
“Alive and Healthy”¹

CAREAssist 2006

Client Satisfaction Survey

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¹ Comment from a survey respondent when asked “What do you especially like about CAREAssist?”

Table of Contents

EXECUTIVE SUMMARY	2
Background	2
Methods.....	2
Key Findings.....	2
Conclusion.....	4
INTRODUCTION.....	5
Purpose	5
Evaluators	5
Previous Surveys.....	5
Key Questions	5
METHODS	6
Survey Development	6
Confidentiality Measures	7
Survey Distribution	7
Data Cleaning.....	7
Analysis Strategy.....	8
FINDINGS	9
Background Characteristics.....	9
Response Rate.....	9
Quality and Satisfaction with CAREAssist Services	10
"Don't change anything." Open-ended Questions about Client Satisfaction.....	12
Referral to Outside Services.....	15
Perceived Quality of Medical Care	15

Cigarette Smoking Among CAREAssist Clients	15
Comparison to Previous Surveys	17
DISCUSSION AND RECOMMENDATIONS.....	21
Overall Quality of CAREAssist	21
Number of Contacts.....	21
Clients' Satisfaction with CAREAssist Service Elements.....	21
What is Especially Liked About CAREAssist.....	22
Changing One Thing About CAREAssist.....	23
Quality of Medical Care	23
Cigarette Smoking Among CAREAssist Clients	23
Conclusion.....	24
ACKNOWLEDGEMENTS.....	25

List of Tables

Table 1: Comparison of Survey Distribution Methods.....	17
Table 2: Types of Agencies Clients Referred to by CAREAssist Staff	19

List of Figures

Figure 1: Client Satisfaction with Service Elements.....	11
Figure 2: Cigarette Smoking among CAREAssist Clients.....	16
Figure 3: Number of Contacts with CAREAssist Staff.....	18
Figure 4: Clients Reporting Referral for Non-CAREAssist Services	19

Appendices:

APPENDIX A: Survey Instruments

APPENDIX B: Response Frequencies

APPENDIX C: Demographic Frequencies

APPENDIX D: Survey Response Comparison

CAREAssist 2006, Client Satisfaction Survey

Background

In 2006, Program Design and Evaluation Services (PDES) designed and implemented the CAREAssist Client Satisfaction survey to answer the following questions:

- Are CAREAssist clients satisfied with the program elements and customer service?
- How does satisfaction vary by demographic characteristics?
- Do CAREAssist clients perceive themselves as receiving high quality medical care?
- Has client satisfaction changed over time?
- Does the number of program contacts vary over time and by demographic characteristics?
- What are the tobacco smoking characteristics of CAREAssist clients and how do they compare with statewide smoking patterns?

Methods

PDES staff reviewed the CAREAssist surveys used in 2005 and 2004. To maintain continuity and enable comparison with previous years' results, the format and content of questions related to client satisfaction, frequency of program contact, referral, and quality of medical care were retained. Extensive changes were made to the cover letter and design of the survey in order to maximize client response.

This year, at the request of CAREAssist administrators, questions about cigarette smoking were included. PDES staff consulted with local experts on tobacco control evaluation, so that questions were consistent with those asked on statewide surveys to facilitate comparison of results. Questions about demographics (except level of education) were not included as these were supplied by CAREAssist administrators. One question was added about client attitude regarding the monetary incentive included in the survey.

Key Findings

Background Characteristics

As in previous surveys, respondents were primarily Caucasian (85%), male (89%) and between the ages of 26 and 55 (83%) with a mean age of 46. Sixteen percent were Hispanic, and 9% were Spanish speakers. The majority of respondents lived within the Portland metropolitan area (71%)

and had some college education (61%). Most clients were insured through either OMIP (37%) or Medicare (38%).

Response Rate

The response rate for the 2006 survey (60%) was remarkably higher than previous surveys. This is most likely because of four key elements: monetary incentive, targeted mailing to non-responders, survey design, and mailing in client's preferred language.

Overall Client Satisfaction with CAREAssist

As in previous years, respondents to the 2006 survey gave high ratings to the CAREAssist program for overall quality, with 93% rating the quality as excellent or good. When asked "If you could change one thing about CAREAssist, what would it be?" most either skipped the question (27%) or responded with "Don't change a thing!" (32%).

Number of Program Contacts

The number of contacts with program staff reported by clients has declined steadily over time. For example the percentage of clients reporting no contact in the past 12 months has risen from 2% in 2002 to 25% in 2006. In the 2006 survey race was the only characteristic significantly associated with number of contacts with people of color reporting significantly fewer contacts than Whites.

Client Recommendations for Change

Though overall satisfaction is high, a significant number of respondents made specific recommendations for improving the program, including refining the paperwork process, quicker follow up on requests, billing processes, quicker pharmacy turnaround, and expansion of the program.

Referral to Other Services

Thirty-four percent of respondents needing a service not provided by CAREAssist were given a referral for outside services. This continues a trend of declining rate of referral as seen in previous years' surveys.

Quality of Medical Care

As in previous years, respondents continued to rate the quality of their medical care as excellent or good.

Cigarette Smoking Among CAREAssist Clients

Current smoking prevalence among CAREAssist clients is much higher (42%) than among Oregon residents overall (19%). However, CAREAssist clients appear to be ready for change as reflected in the high proportion seriously considering quitting within the next month (47%) and their willingness to use free nicotine replacement therapy (83%).

Conclusion

Overall, the CAREAssist program is very well received by clients. Clients often expressed their gratitude for the program and staff with great emotion. Clients also recognize the improvements in the program made by CAREAssist administrators and staff.

Based on client feedback, efforts to improve the program should focus on: (1) improving dissemination of the web-site and brochure, (2) prompter response and follow up on client requests, (3) improved pharmacy turnaround time, (4) smoother, perhaps more direct, billing processes, (5) tracking and possibly increased referral for services not available through CAREAssist, (6) increased automation of the renewal process, and (7) intervention with smoking clients ready to quit.

INTRODUCTION

Purpose

In 2006, the HIV Care Services Section of the HIV/STD/TB (HST) Program of the Oregon Department of Human Services contracted with Program Design and Evaluation Services (PDES) to conduct a survey about clients' satisfaction with Oregon's CAREAssist program, perceptions of the quality of medical care they receive from providers, and cigarette smoking.

Evaluators

PDES is an interdisciplinary, inter-agency evaluation and research unit, jointly established by Multnomah County Health Department (MCHD) and the Oregon Department of Human Services (DHS), Health Services. The mission of PDES is to design public health interventions through employing empirical research, behavioral science, and formative evaluations; evaluate public health programs and disseminate results through technical reports and publications; consult with programs within MCHD and DHS Health Services to provide technical assistance for program design and evaluation; collaborate with external agencies in the design and evaluation of public health programs; and develop funding for new programs, studies, and program evaluations through federal, state, local, and foundation sources.

Previous Surveys

Client satisfaction surveys were conducted in 1999, 2002, 2003, 2004, and 2005 for the CAREAssist program or its predecessor program, ADAP/CHIP. The Data and Analysis unit of HST conducted these surveys with the exception of the 2004 survey, which was conducted by PDES. The 2006 survey asked similar questions to the prior surveys in order to assess trends in client satisfaction and perception of quality of medical care over time.

Key Questions

This survey was designed to answer the following questions:

- Are CAREAssist clients satisfied with the program elements and customer service?
- How does satisfaction vary by demographic characteristics?
- Do CAREAssist clients perceive themselves as receiving high quality medical care?
- Has client satisfaction changed over time?

- Does the number of program contacts vary over time and by demographic characteristics?
- What are the tobacco smoking characteristics of CAREAssist clients and how do they compare with statewide smoking patterns?

METHODS

Survey Development

Consistent with previous years' surveys, PDES staff determined that the best data collection method was a self-administered survey. A departure from previous years' approach was that the survey was confidential but not anonymous. This allowed us to both send surveys in the clients preferred language (English or Spanish) and distribute a second targeted mailing to non-responders, both of which were critical for achieving a good response rate. PDES staff reviewed surveys and reports from the 2004 and 2005 CAREAssist surveys to determine possible modifications of the survey.

PDES staff made extensive changes to the cover letter and overall look of the survey in an attempt to maximize readability and response rate (see Appendix A for cover letter and survey versions).

So that comparison could be made with previous years' results, we kept the questions and response categories for items related to client satisfaction and utilization of the CAREAssist program, as well as for questions related to client perception of quality of medical care received. With the exception of educational level, questions about demographic characteristics were removed because these data were provided by CAREAssist administrators. A new question about client perception of the incentive was included. PDES staff consulted with the manager of the HIV Client Services program to determine new areas for evaluation and program-related events since the 2005 survey, and decided to include questions about cigarette smoking because clients have requested reimbursement for smoking cessation materials and services (nicotine replacement therapy) that are not currently covered by the program. PDES staff consulted with local tobacco program evaluation experts, so that questions were consistent with tobacco questions asked on statewide surveys to facilitate comparison of results. We also included a description of the Oregon Quit Line and the toll-free quit line number in the survey.

A native Spanish speaking PDES staff translated the survey into Spanish. PDES contracted with a Spanish translator to back translate the survey into English. Inconsistencies between the English and back translated version were reconciled with the native Spanish-speaking translator. The design of the survey questions and responses for the English and Spanish version was identical with the exception of question four, which asks about client satisfaction with specific program elements. In the English version, this question is presented as a matrix, in which clients are asked to rate (using columns) the quality of individual CAREAssist products or qualities (listed in rows) by making a single check mark in the corresponding empty cell beneath the appropriate column heading. Our experience with previous self-administered surveys of Spanish-speaking people indicates that this format does not work well for them—many Spanish-speaking respondents will circle the heading of

the column rather than making a check in the empty cell beneath it, thus leaving many blank cells. To address this problem, the cells of the Spanish language version were pre-filled with the ratings that also appear at the column head (Appendix A). Clients were then asked to circle the response that best matched their experience.

Confidentiality Measures

All client data provided by CAREAssist (name, address, demographic information) was imported into a Statistical Package for the Social Sciences (SPSS) database for analysis. Each client was assigned a unique identifier (four digit number) not associated with any identifying characteristic of the client. All other identifiers (name, address, CAREAssist ID number) were stripped from the file. All survey data were entered into this data-file and stored on a limited access secure driver.

All surveys are kept in a locked file cabinet separate from the key linking name with survey identifier.

Survey Distribution

The survey was mailed to all 1,335 CAREAssist clients considered active in the program as of October 1, 2006. PDES staff mailed 1,221 English and 114 Spanish versions of the survey on November 1st, 2006.

All versions of the survey were sent in a standard 9” by 12” manila envelope in which PDES security/privacy business return envelope was enclosed. All return address labels were pre-printed with “CA” and the PDES mail stop code as this preserved client confidentiality and clients are used to getting mail from the CAREAssist program addressed this way. Manila envelopes were chosen as it seemed that less “junk” mail comes in manila envelopes. The envelopes were hand stamped with a neutral but pleasant postage stamp.

The first mailing was a color version on high quality paper and a two dollar bill was glued to the front page of the survey. A second survey was mailed to non-responders at the end of November. The second survey was a black and white version on standard office paper with no incentive.

All surveys returned by March 2nd, 2007 were included in the analysis. Three surveys were received after that date.

Data Cleaning

Two steps were taken to assure high quality data. First, all entered data were cleaned by examining for extraneous and extreme values, comparing with the original data in the surveys, and correcting any mistakes in the database. Second, to check data entry accuracy, a random sample of 10% of the surveys was compared item by item to their corresponding entry in the database. Data entry was 99.8% accurate.

Analysis Strategy

We first describe how respondents answered the survey. For certain key outcomes, such as response rate, overall perceived quality of CAREAssist, number of reported program contacts, and cigarette smoking, we examined differences across a number of demographic characteristics, such as gender, region (Portland metropolitan vs. balance of state), length of time in program, age, race/ethnicity, education, acculturation and level of contact with CAREAssist.

For these analyses, we compared means across subgroups using t-tests, and proportions across subgroups using either Pearson Chi-square tests or Fisher's Exact test when there were few participants. To examine relationships between a key outcome and various demographic characteristics simultaneously, we used regression models. We used significance level (p) of 0.05 for all analyses. All quantitative analyses were conducted with SPSS version 15.0.0.

Analyses were conducted on non-missing and valid or applicable responses. If a respondent checked "not applicable" for a particular survey item or left it blank, this response was not included in the analysis for that item.

We analyzed open-ended questions using an open coding methodology in which themes were not identified *a priori*, but, instead were allowed to emerge from the responses themselves. Initially, we examined all responses, identified discrete categories and coded each response. A second analyst used the coding categories to code all responses, refining and confirming the initially identified categories in the process. Both coders met and discussed themes arising from among the relationships of categories. Each response was allowed as many codes as needed to identify all the discrete dimensions present, therefore the number of responses among categories does not necessarily represent the number of respondents.

FINDINGS

Background Characteristics

This section describes the demographic characteristics of the survey respondents. A complete listing of the frequencies of demographic characteristics is presented in Appendix C.

CAREAssist administration provided demographic information for all clients including gender, race, age, ethnicity, region, preferred language, and insurance type. Respondents were primarily male (87%), Caucasian (85%), living in the Portland metropolitan area (71%), and between the ages of 26 and 55 (83%). Sixteen percent were Hispanic, and 9% were Spanish-speaking. Most of the respondents were non-Hispanic (84%). After Caucasians, African Americans (6%) and those considering themselves to be multi-racial (7%) accounted for the largest racial groupings. Most respondents were insured through either Medicare (37%) or OMIP (36%). Sixty-one percent reported having at least some college education. These proportions are similar to those seen in previous years' surveys (see Appendix D).

Response Rate

Of the 1,335 surveys mailed, 40 were returned as undeliverable (moved, undeliverable as addressed), while another five were returned because the client had died. Seven hundred and forty-eight (748) surveys were returned for an overall response rate of 60% (748/1,290). Seventy-two percent of the returned surveys were received within 30 days of the first mailing, and prior to the second mailing. Ninety-four percent of the returned surveys were received within 30 days after the second mailing (60 days after the initial mailing).

Available demographic data were used to compare responders of the survey to non-responders. Those who responded to the survey were slightly older (mean age = 46) than those who did not respond to the survey (mean age = 42, $p < 0.001$). Type of insurance was also associated with whether a client responded to the survey, with those who had Medicare more likely to respond than those with other types of insurance ($p < 0.001$). Responders and non-responders were not significantly different with respect to any other demographic characteristic including, language, ethnicity, race, gender and residence inside or outside of the Portland metropolitan area.

Quality and Satisfaction with CAREAssist Services

Overall Satisfaction

As in previous years, respondents gave high marks to the overall quality of CAREAssist services, with 93% indicating that quality was excellent or good. Overall satisfaction was not significantly associated with any of the demographic characteristics or the reported number of contacts with the CAREAssist program. Overall satisfaction was associated with the type of service received with those receiving assistance with “other co-pays” ($p = 0.02$) and insurance premiums ($p = 0.05$) more likely to report being satisfied.

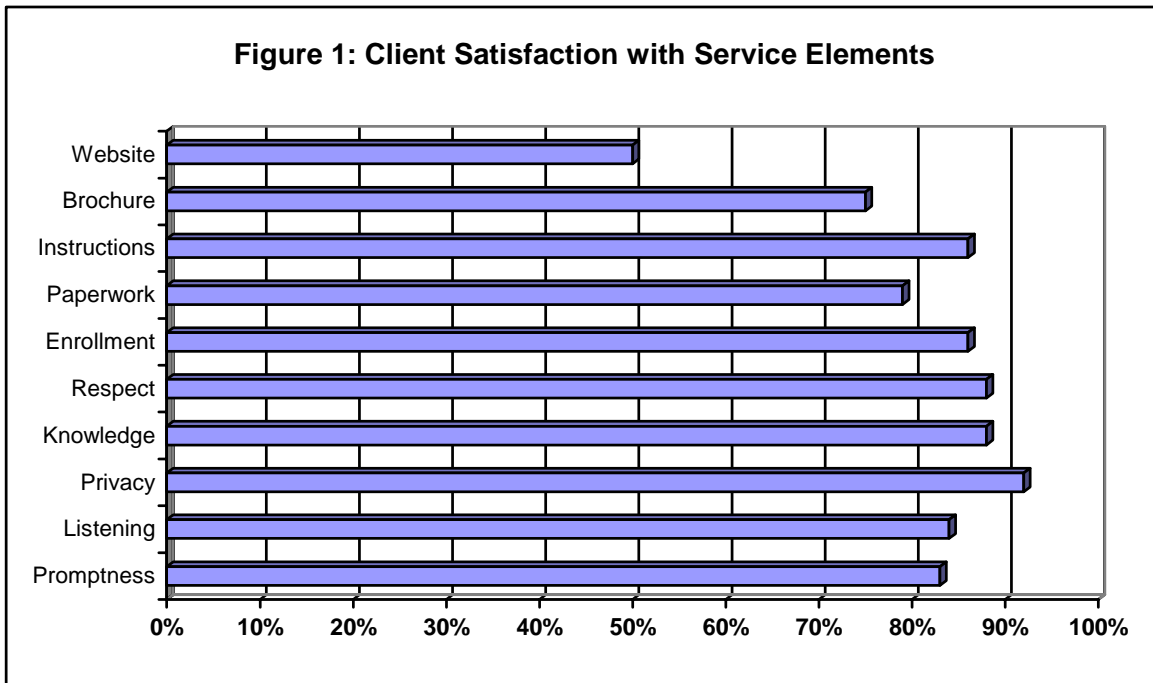
Number of Contacts

Compared to previous years' reports, respondents reported fewer contacts with CAREAssist staff. Twenty-five percent reported no contact in the previous 12 months, 43% reported one to two contacts, and 25% indicated they had three to six contacts with program staff. Being younger, a race other than White, Spanish-speaking, or living in the EMA were significantly associated with fewer contacts. In addition, type of insurance was significantly associated with number of contacts. Those with COBRA had the most contacts, while those with OHP or OMIP had the fewest. When we examined the relationships between number of contacts and these demographic characteristics simultaneously,² we needed to exclude respondents covered by COBRA, OHP, and the VA because of the small number of respondents with these insurance types. In these analyses, race was the only characteristic significantly associated with number of contacts: people of color were significantly more likely to have no contacts with CAREAssist staff than White clients, even after adjusting for the other demographics characteristics. Unfortunately, we were not able to obtain reliable estimates of the associations between number of contacts and each racial minority group separately because of the small number of participants in these groups.

Satisfaction with CAREAssist Service Elements

Every service category except one received at least a 75% satisfaction rating by respondents (see figure 1). In the survey, respondents were asked how satisfied they were with different aspects and elements of CAREAssist services, by selecting one among the following categories: very satisfied, somewhat satisfied, neither satisfied nor dissatisfied, somewhat dissatisfied, and very dissatisfied. In reporting rates of satisfaction, we have pooled the “very satisfied” and “somewhat satisfied” categories. The rates reported are of actual responses (i.e., “missing” values have been excluded from the calculation for the rate.) For all service elements and categories with the exception of the CAREAssist brochure and website, the rate of respondents who skipped the question is less than 5 percent.

² multinomial regression models



Categories related to direct staff contact all received very high approval ratings. Eighty-eight percent of respondents reported being satisfied with the respect and care given by staff as well as the professional knowledge and competence of staff. Over 84% reported being satisfied with the ability of staff to listen and understand their problems. And 83% indicated that they were satisfied with staff's promptness in responding to queries. Ninety-two percent of respondents reported being satisfied with the level of privacy provided with services.

Similarly, respondents were satisfied with the enrollment process, written instructions and amount of paperwork involved with CAREAssist services. Eighty-six percent reported being satisfied with the enrollment process. The same proportion (86%) reported being satisfied with the written instructions on the CAREAssist forms. Seventy-nine percent of respondents were satisfied with amount of paperwork.

The categories receiving the lowest satisfaction rates were the CAREAssist brochure and website with 75% and 50%, respectively, reporting that they were satisfied with these products. We are not confident that these proportions reflect the opinion of all survey respondents, because the rate of respondents who skipped these questions was much higher than for other questions--10% of respondents skipped the brochure question and 21% skipped the website question, while fewer than 5% skipped any other question.

“Don’t change anything.” & “[Change] all of it.” –Two open-ended questions about client satisfaction.

What do you especially like about CAREAssist?

Following the lead of previous surveys, this year’s survey asked clients two open-ended questions about satisfaction meant to elicit the broadest possible range of response (questions five and six, respectively): “What do you especially like about CAREAssist?” and “If you could change one thing about CAREAssist, what would it be?”

Over six hundred clients (n = 623) responded to the question “What do you especially like about CAREAssist?” There were four major categories of responses identified: Help (n = 526), Customer service (n = 217), Paperwork/process (n = 34) and Everything (n = 38).

“The help when I had no hope in sight.” The concept Help was identified by over 500 respondents reporting that what they especially liked about CAREAssist was some kind of help that they were getting from the program. Within the Help category, six dimensions emerged: Unspecified Help, Financial Help, Medication Help, Healthcare Help, Insurance Premium Help, and Provider Co-pay Help.

Of the six dimensions within the Help category, the largest was Unspecified Help with comments that CAREAssist just “helped” in a general but important way (n = 167). Clients said things like, “I am satisfied with all the help you provide me. Thanks to you I have been taking my treatment well, and I feel happy. Thanks to you it is almost as if I wasn't sick.”

In the Financial Help dimension there were 54 responses to the effect that the “financial help” was what was most appreciated, clients responding with comments like, “They lift the financial burden of healthcare.”

There were 120 responses regarding help with medication (Medication Help), saying things like “They help cover the cost of my meds.” Many respondents in the Healthcare Help dimension (n = 107) reporting that what they liked was some kind of “assistance with my health care,” “co-pays,” “coverage,” or having a “medical safety net.” There were 70 responses in Insurance Premium Help dimension reporting that help paying insurance premiums was the service clients liked most with clients reporting simply, “They pay my insurance.” A few responses (8) identified provider co-pays as the most valued service.

“The people! They listen and understand...” Respondents identified customer service as being part of what they most liked about CAREAssist (n = 91) saying they liked the “prompt service,” “follow up,” “Attention paid to and effort applied to assist in resolving co-pay issues” and “great customer service.” Even more comments were made about the positive staff attitude (n = 126): “Everyone I have come into contact with epitomizes the Care in CAREAssist.” and “I feel that I am more than just a number, I feel they do care.”

“Everyone I have come into contact with epitomizes the Care in CAREAssist.”

Several responses (n = 34) praised the program's efficiency, ease of use and paperwork. For example on client said, "How easy it is to use CAREAssist." Other clients reported that they liked "The easy application and renewal process." and "Less paperwork." Several clients (n = 34) responded with great enthusiasm that what they liked most about CAREAssist was, "The whole program!" and "The fact that it exists!"

"Without this I would not be living." A theme (n = 68) that ran through most of the categories, was a sense of relief, stress reduction or appreciation for being alive because of CAREAssist's services. Clients clearly valued customer service, or the financial help, but they also indicated that because of the service or the manner, in which it was delivered, they felt relief or tremendous gratitude, making comments like, "CA saved my life, I could not have paid for prescriptions/health premiums by myself." Another client said, "I appreciate it so much. It's a big relief to have it. The people I deal with are accessible, friendly, and helpful when needed." One client poignantly summed up the feeling with "That [CAREAssist] gives me the opportunity to live a life without thinking that I will die soon, and thanks to that I can move on."

Another theme that ran through some of the categories was the sense that the help received (financial, insurance premiums) enabled clients to afford the basics like food. Some made comments like "...with your financial help I can make my money stretch out so I can eat everyday." Another client said, "The payment of my premium allows me to have money to buy food each month."

If you could change one thing about CAREAssist, what would it be?

"Change nothing--hope and pray they will always be as nice as they are." Of the 545 clients who responded to the question "If you could change one thing about CAREAssist, what would it be?" 238 (44%) responded with comments like "Don't change anything." and "Change nothing--hope and pray they will always be as nice as they are." or "Make them clone themselves for other health service [departments] I HAVE to use." The comments of the remaining 307 clients (56%) recommended some kind of change around four main categories: Customer Service (n = 94), Paperwork/process (n = 149), Coverage (n = 29) and Financial Access (n = 62).

"Make them clone themselves for other health service [departments] I HAVE to use."

Clients, though asked to comment on one thing they would like to see changed about CAREAssist, often referred to multiple things.

"Prompt call back with better communication." Most comments in the Customer Service category asked for some tangible improvement in the delivery of services, such as greater promptness in service (n = 26), better explanation of benefits (n = 28), more face to face contact (n = 8) and more follow through (n = 5). A number of clients commented on trying to reach a staff by saying, "Your phone tree takes 2-3 minutes just to get through and usually 2-5 choices before you even get to talk to someone." A number of comments asked for some kind of change in staff attitude (n = 11) such as (as one client put it) "Friendlier attitude toward clients, returning messages left on voicemail, remembering we are clients, not interruptions."

“Having to enroll every six months is so scary. What if you’re denied, it’s very scary.” Within the Paperwork/process Category clients mentioned issues with enrollment paperwork and process, billing processes, and communication with providers. Most comments were related to simplifying the enrollment/re-enrollment paperwork by either reducing the frequency of having to re-certify by having an annual rather than a semi-annual renewal (n = 32), or just making it easier to fill out (e.g., more pre-filled information that could be quickly checked for any changes) (n = 39). Responses in this category were exemplified by this comment: “The 6 month renewal--I know people move and change so it is necessary for them. For those who don't, it would be efficient all the way around to have a one page signed with any changes and sent back—done.” Some clients recognized that, though they wanted simpler paperwork, the program had made improvements: “As a self-employed person, [make it] easier to reapply with less paperwork. But paperwork has improved a lot!” As the quote that opens this paragraph indicates, for some clients there is considerable anxiety around the whole process of the eligibility review.

“Faster response times to pharmacies for drug co-pays. Sometimes CA approval holds up refill/fill process.” Numerous comments suggesting a quicker pharmacy turnaround time (11), and easier, quicker, or more direct billing of providers or some kind of scaling of billing (n= 29) were also included in the Paperwork/process category. Clients said things like: “Billing should be more current and flexible based on the effect on the life-threatening nature of the situation and its impact of employment.” or “The payment process to clinics, it sometimes takes a long time and then they think they are not going to get paid.” Some clients were frustrated with system restrictions (n = 15) and a small number of clients wanted friendlier language on forms and warnings about being dropped from the program (n = 5).

“Plus my teeth and eye care seem to be gray areas.” In the Coverage category respondents suggested expanding the program. Several were not specific (n = 11), saying things like, “...expand the program.” The remaining comments recommended specific kinds of expansion, such as for coverage of dental care (n = 7) or, smoking cessation materials, eye glasses, or counseling (n = 11).

“Eliminate my monthly share of cost because it is a hardship that contributes to me not having enough to meet my most basic living expenses.” In the Financial Access category a substantial number of comments were made about money and funding, in order to reduce or eliminate the cost share (n = 34), or raising the level of income that one can have and still be eligible for the program (n = 11). A handful of respondents (n = 4) were explicit about feeling the pressure of not being able to meet basic needs. A number of comments (n = 28) were more wishful, wanting, for example, for there to be “more funding from the federal government!”

“The constant worry will still be here tomorrow and tomorrow.”
“...the threats to cut funding are unending, a roller coaster.”

The theme of Accessibility was threaded throughout the coding categories, either financially (e.g., reducing or eliminating costs to clients, expanding coverage, and lowering income barriers to receiving services), through better information and outreach (e.g., website, brochures), or more direct connections between the program and providers. Also woven throughout the comments of respondents is the feeling of anxiety about being dropped from the program, or there not being enough funding to cover the services they feel they need.

Referral to Outside Services

Most respondents (51%) did not need a referral from CAREAssist for outside services. Of the 313 clients who needed a service that CAREAssist could not provide, 62% said they never received a referral from CAREAssist to another service. Of the 79 respondents given a referral, 66% answered that the referrals always met their needs.

A limitation of the survey is that we do not know the reasons for CAREAssist staff not making referrals. The needed service may have been unavailable or staff may have been unaware of appropriate referral sources.

Perceived Quality of Medical Care

The majority of respondents (85%) had seen their primary HIV care provider at least three times in the past year. Thirty-eight percent had seen their provider five or more times in the past 12 months. Ninety-two percent of respondents reported that their primary HIV care provider discussed the importance of getting regular lab work done at least sometimes, and 81% reported that their provider always discussed the importance of getting regular CD4 and viral load lab tests. Respondents reported a similar pattern for their providers' discussion of the importance of taking prescription medication—92% reported that their provider discussed the importance of taking prescription medication at least “sometimes” and 82% of respondents reported that their provider “always” discussed it.

On the whole, respondents to the survey rated their medical care quite highly, with 94% rating the medical care they received in the past 12 months as good or excellent (17% and 77%, respectively).

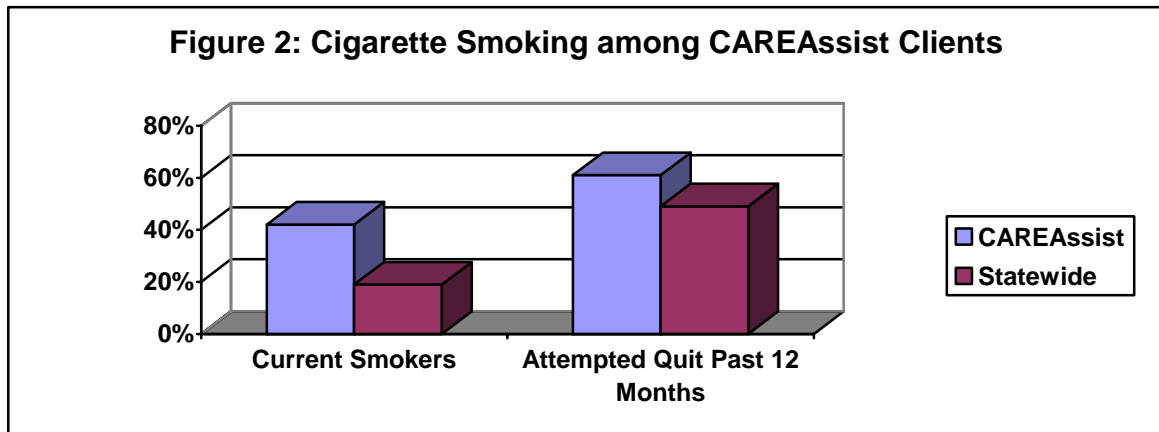
Cigarette Smoking Among CAREAssist Clients

This year's clients were asked questions about their cigarette smoking, including lifetime smoking, recent quit attempts, willingness to use nicotine replacement therapies, and attitudes toward a toll-free “quit line.”

The majority of respondents (69%) had smoked at least 100 cigarettes in their lifetime. “Current smokers” were defined as those who reported currently smoking every day or some days and who had smoked at least 100 cigarettes in their lifetime. Forty-two percent (311) of respondents were “current smokers”—much higher than smoking prevalence (18.6%) among Oregon residents overall (figure 2).³ Of the CAREAssist clients currently smoking, 42% smoked at least a pack a day (20 cigarettes). On the days that they do smoke, current CAREAssist smokers consume an average (median) of 13 cigarettes. Statewide, current smokers consume about the same amount (15 cigarettes per day).

³ All statewide data are from the 2005 Behavioral Risk Factor Surveillance System.

While smoking prevalence among CAREAssist clients is high, a large proportion is ready to quit. Seventy-one percent reported that they would like to quit, and 41% said they were seriously considering quitting in the next 30 days. When asked if they had tried to quit smoking in the past year, 61% of CAREAssist clients said yes. Statewide, 49% of current smokers made serious quit attempts in the previous 12 months (figure 2).



A large proportion of currently smoking CAREAssist respondents seem ready to accept help to quit. Seventy-four percent of the current smokers said they would use nicotine replacement patches or medicine for stopping smoking, if they were available at no cost. At the end of the questions related to cigarette smoking, the survey included a description of the Oregon Quit Line services and the toll-free quit line number.

63% of CAREAssist clients currently smoking thought that a toll-free quit line that offered information, coaching, referral and medication would be helpful.

Oregon's Tobacco Quit Line:

The Oregon Tobacco Quit Line (1-800-QUIT-NOW) is a free, confidential service available to all Oregonians. The Quit Line offers telephone-based coaching designed to help people quit smoking or using tobacco. Quit Coaches help callers make a plan for quitting and provide support, tips and advice for successful quitting. Quit Coaches will determine if a caller is eligible for free nicotine replacement therapy (NRT, or patches). People who use the Quit Line, when they quit, double their chances of success. People who use NRT and call the Quit Line double those chances again.

Comparison to Previous Surveys

Appendix D compares survey results for the current year and the previous five surveys (1999, 2002 – 2005) and identifies some apparent trends in client responses over time. While the question wording varies somewhat for some years (noted in the table), in most cases it is close enough to allow a comparison. We noted with “n/a” where the wording has varied too much to allow comparison.

Many of the differences in response across years were small and most likely do not represent real differences in client opinion. Below we have noted differences between the current and previous surveys that seem larger than would be expected, but we have done no statistical analysis of these data, as the surveys were not designed to test for differences in client responses over time.

The patterns seen are presented not to establish a firm foundation for making conclusions, but rather to inspire further discussion regarding ways that the CAREAssist program can further its goals of continuous service improvement.

Appendix D compares results for eight areas: survey response rate, demographic characteristics, number of contacts with CAREAssist, overall satisfaction, satisfaction with specific program elements, services received, referrals made by CAREAssist and medical care.

Survey response rate

The response rate to the 2006 survey (60%) was remarkably higher than the response rates to either the 2005 (45%) or 2004 (49%) surveys. We think this is a result of four key factors: (1) inclusion of a monetary incentive, (2) surveys sent in client’s preferred language (English or Spanish), (3) “friendly” and attractive survey design, and (4) targeted second mailing to non-responders. Table 1 below compares these factors for the past three surveys.

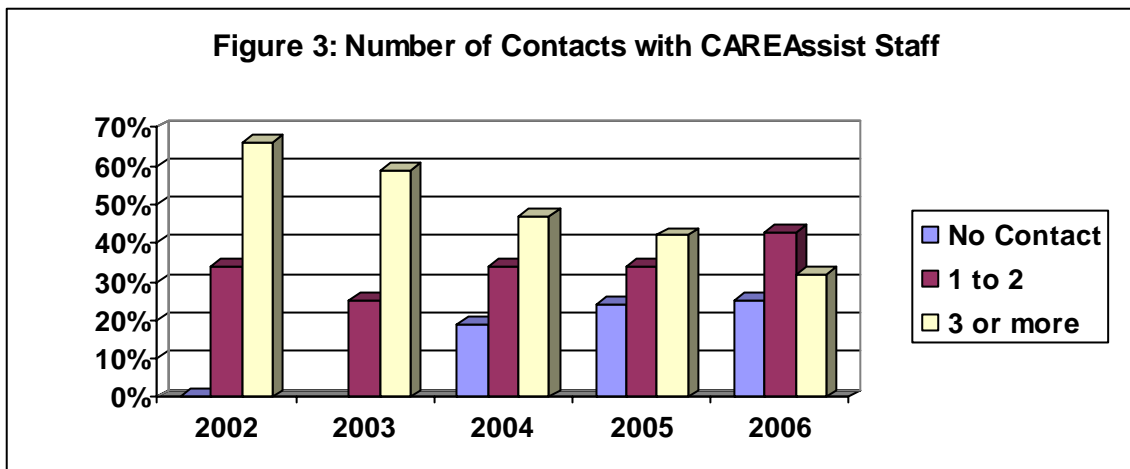
Table 1: Comparison of Survey Distribution Methods			
	2006	2005	2004
Number of Mailings	2	3	1
Spanish Version	Yes	No	Yes
Targeted 2 nd Mailing	Yes	No	No
Incentive	Yes	No	Yes
Response Rate	60%	45%	49%

Demographic characteristics

Most demographic characteristics of respondents (race, gender, and education) have changed little over time. However, the percentage reporting Portland metropolitan area residence rose from a low of 63% in 1999 to a high of 71% in 2006.

Number of contacts with CAREAssist

The data across surveys shows a slow but steady decline in the reported number of contacts with CAREAssist staff (figure 3). The largest percentage of respondents reported having “3-6” contacts with the program (50%) in 2002 and 2003, but this dropped to 34% in 2004 and 2005, and dropped again in 2006 to 25%. There are concomitant rises in the percentage of respondents reporting “no contact” or “1-2” contacts. Specifically, the percentage reporting “no contact” with the program rose steadily from 2% in 2002 to 25% in 2006 (no data available for 2003).



Overall satisfaction

Over the years the percentage of respondents reporting satisfaction with the program has remained high. The percentage was lowest in 2004 with 88% rating services good/excellent and has been at its highest in the past two years at 93% rating services good/excellent.

Types of services received

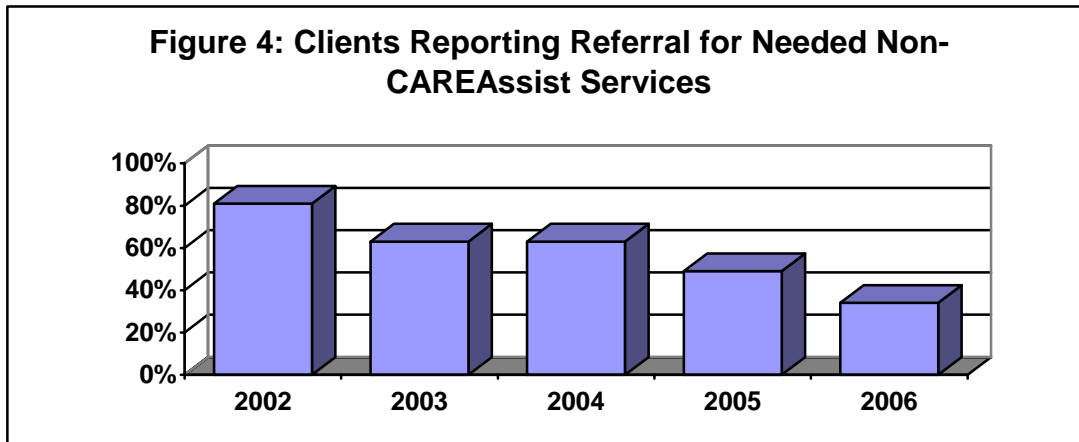
Survey data on types of services received have only been available for the past three years. The percentage that reported receiving help with insurance premiums and full drug co-pays has remained fairly constant (70% - 74% and 45% - 50%, respectively). The percentage of respondents who reported receiving partial drug co-pays seems to be higher this year (47%) than in 2004 and 2005 (39% and 37%, respectively). The percentage of respondents reporting receiving “other co-pays” has steadily risen from 28% in 2004 to 53% in 2006.

Satisfaction with program elements

While there is some variation from year to year in the reported satisfaction with individual service elements, they have still consistently received high satisfaction ratings from respondents. The two exceptions to this pattern are the ratings for the CAREAssist brochure and website 2006.

Referral to other agencies

We found a continued decline in the percentage of respondents reporting referral to another agency for a service that CAREAssist could not provide (figure 4). The percentage receiving a referral was highest in 2002 at 81%, but has steadily declined to a low of 34% reported in this year's survey.



The table below summarizes the types of agencies to which CAREAssist staff referred clients.

Type of Agency	Number of Referrals
Support Services	11
Cascade AIDS Project	10
Medical	9
Dental/Dentist	6
Insurance	5
Case Manager	3
Housing Agency	3
Social Services	3
Out of state referral	2
None	3
Other	2

Medical care

Questions about clients' ratings of the quality of the medical care they received have been asked in only the past three surveys. As in 2004 and 2005, respondents to this year's survey gave high marks to their medical care, with 94% of them rating their medical care as good or excellent. The percentage reporting that their provider regularly discusses the importance of taking prescription medications and of getting regular CD4 and viral load lab tests has remained high over the past three years.

DISCUSSION AND RECOMMENDATIONS

Overall Quality of CAREAssist

The CAREAssist program has consistently received high marks from clients for overall quality, with 93% of respondents in 2006 reporting that the overall quality of CAREAssist services was good or excellent. This should be kept in mind when considering the results and recommendations selected from the remainder of the survey. Evaluation results suggest that fine tuning may be needed, rather than any major corrective action.

Number of Contacts

The number of contacts that clients had with CAREAssist staff declined steadily over time. Clients who were people of color were significantly more likely to report no contacts. We recommend that a closer look be taken at the relationship between race and number of contacts to try to understand the reasons for this relationship. Our findings may result, in part, from differences in the number of months clients have been enrolled in CAREAssist. We did not incorporate these data into our analysis because duration type data are not readily extractable from the CAREWare (CAREAssist case management database).

Clients' Satisfaction with CAREAssist Service Elements

Service elements directly related to staff (e.g., respect and care given, privacy, knowledge) received high satisfaction ratings.

Paperwork

No one likes paperwork, and CAREAssist clients are no exception. While in the open-ended question asking about changing the "one thing about CAREAssist," many responded that it would be to "reduce paperwork," or "an annual renewal rather than every six months," several also recognized the big improvements in reducing the amount of paperwork. We recommend continuing to work to streamline paperwork. One client suggestion that might be particularly fruitful was for CAREAssist to modify the Client Eligibility Review Form (CER) so that enrollment information is pre-filled, requiring clients to initial items that have not changed and update items that have changed. Clients seem unaware that the semi-annual enrollment renewal is a federal requirement and that CAREAssist administration is powerless to change that fact. We recommend that some explanation to that effect be included with the CER paperwork.

Brochure and Website

These two service elements (both having no human intermediary) received the lowest marks for satisfaction of all the service elements (75% and 50%, respectively). These were also the items skipped by the most respondents, possibly indicating a significant degree of indifference. This was also reflected in the significant number of responses to the question “If you could change one thing about CAREAssist, what would it be?” recommending better outreach and information to clients. We echo our evaluation predecessors in recommending that CAREAssist program administrators evaluate the content, value and dissemination of the CAREAssist brochure and CAREAssist website. The CAREAssist website may be unpopular because it is difficult for clients to find (we tried!) by sorting through the maze of the DHS website. We recommend that staff give clients the specific URL for the website or direct them to use a search engine such as Google or Yahoo! to find it more easily—we found it within seconds by using either of these search engines.

Referrals to Other Agencies

A striking and consistent trend in survey responses over the past six surveys was the declining percentage of respondents reporting that they had received a referral from CAREAssist staff for a service they needed, but that CAREAssist was not able to provide. In the 2002 survey, 81% reported receiving this kind of referral, but by 2006, only 34% of those needing a referral reported receiving one. We recommend that CAREAssist administrators conduct a PDSA cycle⁴ of quality improvement by carefully documenting client request for services, action taken or not, and reasons, and then create a plan for addressing unmet needs for referral based on their findings. We recommend that, in tandem with a PDSA cycle, future satisfaction surveys ask clients needing referral but not receiving them, the reasons for non-referral.

What is Especially Liked about CAREAssist

It was clear from the responses to this open-ended question that the CAREAssist program and staff are greatly appreciated by clientele. They reported, often with great emotion, their gratitude for the services—insurance coverage, help with co-pays and so on—and for being treated with respect by the staff. While (as seen in the next question) many would like the paperwork process changed, they also recognize the improvements in paperwork and processes that have been accomplished. What was most striking about responses to this question was the great sense of relief clients experienced by knowing things were “taken care of”; many clients stated that living with HIV disease is stressful and that CAREAssist had a prominent role in helping relieve that stress. Another strong theme among the responses was the respondents’ gratitude to CAREAssist in helping them stay alive—many were convinced that without CAREAssist’s help they would be dead. We recommend that staff be given specific feedback about this item, perhaps in the form of direct quotes from the report.

⁴ PDSA (Plan, Do, Study, Act) or Deming Cycle is a model for continuous quality improvement.

Changing One Thing about CAREAssist

One of the most notable aspects of responses to this open-ended question was that nearly half of the respondents chose to say “Don’t change a thing!” Again, as we review the changes recommended by respondents, that exclamation should be kept in mind.

For clients who did suggest changes, much of the attention focused on simplifying the enrollment process and ongoing paperwork, as discussed earlier. One additional aspect mentioned by several respondents was a quicker pharmacy turnaround time and a smoothing out of the billing process.

Other aspects targeted for change included expanded coverage, greater financial access and improved customer service. Of these three, the area most amenable to being adjusted was likely that which we coded as “customer service.” In this area, respondents were mostly looking for better explanations of benefits and prompter follow up on requests. It seems that many responses to this question addressed areas that CAREAssist may not be able to do anything about such as “increasing federal funding” or perhaps even “expanding the program.” We recommend that CAREAssist administration focus attention on improving those areas in which they have more influence: more automation of enrollment, smoothing of pharmacy process, more direct billing, faster response to client requests, and further training on how staff explain the program and benefits. CAREAssist administration may also want to develop simple fact sheets that keep consumers apprised of federally-mandated changes to the ADAP Program that affect local policy decisions. For example, HRSA now requires enrollment updates twice per year, as well as client information on CD4 and viral load testing. These changes run counter to some client suggestions about streamlining paperwork, so clients may appreciate knowing that their feedback has been heard and that processes will be streamlined as much as possible while obeying mandates that accompany federal funding.

Quality of Medical Care

Respondents to this year’s survey (as in previous years) perceive that they are receiving good to excellent medical care. A high percentage of them report that their providers are regularly discussing with them the importance of taking prescription medications and getting regular lab work. These data are encouraging given that HRSA is ever more concerned with ensuring that ADAP consumers are engaged in medical care.

Cigarette Smoking Among CAREAssist Clients

The smoking prevalence among respondents to the CAREAssist survey (42%) is more than double that among Oregon residents overall. Fortunately, a high percentage desire to quit (72%), are seriously considering quitting in the next month (47%), and would be willing to use free nicotine replacement therapies (83%), indicating that many respondents are ready for change. We recommend that CAREAssist administration: (1) expand drug coverage to nicotine replacement

therapies and (2) work directly with the Oregon Tobacco Prevention and Education Program and other agencies, as needed, to identify smoking clients ready for change, and refer them to services, especially the toll-free Oregon Tobacco Quit Line.

Conclusion

Overall, the CAREAssist program is well received by clients. Clients often express their gratitude for the program and for program staff with great emotion. Clients (at least those that have been with the program for a while) recognize the improvements made by CAREAssist administrators and staff.

Efforts to improve the program would be best focused on: (1) improving quality and dissemination of the website and brochure, (2) prompter response and follow up on client requests, (3) improved pharmacy turnaround time, (4) smoother, perhaps more direct, billing processes, (5) tracking and possibly increasing referrals for services not available through CAREAssist, (6) increased automation of the renewal process, and (7) intervention with smoking clients ready to quit.

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