

Perspectives on Medical Research Involving Men in Schizophrenia and HIV-Related Protocols

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Ethical issues in research on serious physical and mental illnesses have received great attention, and yet little is known about how the perspectives of clinical research participants with different diagnoses may compare. We conducted a preliminary study to examine the attitudes of men enrolled in schizophrenia-related protocols and in HIV-related protocols regarding the importance of medical research, key aspects of research participation, and the acceptability of research involvement by various groups. A total of 33 men enrolled in schizophrenia protocols and 15 men enrolled in HIV-related protocols volunteered for our study. Respondents affirmed the importance of medical research and endorsed many positive things about participation. Autonomy and altruism were identified as motivators for research involvement. Participation by diverse groups was seen as acceptable. Respondents expressed comfort and little stress with the interview process. Men in different diagnostic groups largely saw the issues the same. Our findings thus suggest that people with schizophrenia and HIV/AIDS who are enrolled in protocols may share a number of core attitudes or beliefs related to ethical aspects of research participation. Further study is needed to explore how research involvement may influence perspectives and whether differences in views exist across people with diverse physical and mental illnesses.

Key words: schizophrenia/HIV/research/protocols

Introduction

Over the past 2 decades, biomedical and psychosocial research focusing on 2 illnesses, schizophrenia and

HIV/AIDS, has grown dramatically.^{1–4} These valuable scientific efforts have generated evidence-based therapies that have demonstrably improved quality of life, symptom severity, and functional outcomes for people in our country who are living with these diseases. Nevertheless, enthusiasm for scientific investigation of schizophrenia in particular and, to a lesser extent, of HIV/AIDS has been tempered by concerns about the potential vulnerability of research volunteers with these severe and devastating illnesses.^{5,6} Scientists, advocates, and policy-makers alike have raised awareness of challenges associated with both schizophrenia and HIV/AIDS research, encompassing issues such as stigma and societal disadvantage, cognitive compromise, emotional desperation, and insufficient access to clinical care associated with these health conditions.^{7–9}

Positive efforts to clarify and resolve concerns about the ethical acceptability and necessary safeguards in human research have increasingly sought to include the perspectives of those most affected by these efforts, namely, persons who live out the course of each day with various illnesses. An emerging empirical literature has begun to document the views of people with diverse physical and mental conditions.^{10–15} For example, Edwards, Lilford, and Hewison reviewed 14 empirical studies of participant attitudes, finding that self-concern and altruism were strong motivators for participation and that, in 4 studies of informed consent in clinical trials, at least 80% of participants had been satisfied with the information they had received in making their enrollment decision.¹² In a study of 144 advanced cancer patients' perspectives, Daugherty et al. learned that many had positive attitudes toward research and that the desire for hope and for psychosocial benefit influenced participation decisions.¹³ In our prior data-based work with people with schizophrenia, we documented favorable attitudes toward research.^{14,15} In other studies with other participant groups, we have found that medical research is seen as important, that participation is viewed as beneficial to individuals, science, and society, and that enrollment in studies is affirmed, even when personal benefit is not possible.^{16–18}

While the empirical literature on research ethics issues is growing rapidly, very little is as yet understood through direct comparison of attitudes toward research as expressed

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by protocol participants with differing diagnoses.^{19–22} This is an important consideration because often the ethical attributes of research are linked to the specific diagnosis, as well as to the nature of the illness under study.^{23–26} For this reason, we undertook a preliminary structured interview study to assess the views of men enrolled in schizophrenia-related protocols and in HIV-related protocols regarding the importance of medical research, key aspects of research participation, and the acceptability of research involvement by various groups. We hypothesized that protocol participants, irrespective of illness type, would strongly affirm the importance and acceptability of medical research and strongly affirm participant autonomy and altruism as motivations for participation. We further hypothesized that comparisons across illness type (ie, schizophrenia vs HIV/AIDS) would reveal that people would more strongly endorse attitudes in support of medical research pertaining to their own illness type.

Methods

Procedure

Individuals involved in active protocols at the University of New Mexico Health Sciences Center and the Albuquerque Veterans Affairs Medical Center were eligible for our pilot project. Only protocol participants who expressed interest and gave written permission were contacted by our project coordinator. Information about the pilot project was provided over the telephone, and those protocol participants who indicated willingness to participate were scheduled for an appointment. A trained interviewer obtained written informed documentation of consent and administered the survey instrument and interview. The instrument asked about a wide range of issues pertaining to various aspects of research participation with rating scale measures: (1) 23 items about experience with informed consent on their current clinical protocol; (2) 32 items about other specific experiences with the clinical protocol in which they were currently enrolled; (3) 63 items about 7 hypothetical protocols; and (4) 91 items about general research participation. In addition, 19 demographic measures were assessed, and standard scales^{27–29} assessed symptoms, quality of life, and social support levels. Here we report only on a subset of dependent variables, which asked about general research participation, that are directly relevant to HIV and schizophrenia patients. Volunteers completed the survey and the in-person interview session in 1.5 to 2 hours and received \$25 in compensation.

Safeguards

This study was funded by the National Institute of Mental Health and the National Institute on Drug Abuse and was approved by the institutional review boards of the

data collection sites, and informed consent was documented. Data were confidentially encoded.

Data Analyses

For the portion of the study presented here, we analyzed responses from men who were enrolled in schizophrenia- or HIV-related protocols. Items analyzed as a single dependent measures were subjected to a *diagnostic group* (schizophrenia vs HIV) (between subjects) analysis of variance (ANOVA). For questions that were interrelated as conceptual sets, we added these dependent measures as a within-subjects factor with the design of *item* (within subjects) \times *diagnostic group* repeated measures multivariate analysis of variance (MANOVA). For sets of items concerning specific illnesses, we performed simple contrasts of schizophrenia or HIV items versus other illness items separately for responses from respondents in the respective diagnostic groups. Cohen's *d* (the standardized mean difference) is reported as a measure of effect size.

Correlations of Brief Symptom Inventory (BSI) Global Severity, Short Form-36 (SF-36) Current Health, and Social Support Survey (SSS) total scores with the dependent measures were assessed to describe characteristics of our participants, and the relationships of these measures with dependent measures were examined.

Results

Participant Characteristics

Thirty-three men who were enrolled in schizophrenia-related protocols and 15 men who were enrolled in HIV-related protocols volunteered for our study. Participants with schizophrenia were 41% white, 34% Hispanic, and 25% other ethnicity, while those with HIV were 47% white, 40% Hispanic, and 13% other ethnicity. Of those with schizophrenia, 45% had some college education, and of those with HIV 60% had some college (all others in both groups had some high school or were graduates). All of the men with HIV and 96% of those with schizophrenia were single or not living with a spouse or partner. Mean (SD) age was for people with schizophrenia was 40.1 (SD = 11.0) years and 40.0 (9.7) for those with HIV. Diagnostic groups did not significantly differ by ethnicity, education, marital status, or age.

Mean (SD) scores were 1.1 (0.9) (mean is the 47th percentile for adult outpatients and 96th percentile for adult nonpatients) for BSI Global Severity, 65.6 (22.6) (44th percentile for national adult norms) for SSS, and 51.1 (24.8) (53rd percentile for national norms for adults) for SF-36 Current Health, with no differences between the illness type groups. Respondents in schizophrenia-related protocols had marginally greater psychological symptoms than did respondents in HIV-related protocols (BSI means = 1.1 vs 0.7, $p < .08$, $d = 0.45$) and marginally

better general health (SF-36 Current Health means = 55.2 vs 43.0, $p < .12$, $d = 0.50$). For respondents in schizophrenia-related protocols but not HIV-related protocols, greater BSI Global Severity was correlated with poorer SF-36 Current Health ($r = -0.62$, $p < .001$).

Importance of Medical Research

Participants rated medical research (scale of 1 = “not at all important” to 5 = “very important”) about serious mental illness and serious physical illness as very important (Ms = 4.64 and 4.82) and research about healthy people as less important (M = 3.97; Item main effect $p < 0.01$, maximum Cohen’s $d = 0.85$). Respondents also rated medical research about the illnesses HIV/AIDS, cancer, schizophrenia, and major depression as equally very important (Ms = 4.31 to 4.73; $p > 0.05$; maximum $d = 0.40$).

In comparing the responses of men with schizophrenia with those of men with HIV on the importance of medical research about specific illnesses, an item \times diagnostic group interaction ($p < .03$) was found. Our hypothesis that people would more strongly affirm the importance of medical research about their own illness than other illnesses was only partially supported. Respondents with HIV rated research about HIV as more important than research about schizophrenia or major depression (Ms = 4.93 vs 3.97 to 4.31, both $p < .03$, maximum $d = 1.20$). However, respondents with schizophrenia did not rate research about schizophrenia as more important than research about other illnesses (Ms = 4.64 vs 4.45 vs 4.52 vs 4.48, maximum $d = 0.17$). Nevertheless, respondents with schizophrenia assigned greater importance to research about schizophrenia than did respondents with HIV (Ms = 4.64 vs 3.97, $p < .05$, $d = 0.64$), and those with HIV assigned greater importance to research about HIV than those with schizophrenia (Ms = 4.93 vs 4.48, $p < .05$, $d = 0.43$) (see Table 1).

Perspectives on Participation

Participants from both diagnostic groups strongly agreed that there are “many positive things about participating in research projects” (M = 4.65, scale of 1 = “strongly disagree” to 5 = “strongly agree”) and disagreed that there are “many negative things” (M = 2.24, Cohen’s $d = 2.34$, item main effect $p < .0001$). There was more response variability regarding whether there are “many negative things” than “many positive things” in medical research (SDs = 0.69 vs 1.38, $p < .01$), indicating greater differences in opinion of respondents about whether there are negative aspects of research. For participants with schizophrenia (but not those with HIV), greater perception of “many positive things” about research participation was associated with having higher social support (SSS index, $r = 0.46$, $p < .02$), and greater perception of “many negative things” was associated with more

overall symptoms of illness (BSI Global Severity, $r = 0.53$, $p < 0.01$) and poorer general health (SF-36 Current Health, $r = -0.42$, $p < .03$).

Respondents strongly endorsed participant autonomy (M = 4.67, scale of 1 = “strongly disagree” to 5 = “strongly agree”) and endorsed the role of altruism as a motivation for research enrollment (M = 4.16, item main effect $p < .01$, $d = 0.49$). However, participants with HIV expressed greater agreement than did participants with schizophrenia concerning both altruism (Ms = 4.60 vs 3.74, $d = 0.82$) and autonomy (Ms = 4.83 vs 4.52, $d = 0.30$; diagnostic group main effect $p < .04$) (see Table 1).

Acceptability of Participation by Various Groups

Our volunteers rated research participation by people with cancer, HIV, schizophrenia, and major depression as acceptable (Ms = 3.94 to 4.22, scale of 1 = “absolutely not acceptable” to 5 = “absolutely acceptable”). An item \times diagnostic group interaction ($p < .03$) showed that respondents with HIV rated participation by people with HIV as more acceptable than did respondents with schizophrenia (Ms = 4.47 vs 3.97, $p < .05$, $d = 0.44$), with a similar pattern for participation by people with cancer (Ms = 4.40 vs 4.03, $p < .05$, $d = 0.33$). Respondents with schizophrenia rated participation by people with schizophrenia as more acceptable than did respondents with HIV (Ms = 4.21 vs 3.76, $p < .05$, $d = 0.48$). Respondents in both diagnostic groups assigned similar importance to participation by people with major depression (Ms = 3.93 vs 3.97, $d = 0.03$). Again, our hypothesis that people would more strongly affirm the acceptability of research participation by people with their own illness was only partially supported. Respondents with HIV rated participation by people with HIV as more acceptable than participation by people with schizophrenia or major depression (Ms = 4.47 vs 3.67 to 3.93, both $p < .06$, maximum $d = 0.88$), but respondents with schizophrenia did not show this pattern (Ms = 4.21 vs 3.97 to 4.03; maximum $d = 0.20$).

Respondents rated participation in medical research by people who are in physical pain, in emotional pain, or very sick or dying as equally acceptable (Ms = 3.73 to 3.99). No significant differences in perspectives were found when compared by diagnostic group (see Table 1).

Comfort With the Interview

We asked 2 questions regarding the semistructured interview experience: “How comfortable were you answering these questions about medical research?” and “How stressful was it for you to think about these things?” Respondents overall were comfortable answering questions (M = 4.23, scale of 1 = “very uncomfortable” to 5 = “very comfortable”). Participants with schizophrenia were less comfortable than participants with HIV (respective

Table 1. Perspectives on Medical Research Expressed by 33 Schizophrenia Protocol Participants and 15 HIV Protocol Participants

Perspectives ^a	Diagnostic Group				Effect Size <i>d</i>	Overall	
	Schizophrenia		HIV			Mean	(SD)
	Mean	(SD)	Mean	(SD)			
How important is medical research about: ^{b,c}							
Serious physical illness	4.70	(0.81)	4.93	(0.26)	-0.24	4.82	(0.74)
Serious mental illness	4.61	(1.03)	4.67	(0.62)	-0.06	4.64	(1.00)
Healthy people	4.00	(1.41)	3.93	(0.96)	0.07	3.97	(1.40)
<i>Overall mean</i>	4.43	(0.71)	4.51	(0.71)	-0.11	4.47	(0.77)
How important is medical research about: ^{b,d}							
HIV/AIDS	4.48	(1.25)	4.93	(0.26)	-0.43	4.71	(1.14)
Cancer	4.52	(1.00)	4.73	(0.59)	-0.21	4.62	(0.97)
Major depression	4.45	(1.23)	4.31	(0.89)	0.14	4.38	(1.22)
Schizophrenia	4.64	(1.02)	3.97	(1.18)	0.64	4.31	(1.15)
<i>Overall mean</i>	4.52	(0.81)	4.49	(0.81)	0.05	4.51	(0.87)
In participating in medical research, there are: ^{e,f}							
Many positive things	4.70	(0.59)	4.60	(0.74)	0.10	4.65	(0.69)
Many negative things	2.15	(1.30)	2.33	(1.23)	-0.18	2.24	(1.38)
In deciding to participate in medical research: ^{e,g}							
Autonomy is important ^h	4.52	(0.80)	4.83	(0.80)	-0.40	4.67	(0.86)
Altruism is a motivation ⁱ	3.74	(1.42)	4.60	(0.74)	-0.69	4.16	(1.35)
How acceptable is participation in medical research by people with: ^{j,k}							
Cancer	4.03	(1.26)	4.40	(0.74)	-0.33	4.22	(1.22)
HIV/AIDS	3.97	(1.33)	4.47	(0.64)	-0.44	4.22	(1.26)
Major depression	3.97	(1.19)	3.93	(0.96)	0.03	3.95	(1.21)
Schizophrenia	4.21	(1.05)	3.67	(1.18)	0.48	3.94	(1.18)
<i>Overall mean</i>	4.05	(0.91)	4.12	(0.91)	-0.08	4.08	(0.98)
How acceptable is participation in medical research by people who are: ^{j,l}							
Very sick or dying	3.91	(1.26)	4.07	(1.03)	-0.13	3.99	(1.29)
In physical pain	3.97	(1.16)	4.00	(0.76)	-0.03	3.98	(1.14)
In emotional pain	3.73	(1.42)	3.73	(0.96)	-0.01	3.73	(1.40)
<i>Overall mean</i>	3.87	(1.02)	3.93	(1.02)	-0.06	3.90	(1.10)

^aMeans are from repeated measures item × diagnostic group multivariate analysis of variance (MANOVA) analyses for each item set.

^bScaled from 1 = “not at all important” to 5 = “very important.”

^cItem main effect $F_{2,45} = 7.10, p < .01$; pooled SD = 1.00; item mean differences (> 0.50 within the schizophrenia group, > 0.74 within the HIV group, and >0.41 overall) are significant at $p < .05$ by Fisher’s least significant difference method (LSD).

^dItem × diagnostic group interaction $F_{3,44} = 3.37, p < .03$; pooled SD = 1.04; item mean differences (> 0.43 within the schizophrenia group, > 0.63 within the HIV group, and >0.35 overall) are significant at $p < .05$ by Fisher’s LSD.

^eScaled from 1 = “strongly disagree” to 5 = “strongly agree.”

^fItem main effect $F_{1,46} = 18.11, p < .001$; “many positive things” item was reverse scaled for analysis.

^gItem main effect $F_{1,46} = 7.48, p < .01$, diagnostic group effect $F_{1,46} = 4.80, p < .04$; pooled SD = 1.05. Item mean differences (> 0.42 within the schizophrenia group, > 0.62 within the HIV group, and > 0.35 overall) are significant at $p < .05$ by Fisher’s LSD.

^h“Autonomy is important” is a composite of 2 items (“People should be allowed to make up their own minds about whether to participate in research” and “People who agree to participate should be allowed to change their minds later”); $r = 0.57, p < .0001$.

ⁱ“Altruism is a motivation” is 1 item (“People should participate in research projects that might help others in the future, even if it doesn’t help them personally now.”)

^jScaled from 1 = “absolutely not acceptable” to 5 = “absolutely acceptable.”

^kItem × diagnostic group interaction $F_{3,44} = 3.37, p < .03$; pooled SD = 1.13; Item mean differences (> 0.46 within the schizophrenia group, > 0.69 within the HIV group, and >0.38 overall) are significant at $p < .05$ by Fisher’s LSD.

^lNo significant effects; pooled SD = 1.18.

$M_s = 3.79$ vs $4.67, d = 0.71$, diagnostic group effect, $F_{1,46} = 5.17, p < .03$). Respondents did not find thinking about medical research to be stressful ($M = 4.09$, scale of 1 = “very stressful” to 5 = “not at all stressful”). Participants

with schizophrenia reported more stress with the interview than did participants with HIV (respective $M_s = 4.53$ vs $3.64, d = 0.72$, diagnostic group effect $F_{1,46} = 5.50, p < .03$).

Discussion

In this initial study we sought to determine the usefulness of a semistructured interview method for exploring the perspectives expressed by men enrolled in schizophrenia and HIV protocols regarding medical research. The semistructured interview was tolerated well by the participants, with most indicating a high level of comfort and very little stress associated with the process. We found strong congruence in the views of the importance of medical research about serious physical and mental illnesses and about healthy people. Respondents in both diagnostic groups also expressed similar attitudes toward positive and negative aspects of research participation and the acceptability of involvement by people who are very sick or dying, in physical pain, and in emotional pain. It is intriguing that no clear areas of disagreement were identified between men with HIV and men with schizophrenia.

A pattern emerged in which respondents with HIV/AIDS more strongly endorsed the importance of HIV/AIDS research, altruism as a motivation for participation, and the acceptability of people with HIV/AIDS being involved in human studies than men with schizophrenia did. Interestingly, people with schizophrenia did not see serious mental illness research or schizophrenia research as more important than other illnesses, but they did view participation by people with schizophrenia as more acceptable than did the HIV/AIDS respondents.

The absence of an emphasis on one's own illness (ie, what has been described as a self-interested or "self-serving" bias³⁰) in the responses of people with schizophrenia—when contrasted with this pattern among respondents with HIV/AIDS—may be due to the potential greater lethality of HIV relative to schizophrenia. It may also be due to a lack of appreciation of serious mental illness or due to cognitive differences between the groups—although the similarity of other ratings between the groups seems to imply otherwise. More positively, people with schizophrenia may assign importance to all forms of illness. More exact research designs will be needed to clarify how people with different serious illnesses assign priority to different foci in clinical research.

Our findings thus suggest that people with schizophrenia and HIV/AIDS who are enrolled in protocols may share a number of core attitudes or beliefs that may be characterized as research-receptive. Whether and how these views may be linked to research participation remain unclear: they may lead to protocol enrollment, they may be shaped by the research experience, they may be related to living with serious illness, or they may be views held in common with other people in our society. This result requires further study. Nevertheless, it raises interesting questions about the presumed differences in perspectives toward research between people with different kinds of diseases. Concern about attitudes of seriously ill individuals who may be vulnerable to

exploitation in the research situation, for example, has contributed to the vigorous debate about the need for additional safeguards for protocol volunteers with serious mental illness.^{7,8,31} One final issue reflected in our results pertains to how the opportunity to become involved research is viewed by people living with diverse illnesses. Historically, individuals with HIV/AIDS have been far more active as stakeholders in the research endeavor than have patients with schizophrenia or other mental illnesses. HIV/AIDS advocates lobbied for increased funding and faster approval of experimental drugs, especially during the early years of the epidemic in the United States. Very recently, however, consumers of mental health care and advocacy organizations appear to have grown in their visibility and influence. Over time, these 2 illness groups may have a common concern in supporting access to innovative, promising biomedical research.

The data derived from this pilot project must be interpreted in light of many limitations. The study involved a small sample of men who were enrolled in clinical research protocols in Albuquerque, New Mexico. Our semistructured interview instrument was developed *de novo* for this study, and our methodology relied on self-reported attitudes. Each of these factors may introduce bias. Moreover, the relationship between views of research and actual research-related decision making has not been established. Future work is needed to determine the generalizability of these results and their potential significance. Nevertheless, these data should serve to remind us of the sense of commitment demonstrated by our partners in the research process—the seriously ill people who generously volunteer to help in scientific efforts to better understand the causes and treatment of disease.

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