TOWARDS MORE EFFECTIVE PUBLIC HEALTH PROGRAMMING FOR INJECTION DRUG USERS: DEVELOPMENT, EVALUATION AND APPLICATION OF THE INJECTION DRUG USER QUALITY OF LIFE SCALE

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ABSTRACT

Background: Little attention has been given to the assessment of quality of life (QOL) in injection drug users (IDUs). Some studies have suggested that existing measures are inadequate for use in IDUs.

Objectives: The objectives were: 1) to develop and evaluate a QOL measure for IDUs, the Injection Drug User Quality of Life Scale (IDUQOL), 2) to describe the QOL of cocaine and heroin IDUs and identify its constituents and correlates, and 3) to describe the relation between the QOL of cocaine and heroin IDUs and the use of public health programs.

Methods: The psychometric properties of the IDUQOL were assessed in 61 IDUs, 85% of whom were re-interviewed within 4-weeks. The Flanagan Quality of Life Scale was used to assess the criterion validity of the IDUQOL. The IDUQOL was subsequently applied in a study of 260 Montreal IDUs to identify their most important life areas. Associations between QOL and the use of public health programs and other correlates were assessed using multiple linear regression.

Results: The IDUQOL had good psychometric properties: the test-retest reliability was within accepted standards (intraclass correlation coefficient = 0.71) and the concurrent criterion validity between the IDUQOL and the Flanagan was moderate (Pearson coefficient = 0.57). In the study of 260 Montreal IDUs, housing was the most frequently selected life area of cocaine IDUs. Heroin IDUs most frequently selected money and feeling good about yourself. Both cocaine and heroin IDUs were generally dissatisfied with how these life areas fared. QOL was significantly better for HIV positive IDUs and IDUs who used meal programs, and was worse for IDUs who attended shelters and emergency departments. No strong relations were found with needle exchange program use, methadone or other drug treatment.

Conclusion: The IDUQOL appeared to be a conceptually clear and culturally relevant QOL instrument with good psychometric properties. Programs that address the life conditions of IDUs might be needed foremost to other initiatives. Understanding the constituents and correlates of the QOL of IDUs is important to the development of more effective programs to curb disease transmission, and improve the well-being of IDUs.

RÉSUME

Introduction : Peu d'études ont abordé l'évaluation de la qualité de vie (QdV) parmi les utilisateurs de drogues par injection (UDI). De plus, elles ont déterminé que les instruments que nous possédons sont inadéquats pour utilisation auprès des UDI.

Objectifs : Les objectifs étaient : 1) développer et évaluer une échelle de mesure de la QdV des UDI, l'IDUQOL, 2) décrire la QdV des UDI type cocaïne et type héroïne et identifier ses éléments et les variables qui lui sont corrélées, et 3) décrire la relation entre la QdV des UDI et l'utilisation des programmes de santé publique.

Méthodologie : Les propriétés psychométriques de l'IDUQOL ont été évaluées parmi 61 UDI, dont 85% ont été interviewés deux fois à quatre semaines d'intervalle. L'échelle de la qualité de vie de Flanagan a été utilisée pour évaluer la validité de critères de l'IDUQOL. L'IDUQOL a été par la suite utilisé dans une étude impliquant 260 UDI de Montréal pour identifier les aspects les plus importants de la vie des UDI. Les associations descriptives entre la QdV et l'utilisation des programmes de santé publique et les autres variables ont été explorées utilisant une régression linéaire multiple.

Résultats : Les propriétés psychométriques de l'IDUQOL étaient bonnes : sa fiabilité était acceptable (ICC=0.71) et la concordance entre l'IDUQOL et l'échelle de Flanagan était modérée (corrélation de Pearson=0.57). L'étude menée auprès des 260 UDI a démontré que le logement était l'aspect le plus fréquemment sélectionné par les UDI type cocaïne alors que les UDI type héroïne ont plus fréquemment sélectionné l'argent et le sentiment de bien être. En général, les UDI étaient mécontents du fonctionnement de ces importants aspects de leur vie. La QdV était significativement meilleure parmi les UDI VIH positifs et les UDI qui ont utilisé les programmes de repas. Par contre, cette QdV était moins bonne parmi les UDI qui ont utilisé les refuges et les urgences. Aucune association importante n'a été identifiée

entre la QdV et l'utilisation de programmes d'échanges de seringues, la méthadone ou les autres traitements pour drogues.

Conclusion : L'IDUQOL est une échelle de mesure de la QdV qui a de bonnes caractéristiques psychométriques et qui semble être adaptée culturellement aux UDI. Les programmes qui affectent les conditions de vie des UDI semblent être plus importants que les autres programmes. L'identification des déterminants et des variables associées à la QdV des UDI est nécessaire pour le développement de programmes plus efficaces à réduire la transmission de la maladie et à améliorer le bien-être des UDI.

STATEMENT OF ORIGINALITY

There are several elements of this thesis that constituted original scholarship and advanced knowledge in the domains in which the research was conducted. Firstly, I was involved in the development of the Injection Drug User Quality of Life Scale (IDUQOL). To my knowledge, this is the first quality of life instrument to be developed with input from and for use with injection drug users (IDUs). In addition, I conceived and conducted an evaluation study of the IDUQOL. The study results indicated that the IDUQOL had good psychometric properties, was well received by Montreal IDUs, and captured their individual concept of quality of life. This work provides addiction and HIV researchers with a tool that can be used to better understand the psychosocial aspects of addiction and lives of IDUs, and hence, to develop and evaluate more pertinent programs for IDUs. In addition, this work should help to advance knowledge in the field of quality of life. The IDUQOL is an individualized quality of life measure, a promising type of quality of life scale that is relatively new to the field. The results of the evaluative study provided further insight into the stability of the concept and constituents of quality of life, and from the unique viewpoint of IDUs.

I subsequently planned and conducted a quality of life study in over 250 IDUs. This was the first such investigation to ask IDUs about what was important to them and what constituted their quality of life, and to examine the relation between the quality of life of cocaine and heroin IDUs and the use of public health programs. Few studies have examined the quality of life of drug addicts, and none to my knowledge in relation to cocaine and heroin addiction. As described in this thesis, cocaine and heroin have different pharmacologic actions on the brain and therefore, it is not surprising that the consequences of addiction manifest distinctly for intravenous cocaine and heroin users. In developing public health programs for IDUs in Canada during the HIV era, consideration of the predominant drug of addiction in IDU populations has been markedly absent. This study provided unique insight into the sociological, psychological and circumstantial aspects of individuals addicted to

cocaine and heroin, which may help public health authorities to direct better prevention programs for IDUs. Finally, the results of this study were among the first to demonstrate that programs that address the health, financial situation and living conditions of IDUs might be more effective for curbing disease transmission.

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INTRODUCTION

Drug addiction is a chronic disease that has adverse consequences on psychological, social and physical health. The prolonged use of psychoactive drugs produces changes in the normal functioning of the brain leading to dependence, tolerance, craving and relapse, which can persist for an addict's entire life. Drug addicts often compromise the things that are important to them such as relationships, health or personal safety, in order to satisfy the intense craving of their habit and/or to curb painful withdrawal symptoms. The illegality of psychoactive drugs only serves to further compromise the well-being of drug users, driving them to the margins of society and exposing their vulnerability. Consequently, drug users in general, and injection drug users (IDUs) in particular, engage in behaviours that place them at extremely high risk of illness and infection by transmissible pathogens.

The emergence of the human immunodeficiency virus (HIV) in IDUs the early 1980s generated an interest in IDUs and in the behaviours surrounding drug use. Public health programs were developed to minimize the harms associated with the injection of illicit drugs. These included messages to stop needle sharing and instructions on how to inject more safely, as well as the implementation of needle exchange programs – places where IDUs could easily access clean needles and injection paraphernalia. Substantial controversy ensued for several years regarding the effectiveness of needle exchange programs in preventing HIV transmission. More recently, influential Canadian addiction and public health authorities have asserted that a safe and sanctioned place where IDUs can inject is the next logical step in HIV prevention. However, conclusive evidence regarding the effectiveness of safer injection rooms is lacking. Like needle exchange programs, injection rooms were first implemented in Europe, where heroin is the predominant drug of addiction. The frequency of cocaine addiction among Montreal and Vancouver IDUs questions the feasibility of this approach in Canada.

The public health response to HIV in IDUs has primarily focused on the reduction of

needle sharing and risky injection behaviours. Little attention has been given to the social, economic and psychological aspects that are often problematic and central to risk behaviour and illness. Moreover, few studies have examined the needs of IDUs to identify important areas for intervention. Research that is *preparatory to intervention* has been lacking in programming for IDUs, despite its exigency in directing more effective public health efforts. Thus, this study explored the quality of life of IDUs to gain a better understanding of the welfare, needs and priorities of IDUs. The relation between quality of life and the use of public health programs and other correlates was examined to gain insight into the factors that affect the lives of IDUs. The goal in investigating the quality of life of IDUs was not only to improve the well-being of IDUs, but also to help propose more rational preventive strategies to curb disease transmission.

1 BACKGROUND

1.1 DRUG ADDICTION

The global production and distribution of illicit drugs together with the current AIDS pandemic has forced government and public health officials to reconsider the programs and policies that are employed to reduce the harmful consequences of injection drug use (Nadelmann et al., 1997). This chapter seeks to provide an overview of drug dependence or addiction, its consequences, and the programs that are currently available to IDUs. It will then examine the concept of quality of life and how it may aid in the development of public health strategies to reduce disease transmission, and to improve the circumstances of IDUs.

Drug use and addiction have existed for many years, traversing most continents and cultures. The number of available illicit drugs continues to grow, and it is estimated that there are more than eight million IDUs worldwide (Wodak and Hoy, 2002). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM IV) the essential feature of substance [drug] dependence is "a cluster of cognitive, behavioural, and physiological symptoms indicating that the individual continues use of the substance [drug] despite significant substance [drug]-related problems. There is a pattern of repeated self-administration that can result in tolerance, withdrawal, and compulsive drug taking behaviour" (American Psychiatric Association, 2000). An individual who is severely addicted to drugs will spend the majority of his or her waking hours, wanting, procuring and taking the drug (i.e., heroin and cocaine) at the expense of important social and occupational activities. He or she will often continue to use the drug, despite realization of the destructive effects of addiction.

Tolerance is the need for an increasing amount of a drug to achieve its desired effects, or a diminished effect with use of the same amount of the drug. Metabolic and pharmacologic tolerance result from adaptive changes in the brain and body's ability to metabolize and respond to the drug; an individual who is accustomed to heavy opiate use may use opiates at level that is lethal to the new user. Varied degrees of

tolerance develop according to the drug and to its differential effects on the central nervous system (American Psychiatric Association, 2000). Behavioural tolerance involves a reduced response on reward seeking behaviour consequent to the increasing negative effects of the drug, and environmental tolerance results from having the drug administered in a set of familiar cues (Brust, 1993). It has been demonstrated that addicts who have undergone successful detoxification and treatment will relapse to drug seeking behaviour upon return to former drug using neighbourhoods (Dole, 1972).

Physical dependence is usually defined by an altered state of biology that is induced by chronic drug administration. This results in a complex set of biological events when the blood or tissue concentrations of a drug decline in a prolonged, heavy drug user (American Psychiatric Association, 2000). Withdrawal is a maladaptive behaviour change that is accompanied by physical and/or cognitive symptoms. The physical symptoms of withdrawal can be so discomforting that the addict will often take the drug to relieve these symptoms.

The desirable effects that accompany drug use are largely a result of the drug's pharmacological action on the brain. After crossing the blood brain barrier, the drug binds to a receptor in the mesocorticolimbic dopaminergic system of the midbrain. The neurons in this mesocorticolimbic dopaminergic system manufacture the neurotransmitter dopamine, which is stored in their nerve endings ready for release into the synapses. When electrical signals arrive at the nerve endings, dopamine is released and dopamine receptors on nearby neurons in the nucleus accumbens are stimulated (Goldstein, 1994). Substantial animal data have implicated the nucleus accumbens as the critical target in the mechanisms of action of all drugs of abuse (McLeman et al., 2000). Among their other effects, heroin and cocaine interfere with the release and uptake of dopamine, causing an increase in dopamine in the synapses of the nucleus accumbens. Although cocaine and heroin have different actions on different parts of this pathway, dopamine is the principal neurotransmitter implicated in the reward and reinforcing mechanisms of drug addiction. The dopaminergic

pathway is believed to be the reward pathway that controls normal survival behaviours such as eating, drinking, and sex (Goldstein, 1994). Addictive drugs act on the brain to satiate this same drive, and it is thought that this is what makes a drug addictive. The administration and pharmacologic actions of cocaine and heroin are discussed in detail below.

1.1.1 Heroin

Heroin was the trade name of a drug marketed in 1898 by the Bayer Company to replace the presumed more addictive cough suppressant and analgesic, morphine (Musto, 1997). The first known synthesis of heroin (diacetylmorphine) took place in the laboratory of C.R. Wright in England in 1874 (PBS and WGBH/Frontline Online, 1998). Heroin is produced by the acetylation of the morphine molecule that comes from the active ingredient of opium – the alkaloid morphine – of the poppy *Papaver somniferum*. Heroin is generally administered by vein but can also be smoked. Today heroin is a drug available on the black market, with a street price of $40 for a 10^{th} of a gram – typically one to two injections – in Montreal. Commercially available opiates such as codeine, dilaudid and demerol are prescribed as analgesics, anaesthetics, antidiarrheal agents or cough suppressants and are generally taken orally.

There are two forms of heroin, brown or white. Pure heroin is usually white, and street heroin is generally brown from impurities and additives (i.e., other drugs, sugar, starch, powdered milk, quinine, strychnine or other poisons) (Narconon Arrowhead, 2002). Both brown and white heroin are available on the streets of Montreal (St-Amour and Morisette, 2001). Because the purity and potency of heroin is unknown prior to injection, the potential for overdose is very high. To prepare heroin for injection, it is placed in a cooker (i.e., a spoon or other container for heating), and water is drawn through a syringe and mixed with the heroin in the cooker. If brown heroin is to be injected, a few drops of lemon juice or ascorbic acid, such as "C" powder from a pharmacy, are also added to facilitate dissolution (St-Amour and

Morisette, 2001). The cooker is then heated until the heroin dissolves. Filters, such as cotton, paper or a cigarette filter are usually used to prevent injection of impurities. The filter is placed in the cooker, and the drug solution is drawn into the syringe and injected.

As with all opiates, heroin achieves its desirable pharmacologic effects through binding with an opiod receptor in the ventral tegmental area of the midbrain. There are three major types of opiod receptors, mu, delta and kappa, which are found throughout the brain and spinal cord, in the neural plexuses of the gastrointestinal tract, other parts of the autonomic nervous system and on white cells (Jaffe et al., 1997). Several endogenous opiod peptides – naturally occurring ligands of the opiod receptors – have been identified, the most important of which are the enkephalins, β-endorphin, and dynorphin A. These endogenous opiod peptides have been implicated in behavioural and mood changes, in the regulation of pain threshold, in the endocrine and immune systems, and in autonomic effects (i.e., body temperature, smooth muscle motility, heart rate, and blood pressure) (Jaffe et al., 1997). Although heroin itself is quite inactive as an opiod peptide, it is highly lipid soluble and can rapidly enter the brain where it is metabolized to 6-mono-acetyl morphine and becomes able to bind to the opiod mu receptor. The binding of 6-mono-acetyl morphine to the opiod mu receptor slows down the release of the neurotransmitter gamma-amino-butyrate. This results in increase firing of the dopaminergic neurons in the ventral tegmental area, and a subsequent increase in dopamine in the nucleus accumbens (Goldstein, 1994).

Heroin injection is followed by a sharp increase in brain opiod levels, which produces feelings of intense euphoria. Heroin also produces a sense of tranquillity, decreased apprehension, suppression of the cough reflex, and appears to ameliorate depression, to control anxiety, to reduce anger and to dull self-perception in some users (McKenna, 1982). Undesirable effects of heroin include a slowing of digestion in the small and large intestines leading to constipation, depression of respiration, constriction of the pupils and changes in the neuroendocrine system. Nausea and

vomiting frequently occur in the inexperienced user (Jaffe et al., 1997). Repeated use of heroin over several days or weeks produces tolerance and dependence, therefore increasing the amount of heroin required to prevent withdrawal and the cost of the user's habit. Established IDUs can have habits in the range of $200-$300 per day (Rawson et al., 2000).

Individuals who are addicted to heroin tend to develop such regular patterns of use that daily activities are typically planned around obtaining and injecting heroin. Because heroin has a half-life of two to three hours, the opiod receptors are quickly cleared following discontinuation of chronic use. Withdrawal symptoms (i.e., chills, runny nose) can be observed within eight to 12 hours. The acute withdrawal syndrome is extremely uncomfortable and includes symptoms of hypertension, abdominal cramps and severe flu, which reach peak intensity within 48 hours and generally subside over a period of five to seven days. Less acute symptoms such as feelings of decreased self-esteem, anxiety and other psychiatric disturbances can last for weeks to months (American Psychiatric Association, 2000). However, these feelings cannot be solely attributed to withdrawal as affective disorders and antisocial personalities are prevalent in addicted individuals (Lipsitz et al., 1994). As well, the psychological aspects, conditions and problems that preceded addiction often surface upon discontinuation of drug use, thus causing further discomfort.

1.1.2 Cocaine

Cocaine is a naturally occurring alkaloid found in the leaf of the *Ethroxylon coca* tree that is indigenous to western South America. Natives have used the coca leaves for centuries to obtain their stimulant effects. The pure cocaine alkaloid was isolated in 1859 by Albert Niemann at the University of Göttingen in Germany, and was the first local anaesthetic to be discovered (Musto, 1997). Like heroin, cocaine's addictive properties were largely unknown, and cocaine soon became commercially available in America and in Europe as an additive of Coca-Cola and other tonics. Cocaine was also used for medicinal purposes as an eye anaesthetic, and in treating hay fever and

other allergies due to its ability to shrink nasal and sinus membranes (Musto, 1997). Cocaine's addictive properties were eventually recognized, and restrictions were placed on the manufacturing and distribution of coca products. Cocaine is currently an illicit drug and sells for $20 per quarter gram – generally consumed in two to three injections – on the black market in Montreal.

There are two forms of cocaine – the hydrochloride powder form that can be snorted or dissolved in water and injected, and the alkaloid form, crack cocaine, which is smoked. Both forms of cocaine come from coca paste, which is made by dissolving dried coca leaves in a solution of kerosene or gasoline, alkaline bases, potassium permanganate and sulphuric acid. Cocaine hydrochloride is made by the addition of hydrochloric acid to the coca paste, while mixing the coca paste with a base produces crack (Gold and Miller, 1997). Crack cocaine emerged in the 1980s and became popular because of its low cost and the rapidly achieved high blood levels of cocaine that accompany its use. Crack cocaine is easily volatized and it is pumped directly to the brain by the respiratory system. It has a low bioavailability of 6% to 32% due to pyrolysis that occurs upon heating and volatization (Gold and Miller, 1997).

Injectable cocaine is prepared similar to heroin; cocaine is placed in a spoon or other container and water is added via a syringe. Because cocaine readily dissolves in water, it is generally not heated. Filters are sometimes used (St-Amour and Morisette, 2001) – they are placed in the spoon and the cocaine solution is drawn into the syringe and injected. Injected cocaine has a bioavailability of 100% and therefore it is the purity of the injected substance that determines the subsequent blood concentrations (Gold and Miller, 1997). The effects of injected and smoked cocaine can be felt after approximately 10 seconds and last for 10 to 20 minutes. By comparison, the onset of activity of intranasally administered cocaine takes three to five minutes. Regardless of the route of administration, the pleasurable affects of cocaine disappear even before blood concentrations substantially fall. Cocaine is rapidly destroyed in the bloodstream and has a half-life of 30 to 50 minutes

(American Psychiatric Association, 2000) – much shorter than that of heroin – thus, frequent administrations are necessary to maintain its effects.

Cocaine's most important clinical action is its ability to block the normal conduction of a nerve impulse (Gold and Miller, 1997). Cocaine binds directly to the dopamine transporter in the ventral tegmental area, which prevents the reuptake of dopamine and causes a marked elevation of dopamine in the synapse; the reuptake of dopamine normally terminates action at the synapses. Consequent to these excess dopamine levels, the brain reward pathways (i.e., feelings of pleasure and satisfaction) are altered. This is the most widely accepted explanation for cocaine-induced reinforcement – the increased extracellular dopamine concentrations in the mesolimbic and mesocortical reward pathways in the brain (Boyarsky and McCance-Katz, 2000). Prolonged periods of cocaine use can lead to sustained neurophysiological changes in the brain and hence, to lasting changes in the brain reward pathways (Hyman, 2001).

The acute effects of cocaine begin when it reaches the brain, affecting the mood, cognition and drive states such as hunger, thirst and sex (Gold and Miller, 1997). An immediate and intense euphoria is generally felt, dependent upon the dose and tolerance of the user. This includes an intense pleasurable sensation, a magnification of normal pleasures, a release of social inhibitions, unrealistic feelings of cleverness, and a sense of great competence and power. Cocaine can also enhance sexual activity and the intensity of orgasms. Consequently, sexual fantasies that the user ordinarily would not condone may be acted upon (Goldstein, 1994). Depressant effects such as sadness, decreased blood pressure and psychomotor activity can also be seen in chronic, high-dose users (Gold and Miller, 1997). Side effects of cocaine include tachycardia, hypertension, diaphoresis, a lowered seizure threshold, tremors, urinary and bowel delay and retention, muscular contractions and cutaneous flushing (Gold and Miller, 1997). The magnitude and direction of behavioural and physiological changes depend on many variables including the amount of cocaine injected, the

chronicity of use, and the characteristics of the user (American Psychiatric Association, 2000).

Unlike heroin, whose physical withdrawal generates a sustained, daily habit, cocaine can be used at regular bi-weekly intervals, monthly, daily, or continuously for days in binges. A cocaine binge consists of frequent injections at short intervals (i.e., several times per hour) over a period of a few days without eating or sleeping. The binge generally ends with a crash when the drug supply is exhausted. Intense craving follows, which can lead to another binge. Bingeing is not characteristic of all cocaine habits, and only a fraction of users engage in this self-destructive pattern of use (Goldstein, 1994). The large doses of cocaine that are consumed during binges can cause irregular heartbeats, heart stoppages and even strokes because of the spasm of blood vessels in the brain (Gold and Miller, 1997). Large quantities of alcohol are often ingested alongside cocaine to enhance its euphoric effects and/or to alleviate its dysphoric and stimulant effects (Boyarsky and McCance-Katz, 2000). Because of these extremely potent euphoric effects of cocaine, individuals who use it can become addicted in a very short period of time. Cocaine addicts can spend large sums of money on cocaine, often necessitating involvement in illegal activities and neglect of other responsibilities (American Psychiatric Association, 2000). A clinician in the field wrote "...virtually all thoughts are focused on cocaine during binges; nourishment, sleep, money, loved ones, responsibilities and survival lose all significance" (Goldstein, 1994).

1.1.3 Treatment for heroin and cocaine addiction

The termination of drug use is an extremely difficult process that can involve both physical and psychological processes. It is therefore essential that treatment programs encompass a multifaceted approach. There are many different types of treatment including abstinence-oriented approaches, and treatments that seek to reduce drug use and its complications through substitute medications (Brisette, 2001). Drug treatment can be most broadly classified in two categories: 1) the treatment of

acute withdrawal and/or the initial attainment of abstinence and 2) the maintenance of abstinence and prevention of relapse (Boyarsky and McCance-Katz, 2000). The latter is much more difficult to attain; most addicts will undergo treatment several times before ultimately stopping use. Consequently, fluctuations between treatment, abstinence and use are common, thus emphasizing the chronic nature of addiction.

There are several effective pharmacological approaches for opiate or heroin addiction including agonists, drugs that have similar effects to heroin, and antagonists, drugs which block the effect of heroin. Clonidine and lofexidine are two agonists that are used to minimize autonomic-mediated withdrawal, allowing the addict to be drug-free in as little as three days (Boyarsky and McCance-Katz, 2000). Likewise, short-term treatment with the agonist methadone can be used to block opiate withdrawal by gradually tapering the methadone dose over a period of one to three months. However, short-term (and non-pharmacological treatments) have been found less effective in achieving long-term abstinence, and in reducing drug use in opiate addicts (Kleber, 1981).

Long-term maintenance treatments, of which methadone maintenance is most common, are more effective in reducing drug use and its associated physical, psychological and social morbidity (Farrell et al., 1994). Methadone maintenance has also been shown to reduce HIV transmission (Metzger et al., 1993; Langendam et al., 2000), probably because of the decreased craving and drug use and increased stability of the addict that accompany its use.[1] Methadone has a long half-life of 24 hours and hence can be taken only once daily (Wilson et al., 1995). Although methadone can block withdrawal at low doses, higher doses have been found to improve treatment retention, to decrease craving and to produce greater reductions in drug use (Boyarsky and McCance-Katz, 2000). Withdrawal from methadone is very difficult and addicts often remain in treatment for many years. Consequently, there is some dissatisfaction with this medically supported abstinence (Boyarsky and McCance-

[1] Low-threshold methadone maintenance, which has no strict requirements for complete drug abstinence, is also used to reduce the harms associated with injection drug use.

Katz, 2000). In addition, the demand for methadone treatment is generally greater than what is available in most countries (Wodak and Hoy, 2002).

Although not widely used in Canada, other available substitution therapies include levo-alpha-acetylmethadol, buprenorphine, and naltrexone. Levo-alpha-acetylmethadol is an alternative to methadone, which has a half-life of 92 hours allowing it to be administered every two to three days. Withdrawal from levo-alpha-acetylmethadol is less difficult than that from methadone (Boyarsky and McCance-Katz, 2000). Buprenorphine is a partial agonist that suppresses withdrawal and blocks the effects of heroin at high doses. Buprenorphine has been mainly used in Europe, and appears to be a valuable alternative for maintenance of patients with moderate addiction to opiates (Laqueille et al., 2001). Naltrexone is an antagonist that is used in some settings as a relapse prevention strategy to block the acute effect of opiates. Despite the existence of these treatments that have shown to be effective in reducing heroin use, some individuals continue to use drugs, to commit crimes and to engage in high-risk behaviours while on treatment. Successful pharmacologic therapies need to be used in combination with counselling and other support services and unfortunately, relapse to drug use remains common.

Many pharmacological treatments have been studied for treating cocaine addiction, but none have yet shown to be effective therapy (Boyarsky and McCance-Katz, 2000). Because cocaine does not produce physical dependence, the emphasis in treatment is on the attainment of abstinence and most treatment approaches tend to centre on behavioural, cognitive and adjuvant therapies. Methadone maintenance has been used with cocaine IDUs but with little success (Kolar et al., 1992); intravenous cocaine use has been shown to be prevalent and problematic among cocaine users in methadone maintenance (Kosten et al., 1987). Due to the debilitating psychological dependence that accompanies cocaine addiction, the high prevalence of comorbid medical and psychological conditions that occur as a consequence (Boyarsky and McCance-Katz, 2000), and the absence of an effective pharmacological treatment, cocaine addicts have great difficulty achieving drug cessation and sustained

abstinence.

1.2 CONSEQUENCES OF ADDICTION

Drug addiction is a chronic disease that involves the interplay of social, psychological and physical elements; thus, addiction has adverse consequences on all areas of the addict's life. IDUs often become isolated from their family and friends, have financial and legal concerns, have difficulty maintaining regular employment, and are without a place to live. Consequently, IDUs are at high risk of illness including soft tissue infections, pneumonia, sepsis, endocarditis, psychiatric disorders, tuberculosis, hepatitis and HIV infection. Current public health programs for IDUs are mainly directed towards HIV and more recently, hepatitis C virus (HCV) prevention. Therefore, this section will focus on the determinants and rates of HIV and HCV transmission.

1.2.1 Determinants of HIV infection in IDUs

The major determinant of HIV transmission in IDUs is the sharing of used needles (Nicolosi et al., 1991; van Ameijden et al., 1994; Des Jarlais et al., 1995; Strathdee et al., 1997a). Prior to injection, a small amount of blood is drawn into the syringe to ensure that a vein has been accessed. Consequently, contaminated blood can be present on the needle, as well as on the interior of the syringe. Booting is an injection technique whereby a larger amount of blood is drawn into the syringe and mixed with the drug solution. This is usually repeated several times throughout a single injection to provide a more pleasurable and extended effect of the drug. Booting has also been shown to be associated with HIV infection (Greenfield et al., 1992). Other injection techniques that have been associated with an increased risk of HIV transmission include frontloading and backloading (Jose et al., 1993).[2] IDUs sometimes pool their

[2] Cocaine or heroin is dissolved in water using a cooker or spoon as previously described, and is then drawn into a syringe. In frontloading, a portion of the drug solution is injected into the front of another syringe whose needle has been removed. In backloading, a portion of the drug solution is injected into the back of another syringe whose plunger has been removed.

resources to buy drugs and frontloading and backloading are used to equally divide the drug. The sharing of other injection paraphernalia, such as filters, cookers and water has also been associated with HIV infection (Needle et al., 1998; McCoy et al., 1998; Brogly et al., 2000). Traces of blood can contaminate these items throughout the injection process thus providing a vector for HIV transmission.

Largely due to widespread educational campaigns, most, if not all IDUs are aware of safer injecting techniques. These include the use of a clean needle for each injection, the use of sterile water, cookers and filters, and the rinsing of used needles and syringes with a solution of bleach and water. To be effective, this procedure should be done twice with the bleach and water solution retained in the syringe for 30 seconds each time. Decreases in the injection risk behaviours of IDUs were widely reported in 1990s (Robert et al., 1990; Nicolosi et al., 1991; van Ameijden et al., 1994; Moss et al., 1994; Hunter et al., 1995; Vlahov et al., 1997; Beardsley et al., 1999). However, more recent studies have indicated that although many IDUs have adopted behavioural changes, few were able to maintain low risk practices (Gibson et al., 1998; van Ameijden and Coutinho, 1998; Brogly et al., 2000). The vulnerability within the injecting environment and the power of addiction often preclude elimination of needle sharing and other risky behaviours (Bourgois, 1998).

Other reported determinants of HIV infection in IDUs have included cocaine use (Chaisson et al., 1989; Anthony et al., 1991; Astemborski et al., 1994; Strathdee et al., 1997b; Brogly et al., 2000), attending needle exchange programs (Hankins et al., 1994; Bruneau et al., 1997; Strathdee et al., 1997b), homelessness (Strathdee et al., 1997b; Brogly et al., 2000) and being an ethnic minority (Chaisson et al., 1987; Schechter et al., 1998). Although some sexual transmission of HIV undoubtedly occurs in IDUs, it appears to be secondary to injection-related behaviours. An increased risk of HIV with an increasing number of partners has been found in some IDU populations (Moss et al., 1994), but not in others (Chaisson et al., 1987; Vlahov et al., 1990; Helal et al., 1995). Several studies have reported an increased risk of HIV infection among IDUs who engage in prostitution (Astemborski et al., 1994;

Neaigus et al., 1996; Strathdee et al., 1997b). Other sexual determinants of HIV infection include engaging in homosexual sex among men (Friedman et al., 1995; Williams et al., 1997; Strathdee et al., 2001), having a sexually transmitted disease among women (Strathdee et al., 2001), having an IDU sex partner (Friedman et al., 1995) and having sex when visiting a city with a high prevalence of HIV/AIDS (Williams et al., 1997).

1.2.2 Determinants of HCV infection in IDUs

Like HIV, the sharing of used needles is a major route of HCV transmission in IDUs. HCV is more easily transmitted through parenteral routes than HIV and even a minute amount of blood can be sufficient for infection. Consequently, frequent modes of transmission also include sharing cookers, filters and water. In a study of HCV infection in IDUs in Seattle, 54% of HCV infections were attributed to sharing cookers and filtration cottons (Hagan et al., 2001). Similarly, another study found that sharing cookers was the strongest determinant of HCV infection after adjustment for syringe sharing (Hazards Ratio=3.54, 95% CI: 1.26-9.94). Sharing rinse water (Hazards Ratio=2.29, 95% CI: 1.01-5.20) and filters (Hazards Ratio=1.98, 95% CI: 0.88-4.46) were also strong determinants of HCV infection (Thorpe et al., 2002).

Largely due to the infectiousness of HCV, IDUs are often infected earlier in their injecting career as compared with HIV. Documented rates of HCV infection among young IDUs have been four times higher than rates of HIV infection, and 90% of IDUs were found to be infected with HCV after five years of injecting (Centers for Disease Control and Prevention, 1998). Several studies have also reported increases in the risk of HCV transmission with increasing age and duration of intravenous drug use (Thomas et al., 1995; Denis et al., 2000; Diaz et al., 2001; Hope et al., 2001). Other correlates of HCV infection have included cocaine injection (Thomas et al., 1995; Garfein et al., 1996; Patrick et al., 2001) and frequent needle exchange program attendance (Patrick et al., 2001). Sexual transmission of HCV appears to be infrequent in both IDU and non-IDU populations (Villano et al., 1997; Patrick et al.,

2000; Roy et al., 2001).

1.2.3 HIV in IDUs: global prevalence and incidence

The acquired immunodeficiency syndrome (AIDS) was first recognized as a distinct clinical entity marked by opportunistic infections afflicting gay men in the United States in 1981 (Gottlieb et al., 1981). However, some of the earliest cases of AIDS detected in the United States had a history of injection drug use. Following the identification of the virus causing AIDS (Gallo et al., 1984) and an antibody test for HIV in 1984 (Weiss et al., 1985), it was documented that 58% of IDUs entering inpatient detoxification programs in New York City were infected with HIV (Spira et al., 1984). Further testing of stored blood samples indicated that HIV had entered New York City's IDU population in the mid-1970s, slowly spreading to IDUs in the city and beyond (Des Jarlais et al., 1989).

In Canada, the proportion of incident HIV infections attributed to injection drug use rose from an estimated 2% in 1981 to 1983, to 24% between 1987 and 1990, and to 47% in 1996. In contrast, most recent estimates suggested a decline; injection drug use accounted for 34% of the 4,200 HIV infections in Canada in 1999 (Health Canada, 2002). Early indication of differential HIV transmission in IDU populations in Canadian cities was evident in a study published in 1989 (Coates et al., 1992), reflecting the local availability and use of drugs, and the prevalence of risky behaviours. In Montreal, where cocaine is most frequently injected, an HIV incidence density rate of 5.1 per 100 person-years has been documented (Bruneau et al., 1997), and reported HIV prevalence ranges from 10.7% to 17% (Bruneau et al., 1997; Parent et al., 1998). In Vancouver, where both heroin and cocaine injection are prevalent, an explosive outbreak with an incidence rate of 18.6 per 100 person-years occurred among IDUs in 1996 (Strathdee et al., 1997b). Much like the experience in New York City, this high rate of infection has since declined and stabilized. An HIV incidence rate of 15 per 100 person-years and prevalence rate of 21% was documented among IDUs in Ottawa in the late 1990s (Parent et al., 1998). Reported

prevalence among IDUs in Toronto, Winnipeg and Calgary, where heroin is the drug of choice, is 9% (Millson et al., 1998), 12.6% (Elliot et al., 1999) and 3% (Elnitsky and Abernathy, 1993), respectively.

The rapid spread of HIV among IDU populations in the developed world prompted widespread implementation of HIV testing, education and prevention programs, and it appears that the HIV epidemic among IDUs has probably peaked in much of North America and Western Europe (Wodak and Hoy, 2002). Thus, the challenge of developed nations is to decrease HIV incidence in areas with high rates of infection, and to prevent HIV epidemics in regions with low transmission. The latter is the case in Australia, where an HIV epidemic has been averted and prevalence among IDUs remains below 2% in most areas (MacDonald et al., 1997). The World Health Organization continues to advocate the importance of prevention in high-income countries where prospects of rebounding epidemics loom as a result of public and political complacency and inappropriate prevention efforts that do not reflect changes in the spread of HIV (UNAIDS/WHO, 2001). Harbingers of another HIV epidemic in the homosexual population have recently alarmed public health officials in North America; increases in sexual risk behaviour and in HIV transmission have been reported among men who have sex with men in San Francisco (U.S. Centers for Disease Control and Prevention, 1999) and in Vancouver (Craib et al., 2000; Hogg et al., 2001) following successful prevention efforts throughout the late 1980's and much of the 1990s.

Injection drug use is spreading rapidly in the developing world, paving the way for further HIV epidemics in IDUs. HIV incidence is rising faster in Eastern Europe and Central Asia than anywhere else in the world, with an estimated 250,000 new infections in 2001, most of which were ascribed to injection drug use (UNAIDS/WHO, 2001). The number of individuals diagnosed with HIV in the Russian Federation has almost doubled annually since 1998, with 40,000 individuals newly diagnosed in the first half of 2001 (UNAIDS/WHO, 2001). This increasing rate of HIV infection has been mainly attributed to the liberalization of social and

political norms, mass increases in unemployment and social insecurity, and a heightened accessibility of illicit drugs since the fall of the Soviet Union in 1991. Outbreaks of HIV in IDUs have also been reported in the neighbouring republics of Kazakhstan, Kyrgyzstan, Tajikistan and Uzbekistan (UNAIDS/WHO, 2001).

High rates of HIV transmission have been documented in most Asian countries. HIV was detected among IDUs in Thailand in 1987, and HIV prevalence quickly rose from 1% to over 40% in less than one year (Weniger et al., 1991). From Thailand, HIV spread to injecting populations in Myanmar, China, Vietnam and Malaysia. In Manipur, a northeastern state of India bordering Myanmar, rapid transmission of HIV was detected in its drug-injecting population in 1989, and seroprevalence increased from 0% to 50 % within six months (Sarkar et al., 1993). In 1994, 47% of IDUs in three rural counties of the Yunnan province in southwest China were found to be infected with HIV (Zheng et al., 1994). More recently, HIV prevalence rates of 44% in street IDUs and 38% in IDUs in drug rehabilitation in Ho Chi Minh City, Vietnam were reported (Hien et al., 2001). Rates of HIV infection are also rising in IDUs and sex workers in Indonesia, the world's fourth most populous country (UNAIDS/WHO, 2001). Unfortunately, HIV prevention programs are poorly funded in many parts of Asia. Projects are typically scattered across countries, do not incorporate the necessary scale or coherence, and considerable political hurdles exist (UNAIDS/WHO, 2001).

In Latin America and the Caribbean, HIV is mainly transmitted through heterosexual intercourse; exceptions include Brazil, Argentina, Chile and Uruguay where injection drug use is the main route of transmission. A decrease in HIV prevalence has been reported among IDUs in Sao Paulo, Brazil, where 63% of IDUs were seropositive in 1991-1992, 65% in 1994 to 1996 and 42% in 1999 (Mesquita et al., 2001). A similar decrease in HIV prevalence has been observed in other large metropolitan areas of Brazil, probably due to the government's strong support of prevention activities and extensive state-funded therapy for individuals living with HIV/AIDS. In contrast, a high HIV seroprevalence rate of 65% was recently found in Rosario City, Argentina

where only a limited number of HIV prevention interventions are currently in operation (Siri and Inchaurraga, 2000).

1.2.4 HCV in IDUs: global prevalence and incidence

HCV has emerged as a major epidemic among IDUs in cities across the globe, surpassing that of HIV in almost all injecting populations. It is not uncommon for upwards of 70% of an IDU population to be infected with HCV. Injection drug use is the predominant mode of HCV transmission in developed countries, and is becoming increasingly frequent in the developing world. Increases in the number of cases of liver cancer and of deaths due to HCV in Canada and in the United States are anticipated as a result of the large number of IDUs infected in the 1960' and 1970s (Burak and Lee, 2000).

In Canada, injection drug use is the most important route of HCV infection, accounting for almost 70% of prevalent cases (LCDC, 1999). HCV prevalence rates of 76% and 82% were documented among IDUs in the Montreal St-Luc Cohort (Bruneau et al., 2002) and in IDUs in Vancouver's Downtown Eastside (Patrick et al., 2001), respectively. The HCV incidence density was 29.1 per 100 person-years among IDUs in Vancouver. Similar high rates of HCV infection have been found in IDUs in the United States. An HCV prevalence of 82% and one-year cumulative incidence rate of 16.7% was documented in Seattle IDUs (Hagan et al., 2001). A multi-site study of IDUs admitted to drug treatment programs during 1993 to 1994 reported HCV prevalence rates of 93% among IDUs in Baltimore, 66% in Detroit, 92% in Denver and 69% in San Francisco (Murrill et al., 2002).

Equally high proportions of IDUs in Europe are infected with HCV. Reported HCV prevalence was 86% in IDUs in methadone maintenance London, England (Best et al., 1999) and 77% among IDUs Glasgow, Scotland, with an incidence density of 28.1 per 100 person-years (Roy et al., 2001). High HCV prevalence rates have been documented in IDU populations in Spain (86%) (Bolumar et al., 1996), in Belgium

(78%) (Denis et al., 2000), in Switzerland (82%) (Steffen et al., 2001) and in the Netherlands (65%) (van Ameijden et al., 1993).

Despite the sustained low rates of HIV infection among IDUs in Australia, HCV prevalence rates of 60% to 70% have been found in drug injectors since the early 1970's (Crofts et al., 1997). Likewise in New Zealand, a two-year cumulative incidence rate of 23% (Brunton et al., 2000) and prevalence rate of 84% (Carter et al., 2001) have been reported. Data emerging from Asia indicate that an HCV epidemic is well underway in several countries. In the southeastern region of the Yunnan province of China – a key site for drug trafficking – 99% of IDUs infected with HIV were also infected with HCV (Zhang et al., 2002). HCV prevalence of 66.5% was reported among IDUs in detoxification centres in Bangladesh (Azim et al., 2002). And in Manipur, northeast India, 98% of IDUs were infected with HCV (Eicher et al., 2000).

1.3 CURRENT PUBLIC HEALTH PROGRAMS FOR IDUS

The emergence of HIV in the early 1980's propagated an increase in the epidemiologic research of IDUs, most of which focused on the determinants of HIV infection. Public health initiatives for IDUs were subsequently developed to minimize the risk behaviour and harms associated with drug injection, marking the advent of harm reduction. The aim of harm reduction is to reduce the harmful consequence of drug use through pragmatic, realistic programs; it neither insists on nor objects to drug abstinence (Cheung, 2000). Needle exchange programs have been the cornerstone of harm reduction, and exist in drug using communities to provide needles, bleach, condoms, counselling, and HIV and hepatitis testing to IDUs. In addition, some needle exchange programs offer other services such as counselling, support and referrals. There are roughly one hundred needle exchanges currently in operation across the country.

The public health initiative for IDUs in Montreal consists of over a dozen fixed-site needle exchange programs, a mobile needle exchange van, identified pharmacies for purchasing needles, street-outreach, detoxification units, methadone maintenance programs, support groups and other drug treatment programs. Also available to IDUs in Montreal, although not specifically targeted for injectors, are meal programs, overnight and day shelters, AIDS organizations, and support groups. Programs for HCV prevention consist of educational campaigns and testing, and are mainly add-ons to existing HIV strategies.

Needle exchange programs were implemented in Canada in 1989, prior to the development of a national strategy on HIV and injection drug use. Therefore, the realization of needle exchange programs was the result of isolated efforts from dedicated people in government, public health, and the community. In the absence of a national framework for action, the organization of, and services provided by needle exchange programs varied considerably, and reflected local contexts and ideologies (Hankins, 1998). Examples include the location of the needle exchange, the provision of mobile needle exchange services, quotas on the number of needles dispensed, hours of operation, testing, counselling and referrals, most of which are still governed by local communities and stakeholders.

Support for needle exchange programs as a harm reduction measure came from Europe, where treatment and initiatives for drug addicts have been historically more progressive. However, European IDUs predominantly inject heroin, which requires less frequent injection and confers a lower risk of HIV than cocaine (Anthony et al., 1991; Greenfield et al., 1992; Hudgins et al., 1995), the drug of choice of many Canadian IDUs. This predominance of intravenous cocaine use was not appreciated in the implementation of needle exchange programs in Canada. As a result, one-for-one needle exchange and needle exchange quotas in Montreal were removed several years after the implementation of needle exchanges, following the detection of a stable HIV incidence and an inadequate provision of clean needles (Remis et al., 1998). The explosive increase in HIV transmission among Vancouver IDUs that

occurred alongside the operation of a high-volume needle exchange has also been partially attributed to the prevailing injection of cocaine, which began around 1994 (Schechter et al., 1999). Restrictions on needle exchange quotas in Vancouver have recently been lifted.

Needle exchange programs were implemented in Canada and in the United States in the absence of a suitable strategy for evaluation; their effectiveness in preventing HIV transmission has since been hotly debated. A study of Montreal IDUs demonstrated higher HIV incidence rates in frequent needle exchange attenders than infrequent or non-attenders after thorough control for confounders (Bruneau et al., 1997). More recently, needle exchange programs have been found to have no effect on HCV and hepatitis B incidence among IDUs in Seattle, Washington (Hagan et al., 1999). A significantly elevated HIV incidence in frequent needle exchange attenders (at least once a week) versus non-frequent attenders has also been documented in Vancouver (Schechter et al., 1999). Nevertheless, comprehensive reviews have suggested that although study methodologies may have been imperfect, needle exchange programs appear to be effective in preventing HIV infection (Bastos and Strathdee, 2000; Gibson et al., 2001). The provision of clean needles is an essential component of public health programming for IDUs, but it is evident that much more is required to improve the health and well-being of this population.

1.4 NEW INITIATIVES FOR IDUS

Pending prevention initiatives for IDU finds researchers in Canada again poised to follow the European lead in their support of injecting rooms as a harm-reduction measure (Canadian Centre on Substance Abuse and the Canadian Public Health Association, 1997; Wood et al., 2001; Kerr and Palepu, 2001). Safer injecting rooms are legally sanctioned facilities where IDUs can inject drugs that they have obtained elsewhere. Health care and other services are also provided. The rationale supporting the implementation of safer injection facilities in Canada has been less than convincing. A Montreal study reported that 64% of IDUs mainly injected in

public places and that many IDUs had health problems such as overdose, abscesses, and withdrawal (Craig-Green et al., 2001). The authors then concluded that although Montreal does not have a problematic open drug scene, it is imperative to consider safer injection facilities as a harm reduction measure. A recently published study from Vancouver reported that difficulty obtaining sterile needles, needing help injecting, reusing needles, and frequent heroin and cocaine injection were associated with needle sharing (Wood et al., 2001). The argument was then put forward that safer injecting rooms might eliminate these behaviours.

Safer injecting rooms could indeed help to alleviate some of the problems surrounding injection drug use. It is unclear however that injection facilities are a viable or necessary intervention for IDUs in Canada. Reports from Switzerland indicate that injecting rooms have contributed to an improvement in the medical care of drug users (de Jong and Weber, 1999), and to more hygienic injection practices, although robust assessment with well-designed studies is lacking. Likewise, in Germany, although no formal evaluation has been conducted, injecting rooms have been reported to reduce the risk of overdose, death, and to decrease the open-drug scene (de Jong and Weber, 1999). Concern has been raised regarding whether or not injecting facilities will adequately house cocaine addicts in Canada who often require upwards of 10 injections a day. Moreover, it is not clear that injecting rooms are the most logical step in IDU public health programming. Experience accumulated in studies conducted in Vancouver's Eastside (Strathdee et al., 1997a; Miller et al., 2000; Palepu et al., 2001) and in Montreal (Bellot et al., 2000; Brogly et al., 2000) suggest that housing, health, and poverty may be more pressing issues for IDUs.

Prescription heroin is another initiative that is under consideration for implementation in Canada and the United States. Switzerland was the first country to prescribe heroin in a cohort of heroin-dependent individuals. Although some dissention regarding the research protocol exists, the results suggested that heroin prescription decreased heroin and cocaine use, and improved physical and mental health (Brisette, 2001). A North American clinical trial to assess the effectiveness of heroin

prescription on treatment retention and other outcomes has been designed and is awaiting approval (Brisette, 2001). The outcome of this trial could have important implications on the treatment of opiate dependent individuals as well as on Canada's drug policy and programs. However, like many other initiatives, it is targeted towards heroin IDUs.

It is curious that harm reduction initiatives in Canada have mirrored those of Europe despite important distinctions in drug use, an absence of solid evidence regarding their effectiveness, and indication of more compelling areas for intervention. Instead of focusing on risk behaviour change, programs should perhaps be developed to modify the underlying conditions that place IDUs at risk of disease transmission. Indeed, it has been suggested that public policy in Vancouver, such as the reduction of subsidised housing and monthly distribution of social assistance, might have contributed to the 1996 outbreak of HIV among IDUs (Schechter, 2001). Moreover, drug users have not been asked about what is important to them, and their input into public health programming has been minimal (Hankins, 1998). Certainly, much can be gained by asking cocaine and heroin users about their welfare and needs, and by considering strategies to improve the life conditions of IDUs.

1.5 QUALITY OF LIFE

1.5.1 Concept and measurement

Quality of life is a concept that has to do with the valuation of one's life circumstances or state of affairs. It denotes an appreciation for a particular state of being, for particular life conditions. What constitutes this preferred state of being varies from person to person, and hence, only the individual can define the important aspects (i.e., health, relationships, and living conditions) that comprise his or her quality of life. It follows that an individual's reflection of quality of life involves his or her past experiences, current situation, and personal hope for the future (Calman, 1984). Quality of life is perhaps most aptly defined as an individuals' self-perception of their life in the context of their culture and value systems in which they live (WHOQOL Group, 1994).

Quality of life outcomes are frequently used in medical research to supplement clinical indictors and to incorporate the patient's subjective experience in the decision making process. In an effort to focus on the health status and impact of illness and treatment on the lives of patients, the term health-related quality of life has become preferred by many researchers (Wood-Dauphinee, 1999). Although quality of life is a much broader concept, these terms are often used interchangeably and experts have yet to agree on a definition (Farquhar, 1995).

A large number of quality of life and health-related quality of life measures exist, which incorporate variations of the concepts. These include generic quality of life measures, such as the Short-Form-36 Health Survey (SF-36) (Ware and Sherbourne, 1992), the World Health Organization Quality of Life Assessment (WHOQOL Group, 1998), and the Flanagan Quality of Life Scale (Flanagan, 1978), which are not particular to any patient population. In contrast, disease-specific measures were developed for patients with a particular medical condition. Examples included the

Medical Outcomes Short-Form HIV Health Survey (MOS-HIV) (Wu et al., 1997) and the Arthritis Impact Measurement Scale (Meenan et al., 1980).

Quality of life instruments vary in their administration and determination of the quality of life assessment or score. Some, like the Flanagan Quality of Life Scale, give an equal weighting to all of the items in the scale to determine the quality of life score. In contrast, individualized measures, such as the Patient Generated Index (Ruta et al., 1994b), allow the individual to determine the weighting that is used for each aspect included in the quality of life assessment. Other measures such as the SF-36 and MOS-HIV provide an overall assessment of health-related quality of life in addition to a score for each subscale included in the assessment (i.e., physical functioning, social functioning, role limitations, etc.). Quality of adjusted life years (QALYs) is another type of approach that has been used to assess quality of life. With this approach, the individual is asked questions such as how many years of life he or she would be willing to give up in return for an illness-free existence and the answer is transformed to a QALY unit to represent the worth of one year of life (Hayry, 1999).

Despite the conventional use of quality of life as outcome of medical research, it has some limitations. Quality of life is an abstract concept, and measuring and assigning a numeric value to the quality of an individual's life is a challenging task. A variety of different instruments exists to measure quality of life, which can make comparison across studies difficult. As well, not all instruments have been properly evaluated. Further, quality of life is a dynamic construct, which adds to the complexity of its assessment (Allison et al., 1997).

1.5.2 The quality of life of IDUs: what is known?

In 1981, PH Irwin stated "if there is any group of individuals for whom it seems safe to assume that the quality of life – defined either objectively or subjectively – is at or near its *nadir*, persons who are about to enter treatment for drug abuse must qualify"

(Irwin, 1981). Subsequent studies have indeed found that persons beginning methadone treatment had a poor health-related quality of life. Heroin users at entry to a methadone maintenance program were found to have considerably worse physical and psychological health than that of the general population as measured by the SF-36 (Ryan and White, 1996). The amount of bodily pain reported was also found to significantly increase with increasing use of heroin prior to program entry. Likewise, the quality of life of heroin injectors at treatment entry was poor using the Subjective Quality of Life Profile (Dazord et al., 1998). No differences in quality of life were found according to age, sex or most other sociodemographic characteristics with the exception of having children. Heroin addicts who had children were less satisfied in most of the domains examined. Use of the SF-20 in a heterogeneous group of individuals seeking alcohol and drug treatment, of whom 38% were cocaine addicts and 27% were IDUs, also indicated they had poor self-perceived health and considerable pain (Stein et al., 1998). However, the use of alcohol and other drugs was found to have little effect on physical or role function scores.

Methadone maintenance has been associated with improvements in the health and quality of life of opiate addicts. For instance, the health of opiate addicts, of whom 90% were IDUs, improved over a one-year period in methadone maintenance as measured by the Nottingham Health Profile (Torrens et al., 1997). The above study that used the Subjective Quality of Life Profile also found that the quality of life of heroin addicts, of whom 88% were IDUs, improved considerably after one year of a comprehensive methadone maintenance program (Dazord et al., 1998). Similarly, a study that examined the life activities, self-perceived health and quality of life in heroin addicts found substantial improvements in the two months following treatment entry (Reno and Aiken, 1993).

Only one study of cocaine addicts was identified, although none were IDUs. Among these not-in-treatment crack smokers, the SF-36 demonstrated significant negative associations between the frequency of crack use and all subscales except physical functioning (Falck et al., 2000).

Studies of the effect of HIV on health have suggested a strong association between poor health-related quality of life and intravenous drug use. For instance, in a study of 100 HIV seropositive IDUs – only four of whom were still using drugs – health-related quality of life was associated with a longer time free from drugs as measured by the MOS-HIV (Carretero et al., 1996). In addition, health-related quality of life appeared to be more strongly related to drug use than HIV, and some subscales were thought to have been insensitive to changes in the health of IDUs. Another study that measured the health-related quality of life of HIV infected persons, of whom 34% IDUs, found that injection drug use was associated with lower scores in all six health dimensions of the MOS-HIV (Wachtel et al., 1992). However, a review article later suggested that the MOS-HIV appeared to be of limited in use with IDUs due to the overwhelming effects of drug use and the accompanying chaotic lifestyle that may reduce its responsiveness (Wu et al., 1997).

In sum, the quality of life of IDUs has not been widely studied. The limited data have suggested a poor health-related quality of life of HIV positive IDUs, and IDUs entering treatment, as well as some difficulty measuring their health-related quality of life. Methadone maintenance appears to have improved the health-related quality of life of opiate addicts. Few studies have examined the broader construct of quality of life, and little has been reported on the quality of life of cocaine addicts.

2 OBJECTIVES

Public health programs for IDUs in Canada have centred on behaviour change; few strategies have attempted to change the underlying conditions that place IDUs at risk of disease transmission. However, improving the quality of life of IDUs and amending their marginalization should translate into decreased opportunities for disease transmission. The HIV epidemic has clearly demonstrated that conditions of marginalization are strong determinants of HIV infection, and further, studies have hinted at the link between quality of life and HIV transmission. Poor life satisfaction, social status and future hopes, all of which are components of quality of life, have been associated with HIV risk taking behaviour (Kalichman et al., 1997). Income and employment have been shown to be predictors of life satisfaction in the general population (Argyle, 1997), and poor financial status has been associated with syringe sharing in IDUs (Donoghoe et al., 1992). As well, individuals who frequently use cocaine have been found to have impaired social function (Gawin and Ellinwood, 1988), and social support has been associated with improved health-related quality of life (Gielen et al., 2001).

The overall objective of this research was to provide information to help in the development of more effective public health programs for IDUs. Through identification of the constituents and correlates of the quality of life of cocaine and heroin IDUs, and the relation between quality of life and the use of public health programs, these studies aimed to gain a better understanding the needs and circumstances of IDUs in Montreal. The specific objectives were:

1. To develop and evaluate a quality of life measure for injection drug users, the Injection Drug User Quality of Life Scale (IDUQOL).

2. To describe the quality of life of cocaine and heroin IDUs, and to identify the constituents and correlates of their quality of life.

3. To describe the relation between the quality of life of cocaine and heroin addicts and the use of health care, harm reduction and social service programs. These included needle exchange programs, methadone maintenance, other drug treatment, emergency departments, welfare administration, shelters and meal programs.

Chapters 4 and 5 describe the development and evaluation of the IDUQOL (Objective 1). Chapter 6 provides the results of the subsequent study in which the IDUQOL was applied in a sample of IDUs from the Saint-Luc Cohort (Objectives 2 and 3).

3 SOURCE POPULATION: THE ST-LUC COHORT[3]

The source population for this investigation was the St-Luc Cohort, which has been enrolling and following IDUs in Montreal since September 1988 to study the etiology of HIV infection and more recently, HCV infection. To date, 3,347 IDUs have been enrolled. Eligibility for the St-Luc Cohort included being 14 years of age or older, having injected drugs within the past six months, being a resident of the greater Montreal area and providing informed consent. IDUs in the St-Luc Cohort were recruited from three main sources: 1) the detoxification unit of Hôpital St-Luc in downtown Montreal, 2) referral from collaborating centres for IDUs including shelters, private and public readaption centres, therapeutic communities and other community based organizations for IDUs, and 3) self-referral from word-of-mouth within the injecting community. As shown in Table 3.1, the relative proportion of cohort members coming from the three sources has fluctuated over the years, with word-of-mouth accounting for the majority of IDUs until 1998. Since this time, the majority of new cohort members were recruited from collaborating centres for IDUs. The number of IDUs recruited annually decreased from approximately 300 per year during 1992 to 1999 to 101 in 2001. The identity of the recruitment site was unavailable prior to 1992.

Table 3.1. Recruitment site of IDUs in the St-Luc Cohort, 1992 to 2001.

Year	N	St-Luc detoxification (%)	Collaborating centres for IDUs (%)	Word-of-mouth (%)
1992	284	35.2	23.1	41.6
1993	314	30.3	17.2	52.6
1994	334	19.2	18.3	62.6
1995	307	21.8	10.1	68.1
1996	331	17.2	14.8	68.0
1997	286	19.2	11.5	69.2
1998	306	14.4	29.4	56.2
1999	254	7.5	69.3	23.2
2000*	153	7.4	53.6	35.9
2001**	101	11.9	44.6	42.6

*Recruitment site missing for 5 IDUs. **Recruitment site missing for 1 IDU.

[3] The analyses and text presented on the St-Luc Cohort in this chapter are also the work of S.Brogly.

The first follow-up visit in the St-Luc Cohort was scheduled at three months, and subsequent visits were every six months thereafter until an endpoint was reached such as loss of contact, participant discontinuation or death. The shorter three-month period between the first and second visit was implemented to identify IDUs who were HIV positive at enrolment but had not yet developed antibodies to the virus. Overall, 75% of IDUs who enrolled in the St-Luc Cohort returned for a second visit. The loss to follow-up was, on average, 17% between subsequent visits.

At each visit, information regarding sociodemographics, drug use, injection and sexual risk behaviour, health care and public health program use was collected via interviewer-administered questionnaires. The questionnaires were available in French or English, and were originally based on the WHO questionnaire developed for international multi-site studies of HIV infection in IDUs (World Health Organization and Programme on Substance Abuse, 1994). Research nurses trained to conduct interviews with IDUs administered the study questionnaires in private rooms to foster a comfortable setting in which personal and sensitive questions would be truthfully answered. Approximately 40ml of blood were taken at the baseline visit and at all follow-up visits for IDUs who tested HIV seronegative at the preceding visit. A portion of this sample, 5-10ml, was retained in specimen storage at -70°C. The presence of HIV antibodies was detected using a commercial Enzyme Linked Immunosorbent Assay (ELISA) at Hôpital St-Luc. The Laboratoire de Santé Publique du Québec in Montreal confirmed specimens that were reactive upon ELISA using the Western Blot or the Radioimmunoprecipitation Assay. A stipend of $10 was given to all participants to compensate for their time and transportation. Since July 2001, participants have been given an additional $5 on return for their HIV test results two-weeks after the cohort interview. The research nurses provided pre- and post-test HIV counselling and referrals for HIV/AIDS care and counselling were given as necessary.

The questionnaire underwent substantial revision in December 1991 – many new questions were added, some questions were removed, and the period to which drug

use and sexual and injection behaviours pertained was changed. Consequent to these modifications, information collected before December 1991 was not comparable to that obtained afterwards. Thus, interviews conducted from September 1988 to December 1991 were excluded from the descriptive analyses presented.

Table 3.2 provides selected characteristics of IDUs in the St-Luc Cohort. These descriptive characteristics were determined by randomly selecting one visit for IDUs that were interviewed more than once in the given year; if an IDU had only one visit during the given year, that visit was used. The majority of IDUs in the St-Luc Cohort were white, French-speaking males. Due to the prospective nature of the cohort, the mean age, duration of injection drug use, and proportion of IDUs who were HIV positive increased over time. The proportion of IDUs that reported injecting in the six months before their interview remained relatively stable from 1992 to 2000; injection cessation is characteristic of drug addiction and many IDUs fluctuate between periods of drug use and abstinence. However, in 2001 the proportion of IDUs that reported injecting in the past six months slightly increased to 81%, probably because of changes in the cohort structure to remove long-term non-injectors.

Cocaine has historically been the drug of choice of Montreal injectors, reflecting not only drug preferences but also market availability. The proportion of IDUs who reported injecting cocaine in the month before their interview remained relatively stable from 1992 to 2001; the number of mean cocaine injections has fluctuated from a low of 69 to a high of 93. The proportion of IDUs who smoked crack cocaine also appears to have increased in recent years.

Table 3.2. Selected characteristic of IDUs in the St-Luc Cohort, 1992 to 2001.

Characteristic	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
No. subjects	653	829	876	996	1113	1193	1306	1296	1005	856
% male	80.2	82.8	81.7	82.2	82.3	82.1	83.3	83.8	84.6	85.5
% French-speaking	81.6	81.3	84.2	82.1	81.0	83.7	83.0	85.3	85.9	85.2
Mean age (years)	33.7	34.6	35.1	35.8	36.4	36.8	37.1	37.6	38.4	39.1
Mean years injecting	10.6	11.2	11.3	12.0	12.4	12.8	13.1	13.8	14.4	15.4
% HIV positive	18.7	17.7	17.5	20.4	19.9	19.9	20.4	21.3	22.9	25.8
% injected*	73.7	78.8	78.8	78.7	77.8	76.9	75.3	73.8	74.3	80.8
% injected heroin**	21.6	24.5	28.3	22.4	22.2	21.4	24.0	24.8	21.7	19.1
Mean no. heroin injections**	49.3	47.1	54.1	54.3	50.6	46.3	52.0	37.6	29.9	31.3
% injected cocaine**	64.7	63.2	61.3	65.8	64.5	63.1	67.2	69.4	71.5	69.2
Mean no. cocaine injections**	83.2	93.4	77.3	74.6	68.9	78.9	69.7	73.7	90.3	84.2
% smoked crack**	26.8	25.3	21.9	19.6	22.6	25.6	28.3	30.3	32.9	32.4
Mean no. crack hits**	49.1	44.8	52.7	43.2	36.4	35.8	34.0	52.3	45.4	33.2

*In the past six months. **In the past month.

The overall and annual HIV incidence rates, of the form of incidence density, among IDUs in the St-Luc cohort are presented in Table 3.3. Incidence density is the ratio of the number of new cases of an illness occurring in an aggregate of population-time. The numerator consisted of the number of previously HIV negative IDUs who tested HIV positive in the given year (n), and the denominator was the aggregate of population time covered in the follow-up period for the given year (L). The 95% confidence intervals were calculated using the Poisson distribution, where the estimated variance was n/L^2. The HIV incidence density ranged from a low of 1.82 in 1998, to a high of 4.09 in 1992, with an overall incidence density of 3.09 (95% CI: 2.68, 3.50) from 1992 to 2001.

Table 3.3. HIV incidence density of IDUs in the St-Luc Cohort, 1992 to 2001.

Year	Number of HIV infections	Incidence Rate/100 person-years (95% CI)
1992	18	4.09 (2.20, 5.99)
1993	13	2.37 (1.08, 3.66)
1994	22	3.32 (1.94, 4.71)
1995	28	3.71 (2.33, 5.08)
1996	23	2.75 (1.63, 3.87)
1997	33	3.67 (2.42, 4.93)
1998	17	1.82 (0.95, 2.68)
1999	25	2.86 (1.74, 3.98)
2000	24	3.67 (2.20, 5.13)
2001	12	3.34 (1.45, 5.22)

4 DEVELOPMENT OF THE INJECTION DRUG USER QUALITY OF LIFE SCALE (IDUQOL)

4.1 PRELIMINARY DEVELOPMENT OF THE IDUQOL

Researchers at the Centre for Health Evaluation and Outcome Sciences, St. Paul's Hospital, in Vancouver, British Columbia completed the preliminary development of the IDUQOL (Elliott et al., 2000). At this stage, the quality of life instrument was conceptualized to be relevant to the life experience of IDUs, to capture the variation in quality of life among individuals who inject drugs, and to be responsive to changes in health and socio-economic factors. The instrument was designed to be an individualized measure, and was based on two such measures, the Patient Generated Index (Garratt and Ruta, 1999) and the Schedule for the Evaluation of Individual Quality of Life (McGee et al., 1991). Individualized measures allow the individual to select the dimensions that constitute quality of life, to weight the importance of each dimension and hence, to influence how his or her quality of life is measured (Hickey et al., 1999). It follows that the dimensions that constitute quality of life, as well as the importance and rating of the dimensions can change over time, which increases the difficulty of assessing changes in the quality of life of a study population. In contrast, more traditional standardized measures, such as the SF-36 (Ware and Sherbourne, 1992), have predetermined constituents of quality of life, each with a fixed and often equally weighted relative importance; therefore, only the rating of the constituents can change over time. The increased complexity of individual quality of life assessments is perhaps one reason for the limited use of individualized measures in medical research, despite their apparent advantage in measuring the concept of and change in quality of life.

The initial dimensions or life areas included in the quality of life instrument were identified through a review of medical literature pertaining to IDUs and consultation with IDU health practitioners, community workers and researchers. The life areas that emerged were: HIV/AIDS treatment, drugs, family, feeling good about yourself,

friends, health, independence/choice, living conditions, money, sex, spirituality, sports and leisure, social services, and work. Pictorial representations and descriptive text of these life areas were then created on 5"x5" cards. The instrument was administered as follows. The participant was asked to select the five of the 14 life areas that were most important to him or her. Twenty-five chips were then equally distributed on the five cards representing the life areas, and the individual was asked to move the chips from the life areas that were less important to those that were more important. The participant rated their satisfaction with each area on a Likert scale of one (very dissatisfied) to six (very satisfied). An overall quality of life score was calculated by multiplying the number of chips on each card by its value on the Likert scale and ranged from zero to 150.

A pilot study using this instrument was conducted in 1999 with 97 IDUs in Vancouver (Elliott et al., 2000). The mean age of the 97 participants was 38 years, 29 (29.9%) were female, 30 (30.9%) were living in single occupancy hotels, 14 (14.4%) injected only heroin, and 19 (19.6%) injected only cocaine. The results indicated that quality of life score was relatively normally distributed, and ranged from the lowest possible to the highest possible score.

While the above work was underway in Vancouver, this study was also in its preliminary stages, which involved searching for a quality of life instrument that could be used with IDUs. Independent of the researchers in Vancouver, the individualized approach, and specifically the Schedule for the Evaluation of Individual Quality of Life (Hickey et al., 1996), was identified for potential use. However, it became evident that there was a need to develop a quality of life measure for IDUs. Problems were found with both content and/or administration of existing instruments. For instance, a circular disk was used to determine the relative importance of the life areas of the Schedule for the Evaluation of Individual Quality of Life, which required considerable co-ordination and steadiness not always present in IDUs. As well, the study nurses and researchers of the St-Luc Cohort felt that the sophisticated judgement analysis technique used in the rating of the life areas was

unsuitable for drug injectors. Although the Schedule for the Evaluation of Individual Quality of Life had been used with HIV-infected IDUs in Ireland (Hickey et al., 1996), none of these individuals were still injecting drugs. Standardized measures, developed mainly for use in the general population, were found to be culturally inappropriate for use with IDUs. It has also been suggested that instruments developed for the general population may cause IDUs to cluster at the low end of scales and may not be sensitive to changes in their health-related quality of life (Carretero et al., 1996; Wu et al., 1997). Thus, the IDUQOL was developed from the instrument template constructed by the Vancouver researchers. The following paragraphs describe the development of the IDUQOL that was undertaken as part of this thesis work.

4.2 REFINEMENT OF THE IDUQOL PICTOGRAMS

The pictograms of the life areas initially prepared in Vancouver were drawn by hand and therefore were not accessible for modification, duplication, or use by other researchers. The pictograms were redrawn on a PC using Adobe Illustrator 9.0 and several were modified to provide a more generic representation of the life areas. For instance, sex was originally represented by the word sex placed in the centre of a heart. However, sex is not always an expression of love, particularly among IDUs who often rely on prostitution to support their drug habits. The image was changed to include symbols representing two women, two men, and a man and a woman, and a separate card for partnership was added. Likewise, the pictogram for drugs consisted of a needle and was modified to include a needle, marijuana joint, cigarette, crack pipe, pills, and alcohol. Similar changes were made to the other life area cards.

4.3 INPUT FROM IDUS IN MONTREAL

The next step in the development of the IDUQOL was a focus group discussion with eight IDUs from the Montreal St-Luc Cohort in the fall of 2000. The goal of the focus group was to verify that the text and pictures on the cards were representative

and clear, to ensure the inclusion of all important life areas, and to assess the feasibility of card prompted vs. self-nominated life areas. The focus group was tape recorded and transcribed, and a brief synopsis is provided below.

Of the eight focus group participants, two were female, two were heroin addicts, three were in contact with a drug treatment program, and three were HIV positive. The mean age of the participants was 36 years (21 to 49) and their mean duration of injection drug use was 16 years (3 to 33). There was a great deal of interest when discussing quality of life and it appeared to be of considerable importance to the participants. Not surprisingly, the participants' quality of life varied. One participant commented that he would like to improve his quality of life but wasn't sure how to go about it; he had recently been expelled from a hospice for people living with HIV. Two participants commented on that it was difficult to take steps to improve their lives without the assistance of social programs. However, none of the participants selected social services as being an important life area and many had negative feelings towards particular organizations. It fact, it was suggested to change the card entitled social services to resources, and to remove the names of the Montreal social service organizations listed on the card.

Three life areas were repeatedly discussed and emerged as being important to IDUs: feeling useful, family, and basic necessities such as food and somewhere to live. Most of the participants talked about wanting to do something useful and productive in society, "to do something constructive instead of destructive". Two individuals mentioned that they currently volunteered to do something positive and to give back to others. It was subsequently suggested to change the card entitled work to feeling useful or contributing to society. Three individuals also proposed adding a card for education, as it was an important dimension of their quality of life.

The participants unanimously agreed that it was not difficult to come up with the life areas that were important to their quality of life. When asked to compare their self-nominated areas with those they had selected from the cards, the majority of

participants said that the life areas were basically the same. However, when the self-nominated versus selected life areas were later examined, their congruence was not always apparent. For example, one participant nominated the ability to stop using heroin as being an important area of his quality of life. He then selected spirituality, feeling good about himself, and independence/free choice as being important from the cards. The latter three areas might have been related to his ability to stop using heroin but it was impossible to know without further information. This confirmed the need to ask the participant what the particular life area represents to him or her during the administration of the IDUQOL. In general, the participants preferred to first generate the important life areas on their own, and then to use the cards for further exploration and re-evaluation.

Modifications were made to the IDUQOL as a result of the focus group and subsequent discussions with addiction practitioners, researchers and social workers. These included changing the text on the card for social services to resources and work to being useful. The pictorial representation on the social services card was also changed to include basic necessities such as food and a bed, and the names of the Montreal organizations were removed. Cards for education and drug treatment were also added.

4.4 SUBSEQUENT DEVELOPMENT OF THE IDUQOL

Further modifications were made to the template of the IDUQOL to improve its comprehensiveness and rigor. The six-point Likert scale originally used to measure the individual's satisfaction with the life area was replaced with a rating of 'how well that life area is going at the moment' on a continuous scale of zero (the worst that could be imagined) to 100 (the best that could be imagined). This allowed for more flexibility in the rating of the life areas. As well, the concept of *relative importance* of the life areas – the importance of each life area in relation to the others – was incorporated into the overall quality of life score by using the fraction of 25 chips placed on the life area in the calculation of the overall score. This is similar to the

approach used by the Patient Generated Index (Ruta et al., 1999) and the Schedule for the Evaluation of Individual Quality of Life (Hickey et al., 1996). The overall quality of life score was changed to be the sum of the product of the relative importance or weight of the life area (i.e. the fraction of the 25 chips allocated to the life area), and the rating of the life area (from zero to 100), to produce an overall quality of life score that ranged from zero to 100.

Well-defined procedures are essential to consistent and accurate data collection. Therefore, an administration manual for the IDUQOL was developed using the administration manual of the Schedule for the Evaluation of Individual Quality of Life (O'Boyle et al., 1995) as a guide. The administration manual was written in English, translated to French and then back translated to English to ensure grammatical, conceptual, and semantic comparability.

A small pilot study was then conducted with 20 IDUs from the St-Luc Cohort to assess the ease of administration of the instrument, and to evaluate the acceptability and comprehension of the instrument by both the research nurses and the participants. The participants had a mean age of 38 years (22 to 50 years), a mean duration of injection drug use of 11 years (2 months to 29 years), 18 (90.0%) were male, 5 (25.0%) were HIV positive, 6 (30.0%) were homeless, 15 (75.0%) injected primarily cocaine, and 7 (35.0%) were in drug treatment in the past six months. No difficulty with the IDUQOL administration was encountered in this pilot study. The only change made to the IDUQOL was the elimination of the equal distribution of the chips on the life area cards by the study interviewer – the IDUs preferred to start with all 25 chips themselves.

4.5 PROCEDURE FOR ADMINISTERING THE IDUQOL

The IDUQOL is available in French and English and is administered in a semi-structured interview (a copy of the IDUQOL can be found in Appendix A). The interviewer begins by reading a few brief paragraphs on quality of life to orient the

participant and to stimulate thought on quality of life and the things that are important to him or her. The participant is then asked to nominate five life areas that he or she feels determine his or her quality of life. Now that the participant has begun thinking about the life areas that determine his or her quality of life, the cards are brought out and the participant is asked to select the five of the 17 life areas that are most important to his or her quality of life. The cards depicting the 17 life areas are shown in Figure 4.1.

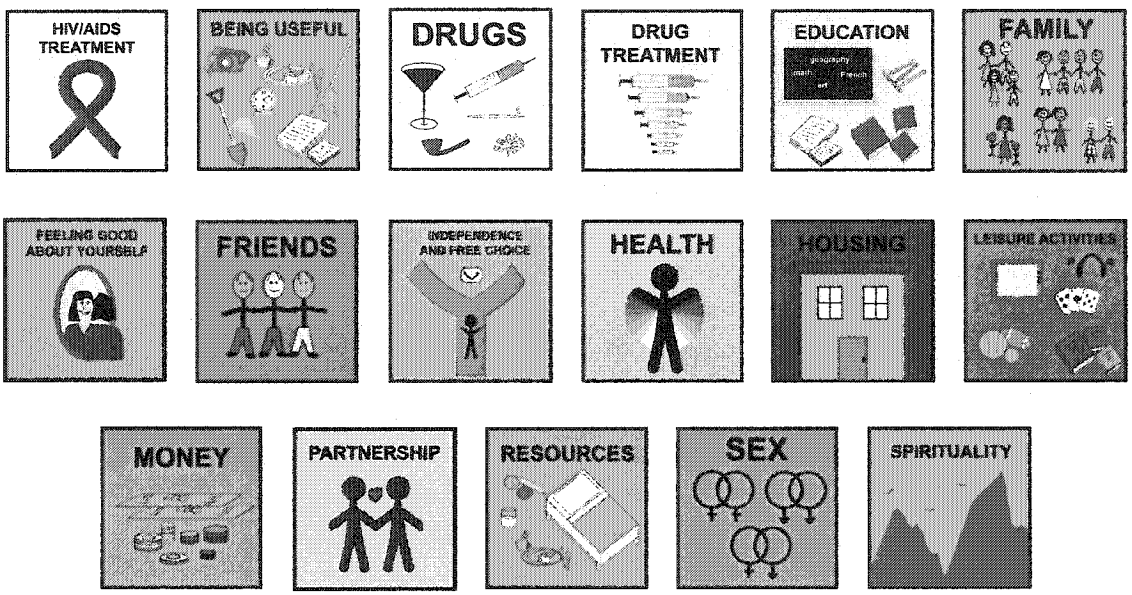

Figure 4.1. Life areas of the Injection Drug User Quality of Life Scale

The number of life areas included in the quality of life assessment can be reduced if the individual assigns a relative importance of zero to a given life area(s). Following the selection of five life areas, the participant is asked to give a brief summary of what the life area means to him or her; evaluation of the life area meanings is necessary to place them in context (O'Boyle et al., 1995). The relative importance of each life area to the individual's quality of life is then determined using 25 chips. The participant is asked to distribute the chips on the cards representing the life areas according to the relative importance of the area to his or her quality of life, with more chips indicating greater importance. There is no maximum or minimum number of chips that can be placed on any life area. Once the individual is satisfied with the weighting of the life areas, he or she is asked to rate how well each area is going on a scale from zero (the worst that can be imagined) to 100 (the best that can be imagined). The IDUQOL quality of life score is calculated as the sum of the product of the rating and the relative importance of each life area (the fraction of chips placed on each life area). The possible range of scores is zero to 100 and higher scores indicate a better quality of life. A sample calculation is provided in Table 4.1.

Table 4.1. Sample calculation of the IDUQOL quality of life score.

Life Area	Relative importance	x	Rating	=	Product
Being useful	5/25		50		10
HIV/AIDS treatment	7/25		100		28
Housing	5/25		80		16
Money	3/25		30		3.6
Resources	5/25		80		16
Total score					**73.6**

4.6 INTERPRETATION OF THE IDUQOL

The IDUQOL is a quality of life measure that was developed to have relevance and meaning to individuals who inject drugs. It reflects the World Health Organization's definition of quality of life as "an individuals' perception of their position in life in the context of the culture and values systems in which they live and in relation to their

goals, expectations, standards and concerns" (Bonomi et al., 2000). The IDUQOL incorporates the individualistic nature of quality of life by allowing the individual to select the life areas that constitute his or her quality of life and to weight the importance of these areas – it does not assume a uniform importance to all IDUs. The variety of life areas included in the IDUQOL capture the multidimensional nature of quality of life: health (HIV/AIDS treatment, drug treatment, health), personal development (education, independence and free choice, being useful, feeling good about oneself, spirituality), relationships (friends, family, partnerships, sex), material comforts (housing, money, resources, drugs) and recreation (leisure activities). The culture and value systems of the individual are reflected through his or her selection of the most important life areas. Finally, the individual's rating of his or her satisfaction with the particular life area captures the individual's perception of his or her life in relation to his or her goals and expectations.

If a quality of life measure is to be used in program evaluation or to compare life circumstances between two groups of IDUs, one must be able to interpret what the score means. Comparison of quality of life scores across age or sex contrasts can indicate how quality of life differs across the contrast, but it may not explicate what a given score means. Some instruments do not include categorical cut-offs for their quality of life scale, and instead simply state that higher scores indicate better quality of life (Burckhardt et al., 1989). Such is the approach taken with the IDUQOL, at least in this stage of its existence.

5 EVALUATION OF THE IDUQOL

5.1 OBJECTIVE

For an instrument to be acceptable for use in epidemiologic research, it is necessary that it reliably and validly measure the desired attribute. Thus, the objective of this study was to evaluate the IDUQOL and to assess the following psychometric properties: test-retest reliability, concurrent criterion validity, and construct validity. The following paragraphs describe the theoretical framework used in the assessment of the IDUQOL.

5.2 METHODOLOGY

5.2.1 Psychometrics

Psychometrics is a concept that has to do with the use of instruments or scales to measure psychological phenomena; it is concerned with the standardization of measurement tools to ensure that attributes are measured in a consistent manner. Psychometrics is a concept that comes to medical research from the social sciences. It provides us with properties to assess the performance of instruments, the most basic of which are reliability and validity. Test-retest reliability is the extent to which the measurement of an attribute on the same individual at two points in time is similar (Streiner and Norman, 1995); thus it refers to the *reproducibility* of a measure. From a psychometric perspective, validity is the extent to which an instrument measures what it purports to measure (Streiner and Norman, 1995). Responsiveness is another psychometric property, which is the ability of an instrument to detect small, but important changes in the construct that is being measured (Lacasse et al., 1999). There are various statistics used to assess the psychometric properties of instruments, and the most common are presented below.

5.2.1.1 Reliability

Reliability is a concept that reflects measurement error. The theory underlying the concept of reliability is the separation of a measurement of X into its true value, T, and its associated error, E. This theoretical relation is expressed as in equation (1),

$$(1)\quad X = T \pm E$$

In any population, T will vary about a mean with a variance of s^2_T (Fleiss, 1986). Assuming that the distribution of errors is independent of the true value T, the estimated variance due to measurement error is s^2_E and the variance of X, s^2_x, can therefore be written as,

$$(2)\quad s^2_x = s^2_T + s^2_E.$$

The reliability coefficient (r) expresses the ratio of the variance between individuals to the total variance,

$$(3)\quad r = \frac{s^2_T}{s^2_T + s^2_E}$$

and can range from zero to one (Fleiss, 1986). A reliability coefficient of zero indicates that all of the variance in the measurement of X is due to error, and a coefficient of one indicates that there is no error in the measurement of X; hence values closer to one indicate better reliability.

The theoretical form of the reliability coefficient presented above differs from the computational form of the reliability coefficient. The statistic most often used to assess reliability is the intraclass correlation coefficient (ICC), which was introduced by RA Fisher in 1958 (Fisher, 1958). The ICC can be calculated using analysis of variance to estimate the variance components. There are various forms of the ICC depending on whether a one-way or two-way analysis of variance is invoked. In a one-way analysis of variance, the variance is partitioned into between subject and

error components, whereas in a two-way analysis of variance, the variance is partitioned between subject, raters and error components (Portney and Watkins, 1993). With respect to the reproducibility of two sets of measurements on a group of individuals, an ICC of one indicates that the second set of measurements was an exact replicate of the first.

The Pearson product-moment correlation coefficient has also been used to assess an instrument's test-retest reliability (Ruta et al., 1994b). The Pearson correlation coefficient originates from linear regression where it is used to determine the extent to which the dependent variable, y, is a linear function of the independent variable, x. The Pearson correlation coefficient is calculated through the method of least squares, which minimizes the residual sum of squares – the difference between the observed y values and those expected from the regression model. The calculation for the Pearson correlation coefficient is given by equation (4),

$$(4) \quad r = \frac{\Sigma (x_i - x_{ave}) \Sigma (y_i - y_{ave})}{s_x s_y}$$

where x_i is the observed value of x for observation i, x_{ave} is the mean value of x, y_i is the observed value of y for observation i, y_{ave} is the mean value of y, s_x is the standard deviation of x, and s_y is the standard deviation of y.

The Pearson correlation coefficient can range from minus one to plus one, and a value of one (or minus one) indicates that y is exactly determined as a linear function of x. However, this does not necessarily mean that the slope of the regression function is in fact one; the Pearson correlation coefficient will equal one for any straight line i.e. y=3+½x, y=3x. From a theoretical standpoint, the Pearson correlation coefficient does not provide an estimate of the reproducibility of a set of measurements taken on a group of individuals at two different points in time – it assesses whether or not the two sets of measurements are related linearly. Nevertheless in practice, the value of the Pearson correlation coefficient and the ICC will be quite close because the

predominant source of error is usually due to random variation (Streiner and Norman, 1995).

5.2.1.2 Validity

In psychometric theory, validity is a concept that has to do with the attribute that is being measured; it is the extent to which the instrument measures what it purports to measure. It follows that providing evidence of the validity of an instrument is a difficult task, particularly when the instrument measures an intangible concept such as quality of life and there is no clinical standard against which it can be compared. As a result, three different aspects of validity, are commonly assessed: content validity, criterion validity, and construct validity (Streiner and Norman, 1995).

Content or face validity has to do with the composition and breadth of the items that are contained in the instrument. It pertains to whether or not the content of the instrument adequately represents the concept to be measured. Content validity is generally assured during the development of the instrument by involvement of individuals from the population in which the instrument will be used, involvement of other experts, thorough review of the literature, pilot testing and refinement of the instrument.

Criterion validity has to do with the concordance between the new instrument and another instrument or *criterion* that is believed to measure the same or a similar concept. The criterion is the standard against which the new instrument is assessed; subsequently, it should have already demonstrated good psychometric properties itself. Concurrent criterion validity is the concordance between the new instrument and the criterion at the same point in time, and predictive criterion validity is how well the new instrument predicts a future assessment by the criterion (Streiner and Norman, 1995). The correlation coefficient is the statistical parameter commonly used to assess criterion validity. The ICC, Pearson correlation coefficient or

Spearman rank correlation coefficient can be used for continuous variables, depending on the form of concordance evaluated.

Construct validity has to do with the relation between the attribute that is being measured and a different variable or construct that is putatively related to it (Streiner and Norman, 1995). For example, a strong relation between level of physical activity and a measure of health status could provide evidence of the construct validity of the health status instrument. Statistical approaches that can be used to assess construct validity include correlation coefficients and parameter estimates from regression models. Construct validity is useful when there is no explicit criterion for the attribute that is being measured. Construct validity is not generally established with a single assessment of the instrument, rather, it is established over time, with continued use of the instrument (Hubley and Zumbo, 1996).

5.2.2 Data collection

To evaluate the usefulness of the IDUQOL as a quality of life measure, the IDUQOL's distribution of scores, test-retest reliability, concurrent criterion validity and construct validity were assessed in 61 IDUs from the St-Luc Cohort. The St-Luc Cohort research nurses invited eligible IDUs to participate in this study at the end of their scheduled cohort interview. Eligible participants must have injected drugs within the past six months and must have provided informed consent as approved by the internal review board of Hôpital St-Luc. Copies of the ethical approval and consent form are provided in Appendix B. The quality of life interviews took place in a private room following the St-Luc Cohort interview; the data collected in the cohort interviews were also used in this study. A trained interviewer administered the IDUQOL and the Flanagan Quality of Life Scale (Flanagan, 1978) in a randomly determined order. Participants were asked to return in one to two weeks, at which time the IDUQOL and Flanagan were re-administered. A stipend of $10 was given to the study participants at all visits to compensate for their time and transportation.

The Flanagan Quality of Life Scale is a 15-item standardized scale that was developed in the 1970's from the responses of 3,000 Americans, which spanned a wide range of social and cultural groups (Flanagan, 1978). The Flanagan included 15 items concerning material comforts, relationships, work, participation in public affairs, social activities and personal growth. Participants were asked to rate their level of satisfaction with each of the 15 items in the Flanagan on a scale of one (highly dissatisfied) to seven (highly satisfied). The level of satisfaction of each item was summed to provide a quality of life score that could range from 15 to 105.

The Flanagan was used as the standard against which to assess the criterion validity of the IDUQOL because it has demonstrated good reliability, content validity, and construct validity (Flanagan, 1978; Burckhardt et al., 1989). In addition, it is a non-health focused instrument with a broad perspective of quality of life and appeared to be more relevant to IDUs than other quality of life measures. The Flanagan Quality of Life Scale was originally developed in English, and has since been validated and translated into Swedish (Burckhardt et al., 1992). Both English and French versions were required in this study. Thus, the Flanagan was translated into French and then back translated into English. A copy of the Flanagan can be found in Appendix C.

The IDUQOL was administered in French or English according to the procedure outlined in Chapter 4, and with the following modifications. If, at the follow-up interview, the participant selected one or more different life areas than those chosen at the baseline interview, the IDUQOL was administered twice, once using the 'new' life areas and once using the life areas that had been selected at baseline. As well, the participants were not asked to explain what the selected life areas meant to them; the meaning of the life areas from the IDUs perspective was examined in a subsequent study. The participant also rated the level of change in his or her quality of life since the baseline interview on a scale of one (greatly decreased) to seven (greatly improved).

5.2.3 Statistical analysis

Differences in the characteristics of IDUs who participated in this study and IDUs interviewed in St-Luc Cohort in 2001 were examined using the Wilcoxon rank sum test for continuous variables and Fisher's exact test for categorical variables. One visit was randomly selected for IDUs that had more than one interview in 2001, and if an IDU had only one interview in 2001 then that interview was used. The test-retest reliability of the IDUQOL was examined by assessing the concordance of the IDUQOL quality of life scores at baseline and follow-up using the ICC with a one-way analysis of variance. The IDUQOL scores were expected to remain fairly stable from baseline to follow-up, and therefore a minimum acceptable correlation coefficient of 0.70 was specified *a priori* (Bech 1999; Garratt and Ruta, 1999). These analyses were performed including all participants, as well as excluding IDUs who reported that their quality of life had changed since baseline (a rating other than four on the seven-point the Likert scale).

Because the quality of life score could range from zero to 100 with the IDUQOL, and from 15 to 105 with the Flanagan, the Pearson correlation coefficient rather than the ICC was used to assess the concordance between the two measures. Here, the intent was to determine whether there was a linear relation between the two measures and not whether the same quality of life score was obtained. Although the Flanagan was selected as the instrument to assess the IDUQOL, it had some limitations. The Flanagan did not capture all the life areas deemed important to IDUs, and did include some extraneous life areas. As a result, a moderate correlation coefficient of 0.40-0.60 was specified *a priori* as acceptable.

Initial evidence of the construct validity of the IDUQOL was sought by examining differences in the quality of life of IDUs according to emergency department visits (no visits or at least one visit in the past six months), the frequency of injection cocaine use ($\leq$ 30, 31 to 100, or $>$ 100 injections in the past month) and living conditions (homeless – defined as living on the street, in a shelter in a hotel – or

stable home), using multiple linear regression. Thus, the β's from the linear regression represented the mean difference in quality of life across the particular contrast, assuming all other variables were held constant. This is discussed in further detail in Chapter 6. Two regression models were constructed, one using the IDUQOL quality of life score as the dependent variable, and one using the Flanagan quality of life score as the dependent variable. The models were adjusted for gender, duration of injection drug use (≤ 5 years or > 5 years) and HIV serostatus (positive or negative). The Flanagan score was scaled, as indicated below, to have the same range of scores as the IDUQOL to facilitate the comparison of results.

$$(5)\ \text{Flanagan}_{\text{scaled}} = (\text{Flanagan}_{\text{score}} - 15) \times 10/9$$

When asked to rate their satisfaction with the 15 items of the Flanagan, 17 IDUs responded that they were neither satisfied nor dissatisfied with a given item – it had no relevance to their quality of life. As specified in the Flanagan administration procedure, the irrelevant item was not included in the calculation of the quality of life score. Instead, the Flanagan quality of life score was calculated using the k items that the IDU had rated, and then was scaled to represent the quality of life score that would have been obtained had all 15 items been included.

$$(6)\ \text{Flanagan}_{15\ \text{items}} = (\text{Flanagan}_{k\ \text{items}}) \times 15/(k)$$

There were relatively few missing data. The Flanagan was not repeated at follow-up for one participant and therefore, the participant was excluded from the assessment of criterion validity for the follow-up visit, and from the test-retest reliability assessment of the Flanagan. No data were missing for the variables included in the regression analysis.

5.3 RESULTS

From April 4, 2001 to July 5, 2001, 63 IDUs from the St-Luc Cohort were interviewed and their quality of life was assessed using the IDUQOL and the Flanagan. Two IDUs were excluded from the study because they had not injected in the previous six months. The 61 study participants had injected on average 13.7 years, 24 (39%) were in a drug treatment program in the past six months, nine of whom were currently in methadone treatment. Representative of the drug scene in Montreal, most of the IDUs in this study were predominantly cocaine injectors, with only seven IDUs having reported heroin use in the past month. Of these seven IDUs, two predominantly injected heroin, three predominantly injected cocaine and two were daily cocaine and heroin injectors. The characteristics of the 61 study participants are provided in Table 5.1.

Table 5.1. Characteristics of the 61 study participants.

Characteristic	Categories	Number of IDUs (%)
Gender	Male	54 (88.5)
	Female	7 (11.5)
Age	Mean (range)	41 (26-63)
Mother tongue	French	55 (90.2)
	English	6 (9.8)
Caucasian	Yes	59 (96.7)
	No	2 (3.3)
Current living conditions	No fixed address	4 (6.6)
	Shelter/hostel	9 (14.8)
	Rent room in hotel/house	8 (13.1)
	House/apartment	40 (65.6)
Married/common law[*]	Yes	6 (9.8)
	No	53 (86.9)
Currently employed[**]	Yes	8 (13.1)
	No	52 (85.2)
Currently receive welfare[**]	Yes	50 (82.0)
	No	10 (16.4)

Table 5.1 cont'd

Characteristic	Categories	Number of IDUs (%)
HIV serostatus	Positive	22 (36.1)
	Negative	39 (63.9)
Currently taking medication(s)	Yes	30 (49.2)
	No	31 (50.8)
Used emergency department past six months	Yes	24 (39.3)
	No	37 (60.7)
In drug treatment program past six months	Yes	24 (39.3)
	No	37 (60.7)
Currently in methadone treatment	Yes	9 (14.8)
	No	52 (85.2)
Years of injection drug use	Mean (range)	13.7 (1.4-31.2)
No. of cocaine injections past month (N=58)	Mean (range)	80.1 (1-630)
No. of heroin injections in past month (N=7)	Mean (range)	17.1 (1-63)
Main source of needles past six months[***]	Needle exchange program	32 (52.5)
	Pharmacy	15 (24.6)
	Health clinic	7 (11.5)
	Other	4 (6.6)

[*]Missing data for two IDUs. [**]Missing data for one IDUs. [***]Missing data for three IDUs.

Comparison of the 61 study participants with IDUs in the St-Luc Cohort interviewed in 2001 showed that the two groups did not significantly differ with respect to gender, mother-tongue, being Caucasian, age, living conditions, duration of injection drug use, crack use in the past month or the number of heroin or cocaine injections in the past month. As a result of the eligibility criteria, a significantly larger proportion of IDUs who participated in this study had injected in the past six months (100% vs. 80.8%).

Of the 61 study participants, 52 (85.2%) returned for a follow-up interview within a mean of 11 days (range 7 to 28 days). IDUs who returned for follow-up did not significantly differ from IDUs who did not with respect to gender, HIV serostatus, welfare receipt, mean duration of injection drug use, mean number or cocaine or heroin injections in the past month, or baseline quality of life scores. However, IDUs

who returned for follow-up had a significantly higher mean age (42.1 vs. 35.6 years), and were more likely to have reported being homeless (40 vs. 0%).

Table 5.2 provides the frequency with which the IDUQOL life areas were selected by the 61 IDUs interviewed at baseline and the 52 IDUs interviewed at follow-up; restriction of the study population to the 52 IDUs who returned for a follow-up interview did not greatly change the presented results. Health, housing and money were among the most frequently selected life areas at both baseline and follow-up. The proportion of IDUs that selected the life area feeling good about yourself as being one of the most important constituents of their quality of life increased from 39.3% at baseline to 63.5% at follow-up. There were also notable changes in the proportion of IDUs that selected partnership, sex and spirituality. Of the 52 IDUs who returned for a follow-up interview, six (11.5%) selected the same life areas at baseline and follow-up, 15 (28.9%) changed one life area, 22 (42.3%) changed two life areas, eight (15.4%) changed three life areas, and one (1.9%) changed four life areas. These 52 IDUs selected, on average, 1.7 different life areas than those they had selected at baseline. Of the 46 individuals who changed one or more life areas, 15 (32.6%) reported that they did remember the life areas they had selected at baseline.

Table 5.2. Frequency of IDUQOL life area selection at the baseline and follow-up visits.

IDUQOL life area	No. of IDUs selecting life area at baseline (%) (N=61)	No. of IDUs selecting life area at follow-up (%) (N=52)
Housing	36 (59.0)	36 (69.2)
Health	34 (55.7)	33 (63.5)
Money	34 (55.7)	32 (61.5)
Spirituality	27 (44.3)	17 (32.7)
Family	26 (42.6)	23 (44.2)
Feeling good about yourself	24 (39.3)	33 (63.5)
Friends	18 (29.5)	13 (25.0)
Partnership	18 (29.5)	10 (19.2)

Table 5.2 cont'd

IDUQOL life area	No. of IDUs selecting life area at baseline (%) (N=61)	No. of IDUs selecting life area at follow-up (%) (N=52)
Independence and free choice	15 (24.6)	10 (19.2)
Being useful	18 (29.5)	12 (23.1)
Drugs	12 (19.7)	9 (17.3)
Sex	11 (18.0)	4 (7.7)
HIV/AIDS treatment	8 (13.1)	6 (11.5)
Drug treatment	5 (8.2)	6 (11.5)
Education	6 (9.8)	4 (7.7)
Leisure activities	7 (11.5)	7 (13.5)
Resources	6 (9.8)	5 (9.6)

As shown in Figure 5.1, the distribution of the IDUQOL scores at baseline ranged from lowest possible score of zero to the highest possible score of 100, with a mean of 53.9 and a median of 60.0. Similarly, the median and mean IDUQOL scores at follow-up were 57.5 and 60.6, respectively, and ranged from 2.8 to 100. The mean difference between the IDUQOL quality of life scores at baseline and follow-up was -3.3 (95% CI: -9.0, 2.4) for group comparisons (i.e., using the standard error), and -3.3 (95% CI: -44.4, 37.8) for individual comparisons (i.e., using the standard deviation). The Flanagan quality of life score ranged from 24.0 to 90.0 at baseline, with a mean and median of 63.3 and 65.0, respectively. At follow-up, the Flanagan score ranged from 22.0 to 91.0, with a mean of 64.1 and a median of 65.0. A plot of the IDUQOL score at follow-up versus baseline and the Flanagan score at follow-up versus baseline are shown in Figures 5.2 and 5.3, respectively.

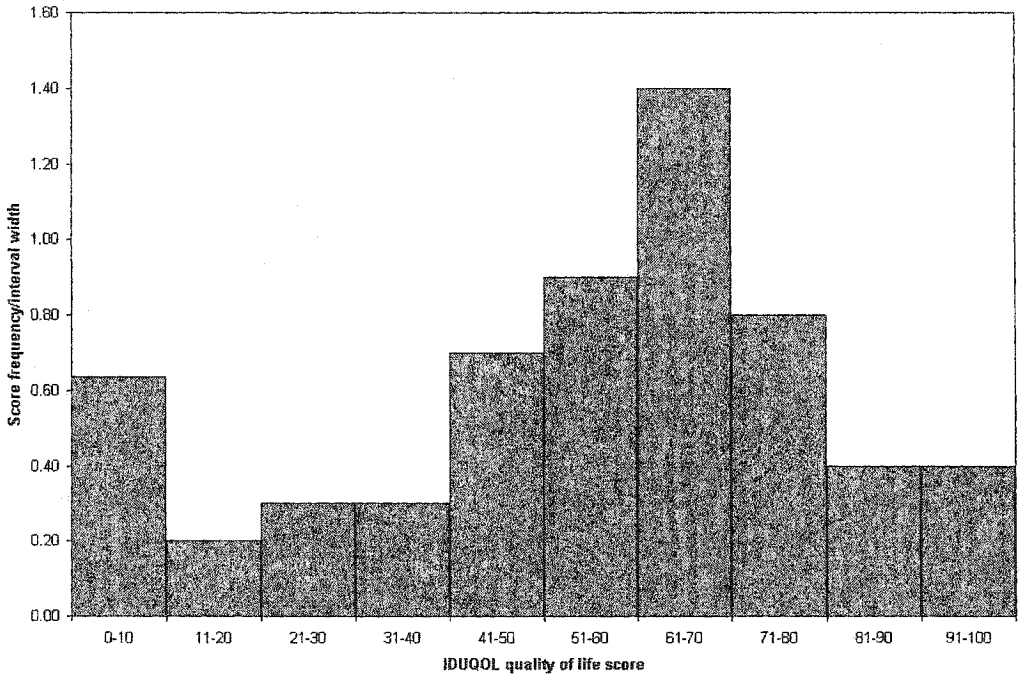

Figure 5.1. Histogram of IDUQOL quality of life scores at baseline (N=61)

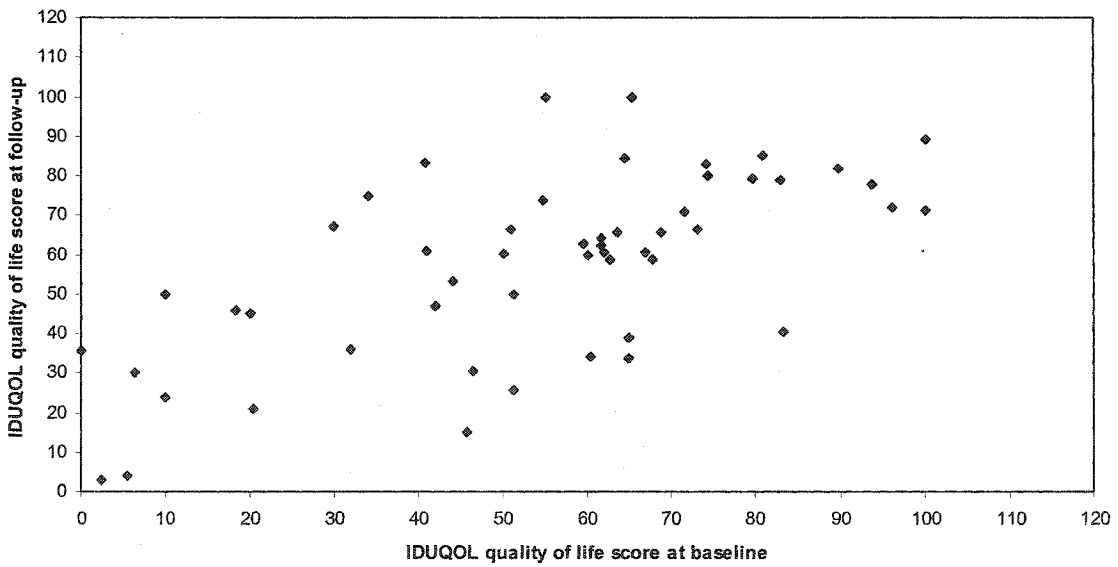

Figure 5.2. Plot of IDUQOL quality of life scores at follow-up vs. baseline (N=52)

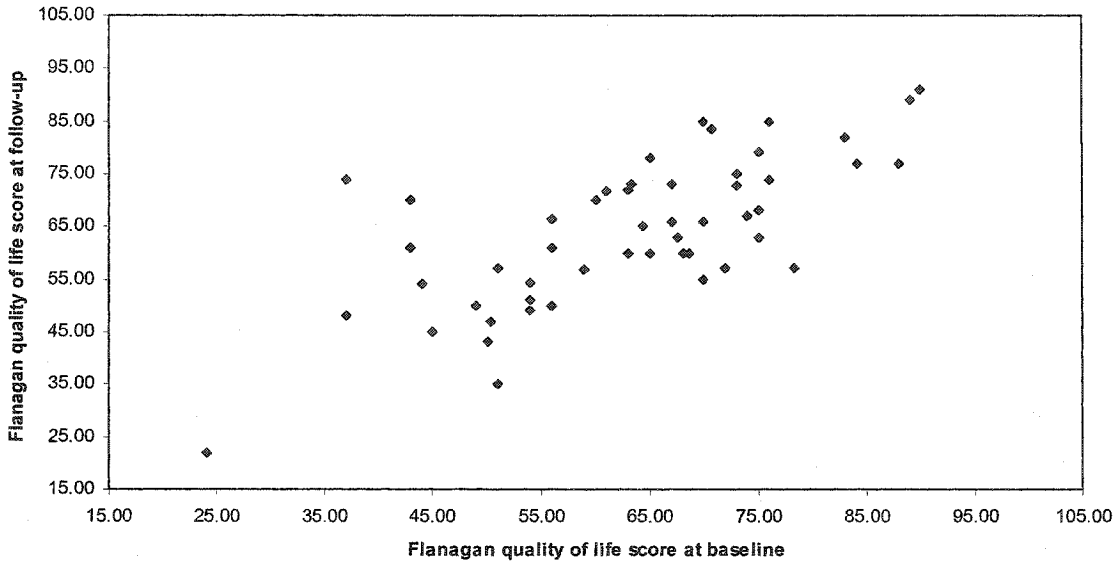

Figure 5.3. Plot of Flanagan quality of life scores at follow-up vs. baseline (N=51)

The results of the psychometric assessment of the IDUQOL are presented in Table 5.3. As shown, the test-retest reliability coefficient of the IDUQOL was 0.71. The coefficient was somewhat lower, 0.64, when the different life areas selected at the follow-up visit were used. The test-retest reliability coefficient of the Flanagan was 0.71. The test-retest reliability coefficients were recalculated for the IDUQOL and the Flanagan including only the 19 IDUs who reported that their quality of life had not changed since baseline. The corresponding correlation coefficients increased to 0.78 for the IDUQOL and 0.75 for the Flanagan. In terms of concurrent criterion validity, the correlation coefficients between the IDUQOL and Flanagan at baseline and follow-up were 0.57 and 0.58, respectively.

Table 5.3. Psychometric properties of the IDUQOL.

Comparison	Restriction	Coefficient
Test-retest reliability[*]		
IDUQOL	None (N=52)	0.710
IDUQOL	IDUs who reported their quality of life did not change over re-test period (N=19)	0.782
Flanagan	None (N=51)[**]	0.714
Flanagan	IDUs who reported their quality of life did not change over re-test period (N=18) [**]	0.748
Concurrent criterion validity[***]		
IDUQOL and Flanagan	Baseline visit only (N=61)	0.569
IDUQOL and Flanagan	Follow-up visit only (N=51) [**]	0.575

[*]ICC. [**]Excludes 1 subject with missing data. [***]Pearson correlation coefficient.

To assess the construct validity of the IDUQOL, the mean difference in the IDUQOL and Flanagan quality of life scores according to cocaine use, emergency department use and homelessness were examined. This analysis included all 61 IDUs interviewed at baseline, and the results are provided in Table 5.4. As shown, IDUs who injected cocaine more than 100 times in the past month had a quality of life that was, on average, 14.71 points lower on the IDUQOL compared with IDUs who injected cocaine 30 times or less in the past month. These results were less pronounced for the Flanagan (mean difference = -9.04). Likewise, IDUs who injected cocaine 31 to 100 times in the past month had a quality of life that was, on average, 8.22 points lower on the IDUQOL and 0.87 points higher on the Flanagan compared with IDUs who injected cocaine 30 times or less in the past month, although statistical significance was not reached. Emergency department use was significantly associated with a lower quality of life as measured by IDUQOL (mean difference = -22.37). A similar although less pronounced association was found

with the Flanagan (mean difference = -10.57). Neither the IDUQOL nor the Flanagan detected important differences in the quality of life of IDUs who had a stable home compared with those who were homeless.

Table 5.4. Mean difference in the IDUQOL and Flanagan scores according to quality of life indicators (N=61).

Quality of life indicator	Mean difference in IDUQOL score (95% CI)	Mean difference in Flanagan score (95% CI)
Cocaine injections past month		
31 to 100	-8.22 (-21.84, 5.41)	0.87 (-8.39, 10.13)
> 100	-14.71 (-30.17, 0.74)	-9.04 (-19.55, 1.46)
≤ 30 (reference)	-	-
Emergency department use		
Visited past six months	-22.37 (-34.87, -9.88)	-10.57 (-19.07, -2.08)
No visits past six months (reference)	-	-
Current living conditions		
Homeless	4.23 (-8.69, 17.14)	1.66 (-7.12, 10.44)
Stable home (reference)	-	-

*Adjusted for gender, duration of injection drug use and HIV serostatus.

5.4 DISCUSSION

The purpose of this study was to evaluate the reliability and validity of the IDUQOL in Montreal IDUs. The IDUQOL demonstrated good test-retest reliability – the reliability coefficient of 0.71 met accepted standards for use with a population, and was higher than that of another individualized measure, the Patient Generated Index (Ruta et al., 1999). When the test-retest reliability analysis was restricted to the 19 IDUs who reported that their quality of life had not changed since the baseline interview, the coefficient increased to 0.78, thus providing some evidence of the responsiveness of the IDUQOL – its ability to detect changes in quality of life. However, when the changes in life area selection were included, the reliability

coefficient decreased to 0.64, similar to that of 0.65 of the Patient Generated Index (Ruta et al., 1999).

It is possible that this decrease in test-retest reliability was a result of the increased number of IDUs that selected feeling good about yourself as being one of the most important areas of their quality of life at the follow-up interview. Feeling good about yourself is less tangible than the other life areas, and therefore may have been more susceptible to moods and recent experiences, which unduly affected the quality of life assessment at follow-up. Perhaps participation in this study affected the IDUs' self-awareness and hence, their self-perception. Additional studies, with a larger sample size, might provide further insight regarding the stability of quality of life constituents and their effect on the measurement of quality of life. Few longitudinal studies have used individualized quality of life measures. Researchers at St. Paul's Hospital in Vancouver are currently studying the effect of life area selection and weighting of the IDUQOL in 250 IDUs.

It should also be noted that the test-retest reliability of the Flanagan of 0.71 was considerably lower than that of 0.78 and 0.84 found over a three-week interval in adults with chronic illness (Burckhardt et al., 1989). This evaluation study used a French version of the Flanagan that had not been previously validated, and it is unknown whether or not the Flanagan performed the same in French and English. However, the French version of the Flanagan was translated by a bilingual sociologist with experience in research, and was back-translated into English by another bilingual individual. It is therefore unlikely that use of a French version alone contributed to the lower reliability. It is plausible that the lower test-retest reliability indicates that quality of life of IDUs is somewhat less stable than that of other individuals. Overall, the results demonstrated that the IDUQOL had acceptable test-retest reliability for use in IDU populations but may be of limited use in a clinical (i.e., individual) setting.

Of the 52 IDUs who returned for a follow-up interview, 88% changed at least one life area, for an average of 1.7 life area changes. This was comparable to the average of

1.7 changes in nominated life areas when using the Patient Generated Index in patients with low back pain over a two-week period (Ruta et al., 1994a), but was greater than the average change of 1.1 life areas over seven months in a healthy population using the Schedule for Evaluation of Individual Quality of Life (O'Boyle et al., 1994). The implications of the changes in life area selection are difficult to surmise at this stage in the IDUQOL's existence; indeed, this remains a major challenge of the individualized approach in longitudinal assessments of quality of life. In sum, the selection of the constituents of quality of life appeared to be an important aspect in measuring the quality of life of IDUs, in determining the stability of quality of life in this population, and in assessing the reproducibility of the IDUQOL.

In the assessment of the concurrent criterion validity of the IDUQOL, a moderate correlation of 0.57 between the IDUQOL and the Flanagan was found. While both instruments seemed to measure the underlying construct of quality of life, this moderate correlation could suggest that the IDUQOL had unique features in the measurement of quality of life in IDUs. The IDUQOL was developed with input from drug injectors and likely quantified quality of life in a way that was more pertinent to IDUs. Conversely, the Flanagan offered no choice in the life areas that constituted the quality of life construct and an equal importance was assumed for each area. Several IDUs responded that a life area(s) included in the Flanagan was irrelevant to their quality of life. As well, the quality of life of IDUs in this study as measured by the Flanagan did not include the entire range of scores from 15 to 105; a low of 22 and high of 91 were obtained.

This study provided some initial evidence of the construct validity of the IDUQOL. Both the IDUQOL and the Flanagan demonstrated that quality of life was negatively associated with the number of cocaine injections in the past month and with emergency department use, which corroborates related findings from other studies (Falck et al., 2000; Palepu et al., 2001). Despite some overlap between the confidence intervals, these relations were more striking for the IDUQOL than the Flanagan, which might suggest that the IDUQOL was more capable of discriminating

between subgroups of IDUs based on quality of life. Contrary to what has been found among homeless individuals with mental disorders (Lehman et al., 1995), neither the IDUQOL nor the Flanagan detected differences in the quality of life of IDUs who were homeless and those who had a stable home. However, the effect of homelessness on quality of life might have been underestimated due to the warm spring and summer months during which the study interviews were conducted. Only 11 of the 21 homeless IDUs selected housing as being an important area of their quality of life, five of whom favourably rated their housing situation (ratings of 65 to 100). Establishing construct validity of an instrument is an ongoing process (Hubley and Zumbo, 1996), and further studies should provide more evidence.

An important consideration when evaluating a questionnaire is the acceptability of the instrument in the population of interest. The study participants had no difficulty understanding the IDUQOL procedure, they showed a strong interest in discussing quality of life, and 85% returned for a subsequent visit. Several participants became quite emotional during the study interviews, which suggested that the IDUQOL tapped into their unique and personal conceptualization of quality of life.

Some limitations must be considered when interpreting the presented findings. The study population was homogeneous, comprised of mainly white, male, cocaine injectors. Cocaine addiction is characterized by a frenetic lifestyle and high-risk behaviour, and the IDUs included in this study may have had a more unstable existence than IDUs who inject other drugs. The low number of heroin addicts in the study population prevented determination of the IDUQOL's properties in cocaine and heroin addicts separately. In addition, IDUs in the St-Luc Cohort are primarily long-term injectors and few young IDUs were included. It follows that the IDUQOL may perform differently in younger IDUs, female IDUs and heroin IDUs. A further shortcoming of this study was the lack of uniformity in the time between visits. However, evaluation of the test-retest reliability of the IDUQOL in IDUs who returned for follow-up within a week of the baseline visit was unchanged from that of the entire study population, and the changes in the life area selection were

independent of the time between interviews.

Finally, a limitation of this and all quality of life studies is the attempt to assign numbers to the experiences and perceptions of individuals to represent their quality of life – reducing something that is immaterial to a number on a scale. Nonetheless, to provide for statistical estimates and inference, we must numerically aggregate the experience of the population.

Overall, the IDUQOL appeared to be a promising tool with unique features: it was developed with input from IDUs, and is an individually tailored measure of quality of life that allows IDUs to select, rate, and weight the life areas that constitute their quality of life. This first assessment in Montreal IDUs demonstrated that the IDUQOL had good psychometric properties and was well received by the study participants. The IDUQOL was subsequently applied in a larger study of 260 IDUs to identify the constituents and correlates of quality of life of cocaine and heroin IDUs, and its relation to the use of public health programs. This study is described in the following chapter.

6 APPLICATION OF THE IDUQOL IN MONTREAL IDUS

6.1 OBJECTIVES

Public health programming for IDUs in Canada has largely followed the European paradigm for opiate addiction; little consideration has been given to the predominance of cocaine addiction among IDUs in Canada, and in Montreal in particular. Further, IDUs have not been asked about what is important to them and their input into public health programming has been minimal. In order to gain a better understanding of the lives and needs of cocaine and heroin IDUs with a view to improved public health programming, the IDUQOL was applied in IDUs of the Montreal St-Luc Cohort. The objectives of this study were:

1. To describe the quality of life of cocaine and heroin IDUs, and to identify the constituents and correlates of their quality of life.
2. To describe the relation between the quality of life of cocaine and heroin IDUs and the use of health care services, harm reduction and social service programs currently available in Montreal. These included needle exchange programs, methadone maintenance, other drug treatment, emergency departments, welfare administration, shelters and meal programs.

6.2 METHODOLOGY

6.2.1 Data collection

The source population for this study was the Montreal St-Luc Cohort. The research nurses invited IDUs to participate in this study following completion of their scheduled interview in the St-Luc Cohort described in Chapter 3. In addition to St-Luc Cohort eligibility requirements, participants must have reported injection drug use in the previous month and must have provided informed consent for the quality of life study as required by the Internal Review Board of Hôpital St-Luc. A copy of the

consent from is provided in Appendix B.

Study participants were given the choice of having their quality of life visit directly following the St-Luc Cohort interview or returning within one week. This time restriction was enforced to ensure that the data collected in the St-Luc Cohort interviews were relevant to those collected on quality of life – the data collected from both interviews were used in this study. Quality of life was assessed using the IDUQOL (Brogly et al., in press). These interviews were conducted in a private room by the same interviewer as the evaluation study described in Chapter 5. Different from the evaluation study, the participant was asked to briefly describe what the five chosen life areas meant to him or her. An additional objective of this study was to evaluate the meaning of the life areas from the IDUs perspective. These results will not be presented as part of this thesis.

6.2.2 Classification of drug of addiction

Given the distinct pharmacological actions of cocaine and heroin, differences in their frequency of administration and their social, behavioural and health related effects, differences in the quality of life of cocaine and heroin addicts were expected. Therefore, IDUs were categorized according to their predominant drug of addiction, and separate models were constructed for cocaine and heroin IDUs. IDUs who only reported heroin injection in the month prior to the study interviews were classified as heroin IDUs, and IDUs who only reported cocaine injection in the previous month were classified as cocaine IDUs. The drug use patterns of IDUs who reported both cocaine and heroin injection were examined to accurately classify these IDUs according to their predominant drug of addiction. In many of these cases, the predominant drug of addiction was apparent. For example, a greater number of days of heroin injection was an indication of the IDUs physical addiction to heroin, and that heroin would be sought foremost to cocaine. Nonetheless, some IDU appeared to be addicted to both drugs and therefore classification was more difficult. Rather than exclude these IDUs from the study, a decision was made based on the IDUs' most

recent drug use as well as their drug use history reported at previous cohort interviews. An addiction clinician at Hôpital St-Luc, Dr. Julie Bruneau, reviewed the drug use of these IDUs and provided her opinion as to the individual's predominant drug of addiction. In the case of discrepancy between the investigator's (S. Brogly) classification and Dr. Bruneau's, the latter was used. The reported heroin and cocaine use and subsequent classification of these IDUs are presented in the results section.

6.2.3 Multiple linear regression

This section briefly describes the statistical approach used in this study. Multiple linear regression is an extension of simple linear regression to include more than one independent variable. Thus, the parameter estimates, β_0, β_1, $\beta_2 \ldots \beta_K$, are determined using the method of least squares (Kleinbaum et al., 1998). The value of the parameter estimate, β_1, $\beta_2 \ldots \beta_K$, represents the slope of the line for the relation between y and the independent variable x_1, $x_2 \ldots x_K$. When an independent variable is continuous, the slope β is the average change in y for each unit change in x, assuming all other variables are held constant (Kleinbaum et al., 1998). When an independent variable is categorical and has for instance j categories, the independent variable is factored into a set of j-1 dummy indicator variables. The remaining category is specified as the baseline or reference against which all dummy variables are compared. Therefore, the slope, β, for a particular dummy variable represents the mean difference in y between the category represented by the dummy variable and the baseline, assuming all other variables are held constant. In this study, most variables were categorical; thus, they were factored into a set of dummy variables. The β's represented the mean difference in the IDUQOL quality of life score across the particular contrast (i.e., the dummy variable vs. the baseline), assuming all other variables were held constant.

There are a number of diagnostic techniques that can be used to verify the assumptions of linear regression, to identify outlying observations that may have had an untoward influence in determining the parameter estimates, and to assess the

collinearity of the independent variables. A plot of the residuals is useful for assessing whether the fundamental assumptions of linear regression were met. The fundamental assumptions are: 1) linearity – the mean value of y is a linear combination of the x's, 2) homoscedasticity – the variance of y is the same for any fixed combination of the x's, and 3) normality – the dependent variable, y, is normally distributed for any fixed combination of the x's (Kleinbaum et al., 1998). A residual plot for a model in which these assumptions are met should have a horizontal rectangular shape with no hint of any systematic trends (i.e., increasing or decreasing variance or curvilinear shapes indicating departures from linearity).

Cook's distance is a statistic that is commonly used to evaluate the influence of an observation on the model. It measures the extent to which the estimated regression parameters change when a particular observation is removed from the model (Kleinbaum et al., 1998). Therefore, it identifies the observation(s) that had the greatest impact on the parameter estimates. Critical values for Cook's distance according to n, k and the specified type I error, α, can be found in statistical tables. For this study, the critical values listed in Kleinbaum, Kupper, Muller & Nizam were used (Kleinbaum et al., 1998).

Near collinearity arises in a model if an independent variable is strongly correlated with a combination of the other variables included in the model (Kleinbaum et al., 1998). The variance inflation factor (VIF) is a statistic that is often used to measure collinearity in multiple linear regression. Values of VIF > 3 for should be investigated further for collinearity.

6.2.4 Variable definition

The independent variables were defined to demarcate important clinical, social or behavioural differences. Consideration was also given to the effect of the variable definition on the regression model. Residual plots of continuous variables were examined to verify the assumptions of linearity, homoscedasticity and normality, and

categorical variables were defined to ensure that the data were not too sparsely distributed.

The public health programs investigated in objective two were carefully selected from the programs for which data were collected in the St-Luc Cohort interviews. Programs that were foreseen to be related to quality of life, and/or were an important element of harm reduction, and for which information was collected in adequate detail for meaningful variable definition were included. The variable definition regarding the use of these public health programs is described below.

The St-Luc Cohort questionnaire collected data differently for the duration of methadone treatment and the duration of other drug treatment. The duration of the IDU's methadone treatment referred to the total time the subject had been on methadone, whereas the duration of other drug treatment referred to treatment within the past six months. It was difficult to distinguish IDUs who were in methadone from those who were in methadone in addition to another type of drug treatment. Thus, drug treatment and methadone treatment were defined to be exclusive variables. Residual plots for methadone and other drug treatment indicated departures from normality, and therefore these variables were categorized. The duration of methadone treatment was defined as none, $\leq$ 18 months, and >18 months, and the duration of other drug treatment was defined as none, $\leq$ four weeks, and > four weeks. Social assistance administration (i.e., signing one's welfare cheque over to a hospital or social organization to receive alloted payments throughout the month) was dichotomously defined (yes or no); there were too few subjects who had their social assistance administered to examine differences in quality of life in relation to the frequency of administration. Data regarding meal program and shelter use were collected in a six category ordinal scale: (daily, two or three times a week, weekly, monthly, only a few times, never), and were collapsed into four categories (daily, less than daily to weekly, monthly or less, and never). Emergency department use in the past six months was defined as no use, one or two visits, and three visits or more.

Needle exchange program use in the past month was defined as no use, infrequent use (< once per week), frequent use (≥ once per week).

Potential confounders of the relation between program use and quality of life included gender, age, frequency of cocaine or heroin injections, health status, living conditions and time of study interview in relation to the receipt of social assistance cheques. Gender was classified as male or female. Age was classified into four categories (≤ 25 years, > 25 to ≤ 34 years, > 34 to ≤ 40 years or > 40 years). Data regarding self-perceived health were collected in a five category ordinal scale (excellent, very good, good, fair, and poor) and were collapsed into three categories: excellent or very good, good, and fair or poor. The IDUs' current housing situation was defined as homeless or stable. IDUs who were living on the street, in a shelter, hotel room, or in a detoxification unit were classified as homeless, and IDUs who were living in a house, apartment, hospice or supervised apartment were classified as having a stable home. The timing of the study visit in relation to receipt of social assistance cheques was also considered because of potential confounding due to the large influx of money in the injecting community during this time. IDUs who were interviewed between the 27th and the 2nd of the month were considered to have had their quality of life assessed during this cheque distribution period.

Other correlates of quality of life examined as part of objective one were selected from the St-Luc Cohort questionnaire using criteria similar to that discussed above for the program utilization models. These variables and their classification are as follows. Ethnic background, vis-à-vis mother tongue, was defined as French or other because of the small proportion of IDUs whose mother tongue was other than French. Similarly, race was defined as Caucasian or other. Other variables that were dichotomously defined included marital status (married/common-law or other), education (≤ high school or ≥ CEGEP), employment status (employed or not employed), monthly income (≤ $1,400 or > $1,400), exchanged sex for drugs or money in the past six months (yes or no), HIV serostatus (positive or negative), attempted suicide in the past six months (yes or no), had an accidental overdose in the

past six months (yes or no), borrowed needles in the past six months (yes or no), lent needles in the past six months (yes or no) and borrowed injection equipment in the past six months (yes or no). The location where fixing most frequently occurred was defined as a public place (bar, restaurant or washroom), outside (park or street), home (own home or a friend's), and other (shooting gallery or hotel). Duration of injection drug use was defined as ≤ three years, > three years to ≤ 10 years, and > 10 years. The duration of HIV seropositivity was defined as the number of years since testing HIV positive in the St-Luc Cohort.

Drug use variables were defined to have clinical relevance to addiction and therefore, both the number of days and the frequency of injection were considered. The number of days of drug use is suggestive of the degree of dependence, whereas the number of injections is suggestive of an individual's habit and tolerance. The data for drug use were in general skewed, thus these variables were dichotomized. The frequency of cocaine injection in the past month was categorized as ≤ 30 injections, > 30 to ≤ 100 injections and > 100 injections. The number of days of injection cocaine use was defined as < 15 days or ≥ 15 days. Because heroin use is more systematic, the frequency of heroin injection was calculated by dividing the total number of heroin injections by the total number of days that heroin was used. The number of days of injection heroin use was defined as < 15 days or ≥ 15 days and the frequency of heroin injection was categorized as ≤ two injections per day, and > two injections per day. Heroin and cocaine use were also defined as any vs. no use as few cocaine IDUs injected heroin and few heroin IDUs injected cocaine. The frequency of alcohol use was also calculated by dividing the total number of drinks consumed by the number of days of use. The number of days of alcohol use was defined as < 15 days or ≥ 15 days and the frequency of alcohol use was categorized as ≤ 3 drinks per day and > 3 drinks per day. Due to the small number of IDUs who used crack and intranasal cocaine, these variables were dichotomously defined as any use or no use.

There were few missing data. Data that were missing were coded according to the response of the study participant at the previous and/or subsequent interview if

available. In the few cases where the participant did not have a previous interview or had not previously responded to the question of interest, the mean value of the variable in the cocaine or heroin IDUs was imputed as appropriate.

6.2.5 Statistical analysis

Differences between 1) study participants and non-participants, 2) study participants and IDUs interviewed in the St-Luc Cohort in 2001 and 3) cocaine and heroin IDUs were assessed using Fisher's exact test for categorical variables and the Wilcoxon rank sum test for continuous variables. Crude regressions were performed for all variables. These regressions were repeated, adjusting for potential confounding effects of gender, age, frequency of cocaine or heroin injection, health status, living conditions and time of study interview in relation to the receipt of social assistance cheques.

Descriptive associations between quality of life of cocaine and heroin IDUs and the use of needle exchange programs, methadone maintenance, other drug treatment, emergency department visits, welfare administration, shelters and meal programs were assessed using multiple linear regression while adjusting for potential confounders. The Cook's distance was used to identify outlying observations and VIF's > 3 were examined for collinearity. Analyses were carried out using SAS version 6.8.

6.3 RESULTS

6.3.1 Descriptive characteristics

From September 11, 2001 to March 18, 2002, 291 IDUs were asked to participate in this study, 265 (91%) of whom consented. Compared with IDUs who participated in this study, IDUs who did not participate were significantly more likely to be female (38.5% vs. 14.6%), to have a mother tongue other than French (23.1% vs. 9.6%), to

be non-Caucasian (19.2% vs. 5.0%), to be employed (26.9% vs. 11.1%), and to have a stable home (88.5% vs. 61.5%). There were no significant differences in the self-perceived health status, HIV serostatus, history of diagnosis of a psychiatric disorder, education, mean income, mean age, mean duration of injection drug use, mean number of heroin injections, or mean number of cocaine injections of participants and non-participants.

Five of the 265 IDUs who completed the quality of life interview were excluded: two IDUs returned for their quality of life visit more than one week after their St-Luc cohort interview, two IDUs had not injected in the past month, and one IDU had incomplete quality of life data. One hundred and sixty-one (61.9%) of the 260 participants had their quality of life interview on the same day as the St-Luc Cohort interview, 79 (30.4%) were interviewed one to three days later, and the remaining 20 (7.7%) were interviewed four to seven days later.

The 260 study participants were compared with IDUs interviewed in the St-Luc Cohort during 2001. The study participants did not significantly differ from IDUs in the St-Luc Cohort with respect to gender, mother tongue, being Caucasian, age, duration of injection drug use, heroin, cocaine or crack use in the past month. However, the study participants were more likely to be homeless (38.5% versus 25.7%).

To examine differences in quality of life of cocaine and heroin IDUs, the IDUs were classified according to their reported drug use. Of the 260 IDUs, 23 (8.8%) reported only having injected heroin in the past month and were classified as heroin IDUs; 209 (80.4%) IDUs reported only having injected cocaine in the past month and were classified as cocaine IDUs; and 28 (10.8%) IDUs reported both heroin and cocaine injection. The drug use patterns and subsequent classification of these 28 IDUs are shown in Table 6.1.

Table 6.1. Classification of the 28 IDUs who injected both cocaine and heroin in the past month according to their predominant drug of addiction.

ID	No. of days of heroin injection	No. of heroin injections	No. of days of cocaine injection	No. of cocaine injections	Classification
1132	25	125	3	150	Heroin
1217	1	1	30	30	Cocaine
1234	1	1	4	24	Cocaine
1286	1	1	17	68	Cocaine
1293	21	84	8	120	Heroin
1591	3	3	8	8	Cocaine
1776	25	250	30	30	Heroin
1938	1	2	8	40	Cocaine
1959	12	12	1	10	Heroin
2375	3	3	20	80	Cocaine
2483	1	2	1	6	Cocaine
2510	1	1	2	2	Cocaine
2794	4	8	2	10	Heroin
2936	20	60	28	400	Cocaine
3034	1	1	1	6	Heroin
3077	3	6	10	20	Cocaine
3241	15	20	1	2	Heroin
3363	1	1	30	180	Cocaine
3714	12	24	12	48	Cocaine
4027	1	1	20	80	Cocaine
4090	1	1	30	180	Cocaine
4106	28	90	20	150	Heroin
4124	3	6	25	50	Cocaine
4149	3	3	4	16	Heroin
4168	4	8	27	135	Cocaine
4186	30	60	1	1	Heroin
4207	20	60	21	210	Cocaine
4209	3	12	4	40	Cocaine

Table 6.2 provides the sociodemographic characteristics of the 227 cocaine IDUs and the 33 heroin IDUs. There were some notable differences in the characteristics of the two groups of IDUs. Cocaine IDUs were older and were more likely to be male, to

be Caucasian, to be unmarried, and to be homeless. The mean age of the cocaine and heroin IDUs was 40 years (19-63) and 33 years (20-49), respectively. The majority of both cocaine and heroin IDUs were unemployed, had a high school education or less, had a mean monthly income of less than $1,400, and were on welfare. There was no significant difference in the proportion of cocaine and heroin IDUs that were interviewed during the period of social assistance distribution.

Table 6.2. Sociodemographic characteristics of cocaine and heroin IDUs.

Characteristic	Cocaine IDUs N (%)	Heroin IDUs N (%)
Sex		
Female	25 (11.0)	13 (39.4)
Male	202 (89.0)	20 (60.6)
Mother tongue		
English/other	19 (8.4)	6 (18.2)
French	208 (91.6)	27 (81.8)
Age		
≤ 25 years	6 (2.6)	8 (24.2)
>25 to ≤ 34 years	29 (12.8)	10 (30.3)
>34 to ≤ 40 years	77 (33.9)	9 (27.3)
>40 years	115 (50.7)	6 (18.2)
Caucasian		
Yes	219 (96.5)	28 (84.8)
No	8 (3.5)	5 (15.2)
Education		
High school or less	191 (84.1)	25 (75.8)
CEGEP or higher	36 (15.9)	8 (24.2)
Living conditions		
Apartment/house	132 (58.1)	28 (84.8)
Rent room in hotel	39 (17.2)	0 (0.0)
Shelter/hostel	24 (10.6)	2 (6.1)
Detoxification unit	4 (1.8)	2 (6.1)
Street/no fixed address	28 (12.3)	1 (3.0)
Married/common-law		
Yes	30 (13.2)	13 (39.4)

Table 6.2 cont'd

Characteristic	Cocaine IDUs N (%)	Heroin IDUs N (%)
No	194 (85.5)	20 (60.6)
Missing	3 (1.3)	0 (0.0)
Employed		
Yes	24 (10.6)	5 (15.2)
No	200 (88.1)	27 (81.8)
Missing	3 (1.3)	1 (3.0)
Receive social assistance		
Yes	190 (83.7)	25 (75.8)
No	34 (15.0)	7 (21.2)
Missing	3 (1.3)	1 (3.0)
Interviewed during period of social assistance distribution		
Yes	44 (19.4)	8 (24.2)
No	183 (80.6)	25 (75.8)
Mean monthly income past 6 months		
≤ $1,400	141 (62.1)	19 (57.6)
> $1,400 (ref.)	83 (36.6)	13 (39.4)
Missing	3 (1.3)	1 (3.0)
Sexual orientation		
Homosexual	11 (4.8)	1 (3.0)
Bisexual	19 (8.4)	5 (15.2)
Heterosexual	197 (86.8)	27 (81.8)
Exchanged sex for drugs or money past 6 months		
Yes	12 (5.3)	6 (18.2)
No	200 (88.1)	27 (81.8)
Missing	15 (6.6)	0 (0.0)

The health attributes of the cocaine and heroin IDUs are shown in Table 6.3. The morbidity associated with drug addiction is clearly illustrated with over 40% of both cocaine and heroin IDUs having rated their health as fair or poor, and upwards of 30% ever having been diagnosed with a psychiatric disorder. Although the difference in proportions was non-significant, approximately 10% of cocaine IDUs attempted

suicide in the past six months while no heroin IDUs reported having attempted suicide. As has been well documented in the St-Luc Cohort and other IDU populations, cocaine IDUs were significantly more likely to be HIV positive (Chaisson et al., 1989; Astemborski et al., 1994; Strathdee et al., 1997b; Brogly et al., 2000).

Table 6.3. Health attributes of cocaine and heroin IDUs.

Health attribute	Cocaine IDUs N (%)	Heroin IDUs N (%)
Self-rated health		
Excellent or very good	24 (10.6)	5 (15.2)
Good	102 (44.9)	14 (42.4)
Fair or poor	101 (44.5)	14 (42.4)
HIV serostatus		
Positive	86 (37.9)	3 (9.1)
Negative	141 (62.1)	30 (90.9)
Mean years since testing HIV positive	4.4 (<1-12.0)	1.5 (<1-4.5)
Ever diagnosed with psychiatric disorder		
Yes	88 (38.8)	11 (33.3)
No	139 (61.2)	22 (66.7)
Attempted suicide past 6 months		
Yes	22 (9.7)	0 (0.0)
No	205 (90.3)	33 (100.0)
Accidentally overdosed past 6 months		
Yes	19 (8.4)	5 (15.2)
No	201 (88.5)	28 (84.9)
Missing	7 (3.1)	0 (0.0)

The drug use and behaviours of the cocaine and heroin IDUs are presented in Table 6.4. The majority of IDUs in both groups were long-term injectors – most had first injected over 10 years ago. The mean age at which cocaine and heroin IDUs began injecting was 24 years (13 to 56) and 18 years (11 to 28). Alcohol consumption was high in both cocaine and heroin IDUs. Although there was no difference in the proportion of cocaine and heroin IDUs that consumed alcohol more than 15 days in

the past month, cocaine IDUs were significantly more likely to have consumed greater than three drinks per day. The mean number of drinks in the past month was 102 (1 to 480) for cocaine IDUs and 81 (1 to 864) for heroin IDUs, respectively. Descriptive of the predominant drug of addiction, a significantly higher proportion of heroin IDUs injected heroin more than 15 days in the past month and injected greater than two times per day. Similarly, a significantly higher proportion of cocaine IDUs injected cocaine more than 15 days in the past month. The mean number of heroin and cocaine injections among heroin IDUs was 41 (1 to 250) and 50 (1 to 150), respectively. In comparison, cocaine IDUs reported a mean of 4 (1 to 20) heroin injections, and 83 (1 to 900) cocaine injections. No striking differences were found in intranasal cocaine and crack use of cocaine and heroin IDUs.

An alarming proportion of cocaine and heroin IDUs borrowed used needles and injection equipment (i.e., cookers, water, filters) and lent their needles in the past six months. There were important differences in the location where cocaine and heroin IDUs frequently injected drugs. The majority of both cocaine and heroin IDUs injected at their own or a friend's home but more cocaine IDUs injected outside and in hotels or shooting galleries and more heroin IDUs injected in a public venue.

Table 6.4. Drug use and behaviour of cocaine and heroin IDUs.

Drug use/behaviour	**Cocaine IDUs**	**Heroin IDUs**
	N (%)	**N (%)**
Duration of injection drug use		
≤ 3 years	6 (2.6)	0 (0.0)
3 to ≤ 10 years	52 (22.9)	13 (39.4)
> 10 years	169 (74.4)	20 (60.6)
Days of alcohol use past month		
≥ 15 days	67 (29.5)	8 (24.2)
< 15 days	160 (70.5)	25 (75.8)
Frequency of alcohol consumption		
> 3 drinks/day	138 (60.8)	12 (36.4)
≤ 3 drinks/day	89 (39.2)	21 (63.6)
Injected heroin past month		

Table 6.4 cont'd

Drug use/behaviour	Cocaine IDUs N (%)	Heroin IDUs N (%)
Yes	18 (7.9)	33 (100.0)
No	209 (92.1)	0 (0.0)
Days of injection heroin use past month		
≥ 15 days	2 (0.9)	16 (48.5)
< 15 days	225 (99.1)	17 (51.5)
Frequency of heroin injection		
> 2 injections/day	3 (1.3)	9 (27.3)
≤ 2 injections/day	224 (98.7)	24 (72.7)
Injected cocaine past month		
Yes	227 (100.0)	10 (30.3)
No	0 (0.0)	23 (69.7)
Days of injection cocaine use past month		
≥ 15 days	70 (30.8)	2 (6.1)
< 15 days	157 (69.2)	31 (93.9)
Number of cocaine injections past month		
> 100 injections	51 (22.5)	0 (0.0)
31 to ≤ 100 injections	71 (31.3)	3 (9.1)
≤ 30 injections	105 (46.3)	30 (90.9)
Used intranasal cocaine past month		
Yes	45 (19.8)	2 (6.1)
No	182 (80.2)	31 (93.9)
Smoked crack cocaine past month		
Yes	74 (32.6)	6 (18.2)
No	153 (67.4)	27 (81.8)
Borrowed used needles past 6 months		
Yes	88 (38.8)	11 (33.3)
No	139 (61.2)	22 (66.7)
Borrowed used injection equipment past 6 mo.		
Yes	91 (40.1)	14 (42.4)
No	136 (59.9)	19 (57.6)
Lent used needles past 6 months		
Yes	47 (20.7)	9 (27.3)
No	180 (79.3)	24 (72.7)
Place where fixing most often occurred		
Own home or friends	158 (69.6)	23 (69.7)

Table 6.4 cont'd

Drug use/behaviour	Cocaine IDUs N (%)	Heroin IDUs N (%)
Bar, restaurant or washroom	8 (3.5)	6 (18.2)
Street or park	45 (19.8)	3 (9.1)
Hotel/shooting gallery	16 (7.0)	1 (3.0)

Table 6.5 provides the health care, social and harm reduction program utilization of the cocaine and heroin IDUs. As shown, a substantial amount of both cocaine and heroin IDUs used meal programs in the past six months – roughly 40% of cocaine IDUs and 30% of heroin IDUs used a meal program at least once a week. Cocaine IDUs more frequently used shelters. Few cocaine or heroin IDUs had their social service cheques administered by an institution, and this precluded its inclusion as an independent variable in the model for heroin IDUs. Needle exchange program utilization was relatively low – over 40% of both cocaine and heroin IDUs did not visit a needle exchange program in the past month. There were no differences in the frequency of emergency department visits in the past six months, the frequency of needle exchange program visits in the past month or the proportion of cocaine and heroin IDUs that were in drug treatment programs other than methadone. Heroin IDUs were significantly more likely to be in methadone treatment, but cocaine IDUs were on methadone for a longer duration. The mean duration of methadone treatment was 21.8 months (0.2 to 60.0) for heroin IDUs, and 33.6 months (0.3 to 88.0) for cocaine IDUs. The mean duration of other drug treatment was 8.3 weeks (0.4 to 26.0) for heroin IDUs, and 5.6 weeks (0.4 to 26.0) for cocaine IDUs.

Table 6.5. Program use of cocaine and heroin IDUs.

Program	Cocaine IDUs N (%)	Heroin IDUs N (%)
Meal program use past 6 months		
Daily	29 (12.8)	4 (12.1)
< Daily to weekly	55 (24.2)	5 (15.2)
Monthly or less	53 (23.3)	6 (18.2)
Never	90 (39.6)	18 (54.5)
Shelter use past 6 months		
Daily	13 (5.7)	0 (0.0)
< Daily to weekly	18 (7.9)	3 (9.1)
Monthly or less	43 (18.9)	1 (3.0)
Never	153 (67.4)	29 (87.9)
Social assistance administered		
Yes	23 (10.1)	1 (3.0)
No	167 (73.6)	23 (69.7)
Not applicable	37 (16.3)	9 (27.3)
Emergency department visits past 6 months		
1 or 2	74 (32.6)	10 (30.3)
≥ 3	14 (6.2)	4 (12.1)
None	139 (61.2)	19 (57.6)
In drug treatment past 6 months		
Yes	51 (22.5)	9 (27.3)
No	176 (77.5)	24 (72.7)
Duration of drug treatment past 6 months		
None	176 (77.5)	24 (72.7)
≤ 4 weeks	24 (10.6)	4 (12.1)
> 4 weeks	27 (11.9)	5 (15.2)
In methadone treatment past 6 months		
Yes	25 (11.0)	17 (51.5)
No	149 (65.6)	16 (48.5)
Missing	2 (0.9)	0 (0.0)
Duration of methadone treatment		
≤ 18 months	6 (2.6)	9 (27.3)
> 18 months	19 (8.4)	8 (24.2)
None	200 (88.1)	16 (48.5)
Missing	2 (0.9)	0 (0.0%)

Table 6.5 cont'd

Program	Cocaine IDUs N (%)	Heroin IDUs N (%)
Needle exchange program use past month		
< Once per week	93 (41.0)	14 (42.5)
≥ Once per week	34 (15.0)	5 (15.2)
None	100 (44.1)	14 (42.5)

*Missing data for 1 IDU.

6.3.2 Quality of life assessment

Histograms of the IDUQOL quality of life scores of cocaine and heroin IDUs are shown in Figures 6.1 and 6.2. The distribution of the IDUQOL scores of cocaine IDUs ranged from lowest possible score of zero to the highest possible score of 100, with a mean of 50.5 and a median of 54.4. The distribution of the IDUQOL quality of life score of the cocaine IDUs appeared to have two peaks – one at 21-30 and another at 61-70. Among heroin IDUs, the quality of life ranged from a low of 6.0 to a high of 88.0 with a mean and median of 49.9 and 52.0, respectively. The histogram indicates a slightly skewed distribution.

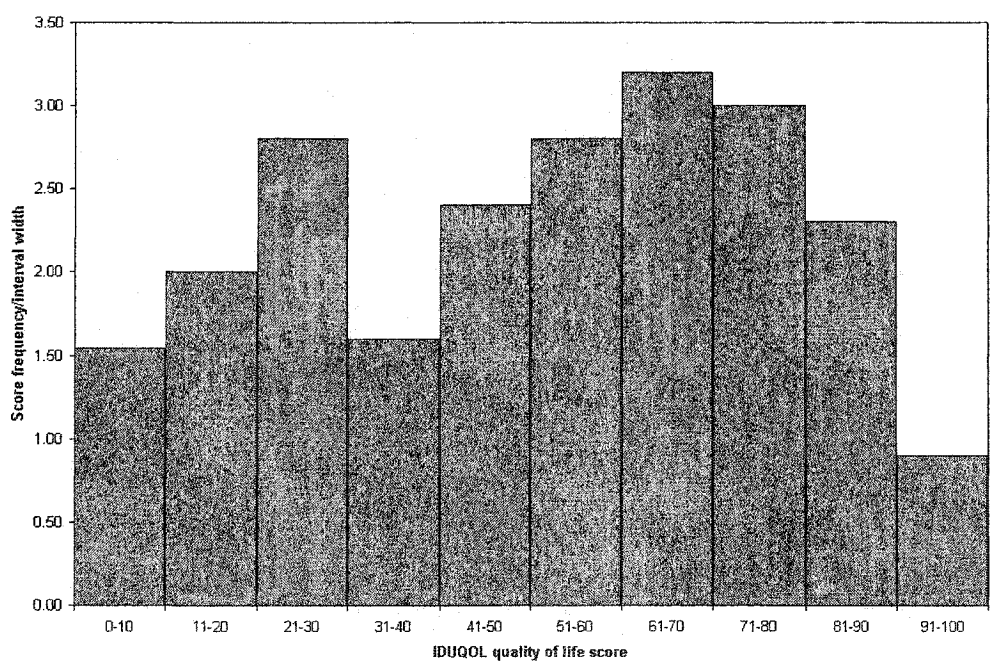

Figure 6.1. Histogram of IDUQOL scores, cocaine IDUs (N=227)

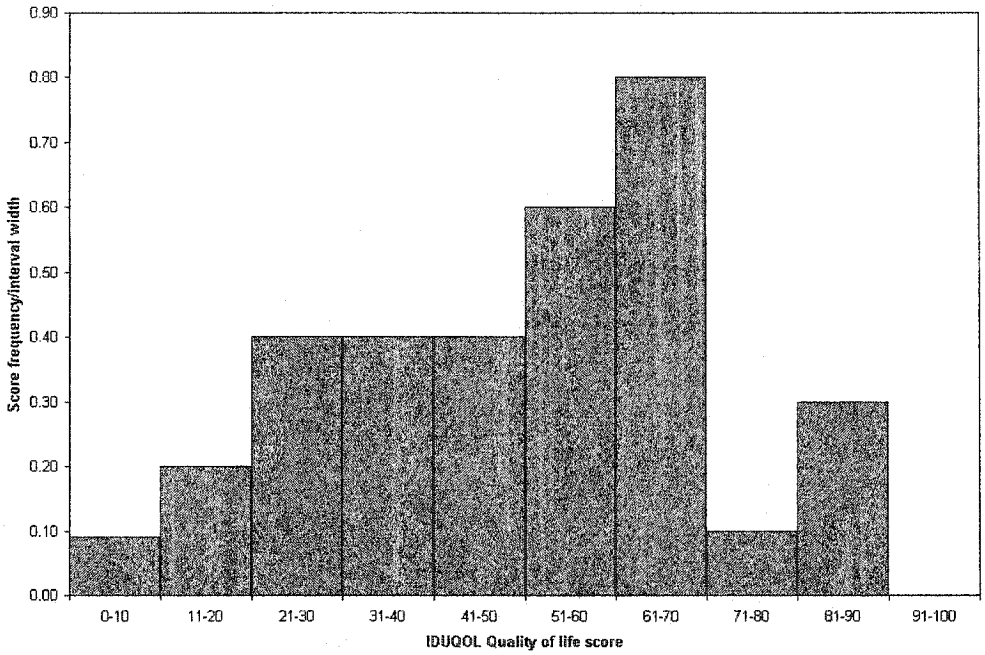

Figure 6. 2. Histogram of IDUQOL scores, heroin IDUs (N=33)

6.3.3 Life area selection, weighting and rating

The frequency of life area selection of the cocaine and heroin IDUs is shown in Table 6.6. It should be noted that IDUs who selected a given life area as being important to their quality of life and subsequently weighted its relative importance as zero were not counted as having selected the given life area. Housing was the most frequently selected life area of cocaine IDUs, whereas heroin IDUS most frequently selected money and feeling good about yourself. Forty-two percent of the cocaine IDUs who selected housing were homeless as compared with 23% of heroin IDUs. Health was the next most important life area of both cocaine and heroin IDUs. Overall, the most important life areas were generally the same for both heroin and cocaine IDUS. These included housing, health, feeling good about yourself, money, family and partnerships. Resources, education, sex and HIV/AIDS treatment were among the least frequently selected life areas. As would be expected, the majority of IDUs that selected HIV/AIDS treatment as being an important component of their quality of life were HIV positive (83% of cocaine IDUs and 100% of heroin IDUs).

Table 6.6. Frequency of IDUQOL life area selection of cocaine and heroin IDUs.

	Cocaine IDUs (N=227)		Heroin IDUs (N=33)	
IDUQOL Life area	**N (%)**	**Rank**	**N (%)**	**Rank**
Housing	130 (57.3)	1	13 (39.4)	5.5
Health	124 (54.6)	2	16 (48.5)	3
Feeling good about yourself	95 (41.9)	3	18 (54.6)	1.5
Money	92 (40.5)	4	18 (54.6)	1.5
Family	90 (39.7)	5	13 (39.4)	5.5
Partnership	73 (32.2)	6	14 (42.4)	4
Friends	65 (28.6)	7	12 (36.4)	7
Spirituality	58 (25.6)	8	8 (24.2)	9.5
Being useful	51 (22.5)	9	8 (24.2)	9.5
Drugs	43 (18.9)	10	10 (30.3)	8
Independence/free choice	41 (18.1)	11	6 (18.2)	12
Drug treatment	36 (15.9)	12	7 (21.2)	11
Resources	32 (14.1)	13	2 (6.1)	15.5
Leisure activities	30 (13.2)	14	4 (12.1)	13.5
HIV/AIDS treatment	29 (12.8)	15	1 (3.0)	17
Education	27 (11.9)	16	4 (12.1)	13.5
Sex	26 (11.5)	17	2 (6.1)	15.5

Table 6.7 provides the mean weighting and rating of the IDUQOL life areas. The data indicated that cocaine and heroin IDUs were, in general, dissatisfied with how their important life areas were going at the moment. The distribution of the ratings for most of the life areas spanned the entire range from zero, the worst that could be imagined, to 100, the best that could be imagined, thus indicating that some IDUs were content with the given life area. Cocaine IDUs were more satisfied with their independence and free choice than heroin IDUs – the mean difference in rating between cocaine and heroin IDUs was 32.82 (95% CI: 7.51, 58.13). However, heroin IDUs were more satisfied with their relation with a partner – the mean difference in the rating between cocaine and heroin IDUs was -19.75 (95% CI: -35.55, -3.95), and with their leisure activities partner – the mean difference in the rating between

cocaine and heroin IDUs was -39.47 (95% CI: -60.96, -17.98). The life areas that were, on average, weighted the most important were drug treatment, drugs, health and family for cocaine IDUs, and drugs, sex and money for heroin IDUs.

Table 6.7 Weighting and rating of the IDUQOL life areas of cocaine and heroin IDUs.

	Cocaine IDUs		Heroin IDUs	
Life Area	**Mean weight (Range)**	**Mean rating (Range)**	**Mean weight (Range)**	**Mean rating (Range)**
Housing	5.4 (1.0-13.0)	48.4 (0.0-100.0)	4.5 (2.0-10.0)	41.9 (0.0-100.0)
Health	6.3 (1.0-25.0)	58.6 (0.0-100.0)	4.6 (1.0-10.0)	61.9 (0.0-100.0)
Feeling good about yourself	5.3 (1.0-13.0)	49.6 (0.0-100.0)	5.1 (2.0-20.0)	48.1 (0.0-95.0)
Money	5.4 (1.0-21.0)	40.3 (0.0-100.0)	6.1 (1.0-10.0)	37.1 (1.0-90.0)
Family	6.3 (1.0-22.0)	51.7 (0.0-100.0)	5.8 (2.0-10.0)	57.7 (0.0-95.0)
Partnership	5.1 (1.0-11.0)	31.4 (0.0-100.0)	5.0 (2.0-10.0)	51.1 (0.0-95.0)
Friends	4.4 (1.0-10.0)	48.3 (0.0-100.0)	4.9 (2.0-8.0)	60.4 (10.0-100.0)
Spirituality	5.9 (1.0-19.0)	57.6 (0.0-100.0)	5.1 (2.0-13.0)	53.8 (30.0-100.0)
Being useful	4.7 (1.0-10.0)	48.2 (0.0-100.0)	3.8 (1.0-7.0)	31.3 (0.0-80.0)
Drugs	6.4 (1.0-15.0)	61.5 (0.0-100.0)	7.0 (4.0-15.0)	53.0 (0.0-80.0)
Independence and free choice	5.2 (1.0-21.0)	69.5 (0.0-100.0)	4.3 (2.0-6.0)	36.7 (0.0-80.0)
Drug treatment	6.8 (1.0-25.0)	42.0 (0.0-100.0)	4.1 (3.0-6.0)	30.7 (0.0-100.0)
Resources	4.2 (1.0-10.0)	50.4 (0.0-100.0)	5.5 (3.0-8.0)	50.0 (20.0-80.0)
Leisure activities	3.5 (1.0-6.0)	33.0 (0.0-100.0)	3.5 (2.0-5.0)	72.5 (60.0-90.0)
HIV/AIDS treatment	5.7 (1.0-13.0)	44.4 (0.0-100.0)	3.0 (ND)*	40.0 (ND)*
Education	4.5 (1.0-14.0)	39.7 (0.0-100.0)	5.0 (3.0-6.0)	40.0 (0.0-75.0)
Sex	4.7 (1.0-14.0)	56.9 (0.0-100.0)	7.0 (4.0-10.0)	55.0 (30.0-80.0)

*ND: not determined, too few observations.

6.3.4 Crude and adjusted results

The crude and adjusted results for the sociodemographic variables are shown in Table 6.8. Due to the small number of heroin IDUs, there were considerable changes in the point estimates when adjusting for confounders. No striking differences in the quality of life of cocaine or heroin IDUs were found according to gender, mother tongue, being employed, married or Caucasian, or having a monthly income ≤ $1,400. However, quality of life was strongly related to living conditions in cocaine IDUs. The quality of life of cocaine IDUs who were homeless was, on average, 11.97 points lower than IDUs who had a stable home. The estimated mean difference in heroin IDUs was 15.01 and the confidence interval was wide and included zero. The period of social assistance distribution was mildly suggestive of a better quality of life in cocaine IDUs whereas the opposite was found for heroin IDUs. Consideration must be given to the wide confidence intervals, particularly for heroin IDUs.

Table 6.8. Mean difference in the quality of life of cocaine and heroin IDUs according to sociodemographic characteristics: crude and adjusted results.

Characteristic	Cocaine IDUs (N=227)		Heroin IDUs (N=33)	
	Crude	Adjusted*	Crude	Adjusted*
Sex				
Female	-2.32 (-13.18, 8.54)	-2.80 (-14.07, 8.48)	1.35 (-14.03, 16.73)	-0.27 (-19.05, 18.50)
Male (ref.)	-	-	-	-
Mother tongue				
Other	-3.19 (-15.47, 9.08)	-2.97 (-14.83, 8.88)	-4.26 (-23.69, 15.17)	-3.04 (-26.86, 20.78)
French (ref.)	-	-	-	-
Age				
≤ 25 years	0.79 (-20.75, 22.33)	-2.93 (-25.25, 19.38)	8.22 (-15.03, 31.47)	11.40 (-16.99, 39.80)
>25 to ≤ 34 years	2.29 (-8.40, 12.98)	1.55 (-8.91, 12.01)	11.31 (-10.92, 33.54)	9.58 (-15.02, 34.18)
>34 to ≤ 40 years	-1.05 (-8.62, 6.53)	-1.28 (-8.57, 6.00)	-1.85 (-24.54, 20.84)	2.36 (-23.93, 28.66)
>40 years (ref.)	-	-	-	-
Caucasian				
No	12.46 (-5.91, 30.84)	9.02 (-8.65, 26.70)	1.79 (-19.17, 22.75)	10.13 (-17.72, 37.99)
Yes (ref.)	-	-	-	-
Education				
High school or less	5.26 (-4.03, 14.54)	-0.41 (-9.75, 8.93)	-7.78 (-25.09, 9.53)	-10.96 (-37.50,15.59)
≥ CEGEP (ref.)	-	-	-	-

Table 6.8 cont'd

Characteristic	Cocaine IDUs (N=227)		Heroin IDUs (N=33)	
	Crude	Adjusted*	Crude	Adjusted*
Living conditions				
Homeless	-13.21 (-19.88,-6.54)	-11.97 (-18.65,-5.30)	0.33 (-20.64, 21.30)	15.04 (-16.80, 46.87)
Stable (ref.)	-	-	-	-
Married/common-law				
Yes	7.63 (-2.36, 17.62)	8.41 (-2.07, 18.90)	11.17 (-3.67, 26.00)	12.84 (-3.83, 29.50)
No (ref.)	-	-	-	-
Employed				
Yes	0.28 (-10.78, 11.34)	-3.20 (-14.16, 7.75)	6.55 (-14.28, 27.38)	3.28 (-21.12, 27.68)
No (ref.)	-		-	-
Average monthly income				
≤ $1,400	5.86 (-1.13, 12.84)	2.36 (-4.68, 9.39)	1.98 (-13.39, 17.35)	1.26 (-17.46, 19.97)
> $1,400 (ref.)	-	-	-	
Interviewed during social assistance distribution				
Yes	6.45 (-2.11, 15.01)	6.84 (-1.43, 15.11)	-8.15 (-25.44, 9.14)	-13.65 (-36.96, 9.67)
No (ref.)	-	-	-	-
Sexual orientation				
Homosexual	-7.88 (-23.75, 7.99)	-7.80 (-22.86, 7.27)	3.15 (-16.31,22.61)**	6.27 (-18.55,31.09)**
Bisexual	2.48 (-9.82, 14.79)	5.16 (-6.97, 17.30)		
Heterosexual (ref.)	-	-	-	-
Prostituted past 6 mo.				
Yes	-4.50 (-17.08, 8.07)	-1.76 (-15.68, 12.17)	-10.66 (-29.76, 8.44)	-17.64 (-43.64, 8.36)
No (ref.)	-	-	-	-

*Adjusted for gender, age, self-reported health status, living conditions, number of cocaine injections for cocaine IDUs, frequency of heroin injection for heroin IDUs, and time of study interview in relation to the distribution of social assistance cheques as appropriate. **Refers to homosexual or bisexual vs. heterosexual for heroin IDUs.

Table 6.9 provides the crude and adjusted results of linear regression for the health attributes. As shown, quality of life was strongly related to self-rated health. Cocaine IDUs who rated their health as excellent or very good had a quality of life that was, on average, 10.36 points higher on the IDUQOL as compared with IDUs who rated their health as fair or poor. The corresponding mean difference in heroin IDUs was 23.21. Cocaine IDUs who rated their health as good had a quality of life that was, on average, 9.89 points higher on the IDUQOL. These results were less pronounced for

heroin IDUs. The results also suggested that cocaine and heroin IDUs who were HIV seropositive had a better quality of life than IDUs who were HIV negative. Although non-significant, quality of life increased with an increase in time since testing HIV positive. Cocaine IDUs who overdosed in the past six months had a quality of life that was, on average, 14.31 points lower than IDUs who did not. The mean difference of -9.93 in heroin IDUs was not significant.

Table 6.9. Mean difference in the quality of life of cocaine and heroin IDUs according to health attributes: crude and adjusted results.

Health attribute	Cocaine IDUs (N=227)		Heroin IDUs (N=33)	
	Crude	Adjusted*	Crude	Adjusted*
Self-rated health				
Excellent/very good	13.04 (1.62, 24.46)	10.36 (-0.80, 21.52)	12.43 (-9.77, 34.63)	23.21(-4.02, 50.44)
Good	9.93 (2.87, 16.99)	9.89 (2.92, 16.86)	-2.57 (-18.68, 13.53)	2.14 (-16.74, 21.03)
Fair/poor (ref.)	-	-	-	-
HIV serostatus				
Positive	6.67 (-0.29, 13.62)	6.86 (0.16, 13.57)	18.64 (-6.61, 43.89)	24.71 (-5.01, 54.44)
Negative (ref.)	-	-	-	-
Years since testing HIV positive	0.84 (-0.29, 1.97)	0.95 (-0.18, 2.08)	6.54 (-2.85, 15.94)	10.41 (-0.87, 21.69)
Ever diagnosed with psychiatric disorder				
Yes	-5.86 (-12.80, 1.08)	-2.47 (-9.34, 4.40)	-8.55 (-24.19, 7.08)	-3.39 (-22.54, 15.76)
No (ref.)	-	-	-	-
Attempted suicide past 6 mo.				
Yes	-12.43 (-23.81, -1.05)	-9.77 (-21.06, 1.52)	N/A	N/A
No (ref.)	-	-	-	-
Overdosed past 6 mo.				
Yes	-20.57 (-32.55, -8.59)	-14.31 (-26.37,-2.25)	-2.69 (-23.64, 18.26)	-9.93 (-37.25, 17.39)
No (ref.)	-	-	-	-

*Adjusted for gender, age, self-reported health status, living conditions, number of cocaine injections for cocaine IDUs, frequency of heroin injection for heroin IDUs, and time of study interview in relation to the distribution of social assistance cheques as appropriate.

The crude and adjusted mean differences in quality of life according to drug use and behaviours are provided in Table 6.10. As shown, quality of life did not appear to be strongly related to duration of injection drug use, alcohol consumption, borrowing

needles or lending needles. However, quality of life was related to heroin and cocaine injection. Heroin IDUs who injected more than twice a day in the past month had a quality of life that was, on average, 13.39 points lower than heroin IDUs who did not, although the 95% CI was quite wide. Likewise, cocaine IDUs who injected cocaine 100 times or more had a quality of life that was, on average, 7.07 points lower than cocaine IDUs who injected cocaine 30 times or less. This difference was more pronounced for cocaine IDUs who injected 31 to 100 times (mean difference = -11.42). Cocaine IDUs who smoked crack cocaine had a quality of life that was, on average, 8.05 points lower than IDUs who did not smoke crack. In contrast, heroin IDUs who used cocaine intranasally had a quality of life that was, on average, 27.41 points higher than IDUs who did not, although this result was non-significant. Cocaine IDUs who injected in public places had a worse quality of life than cocaine IDUs who mainly injected at home or at a friend's house. The mean difference for cocaine IDUs who mainly injected in a hotel or shooting gallery was -19.48.

Table 6.10. Mean difference in the quality of life of cocaine and heroin IDUs according to drug use and behaviours: crude and adjusted results.

	Cocaine IDUs (N=227)		Heroin IDUs (N=33)	
Drug use/behaviour	**Crude**	**Adjusted***	**Crude**	**Adjusted***
Duration of injection drug use				
≤ 3 years	-2.20 (-23.53, 19.12)	-1.44 (-23.23, 20.36)	5.07 (-10.20,20.35)**	6.09 (-20.17, 32.36)**
3 to ≤ 10 years	-1.94 (-10.08, 6.20)	0.28 (-7.89, 8.45)		
> 10 years (ref.)	-	-	-	-
Days of alcohol use past mo.				
≥ 15 days	3.10 (-4.34, 10.55)	3.46 (-3.64, 10.56)	-1.58 (-19.11, 15.96)	-2.61 (-24.84, 19.62)
< 15 days (ref.)	-	-	-	
Alcohol consumption				
> 3 drinks/day	-4.36 (-11.31, 2.58)	-3.13 (-9.85, 3.60)	-2.10 (-17.71, 13.51)	-2.74 (-23.12, 17.64)
≤ 3 drinks/day (ref.)	-	-	-	-
Injected heroin past mo.				
Yes	6.24 (-6.32, 18.80)	7.58 (-4.92, 20.08)	N/A	N/A
No (ref.)	-	-		
Days of injection				

Table 6.10 cont'd

	Cocaine IDUs (N=227)		Heroin IDUs (N=33)	
Drug use/behaviour	**Crude**	**Adjusted***	**Crude**	**Adjusted***
heroin use past mo.				
≥ 15 days	N/A	N/A	-5.86 (-20.75, 9.03)	-4.48 (-23.53, 14.58)
< 15 days (ref.)			-	-
Frequency of heroin injection past mo.				
> 2 injections/day	N/A	N/A	-6.19 (-22.92, 10.54)	-13.39 (-37.84,11.06)
≤ 2 injections/day (ref.)			-	-
Injected cocaine past mo.				
Yes	N/A	N/A	-0.20 (-16.56, 16.16)	-0.78 (-21.49, 19.94)
No (ref.)			-	-
Days of injection cocaine use past mo.				
≥ 15 days	-4.25 (-11.59, 3.10)	3.30 (-8.00, 14.60)	N/A	N/A
< 15 days (ref.)	-	-		
Number of cocaine injections past mo.				
> 100 injections	-8.47 (-17.06, 0.12)	-7.07 (-15.58, 1.44)	N/A	N/A
31 to ≤ 100 injections	-11.29 (-19.03, -3.56)	-11.42 (-18.97,-3.87)		
≤ 30 injections (ref.)	-	-		
Used intranasal cocaine past mo.				
Yes	-3.95 (-12.46, 4.57)	-4.09 (-12.46, 4.29)	23.08 (-7.28, 53.43)	27.41 (-10.06, 64.88)
No (ref.)	-	-	-	-
Smoked crack cocaine past mo.				
Yes	-9.95 (-17.09, -2.82)	-8.05 (-15.02, -1.09)	5.39 (-14.00, 24.79)	6.82 (-21.77, 35.41)
No (ref.)	-	-	-	-
Borrowed needles past 6 mo.				
Yes	-5.56 (-12.50, 1.38)	-2.59 (-9.36, 4.18)	4.20 (-11.67, 20.08)	0.61 (-19.86, 21.09)
No (ref.)	-	-	-	-
Lent needles past 6 mo.				
Yes	-5.82 (-14.18, 2.54)	1.34 (-7.61, 10.28)	4.99 (-11.79, 21.77)	-1.57 (-22.73, 19.58)
No (ref.)	-	-	-	-
Borrowed injection equipment past 6 mo.				
Yes	-7.91 (-14.77, -1.04)	-5.10 (-11.77, 1.57)	10.93 (-3.75, 25.60)	10.64 (-6.66, 27.95)

Table 6.10 cont'd

	Cocaine IDUs (N=227)		Heroin IDUs (N=33)	
Drug use/behaviour	**Crude**	**Adjusted***	**Crude**	**Adjusted***
No (ref.)	-	-	-	-
Place where fixing most often occurs				
Bar/restaurant/WC	-18.80 (-36.68, -0.91)	-10.51 (-28.17, 7.14)	13.37 (-6.00, 32.74)	12.15 (-11.92, 36.23)
Street or park	-3.17 (-11.51, 5.17)	3.51 (-5.10, 12.12)	-12.99 (-38.93,12.94)	-18.69 (-49.29,11.92)
Hotel/shooting gallery	-26.51(-39.46,-13.56)	-19.48 (-32.43, -6.53)	0.34 (-42.82, 43.50)	-8.22 (-69.30, 52.85)
Home or friends (ref)	-	-	-	-

*Adjusted for gender, age, self-reported health status, living conditions, number of cocaine injections for cocaine IDUs, frequency of heroin injection for heroin IDUs, and time of study interview in relation to the distribution of social assistance cheques as appropriate. **Refers to 3 to ≤ 10 years vs. 10 years or more.

Table 6.11 provides the crude and adjusted relations between the quality of life and program use of cocaine and heroin IDUs. Quality of life did not appear to be related to social assistance administration or needle exchange program use. Meal program use was suggestive of a better quality of life in cocaine IDUs. As well, quality of life was strongly related to the frequency of shelter use in cocaine IDUs; cocaine IDUs who used shelters daily had a quality of life that was, on average, 15.11 points lower than cocaine IDUs who never used shelters. Similar although non-significant results were found for cocaine IDUs who used shelters at least once a week and monthly or less. Quality of life was also negatively associated with emergency department use in cocaine IDUs. Cocaine IDUs who visited an emergency department three or more times in the past six months had a quality of life that was, on average, 16.33 points lower than IDUs who did not visit an emergency department. A similar, although less pronounced association was found for cocaine IDUs who used the emergency once or twice. Despite some imprecision, cocaine and heroin IDUs who were in methadone treatment for more than 18 months appeared to have a better quality of life than IDUs who were not in treatment. Although the estimated mean difference for IDUs who were in treatment and those who were not were negative for both models, no strong relation between quality and life and drug treatment was found in cocaine or heroin IDUs.

Table 6.11. Mean difference in the quality of life of cocaine and heroin IDUs according to program use: crude and adjusted results.

Program	Cocaine IDUs (N=227)		Heroin IDUs	
	Crude	Adjusted*	Crude	Adjusted*
Meal program use past 6 mo.				
Daily	-4.70 (-15.62, 6.21)	6.07 (-4.92, 17.07)	4.83 (-19.56, 29.23)	4.06 (-25.07, 33.20)
< Daily to weekly	1.32 (-7.43, 10.07)	7.31 (-1.28, 15.91)	-1.27 (-23.58, 21.05)	-0.34 (-27.27, 26.60)
Monthly or less	5.43 (-3.42, 14.28)	9.80 (1.08, 18.51)	-7.37 (-28.17, 13.44)	-9.70 (-33.52, 14.13)
Never (ref.)	-	-	-	-
Shelter use past 6 mo.				
Daily	-24.81(-39.07,-10.55)	-15.11 (-29.64, -0.59)	2.02 (-21.00, 25.05)*	5.10 (-28.28, 38.48)
< Daily to weekly	-13.72 (-26.02, -1.42)	-7.90 (-20.55, 4.76)		
Monthly or less	-11.79 (-20.31, -3.28)	-9.80 (-18.51, -1.10)		
Never (ref.)	-	-	-	-
Social assistance administered				
Yes	4.36 (-6.89, 15.62)	3.00 (-7.80, 13.80)	N/A	N/A
No (ref.)	-	-		
Emergency department visits past 6 months				
1 or 2	-9.90 (-17.08, -2.71)	-9.44 (-16.55, -2.33)	-1.51 (-18.68, 15.65)	-5.86 (-29.14, 17.43)
≥ 3	-19.96 (-33.96, -5.96)	-16.33 (-29.82, -2.85)	-1.40 (-25.57, 22.77)	-0.66 (-29.61, 28.29)
None (ref.)	-	-	-	-
Duration of drug treatment				
≤ 4 weeks	-6.61 (-17.76, 4.53)	-7.05 (-17.64, 3.54)	-3.58 (-27.10, 19.93)	-11.43 (-39.87,17.01)
> 4 months	-0.95 (-11.53, 9.63)	-3.57 (-13.96, 6.83)	-7.77 (-29.18, 13.63)	-7.80 (-43.37, 27.77)
None (ref.)	-	-	-	-
Duration of methadone treatment				
≤ 18 months	-13.34 (-34.42, 7.75)	-11.15 (-32.07, 9.77)	-0.04 (-18.18, 18.10)	2.44 (-19.14, 24.01)
> 18 months	9.37 (-2.84, 21.59)	8.69 (-3.33, 20.70)	6.69 (-12.16, 25.54)	23.56 (-4.38, 51.49)
None (ref.)	-	-	-	-
Needle exchange program use past mo.				
< Once per week	3.21 (-4.12, 10.53)	4.37 (-2.75, 11.49)	-0.87 (-17.48, 15.74)	-3.94 (-26.70, 18.82)
≥ Once per week	-7.94 (-18.03, 2.15)	-1.68 (-12.52, 9.17)	-1.10 (-24.00, 21.80)	1.34 (-29.41, 32.09)
None (ref.)	-	-	-	-

*Adjusted for gender, age, self-reported health status, living conditions, number of cocaine injections for cocaine IDUs, frequency of heroin injection for heroin IDUs, and time of study interview in relation to the distribution of social assistance cheques as appropriate.

6.3.5 Multivariate results: program use models

The results of multiple linear regression for the relation between quality of life and program utilization of cocaine and heroin IDUs are provided in 6.12. Quality of life was most strongly related to meal program, shelter and emergency department use in cocaine IDUs. Programs that were targeted towards IDUs, such as needle exchange programs, methadone and drug treatment, generally showed weaker relations to quality of life in cocaine and heroin IDUs.

The point estimates for the mean difference in quality of life according to meal program and shelter use were somewhat similar for both cocaine and heroin IDUs. Cocaine IDUs who used meal programs had a better quality of life than cocaine IDUs who did not; this relation was most pronounced for IDUs who used meal programs daily (mean difference in quality of life = 18.42). The estimated mean difference in quality of life according to meal program use also suggested a better quality of life in heroin IDUs, although the confidence intervals were extremely wide and included zero. Cocaine IDUs who used shelters had a worse quality of life than IDUs who did not, even after adjusting for homelessness. Again, this relation was most pronounced for IDUs who used shelters daily (mean difference in quality of life = -19.14). Despite substantial imprecision, a similar estimated mean difference was found in the quality of life of heroin IDUs who used shelters and those who did not.

Although the confidence intervals were wide and included zero, the estimated mean difference in quality of life according to emergency department use suggested that it was associated with a better quality of life in heroin IDUs. Conversely, cocaine IDUs who visited an emergency department three times or more in the past six months had a quality of life that was, on average, 15.60 points lower on the IDUQOL than IDUs who did not; quality of life was, on average, 9.67 points lower for cocaine IDUs who visited emergency departments once or twice in the past six months. Although not significant, the estimated mean difference in quality of life according to the duration of methadone treatment indicated that a longer duration was associated with a better

quality of life in heroin and cocaine IDUs. A similar relation was found for other drug treatment in heroin IDUs. The mean difference in the quality of life of IDUs who attended needle exchange programs weekly or more and IDUs who did not was 15.26 for heroin IDUs and 1.04 for cocaine IDUs. Neither result was significance.

The overall F-test for the program utilization model was significant for cocaine IDUs and explained 28.2% of the variance in quality of life. However, the overall F-test for the program utilization model was insignificant for heroin IDUs. Regression diagnostics for the cocaine IDUs model showed that there was no collinearity or extremely influential observations. Collinearity was detected for most of the variables in the heroin IDUs model as assessed by a VIF >3.

Table 6.12. Mean difference in the quality of life of cocaine and heroin IDUs according to program use: multivariate results.*

Program	Cocaine IDUs N=227	Heroin IDUs N=33
Meal program use past 6 mo.		
Daily	18.42 (5.43, 31.40)	6.23 (-35.64, 48.11)
< Daily to weekly	13.75 (4.44, 23.07)	17.03 (-53.68, 87.75)
Monthly or less	14.66 (5.53, 23.79)	8.36 (-47.04, 63.77)
Never (reference)	-	-
Shelter use past 6 mo.		
Daily	-19.14 (-36.62, -1.65)	-20.31 (-102.67, 62.05)**
< Daily to weekly	-11.23 (-24.88, 2.42)	
Monthly or less	-13.21 (-22.44, -3.98)	
Never (reference)	-	-
Social assistance administered		
Yes	-2.17 (-12.98, 8.64)	N/A
No (reference)	-	-
Emergency department visits past 6 mo.		
1 or 2	-9.67 (-16.75, -2.58)	7.64 (-37.90, 53.17)
≥ 3	-15.60 (-29.42, -1.78)	26.79 (-42.00, 95.58)
None (reference)	-	-
Duration of drug treatment		
≤ 4 weeks	-3.90 (-14.49, 6.69)	-23.71 (-86.31, 38.88)

Table 6.12 cont'd

Program	Cocaine IDUs N=227	Heroin IDUs N=33
> 4 months	-1.88 (-12.36, 8.59)	18.18 (-60.69, 97.05)
None (reference)	-	-
Duration of methadone treatment		
≤ 18 months	-14.37 (-34.69, 5.96)	-1.78 (-53.95, 50.39)
> 18 months	5.68 (-6.26, 17.62)	32.29 (-23.01, 87.59)
None (reference)	-	-
Needle exchange program use past mo.		
< Once per week	1.04 (-6.27, 8.35)	-6.88 (-42.33, 28.57)
≥ Once per week	-1.68 (-12.39, 9.02)	15.26 (-37.91, 68.43)
None (reference)	-	-

*Adjusted for gender, age, self-reported health status, living conditions, number of cocaine injections for cocaine IDUs, frequency of heroin injection for heroin IDUs, and time of study interview in relation to the distribution of social assistance cheques. **Refers to any use vs. no use.

6.4 DISCUSSION

This study demonstrated that there were important differences in the characteristics, social environment, drug use and behaviours of cocaine and heroin IDUs. Compared with heroin IDUs, cocaine IDUs were older, more likely to be male, to be Caucasian, to be unmarried, to be HIV positive, and to be homeless. As well, cocaine IDUs consumed more alcohol and injected more frequently than heroin IDUs. Although the majority of both cocaine and heroin IDUs predominantly injected in their own home or in a friend's, cocaine IDUs were more likely to inject outside and heroin IDUs were more likely to inject in a public place. Accordingly, some important distinctions in the constituents and correlates of the quality of life of cocaine and heroin IDUs were identified.

As has been found in other studies (Ryan and White, 1996; Dazord et al., 1998), the quality of life of IDUs in this study was generally poor. Although the mean and median IDUQOL scores were similar in cocaine and heroin IDUs, the distribution of scores suggested some differences in their quality of life. Very few heroin IDUs had a quality of life score at the high end of the IDUQOL scale, and the highest quality of

life score among heroin IDUs was 88. In contrast, cocaine IDUs spanned the entire range of scores and there appeared to be two groups of cocaine IDUs – one at the low end of the scale and another at the mid-to-high end. It seemed that some cocaine IDUs were capable of injecting without adversely compromising their overall well-being, whereas few heroin IDUs had a very good quality of life. Perhaps heroin addiction generally has a more pervasive effect on quality of life than cocaine addiction. It is also possible that more advantageous heroin IDUs were underrepresented given the small number of heroin IDUs in this study.

The most important life areas were similar for cocaine and heroin IDUs and included housing, money, feeling good about yourself, health, family and partnership. Both cocaine and heroin IDUs were, in general, dissatisfied with how these important life areas fared. There were some differences in the position of the life areas according to their frequency of selection. Heroin IDUs most frequently selected money and feeling good about yourself as being the most important constituents of their quality of life, whereas housing was the most frequently selected life area of cocaine IDUs. Because heroin addiction involves physical as well as psychological aspects, heroin IDUs commonly plan their heroin use to prevent withdrawal sickness. Therefore, money to procure drugs is a daily need of heroin IDUs. In contrast, cocaine injection is often more haphazard – there is no physical addiction requiring daily injection. Yet, when money is available for injection, cocaine use can continue unabated and other important responsibilities can be neglected (Gold and Miller, 1997). Cocaine addicts often have difficulty maintaining an organized lifestyle and a stable residence (Brogly, 1999). In this study, cocaine IDUs were significantly more likely to be homeless than heroin IDUs.

Feeling good about yourself was important to both cocaine and heroin IDUs. Feeling good about yourself is less tangible than the other life areas, and speaks more to the self-perception or self-esteem of the individual. Directly improving the self-perception of IDUs through public health strategies is probably unfeasible. However, ameliorating the other important life areas of IDUs may lead to better overall self-

perception and possibly, to less risk taking behaviour. Poor life satisfaction and future hopes have been associated with HIV risk taking behaviour (Kalichman et al., 1997).

Despite the dominance of drugs in IDUs' daily lives, few IDUs selected drugs as being an important constituent of their quality of life. Slightly more heroin IDUs selected drugs as being an important aspect of their quality of life, perhaps because of withdrawal sickness that occurs in the absence of heroin injection. Although many IDUs in this study were homeless and concerned about money and living conditions, few IDUs selected resources as being important to their quality of life. This could indicate that the resources available to IDUs did little to improve their well-being, were not widely utilized, and/or did not target the needs of these IDUs. It is interesting to note that none of the IDUs who participated in the focus group during the development of the IDUQOL selected resources as being important to their quality of life, even though several IDUs said it was difficult to improve their lives without the assistance of social programs. Perhaps another life area card is capturing these facets – examination of the life area meanings should provide some insight.

In terms of the correlates of quality of life, cocaine and heroin IDUs who were HIV positive had a better quality of life than IDUs who were HIV negative. The same result was found in the evaluation study of Chapter 5, and these results were even more striking (mean difference= 26.0, 95% CI: 12.6-39.5). In contrast, studies of HIV positive individuals, of whom a small percentage were IDUs, have demonstrated that the quality of life of HIV positive individuals was extremely low (Wachtel et al., 1992; Carretero et al., 1996). However, it has been suggested that the instrument used to measure quality of life in these studies – the MOS-HIV – might be of limited use in IDUs due to the overwhelming effects of addiction that reduce its responsiveness (Carretero et al., 1996; Wu et al., 1997). Perhaps the observation in this study that quality of life was better in HIV positive IDUs provides support for these assertions.

The finding that the quality of life of HIV positive IDUs was, on average, better than that of IDUs who are HIV negative is intriguing. This could be due to improved medical care of HIV positive IDUs. A previous study of behaviour change following an HIV positive test result among IDUs in the St-Luc Cohort found that compared with HIV negative IDUs, HIV positive IDUs were more likely to seek medical care (Brogly et al., 2002). However, other studies have demonstrated that HIV positive IDUs have barriers to appropriate medical care and antiretroviral therapy for HIV (Strathdee et al., 1998; Carrieri et al., 1999). It would be interesting to examine the relation between quality of life and HCV positivity. HCV serostatus was not routinely tested among the study participants, which prevented its evaluation in this investigation.

The quality of life of HIV positive IDUs could also be better than that of HIV negative IDUs because of the greater number of services and organizations that are available to HIV positive IDUs. There are a number of AIDS organizations in Montreal that provide services such as drop-in centres where clients can spend time and interact with other positive individuals, workshops to improve life skills, food and groceries, crisis intervention, financial aid, legal and tax advice, complementary and alternative medicine, and access to hospices and palliative care. Thus, even if HIV positive IDUs are not dealing with their HIV illness per se, a wide range of services is available to them. Unlike programs that are directed towards IDUs, these HIV/AIDS programs tend to focus on basic needs. Further, it is possible that being a member of an AIDS organization gives IDUs a sense of belonging and somewhere to turn to in a time of crisis.

Contrary to what was found in the evaluation study presented in Chapter 5, cocaine IDUs who were homeless had a significantly worse quality of life than IDUs who were not homeless. This could perhaps be explained by the time during which the studies were conducted. IDUs in the descriptive study were interviewed during the fall and winter months – from September to March – whereas IDUs in the evaluation study were interviewed between April and July. As a result, the weather appears to

have been a modifier of the relation between quality of life and homelessness in IDUs. This finding could be important to subsequent studies of the quality of life of IDUs, and to the development and evaluation of community housing programs should they be implemented for IDUs.

Self-rated health was strongly correlated with quality of life in cocaine IDUs; cocaine IDUs who rated their health as excellent, very good or good had a better quality of life than IDUs who rated their health as fair or poor. These results were less pronounced in heroin IDUs. Self-reported health was also strongly correlated with health-related quality of life in a study of drug addicts in methadone maintenance (Torrens et al., 1997), and it was found to be the most important correlate of depression among IDUs not in treatment (Steer et al., 1992). Also related to health, cocaine IDUs who attempted suicide or had an accidental overdose in the six months before their study interview had a worse quality of life than IDUs who did not. A similar mean difference was found in heroin IDUs who overdosed, although the results were clearly not significant. Taken together, these finding may provide further evidence of the construct validity of the IDUQOL – health is an important component of the broader construct of quality of life (Leplège and Hunt, 1997).

In terms of drug use, no strong relation between quality of life and the frequency of heroin injection was found in heroin IDUs. In contrast, the quality of life of IDUs who injected cocaine 31 to 100 times, or more than 100 times in the four weeks before the study interview was worse than IDUs who injected 30 times or less, which corroborated the findings presented in Chapter 5. Likewise, cocaine IDUs who used crack cocaine had a quality of life that was worse than IDUs who did not. These results supported those of another study, which found negative associations between the health-related quality of life of crack smokers and the frequency of crack use (Falck et al., 2000). The lower quality of life among crack users could be due to the damaging effects of crack cocaine use. As well, a study conducted among IDUs in the St-Luc Cohort and in Vancouver found that IDUs who used crack cocaine were more likely to stop injection (Bruneau et al., 2001b). Because drug cessation often

occurs at a low-point in the IDUs drug career, this could perhaps partially account for the low quality of life observed among crack smokers in this descriptive study.

Although no striking relations between quality of life and the period of social assistance were found, it nonetheless warrants consideration. The results were suggestive of a positive relation between quality of life and the period of social assistance distribution among cocaine IDUs, whereas the opposite was found in heroin IDUs. The majority of IDUs in this study received social assistance, which results in a large influx of money in the injecting community. The experience in Vancouver and Montreal has suggested that drug use increases (Currie et al., 2000; Bellot et al., 2000) and overdose is problematic (Stevens, 2000) during this period of welfare cheque distribution. This is not to suggest that social assistance should be terminated in IDUs. On the contrary, the termination of social assistance would probably result in more crime, homelessness and illness among IDUs. However, there may be alternative modes of distribution of financial aid to help IDUs maintain more stable lives. Further research in this area is required.

Compared with cocaine IDUs who mainly injected in their own home or a friend's, cocaine IDUs who predominantly injected at a hotel or shooting gallery had a significantly worse quality of life. Quality of life was also poorer in heroin IDUs who mainly injected in a hotel or shooting gallery. This relation was more pronounced for heroin IDUs who predominantly injected outside. Based on these results, it seems possible that safer injecting facilities could make a difference in the lives of some IDUs. However, only 3 (9.1%) of heroin IDUs in this study predominantly injected outside, and only 16 (7%) of cocaine IDUs predominantly injected in a shooting gallery or hotel. Although IDUs who would otherwise inject in a private location may use safer injecting facilities, a major reason for their implementation in Europe was to decrease the open drug scene. Thus, intervening on more prevalent correlates of quality of life would perhaps be a more prudent public health approach.

The main objective of the descriptive study was to evaluate the relation between quality of life and the use of public health programs available to IDUs in Montreal. The results suggested that programs that were targeted towards IDUs, such as needle exchange programs, methadone and drug treatment, showed little relation to quality of life. As well, few IDUs frequently attended needle exchange programs, although they are the underpinning of harm reduction for IDUs in Canada. In contrast, other social programs available to IDUs in Montreal but not specifically targeted for injectors, such as meal programs, were frequently used by IDUs and showed a marked association with quality of life. Much like the services that are available to HIV positive individuals, meal programs are directed towards the subsistence of IDUs and not drug use and its associated risky behaviours.

It is possible that IDUs who attend meal programs take better care of themselves, have a better self-perception and hence, a better quality of life. IDUs who use meal programs may be more organized and capable of obtaining their essential needs. In addition, good nutrition may improve quality of life by promoting health and preventing illness in IDUs. Food is a sensory and psychological pleasure in its own right, which may add a sense of security to the lives of IDUs (Amarantos et al., 2001). Given that the dopaminergic pathway on which addictive drugs act is also believed to be the reward pathway that controls normal survival behaviours such as eating, drinking, and sex (Goldstein, 1994), perhaps sustained nutrition somehow lessens the detrimental rewarding behaviours of addictive drugs. In any case, promoting good nutrition and attendance at meal programs could make a difference to the well-being of IDUs. Of note, l'Anonyme, the mobile needle exchange van in Montreal, has recently begun providing small meals to attract more clientele.

In contrast to the findings regarding meal program use, this study showed that the quality of life of cocaine IDUs who used shelters was worse than that of IDUs who did not, even after controlling for homelessness. It is likely that IDUs who seek refuge at shelter are extremely destitute and have nowhere else to turn. Indeed, other studies have shown that homeless persons face numerous barriers to receiving

appropriate health care (Kushel et al., 2001). As well, a high prevalence of physical and mental illness has been documented among homeless individuals (Braucht et al., 1995; Kushel et al., 2001). However, the relation between quality of life and shelter use found in this study persisted even after adjusting for self-reported health status and history of diagnosis of a psychiatric disorder (data not shown). It may be that IDUs are not welcomed by other clientele at shelters because of their injection drug use and are hence, are ostracized. Given the low quality of life of IDUs who use shelters and of IDUs who have no stable home, and the increased risk of HIV found among homeless individuals (Metsch et al., 1995; Strathdee et al., 1997b; Brogly et al., 2000), community housing for IDUs should be investigated further. Researchers in Vancouver have suggested that evaluation of interventions to increase the availability of safe, affordable housing is needed (Palepu et al., 1999). Further, a study of homeless mentally ill persons found that abusers of alcohol and other drugs did have the desire to live independently, although the authors were uncertain of the ability of IDUs to maintain stable community housing (Schutt and Goldfinger, 1996).

The quality of life of cocaine IDUs who visited emergency departments was lower than the quality of life IDUs who did not, and this relation was more pronounced for IDUs who visited an emergency department three or more times in the past six months than for IDUs who visited the emergency once or twice. These results supported related findings from a study of IDUs in Vancouver. Disadvantaged IDUs, that is IDUs who were HIV positive, who injected more than four times a day and who were homeless, were more likely to visit the emergency (Palepu et al., 2001). The main reasons these IDUs visited the emergency department were soft-tissue infections and problems directly related to injection drug use (Palepu et al., 2001). Safe injection rooms aim to improve access to medical care and the treatment of IDUs. Perhaps providing health care services in an environment that is supportive of IDUs, such as an injection facility, would reach a wider number of drug users and help the most disadvantaged IDUs; health was an important component of the quality of life of cocaine and heroin IDUs.

The absence of a relation between quality of life and methadone treatment contradicts findings of other health-related quality of life studies in IDUs (Reno and Aiken, 1993; Torrens et al., 1997; Dazord et al., 1998). This discrepancy could be due to different study methodologies. The previous studies compared within individual changes in health-related quality of life over a one-year period from treatment entry (Torrens et al., 1997; Dazord et al., 1998), whereas this study examined the difference in quality of life between individuals across a contrast – the duration of methadone vs. no methadone – at a single point in time. In addition, not all of the IDUs in this study who were on methadone treatment were on a methadone maintenance program, which may have affected the results. Unlike the other studies, the majority of IDUs in this study were cocaine IDUs and not opiate addicts, and methadone has been found to be less effective in cocaine users (Kolar et al., 1992). It follows that the results may be different in a larger study of heroin IDUs. Alternatively, it is possible that methadone is more strongly related to health-related quality of life than quality of life; methadone may reduce craving and drug use but may not address other consequences of drug addiction. Finally, an inclusion criterion of this study was having injected drugs in the past month. Subsequently, IDUs who participated in this study may have been individuals for whom methadone had little effect on their drug consumption and overall quality of life.

Some limitations must be considered when interpreting the study findings. As with all descriptive studies, this study suffers from ambiguity regarding the temporality of the relation between quality of life and program use and other characteristics of IDUs. Consequently, it is difficult to know whether use of a given program or if a particular characteristic or behaviour was antecedent or consequent to quality of life. For instance, it is impossible to know whether regular use of meal programs improved quality of life, or if IDUs who attended meal programs had a better quality of life, which motivated them to seek nourishment. It was nonetheless possible to assess which programs and characteristics seemed to be important correlates of the quality of life of IDUs. Such data may be helpful in subsequent studies of the quality of life

of IDUs, and further, should provide insight to the development of new initiatives for IDUs.

Twenty-six IDUs refused to participate in this descriptive study. These IDUs were more likely to be female, to be non-Caucasian, to have a mother tongue other than French, to be employed and to have a stable home than the study participants. It is therefore possible that the study results might not validly characterize the quality of life of IDUs and its relation to public health programs and other correlates. It appeared that more disadvantaged IDUs were included. However, this is exactly the population of IDUs for whom public health programs and services are most needed. Moreover, the refusal rate was quite low (8.8%) and hence, probably did not greatly affect the results.

The small number of women included in this study prevented evaluation of quality of life in men and women separately. Although the study findings suggested that quality of life was unrelated to gender, there might be differences in the constituents, correlates and determinants of the quality of life of male and female IDUs. Other studies have demonstrated differences in the sexual and drug use behaviours and social environment of female and male IDUs (Abdul-Quader et al., 1990; Anderson et al., 1990; Maher, 1997; Pivnick et al., 1994; Bruneau et al., 2001a). As well, few heroin IDUs were included in this study, which limited the evidence regarding the constituents and correlates of quality of life. Investigations of the quality of life of younger IDUs, female IDUs, and heroin IDUs may provide further insight. It is encouraging that the IDUQOL is currently being used in Australia and is planned for use in California, where heroin is predominantly injected. As well, a study is underway in Vancouver where approximately 35% of IDUs are women, 25% are native Canadians, and most are English speaking.

A potential limitation of this study is the validity and reliability of interview data from IDUs. Although studies have shown IDUs' reports of drug and sexual behaviour to be reliable (McElrath et al., 1994; De Irala et al., 1996) and valid

(Dowling-Guyer et al., 1994), it is nonetheless concerning. Several efforts were taken to ensure that the self-reported information was valid. The interviews in the St-Luc Cohort were conducted by trained and experienced research nurses in private rooms. In addition, sensitive questions were placed towards the end of the questionnaire. With respect to the data collected on quality of life, the same interviewer administered the IDUQOL in the evaluation study of Chapter 5 and in the descriptive study of Chapter 6. The study interviewer was carefully trained to administer the IDUQOL in a consistent manner. She had extensive experience working with drug users and homeless individuals. Several participants became emotional during the study interviews, which suggested that they were speaking truthfully about their lives and the things that were important to them. Finally, potential misreporting was examined through use of a sentinel question. This sentinel question was part of the St-Luc questionnaire was written such that an individual could not answer yes unless they were outright lying or were answering arbitrarily. None of the IDUs in this study answered yes to the sentinel question.

Aside from misreporting, misclassification could have arisen from other sources. Missing data were replaced by the IDUs' previous or subsequent visit in the St-Luc Cohort. If an IDU refused to respond to a particular question because he or she had engaged in behaviour not previously reported, then carrying his or her last value forward could have resulted in bias. There did not appear to be any trends in missing data aside from having accidentally overdosed in the past six months. All of these IDUs had previously responded that they had not overdosed, which could indicate that they were uncomfortable admitting that they had indeed overdosed. As expected, quality of life was negatively related to having overdosed, and the results were unchanged when the responses of these IDUs were changed to having had overdosed.

Although the IDUQOL appeared to overcome some of the shortcomings of other quality of life measures used with IDUs, its limitations should be noted. The studies presented in this thesis are the first to use the IDUQOL and thus, it is not yet a

'perfect' measure. Based on the interviews of the 260 cocaine and heroin IDUs in the descriptive study, it was apparent that some participants could have selected more than five life areas as being important components of their quality of life. Therefore, the IDUQOL assessment could have been too restrictive for some IDUs, which may have influenced – increased or decreased – their overall IDUQOL quality of life score. It is however unlikely that this misclassification was differential. The restriction of selecting only five life areas could perhaps partially explain the frequent life area changes observed from baseline to follow-up in the evaluation study of Chapter 5. Had the IDUs been permitted to select all life areas that were important to them, changes in the life area selection from baseline to follow-up might have been reduced. On the contrary, narrowing the IDU's choice to only five areas could have provided a more robust quality of life measure as it was based on his or her most immediate concerns. Future studies should provide more insight – the number of life areas included in the IDUQOL score is currently under study in Vancouver IDUs (Palepu 2001, personal communication).

Finally, there were some limitations in assigning numbers to the experiences and perceptions of individuals to represent the quantity of their quality of life (Joyce et al., 1999). Certainly the IDUQOL, as with all quality of life measures, does not completely characterize this abstract concept. Nonetheless, the IDUQOL seemed to perform better than other quality of life instruments used with IDUs, and the results suggested that the IDUQOL appeared to characterize the concept of quality of life. Future studies should help to refine the IDUQOL and to improve its usefulness as a quality of life measure.

7 SUMMARY AND CONCLUDING REMARKS

The first part of this investigation involved the development and evaluation of a quality of life instrument for IDUs – the IDUQOL. Evaluation of the IDUQOL suggested that it had good test-retest reliability. As well, allowing a choice of the life areas or the constituents of quality of life appeared to be an important aspect in measuring the quality of life of IDUs and in determining the stability of quality of life in this population. Overall, the quality of life of IDUs seemed to be somewhat less stable than that of other populations. The IDUQOL performed well against its criterion, the Flanagan Quality of Life Scale, and seemed to quantify quality of life in a way that was more pertinent to IDUs. The IDUQOL was more capable of discriminating between subgroups of IDUs on the basis of quality of life. Taken together, these results suggested that the IDUQOL is a promising quality of life measure for IDUs. Further studies should provide more information regarding the stability of quality of life in IDUs, the determinants of quality of life in IDUs and the responsiveness of the IDUQOL to changes in quality of life. In addition, evaluation of what the important life areas meant to IDUs is underway and may help to place the study findings in context. The IDUQOL could prove useful in evaluating safe injecting rooms, heroin prescription and HIV vaccines – programs that are currently being considered for their feasibility in Canadian and other IDU populations.

The second part of this investigation involved the application of the IDUQOL in 260 IDUs. The life areas that were the most important constituents of the quality of life of cocaine and heroin IDUs were generally the same and included health, housing, money, feeling good about yourself, family and partnership. Although basic necessities appeared to be lacking in IDUs, the life area, resources, was not frequently selected as being an important constituent of their quality of life. This could suggest that the resources available to IDUs did not address their needs. In general, both cocaine and heroin IDUs were dissatisfied with how their important life areas fared. Intervening on these important life areas would perhaps make a marked difference in the lives and well-being of IDUs.

Overall, the results suggested that programs targeted for IDUs, such as needle exchange programs, methadone and drug treatment, had little relation to quality of life. In contrast, a strong relation between better quality of life and meal program use was found. As well, HIV positive IDUs had a better quality of life than IDUs who were HIV negative, possibly because of the extensive programs that were available to them. Unlike the majority of programs that are targeted for IDUs, programs and services for HIV positive individuals are not directed at behaviour change; rather, they focus on living conditions and basic needs. Perhaps the reason for the sustained rates of HIV transmission in drug using populations with access to sterile needles is that interventions have tried to change risk behaviours without addressing the life areas that are important to drug users. Prevention models have failed to incorporate the social context of injection drug use, and the structural factors that influence vulnerability to risky behaviour and to illness.

This study described the quality of life of IDUs in Montreal who were addicted to cocaine and heroin. Although no conclusions can be made regarding the determinants of quality of life, the study results nonetheless provided insight concerning the social and psychological aspects of individuals with drug addiction, which may help public health authorities to better direct prevention programs for IDUs. As suggested by this work, programs that address the life conditions and essential needs of IDUs might be needed foremost to other initiatives. Eliminating the underlying circumstances and conditions that lead IDUs to engage in risky practices could do much more to improve the well-being of IDUs, and to stem the tide of HIV.

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APPENDIX A: IDUQOL ADMINISTRATION MANUAL AND ASSESSMENT FORMS

IDUQOL ADMINISTRATION MANUAL

STEP 1 – BRIEF LIFE ASSESSMENT

Say to the participant:

"We are going to spend the next few minutes talking about the things in life that are important to you, your well being, happiness and satisfaction with life. Most of us don't spend a lot of time thinking about these things. I would like you to try and be as honest as possible in your responses."

Q1 *Ask the participant:*

"On a scale of 0 to 10, how would you rate your quality of life right now? Zero indicates that things are as bad as you can imagine and 10 indicates that things are as good as you can imagine."

Record the participant's response on the second page of the IDUQOL assessment form in the space marked Q1. Note: If the participant asks what is quality of life, reply that it is however he/she defines it.

STEP 2 – INTRODUCTION

Read the following to the participant:

"For each of us, happiness and satisfaction in life depends on the areas of life that are most important to us. What is considered important in life varies from person to person. When these important areas are present or going well, we are generally happy. When they are absent or going badly we feel worried and unhappy. In other words, these important areas determine the quality of our lives."

"I am interested in knowing what the most important areas of your life are at the moment. We generally don't spend a lot of time thinking about these things and we often only notice that certain things are important when something happens to change them. Sometimes it is easier to identify what is important by thinking about the areas of life that would or do cause us most concern when they are missing or going badly."

STEP 3 – PARTICIPANT NOMINATED IMPORTANT LIFE AREAS

Q3.1-Q3.5 *Ask the participant:*

"What are the five most important areas of your life at the present – the things which make your life a relatively happy or sad one at the moment....the things that you feel determine the quality of your life."

Write the name of the five nominated life areas on page 2 of the IDUQOL assessment form in the spaces marked Q3.1 to Q3.5.

STEP 4 – CARD SELECTED LIFE AREAS

Q4.1-Q4.17 *Ask the participant:*

"Now that you have begun thinking about the life areas that are important to you, I am going to show you some cards to help you further explore your feelings. From these cards, select the 5 most important areas of your life at present – the things that you feel determine your quality of life."

Record the selected life areas in the appropriate space Q4.1-Q4.17 on page 3 of the IDUQOL assessment form.

STEP 5 – MEANING OF SELECTED LIFE AREAS

You must now establish what the participant means by each life area selected as being important, i.e. spirituality might relate to one's spiritual life or to the social dimension of religious gatherings. Similarly, sex might relate to the relationship with one's primary partner, casual sex or sex work to generate money.

Q5.1-Q5.17 *Ask the participant:*

"Can you briefly tell me what each life area means (or represents) to you?"

Write the brief responses in the appropriate space Q5.1-Q5.17 on pages 4 and 5 of the IDUQOL assessment form. Note: Probe further if the response it too vague or unclear i.e., What do you mean by that? Can you explain...?

STEP 6 – WEIGHTING OF THE LIFE AREAS

Q6.1-Q6.17 *Say to the participant:*

"Often we value some areas in life as being more important than others. Now that you have selected the 5 important areas of your life, I would like you to indicate how important each area is to you using these chips. There are 25 chips in total. I would like you to show me how important these areas are in relation to each other by placing a larger amount of chips on the areas that are more important to you and fewer chips on the areas that are less important to you. For example, the area of least importance to you may have only 1 chip on it, the area of most importance may have 15 chips on it and the other 3 areas may have 3 chips each. There is no maximum or minimum number of chips that can be placed on any card."

Record the number of chips placed on each life area in the appropriate space Q6.1-Q6.17 on pages 6 and 7 of the IDUQOL assessment form.

STEP 7 – RATING OF LIFE AREAS

Q7.1-Q7.17 *Say to the participant:*

"Now that you have rated the importance of each life area, I am going to ask you to rate how well each area is going for you right now using a scale of 0 to 100. Zero indicates that things are the worst that you can imagine for the life area and 100 indicates things are the best that you can imagine for the life area. For each life area, select a number from 0 to 100 that represents how well that area is going for you right now."

Record the participant's rating of each life area in the appropriate space Q7.1-Q7.17 on pages 6 and 7 of the IDUQOL assessment form.

STEP 8 – REPEAT THE BRIEF LIFE ASSESSMENT

Q8 *Say to the participant:*

"Now that we have spent a few minutes reflecting on your life, what is important to you and how you feel about your important life areas, I would like to ask you again, on a scale of 0 to 10, how would you rate your quality of life at the moment? Zero indicates that things are as bad as you can imagine and 10 indicates that things are as good as you can imagine."

Record the participant's response on page 8 of the IDUQOL assessment form in the space marked Q8.

The participant has now finished their interview and may leave. Complete questions C1-C4 on the last page of the IDUQOL assessment form.

IDUQOL ASSESSMENT FORM

Name of interviewer: _____

Date of interview (in numbers): _____/_____/_____
DAY / MONTH / YEAR

Participant NUM: **NUM** _____

Participant NUMERO: **NUMERO** _____

STEP 1. BRIEF LIFE ASSESSMENT

Q1 _____

STEP 3. PARTICIPANT NOMINATED 5 MOST IMPORTANT LIFE AREAS

Q3.1 _____

Q3.2 _____

Q3.3 _____

Q3.4 _____

Q3.5 _____

STEP 4. CARD SELECTED LIFE AREAS

Indicate the 5 selected life areas by placing an X on the line beside the life area.

Q4.1	**BEING USEFUL**	_____
Q4.2	**HIV/AIDS TREATMENT**	_____
Q4.3	**DRUGS**	_____
Q4.4	**DRUG TREATMENT**	_____
Q4.5	**EDUCATION**	_____
Q4.6	**FAMILY**	_____
Q4.7	**FEELING GOOD**	_____
Q4.8	**FRIENDS**	_____
Q4.9	**HEALTH**	_____
Q4.10	**HOUSING**	_____
Q4.11	**INDEPENDENCE**	_____
Q4.12	**LEISURE ACTIVITIES**	_____
Q4.13	**MONEY**	_____
Q4.14	**PARTNERSHIP**	_____
Q4.15	**RESOURCES**	_____
Q4.16	**SEX**	_____
Q4.17	**SPIRITUALITY**	_____

STEP 5. MEANING OF THE SELECTED LIFE AREAS

Q5.1 BEING USEFUL_____

_____

Q5.2 HIV/AIDS TREATMENT_____

_____

Q5.3 DRUGS_____

_____

Q5.4 DRUG TREATMENT_____

_____

Q5.5 EDUCATION_____

_____

Q5.6 FAMILY_____

_____

Q5.7 FEELING GOOD _____

_____

Q5.8 FRIENDS_____

_____

Q5.9 HEALTH_____

_____

Q5.10 HOUSING_____

_____

Q5.11 INDEPENDENCE_____

_____

Q5.12 LEISURE ACTIVITIES_____

_____

Q5.13 MONEY_____

_____

Q5.14 PARTNERSHIP_____

_____

Q5.15 RESOURCES_____

_____

Q5.16 SEX_____

_____

Q5.17 SPIRITUALITY_____

_____

STEPS 6 & 7. WEIGHTING AND RATING OF THE LIFE AREAS

LIFE AREA	NUMBER OF CHIPS (STEP 6)	RATING OF LIFE AREA (STEP 7)
BEING USEFUL	Q6.1 _____	Q7.1 _____
HIV/AIDS TX	Q6.2 _____	Q7.2 _____
DRUGS	Q6.3 _____	Q7.3 _____
DRUG TREATMENT	Q6.4 _____	Q7.4 _____
EDUCATION	Q6.5 _____	Q7.5 _____
FAMILY	Q6.6 _____	Q7.6 _____
FEELING GOOD	Q6.7 _____	Q7.7 _____
FRIENDS	Q6.8 _____	Q7.8 _____
HEALTH	Q6.9 _____	Q7.9 _____
HOUSING	Q6.10_____	Q7.10_____
INDEPENDENCE	Q6.11_____	Q7.11_____

LIFE AREA	NUMBER OF CHIPS (STEP 6)	RATING OF LIFE AREA (STEP 7)
LEISURE ACTIVITY	Q6.12_____	Q7.12_____
MONEY	Q6.13_____	Q7.13_____
PARTNERSHIP	Q6.14_____	Q7.14_____
RESOURCES	Q6.15_____	Q7.15_____
SEX	Q6.16_____	Q7.16_____
SPIRITUALITY	Q6.17_____	Q7.17_____

STEP 8 - REPEAT BRIEF LIFE ASSESSMENT

Q8 _____

INTERVIEWER COMMENTS (complete after participant has left):

COM1 **What was the level of intoxication of participant?**

_____

0=sober, 10=very high

COM2 **How well did the participant understand the method?**

_____

0=did not understand at all, 10=very well

COM3 **How would you rate the overall validity of information obtained?**

_____

0=extremely poor, 10=excellent

COM4 **How many minutes did it take to complete the interview?**

_____

Number of minutes

APPENDIX B: ETHICAL APPROVAL AND CONSENT FORMS

CHUM

COMITÉ D'ÉVALUATION SCIENTIFIQUE
Hôtel Saint-Luc du CHUM

Le 17 novembre 2000

Dr Julie Bruneau
Psychiatre

SL 00.070 **La qualité de vie (QdV) d'usagers de drogue par injection (UDIs) à Montréal. Cette étude va modifier et finaliser un instrument spécifique aux UDIs pour mesurer leur QdV. Nous identifierons des domaines de vie importants pour les UDIs, décrirons leur QdV et la comparerons à travers des sous-groupes. Nous effectuerons également une étude longitudinale sur la stabilité et les déterminants de la QdV.**

Docteur,

J'ai le plaisir de vous aviser qu'à sa réunion du 14 novembre 2000, le comité d'éthique de la recherche a approuvé en principe le projet cité en rubrique. Bien que le comité croie qu'il serait souhaitable d'obtenir le consentement des mineurs de 14 ans et plus, il jugerait acceptable qu'un mineur âgé de 14 ans et plus donne seul son consentement vous jugez qu'il ne serait pas recrutable autrement. Le comité base son avis sur l'interprétation qu'il fait du terme « expérimentation » à l'article 21 du code civil du Québec.

Le comité d'éthique vous demande d'apporter les corrections indiquées au formulaire de consentement que vous trouverez ci-joint et d'y spécifier les points suivants:

-Préciser en quoi consiste la cohorte St-Luc?

-Puisqu'il y a un stress possible imposé au sujet, lorsqu'il réalisera qu'il a de moins en moins de qualité de vie, il faudrait prévoir dans le formulaire de consentement, la référence à un professionnel compétent à qui le sujet puisse se confier.

Vous voudrez bien nous retourner deux copies du formulaire modifié, dont l'une indiquera en surligné les modifications. La deuxième copie vous sera retournée avec l'estampille d'approbation.

COMITÉ D'ÉVALUATION SCIENTIFIQUE
Hôpital Saint-Luc du CHUM

Il est entendu que vous ne pouvez commencer le recrutement de sujets avant que le formulaire de consentement modifié n'ait été approuvé.

Je vous prie d'agréer, Docteur, l'expression de mes salutations distinguées.

Le vice-président du comité d'éthique,

André Lavoie, avocat
AL/nf
p.j. formulaire de consentement annoté

CONSENT FORM: EVALUATION STUDY

INFORMATION AND CONSENT FORM REGARDING A STUDY OF THE QUALITY OF LIFE AMONG MONTREAL INJECTION DRUG USERS

PRINCIPAL INVESTIGATOR: DR. JULIE BRUNEAU

INTRODUCTION

You are already enrolled in the St-Luc Cohort. The purpose of this cohort is to estimate the proportion of HIV infected intravenous drug users (IDUs) in Montreal and to identify factors and processes which explain an elevated HIV incidence among IDUs who have access to sterile injection equipment. As a participant of the St-Luc Cohort, you already have interviews every six months during which a nurse administers a questionnaire to you, and takes a blood sample to test for HIV infection (and other infections for research purposes).

The current study aims to evaluate a quality of life measure in individuals who inject drugs in Montreal. Quality of life can be described as an individual's satisfaction with their life and view of their overall well being. Thus, it is based on a person's past experiences, present lifestyle and personal hopes for the future.

If you agree to participate in this study, your consent will be requested. This consent form addresses only the study on quality of life, which is separate from the main study on HIV. If you refuse to participate in this study, you will not be removed from the HIV study.

OBJECTIVE OF THE STUDY

The objective of this study is to evaluate the quality of life questionnaire and to assess and describe the quality of life of intravenous drug users in Montreal.

PARTICIPATION

If you agree to participate in this study, we will ask you to meet one of the research nurses at the study site of the St-Luc Cohort, located at Campus St-Luc of CHUM.

1. We will ask you to complete a short interview through which we will assess your quality of life. One of the two questionnaires on quality of life has already been validated in other groups of the population. The other questionnaire was developed with the collaboration of individuals who inject drugs in Montreal and Vancouver. The first interview will take approximately 30 minutes to complete and will be done after your interview for the HIV study.
2. We will ask you to return in 1 to 2 weeks to repeat the interview. We will need to contact you, by the method of your choice, to remind you of your visit. This second interview will also take approximately 30 minutes.
3. As part of the data analysis, we need to use the information on your quality of life, with that collected by the research nurses in the main study on HIV of which you are

already a participant. This information will be linked by a numerical code; neither your name nor any other nominal information will be used.

RISKS AND BENEFITS

There are no potential risks associated with your participation in this pilot study. If, however, you would like to talk further about your life and concerns with a health professional, you can contact Dr. Brissette, chief of Detoxification Unit at 281-2421. By participating, you will be contributing to our understanding of the quality of life of individuals who inject drugs. Our results may help develop public health programs that improve the life conditions of individuals who inject drugs in Montreal and elsewhere.

COMPENSATION

There is no direct cost associated with this pilot study. At each visit, you will receive $10.00 as compensation for your time and transportation.

YOUR RIGHTS

You have the right to ask any questions that you may have, and the study interviewer will take the time to provide you a satisfactory answer.

VOLUNTARY PARTICIPATION AND RIGHT TO WITHDRAW

Your participation in this project is at your own free will. You can withdraw from the study anytime. Your participation and withdrawal from this study will be fully respected and will not be held against you.

CONFIDENTIALITY

All information collected from you will be treated with strict confidentiality. No names or other information that could identify you will be released. The database used for statistical analyses will not contain any nominal information. A four-digit number code will be used to identify all information that pertains to you. Only the study interviewers will be able to link your code to your name. The code will be kept in a locked file or in a computer with a controlled access by password. The results of this study will be used for scientific communication only.

ADDITIONAL INFORMATION

If you would like to obtain additional information about this study, you may contact Dr. Julie Bruneau at For any other questions or complaints please contact, Mr. Mammoud D'Houib at

CONSENT FORM

QUALITY OF LIFE AMONG MONTREAL INJECTION DRUG USERS

By signing this form, I acknowledge having received and read a copy of the information sheet concerning this study. I have had the opportunity to ask any questions I may have, and they have been answered to my satisfaction. By signing this form, I agree to participate to this study. I understand that I may withdraw from this agreement at any time. I understand that my decision will not change my health care or legal rights, and that all information will be kept strictly **confidential**. My file will be coded and kept in a place where only the research team will have access. I do not renounce any of my legal rights nor free the researchers and the hospital of their legal and professional responsibilities.

1. **I agree to be interviewed by the research team**

2. **I agree that all the information collected by the St-Luc Cohort can be linked in a confidential manner with the present pilot study using only my participant code**

Your signature: _____ Date: _____

Write your name in block letters: _____

Signature of the tutor: _____ Date: _____
(if applicable)

Date of birth: _____ Telephone number: _____
(Year / Month / Day)

I recognize having given to the participant a copy of this consent form and a copy of the explanations.

Name of the nurse : _____

Signature of the nurse : _____ Date : _____

Name of the witness : _____

Signature of the witness : _____ Date : _____

Signature of researcher : _____ Date : _____

CONSENT FORM: DESCRIPTIVE STUDY

INFORMATION AND CONSENT FORM REGARDING A STUDY OF THE QUALITY OF LIFE AMONG MONTREAL INJECTION DRUG USERS

PRINCIPAL INVESTIGATOR: DR. JULIE BRUNEAU

INTRODUCTION

You are already enrolled in the St-Luc Cohort. The purpose of this cohort is to estimate the proportion of HIV infected intravenous drug users (IDUs) in Montreal and to identify factors and processes which explain an elevated HIV incidence among IDUs who have access to sterile injection equipment. As a participant of the St-Luc Cohort, you already have interviews every six months during which a nurse administers a questionnaire to you, and takes a blood sample to test for HIV infection (and other infections for research purposes).

The current study aims to define and describe what is the quality of life of individuals who inject drugs in Montreal. Quality of life can be described as an individual's satisfaction with their life and view of their overall well being. Thus, it is based on a person's past experiences, present lifestyle and personal hopes for the future.

If you agree to participate in this study, your consent will be requested. This consent form addresses only the study on quality of life, which is separate from the main study on HIV. If you refuse to participate in this study, you will not be removed from the HIV study.

OBJECTIVE OF THE STUDY

The objective of this study is to describe the quality of life of IDUs in Montreal and to determine how various drug-related and lifestyle factors affect quality of life.

PARTICIPATION

If you agree to participate in this study, we will ask you to meet one of the research nurses at the study site of the St-Luc Cohort, located at Campus St-Luc of CHUM.

1. We will ask you to complete a short interview through which we will assess your quality of life. The quality of life questionnaire was developed with the collaboration of individuals who inject drugs in Montreal and Vancouver. The interview will take approximately 20 minutes to complete.
2. As part of the data analysis, we need to use the information on your quality of life, with that collected by the research nurses in the main study on HIV of which you are already a participant. This information will be linked by a numerical code; neither your name nor any other nominal information will be used.

RISKS AND BENEFITS

There are no potential risks associated with your participation in this pilot study. If, however, you would like to talk further about your life and concerns with a health professional, you can contact Dr. Brissette, chief of Detoxification Unit at By

participating, you will be contributing to our understanding of the quality of life of individuals who inject drugs. Our results may help develop public health programs that improve the life conditions of individuals who inject drugs in Montreal and elsewhere.

COMPENSATION

There is no direct cost associated with this pilot study. At each visit, you will receive $10.00 as compensation for your time and transportation.

YOUR RIGHTS

You have the right to ask any questions that you may have, and the study interviewer will take the time to provide you a satisfactory answer.

VOLUNTARY PARTICIPATION AND RIGHT TO WITHDRAW

Your participation in this project is voluntary. You can withdraw from the study anytime. Your participation and withdrawal from this study will be fully respected and will not be held against you.

CONFIDENTIALITY

All information collected from you will be treated with strict confidentiality. No names or other information that could identify you will be released. The database used for statistical analyses will not contain any nominal information. A four-digit number code will be used to identify all information that pertains to you. Only the study interviewers will be able to link your code to your name. The code will be kept in a locked file or in a computer with a controlled access by password. The results of this study will be used for scientific communication only.

ADDITIONAL INFORMATION

If you would like to obtain additional information about this study, you may contact Dr. Julie Bruneau at (For any other questions or complaints please contact, Mr. Mammoud D'Houib at

CONSENT FORM

QUALITY OF LIFE AMONG MONTREAL INJECTION DRUG USERS

By signing this form, I acknowledge having received and read a copy of the information sheet concerning this study. I have had the opportunity to ask any questions I may have, and they have been answered to my satisfaction. By signing this form, I agree to participate to this study. I understand that I may withdraw from this agreement at any time. I understand that my decision will not change my health care or legal rights, and that all information will be kept strictly **confidential**. My file will be coded and kept in a place where only the research team will have access. I do not renounce any of my legal rights nor free the researchers and the hospital of their legal and professional responsibilities.

1. **I agree to be interviewed by the research team**

2. **I agree that all the information collected by the St-Luc Cohort can be linked in a confidential manner with the present pilot study using only my participant code**

Your signature: _____ Date: _____

Write your name in block letters: _____

Signature of the tutor: _____ Date: _____
(if applicable)

Date of birth: _____ Telephone number: _____
(Year / Month / Day)

I recognize having given to the participant a copy of this consent form and a copy of the explanations.

Name of the nurse : _____

Signature of the nurse : _____ Date :_____

Name of the witness : _____

Signature of the witness : _____ Date :_____

Signature of researcher : _____ Date :_____

APPENDIX C: THE FLANAGAN QUALITY OF LIFE SCALE

FLANAGAN QUALITY OF LIFE SCALE

Name of interviewer: _____

Date of interview (in numbers): _____/_____/_____
DAY / MONTH / YEAR

Participant NUM: **NUM** _____

Participant NUMBER: **NUMERO** _____

Quality of life visit number: **QVIS** _____

Please indicate the order in which you administered the quality of life measures by placing an X beside the measure that was administered first.

Flanagan Quality of Life Scale _____

Injection Drug User Quality of Life Scale _____

Say to the participant: I am going to read you a list of things which people have said are important to their way of life. For each of these things, please select the card that best describes your satisfaction with how well your needs and wants are being met in this area.

Read the brief description of each domain before asking the participant how satisfied they are with the domain. Show the participant the blue response cards indicating the different levels of satisfaction for how well their needs and wants are being met.

F1. MATERIAL COMFORTS – For example, wanting to live in a nice place, having good food, having an increasing salary and security for the future.

a. At this time in your life, what best describes your satisfaction with how well your needs and wants for material comforts are being met?

1. Highly dissatisfied
2. Dissatisfied
3. Somewhat dissatisfied
4. Neither dissatisfied nor satisfied
5. Somewhat satisfied
6. Satisfied
7. Highly satisfied
8. No need (do not read this response)

F1a _____

F2. HEALTH AND PERSONAL SAFETY – For example, being in good shape, having energy, being free from anxiety and distress and avoiding physical harm.

a. At this time in your life, what best describes your satisfaction with how well your needs and wants for health and personal safety are being met?

1. Highly dissatisfied
2. Dissatisfied
3. Somewhat dissatisfied
4. Neither dissatisfied nor satisfied
5. Somewhat satisfied
6. Satisfied
7. Highly satisfied
8. No need (do not read this response)

F2a _____

F3. RELATIONSHIPS WITH YOUR PARENTS, BROTHERS, SISTERS AND OTHER RELATIVES – For example, communicating, talking, visiting, understanding and doing activities with your family, helping your family and being helped by your family.

a. At this time in your life, what best describes your satisfaction with how well your needs and wants for relationships with these relatives are being met?

1. Highly dissatisfied
2. Dissatisfied
3. Somewhat dissatisfied
4. Neither dissatisfied nor satisfied
5. Somewhat satisfied
6. Satisfied
7. Highly satisfied
8. No need (do not read this response)

F3a _____

F4. HAVING AND RAISING CHILDREN – This involves being a parent, helping your children, teaching your children and caring for your children.

a. At this time in your life, what best describes your satisfaction with how well your needs and wants for having and raising children are being met?

1. Highly dissatisfied
2. Dissatisfied
3. Somewhat dissatisfied
4. Neither dissatisfied nor satisfied
5. Somewhat satisfied
6. Satisfied
7. Highly satisfied
8. No need (do not read this response)

F4a _____

F5. CLOSE RELATIONSHIPS WITH A PARTNER

a. At this time in your life, what best describes your satisfaction with how well your needs and wants for relationships with relations with a partner are being met?

1. Highly dissatisfied
2. Dissatisfied
3. Somewhat dissatisfied
4. Neither dissatisfied nor satisfied
5. Somewhat satisfied
6. Satisfied
7. Highly satisfied
8. No need (do not read this response)

F5a _____

F6. CLOSE FRIENDS – Sharing activities, interests and views with friends, being accepted, visiting, giving and receiving help, love, trust, support and guidance.

a. At this time in your life, what best describes your satisfaction with how well your needs and wants for close friends are being met?

1. Highly dissatisfied
2. Dissatisfied
3. Somewhat dissatisfied
4. Neither dissatisfied nor satisfied
5. Somewhat satisfied
6. Satisfied
7. Highly satisfied
8. No need (do not read this response)

F6a _____

F7. HELPING AND ENCOURAGING OTHERS – This includes all relationships with adults or children other than relatives or close friends.

a. At this time in your life, what best describes your satisfaction with how well your needs and wants for helping and encouraging others are being met?

1. Highly dissatisfied
2. Dissatisfied
3. Somewhat dissatisfied
4. Neither dissatisfied nor satisfied
5. Somewhat satisfied
6. Satisfied
7. Highly satisfied
8. No need (do not read this response)

F7a _____

F8. PARTICIPATION IN ACTIVITIES RELATED TO LOCAL AND NATIONAL GOVERNMENT AND PUBLIC AFFAIRS - Keeping informed through the media (newspaper, radio, television), voting, participating in society (to be involved in community organisations for example), having political ideas and religious freedom.

a. At this time in your life, what best describes your satisfaction with how well your needs and wants for participating in these activities are being met?

1. Highly dissatisfied
2. Dissatisfied
3. Somewhat dissatisfied
4. Neither dissatisfied nor satisfied
5. Somewhat satisfied
6. Satisfied
7. Highly satisfied
8. No need (do not read this response)

F8a _____

F9. LEARNING – For example, taking courses and improving your knowledge.

a. At this time in your life, what best describes your satisfaction with how well your needs and wants for learning are being met?

1. Highly dissatisfied
2. Dissatisfied
3. Somewhat dissatisfied
4. Neither dissatisfied nor satisfied
5. Somewhat satisfied
6. Satisfied
7. Highly satisfied
8. No need (do not read this response)

F9a _____

F10. UNDERSTANDING YOURSELF – Knowing your strengths and limitations, knowing what life is about and making important life decisions. For some people this includes religious or spiritual experiences. For others, it is an attitude or a philosophy towards life.

a. At this time in your life, what best describes your satisfaction with how well your needs and wants for understanding yourself are being met?

1. Highly dissatisfied
2. Dissatisfied
3. Somewhat dissatisfied
4. Neither dissatisfied nor satisfied
5. Somewhat satisfied
6. Satisfied
7. Highly satisfied
8. No need (do not read this response)

F10a _____

F11. WORK – Working at a job or at home that you consider to be interesting, rewarding and worthwhile.

a. At this time in your life, what best describes your satisfaction with how well your needs and wants for work are being met?

1. Highly dissatisfied
2. Dissatisfied
3. Somewhat dissatisfied
4. Neither dissatisfied nor satisfied
5. Somewhat satisfied
6. Satisfied
7. Highly satisfied
8. No need (do not read this response)

F11a _____

F12. **EXPRESSING YOURSELF** – In a creative manner through music, art, photography, practical or leisure time activities.

a. At this time in your life, what best describes your satisfaction with how well your needs and wants for expressing yourself are being met?

1. Highly dissatisfied
2. Dissatisfied
3. Somewhat dissatisfied
4. Neither dissatisfied nor satisfied
5. Somewhat satisfied
6. Satisfied
7. Highly satisfied
8. No need (do not read this response)

F12a _____

F13. **SOCIALISING** – For example, meeting other people, doing things with them, giving or going to parties.

a. At this time in your life, what best describes your satisfaction with how well your needs and wants for socialising are being met?

1. Highly dissatisfied
2. Dissatisfied
3. Somewhat dissatisfied
4. Neither dissatisfied nor satisfied
5. Somewhat satisfied
6. Satisfied
7. Highly satisfied
8. No need (do not read this response)

F13a _____

F14. **READING, LISTENING TO MUSIC OR OBSERVING SPORTING EVENTS OR ENTERTAINMENT.**

a. At this time in your life, what best describes your satisfaction with how well your needs and wants for these activities are being met?

1. Highly dissatisfied
2. Dissatisfied
3. Somewhat dissatisfied
4. Neither dissatisfied nor satisfied
5. Somewhat satisfied
6. Satisfied
7. Highly satisfied
8. No need (do not read this response)

F14a _____

F15. **PARTICIPATION IN ACTIVE RECREATION** – Such as sports, traveling, sightseeing, playing games or cards, singing, dancing, playing an instrument, acting and other such activities.

a. At this time in your life, what best describes your satisfaction with how well your needs and wants for participation in active recreation are being met?

1. Highly dissatisfied
2. Dissatisfied
3. Somewhat dissatisfied
4. Neither dissatisfied nor satisfied
5. Somewhat satisfied
6. Satisfied
7. Highly satisfied
8. No need (do not read this response)

F15a _____