Factors Affecting Medication Adherence among the Homeless: A Qualitative Study of Patients' Perspectives

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Abstract

Objective: Non-adherence to medication regimens is a major obstacle to the success of medical therapy. The purpose of this study was to examine the factors affecting medication adherence among the homeless population in downtown Toronto.
Design: Qualitative study using semi-structured interviews.
Setting: Interviews were conducted in two community centres in downtown Toronto.
Participants: Of 24 participants, four were staff and 20 were homeless individuals.
Method: Semi-structured interviews targeted factors affecting medication compliance as well as demographic data, income, attitudes towards health and medical needs. Content analysis was used to identify, code and categorize themes in the data.
Findings: A number of barriers to medication adherence were identified among the participants. Those barriers were found to affect three main areas: access to medication, retaining medications and following the treatment regimen.
Conclusion: Due to the diversity of causes of non-adherence, it is of great importance for healthcare professionals to consider cases individually and modify the treatment approach accordingly.

Introduction

Absolute homelessness is used by the United Nations to describe those without any physical shelter. This includes those who sleep in vehicles, parks, abandoned buildings or other places not intended for human habitation.[1] In this study, homelessness refers to those who are absolutely homeless, as well as individuals who sleep at shelters. Shelter capacity is a valuable starting point for estimating the size of the homeless population; however, it leads to an underestimation because it does not include individuals who sleep on the streets. The Toronto Report on Homelessness 2000 reports that shelter capacity in Toronto is approximately 4200 places.[2] The total number of individuals staying in Toronto's emergency shelters rose from 22,000 in 1988 to over 28,800 in 1998, an increase of 33%. The Toronto Homelessness Action Force reports that between 1992 and 1998, shelter use increased by 80% for youths, 78% for single women, 55% for single men and 123% for families. Street patrols also report more people with mental illness and addictions.[2]

Homeless people are generally at a high risk for morbidity and mortality.[1] A study conducted by researchers at the University of Ottawa and Carlton University showed that members of the homeless population in that area had higher rates of chronic conditions.[3] It has also been found that despite their high usage of medical services, many homeless people wait until their medical problems become serious before seeking treatment.[4] Causes of disease severity among the homeless include extreme poverty, delays in seeking care, cognitive impairment and non-adherence to therapy.[1] The latter is the main focus of this study.

As described by Seltzer *et al*, "the achievement of a treatment goal is dependent upon accurate diagnosis, appropriate therapy and adequate compliance."[5] Non-adherence to medication regimens is a major obstacle to the success of therapy. Some of the consequences of non-compliance include increased morbidity, prescribing of additional medications, increased physician visits, hospital admissions and increased cost of health care.[6] As defined by Cameron *et al*, and for the purpose of this study, compliance is "the extent to which a person's behaviour coincides with medical or health advice."[6] Some of the proposed reasons for medication non-compliance include distress from side effects, lack of perceived benefits of the medication, lack of trust in clinician and the denial of having medical needs.[6] Other factors have also been identified to influence compliance. These include psychiatric diagnosis, social instability and chronic illness.[5] There is very little information in the health care literature addressing barriers to treatment adherence among the homeless population in particular. The purpose of this study is to gain insight into the factors leading to treatment non-adherence among members of the homeless population with mental health or physical health needs. This study focuses mainly on the medication aspect of treatment; however, other aspects were commented on as they emerged. Results of the study can be used to educate healthcare professionals who care for homeless people and to develop further research questions.

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Research Methods

Recruitment and Data Collection

All study participants were either homeless at the time of the interview or have previously been homeless, in which case questions focused on that period of time. Recruitment was conducted in the setting of two community centres in downtown Toronto. A total of twenty participant interviews were conducted. Purposeful sampling was used and participants were selected to maximize appropriate information and elicit the richest data relevant to the research question. Moreover, four staff key informant interviews were conducted to gain an understanding of the issue from the providers' perspective. Purposeful sampling of staff was used to maximize diversity. Interviewed staff included hostel, housing and resource centre workers, as well as an individual support worker. Staff interviews provided a source of knowledge of the services available, as well as medication rules in hostel and shared accommodation settings.

Semi-structured face-to-face interviews were used where questions were previously prepared to guide the interview; however, there was flexibility to further explore the interviewee's answers. The questions used were intended to be open-ended, neutral, sensitive and clear to the interviewee. Duration of interviews was approximately 45 minutes. Due to the vulnerability of the population, many being homeless with mental illness, interviews were not tape-recorded; however, thorough field notes were taken during the interviews. Many parts of the conversation were recorded verbatim; where not possible, field notes were used in the analysis.

Analysis

An editing organizing style of analysis was used,[7] where text relevant to the research question was highlighted and categorized and interpretive notes or observations were made.[8,9] Text was analyzed by the investigator using the approach of immersion and crystallization as described by Crabtree and Miller.[7] After completing this initial review, a matrix was constructed to visualize emergent patterns and facilitate comparisons across cases. Emerging themes were then evaluated and discrepancies in interpretation were resolved by returning to the text. An iterative process of collecting and analyzing data was used throughout the study, where analysis was concurrent with data collection and the text was continuously revisited. Validity was addressed at various stages of the analysis through consultation with an interdisciplinary team of advisors that included health professionals, a qualitative research advisor and front line community workers.

This study was approved by the Research Ethics Board of the Centre of Addiction and Mental Health.

Results

The average age of participants in the study was 45 years with a range of 30 to 62 years. When asked about location of sleep, 12 individuals reported either spending nights on the street or at shelters; the remaining eight individuals reported currently residing in subsidized shared accommodations, with previous stays within the shelter system. Reported places for obtaining meals, clothing and personal items included shelters, drop-in centres and churches. Ten of the twenty participants were asked about their last completed level of education: nine of them indicated it was between grades 8 and 12, while one individual reported dropping out of first year college due to a diagnosis of schizophrenia. The previous information provided a framework for understanding the socio-economic status of participants in the study, as well as their sources of essentials such as food and clothing.

Alcohol and drug addiction were the most commonly identified personal routes into homelessness, as reported by the participants. Other identified routes included gambling, abusive situation, relationship breakdown, injury, loss of a job and mental illness. A variety of medical problems were indicated by participants in the study, including anaemia, asthma, hypertension, diabetes, chronic back pain, arthritis, ulcers, deep vein thrombosis and high cholesterol. Mental illness was reported by seven of the 20 participants. Specific conditions included anxiety, schizophrenia, depression and borderline personality disorder. This demonstrates the diversity of medical needs present among participants. When asked about the location where participants seek medical attention, only one individual indicated having a family physician. Others reported seeking medical attention at walk-in clinics, a local hospital's Emergency Department and at a local health bus. One of the main concerns raised by this pattern is the lack of continuity of care received by patients when they frequent an emergency department, for example, as opposed to a regular physician.

The medication-taking process can be divided into three stages: access to medications, retaining medications and compliance with the prescribed regimen. These stages are interrelated in that the latter cannot be achieved unless the former two stages are accomplished. Unless barriers to obtaining and retaining the medications are resolved, efforts aimed at increasing compliance with the regimen are futile. Themes emerging from the study shed light on barriers to medication adherence at each of these three stages (Table 1).

Table 1. Themes of Barriers Sorted by the Stage of the Medication-taking Process

Stage Affected	Barriers
↓	
Accessing Medication	Financial System-related Social Isolation
↓	
Retaining Medication	Erratic Lifestyle Stolen Medications Financial (Selling Medications)
↓	
Following Regimen	Alcohol and Drug dependency Inability to follow directions Mental Illness Lifestyle Factors
↓	
Low priority of health	

Access to Medications

Factors affecting access to medications included financial barriers, system-related barriers, as well as social isolation. Seventeen of the twenty participants had some form of a drug card. However, since the dispensing fee charged at pharmacies presents a financial obstacle, individuals indicated the need to fill prescriptions at pharmacies that waive the fee. Many patients expressed the need for physicians to be aware of their financial situation. When a patient is prescribed a medication beyond their drug coverage or their financial capacity, the success of treatment becomes a factor of combined effort to find alternatives. For patients with no drug coverage, system-related barriers come into play.

A theme emerging from staff interviews was the challenge to homeless individuals of mobilizing the system to meet their healthcare needs. Such challenges may include pursuing a source of drug coverage or seeking healthcare professionals. When faced with obstacles in their interactions with the healthcare system, many feel frustration or inadequacy to continue pursuing services. Social support is important especially in individuals who are unable to manage their own medications. Interviewed staff expressed a concern due to the lack of a support network for many of the homeless. Preventing social isolation and providing treatment monitoring where needed may be necessary to insure a homeless patient's access to services (Table 2).

Table 2. Barriers to Accessing Medications

a) Financial
A 62-year-old female described having been prescribed eye drops that exceeded her financial capacity and was not covered, which prevented her from filling the prescription. She said "I went back to the doctor after 6 weeks for the next appointment. I didn't tell him that I didn't buy it. He just thought it didn't work"

b) System-related
A patient without any drug coverage expressed frustration with the length of the process of calling the Emergency Drug Card Line in order to cover a prescription for his psychiatric illness. He explained "it can take days to weeks to get a prescription filled and covered. Then I ask myself, do I want to take this stuff?" He concluded by indicating that he did not fill that prescription

c) Social Isolation
A special needs patient who has been repeatedly hospitalized for poorly controlled diabetes explained that she had not taken her medication for the past three months. The patient described having difficulty moving around due to leg pain and therefore neither renewing her health card nor seeing a physician for many months. She had no social contacts and did not have a regular physician. She was noted by the investigator to be unable to manage her medication and in need of monitoring.

Retaining Medications

One of the barriers identified to retaining medications was moving from one hostel to another, while leaving medications behind. The hostel worker interviewed, as well as a number of participants, felt that this situation commonly occurred. Medication theft represents another obstacle to retaining medications. The resource centre staff member interviewed expressed a concern regarding the frequency of medication theft. She explained her need to advise individuals to take their medications in private. Six participants indicated having their medications stolen in the past. Some of the stolen medications as reported by the participants included Percocet, benzodiazepines, Prozac and inhaler (which, as indicated by participants, are commonly used as crack pipes). A patient whose medication has been stolen may face difficulty in replacing it due to an inability to prove their credibility. A number of patients indicated feeling that their homeless status led to their integrity being questioned and therefore being denied replacement medications when the original had been stolen. Physicians need to be aware of the risk of medication theft in order to work with their patients on preventing it.

Selling medication was a theme commonly identified by participants as well as the individual support worker. Two of the participants explained that they have sold their medications when short for money in the past (See Table 3).

Table 3. Barriers to Retaining Medications

a) Erratic lifestyle
The interviewed hostel worker explained, "Leaving meds behind is very common. We can call shelters in the city and leave a message saying the person left medications here, but how can we know where he is, and it is also confidential." She clarified that due to confidentiality issues, the only option is for the individuals to return and pick up their medications in person.

b) Stolen Medications
A 37-year-old patient whose anti-depressant medication was stolen described his experience of being denied replacement by healthcare professionals saying, "When you are homeless, they don't buy your story." The patient resorted to buying the medication off the street.

c) Financial (Selling Medications)
A patient who sleeps in shelters and parks indicated that he has sold his medication in the past in order to obtain "bus money and cigarettes." He added that he sometimes used this money to buy alcohol. The Individual Support Worker interviewed indicated; "It is common to triple or quadruple doctors to get scripts and sell them. Almost anything has a price on the street."

Table 4. Barriers to Following the Medication Regimen

a) Alcohol and Drug dependency
A patient noted its effect on medication adherence by saying "When I go gambling or take drugs, I won't go back to take my meds." Another participant noted that because of his awareness of the interaction between alcohol and his prescription medications, he chooses to drink and not take the medications

b) Inability to follow directions
A currently housed, but previously homeless, patient expressed his past difficulties saying, "If I have to take [the medication] with food, first I have to find a place to eat." He clarified that while homeless, he relied on meals provided in hostels and churches.

c) Mental Illness
Staff expressed concern that mental illness is common and shows as denial to need for treatment. A staff member explained, "the condition worsens, once they stop the medication, and then you can't reason with them." A community center staff added, "I see the sequel of not taking meds in their behavior … a change in their eyes, the way they say things, the way they act or react to other people."

d) Lifestyle factors – Unstable residence
A 46-year-old patient who is on long term Coumadin treatment described having to devise creative methods to keep in constant contact with the healthcare team as required for his treatment monitoring. He said " Every Monday I have blood test. They call the drop-in center with the results. I get it from there… Then, I go to the hostel to take [the medication]. I tell them the changes if any."

e) Low priority of health
When asked about the importance of health to him, a patient responded, "Health is not important to me. Money is more important. I generally don't have any. Food too." He added, "I put health at a lower priority, I'd wait for a week, if I feel bad still, I will go see a nurse. I usually try to let it pass."

Following Regimen

Barriers to following a medication regimen among participants included fear of dependency and distress due to side effects, particularly in relation to psychiatric medications. Alcohol and drug abuse are not uncommon among the homeless.[10-15] Alcohol and

drug dependencies were also identified as barriers to following medical regimens among a number of participants. Other challenges to adherence included difficulty following directions, such as taking the medication with food. Also, an individual's inability to manage his/her own medication schedule can be due to mental illness, which was a concern expressed by staff of the subsidized housing facility. Lifestyle factors such as having an unstable location of residence can become an obstacle to keeping contact between health professionals and the patient with respect to their treatment. Participants identified placing health at a low priority as a barrier to both access and adherence to medications. A number of those who identified health to be at a low priority also demonstrated a willingness to wait for a period of time before seeking medical attention.

Related Areas of Care

Among the advantages of conducting a qualitative study is the ability to explore areas related to the research question as they arise. Throughout the interviews, two areas of need (diet and dental care) appeared to have an important effect on the health of the population of interest. Diet modification is an important strategy for disease prevention that physicians advise in many situations. However, when the sources of meals are hostels and drop-in centres, as is the case with members of the homeless population, an individual may not be able to follow the recommended diet. Two participants, one with diabetes and another with high cholesterol, expressed their inability to follow the diet recommended by their physician. One of the patients explained *"you can't eat the right thing when you don't have the money"*.

The need for dental care was also a recurrent theme throughout the interviews. A patient on methadone treatment said, *"Methadone rots my teeth, but I can't afford to go [to the dentist]"*. Another patient explained, *"I have eight [teeth] at the bottom and nothing at the top [… I] can't chew."* These situations clearly influence a person's ability to maintain a healthy diet.

Study Limitations

Gathering qualitative accounts from members of the homeless population was valuable in identifying key issues that can guide future initiatives. Qualitative content analysis allowed for gaining an understanding of the context relevant to the issue of interest. Content analysis is limited by language factors as used in the presented questions and the participants' answers. While it is not clear how representative the sample was of all homeless people, the themes and key findings of this work likely apply to many Canadian settings.

Conclusion

The homeless population is one with unique needs, as homelessness has major effects on all aspects of the individual's life. Some of the challenges faced by homeless individuals include extreme poverty, erratic lifestyle and lack of access to necessities such as food, shelter and healthcare. Interviewing both staff and homeless individuals provided a better understanding of the issue by examining both perspectives.

The study indicated the presence of a variety of barriers to medication adherence among the homeless population affecting different stages of the medication-taking process. A number of recommendations can be made to increase levels of medication compliance among members of the homeless population. Difficulties accessing medication were due to system barriers such as drug coverage, deductibles and transportation. Policy-makers need to attend to these issues if they wish to reduce healthcare costs for homeless individuals. Improving medication retention involves coordination between shelters, pharmacists and physicians. Safe storage of medications at shelters and flexibility in refilling non-narcotic non-benzodiazepine prescriptions that have been lost or stolen could be of benefit. Following the medication regimen is difficult and problematic, even in the non-homeless population.[16] Regular monitoring of compliance is needed, especially for individuals unable to manage their own medications. A therapeutic patient-provider relationship is important, along with effective communication. Moreover, outreach support and individualized comprehensive services may enhance levels of adherence to treatment. Enlisting the assistance of shelter workers and the use of blister packs, dispensed at frequent intervals, may help to improve a homeless person's ability to follow the treatment regimen. The study further suggests a need for dental care services among members of the homeless population. Also, facilitating access to necessities, such as foods that are consistent with a healthy recommended diet, may be of benefit.

Findings in similar research areas can be used to educate practitioners who provide health care to the homeless population. It is of major importance for healthcare professionals to consider the psychosocial variables that affect the patient's compliance when prescribing therapy. Due to the diversity of causes of non-adherence, it is necessary to consider cases individually and modify the treatment approach accordingly.

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