

**A Study of the Deaths of Persons who are Homeless in Ottawa –
A Social and Health Investigation.**

**Report to the City of Ottawa¹ Vol. 1
Housing Branch
Ottawa, Ontario**

**by
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**“Every Tree and Leaf and Star
Show how the universe is part of this one cry
That every life is noted and cherished
And nothing Loved is ever lost or perished.”**

Madeleine L’Engle

Sincere thanks are extended to the many individuals who, with significant support from their organizations, gave their time and insights into the lives and deaths of people who are homeless in Ottawa from their considerable knowledge and experience. Some of these are named.

Many others including family members, friends and providers of service who took part in interviews are anonymous, but despite this anonymity they are recognised not only for their critical contributions to the study’s developments and results, but also in recognition of the hope and optimism that they extend not only for the future of those who are homeless, but also to those who work and volunteer and befriend those who live and die without a home.

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Chapter 1: Introduction to “A Study of the Deaths of Persons who are Homeless in Ottawa: A Social and Health Investigation.”

There is profound concern in Ottawa about the deaths of people who are homeless. These deaths seemed to occur more frequently and prematurely than in typical age-comparable Canadians. The study that we embarked on required that we try to understand the complex issues around their lives and deaths.

Gaining understandings of death and dying in our society has never been easy. In this study of people who were homeless, the people who are being studied were also members of an elusive population, - members of a group of people whose day-to-day lives are substantially different to typical adult mainstream activities, and people who have been recognised as socially excluded. The report on the study that was accomplished and presented here of the “Deaths of Persons who are Homeless in Ottawa: A Social and Health Investigation” is a qualitative study that looks to piece together accounts of individuals’ lives, in the hope of understanding their lives, determining contributors to their deaths and preventing these deaths when possible.

Jeff was born and lived in the Maritimes until he was in his late teens. His Mom and Dad both died in a car accident when he was quite young and he lived with his sister and an aunt and uncle until he left school at 16. Jeff was quite unhappy after his mom and dad died and he didn’t get on with his uncle who was said to have made unfair demands of him, expecting him to do everything on command, to get great marks at school, and to be the best player on the basketball team.

Jeff was introduced to street drugs whilst at high school and found they made him feel so good he never wanted to quit. He started skipping school, and relationships with his family deteriorated as things went downhill at school. He eventually left town and went to Montreal, and then Ottawa and backwards and forwards between the two cities.

He was in and out of the Ottawa shelters for many years because he spent any money he got hold of on drugs. He had jail sentences for theft to support his habit. He got the occasional job but lost them almost immediately because he didn’t show up to work regularly. “I think he might have been a dealer too.” (service provider) He was diagnosed with HIV five years ago which he believes he got through sharing needles in prison, years before he was diagnosed. Public health nurses and outreach workers encouraged him to get medical help and regular check ups. He was not interested in medication, and said, “What’s the point, I’m already dying.” He seemed to get enough to eat, shelter and showers when he wanted them, but his health declined rapidly over the last few months and he finally agreed to be taken into a palliative care program as he was unable to feed himself or get around to get what he needed. (continued.)

He was in severe pain which the program tried to help him manage. He wanted to get well enough to return to the Maritimes where “he really belonged.” No family visited him but some service providers who knew him on the street did. He knew a couple of friends in the shelter. He managed to write some instructions to be followed after his death. He was 43 when he died of HIV/AIDS related illnesses. He didn’t make it back to the Maritimes.

His sister could not attend the funeral but she said that despite the problems that he caused he was a good person whose life was ruined by drug addiction. “That’s all he ever wanted.” She thought his uncle was very hard on them when they were kids and nobody could meet his expectations. “We all got booted around when we didn’t do what he wanted.”

Information sources: relative, two service providers, a friend and documented information.

In order to protect identity and confidentiality, Jeff is a fictional person whose story is reconstructed from the stories of many.

Outline of the report

This report outlines the purposes of the study and includes: the research questions that needed to be asked and answered; how we went about conducting the study; the results; and finally, the ensuing recommendations which were informed by our observations and analyses. (A full technical description of the methodology is found in Volume 2. Volume 3 contains all the tools that were developed and used during the study. Volume 4 is a training manual for interviewers.)

Purposes of the Study

This investigation aimed to:

- Develop a sustainable methodology to study deaths occurring among persons who are homeless in Ottawa. ‘Sustainable methodology’ means developing an approach that can be used on an ongoing basis. This part included developing networks of community connections and means by which information about deaths can be collected. As well as finding out about the people who had died themselves, the questions included “What were the contributing factors to death?” and “How, when possible, could these deaths be prevented?”
- Provide a pilot study to assess the methodology and make recommendations. The study’s work started in April 2002 and was completed in May 2003.
- Provide recommendations based on data collected during the pilot regarding prevention of death amongst people who are homeless in the City of Ottawa.

How the study was conducted

Developing a sustainable methodology

The development of the sustainable methodology started with a literature review. The approach to the literature adopted by this study was in two parts. The first part was to identify methods of discovering about homelessness and death in order to retrieve best practices in current research. We found that there were very few multiple-case studies conducted concerning people that had died. The second part of the literature search and review was to provide a basis of understanding with regard to homelessness to support the study. There is an abundance of material globally regarding homelessness, in addition to the research that has been conducted and continues to be conducted in Canada and Ottawa on homelessness.

Despite the existence of a large amount of critical material related to homelessness, the methodology that was to be developed had no clear precedents. The study that was designed was to be not only a pilot study, but also a pioneer study.

Because of the nature of this study we firstly identified the primary sources of information. We determined that there was a need to develop tools from scratch to use with these primary sources, which would enable us to answer the research questions. The design incorporated the collection of data on a case-by-case basis, providing us with multiple case studies.

We defined people who were homeless as people who were absolutely homeless or users of shelters and other services targeted at homeless people at the time of death.

The time frame that was adopted for the study was the seven-month period from June 2002 to January 2003. The number of cases that were identified during this time period was 25. Data were collected retrospectively outside of the time frame.

Developing Networks and Interviews

We worked to develop relationships with community networks and organizations by making personal contacts with individuals, attending community meetings, and other community activities. (We were limited because of time and regulations in establishing information conduits with the Coroner's offices, police, and hospitals. These organizations have protocols regarding the release of information, as well as additional requirements for approval of research.) With the community's help, we conducted 38 in-depth, unstructured but guided interviews with three groups of people:

- service providers, volunteers, and others who met the person largely in a service provider capacity;
- friends and acquaintances of the individual who died;
- and family members.

The majority of the interviews were with service providers. Information was also gained from other public domain sources including newspaper articles, and Internet postings.

Collation and Analysis of the Data

We collated the data in the form of individual case studies using line numbers to track the source of the data. The data were then combined and organized according to categories. Our system of coding and classification was based on grounded data (see methodology report for more details) and the categories covered by our questionnaires. Each piece of text was categorized according to our classification system. We analyzed for content systematically using our definitions.

Demographics, common themes, and other characteristics about the individuals and their experiences were classified using this coding system. Further, additional data included for example, comments about services and gaps. A part of the aggregated data would look like the sample below.

A Sample of Aggregated data.

Category (demographic, themes, characteristics, other)	Classification label	Text content
Precursors to death	Addictions	The last six months, {...} was not the same. {...} was using heavily. {...} had HIV but she was using drugs very heavily. CASE 21 L. 34
Precursors to death	Emotional health changes	“{...} didn’t care, it seemed like {...} gave up. CASE 21 Line 233
Precursors to death	Physical health changes Emotional health changes	{...} was very sick, really sad and needed support Case 21 Line 44
Precursors to death	Behavioural changes	The last three months {...} was ripping people off, things {...} wouldn’t normally do. CASE 17 Line 16
Precursors to death	Emotional health changes	before he got really sick {...} was proud about his appearance CASE 2 Line 109
Demographics	Primary medical cause of death	Case 5 (heart attack)
Demographics	Primary medical cause of death	Case 8 cancer (metastasis, lung cancer)
Demographics	Primary medical cause of death	Case 17 Murdered
Demographics	Primary medical cause of death	Case 2 HIV/AIDS related illnesses
Demographics	Primary medical cause of death	Case 21 HIV/AIDS related illnesses

Chapter 2: Who were the People?

“It is much more important to know what sort of patient has a disease than what sort of disease a patient has.” Sir William Osler

Age at Time of Death

Both women and men died at ages that appear to be much lower than would be expected, (on average 52 years for men and 39 years for women) and although proportionally less deaths were recorded for women, these women were notably young. The figure below illustrates the comparison between the expected age of death based on the most recent national averages from census data (Statistics Canada, 2002³) and those found among our sample of homeless persons.

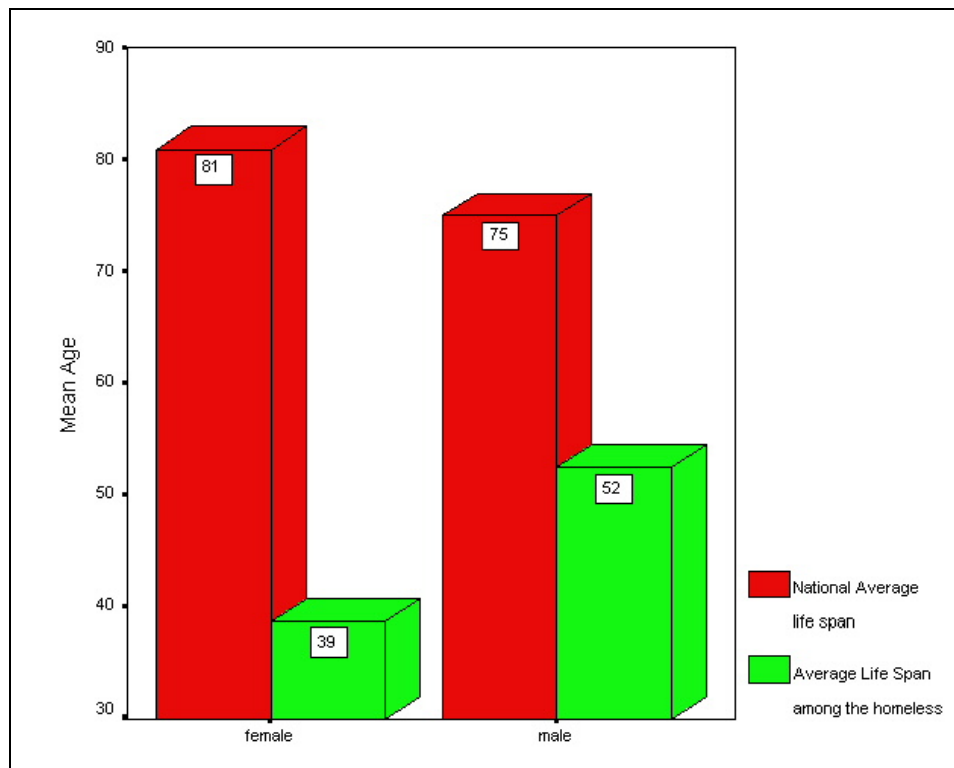
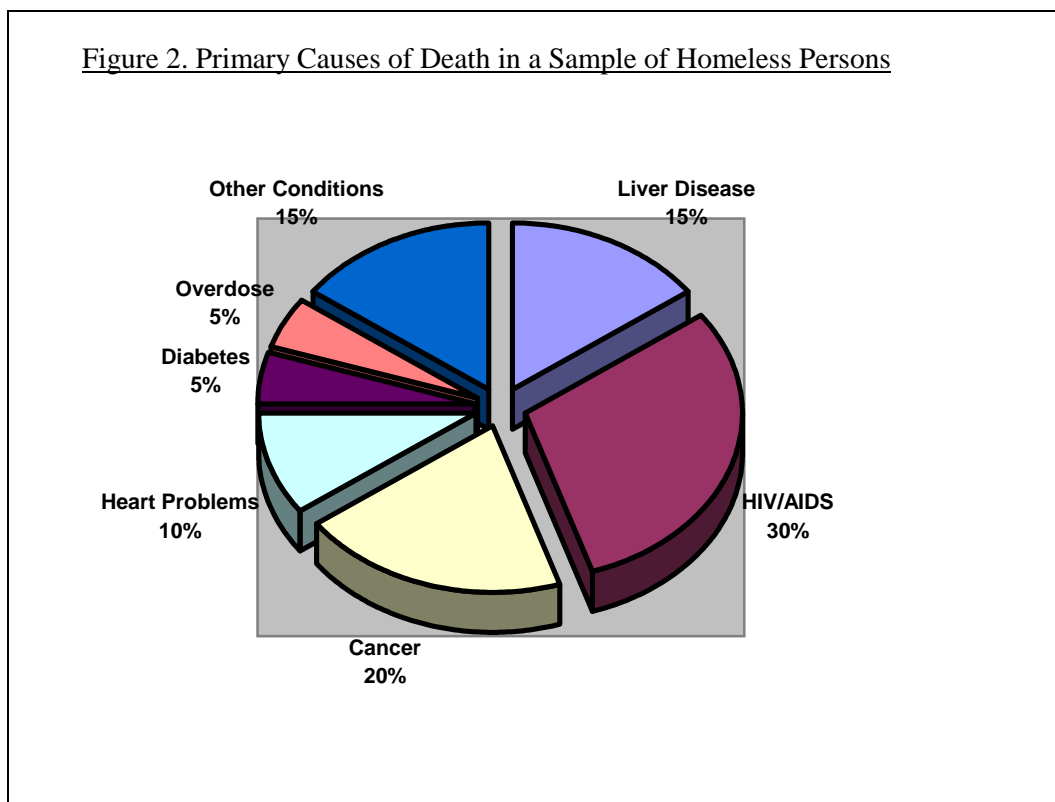


Figure 1. Comparison of the National Average Life Span Expectancies for Men and Women with the Life Span of Homeless Individuals included in this study.

³ Statistics Canada (2002) Life Expectancy at Birth. Obtained from Health Status at <http://www.statcan.ca/english/Pgdb/health26.htm>.

Health Conditions leading to Death

Our findings show that the majority of the group of people who were homeless and who died during the period of the study were extremely ill. Many had multiple conditions that required treatment with numerous medications. As can be seen in Figure 2, the primary medical causes of death were HIV/AIDS and related illness, cancer (five cases), and liver failure due to disease or cirrhosis. It should be noted that these proportions are based on a sample of 20 individuals, and that for five of the cases it was not possible to access medical records.



Associated Complicating Health Conditions Leading to Death

There were many other conditions associated with the deaths, which included Hepatitis B and Hepatitis C (30% of the cases), Cancer (secondary to HIV/AIDS, 10%), heart problems, liver and kidney problems, and diabetes. In addition, about (40%) of the cases had either a diagnosis or a suspected diagnosis of mental illness. Addictions were reported in over half of the group, with alcohol and cocaine being most commonly mentioned. Tobacco use was less well documented, but appeared to be in very common use (about 80% of known cases). Also, some individuals died with conditions directly attributable to smoking (10%). In a number of the cases, illegal drug use was connected with attempts to manage pain (10%).

Housing and Shelter

The data indicate that for many years prior to death, housing and shelter was uncertain for most, and street living was dominant for both men and women. We came to understand that shelter living and living on the street were mostly seen as synonymous with homeless living. It was difficult to obtain accurately dated records of housing history. The locations of the deaths were in hospices and hospitals, with the exception of two cases for which no information was available.

Status

As can be seen in the table below, about 45% of individuals included in the study were single with no known previous long term relationships. Twenty five per cent of the individuals were understood to be single at the time of death, but had been previously married or had a past involvement in long-term relationships. Twenty per cent of the individuals were reported to be in long-term or common-law relationships at the time of death, and one of these was reported as previously married.

SINGLE	LONG TERM RELATIONSHIP AT THE TIME OF DEATH	SINGLE AT THE TIME OF DEATH -- PREVIOUS RELATIONSHIPS OR MARRIAGES	UNKNOWN RELATIONSHIP STATUS
44%	20%	24%	12%

Education and Work History

Little information was available with respect to the individuals' education and work history, but what was available suggested that most may not have completed high school and did not have any training or further education for work. When individuals were reported to have had jobs, the jobs described were 'entry-level' type positions and of short duration.

Income

For income, the majority of individuals had been receiving different government benefits. Thirty six percent of the individuals in the study received benefits from the Ontario Disability Support Program and 20% received Family Benefits Allowance - ODSP benefits. A smaller percentage of individuals were reported to have been receiving either Canada Pension Plan or shelter or personal needs allowances (PNA). For about a third of the individuals in the sample, no sources of income could be identified. There were no reports of individuals receiving veterans' benefits. No individual was reported as having received income from employment or employment insurance benefits in the recent past.

Some individuals were reported to have been involved in panhandling, prostitution, drug dealing, unspecified criminal “wheeling and dealing,” and “engaged in criminal activities.” Nearly half of the individuals were known to have criminal records. On occasion, individuals were reported to have received money gifts from family and friends.

Citizenship and First Language

All cases reported were identified as Canadian citizens and all cases were reported as speaking English. About 10% of the people in the study had a first language other than English or French.

Spirituality and Wishes for the Future

We learned that over half of the individuals had religious or spiritual connections. All religious affiliations that were identified were Christian denominations, including Roman Catholic and Protestant. No information was available on the spiritual affinities and practices, if any, of nearly half the sample.

Respondents reported a variety of wishes and visions for the future. Those individuals who were drug addicts or alcoholics had short-term, day-to-day vision and rarely talked beyond “next week.” Some individuals had no visions or wishes of which they spoke. Others were pragmatic, recognizing their situation and hoped to “live as long as I can and to make sure no one screws me around.” Some individuals had expressed visions of having a family and ‘normal’ lives, having a home, making use of a particular talent or skill that he or she possessed, and getting a coveted job. Some individuals were always looking for peace.

We come in all colours, ages, shapes and sizes.
We are alcoholics and abstainers,
our families are rich and our families are poor,
our moms and dads loved us
and our moms and dads beat the shit out of us,
we do drugs and we wouldn't touch the stuff,
we are suffering from mental health problems
and we are painfully sane,
we are fearful and we are fearless,
crooked and trustworthy,
atheists and true believers,
personable and private
and many, many more things.
We are the homeless of your community
and we wish to speak to you.
What is more, we wish to speak to you as equals
in what we all know can be a very unequal society.
We want to heal that society
and in the process, heal ourselves.

We need your help and, more importantly, your understanding.

Street Speaks Report, Calgary, 1996

Statistics are human beings with the tears wiped off. -- Paul Brodeur

Chapter 3: Long-term Contributors to Homelessness and Death

The immediate causes of death in most of the cases are not difficult to identify, but the long-term contributors to homelessness and death are much more complex. There are, however, some recurring themes in the reports of those who were interviewed regarding the lives and deaths of those included in the study.

In summary, evidence of longer-term contributors to homelessness and death included a range of factors which we have categorized thematically as follows:

- i) Life Course Development, Life Events, and Lifestyle.
- ii) Experiences of Housing, Homelessness, and Shelter.
- iii) Experiences of Health Care
- iv) The Influence of Relationships.

i) Life Course Development, Life Events, and Lifestyle

- **Life course development** is defined here as notable events or factors affecting the individual in early life, and which possibly contribute to homelessness. Some of the characteristic events or factors that were identified by those participating in the study were as follows:
 - Emotional, physical, and sexual abuse were identified as being present in childhood or adolescence for some of the individuals.
 - Learning and other disabilities were often identified as negative conditions affecting a person's schooling, employment, and social relationships
 - In some cases, sudden negative changes in behaviour were reported. For example, one individual's behaviour 'changed' for the worse in grade school and continued to deteriorate during adolescence. Also, the reports show that these sudden changes and their reasons were virtually never investigated.
 - Importantly, in some cases it was difficult to determine if there were any developmental links with adult homelessness. Respondents were at a loss to provide any reasons why some individuals ended up having such difficult lives, when the individuals were described as having 'normal' upbringings.
- **Life events** are defined here as notable events in a person's life, such as births, deaths, and marriages. Some respondents identified specific life events as pivotal contributors to an individual's life, homelessness and, death.
 - The death of a parent when a child (who became a homeless adult) was young. An early death of a parent has been reported as an

- event that may cause trauma and upheaval in a child's life with consequences for adult life.
- The birth of a child to a school-aged mother, who may not have been ready to be a parent, and who may have had to give her child up to care.
 - The remarriage of a parent may have contributed to family dissension or the child's sense of alienation from the family
- Some respondents named **lifestyle** as a long term contributor to death.
- Lifestyles that included risky behaviours such as drug and alcohol use and addictions, inadequate or non-existent sexual protection practices, and involvement in prostitution were linked to some individuals who had acquired serious communicable diseases.
 - Lifestyles that included uncertainty and risk seemed to be “part of the excitement” for some individuals. This included instability of housing and shelter.
 - When upheaval and crisis were present in their personal relationships, and their daily living was “on the edge,” some individuals were reported as “thriving” or being at their best. This lifestyle “preference” sometimes precluded the individual from maintaining accommodation and keeping employment.

ii) Experiences of housing, homelessness and shelter

- **Instability of housing or chronic homelessness** was a commonly reported theme and cited as a long term contributor to death.
- Many of the individuals in the study were described as ‘always unstably housed.’ There were reports of several factors contributing to the lack of stable housing. Some individuals were reported to have had problems understanding the requirement of maintaining stable housing, such as understanding and dealing with eviction notices. Others had problems meeting the financial and social conditions of where they were housed.
 - Time in prison was reported to contribute to insecure housing situations. It was difficult to maintain long term stable housing, due to intermittent periods of incarceration during which housing was lost.

- A home that provided safety had great importance for women. A recurring theme concerned the safety of some housing for women. Women in our study were reported to have felt unsafe and harassed by landlords in boarding houses and rooming houses. This in some instances contributed to the abandonment of housing arrangements.
 - One service provider said, “Had there been more help in being able to offer (this client) a more stable living arrangement, (this client) would still be alive today.” This was said in the context of the client’s need to establish a regular eating, resting, sleeping, and medication regime in safety, which this client could not achieve without a home.
- Associated with this theme of instability, our data suggest that individuals’ attitudes towards their own state of homelessness appeared to have acted directly to diminish their opportunities to acquire shelter or other form of accommodation.
- Some respondents indicated that some individuals did not express much concern about obtaining stable housing, and some individuals were described as “not unhappy about being homeless.”
 - Some individuals had clearly expressed their dislike for shelter living. Individuals disliked the institutions and their regulations, and disliked the other people who accessed and used shelter services.
 - Some reports indicated that in many cases homeless individuals found it difficult to adjust to shelter living and expressed dislike for that environment, in particular the noise levels, the over-crowding, and the lack of privacy.

iii) Experiences of Health care

The area of health care is a prominent theme in terms of long term contributors to homelessness and death. Health care themes based on the data are distributed over several areas which are summarized as follows:

1. Health care and self-care and its relationship to housing and shelter
2. Usage of health care services
3. Issues of trust.
4. The difficulties and complexities of engaging with medical services
5. Mental Health: Diagnosis and treatment

6. Addictions and substance abuse
 7. Harm reduction issues
- 1. Health care and self-care and how these related to lack of housing and shelter were common themes.
- Some of the individuals who were trying to get their lives in order and look after themselves independently, found that these undertakings were unachievable without stable housing or accommodation.
 - There were difficulties associated with the use of medication for those who were trying to maintain their health. For those who had no home, it was difficult to keep and carry a number of medications. It was also difficult for those who were trying to be compliant with medication regimes to take medications on a planned regular schedule, when their day-to-day activities were typically unplanned.
- 2. Usage of health care services: Data suggest that non-usage or under-utilization of health care may have been a contributor to death.
- Some reports indicate that homeless individuals accessed medical care sporadically and not necessarily based on urgent needs. Some service providers reported that despite the apparent lack of obstacles, many homeless individuals were not willing to use the services.
 - In some cases individuals in the study refused treatment.
 - In some of the cases studied in this investigation, individuals appeared to be more likely to access medical care services as they became more ill, more symptomatic, and unable to take care of themselves.
 - Further, individuals who understood the certain outcome of illnesses frequently chose to discontinue treatments that may have prolonged life.
 - There is evidence that some individuals may have refused some aspects of care because of self-perceptions of burden to others and unworthiness to receive care. This finding may be linked to many complex psychological and emotional impacts of homelessness and street living and should be studied further.
- 3. Issues of trust: some of the reasons for non-usage and underutilization of health care seem to be linked to the lack of trust in the health care system and its service providers.
- Some people in the investigation would not accept diagnoses, would not take the advice of nurses, and would not consult doctors because they did

not trust them. There were several examples of mistrust of ‘mainstream’ health-care professionals. Some examples of mistrust seem to have been directly related to previous experiences of taking medications and unpleasant side effects. Other reasons for mistrust could not be determined from the evidence.

- The difficulties and complexities of engaging with medical services: the health-care professionals and other service providers that we encountered during the study recognized the difficulties and complexities of engaging with medical services by people who were homeless.
 - Mainstream services were seen to be particularly difficult to access by homeless people. Homeless people felt their appearance and their status of homelessness contributed to negative discriminatory service and treatment.
 - Making an appointment was difficult for some people and thought to be related to mistrust for medical services.
 - Seeing a nurse or a doctor was seen as a difficult step to take and also thought to be related to mistrust for medical services and a reluctance to identify with others who had serious problems. A service provider said, “People don’t want to go because they don’t want to be like the other people in the waiting room.” In some cases of serious illnesses, service providers felt that the person needed to acknowledge and accept the severity of his or her condition before seeing a doctor or a nurse.
 - The ‘pull’ of street life acted in direct competition for health care for some. “Love of drama and risk-taking on the streets doesn’t mix well with medications and side effects.”

“Mental illness changes your life forever. The medications don’t always work.” - relative

- 5. Mental Health: Diagnosis and Treatment: The lack of diagnoses of mental illnesses and failure to get mental health treatment was frequently seen as a longer-term contributor to homelessness and a direct influence on the incidence and progression of social and other health determinants of homelessness.
 - The lack of diagnosis and treatment for some people meant that some of their behaviours excluded them from getting services. For example, some workers would try to offer services, but people would avoid interaction or run away.
 - Shelters for the homeless assisted and accommodated individuals who were mentally ill except when their behaviours were evidently dangerous

to themselves and others. In some cases, the police were called to assist in removing the ill person.

- The refusal of medication was attributed to declining mental health for some individuals in the study. This was frequently seen as a deliberate choice made by the individual. A service provider talking about a client said, “I think if the client had followed medical prescriptions that would have helped {in terms of correcting the illness}. But it was a choice, I think he was exercising a choice there.”
- Many of the respondents attributed the obstacles of obtaining proper mental health care to be a result of deinstitutionalization and an under-resourced hospital and community mental health care system.
- Concurrent disorders of addictions and mental illness were also seen as a long-term contributing factor to homelessness and death.

“There is a real problem with some people with psychiatric disabilities. It is the illness that keeps people from accessing the services they need. With mental illness, a person cannot access help because they can’t make the decisions to go. The illness itself can cause the problem of preventing access.” - service provider.

- 6. Addictions and substance abuse: Addictions were seen as major contributors to people’s deaths.
 - Some people failed to access treatment for addictions and substance abuse when they wanted it and were ready for it, because suitable programs were not available at the time of need.
 - Some individuals did not seek treatment for addictions at any time. “{he/she} never seemed ready for any kind of rehab treatment for {his/her} addiction.
 - Some individuals were reported to have started treatments for addiction and rehabilitation that were never completed and never successful.
 - For some individuals in our study, it appeared that use of alcohol or drugs was directly related to easing conditions of pain.
 - Smoking tobacco was a contributor to serious disease conditions.
- 7. Harm reduction issues: we found that the community, service providers, and clients have varying opinions. Harm reduction programs may be contributors to either prolonging an individual’s life or shortening the life of

an individual depending on the values stance and perspectives of the speaker. One service provider noted that, “Harm reduction is an emotional issue.”

- Many respondents saw that harm reduction enabled an improved quality of life for an individual.
- The managed alcohol program was seen as “a way of keeping those badly off, off of the street.”
- Some respondents opposed harm reduction and saw it as a contributor to a person’s death. For example, it was felt that giving alcohol to someone who had liver disease would seem to be contra-indicated and could have contributed to the exacerbation of a person's condition.
- Respondents who were critical of harm reduction, observed that methods of harm reduction which incorporated an emphasis on abstinence had been abandoned.
- The measurements that are employed to assess the impact of harm reduction programs may indicate medical status but were noted to omit other aspects of a person’s life.

iv) The Influence of relationships

“The Primary need for most individuals is to be loved, accepted and be respected. People are starved for relationships,” (service provider.)

An individual’s ability to connect with others and to form and sustain trusting human relationships seems to be fundamental to maintaining an independent healthy life. For those included in our study, we have been able to gather information about many dimensions of their everyday relationships. These include relationships with service providers, street friends, and family. Three main themes emerged from the data, which can be summarized as follows:

1. The nature of the individual’s personal connections with others based on reports
 2. Evidence regarding the quality of relationships gathered from direct observation
 3. Evidence of profound loss.
- 1. Many similar themes have emerged regarding personal connections with others in the lives of those who have died homeless.
- Many individuals in the study were characterized as being isolated, and/or having superficial relationships. In many cases respondents described

street friends as members of “loose-knit groups of people who hung out together or shared drugs and alcohol.”

- In some instances, acts of aggression such as stealing and physical assaults were described to take place within these groups.
- In several instances, friendships amongst people who were homeless were described as lacking emotional support. This inability to provide support for others was attributed to the hardships of homelessness and the efforts directed towards self-survival on the street.
- Some of the individuals were without relationships with close partners or spouses at any time during their lives. “Never married, did not have many stable or long lasting relationships....because {he/she} focused on drugs.” Others had been married or in long-term relationships in the past.
- It should also be noted that in some of the cases individuals were described to have had close personal relationships at the time of death. These relationships often had negative features including violent behaviour, prostitution, and addictions.
- Many individuals were reported as not having any real friends, never talking about friends including people on the street or family members, and always being on their own.
- Respondents commented repeatedly on the loneliness of many clients. Other people were described as ‘loners’ whether through rejection or from what appeared to be deliberate self-isolation and choice.
- Some poor connections were explained by a person’s mental illness and reclusive behaviours.
- There were also accounts of individuals who had personal characteristics that would not seem to dispose them to loneliness and isolation, but who were still apparently without family and friends. “He was very kind and friendly but seemed to have few close contacts.”
- Some individuals viewed their relationships with service providers as very important.
- Sometimes shelter staff is seen as ‘family.’

“Homeless people have low self-esteem...{we need to be working on} building up relationships and trust so that they understand they are part of this community and have a right to access services.” - service provider.

- 2. Evidence gathered from direct observations.
 - There were records that did not include records of friends or contact persons to be notified in case of death.
 - Service providers and family members were often unable to name friends.
 - There was a lack of records in many cases concerning next-of-kin.
 - There were indications in records or in conversations that there was no longer any contact with family for a number of reasons which sometimes included alienation from the family or the deaths of family members.
 - Some individuals may have noted the names of one or two people in the way of close friends to inform in the case of emergency and death.
 - The memorials and funerals of some individuals were attended by few people other than service providers. “No one mourned him.... He was not friends with anyone. No one called after his death.”

- 3. The **expression of grieving and feelings of loss** from many in the community were recounted.
 - Despite evidence suggesting that relationships on the street may lack supportive dimensions, many surviving people who were homeless experienced profound feelings of loss and grief when others had died.
 - Many service providers related personal grief in reaction to the death of a client. Individuals who passed away were missed, and the city landscapes were described as changed as a result of the death.

These accounts suggest that the number and quality of relationships at different levels and over a lifetime in conjunction with an individual’s sense of self-esteem and self-worth, influence the direction of an individual’s life. They also appear to play a significant role in shaping attitudes towards and access and engagement with services.

Janie was known on the Ottawa streets for many years. She grew up in Ontario in a 'normal' family environment. "We thought she might have had signs of mental illness when she was in her teen years as she got really depressed sometimes but we thought it was just her age," said her mother. "She made it through school although she wasn't a great student. She got pregnant just after high school but didn't want to stay with us, so we kept and eventually adopted the baby. Janie didn't like to come back and visit. She went to Ottawa to go to college but that didn't work at all."

Janie did get admitted to a psychiatric hospital after a couple of years of staying with different friends, and was there for several months. The hospital taught her about how to look after herself and she was in supportive living for a short while after she was discharged. She hated it there and eventually ended up in the market area and also using the women's overflow shelter overnight. Street outreach workers tried to keep an eye out for her because she had days of depression and would disappear and they would be worried about her. Then someone would manage to find her and get her to the doctor and she would seem to be OK.

She was a nice-looking pleasant woman who somehow managed to keep clean and tidy using the drop-in showers and finding clothes. Even though she kept her distance from most people, she would hook up with guys in the bars who she would end up staying with. She used to talk sometimes about how she felt trapped, because if she got somewhere to stay she was always expected to provide sexual favours. She needed glasses which she lost more than once or twice; she probably lost her medication too as she had nowhere to keep it. Her teeth were starting to look bad.

She used drugs and alcohol although she was more of an abuser, not an alcoholic or drug addict. It seemed to help her cope. She smoked cigarettes all the time. Workers tried to get her into some safe housing but she seemed to sabotage any help. She didn't cause any trouble except for not taking the help that she was offered.

She was found passed out on the street and it looked like she might have taken something really bad. We don't know the cause of her death for sure but we heard that she died because a friend saw her being taken off in the ambulance and called on her in the hospital. She was really young - only 30 years old.

Information from mother, friend, outreach worker and other service provider.

In order to protect identity and confidentiality, Janie is a fictional person whose story is reconstructed from the stories of many.

Chapter 4: Preventive Strategies

“Could we have prevented his death? We are dealing with the symptoms but not the root causes. We need to deal with the issues. What can we do to make a change?” (service provider)

One of the questions put to our respondents was whether or not any given death on the street could have been prevented. When people were extremely ill, respondents could not envisage strategies that would have prevented death. Many respondents understood that death was inevitable and the goal was not necessarily to prolong life but to keep the individual comfortable in the remaining days.

Respondents offered more comments regarding strategies that could be used over a longer term. We found that respondents identified contributing factors that were related to the person about whom they were being interviewed, and for the most part discussed preventive strategies applicable to the target case. For example, a respondent may have felt that homelessness and death were, for a given case, a direct result of an individual’s use of alcohol, drugs or the effects of mental illness. Preventing these addictions or illnesses in the first place were generalized strategies. Respondents felt that the provision of shelter, mental health services and addiction and rehabilitation programs were powerful preventive strategies. Few respondents saw homelessness and death as simple problems with simple solutions. We found that there is an implicit assumption by respondents in that ‘a place to call home’ is a basic requirement for good health and social welfare. As a preventive strategy to homelessness, it is the first major step.

Our study has identified potentially significant contributors towards homelessness and death, or at the least, conditions that are evidently closely associated with homelessness and death, such as the paucity or absence of personal relationships. On a more complex level, some respondents felt that the best preventive strategies were those which related to what they saw as the ‘root causes’ or primary contributors to homelessness which were no fault of the individual but brought on by external factors, some of which we have identified when discussing the contributors to homelessness and death.

For this chapter on preventive strategies, we report evidence in three main areas: addressing homelessness and death through the provision of services; the role of service providers as ‘agents’ of preventive strategies; and understanding individual choice in strategies and interventions.

Addressing homelessness and death through the provision of services

The following section outlines areas where respondents identified possible means of intervention and prevention. These areas were divided into distinct categories related

to areas such as basic needs, shelter accommodation, health care, special care and palliative care, and mental health services.

Basic needs

Apart from a place to call home, homeless individuals were generally reported to be able to obtain basic needs in Ottawa. We did not find any evidence of death by starvation or malnutrition, lack of clothing, or exposure. However, many of our respondents mentioned that meeting basic needs was often challenging. Many individuals on the street were said to spend a significant amount of time involved in negotiating basic needs. For example, a person who had been directed toward gaining accommodation in one part of the city, was required to travel to provincial offices daily in another part of the city, needed to acquire daily meals in the inner city area, and travel again to return to the place of accommodation. A service provider reported that, “Access to services are day-to-day challenges. In order to access services you need to get to them. Transportation was a challenge. There have been a lot of cutbacks.... a lot....and we don’t have bus tickets.”

We also found evidence that service providers, especially outreach workers and some health care providers, were actively involved in pursuing basic needs with and on behalf of their clients. Negotiation and advocacy on behalf of clients in accessing basic needs was also reported to be time-consuming for the service providers.

Of marked concern was the evidence provided about the availability of services addressing basic needs for hard-to-serve women. Hard-to-serve women are women who do not conform to shelter or other service rules and regulations for reasons of addictions and possibly other behaviours. For example, in order to stay at the women’s shelter, women have to be sober and not ‘using.’ Another example is that the overflow shelter for women is not open all year round. One service provider asked, “There are huge gaps in the system for women addicts because no one wants them so where do they go? Why doesn’t anything exist for women while for men there are some options?” Many services provided for people who are homeless are not gender specific; however, some respondents gave an impression of inequities in services to women with regard to basic needs.

All groups of respondents recognized the importance of meeting basic needs for the survival of homeless individuals. They identified a need for improvements in access and delivery and felt that service providers needed to reduce the amount of time spent in accessing basic needs for clients. For example, many service providers felt that if there were central coordination of provision of clothing and seasonal supplies, this would be a more efficient way of ensuring provision, would benefit clients, and would result in less time being spent by service providers on acquiring such items.

Shelter accommodation

Some respondents noted that shelter accommodation, which was designed to meet short-term shelter needs often culminated in being a long-term solution to a situation of

homelessness. The longer the period of time individuals were involved in the shelter system, the less likely they were to make a change to other forms of accommodation. Respondents suggested strategies that included ‘hooking up with services’ whilst in the shelter in order that “you may get out.” These services would include such help as accessing housing and other support services. They also reported that the availability of other forms of accommodation particularly supportive housing, which was seen as a preventive strategy for chronic homelessness, were rarely available.

Health care, special care, and palliative care.

Because “the health services are not always there when needed,” and “because the population is transient and people move around a lot,” health care and follow-up were often very difficult to implement. Mainstream health services typically provide a one-size-fits-all approach to health care that does not readily meet the needs of the homeless, the transient, and others who are hard-to-serve.

Some preventive strategies in terms of health care are already addressing these problems. For example, health care is available through a system whereby public health services work on the streets, in close conjunction with the shelters and other community organizations. Public health care and funding in Ottawa also targets ‘special populations’ such as sex trade workers, intravenous drug users, and those with HIV/AIDS and sexually transmitted diseases, some of whom are homeless individuals. Individuals with deteriorating health, and who are homeless or at risk for homelessness, are able to receive special care or palliative care provided through the Inner City Health Project. The Home Hospice, a palliative care program located at the Mission, was highly praised without exception by informants based on the care that was provided to individuals who were dying, and the understanding and acceptance that staff gave to clients in their last days of life.

Informants were in agreement that the provision of these specific services to people who were homeless meant that marginalized individuals received care that they would not have accessed through mainstream services. These directed services and the people that provided them were also reported to provide hope to individuals for a better quality of life.

The effectiveness of these specific health care services as a preventive strategy is dependent on the design, planning and coordination of services, and the location of the delivery of services, in particular “being on the streets.” Service providers recognised the potential of preventive strategies that were founded on the “rapport of health departments, agency and community agencies and the effects of health outreach.”

Mental health services

From the evidence that we received, respondents thought that a person’s poor mental health affected their ability to participate in a ‘typical’ life and everyday adult activities, and may have indirectly contributed to death. Mental health services which

were frequently cited as inadequate were seen by respondents as the poor cousin of health services. In addition, health services in general could not always be utilized effectively by the individual when mental health services were not in place. We also found that, because of the shortage of access to specialist health services, staff applied an unintentional ‘filter’ to available services. Some specialists “tend to see the people that staff are most worried about,” which included people who were deteriorating globally and were increasingly symptomatic. People who were mentally ill were clearly at risk for continuing homelessness and other problems including the limitations of capacity to make self-care and health care decisions.

Some of the preventive strategies offered were improved resourcing of mental health services including more hospital beds, and the development of a form of collaborative care that permits mental health care and physical health care to be addressed concurrently on the street.

Service providers as ‘agents’ of preventive strategies

The homeless population was recognised as a challenging group of people for whom to provide service. Many service providers and family members that took part in the study commented on the importance of the ‘right’ staff and volunteers for the job of working with the homeless. This referred to a specific set of skills that workers brought to the job. For example, these include skills such as the provision of emotional support, knowledge of crisis intervention, and the ability to help forge links between those who are homeless and services in general. In addition, workers’ positive attitudes and empathy for people who are homeless are perhaps their greatest tools for doing “frontline” work.

For reasons that were not always clear from the data gathered in our study, some homeless persons were reluctant to access personal health care and other services. Developing trust was seen by the service provider as a necessity in order to work with homeless individuals. Dedicated service providers often gained trust with an investment of time, sometimes over years. The empathy and understanding of staff and the development of trusting relationships allowed the individual to take up services that he or she may have previously declined.

Service providers themselves recognized that in the provision of services such as health care, gaining access to basic needs, support to solve legal difficulties and in other challenges, there was an overall effect that was greater than helping the individual meet the need or solve the problem at hand. It has been suggested that some individuals who are homeless may lose hope if they are not able to connect with services. One service provider summarized this as, “Involvement in services can provide hope. If people weren’t getting services they might feel different. It’s about the positive....finding the positive.” Outreach workers were also noted to provide support and enablement not only to their clients but also to other workers.

Based on our data, it was notable that service providers played a significant role in the lives of people who were homeless. In addition, they were greatly involved in the provision of emotional support, encouragement, and direction for vulnerable people. We therefore see that service providers are not only agents of delivery of preventive strategies but their involvement is a preventive strategy itself.

Understanding individual choice in strategies and interventions.

We found that many of the identified needs of the individuals who had died were not confined to aspects of daily living and material needs. Some individuals had personal skill deficits in being able to take care of themselves. Perhaps more importantly, other preventive strategies and the predicted success of different interventions appeared to relate directly to individual choice, that is, the individual's desire for change, and the perception of the ability of the individual to choose his or her pathways. One service provider warned however that, "We need to be careful about romanticization, the ideas of people having real choices," because the realities of the lives of homeless individuals impeded an authentic ability to choose.

Trying to remedy a person's situation of homelessness and concomitant conditions such as addictions was never the sole responsibility of the service provider but was ultimately the responsibility of the individual. It was reported that people had to make some commitments to change; they needed to have goals to work towards and they needed to see 'down the road' as well as attending to the immediate satisfaction of needs. At the same time, it was recognized that given such lives of deprivation and few resources that nobody could do this alone, and the support that service providers was a critical piece in rebuilding, recovery, and rehabilitation processes. Support could also be derived, enhanced and/or mediated through a faith perspective, and religious or spiritual beliefs. One volunteer summarized how the individual's self evaluation was a preventive strategy in itself. "Preventing death is beyond disease prevention: it is people knowing how to treasure and honour themselves."

Another experienced observer of street life provided some insights into preventive strategies, "We need to provide safety, from misfits and predators. These are terrifying aspects of our lives. These may include children's own parents. The second thing is we need to provide values, which include things like structure and clarity. Constancy is something. Not giving people such a mix of messages. There is an absence of values or direction for kids. Time and care may be absent from the system." Ensuring the emotional and physical safety of children and adults and the transference of robust values systems are seen as preventive strategies of homelessness and untimely death that require early development and lifelong vigilance.

Chapter 5: Recommendations

Leo Rosten said, “The purpose of life is to matter, to have it make a difference that you have lived at all.” The people that participated in this study participated in the hope that some of the findings would lead to changes and innovations that would contribute to the prevention and reduction of deaths in people who were homeless. In this chapter, we discuss recommendations drawn from conducting the study and other evidence. Our recommendations implicitly support the careful review of the preventive strategies which respondents identified with regard to services and observed needs and prevention of homelessness and deaths in the previous section. (We have discussed in more detail and made recommendations with regard to the research methodology in a separate methodology report.)

Sharing of information about death

We found that organizations were aware of how devastating it can be to receive incorrect information about death. However, discrepancies in reporting in the media and the ‘real’ truth arises from time to time. In all cases of death we believe there is a need to confirm and verify the information.

- We recommend the development of an information-sharing protocol between agencies in order to establish clear standards and procedures to be followed by all agencies in the specific instances of people who were homeless and who died.
- We recommend the establishment of a central means of disseminating information to service providers and friends and acquaintances with regard to deaths of people who are homeless which respects the individual and observes the necessary confidentiality.
- In conjunction with these recommendations, we suggest the availability of a toll free number to allow family members to contact the City’s services for people who are homeless and who have died.

Community Organizations

There are over 40 organizations in Ottawa to our knowledge that are involved in service provision with homeless persons. Some of these organizations appear to be well-connected with each other and workers have opportunities to connect at common venues. However, other organizations do not participate in such activities. The effectiveness of overall service design, provision and delivery of the services including the voluntary sector, is dependent on knowledge, collaboration, and coordination.

- We recommend the mapping of organizations that serve people who are homeless and annual distribution and maintenance of such a map.
- We also encourage the dissemination of this information to all people who are homeless, and workers.

Supporting community organizations and community workers

- Whilst recognising that some coordination roles are supported from some organizations, we recommend an assessment of existing collaborative activities.
- We strongly urge that the City take steps to enable the inclusion of organizations that are not funded by the City in order to help provide a concerted approach to homelessness. This inclusion could incorporate access to training, and employee support activities such as bereavement counselling
- Developing community capacity is a recent concept designed to be of use in maximizing resources and developing what is already there in the community. We recommend care in the adoption of such concepts because they are often viewed as unhelpful when organizations and individuals are considerably over-stretched or have experienced budget and staff losses. The assumption of additional roles, however well-facilitated, has been found to lead to burn-out and consequent losses of developed relationships, trust with vulnerable populations and expertise.

Street Outreach Workers

Our research highlighted the very difficult and specialized work of people who work with homeless people. We found that outreach workers, especially those that are on the street, do difficult work often without significant back-up support. We have observed, and anecdotally have been informed that outreach workers are a ‘stable bunch,’ who are faithful to their work and their clientele. Outreach workers develop trust in their relationships with street people. They keep an eye on the landscape and if a person who is part of the landscape goes missing or needs help, they do their best to ensure that the person is safe and sound.

- We recommend research into the roles, responsibilities, relationships and needs (including training needs) of street outreach workers and the implementation of steps to support them.
- We recommend the provision of grief counselling or similar supports where individuals, whether family members, friends or service providers can talk freely and in confidence about the death of a person close to them.

It is highly evident that a significant direction for the prevention of chronic homelessness should be based around the support that should be provided to the service providers themselves. This includes in part the opportunity for individual service providers to benefit from presentations and the sharing of expertise and information, as some can now in Street Health Coalition and Street Outreach Network meetings.

- We recommend that service providers received increased support in various areas. We also strongly encourage the development and use of structured professional training that promotes for example, skilled helping, understandings and perspectives on complex societal processes, collaboration, conflict resolution and mediation.

Health Services

Health services that are provided specifically with the homeless and other groups considered hard-to-serve and often associated with homelessness, from all accounts provide an exceptional respectful service to people who are homeless. The provision of such services as through the Inner City Health Project and other organizations such as OASIS, appears to have a positive influence on clients' accessing services and taking medication. Programs geared towards prevention, treatment and management of diseases such as HIV/AIDS, Hepatitis B and C are more likely to succeed if they are creative.

- We recommend further research through discussions with all service providers who provide services to those who are homeless concerning the provision of targeted health services and the possible enhancement of such services through creative and collaborative approaches.
- We recommend that health services to people who are homeless obtain the funding required.
- We recommend that wherever feasible, the wishes of a person to die in a place of their choice be accommodated as far as possible.
- We recommend the Special Care Unit and Hospices are supported to facilitate volunteers and others to care for the dying person wherever possible.

Harm Reduction Programs

There appears to be some ambivalence of service providers towards the efficacy of "harm reduction" programs.

- We recommend that there be ongoing evaluation of harm reduction programs. Evaluations should incorporate understandings not only of inputs and outcomes, but also attitudes and experiences with input from all stakeholders, most

importantly including users as well as those people who are potential users of the programs.

Until the lions have their own historians, the history of the hunt will always be from the hunter's perspective. – African Proverb.

Services to Women

As a result of the accounts that were provided to us with regard to gaps in services and instability of shelter and housing for women,

- We recommend a review of the provision, nature and suitability of shelter, housing and other services to homeless women.

Chapter 6 Conclusion

“Homelessness is not just a physical state, it’s a way of being and existing, a way of connecting with the world, and it is multi-faceted. The closer you look the more complicated it becomes.” (expert on homelessness)

In concluding this study, we make some tentative observations concerning homelessness and death. We looked at some people’s entire lives and asked if there were any common pictures of the lives and deaths of these people who were homeless. Not unlike other studies, we found that homelessness is complex. Extreme poverty, poor health, physical disabilities, addictions and mental illness, lack of education and unemployment, are some of the common themes that accompanied the lives of people who were homeless. Although we were only able to collect data that were suggestive of how or why the individuals that we studied became homeless, some of the direct causes of death that could be determined were conditions that are highly correlated with drug-taking, alcohol abuse, specific sexual involvement including involvement in the sex trade, and smoking. All of these constitute lifestyles of risk for high incidence and deaths from associated diseases and conditions. Other deaths did not fit this pattern. Some individuals were not ‘street involved,’ and did not appear to be involved in street ‘subcultures,’ but may have been considered as such because they were homeless.

Our data suggest that chronic homelessness also appears to have some associations with the development of an individual’s sense of self and his or her personal relationships. We see that further work would need to be done on the role of early negative experiences, as a link with urban street living, and as possible instigators of a pathway to homelessness.

We are aware of the dangers in researching and reporting case studies. The methodology used in this study was designed to collect extensive data about broad aspects of the individual’s life and was not problem focused. However, because of some obstacles in collecting data and the nature of the relationships developed by homeless persons, much of our data were collected from individuals who were involved in service provision capacity with the individual. Indeed, some of the people who died were not well known to their families and had superficial friendships on the street. For these reasons, we are aware that the data collected were skewed toward a problem-view of the homeless individual. We, therefore, caution that solely addressing homelessness as an individual or medical problem is insufficient. It is important that a larger perspective be taken to ensure this does not happen. An alternative perspective would suggest that homelessness is a social construct that needs to be addressed at a societal level.

This research study on homelessness and death has given some insights into the personal lives of individuals and the processes that are in place to assist them. In order to address the issues, practical and political, support is needed. At a practical level, the provision of shelter, health services and basic needs and the intercession of service providers offer individuals some connection with society. However, for some we submit

that the disconnection with the mainstream may, regardless of such provisions, have become so great that there is evidence of violent and criminal behaviour, withdrawal, and exclusion. Based on our evidence, providing ‘soft’ supports, that is, moral, emotional, and compassionate and empathic caring, supports which outreach workers and direct-service providers are well-placed to make, means that a connection or reconnection with mainstream society becomes possible. With an understanding of this nature, the will to make sure the conditions of support are in place then becomes a political decision.

Homelessness has been described as “a very fluid social problem.” (Fitzgerald, Mack, & Dail, 2001⁴) From a research perspective, the study of homelessness and death requires a fluid methodology. The data require constant review and preventive strategies require adjustments. But above all, homelessness is about the human beings who were the focus of our study and who lived and died. We have learned that they, too, had visions of their future where they were part of society in every way, especially the unremarkable ways. Individuals had dreams of having a home, being surrounded by loving family, and friends, having a pet, going to restaurants and being treated with respect. Ultimately, such dreams were about the restoration of dignity and hope.

⁴ Fitzgerald, S.F., Shelley, M.C., Dail, P.W. (2001) Research on Homelessness: Sources and Implications of Uncertainty. American Behavioural Scientist, 2001, 45, 1, Sept:121-148.