to live without drugs could be used as a measuring stick for successful recovery. One consumer felt that medications were “really holding me back” (Patty 16) while another participant shared that she was clinging to the hope that “I think one day I will be off my medication. (Focus Group 2, 10)

Hope of regaining one’s health was expressed.

- **“I’m hoping that I’m getting recovered. It should be like before I was sick.” (Tina 19)**
- **“I wish I could get off them. I wish I could be normal again.” (Patty 14)**

For one participant, medication treatment had already been successful in her life:

- **“I feel like normal, just like I did before.”(Louise 2)**

Participants fought hard to make sense of their experience of being given a diagnosis of mental illness and of being prescribed psychiatric medication. Being subjected to stigma did not help matters, in particular as they themselves could hold preconceived ideas about what it meant to be a consumer. Some consumers endeavoured to have pragmatic expectations of their mental health professionals and the care provided. Some respondents remained pessimistic and in doubt about the ultimate benefits of any kind of treatment, whereas a number of participants made cautiously optimistic assessments of quality of life having improved since being on medication.

For most participants, being diagnosed with a mental illness meant that they were expected to accept having to take psychiatric medications and quite possibly to do so “for the rest of their lives.” Some held on to a belief in the power of the “right medication” while others clung to the hope to live without medication some day. This group of consumers tried to develop philosophical outlooks that let them come to terms with their mental health status and of remaining realistic while retaining some hope for the future, where they would not be “down forever.”

Summary

Participants in this study all had for years (73% for more than 10 years) received psychiatric services in the hospital and the community, had been followed by various mental health professionals, and had been exposed to a myriad of pharmacological treatments.

Often it was a severe crisis which precipitated search for psychiatric help. Accessing care for mental health concerns could be a varied experience entailing waiting lists, tardy referral processes, high staff turnover at mental health teams and outpatient clinics - which impeded the establishment of trusting relationships – and practitioners trying to placate their suicidal patients. Some participants, however, encountered no problem in obtaining satisfying medical attention. A number of participants, even though they held some critical views about the health care system, expressed their appreciation of the help they had been receiving and were grateful for interventions that may have saved their life. Some felt that overall “the system” was improving.

Not all participants had always been clear on or in agreement with their diagnosis, and some had at some point been in denial of having a mental illness which could lead to refusal of medication treatment. At the time of this study, however, participants generally expressed acceptance of their illness and, if currently prescribed, agreement that they needed to take psychiatric medications.

Also, this group of consumers was resourceful in finding out more information about their illness and the medications prescribed to them, with the Internet functioning among the prime sources, which could be confusing but also empowering.

On the whole, participants spoke in positive terms about their physician, who was widely perceived as a support person, who listened and made time for questions. Doctor’s visits could be perceived as satisfying if consumers considered themselves as “doing well,” only expected a “routine check-up” and felt that they could be seen more often if the need arose. In some instances, participants were clearly dissatisfied with their visiting time. Some consumers and their physician seemed able to forge satisfying relationships, characterized by mutual respect, openness, and good communication, but there were also negative comments about lack of a consistent treatment plan, breakdown in communication, or poor empathy. Some therapeutic relationships were described as “rocky.” Some participants felt that there was too much emphasis on medication and that the therapeutic encounter should go beyond the prescribing and monitoring of medications. In this context, the case managers at the mental health teams could be the first emergency contact, play a significant role by being available more often and easily, help in problem-solving and arrange earlier doctor’s visits if needed.

In some instances, psychiatric treatment could be perceived as so “haphazard” that consumers could feel like they were treated like a “guinea pig”, i.e. several came to realize that the prescription of psychotropic drugs could be a “trial and error” process, that treatment often meant being on a “cocktail” of changing psychotropic medication, whose interaction nobody could predict, and which demanded them to place their trust in the physician. Participants expressed a clear need and willingness to trust their doctor on an interpersonal level and with respect to competency and care, though when their health was not improving or other problems occurred, they could “lose faith.”

In severe crisis, often at the beginning of the therapeutic relationship, handing over all control to the physician could be seen as necessary. Participants seemed to accept that their decision-making capacity could at such times be compromised and that ultimately they needed to defer to the physician’s expertise.

Some participants felt “on par” with their doctor who involved them in decision-making, while others found themselves at a disadvantage in the therapeutic relationship. Participants recognized a power imbalance between them and their doctor, which they may have interpreted

as being created by the difference of medical expertise. Some participants found that an “equal partnership” was not a realistic expectation: as physicians were specially trained, there was always going to be an asymmetry of knowledge and education. Being involved in medication decisions and generally being “proactive” and “empowered” could be seen as desirable, but very difficult to achieve, especially when one was acutely suffering from a mental illness. When consistently strong disagreements about treatment or interpersonal tension occurred in the therapeutic relationship, some participants mentioned that they had thought about or actually followed through with a change of practitioners, which could, however, be considered a very difficult and intimidating step to take.

In terms of psychiatric treatment, some participants had also considered their options. Other possible coping strategies - alternative or complementary to the pharmaceutical treatment - had been contemplated and pursued by consumers. Also, having made negative experiences with going “cold turkey” on their own, some participants desired to be “weaned off” from their medications by health professionals in a “safe” environment, though they hardly dared to bring up the issue or had found their physician not necessarily in agreement with such ideas.

Participants frequently expressed mixed attitudes about taking psychiatric medications. On the positive side, they stated how medications were appreciated and described tangible benefits such as making them feel better or “almost symptom-free,” keeping them calm and able to function, provide better sleep without nightmares, and may be helping to reduce suicidal ideation. The power of psychiatric medications was often seen in their ability to stabilize one’s condition rather than necessarily leading to complete quality of life or even affecting cure. Conversely, some respondents seemed to have doubts whether the drugs were working or being overrated and just used as a “quick fix.”

However, participants suffered from adverse effects such as weight gain and emotional “dulling”, and experienced risks such as diabetes and severe reactions such as Lithium toxicity. Some wondered whether they simply “had a much more sensitive system” to experience such many and severe responses. Some participants felt that side effects had to be accepted as a “trade off” for the drugs’ benefits, or trusted the vigilance of their doctor, while others were acutely aware of and concerned about hazards, which impacted on their level of acceptance of psychotropic drugs.

The experience of adverse effects of the prescribed drugs was common, yet not every physician seemed to make it a point of discussing possible side effects and risks with their patients and rather preferred to concentrate on benefits. Some practitioners even questioned the side effects as they were reported to them by the consumers. Some consumers also rather did not wish to know about all possible risks for fear of being disheartened.

There could be a fear of developing an addiction to the medications or of becoming overly dependent on the team. At the same time, some participants were concerned that they would be cut off from mental health care if they stopped taking the prescribed medication or did not fit the mandate of the teams any more by becoming too well. According to one participant, consumers did at times present themselves as more disabled than they actually were in order to retain eligibility for support by the team.

Perhaps in an effort to regain some control over their health, participants not uncommonly engaged in negotiating processes with their physician by trying to reduce and increase their dosages, applying for respite care, or agreeing on PRN medications. Through such negotiations consumers could feel as having a say in their own care, though they were not always successful in their proposals. While several participants pursued the goal of minimizing intake rather than increase doses, in some instances, participants themselves felt their health was so fragile that they could be hesitant to consent to their doctor’s proposal of medication reductions for fear of recurring symptoms and relapse.

All participants presently receiving psychiatric medications stressed that now they were being

adherent to their medication regimen as determined by their doctor. (13 out of 15 respondents were being prescribed medications; one participant was no longer on medication and another participant self-administered her antidepressant and was presently not taking it) Some participants were adamant that they had always been taking their medications exactly as prescribed. At the same time, many participants admitted to some form of “non-compliant” behaviour in the past - experimenting, overdosing, or stopping medication altogether. Remarkably, such unilateral changes to their medication regimen consisted most often in skipping doses or even going “cold turkey,” whereas only two participants mentioned that they had made significant increases on their own or even taken an overdose. These actions may reflect a perception that taking less medication was generally preferable. Causes for stopping or refusing all medication included rejecting medications on principle, feeling better and wanting to test if one still needed the medication, experiencing severe side effects and being worried about risks, or “not being in the right frame of mind.”

Some participants related that they had stopped all drug intake in earlier phases of their illness, when they could have been in denial of their illness, had not yet become used to medications, or been resistant to the very idea of psychiatric medication. Perhaps after some years of living with a mental illness and receiving psychiatric treatment, they had become more accepting of their medication regimen and the advice of their physician.

Repercussions of non-adherence included severe withdrawal experiences, recurrence of symptoms, or (re) hospitalization and thus running the risk of losing one’s status, housing, job, or belongings. Not the least due to negative experiences previously made at times of self-dosing, consumers stressed that they were now staying on the medications because of fear to suffer a relapse, “running off the rails,” going back to that “dark place”, or “ending up” in hospital. Despite misgivings and uncertainties about psychiatric drugs, even after having very real concerns and being subjected to bad experiences with medications’ adverse effects and severe risks, some of these participants now voiced that it was even more “scary” or “dangerous” when not taking the medication as prescribed. Adherence after all was viewed as preferable, and they now would not make any changes without consulting their physician.

Some participants were afraid of opting for either action, of both taking and not taking their medication, leaving them a conflicted situation. Between pressure to acquiesce to the regimen, the temptation to self-dose, worry about toxicity and side effects, the stigma of mental illness, the uncertainty and costs of alternative treatment, and the dread of withdrawal effects and hospitalization, participants could feel trapped, seeing no viable alternatives. We heard that some participants felt “stuck,” that hope was coupled with fear, that they did not see any other options but to follow the prescribed regimen and “hope for the best.”

Participants also spoke about the painful experience of stigma, about embarrassment and discrimination as a result of taking psychiatric medications and thus being identifiable as a consumer. Some were afraid that others found out and they may lose their jobs or important relationships, thus preferring to keep quiet about their mental health status. They also could feel shame and view the medication as a constant unwanted reminder that they were mentally ill.

Accepting life with a mental illness, with a prospect of having to take psychiatric medications for “the rest of their life,” was found very hard by some participants. Yet, there were also respondents who were unwaveringly positive about their treatment with medications, spoke in high terms about their physician, were mostly unconcerned about side effects, had made their peace with their treatment, set new personal goals, and only wished that other consumers could have as positive an experience.

As past or present recipients of psychiatric care and at times holding ambivalent attitudes towards pharmacological strategies, participants faced the challenge of making sense of suffering from a mental illness, being in the hands of a physician and being prescribed psychiatric medications, and they were trying to find their own compromise with modern mental health care. Thus, taking

medications was not always simply a question of “complying” with a regimen of potent medications prescribed to them. Rather, it could be the consequence of a complex interplay of many factors such as trust in the medical system, agreement with the diagnosis, acceptance of pharmaceutical products, experience of tangible benefits versus hazards, outlook on life, experience of alleviated symptoms, previous histories of being on or off medications, perception of a lack of choices, and the interaction with and confidence in the expertise of the physician.

Discussion

Consumers' self-agency

Thus, when taking the long view, participants' experiences show that medication management and the role of medications in patients' lives went far beyond consumers simply passively following a regimen routine according to the instructions given by their physician. Rather, some consumers wanted to be a "participant in medication taking", though they knew from experience "how hard it is when you're not well to be your own advocate" and could even "blame" themselves for not being more "proactive."

Despite this, participants in this study could be found being proactive in many different ways: for example, they had at times engaged in negotiations with their physician about the choice of medication, the timing of their medication intake, increased or decreased dosages or the prescription of PRN medications and the prescription of "respite care." Consumers reported that they had been able to "persuade" their physician, were gauging when it was an opportune time for such negotiations or that they had been able to "talk their way out" of pending hospitalization. Moreover, participants could decide to become "more independent" of their physician or to refuse to be "shoved around."

In addition, while they may not have been able to see any viable alternatives – though they wondered about and sought help in non-pharmacological options - or were usually not given any choices about neither the physician nor the treatment, participants did make an effort of self-regulation and an attempt to retain or gain some personal control over their mental health condition and its management by taking their treatment into their own hands. Two participants had, for the time being, decided to try to deal with their mental health concerns without the aid of psychotropic medications.

Medication adherence

The majority of this study's group of consumers had at some stage of their treatment made unilateral decisions about their medication and made an active choice of decreasing - or more rarely increasing - their dosage or stopping to take their medications altogether. Their reasons for doing so were various, including denial of their illness, rejection of treatment with medication, severe side effects, concern about risks, or curiosity as to how they would fare with higher or lower doses, or completely without the drugs. Reportedly, they had been subjected to withdrawal symptoms and some had experienced the serious consequences of going "cold turkey."

Yet, when being interviewed participants consistently stated that they were currently taking their medication as prescribed, that they needed it, that they consulted their physician about possible alterations, and that deviating from the regimen would be "foolish" or even "dangerous." Thus it would appear that these consumers decided to participate in our study at a point in their life where they had come to some reconciliation with their psychiatric care, with some actually embracing the pharmacological treatment and others at least being resigned to it.

Challenges for the therapeutic relationship

Also, participants did their own research of their illness and their medication while remaining "discerning" about sources such as the Internet. In some instances, they confronted their physician with new knowledge on their medications, doses and side effects. The doctor's expertise was rarely ever challenged, though, for example, for one consumer the young age of her psychiatrist left her wondering about a higher level of expertise of a more senior doctor. On occasion, a consumer's initiative or a disagreement about care could result in conflict in the therapeutic relationship, with the consumer feeling that they did "not see eye to eye" with their physician and found themselves in a "big fight" or a having a "really big beef" with their doctor. Or there could be a deliberate decision on the part of the consumer "not to butt heads" with their physician and withhold criticism.

Furthermore, some consumers at times chose to push for a change of clinicians by demanding a different case manager, team physician or hospital doctor, leaving the team in preference of care by a psychiatrist in private practice or of non-pharmacological care at the Centre of Concurrent Disorders, or moving from one team to another in a different municipality. Other participants consciously decided to stay with their physician despite problems as they appreciated continuity of care, realized that finding or debriefing a new doctor would be challenging, were skeptical of care outside the team, or were staying out of a sense of loyalty. Also, consumers could take what they needed from the team, i.e. if the relationship with the physician was not satisfying, seeing the case manager could in itself be recognized as beneficial and as a trade off.

Positive aspects of the relationship

With respect to the therapeutic relationship, consumers had their own ideas and preferences about the interpersonal dynamics and physician's attitudes and behaviours that they considered as important. Participants recognized psychiatrists "who really care, who were open to questions and very willing to try new things, really wanted me to get well," who involved them in decisions and treated them as equal partners, for example by their physician discussing with them the pros and cons of the medication. They wanted to feel that their own suggestions were welcome and they were being treated with respect. Consumers wished for their physician to be non-judgmental and not be "bossy" or "pushy". They appreciated it when their physician made time for questions and displayed good communication and interpersonal skills, as manifested in listening, encouraging the client to talk, and showing empathy. Participants valued when their physician remembered their story and they welcomed their physician applying psychotherapy.

Participants were sensitive to the physician showing "kindness", being truly "caring" and interested in their quality of life beyond the taking of medication. They appreciated the physician assisting them through other life struggles (e.g. with alcohol and smoking problems) and proclaimed that their doctor was generally playing an important part in their support system. Even when therapeutic encounters usually were brief and infrequent, consumers could feel that this was so because they were obviously doing well, and they often had the sense that their physician would be available if the need arose.

Physician taking charge

Consumers were aware that their own competency and ability to make decisions could be called into question if they seemed too ill. Yet, they agreed that in times of severe crisis their physician might have to take charge, and even when they felt better some participants consciously deferred to their physician's expertise. Participants could appreciate it if they thought that their physician was "sure" about the diagnosis and the treatment, had the necessary training and knowledge and could be trusted to make the "right decisions" about their health.

Barriers to the relationship

Conversely, consumers regarded other aspects of the therapeutic relationship as detrimental or found the physician as lacking in desirable qualities. Physicians could be seen as adopting a paternalistic attitude as manifested in talking down to the consumer ("he's up there and I'm down here"), excluding them from medication discussions and making unilateral decisions. The physician could also be perceived as having/taking too little time and as just following a "formula of questions." Consumers viewed it critically if their physician was not engaging them in a "dialogue" or "more of a conversation" and if communication generally was poor. At times, mutual honesty and openness could be missing from the therapeutic encounter. Participants took note when the physician was "utilitarian" and "business like" rather than being "warm" and interested and offering "comfort," and failing to draw the consumers out of their shell in order to find out how they were really doing. Physicians' empathy could be viewed as limited as they could never "really know" what it was like to be mentally ill and on psychotropic medications. In uncertain situations, for example with the issue of more unusual side effects, doctors were suspected of just diagnosing and prescribing "from a book." Some participants felt that the physician may be using prescriptions as a "quick fix," generally placing too much emphasis on medications and seeming to "push pills."

Consumers were aware that psychiatric treatment was often a “trial and error” process, that they could feel like they were being treated like a “guinea pig,” and that the physician may be using different medications in a “crapshoot.” This could undermine their trust and lead to frustration, yet some participants sounded like they had resigned themselves to the physician having to “play around.” In a few instances, participants held their physician responsible for symptoms not improving or for prescribed medications being difficult to tolerate. In consumers’ experience, their concerns or reports of side effects of medications were not always respected by their physician. For participants it was particularly exasperating when their suicidal thoughts were simply dismissed by their physician.

Also, participants perceived that there could be a lack of treatment planning and that new physicians appeared not to have studied clinical notes from their predecessor or even their own notes, leaving clients with a sense of always having to go over everything again and again. Participants felt that high staff turnover at the mental health teams or the hospital outpatient clinic made it hard for them to establish long-lasting, trusting, dependable relationships with their physician, counsellor, or nurse.

Ambivalence about benefits and risks

In terms of being treated with pharmacological products, participants realized that medications were not necessarily the ideal solution. Consumers could appreciate tangible benefits of medications, most notably being stabilized, being better able to function, and symptoms being improved. But motivation for taking psychotropic medications could also derive from fear – fear of recurrence of symptoms, relapse, and of (re)hospitalization and loss of their job, belongings, and housing. Moreover, taking medications could have definite downsides, such as dependency, adverse effects, and stigma and being a constant unwanted reminder of one’s mental illness. Thus, some participants took their medications with deeply conflicted feelings and a sense of having no real options. For example, while in her experience “side effects are huge” a consumer wondered “what’s the best of two evils. I don’t know.” When comparing how it was before taking medications, it seemed to another consumer like a matter of “hell if I do, hell if I don’t.” Fear of “another breakdown” or being “out of control again” led one consumer to admit “I don’t know what other options I have” and another to conclude “I have to take it, there is no other choice for me.”

The role of medications

In short, medications and their management could play a significant role in varied aspects of the life of participants, including defining their status as mental health consumers, being the cause of ambivalent but strong emotions, confirming eligibility for care by the mental health team, or in being subjected to stigma and discrimination.

Our participants were a small but heterogeneous group, each with their individual story, their own perception of their illness, and personal reasons for taking psychotropic medications as prescribed or for making their own modifications to the regimen. The fact that 6 out of the 15 participants became very emotional and tearful during the interviews reflects that even those consumers who volunteered to speak about medications could be touched on a deeply personal level when discussing their experiences as consumers, their treatment and their relationship with their mental health professionals. Such privileged information also demonstrates the immediacy of consumers’ lived experiences that is accessed when adopting a qualitative explorative research approach based on individual and group interviews.

Recommendation

This study points to the need for further inquiries in order to shed more light on the complex role and meaning of medications for mental health consumers. Future research might address the issue of how consumers can become more empowered in medication management as well as how to help inform and guide clinicians in their practice, so that both service recipients and providers can be more effective partners in the therapeutic process.

Appendix A

Vancouver Coastal Research Centre for Mental Wellness

"Psychiatric medication and the therapeutic relationship" (January 16, 2008)

INTERVIEW QUESTIONS

() Primary questions in **bold** plus possible >probes

(1) To begin with, can you please tell me how long you have received medical services for your mental health concerns?

> How long have you been seeing your present physician?

(2) Are you presently on any psychiatric medications and do you know what they are for?

- > Has your doctor explained to you your diagnosis?
- > Where do you get your information about your illness and your medications?
- > Is the information provided clearly in plain language?
- > Is your medication order complicated?

(3) How would you describe your relationship with your physician?

- > Do you trust your doctor to make the right decisions about your health?
- > Does your doctor make time for your questions?
- > Are you satisfied with the duration of your doctor's visits?
- > Does your doctor show understanding for your situation?
- > Do you feel treated with respect?

(4) Does your doctor discuss with you the risks, side effects and benefits of your medication?

(5) How do you feel about taking medications?

- > Are you concerned about side effects of your medication?
- > What kind of role do medications play in your life?
- > Do you believe that your medications are helping you to feel better?
- > What is the most frustrating aspect of being on medication?
- > Do you think that there is too much emphasis on medications in treating your illness?

(6) Do you feel like you are an equal partner when talking with your doctor about which medications would be good for you?

- > How do you think does your physician decide what medication to prescribe to you?
- > Does your doctor involve you in the making of decisions about your treatment?
- > Does your doctor recognize your expertise when it comes to the impact of medication on your body?
- > Does your doctor recognize your expertise about how medications affect your quality of life?

(7) If you could change one thing about your relationship with your doctor, what would it be?

Cont.

(8) When you have been on medication, have you always taken it as prescribed?

- > What motivates you to take your medication?
- > Do you feel pressured into taking your medications?
- > What helps you to follow your medication regimen?
- > Does anybody help monitor that you are taking your medication?
- > What kind of things make it harder for you to take your medication?
- > Do you feel that you yourself should determine how to manage your medications?
- > Do you feel comfortable telling your doctor about any changes you yourself have made to your medication regimen?

(9) Is there anything else you would like to tell me about this topic?

(10) How was this interview experience for you? Would you be willing to speak to me again, in a group with other people we have interviewed?

We are planning a follow-up group discussion with the individuals who have participated in this study, to help us to clarify and validate any tentative conclusions coming out of the initial interviews. The discussion would be based around themes that have been identified from the initial interviews, and also would involve asking participants if any important areas had been missed – i.e. did we get it right? All participants would be invited, so that the group would be up to 12 persons. The discussion will be facilitated by Ruth Gump, Research Assistant, and will not be taped, although some notes may be written down.

APPENDIX B

Interview Consent Form

Study title: Psychiatric medication and the therapeutic relationship

Principal Investigator: Simon Davis, Director, Grandview Woodlands Mental Health Team and Lecturer, UBC School of Social Work and Family Studies. Phone: 604-251-2264.

Co-Investigator: Lyn Jongbloed, Associate Professor, UBC School of Rehabilitation Sciences. Phone: (604) 822-7392

Purpose:

This project is sponsored by the Vancouver Coastal Research Centre for Mental Wellness (VCRCMW), whose mandate is to study issues that are of relevance to consumers of psychiatric services. The VCRCMW is a research group made up of service providers and service recipients. This study explores the role psychiatric medication plays in the lives of mental health consumers, in particular as it is affected by the relationship with the prescribing physician. This study seeks to identify values, attitudes and practices that make for an effective collaboration between service recipients and prescribing physicians, and so your experiences and input are extremely valuable. Results of the study will be shared with you and the other participants, and will also be used to make recommendations that will be shared with clinical staff at Vancouver Coastal Health.

Study procedure:

The study involves an interview and the option of a follow-up group discussion. The questions relate to your experiences as someone who has been prescribed psychiatric medication. The interview should take about an hour, and will not exceed 90 minutes. The interview will be audio-taped and the interviewer may also write down some comments. Participants will be invited to attend a follow-up group discussion to help validate the findings. This will be held at the same location, at a time to be given to you by the interviewer, and would last 60 – 90 minutes. Participants will be given a copy of the final report. *Your authorization of this form concerns only the initial interview.*

Potential risks:

(See also “Confidentiality” below.) Your identity will be kept in strict confidence. Your participation will not in any way jeopardize any benefits or entitlements, or be shared with any service provider. Interview data including audiotapes will be kept secure and will be destroyed after the completion of the study. You will be given an opportunity to discuss the experience at the end of the interview, and provide feedback about the process. It is not anticipated that the interview will be a stressful experience, but support and referral information can be offered by the Principal Investigator, who is an experienced counselor.

Cont.

Potential benefits:

It is hoped that the interview will be a positive and educative experience, for example in exploring how better patient-physician collaboration could be achieved. Participants will also be given a copy of the final report. (Please tell us how this would be arranged, for example by mail, e-mail attachment, or pick-up).

Confidentiality:

Your identity will be kept in strict confidence. Your participation will not in any way jeopardize any benefits or entitlements, or be shared with any service provider. There will be a written report based on the interviews, but identities or information that might identify an individual will not be disclosed. No one has been asked to identify you as a possible participant. The interview data, including the audiotapes, will only be shared with the Principal Investigator, Co-Investigator and Research Assistant. This data – tapes, written material and computer files – will be kept securely locked and will be deleted after the completion of the study. Concerning the follow-up group discussion, participants will be asked to respect confidentiality, but complete confidentiality is not possible in this context.

Remuneration:

Participants will be given a \$25.00 honorarium for attending the interview, and will be given an additional \$25.00 for attending a follow-up discussion, which will be a group format.

Contact for information about the study:

If you have any questions or desire further information about the study please contact Simon Davis at 604-251-2264 or simon.davis@vch.ca.

Contact for concerns about the rights of research subjects:

If you have any concerns about your rights or treatment as a research subject you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.

Consent

Your participation in this study is completely voluntary. You may refuse to participate or withdraw from the study at any time. Your participation or non-participation will not in any way jeopardize any benefits or entitlements, or be shared with any service provider.

Your signature below indicates that you consent to participate in this interview, and that you have received a copy of this consent form for your own records.

Participant signature

Date

Please tell us below how you would like to receive the report coming out of this study (e.g., mailing address, e-mail, pick-up):

Appendix C

Focus group Consent Form

Study title: Psychiatric medication and the therapeutic relationship

Principal Investigator: Simon Davis, Director, Grandview Woodlands Mental Health Team and Lecturer, UBC School of Social Work and Family Studies. Phone: 604-251-2264.

Co-Investigator: Lyn Jongbloed, Associate Professor, UBC School of Rehabilitation Sciences. Phone: (604) 822-7392

Purpose:

This project is sponsored by the Vancouver Coastal Research Centre for Mental Wellness (VCRCMW), whose mandate is to study issues that are of relevance to consumers of psychiatric services. The VCRCMW is a research group made up of service providers and service recipients. This study explores the role psychiatric medication plays in the lives of mental health consumers, in particular as it is affected by the relationship with the prescribing physician. This study seeks to identify values, attitudes and practices that make for an effective collaboration between service recipients and prescribing physicians, and so your experiences and input are extremely valuable. Results of the study will be shared with you and the other participants, and will also be used to make recommendations that will be shared with clinical staff at Vancouver Coastal Health.

Study procedure:

This focus group follows from your earlier participation in one-on-one interviews that addressed your experiences as someone who has been prescribed psychiatric medication. From reviewing these interviews several common themes, and some tentative recommendations, were identified. For clarification, we would like to review these themes with you, to see if our interpretations are reasonable. This group discussion should take about an hour, and will not exceed 90 minutes. The discussion will be audio-taped, and the focus group leader may write down some comments on flip-charts. Participants will be given a copy of the final report.

Potential risks:

Your participation will not in any way jeopardize any benefits or entitlements, or be shared with any service provider. Interview data including audiotapes will be kept secure and will be destroyed after the completion of the study. No information identifying individuals will be included in any report coming out of this study. It is not anticipated that the focus group will be a stressful experience, but support and referral information can be offered by the Principal Investigator, who is an experienced counselor.

Potential benefits:

It is hoped that the interview will be a positive and educative experience, for example in exploring how better patient-physician collaboration could be achieved. Participants will

also be given a copy of the final report. (Please tell us how this would be arranged, for example by mail, e-mail attachment, or pick-up).

Confidentiality:

There will be a written report based in part on the focus group, but identities or information that might identify an individual will not be disclosed in this report. Your participation will not in any way jeopardize any benefits or entitlements, or be shared with any service provider. No one has been asked to identify you as a possible participant. The interview data, including the audiotapes, will only be shared with the research committee – members of VCRCMW. This data – tapes, written material and computer files – will be kept securely locked and will be deleted after the completion of the study.

A focus group is a discussion among several individuals, facilitated in this case by the person who conducted the initial interviews. Participants will be asked at the start of the discussion to follow some ground rules, in particular to be respectful of others, and to be mindful of confidentiality – what is spoken in the group should remain within the group. While participants will be encouraged to not disclose contents of the discussion outside of the group, you should be aware that we cannot control what other participants do with the information discussed. In short, complete confidentiality is not possible in this context.

Remuneration:

Participants will be given a \$30.00 honorarium for attending the focus group.

Contact for information about the study:

If you have any questions or desire further information about the study please contact Simon Davis at 604-251-2264 or simon.davis@vch.ca.

Contact for concerns about the rights of research subjects:

If you have any concerns about your rights or treatment as a research subject you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.

Consent

Your participation in this study is completely voluntary. You may refuse to participate or withdraw from the study at any time. Your participation or non-participation will not in any way jeopardize any benefits or entitlements, or be shared with any service provider.

Your signature below indicates that you consent to participate in this focus group, and that you have received a copy of this consent form for your own records.

Participant signature

Date

Appendix D: Interview Recruitment Poster

The Vancouver Coastal Research Centre for Mental Wellness
is seeking to conduct interviews about

Your experiences with medication

Have you ever been prescribed
psychiatric medication for at least 6 months?
Are you willing to talk about the role of medication in your life
and in your relationship with your physician?
Are you 19 years or older?

Then we would like to speak to you.

Honorarium: \$25 per interview

<u>Duration of interview:</u>	60-90 minutes; the interview will be recorded
<u>Where:</u>	Grandview-Woodlands Mental Health Team 300-2250 Commercial Drive, Vancouver
<u>When:</u>	A convenient time to be arranged.
<u>Interviewer:</u>	Ruth Gumpp, Research Assistant
<u>Contact:</u>	Simon Davis Email: simon.davis@vch.ca Phone: (604) 251-2264

Our research group is dedicated to studying issues that are of concern to consumers today. Complete confidentiality is ensured. For more details, see below.

Cont. Page 2

What is this study about?

Previous reports from psychiatric service recipients have found that the experience of being prescribed psychiatric medication may not be an altogether satisfying one. For example, there may be some question as to whether persons being prescribed medication feel they are being fully consulted, or if they are receiving all the information necessary to make informed decisions. The study will explore this by asking people about the role medication plays in their lives, in particular as it is affected by the relationship with the prescribing physician.

How would my confidentiality and privacy be protected?

This project has been reviewed and passed by the research ethics committees of both Vancouver Coastal Health and the University of British Columbia. Identities of individuals agreeing to be interviewed would be kept completely confidential. Participation in the study would in no way have an adverse effect on a participant's relationship with a service provider, or on receipt of any benefits or entitlements. Potential participants would be given a detailed consent form at the time of the interview, and have the option of withdrawing from the study at any time.

Is there any compensation for doing the study?

Participants completing the one-on-one interview will be given an honorarium of \$25.00. To help clarify the study's conclusions there will be a follow-up group discussion, and participants volunteering for this will be paid an additional \$25.00.

How is "psychiatric medication" defined in this study?

This refers to antidepressant, anti-anxiety, antipsychotic or mood stabilizing medication, taken for at least six months. Please phone the contact number for further clarification.

Who is behind this study?

The Vancouver Coastal Research Centre for Mental Wellness (VCRCMW) is a research group made up of psychiatric service providers and service recipients. Its mandate is to engage psychiatric consumers more fully in the research enterprise, by studying questions that consumers have identified as important, and by employing consumers as researchers. VCRCMW is funded in part by a grant from Vancouver Coastal Health; however, it is an independent body and has no affiliation with private sector organizations, such as the pharmaceutical industry.

What will the results of the study be used for?

This study seeks to identify values, attitudes and practices that are supportive of an effective collaboration between service recipients and prescribing physicians, and hopefully will inform the activities of both. To that end, results will be shared with all participants completing the study and will be made available more widely, on-line, for clients and staff of Vancouver Community Mental Health Services and other community mental health agencies.