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# Research INSIGHTS

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Perspectives on their Quality of Life Provided by Persons with Serious Mental Illness who are on a Community Treatment Order: A Naturalistic Enquiry Involving 'Critical Case Sampling'

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# **Perspectives on their Quality of Life Provided by Persons with Serious Mental Illness who are on a Community Treatment Order: *A Naturalistic Enquiry Involving ‘Critical Case Sampling’***

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**Objective:** The objective of this study was to explore quality of life (QoL) issues in individuals with a severe and persistent mental illness, who are under a community treatment order (CTO).

**Method:** A convenience sample of eight persons so afflicted, who were following a community care plan under a CTO, participated in the study. The sample included three males and five females, ranging in age from 32 to 55 years who had been previously hospitalized at the Regional Mental Health Care. A phenomenological approach suitable for uncovering salient themes in the lived experiences of this client group was used. To reduce bias due to interviewing style, each participant was interviewed using the Corring Quality of Life Interview Protocol with additional questions regarding CTO experiences. This method regulated the focus and depth of detail sought across interviews, carried out by four masters level students. Incisive probes and cues helped to reliably tease out symptom and environmental interactions using strategies such as ‘triangulation’ of multiple perspectives, content saturation and peer de-briefing.

**Results:** Major themes emerged from a constant comparative analysis (an inductive method that eschews trends from the context of each participant’s experience). These included: the lack of knowledge regarding illness; the need for symptom management despite medication side-effects; the lack of contentment with current social relationships; lack of daily activities; desire for increased activity and meaningful occupation; insufficient awareness of personal strengths; a desire to help others; satisfaction with increased stability in their lives as a result of the planned intervention under a CTO including decreased hospitalizations (despite enduring regular supervision and the resulting loss of control).

**Conclusions:** The results of this study demonstrate that multiple factors contribute to the perceived quality of life when working with persons on a CTO. It is imperative that clients are given the opportunity to discuss which factors have the most profound influence on them and the quality of their lives. The limitations of design including the ‘unblinded’ methodology and the lack of information on all the services used by clients’ pre and post-CTO are recognized.

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**Key Words:** *quality of life, severe mental illness, community treatment orders*

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## Introduction

Significant advancements in treatment for individuals with serious and persistent mental illness (SPMI) have resulted in a movement towards deinstitutionalization and community integration (Mitelman & Buschbaum, 2007). Increasingly, these individuals have been encouraged to become integrated into society, with some under the auspices of community treatment orders (CTO, Gray & O'Reilly, 2005). Quality of life (QoL) issues for individuals with a SPMI has been a growing research interest, but little is known how these issues pertain to those individuals who are receiving treatment under a CTO.

**Community Treatment Orders:** CTOs are “legal interventions intended to improve treatment adherence among persons with serious mental illness” (Swartz & Swanson, 2004, p.585). CTOs are used in order to support mentally ill individuals with the aim of preventing homelessness, incarceration, re-admission to hospital and relapse (Swartz & Swanson, 2004). The legislation enabling this procedure was recently introduced in Ontario in 2000 under Bill 68 (Ontario Ministry of Health and Long-Term Care, 2009), the aim being to provide and require necessary treatment to increase the tenure of persons with SPMI in community living. The basis of the CTO is a treatment plan agreed upon by the ‘competent’ patient or the substitute decision-maker, the physician, and if applicable, case workers in the field. The patient must also be able to comply with the provisions of the CTO and the designated services be available in the community. A psychiatrist or a physician who is an employee of a psychiatric institution can issue a CTO. The physician must determine that during the previous 3 years the individual has been a patient in a psychiatric facility on 2 or more occasions or for at least 30 days in total, or has been the subject of a previous CTO and must also develop a community treatment plan before issuing a CTO. The physician must examine the individual within 72 hours of entering into the plan, get the individual’s or their Substitute Decision Maker’s consent and ensure the provision of rights advice. A CTO can be in effect for a period of up to 6 months, can be renewed within one month of it expiring (indefinitely, if the criteria are met) and can be challenged by the patient at a Board of Review. The vast majority of clients under CTOs are middle-aged, with a diagnosis of either schizophrenia or schizoaffective disorder (Dreezer & Dreezer, 2005).

One of the main arguments put forth by those who oppose CTOs is related to autonomy and coercion of patients. It is thought that such coercion may ultimately

extend to other forms of psychiatric or physical treatment. Some argue that freedom of choice should in some cases be limited based on the negative consequences that arise from that freedom, while others consider autonomy as absolute regardless of circumstance (O'Reilly, 2004).

One of the primary arguments made in favour of CTOs is that they provide a source of support for deinstitutionalized individuals who lack insight into their own illness and who may, consequently, pose a risk to their own safety and/or the safety of others (O'Reilly, 2004). Research has shown that CTOs can result in a decrease in violent behaviours, a reduction in hospital admissions and an increase in the use of community-based support programs and housing (O'Brien and Farrell, 2005; Swartz and Swanson, 2004) and hence affect the client’s Quality of Life (QoL).

**Quality of Life:** There is still no agreed upon definition of QoL in the literature, as this concept has many components and subjective aspects that are unique to an individual (Awad, 1999). Many researchers share the idea that in order to measure QoL, the client’s values, thoughts and feelings must be known to gain insight into the client’s perception of his or her own life (Prince & Gerber, 2001; Wolf, 1996; Simmons, 1994). Sainford, Becher and Diamond (1996) have argued that those tools which do not consider the client’s perception of QoL may lead to improper interventions that do not focus on what is meaningful, important and needed by the client.

There are currently various tools that measure different domains of QoL. These are mostly quantitative tools, and may not be practical in clinical settings where time is limited. Recently, however, research supporting the use of qualitative tools that focus on the client’s perspective in addressing QoL issues has surfaced (Laliberte-Rudman, Yu, Scott, & Pajouhandeh, 2000; Chan, Krupa, Lawson & Easterbrook, 2005; Corring, 2007).

The Corring Quality of Life Interview Protocol (CQoLIP©) is a new qualitative tool that was developed to capture the QoL issues important to persons with serious mental illness. It has four domains that were determined from analysis of in-depth interviews and focus groups (Corring, 2004). These domains are: (a) the experience of illness; (b) relationships; (c) occupation; and (d) sense of self. The CQoLIP has been field tested by clinicians with their clients who they see in everyday practice. (Corring, D.J., C. Charach, R. Jantzi, A. Neiman, T. Robinson, J. Rouffer, 2007). The CQoLIP was found to provide an in-depth, unique assessment of Quality of Life that

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valued and incorporated the client's perspective. This was done through domains that were representative of the issues their clients expressed as important in their lived experiences. The authors' suggestions for formatting changes were incorporated in the present form of this tool. It must be emphasized that this is a qualitative evaluation tool and therefore does not have the usual statistical indices of validity and reliability. Through its original research, subsequent field testing and congruence with other research findings it has been shown to be useful in assessing quality of life issues identified as important by persons with severe and persistent mental illness.

Although CTOs do restrict individuals' autonomy, this strategy for the community treatment of the severely mentally ill has been found in other jurisdictions to also offer significant therapeutic benefits (O'Brian & Farrell, 2005). Typically the CTO treatment plan would embody nothing more intrusive than routine discharge advice. CTOs ensure that individuals who do not have the insight to recognize that they are ill or need treatment engage in the follow-up and receive appropriate care. Otherwise, it can be difficult for these individuals to manage their illness and may pose a risk to themselves and/or to others and be forced to return to hospital. This study intended to assess changes in QoL as revealed in the lived experiences of severely mentally ill clients during community rehabilitation, which was regulated by a CTO.

## Methods

**Approach:** Owing to the subjective nature of QoL, a phenomenological approach was used in which semi-structured, in-depth interviews occurred. The aim of phenomenology is to gain an in-depth understanding of the lived experience of a person, by taking a holistic approach (Depoy and Gitlin, 2005). Interviews were guided by The CQoLIP protocol as well as additional questions regarding CTOs

**Participants:** Participants were purposively recruited from the Regional Mental Health Care London and St. Thomas (RMHC) facilities. Inclusion criteria were as follows: participants were to be diagnosed with a SPMI, be under a CTO, living in the community, at least 18 years of age and capable of providing informed consent to participate. It should be noted that there was an extensive discussion with the university Research Ethics Board regarding the need for Substitute Decision Maker (SDM) consent. Expert opinion from psychiatrists experienced in research and research ethics was sought. It was concluded that SDM consent was not necessary since such a procedure referred only

to consent to treatment under the Mental Health Act. Hence, in the present case, participants could give consent to participate in the research if found competent to do so by their treating psychiatrist.

**Recruitment:** Twelve individuals, who met the inclusion criteria, were initially contacted by a familiar health care professional (i.e. coordinator or primary worker of the Assertive Community Treatment Team) to determine their interest in participating in the study and were assessed by their psychiatrist for their ability to consent to participation in research and to the release of personal information (police contact time). Eight of the 12 individuals agreed to participate in the study, three females and five males between the ages of 32 and 55. Three of the participants were diagnosed with bipolar disorder, three with schizoaffective disorder and two with schizophrenia. Three participants have had experience with the mental health care system for more than 20 years, four for 10 – 20 years and one had experience for 5 years.

**Procedure:** The CQoLIP is a qualitative, semi structured interview tool (Appendix A). The tool includes questions within the four domains: experience of illness, relationships, occupation, and sense of self. Within each domain, there are additional probes, along with cues that the interviewer uses as possible indicators of any issues within a domain (see Appendix B for more detail). The probes and cues were designed to enable the client to provide detailed descriptions of the important aspects of their QoL. An additional domain regarding CTO implementation was added to the interviews. Participants were asked about their lives pre- and post-CTO, and how the CTO has impacted their lives. These questions were aimed to further develop the understanding of the influence that CTOs have on their lives. Interviews took place at the main hospital site, local Assertive Treatment Team (ACT) team offices or the patient's home. Each interview lasted approximately 40-90 minutes.

**Data collection:** The four interviewers were all Masters of Science students, trained to use the CQoLIP by its developer prior to recruitment of the participants. Each interview was audio taped and transcribed verbatim. The lead researcher reviewed first transcripts of interviews completed by students in order to provide monitor interview techniques and ensure quality of interviews. All recordings and transcripts containing identifiable information were kept within a secure environment for the duration of the study. Information regarding police contact time for each participant was extracted from the London police database.

**Data analysis:** The transcripts were analysed using a constant comparative method (Glaser & Strauss, 1967). Along with the supervising researcher, each interviewer coded all eight transcripts, eventually convening to discuss the codes and negotiate meanings. Themes were then determined for each domain within the interviews by analysing the codes generated. Trustworthiness strategies such as triangulation, saturation, thick description and peer debriefing were used in the analysis. A clear description of data collection and analysis is provided by Depoy and Gitlin (1994).

Triangulation requires that ones source of information is checked against one or more different types of sources to determine accuracy of hypothetical understandings (DePoy & Gitlin, 1994). Triangulation for this study was achieved through the use of multiple researchers. Saturation is the point at which the investigator has obtained sufficient information to gain an understanding of the phenomenon and when further information gathered does not provide any new insights (DePoy & Gitlin, 1994). Six to eight in-depth interviews are considered sufficient to explore a phenomenon in depth and reach saturation (McCracken, 1988). Eight individuals participated in this study. The development of “thick” in-depth descriptions and interpretations of different contexts leads to the ability to transfer meanings in one context to another (DePoy & Gitlin, 1994). Finally, peer debriefing is a technique that ensures data analysis is representative of the phenomenon under investigation. It requires the use of more than one investigator in the analytic process. All of the researchers in this study were involved in the analysis of the transcripts, which “provides an opportunity for the investigator to reflect on other competing interpretations offered in the peer review process and in this way strengthen the legitimacy of the final review process”. (DePoy & Gitlin, 1994, p. 129)

**Ethics:** Ethical approval for this study was obtained from the University of Western Ontario research ethics board and the Clinical Research Suitability and Impact Committee at RMHC. Each participant was fully informed about the study and the anticipated risks and benefits. Each participant completed a consent form prior to commencement of interviews. Please note the earlier discussion regarding the process used to ensure that participants were able to provide informed consent. Furthermore, participants were informed that they may withdraw from the study at any point without consequence.

## Results

The themes identified in the analysis are organized in relation to the four domains within the CQoLIP, in addition to the "effect of CTO", as presented in Table 1.

**Table 1 Themes Identified in the Analysis**

Domain	Theme
Experience of Illness	<ul style="list-style-type: none"> <li>• Symptom management despite medication side-effects</li> <li>• Limited knowledge and education regarding illness</li> </ul>
Relationships	<ul style="list-style-type: none"> <li>• Lack of contentment with current relationships</li> </ul>
Occupation	<ul style="list-style-type: none"> <li>• Lack of daily activities</li> <li>• Desire for increased activity and meaningful occupation</li> </ul>
Sense of Self	<ul style="list-style-type: none"> <li>• Awareness of strengths</li> <li>• Desire to help others</li> </ul>
Effect of CTO	<ul style="list-style-type: none"> <li>• Loss of freedom and control</li> <li>• Increased stability and decreased hospitalizations</li> </ul>

Under the Experience of Illness domain, seven of the eight participants reported feeling anxious or afraid, while the remaining participant denied experiencing any symptoms at all. The participants reported that side effects of their medications included dry mouth, sedation, weight gain, and lack of motivation. Despite these side-effects, many of the participants felt that taking their medication regularly was important and effective in controlling the symptoms of their mental health condition. For instance, Dorothy stated, *"it's true what they say about the medication. When you're on it for so long, your bad symptoms start getting better. It can go away."* In addition, four of the eight participants stated that they did not receive any education regarding their illness. One participant reported that she received some education, but mostly researched the illness herself.

With regards to relationships, Seth stated, *"I would like to see more of them" referring to family members.* Additionally, Diane stated *"It's been a bit empty, as far as friends are concerned."* This expressed lack of contentment with relationships was often accompanied by a desire to improve current relationships with family members and/or friends. Furthermore, it was found that the majority of the participants reported having few friends, and of those friends it was common that they too had a mental illness.



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Under the domain of occupation, seven of the participants stated that their typical days were lacking in sufficient activity. Six of those participants highlighted a desire for increased activity and engagement in meaningful occupation. When asked if she was happy with the amount of activities completed each day, Dorothy stated, "Not really. At one point in my life I got used to being very busy. So I'd like to be busy again." Some of the participants noted that their lack of engagement in activity was due to their health status and symptoms and/or lack of adequate income: "I can't do what I used to be able to do. I was quite active in sports, baseball, hockey." (Kyle). Many of the participants highlighted the desire to engage in creative activity, such as artwork, or wanting to engage in more physical activities.

The domain of 'sense of self' illustrated that there were varying degrees of awareness of their strengths amongst participants. One participant declared "I am a very strong person" (Dorothy) and expanded by saying she could deal with physical pain. Other participants also demonstrated knowledge and recognition of their strengths, "I know that I can be loving. I think I can be fair. I'm learning to forgive" (Diane). Upon further prompting to identify strengths, the participants identified such factors as their desire to help others, being organized and artistic endeavours. Most participants identified concrete strengths (such as being strong in the literal sense) while others were more abstract, for example "I've learned that I can be open and I find that a strength" (Diane). When asked to describe a time in which they had helped another person, all participants (with the exception of one) were able to talk about an example. They took great pride in helping someone else. One participant stated, "I'd rather help other people than sometimes help myself" (Betty).

Questions regarding the participants' CTO lead to two additional themes. Loss of freedom and control was discussed by most of the participants. They were not happy about the fact that they were forced against their will to participate and to accept services they found intrusive. This is not a surprising finding given the nature of a CTO. Research in the area of perceived control and the importance of this construct for the QoL of individuals' with a SPMI and overall well-being has reinforced the positive relationship between these constructs (Bengtsson-Tops, 2004; Eklund, Bäckström, & Hansson, 2003).

In spite of this, most participants also felt that the CTO provided them with more stability in their once chaotic lives, as well as decreased hospitalizations. One participant described life before a CTO as "hell" (Diane) while another participant stated that life on a

CTO is "better for me right now" (Betty). Betty also described the 'good' and the 'bad' of being on a CTO: "I get tired of them (referring to ACT Team) having to come every day, but it's helping me so it's good."

## Discussion

**Experience of Illness:** Increased QoL for individuals with a SPMI has been one justification given for the use of CTOs (Grob, 1994); however, while some areas of life do show positive changes, others show room for improvement. The participants' subjective view of their experiences of their illness and its effects on various aspects of their lives was explored in this study. Most of the participants reported that the symptoms of their illness made them feel anxious or afraid, and while medications helped to alleviate the symptoms, they also had various negative side effects. As a result, the participants believed their mental illness affected their ability to make plans for the future, despite being under a CTO.

Weight gain is a source of physical and psychological discomfort and can lead to non-adherence to antipsychotic medication (Kawachi, 1999; Weiden, Mackell, & McDonnell, 2004). Distress and embarrassment with weight gain is also related to a lower self-reported QoL and more reports of symptoms consistent with depression (Covell, Weissman, Schell, McCorkle, Summerfelt, Weiden, Essock, 2007). Dry mouth can cause soreness, ulcers, infections, and loss of teeth, and other dental problems (Daniels & Wu, 2000). Perceived poor dental health may contribute to low self-esteem and avoidance of social interactions (Covell et al., 2007), thus contributing to decreased QoL.

Distress due to sedation is related to feeling low in energy and tiring very quickly (Covell et al., 2007). Lou, Kearns, Oken, Sexton and Nutt (2001) found that fatigue is positively correlated with reduced motivation. Lack of motivation creates problems with commitment, planning, and the implementation of future plans (DiClemente, Nidecker, & Bellack, 2008). Since antipsychotic medications are helpful in managing mental illness it is important for mental health service providers to address the aforementioned issues.

Limited education with respect to their illness was another emerging theme amongst the participants. Education is a valuable tool that can be used to dispel the myths surrounding mental health and mentally ill individuals (Rüsch, Angermeyer, & Corrigan, 2005). Stigma and stereotyping often lead to lowered social standing, ambitions and self-esteem (Lundin, 1998). Stigma can be reduced by educating individuals with a

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SPMI, their family members, healthcare providers and society in general about the true characteristics of mental illness and the options that are presently available to manage it.

**Relationships:** Participants were asked to answer a number of questions related to their relationships with family members and friends, their intimate relationships, the perceived level of support they receive through these relationships, and whether or not family members or friends had relationships with had issues with their mental illness. Most participants expressed a lack of contentment with the quantity, quality, or both, of their current relationships.

According to Harvey et al. (2007), the social relationships engaged in by individuals with schizophrenia during the course of their illness are significant predictors of clinical outcome. Further relationships with both family members and friends make positive contributions to clinical and social outcomes. In further support of these findings, Harrison et al. (2001), found that a critical relationship exists between social isolation and poorer clinical outcomes.

**Occupation:** Occupation was a significant component of the participants' QoL in this study. Virtually all of the participants felt that they did not engage in sufficient activity each day and desired to engage in creative activities, meaningful occupations/or more physical activity. Previous studies have found that satisfaction with the occupations that one engages in daily is related to his or her QoL (Aubin, Hachey, & Mercier, 1999). Furthermore, engagement in *meaningful* occupations has been shown to positively be related to one's QoL (Goldberg, Britnell, & Goldberg, 2002). Similarly Eklund, & Leufstadius (2007, p.303) concluded that "perceived meaning and satisfaction ought to be prioritized when setting goals in occupational therapy practice..." Previous studies have shown that physical activity and active leisure is beneficial to individuals with a mental illness, as it can also provide options for occupational engagement, social opportunities and an overall healthier lifestyle (Shimitras, Fossey & Harvey, 2003).

**Sense of Self:** The two themes under the domain of sense of self, identification of strengths and desire to help others, are related. The ability to identify one's strengths is a key component of self-efficacy. Self-efficacy is the idea that people's behaviour, performance, motivation, and emotions are heavily

based on what they believe about themselves. For clients experiencing a SPMI, their beliefs about themselves and their ability to identify strengths and abilities greatly influences their actual performance and participation. A belief in one's ability to help others will influence their desire and ability to actually do so. The participants in this study had varying degrees of insight into their strengths. It has been found that person's experiencing SPMI with higher self-efficacy have a greater ability to cope with adverse events. Self-efficacy has a positive effect on psychosocial functioning and develops from four sources: social persuasion, vicarious experience, mastery experience, and somatic and emotional states (Mancini, 2007). Self-efficacy is a key component of sense of self, especially for person's experiencing a SPMI. Developing an enduring sense of self while experiencing a SPMI is a challenging and evolving process, however, the construction of sense of self is an active component of recovery (Davidson and Strauss, 1992) and should be considered by all providers of healthcare service.

**Community Treatment Orders:** The perceived loss of control and freedom experienced by many of the participants is not a surprising finding given the nature of a CTO. There is strong evidence in other studies for the association of perceived control and the overall well-being of individuals' with a SPMI (Bengtsson-Tops, 2004; Eklund, Bäckström, & Hansson, 2003). Healthcare professionals working with clients with a mental illness should provide and encourage their clients to establish and maintain control over their daily activities and thereby become an integral part of their own treatment planning. Clients may experience a lack of control in other aspects of their life, such as forced medication for symptoms, which may not be possible or wise to alter. Offering choices and autonomy for daily activities and meaningful occupations may help address this issue. In fact, Eklund (2007) suggested "perceived control should be included in the clinical reasoning of occupational therapists working in mental health care" (p.541).

According to the study participants, their CTOs have, generally, created structure and stability in their lives. CTOs have resulted in a reduction of mental health crises, which usually led to police intrusions into their lives prior to implementation of the CTO. They experienced a reduction in post-CTO police contact time, as illustrated in Table 2.

Pseudonym	Pre CTO time span of police contact time	Pre-CTO police contact time (in minutes)	Pre-CTO Police Contact Time / Month	Post CTO time span	Post-CTO police contact time (in minutes)	Post-CTO Police Contact Time / Month	Difference in Police contact time (minutes /month) between pre and post CTO
Kyle	Jul 05 - Feb06 = 7 months	7159	1022.7	Jul 06-Mar-08 = 21 Months	30	1.4	1021.3
Dorothy	Nov 02 - Jun05 = 32 months	1503	47	Aug 05 – Mar 08 = 32 months	0	0	47
Seth	Apr03- Nov04 = 19 months	1993	104.9	Jan 05 – Mar08 = 38 months	230	6.1	98.8
Diane		0	0	Jul 07-Mar 08 = 8 months	0	0	0
Edward	May 04- Sep 05 = 16 months	448	28	Nov 04-Apr05 & Sep 05 to Mar 08 = 35 months	419	12	16
Ginny	Feb 07 - Marc07 = 1 month	624	624	Aug 07-Mar08 = 7 months	0	0	624
Betty	Jul 02 - Feb06 = 43 months	7941	184.7	Mar 06- Mar08 =24 months	272	11.3	173.4
Brittney	Mar01- Nov05 = 57 months	6121	107.4	Jan 06- Mar 08 = 26 months	2294	88.2	19.2

## Conclusion

Corring (2004) described various facilitators and barriers that persons with a SPMI face in relation to their pursuit of QoL. Stigma was seen as a significant barrier, while facilitators included supportive relationships, proper services, systems and policies. Medication was seen as a facilitator, but also as a barrier due to issues with side-effects and compliance. Medications that managed the symptoms of the illness so that the person could focus on other areas important to their quality of life were seen as a major facilitator. Services, systems and policies act as facilitators when they exist, but also as barriers when they are inadequate. For example, a service was seen as a barrier when that service was not matched with an expressed need of the individual or when an expressed need could not be met because the service did not exist.

This study highlights similarly important issues of relevance to health service providers working with individuals with a SPMI who are on a CTO. Participants' were able to talk about improvements in symptoms and levels of anxiety related to their illness but still had unaddressed needs in building and rebuilding relationships and meaningful activities in their lives. The results of this study confirm the findings of Corring (2004). The results of this study demonstrate that multiple factors contribute to an individual's perceived quality of life, which is of critical importance in working with this population. It

is imperative that clients are given the opportunity to talk about which factors have the most profound influence on them and their quality of life. This study has also shown that CTOs may have an impact on a person's QoL through improvement in the management of mental illness, in overall functioning and in independent living in the community.

## Limitations of this Study

Like all research this study had its limitations. The participants were few in number so transferability of the results to others dealing with the same illnesses and community treatment orders is limited. Perhaps there are unique features of the CTO services provided in the geographical area where participants lived that may have had an effect on the results. Because the objective of CTOs is to increase care in the community, future replications of this qualitative study should investigate the rates of community services used before and following a CTO. The reduction of police involvement provides a realistic backdrop to improvement in clients' QoL. The number of police calls in addition to contact time would provide a more realistic measure of the frequency of such crisis interventions by the police. Finally, the study was not 'blind' and interviewers in this study were student occupational therapists; it is possible that more experienced interviewers may have gleaned additional insights.



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## APPENDIX A

### The Corring Quality of Life Interview Protocol (CQoLIP)©

Author: Deborah J. Corring, PhD

The Corring Quality of Life Interview Protocol is designed to be used with an individual in a one to one interview and is focused on exploring quality of life issues important to that person. The protocol has been developed using the results of a qualitative research project that involved individuals diagnosed with schizophrenia and other severe and persistent mental illnesses in the identification of the important domains of quality of life for these individuals.

Diagnosis:	Duration of mental illness:
Gender:	Age:

Person completing interview:
Date:

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## Corring Quality of Life Interview Protocol

### The CQoLIP Interview Protocol

#### *Domain – Experience of Illness*

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##### *Sub component probes/inquiries*

What is it like for you to experience the symptoms of your illness?  
Are they causing you to be afraid or anxious?  
Are the medications you take helpful in controlling symptoms? Are the medication side effects troubling you? In what way?  
Do you feel the illness is affecting your plans for the future? (career, marriage and family plans)  
Are you worried about the return of psychotic symptoms?  
Have you received education about your illness?

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##### *Cues*

Signs of hallucinations, disordered thought, lack of motivation etc. present  
Expressing feelings of anxiety or fear, signs of distress  
Demonstrates knowledge of medications and their side effects  
Expressing sense of loss of dreams and hopes once had for the future  
Overprotective of self, expressing feelings of feeling vulnerable, unwilling to take risks, family advising client to avoid stress  
Demonstrates knowledge/ understanding of illness

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##### *Response*

Issue(s)  
Enabler    Barrier

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#### *Domain – Relationships*

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##### *Sub component probes/inquiries*

Tell me about your relationships with your family. How do they help you? Are they sometimes not helpful? How understanding are they of you and your illness?  
Do you have an intimate relationship with someone? If answer is yes - Is this person able to understand you and your illness? Tell me more about how he/she understands and supports you or does not understand and support you. If response is no – Would you like to have an intimate relationship with someone? What is stopping you?  
Do you have people in your life that you consider to be friends?  
Are they supportive?  
Do they sometimes have an issue with your mental illness?  
Do they also have a mental illness?  
Please describe the relationship you have with the service providers with whom you interact?

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##### *Cues*

Can provide description of relationships with family. Able to identify how family supports or doesn't support. Relays how family understands/doesn't understand their illness.  
Able to describe an individual with whom they have an intimate relationship  
Able to articulate what they are hoping for in relationships for the present and the future  
Able to talk about an individual or individuals with whom they have a friendship  
Talks about withdrawing from contact with friends when ill  
Involvement in peer support activities  
Talks about how professionals are helpful, or not helpful  
Describes professionals as caring or not caring

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##### *Response*

Issue(s)  
Enabler    Barrier

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#### *Domain – Occupation*

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##### *Sub component probes/inquiries*

Tell me about what you do each day.  
Are you happy with how much you do each day?  
If says no, then What would you like to be doing?  
What's holding you back?  
Do you work or wish to work?  
Do you have any concerns or worries about working?  
What type of work would you find meaningful?  
What has been your experience with employers?

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##### *Cues*

Evidence of engagement or non engagement in meaningful occupations

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Complaints of lack of things to do, being bored, having too much time on his/her hands  
 Articulates areas of interest  
 Articulates interest in working past or present  
 Articulates areas of concern  
 Articulates interest in a particular type of work  
 Talks about past experience with employers, co- workers etc.

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*Response*

Issue(s)  
 Enabler    Barrier

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*Domain – Sense of Self*

*Sub component probes/inquiries*

How do you feel about your own mental illness?  
 How do people that you meet react once they have discovered that you have a mental illness?  
 Why do you think you/they react the way they do?  
 What might help you/them to react differently?  
 How would you describe your strengths as a person?  
 What is that you do best?  
 Tell me about a time when you helped someone.

---

*Cues*

Describes a poor sense of self  
 Describes elements of self stigma  
 Describes experiences of stigma OR experiences of acceptance by others  
 Talks about societal attitudes, effects of media images etc.  
 Able or unable to express ways to manage reactions from others  
 Is able to identify how these reactions help or hurt  
 Able or unable to identify strengths  
 Able or unable to identify a personal strength  
 Describes an experience of helping others

---

*Response*

Issue(s)  
 Enabler    Barrier

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*Additional Issues Identified in Interview*

Probes/ Inquires to be used

- What are the important things in your life that we have not talked about yet that you are happy with?
  - What are the important things in your life that we have not talked about yet that you are unhappy with?
  - What helps/might help you obtain these important things?
  - What gets in the way of you obtaining these important things?
- 

*Response*

Issue(s)  
 Enabler    Barrier

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Summary Chart

Domain	Issue(s)	Enabler	Barrier
Experience of Illness			
Relationships			
Occupation			
Sense of Self			
Other			

Action Plan

Additional questions:

Community Treatment Order:

Do you remember when your CTO started?  
 Tell me about life before.  
 Tell me about life after.

Police contact time:

Have you had contact with the police?  
 If so, how was it?  
 What is your relationship with them?  
 Has your contact time with the police changed since being on a CTO?

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## APPENDIX B

### The Corring Quality of Life Interview Protocol (CQoLIP)© Evaluator Handbook

#### Introduction

Two dominant themes emerged during analysis of the participants' transcripts in the research project noted above. They crossed all domains, influenced the linkages between domains, and clearly influenced how individuals frame their expectations regarding quality of life. The first was the presence of stigma (as experienced and as anticipated) from others with whom they interact, but also the experience of stigma towards self and others like "them" (others with mental illness). Stigma influenced their actions in everyday life as well as their planning for the future in a very profound way. The second was the pervasive fear of the symptoms of psychoses (hallucinations, and delusions), and the possible reoccurrence of psychotic symptoms. Living one day at a time, being overprotected by family members, and guarding against "getting worse" also influenced their actions in a profound way.

Analysis of the interview and focus group data also resulted in the identification of four primary domains important to quality of life for individuals living with mental illness: (1) the experience of illness; (2) relationships; (3) occupation; and

(4) sense of self. Within each domain sub components were identified as noted in the table below. The domains and their sub components are not linearly related, hierarchical or progressive. For example, individuals may feel less satisfied with a particular domain at a point in time perhaps due to a relapse of the illness, but, once recovered, regain satisfaction in that same domain. The domains are not entirely independent of each other. They may often be linked. All are important in their own right, and need to be explored independently. Enablers and barriers to achieving satisfaction in these domains were also identified in the data analysis. The variations in the desired balance between domains are very much determined by the individual.

The results of this study suggest that quality of life for individuals living with severe and persistent mental illness can be defined as the balance of achieving a positive day to day experience of illness, a full range of supportive relationships, the acquisition of a meaningful, manageable activity level, a positive sense of self and a feeling of being valued by helping others. Necessary supports to these domains for some individuals include adequate financial resources, and spirituality.

The results of this study support the WHO assertion (Orley et al., 1998) that quality of life is an individualized, subjective, experience. Quality of life is indeed a "moving target" changing in response to illness, age and other contextual factors specific to the individual.

Finally, in order to gain a full understanding of quality of life issues pertinent to each individual, the results of this study indicate that quality of life is best evaluated using qualitative methods, at least until we are at the point of understanding the construct well enough to develop the appropriate quantitative measures.

The Corring Quality of Life Interview Protocol (CQoLIP)© has been developed for use by researchers/ evaluators as a possible alternative and/or adjunct to the current measurement tools available. The process for development of this protocol is borrowed in large part from that developed by Morse and colleagues (Morse et al., 2000) in the development of qualitatively derived assessment guides, with adaptations to suit this tool's use as an interview guide for research and evaluation.

#### The CQoLIP Interview Process

This protocol has been constructed using the richness of the data analysis of the qualitative research inquiry that has preceded it. The questions that make up the protocol are to be used much like probes are used in a qualitative interview so that issues of importance to the individual involved can be thoroughly identified and understood. The interview calls upon the researcher/evaluator to utilize critical thinking, facilitation and creative problem solving skills to ensure that the issues important to the individual's achievement of a desired quality of life are identified, thoroughly described, and personally evaluated.

The interview guide consists of three components: the four domains identified as important to quality of life in this study; inquiries (probes) associated with the subcomponents of each of these domains drawn from the analysis of the data of this study; and cues that the researcher/evaluator should watch for as possible indicators of the presence of issues/concerns in a domain. The inquiries (probes) and cues are intended to assist the researcher/evaluator in supporting the client to fully describe in more detail the important elements of their desired quality of life.

Although the guide appears to be linear with distinctly separate components, the components are closely related, and interlink and overlap with each other. Clients will differ in how they move through the guide, and in the emphasis or importance they assign to different components, and should be allowed to do so at a level with which they feel comfortable. There should be no imposed time limits. The interview can be completed in one interview or several interviews depending on the ability and willingness of the client to participate. The protocol can be used at any time in the treatment and rehabilitation process, and can be repeated at any point it seems reasonable to do so.

As the CQoLIP is a semi-structured interview approach it is important that the evaluator have and use all of their interviewing skills. Probing for complete responses with persons who are not overly verbal, being sure to validate all assumptions made, and supporting the client through the process will be necessary. It is preferred that the interview be audio taped so that the evaluator can focus on the above noted areas. If this is not possible the evaluator should either take the time in the interview to make careful notes about the client responses, or do so immediately following the interview.

As noted previously the interviewer must take the time to fully explore all sub-component probes/inquiries for each domain. This is not a time-limited process nor does it need to be completed in one interview.

#### Analysis of Responses

Review audiotapes or notes from interview(s) for each domain, identify the issues that the client has noted are important to them in each domain, and the barriers and enablers that are associated with these issues. Note these in the response section of each domain. Complete the summary chart. If there are issues that do not fit within one of the domains note them the "Other" section. Use the summary to develop an action plan with the client.

The summary and action plan can be used for reporting back to the clinical team and as the foundation of a clinical note. Finally, as this is a new research tool and still under development please complete the research report and return to the author at [deb.corring@rogers.com](mailto:deb.corring@rogers.com).

Why use the CQoLIP with your client(s)?

The benefits of using this protocol are several. It can provide a detailed, descriptive story of the person's perspective on their quality of life at the place and time of evaluation. It can be used at any stage of illness, or years of experience with an illness. It will individualize our understanding of the issues important to the person in question, and facilitate our understanding of the types of services that clients find helpful to achieving their desired quality of life. It will enable the evaluator to track issues over time that add or detract from quality of life.

The CQoLIP© is likely to be criticized as a useful outcome measure by some researchers/evaluators and administrators in the mental health field. The obvious need for sufficient time to administer it well (much longer than most quantitative tools), and the skills an experienced researcher/interviewer requires may cause problems for those researchers conducting time pressured evaluation and research projects.

It has been this researcher's observation that many investigators add a quality of life measure to their overall study (one that generally does not focus solely on quality of life but more likely on treatment effectiveness of a medication or other treatment) as a concession to the current political correctness of including a quality of life measure in research. When asked what measure they are using to evaluate the quality of life, most respond quickly with the name of the measure but when questioned further regarding what domains are evaluated with the measure they are less able to respond with specifics. As noted in the literature review of quality of life, even studies that focus on the issue of quality of life specifically use measures that have been developed without the benefit of defining the construct.

So one might ask: Is evaluating the quality of life of individuals with severe and persistent mental illness sufficiently important to use an evaluation tool like the CQoLIP© that is admittedly time, labour, and skill intensive? The significant activity and participation limitations (using the International Classification of Functioning, Disability and Health as a framework) that individuals living with a diagnosis of schizophrenia experience, confirm that acquiring a satisfactory quality of life while living with this severe and persistent illness is a complex, and challenging task. Acquiring an adequate appreciation of this complex construct necessitates the commitment of time and resources. The CQoLIP© has been developed to explore the complexity of the components of quality of life for the individual, and is ideally suited to provide a deeper understanding of the issues in our ongoing efforts to develop an adequate definition of this construct that will be supported by clients and professionals alike. Decisions to use this tool in measuring quality of life will depend upon the answer to the opening question in this paragraph. Like the construct of quality of life this will be an individually influenced decision.

*Table 1. Domains and sub-components*

Domain	Sub Components	Enabler	Barrier
Experience of Illness	Tyranny of psychoses		x
	Medications	x	x
	Loss of life roles/dreams		x
	Financial resources limited		x
	Living one day at a time	x	
	Illness education	x	
	Gaining control	x	
Relationships	With family members	x	x
	With intimate others	x	x
	With friends	x	x
	With the "own"	x	
	With service providers	x	x
Occupation	Lack of things to do		x
	Keeping active	x	
	Working	x	
	Attitudes of employers		x
Sense of Self	Shaped by societal attitudes		x
	Shaped by the media		x
	Self doubt/criticism		x
	Positive self image	x	
	Feeling valued	x	
	Spirituality	x	