The Journal of Mental Health Policy and Economics
J Ment Health Policy Econ **8**, 71-81 (2005)

Using Willingness to Pay to Measure Family Members' Preferences in Mental Health

Norah E. Mulvaney-Day*

Ph.D., Center for Multicultural Mental Health Research, Cambridge Health Alliance, Harvard Medical School, Department of Psychiatry, Somerville, MA, USA

Abstract

Background: Willingness to pay is a valuation technique that has rarely been applied in mental health economics. First used in environmental economics to measure the intangible value of environmental improvements, WTP has increasingly been used in health care economics. The technique may be useful in mental health policy research where it can be critical to include the intangible impact of mental health treatment on individuals other than the person with illness, such as family members, in cost-benefit analyses.
Aims of the Study: The goal of the study was to test the application of WTP in a sample of individuals who have family members with serious mental illness. This paper describes the survey development process and the feasibility analysis that was conducted as part of the study.
Methods: A mail survey was designed by the author in two phases and utilized cognitive pretests and focus group pretests in the process of development. Qualitative analysis of this process resulted in a revised survey instrument that was then distributed to a random sample of 2000 individuals who have family members with mental illness. Feasibility was evaluated based upon the study response rate, the willingness to pay item response rate and an outlier response analysis.
Results: Qualitative analysis during the survey development process found that it was critical to consider two areas of concern in the application of WTP with this population in the mental health field. Some respondents experienced a highly emotional response to the initial versions of the survey, and complex probabilities were difficult for the respondents to answer. These findings resulted in significant modifications in the survey design. The analysis of response rate, WTP item non-response rate, and outlier responses found no significant concerns regarding overall feasibility of WTP with this population.
Discussion: Based upon the results from this study, WTP is a potentially useful tool for further research in the mental health policy and economics field. However, significant accommodations must be made in survey design to account for a possibility of a high level of emotional distress for those dealing with the illness of a family member. Some of these modifications may be in contrast to the recommendations currently being followed in health care economics. Face-to-face surveys may be preferred in some cases, such as with elderly respondents. Limitations of this study include the lack of targeted follow-up due to the anonymous study design and the fact that there are so few models for WTP studies in mental health.
Implications for Mental Health Policy: Given that effective mental health programs can be matched with additional expenditures, it is important to explore comprehensive measures of value for treatment in cost-benefit analysis. The values of persons whose family members have serious mental illness are important to consider in setting policy. The success of this study suggests that WTP could be used in other settings, e.g., to understand community preferences for mental health treatment programs, to understand differences in preferences across multiple stakeholder groups.

Received 16 March 2004; accepted 30 March 2005

Introduction

More than four decades ago, Rashi Fein argued that an understanding of the costs of mental illness must be expanded to include loss of work days as well as the psychological distress resulting from illness.[1] Since then, others have argued that justifying public expenditures on mental health services should be evaluated according to a broad definition of the value of care, particularly given that, in some cases, better mental health services do not necessarily result in cost offsets and yet may lead to socially desirable outcomes.[2,3] Despite the growing recognition that some measure of value must be incorporated into public policy decisions regarding mental health service delivery, few studies in mental health economics include measures of the broader psychosocial impacts of improved mental health services.[4,5]

One technique for estimating the value of health care treatment that is increasingly being applied in health policy research is the willingness to pay technique (WTP).[6-9] This technique is administered by means of a survey, in which the respondent is asked how much he or she is willing to pay for a specific treatment outcome. The WTP value is considered a comprehensive measure of value, one that theoretically includes the respondent's value for both direct and indirect costs, including intangible costs such as the pain and

* **Correspondence to:** Norah E. Mulvaney-Day, Ph.D. Center for Multicultural Mental Health Research, Cambridge Health Alliance, 120 Beacon St., 4th Floor, Somerville, MA 02143, USA.
Tel.: +1-617-503 8448
Fax: +1-617-503 8430
E-mail: nmulvaney-day@charesearch.org
Source of Funding: Funding for this research was provided in part through a National Institute of Mental Health Training Grant (T32 MH16846) and through a dissertation support award from the Heller School Alumni Fund.

suffering associated with the illness. Some of the advantages of WTP as a valuation technique are its flexibility across different stakeholder groups and its ability to estimate the value of treatment for those other than the treated individual, usually referred to as the ''non-users'' in the literature. However, in health economics to date, WTP has mostly been used to measure the value of treatment outcomes for the user of the treatment,[7] with only a few exceptions where the non-user values of family members and others were measured.[10-12] Potential disadvantages of the WTP method include the possibility that the hypothetical nature of the WTP scenario may result in an overestimation of the ''true'' WTP value,[13] the potential for ''yea-saying''[6] and concerns that the WTP value may not be sensitive to changes in the scope of the health outcome.[14]

Using a measure that incorporates an estimate for these intangible impacts in economic estimates may be particularly important in the mental health field, given the level of subjective burden associated with serious mental illness.[15-18] Failure to include some measure for these impacts may result in estimates that seriously underestimate the true costs of illness. Applying economic valuation techniques to measure the value of intangible quality of life improvements in mental health evaluations can be difficult.[4,19] Nevertheless, although limited, the work that has been done suggests that WTP is a useful and applicable methodology in the mental health field.[10,20-22]

The primary purpose of this study was to supplement this limited literature by assessing the WTP technique in the mental health field with a population of family members. WTP was originally developed to measure public goods in environmental economics,[23,24] and many of the guidelines followed by health services researchers in the design and administration of WTP studies are based on early recommendations made by a federal panel of National Oceanic and Atmospheric Administration (NOAA) experts in the environmental field.[25] It is not immediately obvious, however, whether these NOAA recommendations are necessarily applicable for all WTP studies in health care,[6,26] and particularly whether they apply in mental health economics where so few WTP studies have been conducted. A secondary purpose of this study was to try to apply these recommendations in a WTP study in the mental health field.

A mail survey was designed by the author and administered to a national random sample of members of the National Alliance for the Mentally Ill (NAMI), a support and advocacy group for those who have family members with serious mental illness (SMI). In this paper, I will discuss the feasibility of applying this methodology with this population, and in particular whether the recommendations made in the NOAA report were found to be applicable with this particular study population. In order to analyze the feasibility, two different components of the study itself will be described.

First, the two-staged survey development process will be outlined and the qualitative analysis conducted while adapting this instrument will be described. The qualitative work that was conducted as part of this process consisted of cognitive interviewing and a group pretest. In particular, the recommendations made both by the NOAA panel and by researchers using WTP in health care economics will be assessed according to the unique characteristics of both the mental health field and the population sampled for this study – non-users.

Secondly, the overall feasibility analysis conducted using the data from the completed mail survey will be reported. This analysis uses common measures of successful application for WTP surveys such as item non-response and study response rates to evaluate the general applicability of this methodology in the mental health field. Based upon these findings, I will make some recommendations for future applications of this technique in mental health services research.

Methods

This study utilized a mixed methods approach to adapting and analyzing the feasibility of WTP for persons who have family members with serious mental illness. Given that concerns have been raised in the WTP literature regarding the sensitivity of valuing illness in monetary terms,[27] and since WTP has never been applied in the mental health field with family members, the qualitative survey development process was considered a critical component of this study. Few studies report the preliminary research and testing of the WTP question,[28] and, in general, researchers in health economics do not use or report qualitative, survey development methods in their work.[29,30] Here, the qualitative methods used in the development of the WTP scenarios are described first, and then the quantitative methods used in the subsequent mail survey are outlined.

Development of WTP Scenarios

Two WTP questions (WTP-A and WTP-B, **Appendix I** and **Appendix II**) were adapted from the health economics literature.[31,33-35] The two WTP questions were then subjected to rigorous evaluation, by means of a cognitive interview with two persons who had family members with serious mental illness and a group pretest with NAMI members (n=21). The research goal for this phase was twofold – to test whether the WTP scenarios were meaningful and understandable, and to explore the potential for a negative reaction to the questions.

Cognitive Interviews

Cognitive interviews were conducted early in the process of survey development to provide in-depth information about the effectiveness of the WTP scenarios at capturing the construct of intangible effects of illness for this population. Cognitive interviewing is considered by many to be a critical component of survey development,[36,37] especially when developing new measures. The interviews were conducted by the author on separate occasions with two middle-aged women who both had adult children with serious mental illness. One was a current member of NAMI, and the other had belonged to the organization in the past. Both were

referred by colleagues of the author who knew them personally. The two WTP questions were mailed to the respondents who completed the questions and then were interviewed in a debriefing session by phone.

The cognitive interviewing method used was retrospective cognitive probing.[36] Each respondent was asked in an open-ended debriefing session what they were thinking when they answered WTP-A and then WTP-B. This technique has effectively been utilized in other studies in the mental health field.[38] The conversations explored whether there was any expression of discomfort with the questions, either in the way they were worded or in the information they were trying to generate. The cognitive interviews also explored whether the respondent was able to consider the hypothetical situation and respond in a meaningful way. During the interviews, notes were taken by hand.

Group Pretest

A group pretest was held at the end of a meeting of the state chapter of NAMI. The NAMI research director in the national office referred the author to one of the persons leading this meeting, who arranged to put the study pretest on the agenda. The objective of this group meeting was to test the WTP questions with as many NAMI members as possible, while at the same time observing immediate reactions to the questions in order to evaluate their feasibility. In order to accomplish both objectives, the author held a large group pre-test rather than a smaller, more structured focus group.

The author met with the NAMI group at the end of their regular monthly business meeting. After describing the study briefly, the author distributed WTP-A and WTP-B to the individuals in the group, and they all read and completed the two scenarios. The survey questions were then discussed in the group. The author had prepared an interview guide to guide the discussion. At the very end of the meeting, those respondents who wanted to do so passed in their completed pencil and pen surveys to the author. In addition, the author took notes during the discussion.

Analytic Procedures

There were three sources of data for the qualitative analysis of the development of the WTP questions: the author's notes from the cognitive interviews, the author's notes from the group pretest process and the actual completed WTP questions from the group pretest for those who passed in their survey (n=8). The analysis was conducted using constant comparison, a method based upon grounded theory[39] by which the major themes that emerged during the cognitive interviewing were then reflected upon in an iterative fashion when analyzing the notes from the group pretest, and while organizing the responses to the WTP questions from the group pretest. Both open and close-ended responses to the WTP questions from the pretest were entered in a table, outlined and analyzed by comparing the responses received. Since only a little more than a third of the group returned the survey, and the WTP questions varied across different versions of the survey (see below), the analysis was also based upon comparing the WTP items of those who turned in the survey with the WTP items in the surveys of those respondents who did not.

Mail Survey

Measures

Feedback in these early stages of survey development resulted in significant revisions to WTP-A and WTP-B, which were combined into a single question (WTP-C) and included in the final version of the survey. WTP-C (see **Appendix III**) consisted of a single item asking the respondent how much he or she would pay for a medication for the family member with SMI that would significantly improve his or her functioning.

In addition to WTP-C, the final survey also included a number of other measures. Thirty-day expenses on behalf of the family member with SMI were measured using a scale adapted from Tessler and Gamache.[40] Respondents were asked to record expenses in 5 broad categories: pocket money, personal expenses, medical expenses, living expenses and other. Each of these categories was further broken down into several components. Respondents first checked whether they helped with any expenses in the broad categories during the last 30 days. If they responded affirmatively, they were then asked to specify how much they spent in each specific area. For example, if the respondent had helped pay for personal expenses, he was then asked to specify the exact amount in the following categories of personal expenses: transportation, clothing, cigarettes, personal items, and other. Following data collection, all responses in the ''other'' categories were reviewed, and in some cases new categories, such as entertainment, were created.

Measures of the family member's symptomatology and need for help with activities of daily living were also included in the survey. Both measures were modified in order to shorten the number of items, due to the need to keep the mail survey instrument brief and encourage good response rates. Symptomatology measures were adapted from the BASIS 32, an outcomes instrument widely used in mental health evaluation and research.[41] Two to four items were selected from each of the five following symptom categories: relation to self/others, daily living/role functioning skills, depression/anxiety, impulsive/addictive behavior and psychosis. Respondents were asked to check whether the family member with SMI had ever experienced the symptom, and if so, the severity in the last year. The activities of daily living measures were adapted from Tessler and Gamache.[42] Four out of the original eight categories were chosen for measurement: household tasks, managing money, taking medication, and personal self-care. Respondents were asked how many times per week the family member needed help with the task, how often the respondent did the helping, and whether the respondent minded helping. Although both the symptomatology measure and the ADL measure were modified from their original form, alphas run for these modified scales were above 0.80 in both cases.

Measures of the family member's illness and treatment history, living situation and demographics, and respondent

demographics were also included. These items were adapted from other surveys conducted with persons who have family members with serious mental illness.[40,43]

Administration

The survey was mailed to a random anonymous national sample of 2000 persons belonging to NAMI, a family support and advocacy group. One week later, a reminder postcard was sent to every person in the sample. Given the anonymity of the study design, it was impossible to mail targeted follow-up letters to those who had not responded. Out of the 810 surveys returned, 660 were eligible cases with a living family member with SMI. After weighting the original sample size for ineligible non-returns, the study response rate was 40%.

This response rate is similar to other WTP studies in health care using a similar methodology. Response rates for mail studies without extensive follow-up that were found in the literature review range from 42%[31] to as low as 7.6% in a general population national mail survey.[44] Response rates for mail studies with follow-up letters were generally higher, ranging from 57%,[45] to 64%,[46] to a high of 77%.[47] However, all but one of the samples for these mail studies were drawn from treatment clinics using non-random sampling techniques, which introduce biases inherent to non-probability sampling techniques. Most WTP studies in health care have been conducted using convenience samples, and have been criticized for limited generalizability across income and ethnicity.[28] At the same time, it is important to note that NAMI members are not necessarily representative of the population of persons with family members who have serious mental illness. In general, they are better educated, have higher income levels and represent fewer ethnic minorities than the general population,[32,48] which may also make them more responsive to mail surveys such as the one used in this study.

Analytic Procedures

The quantitative portion of the feasibility analysis consisted of three stages. First, the study response rate was analyzed by comparing early and late returns in order to identify potential biases. Then, WTP non-response and zero responses were analyzed. The WTP item non-response is considered an important indicator of the overall feasibility of the question in a WTP study. It is also important to analyze zero responses closely in order to identify whether the study yielded a high number of so-called ''protest zeros.'' Protest zeros are zero responses in which respondents do not necessarily value the commodity at a low level, but instead may believe they should not have to pay for the medication, either because government should pay for it, insurance companies should cover it, and so on. Chi Square procedures were used in order to identify differences between those who either did not answer the WTP question or were willing to pay no money, and the rest of the sample.

Lastly, outlier responses were analyzed. There are frequently concerns in WTP surveys that due to the hypothetical nature of the question, respondents may seriously overestimate their ''true'' willingness to pay.[13] Initial analysis of outlier responses was conducted by calculating the ratio of WTP with the respondent's income. Income was measured categorically, and so the value used was the midpoint in the range for each category. Chi-square tests compared differences between those WTP more than 25% of their income with the rest of the sample.

In order to analyze more closely the outlier responses, the author determined a cut point where an unreasonable WTP amount was more than 50% of a respondent's annual income. Determining this cut point was necessarily arbitrary. A review of other WTP studies yielded no consistent framework for such a judgment. For example, one study did not include those who were WTP more than 50% of their income for arthritis medication in the analysis, deeming that these cases gave unreasonably high responses.[49] In contrast, another study based the analysis on a comparison between those families WTP more than 50% of their income for nursing home services for their family members and those WTP less than 50%.[50] The literature on out of pocket burden for mental health care expenses provides some guidance in the definition of excessive burden that can be extended here. For example, one study defined spending more than 20% of an individual's income on out of pocket mental health care expenses as a burden.[51] Given that the WTP amount here was presented as a comprehensive scenario that theoretically included living expenses as well as treatment expenses, and that a definition for an *unreasonable* amount should be higher than actual burden, a willingness to pay amount of more than 50% of the respondent's yearly income was chosen as the cut point for an unreasonable response.

Results

Qualitative Analysis in the Development of WTP Questions

WTP-A in the first draft of the survey was based on a WTP question in health economics that valued a ''cure'' for the disease[49] and used an open-ended response format (See **Appendix I**). Following recommendations by the NOAA panel to adopt a dichotomous choice format for WTP questions, WTP-B was designed as a simple yes/no alternative, with bids varying from very high to very low amounts across several different versions of the question, a format that has been successfully applied in other WTP studies in health care.[52,53] The valuation scenario was presented under conditions of uncertainty, and the chance that the drug would work varied at either 50% or 80% to test changes in responses based on the scope of the good valued (See **Appendix II**). Outcome scenarios were based on case descriptions used in the development of the Basis 32.[41]

Two overarching themes emerged from the qualitative analysis of the survey development process with implications for survey design using WTP in the mental health field – *emotional responses to the WTP questions* and *evaluating choices in the WTP scenario*. These findings prompted the researcher to reconsider the utility of the NOAA recommendations in this specific context and resulted in

significant revisions to the WTP-A and WTP-B questions.

Emotional Responses to the WTP Questions

First, in both the cognitive interviews and the group pretest, respondents had strong immediate emotional responses to being asked to value their family member's health in monetary terms. In WTP-A, respondents had a difficult time thinking about placing a monetary value on a ''cure'' for their family member's illness, as the notion of a ''cure'' was too abstract, and many within the group were skeptical that such a cure could ever be found. Other respondents expressed anger at being asked how much they were WTP when they were already spending so much money. Particularly in response to WTP-B, the respondents were angry about being asked to pay for something that might not work.

In response to these reactions, revisions were made, and the final WTP-C presented a valuation scenario that focused on simple and concrete quality of life outcomes rather than a ''cure,'' by asking the respondent's willingness to pay for a medication that would allow the individual to live independently, with a job and friends. Although much care for chronic mental illness includes more than just drug treatment, using medication as the catalyst for the quality of life outcomes in the WTP scenario was based upon the need for generalizability across multiple forms of mental illness. Recent data show a substantial number of persons use prescription drugs to treat mental health and substance abuse disorders,[54] and this scenario was thought to have the broadest applicability. By focusing on medication in the WTP scenario, it is nevertheless possible that this study may not represent those whose family members are not taking medication and who may have found the scenario irrelevant to their situation.

The hypothetical WTP scenario was also designed to be comprehensive. Respondents were asked to imagine that the medication was the only item they needed to finance for their family member to achieve the quality of life outcomes and to consider the cost savings from other services that the family member would no longer need. In this way, the scenario was designed to be applicable even to those respondents who had family members who received multiple services other than medication.

In addition, an extensive introduction was added to place the final WTP-C in context. The introduction included wording that reassured the respondent that although the ''true cost'' of mental illness could never be measured in monetary terms, the attempt to estimate a WTP value would provide important and helpful information to policy makers. Some have suggested that decisions concerning values and preferences should take place as part of an interactive process in which the respondent has time to reflect on the decision.[55-57] With this population, and possibly by extension other non-user populations where the illness being valued has had a devastating impact on a family member, survey administration may require a more lengthy process than simply asking the WTP question outright.

Evaluating Choices in the WTP Scenario

Secondly, the respondents displayed some difficulty evaluating how much to pay for the medication given the chance that it would not work. Some respondents felt that asking a simple dichotomous yes/no question presented them with an impossible choice between helping their family member and financial ruin. In the pretest, out of those who turned in a completed survey (n=8), all answered yes to this dichotomous choice question except for two respondents who refused to answer either of the WTP questions and one person who didn't understand the question. This finding suggests that the potential for ''yea-saying'' that has been observed in WTP studies using dichotomous choice in health economics may be even more likely to occur in the mental health field.[6] Further, even thought the pretest took place in an in-person group setting, none of the pretest respondents who received surveys with a high cost for the medication and a 50% chance of effectiveness returned the survey. This observation suggests that persons who really cannot afford the medication being valued or find the valuation scenario too risky may choose not to turn in the survey, rather than admit they are not willing to pay.

As a result of this analysis, an alternate response format was adopted using a payment scale mechanism instead of a dichotomous choice response format. The payment scale lists a series of values from very low to very high, and the respondent picks the WTP value from that list. This type of response has been widely used in health economics with successful results.[6,58,59] The rationale for this change was that it was important to allow the respondent to choose at least some amount, even if it is very small, in order to avoid the possibility that forcing a choice in response to a single monetary value might result in refusal to answer the question.

The complex probabilities were also dropped from WTP-B. Although the NOAA panel had recommended that tests of sensitivity to the size of improvement be included in all WTP surveys, there is some indication that such tests may not always be applicable in health and mental health economics, e.g., cases in health care where one either receives the good or does not such as mammographies.[12,28] In this study, the probabilities were dropped in order to avoid unnecessary abstractions in the hypothetical scenario and to avoid frustrating respondents who were already paying a significant amount of money for treatments that may not work. **Table 1** summarizes the characteristics of the original WTP-A and WTP-B in the initial draft of the survey, the recommendations made by the NOAA panel related to these survey elements, and the modifications made with WTP-C in the second and final version.

Analysis of Mail Survey: Response Rate, Item Non-Response and Outliers

An analysis was conducted to assess the use of WTP as an estimation tool with this population. A rough measure of the feasibility of this estimation tool with this population is the study response rate. At 40%, the response rate was, in fact, higher than the 35% that the NAMI research director had

Table 1. Summary of Survey Design Characteristics by NOAA Recommendations

Characteristic of Survey Design	NOAA Recommendations	WTP-A	WTP-B	WTP-C (in survey)
Valuation scenario	No comment	Cure	Change in symptoms	Concrete quality of life outcomes.
Response format	Dichotomous choice	Payment card	Dichotomous choice	Payment card
Consistency tests	Included test of WTP to size of health effect		Included test for the scope of the health change.	Test dropped. No complex probabilities were asked.
Introduction to the WTP questions	No comment	None	None	Extensive introduction added.
Mode of administration	Face-to-face, interviewer administered			Mail, self-administered.
Account for hypothetical bias	Included budget constraint reminder			Included budget constraint reminder

said to expect in a survey of this kind (L. Hall, personal communication, 1999). An analysis of early versus late returns found no difference in the sample groups according to income, degree of financial contribution to family member, number of diagnoses of family member, severity of symptoms, region of country, relationship to family member, whether family member lived with respondent, and WTP amount. The only difference was that later returns were slightly more likely to report having a family member with no need for help with activities of daily living (ADLs) (Chi Square = 8.159, p=.043). Taken together, the response rate and the analysis of early versus late responders supports the overall feasibility of using WTP with this population.

Item non-response of the WTP question was also assessed as an important measure of overall feasibility. The item non-response for the WTP question was 11.3%. In comparison with other self-administered surveys, this non-response rate was higher than others that used dichotomous choice for eliciting response but lower than studies using simple open-ended elicitation methods.[45,46,58,60] A broad range of variables was tested using Chi-Square tests, and those who did not answer the WTP question had lower income, education and need for help with ADLs, and were significantly more likely to be over 65 years of age (p=.001). These results suggest that for this survey, and in this population, those who are elderly or whose family member functioned fairly well may have become frustrated with the complexity or seeming irrelevance of the WTP question and refused to answer it.

The potential for protest zeros was also analyzed using Chi-Square tests. Here, 6.3% of the sample was willing to pay no money for the medication for their family member. The only significant differences between zero responses and the rest of the sample were that they had lower income, savings and education. In contrast to the missing data analysis, none of the other demographic or illness severity variables were significant, indicating that most in the sample likely answered zero not as a protest but because they really could not afford to pay.

Finally, the possibility of unreasonably high responses was also examined. The ratio of the respondent's WTP amount over yearly income was calculated, and cut points of greater than 25%, greater than 50% and greater than 100% were determined (see **Table 2**). As can be seen from these data, only a small proportion of the sample gave potentially unreasonable responses to the WTP question in terms of percentage of income. For example, considering a 50% cut point, only 2.5% of the sample gave an answer in this realm, thus providing little evidence of unreasonable responses to the WTP question. Analysis comparing those who were willing to pay more than 25% of their income (n=60) with the rest of the sample found those with lower income, higher savings and over 65 years of age were more likely to state a WTP amount that was more than 25% of their income. None of the other demographic and illness severity variables tested in the previous feasibility analyses were significant here.

In order to analyze these cases further, the respondents who were willing to pay more than 50% of their income (n=13) were compared not only to the reported income but also to reported savings. All of these cases had included information on savings. Eight of these outlier cases reported enough savings to pay the stated WTP amount for more than 10 years into the future. Three of these cases reported enough savings to finance two years at the stated WTP amount. And two cases reported enough savings to finance a single year of the WTP amount given. None of these responses, then, can

Table 2: WTP to Income Ratio (n=512)

Proportion of annual income	N	Percent
Greater than 25%	60	11.7
Greater than 50%	13	2.5
Greater than 100%	2	.4

be considered entirely unreasonable when the household savings are taken into account.

Discussion

Evaluating the value of mental health outcomes within an economic framework is critical, and yet most cost estimation techniques do not include a means of incorporating the impact of these outcomes for those other than the individual with illness. Recommendations have been made to use WTP to conduct normative analyses of the impact of particular mental health treatment options on wellbeing for the family and society as a whole.[61] However, there have been strikingly few studies testing the applicability of WTP in this arena.

Based upon the results from this study, WTP is a potentially successful tool for further research in samples of individuals who have family members with serious mental illness. The findings from this study provide evidence not only that this measurement technique may be transferable into the mental health field, but that further use of this technique to measure non-user preferences is also warranted, both in mental health and general health care. Response rates and item non-response rates revealed no pattern of extraordinary difficulty in answering the WTP question in this area of policy research.

It is important to note, however, that some of the changes incorporated into the final WTP-C question were in contrast to recommendations made by the NOAA panel (see **Table 1**). There are several aspects of conducting willingness to pay surveys with non-users in mental health services research that need to be considered. First, the potential for a high level of emotional distress needs to be considered in the design of the questions. A clear introduction that describes the reasons for asking the WTP questions and reassures the respondent that WTP does not in any way represent the ''true personal cost of illness'' are important to include. It may also be necessary to place the question in a policy context first in order to elicit reasonable responses.

Mode of survey administration is also important to consider, and the results of this survey are mixed. There is some evidence that WTP surveys administered by mail are less vulnerable to social desirability bias.[62] The qualitative work for this study found that some respondents were reluctant to refuse to pay, suggesting the risk of social desirability bias may be higher in this population, thus making surveys that are self-administered more appealing. The mail survey administered in this study did demonstrate overall feasibility.

At the same time, the qualitative process of survey development revealed a measure of sensitivity in administering WTP questions with this population that suggests a face-to-face format is preferable in some situations, depending upon the severity of the family members' illness and the overall level of distress. In addition, the analysis of the mail survey found that those with the greatest challenges understanding and responding to the WTP questions in this study were the older respondents. It may be necessary to consider face-to-face formats with this population, instead of using mail or self-administered surveys, in order to provide explanations for elderly respondents if the question is confusing. Using face-to-face surveys is consistent with the NOAA guidelines, and should be carefully considered in respect to the study's objectives and target population.

Regardless of the mode of administration, the use of payment cards rather than dichotomous choice formats may be an effective way to decrease the potential of ''yea-saying'' from respondents who do not wish to admit they cannot afford a specific amount and risk appearing as if they do not want to help their family members. When using WTP with this population it is also important to remind respondents to answer the questions even if the family member is not currently seriously ill.

Despite a concern by this author that eliciting WTP from people who have seriously ill family members might result in inconsistent and unreasonably high amounts, this study did not encounter a high number of potentially irrational results. There are a number of possibilities for why this did not occur. Consistent with NOAA guidelines, the scenario was explicit in reminding people to place their WTP value within a budget context, and to think clearly about how much they could afford. This reminder may have impacted this population effectively. Alternately, the respondents may have been trying to game the results in a negative direction. They may have interpreted the policy implications of the survey to mean that the lower WTP amount they gave, the less the government might recommend charging for a particular medication. Another possibility is that although the hypothetical scenario was written in order to elicit the respondent's value, some may have perceived the question to

represent what the respondent thought the medication might cost on the market. In these cases, the respondent may have given their best guess of the market value for the medication, thus failing to estimate a comprehensive value for the improved outcomes in their family member's life. A final possibility is that some respondents were not able to consider accurately the comprehensive costs of all other services provided to the family member and represent the value of that amount in the hypothetical WTP value. More in-depth surveys conducted in a face-to-face format might provide an opportunity to explore in greater depth the other services the respondent is covering on behalf of the family member and whether the WTP scenario truly captures the value of this care for the respondent.

There were a number of limitations to this study. First, the low response rate, although expected, may mean that the study is not feasible in some subset of the NAMI population. Although the analysis of early versus late respondents did not reveal serious systematic differences between these groups, it was impossible to compare the final study sample with the demographics of the NAMI population as a whole, given that these data are not collected on a national level. It is important to conduct further studies with a broader population using random sampling techniques and extensive follow-up in order to evaluate further the feasibility of this technique across SES and race/ethnicity.

Another limitation of the study concerns the fact that there are so few models for WTP surveys in mental health. Although the survey questions were tested extensively, the lack of comparable studies in the mental health field limit the ability to compare the feasibility of this mode of administration and survey items with other studies. Thus, the recommendations made for applicability of WTP in this population need to be tested and replicated in future studies. Finally, the WTP item non-response rate of 11.3%, although lower than some comparable studies, was sufficiently high enough to warrant further research regarding questionnaire format and administration. Future studies should be conducted in order to test a means of decreasing this level of non-response and improving overall response to the WTP question.

However, the overall feasibility was very promising, given that family members are a crucial stakeholder group and WTP studies are rarely conducted with them. The success of this administration suggests that WTP could be used in a number of other settings and populations groups, e.g., to analyze the community's preferences for mental health treatment programs, to evaluate the value of different treatment regimens for individuals with illness and their family members, and to understand differences in preferences across numerous stakeholder groups. The WTP values of family members could be combined with those of patients in order to calculate a more comprehensive estimate of the value of different treatment modalities when evaluating the costs and benefits of a program. Comparison between WTP and other standard measures of treatment preferences such as the time trade-off and standard gamble techniques would also be important to study with this population.[63,64] It is important to continue to explore ways of including the values of stakeholders in the evaluation of the benefits of mental health treatment programs, given that effectiveness is also often matched with additional expenditures, and yet the program may improve individual wellbeing and social welfare.

Acknowledgements

I would like to acknowledge the National Alliance for the Mentally Ill for their support for this study. I would also like to acknowledge Margarita Alegria, Pinka Chatterji and Thomas McGuire for helpful suggestions on earlier versions of this paper.

References

1. Fein R. 1958. *Economics of mental health*. New York: Basic Books Inc.
2. Rosenheck R. Cost-effectiveness of services for mentally ill homeless people: the application of research to policy and practice. *Am J Psychiatry* 2000; **157**: 1563-1570.
3. Sturm R. The myth of medical cost offset. *Psychiatr Serv* 2001; **52**: 738-768.
4. Pleil AM. The importance of considering non-monetary costs and benefits in selecting pharmacologic interventions in mental health. *Psychopharmacol Bull* 1995; **31**: 727-734.
5. Evers SMAA, van Wijk AS, Ament AJHA. Economic evaluation of mental health care interventions. A review. *Health Econ* 1997; **6**: 161-177.
6. Hanley N, Ryan M, Wright R. Estimating the monetary value of health care: lessons from environmental economics. *Health Econ* 2003; **12**: 3-16.
7. Olsen JA, Smith RD. Theory versus practice: A review of 'willingness-to-pay' in health and health care. *Econ Eval* 2001; **10**: 39-52.
8. Klose T. The contingent valuation method in health care. *Health Policy* 1999; **47**: 97-123.
9. Deiner A, O'Brien B, Gafni A. Health care contingent valuation studies: a review and classification of the literature. *Health Econ* 1998; **7**: 313-326.
10. Zarkin GA, Cates SC, Bala MV. Estimating the willingness to pay for drug abuse treatment: A pilot study. *J Subst Abuse Treat* 2000; **18**: 149-159.
11. Chiu L, Tang K-Y, Shyu W-C, Chang T-P. The willingness of families caring for victims of stroke to pay for in-home respite care – results of a pilot study in Taiwan. *Health Policy* 1999; **46**: 239-254.
12. Liu J-T, Hammitt JK, Wang J-D, Liu J-L. Mother's willingness to pay for her own and her child's health: A contingent valuation study in Taiwan. *Health Econ* 2000; **9**: 319-326.
13. Blumenschein K, Johannesson M, Yokoyama KK, Freeman PR. Hypothetical versus real willingness to pay in the health care sector: results from a field experiment. *J Health Econ* 2001; **20**: 441-457.
14. Hammit JK, Graham JD. Willingness to pay for health protection: inadequate sensitivity to probability? *J Risk Uncertain 1999;* **8**: 33-64.
15. Lefley HP. The consumer recovery vision: will it alleviate family burden? *Am J Orthopsychiatry* 1997; **67**: 210-219.
16. Lefley HP. Synthesizing the family caregiving studies: implications for service planning, social policy and further research. *Fam Relat* 1997; **46**: 443-450.
17. Solomon P, Draine J. Adaptive coping among family members of persons with serious mental illness. *Psychiatr Serv* 1995; **46**: 1156-60.
18. Greenberg JS, Kim HW, Greenley JR. Factors associated with subjective burden in siblings of adults with severe mental illness. *Am J Orthopsychiatry* 1997; **67**: 231-241.
19. Chisholm D, Healey A, Knapp M. QALYs and mental health care. *Soc Psychiatry Psychiatr Epidemiol* 1997; **32**: 68-75.
20. Voruganti LNP, Awad AG, Oyewumi LK, Cortese L, Zirul S, Dhawan R. Assessing health utilities in schizophrenia: a feasibility study. *Pharmacoeconomics* 2000; **17**: 273-86.
21. O'Brien BJ, Novosel S, Torrance G, Streiner D. Assessing the economic value of a new antidepressant: a willingness to pay approach. *Pharmacoeconomics* 1995; **8**: 34-45.

22. Unutzer,J, Katon WJ, Russo J, Simon G, von Korff M, Lin E, Walker E, Ludman E, Bush T. Willingness to pay for depression treatment in primary care. *Psychiatr Serv* 2003; **54**: 340-345.
23. Diamond PA, Hausman JA. Contingent valuation: is some number better than no number? *J Econ Perspect 1994;* **8**: 45-64.
24. Portney PR. The contingent valuation debate: why economists should care. *J Econ Perspect* 1994; **8**: 3-17.
25. Johannesson M, Weinstein MC. 1996. Designing and conducting cost-benefit analyses. In *Quality of Life and Pharmacoeconomics in Clinical Trials*, ed. B Spilker. Philadelphia: Lippincott-Raven Publishers
26. Smith RD. The discrete-choice willingness-to-pay question format in health economics: Should we adopt environmental guidelines? *Med Decis Making* 2000; **20**: 194-206.
27. Gafni A. Willingness to pay: what's in a name? *Pharmacoeconomics* 1998; **14**: 465-470.
28. Wagner TH, Hu T-w, Duenas GV, Pasick RJ. Willingness to pay for mammography: item development and testing among five ethnic groups. *Health Policy* 2000; **53**: 105-121.
29. Coast J. 1999. The appropriate uses of qualitative methods in health economics. *Health Econ* **8**: 345-53.
30. Chilton SM, Hutchinson WG. Do focus groups contribute anything to the contingent valuation process? *J Econ Psychol* 1999; **20**: 465-83.
31. Ryan M. Using willingness to pay to assess the benefits of assisted reproductive techniques. *Health Econ* 1996; **5**: 543-58.
32. Leighninger RD, Jr., Speier AH, Mayeux D. How representative is N.A.M.I.? *Psychiatr Rehabil J* 1996; **19**: 71-73.
33. Donaldson C, Shacklet P, Abdalla M, Miedzybrodzka Z. Willingness to pay for antenatal carrier screening for cystic fibrosis. *Health Econ* 1995; **4**: 439-452.
34. Chestnut LG, Keller LR, Lambert WE, Rowe RD. Measuring heart patients' willingness to pay for changes in angina symptoms. *Med Decis Making* 1996; **16**: 65-77.
35. Johannesson M, Jonsson B, Borgquist L. 1991. Willingness to pay for antihypertensive therapy – results of a Swedish pilot study. *J Health Econ* 1991; **10**: 461-473.
36. Collins D. 2003. Pretesting survey instruments: An overview of cognitive methods. *Qual Life Res* **12**: 229-238.
37. Fowler FJ. 1995. *Improving Survey Questions*. Thousand Oaks, CA: Sage Publications
38. Ware NC, Dickey B, Tugenberg T, McHorney CA. CONNECT: A measure of continuity of care in mental health services. *Ment Health Serv Res* 2003; **5**: 209-221.
39. Strauss A, Corbin J. 1990. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Newbury Park, CA: Sage.
40. Tessler R, Gamache G. 1994. *Toolkit for evaluating family experiences with severe mental illness*, Health Services Research Institute, Cambridge, MA
41. Eisen SV, Grob MC. 1996. BASIS 32: Behavior and Symptom Identification Scale. In *Outcomes Assessment in Clinical Practice*, ed. B Dickey, pp. 65-9. Philadelphia, PA: Williams and Wilkins
42. Tessler R, Gamache G. 1996. The Family Burden Interview Schedule – Short Form. In *Outcomes Assessment in Clinical Practice*, ed. B Dickey, pp. 110-2. Philadelphia, PA: Williams and Wilkins
43. Franks DD. 1987. *The high cost of caring: economic contribution of families to the care of the mentally ill*. Unpublished dissertation thesis. Brandeis University, Waltham, MA. 190 pp.
44. Larson RA. Patients' willingness to pay for pharmaceutical care. *J Am Pharm Assoc* 2000; **40**: 618-624.
45. Ryan M. Valuing psychological factors in the provision of assisted reproductive techniques using the economic instrument of willingness to pay. *J Econ Psychol* 1998; **19**: 179-204.
46. Johannesson M. The contingent valuation method – appraising the appraisers. *Health Econ* 1993; **2**: 357-359.
47. Eastaugh SR. Willingness to pay in treatment of bleeding disorders. *Int J Technol Assess Health Care* 2000; **16**: 706-710.
48. Hatfield AB, Gearon JS, Coursey RD. Family members' ratings of the use and value of mental health services: results of a national NAMI survey. *Psychiatr Serv* 1996; **47**: 825-831.
49. Thompson MS. Willingness to pay and accept risks to cure chronic disease. *Am J Public Health* 1986; **75**: 392-396.
50. Chiu L, Tang K-Y, Liu J-L, Shyu W-C, Chang T-P. Willingness of families caring for victims of dementia to pay for nursing home care: results of a pilot study in Taiwan. *J Manag Med* 1998; **12**: 349-360.
51. Ringel JS, Sturm R. Financial burden and out-of-pocket expenditures for mental health across different socioeconomic groups: results from healthcare for communities. *J Ment Health Policy Econ* 2001; **4**: 141-150.
52. Johannesson M, Johansson P-O, Kristrom B, Gerdtham U-G. Willingness to pay for antihypertensive therapy – further results. *J Health Econ* 1993; **12**: 95-108.
53. O'Brien B J, Goeree R, Gafni A, Torrance GW, Pauly MV, Erder H, Rusthoven J, Weeks J, Cahill M, Lamont B. Assessing the value of a new pharmaceutical: a feasibility study of contingent valuation in managed care. *Med Care* 1998; **36**: 370-384.
54. Zuvekas S. Prescription drugs and the changing patterns of treatment for mental disorders, 1996-2001. *Health Aff* 2005; **24**: 195-205.
55. Shiell A, Seymour J, Hawe P, Cameron S. Are preferences over health states complete? *J Outcome Meas 2000;* **9**: 47-55.
56. Dolan P. Whose preferences count? *Med Decis Making* 1999; **19**: 482-6.
57. Sen A. Rationality and social choice. *Am Econ Rev* 1995; **85**: 1-24.
58. Donaldson C, Thomas R, Torgerson DJ. Validity of open-ended and payment scale approaches to eliciting willingness to pay. *Appl Econ* 1987; **29**: 79-84.
59. Olsen JA, Donaldson C. Helicopters, hearts and hips: Using willingness to pay to set priorities for public sector health care programmes. *Soc Sci Med* 1998; **46**: 1-12.
60. Thomas R, Donaldson C, Torgerson DJ. Who answers 'willingness to pay' questions? *J Health Serv Res Policy* 2000; **5**: 7-11.
61. Healey A, Chisholm D. Willingness to pay as a measure of the benefits of mental health care. *J Ment Health Policy Econ* 1999; **2**: 55-58.
62. Whittaker D, Vaske JJ, Donnelly MP, DeRuiter DS. Mail versus telephone surveys: potential biases in expenditure and willingness-to-pay data. *J Park Recreation Admin* 1998; **16**: 15-30.
63. Bennett KJ, Torrance GW. 1996. Measuring health state preferences and utilities: rating scale, time trade-off, and standard gamble techniques. In *Quality of Life and Pharmacoeconomics in Clinical Trials*, ed. B Spilker. Philadelphia: Lippincott-Raven Publishers
64. Hargreaves WA, Shumway M, Hu T, Cuffel B. 1998. *Cost-outcome methods for mental health*. San Diego: CA: Academic Press

Appendix I

WTP-A

Now, think about the problems that you have circled on the previous page. What is the most you would be willing to pay on a **yearly** basis for a complete and permanent remission of your family member's mental illness?

- In other words, what is the most you would pay each year to relieve your family member of all problems due to mental illness?
- Assume that you will pay the same amount yearly from your available income, and that your family member's mental illness will not recur during this time.
- When deciding how much you would pay, you may want to consider any savings in expenses that might result from the remission.
- Be sure to consider your budget in your answer, and remember that the money you spend on this will not be available to spend on other things.

(Please consider all the monetary amounts below carefully. Check yes if you are willing to pay that amount. Check no if you are not willing to pay that amount. Then, circle the **maximum** amount you are willing to pay **each year**.)

Willing to pay:	YES	NO
$0	—	—
$250	—	—
$500	—	—
$1000	—	—
$1500	—	—
$2500	—	—
$5000	—	—
$10,000	—	—
$20,000	—	—
$30,000	—	—
$40,000	—	—
$50,000	—	—
$100,000	—	—
$150,000	—	—
$ 200,000	—	—

If you circled $200,000 above, what is the maximum amount you would be willing to pay each year?

$ _____

Appendix II

WTP-B

For the next question, we would like you to think about a person who is experiencing an acute episode of mental illness. This person is not your family member. She is taken to be evaluated, and is asked a number of questions that are used to determine her health. On one typical measure of mental health, she receives a score of 4, which is a very poor score. Below is a description of this person's behavior when she is first evaluated and scores a 4.

SCORE 4

The patient appears severely distressed and makes numerous references to suicide. She is clear that she plans to overdose on alcohol and sedatives. She is experiencing insomnia, dizziness, rapid heartbeat, and extreme feelings of worthlessness in life. She reports hearing voices and is afraid to leave her house for fear some stranger will try to hurt her. She is bingeing on shots of whiskey five days a week. She is having a hard time managing day-to-day life. She is neglecting the cleaning, shopping and other household tasks. She has been unable to find work though she claims to be looking for it. She feels extremely isolated.

Now, imagine that this person enters a period of treatment. At the end of treatment, this person is again evaluated. This time she scores a 1, which is a very good score. Below is a description of this person's behavior after treatment when she scores a 1.

SCORE 1

Client appears much less depressed and anxious. She says she no longer wants to kill herself and feels more optimistic about the future. She has stopped drinking and is going to AA meetings. Her physical symptoms of dizziness and rapid heartbeat have stopped. She is no longer hearing voices, nor feeling fearful when she leaves the house. She is finding it easier to take care of herself and her home. She has also developed a good working relationship with a therapist and reports feeling less isolated. She has an appointment next week with a job counselor.

Now, think about your family member. For this question, we are going to ask you to imagine that your family member is experiencing symptoms similar to the person at SCORE 4 above. He or she is struggling with a serious mental illness that is treatment resistant, and remains stuck at SCORE 4 on the outcome measure described above.

- Assume that a new drug becomes available that could move your family member from SCORE 4 to SCORE 1.
- This drug is effective 50/80% of the time. In other words, 1 out of 2/4 out of 5 people will experience a successful outcome.
- By successful, we mean that a person who takes the medication as prescribed will stay at SCORE 1 for an entire **year**.
- If it works, the medication and a monthly consult is the only psychiatric medical expense that the family member will need during this time. The family member may still need some help with living expenses, but at a much lower intensity than before.
- You cannot reduce or stop the payments for *that entire year* once you start, even if your family member does not respond to the medication.

Would you be willing to pay **[one of the following values is inserted: $25, $75, $150, $350, $500, $1500, $5000]** a month for this drug for the next twelve months? (please circle)

1 YES
2 NO

If no, why not?

_____
_____
_____
_____

Appendix III

WTP-C

Introduction to WTP question

As you know, there are many medications currently being developed to treat these and other symptoms of serious mental

illness. Some of these medications are very expensive. Sometimes they work well, and sometimes they do not work so well. Families often must make difficult decisions about treatment for their family members based upon the resources they have available.

One of the realities of our current health care system is that treatment for serious mental illness is not always available for everyone. People's ability to pay and willingness to pay out of pocket for treatment and services will vary. Families all have many obligations and monetary responsibilities. Some families may be able to contribute to their family member's care, while other families may need help from government programs such as Medicaid. In order to understand the impact of serious mental illness on the family, policy makers need to know how these financial demands differ from family to family. One way you can help us understand this impact is by estimating how much you would pay for improvements in your family member's ability to function.

We understand that asking the monetary value for such improvements is crude and varies tremendously. Certainly, the true value of these improvements to yourselves and your family member can never be expressed simply in monetary terms. Nevertheless, by getting a sense of how much you would pay for improvements in the functioning of your family member, you can help us provide policy makers with very valuable information about the impact of serious mental illness on families. Hopefully, this information can be used to make real, concrete improvements in people's lives.

THE QUESTION

For this next question, we would like for you to consider a possible scenario. Imagine that a new medication is available that could dramatically improve your family member's functioning. Whatever your family member's current problems, this medication decreases the symptoms of serious mental illness in such a way that your family member is able to live a stable life. For example, family members with serious mental illness who were previously unable to work are now able to support themselves independently, without help from you or government programs. Family members who were unable to maintain social relationships are now able to develop and sustain social supports and friendships. In other words, this new medication decreases the symptoms and problems associated with serious mental illness in such a way that your family member is able to maintain a job, friends, a stable place to work, and other aspects of a typical life.

Consider the following:

- The medication is not covered by health insurance
- **You** will need to pay for this medicine out of pocket for your family member each year.
- This is the only psychiatric expense your family member will have during this time.

Now, given your income and savings, what is the most **you would be willing and able to pay on a yearly basis for this medication?**

- Assume that you will pay the same amount yearly from your available resources and that your family member's improved function will continue during this time.
- Be sure to consider any savings in your current expenses that might result from your family member's improved function.
- Remember that the money you spend on this will not be available to spend on other things.

(Please consider all the monetary amounts below carefully. Please check and then circle the **maximum** amount you are willing to pay **each year**.)

Willing to pay:
$0
$250
$500
$1000
$1500
$2500
$5000
$7500
$10,000
$20,000
$30,000
$40,000
$50,000
$100,000
$150,000
$200,000

a. If you circled $200,000 above, what is the maximum amount you would be willing to pay each year?

$_____