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THE PROCESS OF SELF-REPORT OF IMPAIRMENT IN CLINICAL RESEARCH

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Abstract

This paper examines how labels for impairment are negotiated by people with disabilities during clinical assessment. It builds on Robert Murphy's (1987) explanations of the disability experience as rooted in the individual's sense of having multiple past, present and intended future body-selves. Using transcripts of five consecutive daily clinical research assessments, it describes the conduct of clinical research assessments with an older man with stroke-related motor impairments and dysphoria. It also examines how the researcher as Other shapes a person's sense of identity, experience and quality of life by regulating the medical labels for personal experience, and by authoring socially authoritative scientific models of disabilities. Points of dissension (regarding identity, discourse and time perspectives) and collaboration are identified and then illustrated with excerpts from the transcripts. Analysis reveals how salient personal experiences are locally asserted in discourse, and selectively misrepresented in the clinical research record.

Keywords

disability; self-report; discourse; aging; clinical research

INTRODUCTION

The self-representations of impairment[*] by people with disabilities and the influences of others on these representations is examined in this paper. It contributes anthropological insights by drawing from the experiences of two experts on living with impairment. The first expert is Robert Murphy, an anthropologist who describes his own progressive disability in *The Body Silent* [1]. The second expert is an elderly man with arm weakness from a stroke whom we observe as he explains his state of health and disability during five daily standardized tests for a clinical psychology research study. These two experts show how a subject's concern with discourse, personal identity and meanings shape the self-reports that researchers regard as an unsullied picture of subjective experiences. The influence of these factors on measurements of health is inadequately captured by survey-based behavioral

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[*] The terms used here follow the WHO nomenclature [77, *cf* 78] which defines *impairment* as the loss of physical function, and *disability* as a limited ability to perform activities. *Handicap* refers to problems caused by the disability in a society. Thus, polio may both limit a person's ability to use their legs (the impairment) and to climb stairs (the disability). The social fall-out is that employers refuse to hire the person (the handicap).

research or clinical diagnostic approaches. Behavioral and clinical science tends to view research data as value free and context independent representations of the world.

The example below illustrates how social contexts influence the data on health. Compare the first quote from a journal article where clinical psychology researchers report findings with the second quote drawn from a taperecording of the actual research interview. The article presents results from a large quantitative survey of daily changes in health and mood among elderly people. The quote illustrates some of the presuppositions of behavioral science research. The decontextualized nature of survey data provides no information on the content or context of the reasons subjects give for their answers. Thus, the authors are forced to speculate about what type of person might correspond to their data,

> As more is learned about individual differences in intrapsychic variation, however, it may be that close analysis of idiosyncratic patterns in association with other information about the person will enable understanding of the *person*. One *subject's data* was characterized by variation concentrated in the joint shifting of annoyance, irritability, and sadness. Variation of these three affect items had relatively little to do with any of the positive affects with the more extreme negative terms depression and worry. *One may imagine this person* as one with no lack of general affective responsiveness but who exhibits *an underlying critical nature* associated with proneness to disappointment as a recurrent theme … Another curious example is the data of a one-factor subject whose happiness, contentment, and lack of depression and sadness occur in concert with being annoyed and irritated. *It does seem that such people exist in real life!* [2, p. P196, (emphasis added)].

The quote attests to the traditional behavioral science view of data collection as relatively unproblematic and of focusing on personality types rather than on actions in social contexts. It exemplifies the doctrine of operationalization in psychometric research whereby a concept or process is reduced to a composite measure of traits or survey items. The quote also illustrates a trend towards the analyses of individual cases [3], but without the social sciences' perspective on individuals as self-determining and purposeful whole persons [4–7].

Now, for comparison, let us eavesdrop on the actual conversation of one of the people 'imagined' above rather than simply speculating 'such people exist in real life.' Here, the subject quoted above has just answered that he is 'having excruciating pain,' and is next asked,

Researcher:	Right now, are you feeling sad?	144-5
Mr Vetch:	Yes.	145-5
Researcher:	You answered you felt sad. Is it extremely sad, a little bit?	146-5 147-5

Mr Vetch: It ain't bad. You know when you—you ask me questions but, but **when something hurts you how could you feel happy?**

Researcher: It depends on the person. It is such a personal thing.

Mr Vetch: **Must be you are a stupid person to feel good**.

Researcher: Not necessarily, there are different reasons. Some people have a lots of reasons to feel bad.

Mr Vetch: **You know *I* am not stupid!**

This dialogue contradicts the journal article's conjecture about a generalized underlying nature or personality disposition. The interview settings during which talk about personal experience is transformed into scientific data are problematic, sometimes contentious, interactions even in the most standardized tests. Using parody, Mr Vetch challenges the researcher's authority and basic rationality, "how could you feel happy …," and "Must be you are a stupid person to feel good." He also claims his reply is intelligent, "You know I am not stupid," and sensible in the context of his whole life. He decries the fragmentation of his experience and identity into the disconnected abstract labels of quantitative measurements, such as degrees of pain or of sadness (e.g. some, a little). The transcript shows that the researcher–Other authoritatively directs a process of selective forgetting [8] and dismembering of experiences from the body of personal and social contexts in order to make usable data.

However, subjects do not acquiesce to forgetting. They contest and reframe the task, the questions, and even the meaning and form of the set answers they designate. Subjects attend to the explicit questions, but also to cultural expectations for conversation, social interactions and to the composite self-image which builds across the separate questions and answers across the whole interview. The subject's reinterpretations do not become part of the data, even though they are prominent in the process of negotiating answers and translating experiences.

This paper aims to describe the negotiation of labels for daily self-reports of health and affect occurring when personal concerns and meanings are made into 'data' during clinical psychology research tests. It asks several questions. In what ways do subjects seem to understand research questions and construct answers? How does the researcher–Other help, alter, or subvert the representations of those understandings? How does a subject's attention to interactional features (e.g. language performances, self-image and pragmatics) contribute to or mask the very variations in standardized scores regarded as indexical of the internal states?

The goal here is not to catalog the epistemology, limits and strengths of behavioral and biomedical research; these are provided elsewhere [9–14]. The purpose is to provide anthropological descriptions of the construction of public labels for personal experience in actual instances of research interview question and answer sequences. It builds from a view of subjects as intending [15], self-aware beings who judge a variety of contextual dimensions and who work to shape and are shaped by their situations.

This paper begins by describing the nature of ‘Others’ contributing to the construction of impairment self-reports from the perspective of two people with personal expertise in living with disability. It outlines Robert Murphy’s conceptual framework for disability experience. Next it extends his framework to analyze transcripts of a clinical researcher conducting research interviews with an elderly man. It closes by summarizing the findings and discusses overlaps in experiences between the two experts.

Studies of the ‘Other’ in the lives of people with disability reveal the collective force of sociocultural concepts of health and functioning on shared and personal values and beliefs about disability and the disabled. Earlier studies focused on informal daily contacts with friends, family and community members, and more recently on encounters with formal institutions, including patient–doctor interactions and medical training in seminal works on science and biomedicine [16–18, 11, 10, 19–21].

Another category of ‘Others,’ the clinical researcher, also shapes the conditions and experiences of disability. As a “culturally designated expert” [22, pp. 9–10, 23] the clinical research psychologist–Other doubly informs the conditions of life of persons with disabilities. First, during the face-to-face interviews the experts restrict the categories that subjects can use to describe themselves. The researcher shapes the report of subjective experience, for example, by limiting the dialogue to ‘scientific’ concerns and categories, by regulating the acceptable forms for describing experiences, and by giving medical labels to aspects of personal experience (labels which come to stand for the whole person, e.g. the ‘dementia case’). That is, the psychologist researcher makes both the data and the person.

Second, these designated experts compose authoritative scientific models of ‘The Disabled’ populations. These data becomes part of the collective knowledge of a society which is used to legislate nation-wide medical practices and public policies. Also, these same scientific models infuse contemporary social and media images of people with impairments. Thus, the clinical psychology Other shapes the broad and the immediate conditions of life for people with disabilities. It is important to develop our understanding of these processes.

‘THE OTHER‘ IN EXPERIENCES OF DISABILITIES: ROBERT MURPHY’S THREE BODY/SELF POTENTIALITIES

Robert Murphy’s *The Body Silent* (TBS) is an anthropologist’s description of his own physical weakness and impairments due to a benign spinal tumor. It tells how he comprehends the progression into quadriplegia and immobility, the changes in himself and in his relationships with the world. Woven into the telling is a heuristic for exploring the processes and nature of disability. His insights into the ‘Other’ (social Others, and his former able-selfs as Other) and experiences of disabilities will shed light on the transcripts of clinical research interviews examined in the next section. This brief summary does not allow for discussion of how TBS echoes and diverges from the growing scholarship on the body and embodiment [24, 13].

Murphy argues that experiencing disability heightens awareness of a break in the continuity in one's habits for making meanings and selves. The awareness taps two realms, person-centered processes of meaning-making, and cultural levels of meaning-making. The first realm is identified as the dialectic between urges for withdrawal and engagement at three levels of '*being*:' the body, the body and its relationship to self-awareness, and the self and society. Discussion of these form the bulk of his book. Another significant level of withdrawal focuses on the possibilities for *becoming*. This focuses on the socially expectable future life course [25, 26] (e.g. marriage, work, family, retirement) and selfs each with an implicit cultural teleology for continued development of the self and social life. The second realm concerns the reversal of fundamental cultural logics for defining the self, guilt and states of mind (Table 1).

Being and the experience of disability

Murphy argues that the experience of being in the world is permeated by impulses to withdraw or sequester [1, p. 109ff] as well as to join with others. While the impulse to sequester is shared by all people, it is heightened for people with disabilities. The impulse extends inward, to instill a sense of withdrawal of oneself from one's body—"separated from others, and riven from within" [1, p. 227]. The impetuses to withdraw and *ennui* [1, p. 89] are both conscious and unconscious, both self and other motivated.

Each arena of sequestering, the biophysiological, body-self and sociocultural reinforces the others. Biophysiological impetuses to withdraw derive from what Murphy describes as a visceral fatigue, pain and lessened endurance for each day's tasks. Architectural barriers further sap the energy of those living with impairments. For example, stairs and carpeted hallways limit wheel-chair user's mobility and informal visiting. Next, the body-self alienation is a sense of an obsolete 'habitus' of self; the body is no longer a silent apparatus of expression and landscape of self. It assumes an alienated ('Other') other role as an impediment. Similarly, he grapples with withdrawal from customary identities as an active man. Desires to withdraw are further motivated by ideals in American culture which highly value independent movement, upright stature [27, 28] and images of perfect whole bodies, as reflected in patterns of avoidance, denigration and ascriptions of spoiled identities to the disabled. Acting in concert these factors beyond the individual's control erode the social and personal resources that are needed to resist the urge to withdraw.

Becoming and the experience of disability

"The Body Silent" offers valuable insight into these three arenas of being in the present time. Yet, these do not explain the emotional impact of the changes caused by the sequestering. A fuller explanation is achieved when these situations of 'being' are acknowledged as shaping (retrospectively, 'who was I?' and prospectively, 'who can I be?') the lifelong unfolding of the biographic self [29] of a person and possible 'becomings.' The removal of socially expectable futures [25] and potential for life changes weighs heaviest.

Simply stated, the onset of impairments transforms present-day experience by foreclosing a multitude of potential futures and selves, and also retrospectively, redefines the meanings of past events and identities that validate a person's current identity and achievements. Murphy views disability as an assault on his potential for future possibilities, not just on his earthly body and the three different dimensions of body-selfs. The existential burden of impairment is attributed to obsolescence of expected futures in the three dimensions of body-self. Becoming dislocated from the life one expects or wishes to live is catastrophic with or without disabilities, striking at the heart of the psyche that animates the culturally defined vessels and bodies of mindful persons [15]. Sustaining a perception of continuing personal biography, including the search for an encompassing ontology is important to functioning across the lifespan [26, 29–36].

Murphy's account of “being in the world” with disabilities documents how his sense of the present is enmeshed with the past and the possibility of several futures. That is, the self is sensed as a seamless flow of past–present–future(s). Impairments limit the unfolding of future biographies. But, disabilities also redefine the past. They put into question the meanings of past events and experiences in light of the present and future lived experiences. These implicit developmental or teleological perspectives are key to the interpretive framework offered by his three dimensions view of biological–personal–social features of disability experience.

It is worth noting that some have argued [37] that such simple, easily stated beliefs with deep cultural and individual significance are ignored or devalued in the practice [38] of social analyses. That is, there is a bias towards complex and pervasive symbols [39] as markers of the most significant cultural truths. Murphy's depiction of the existential issues of ‘becoming’ is a distinctive contribution to extending disability studies beyond the sociology of roles and relationships. This futuricity is a dynamic of the clinical research dialogues examined below.

Reversals of cultural logic and the experience of disability

Profound differences occur in the cultural definitions of the person. The second major focus of TBS is the direction of attributing meaning. For example, in American culture there is a causal chain that goes from wrongful act to guilt to shame to punishment. A fascinating aspect of disability is that it diametrically and completely reverses the progression while preserving every step. The sequence of the person damaged in body goes from punishment (the impairment) to shame to guilt, and finally to the crime. This is not a real crime but a self-delusion that lurks in our fears and fantasies, in the haunting never-articulated question: What did I do to deserve this?

In this topsy-turvey world of reversed causality, the punishment—for this is how crippling is unconsciously apprehended—begets the crime. All of this happens despite the fact that the individual may be in no way to blame for his condition [1, p. 93].

The cultural reversals are widespread. In disability the body is switched from a silent background for the self to the foreground as an externalized object of constant awareness. The basis of one's identity is switched from achievements and social identities to that of inabilities of the body. The impairments become a master identity [40, 20] overshadowing all other identities. Again, the social meanings that body posture communicate (to others and oneself) now become misleading. For example, limited physical movement may be interpreted incorrectly as passivity, because it is an implicitly understood idiom of distress [41] or depression, even though walking off in a huff is impossible. Westerners are socialized to link activity with well-being, thus inactivity may be interpreted as a sign of depression (by those with and without disabilities alike), illustrating the reversed reasoning where ‘the punishment begets the crime.’

Murphy’s own background may shape the insights offered by the TBS. Clearly his account is woven with ethnic and cultural threads from an Irish-American family man at midlife, a lifelong self-professed intellectualizer, actively pursuing an academic career. How are the existential and social dilemmas he perceives reflections of contemporary sensitivity to the inequalities in social power, and to privileging private experience [42]? Further, in what ways is TBS and the nature of its insights defined by his own stage in the cultural life course, and developmental stage related concerns and styles of reasoning [43, 44], or the stage in the disease trajectory? These questions cannot be explored here.

To summarize, Murphy posits that the experience of disability revolves around several points. One is the urge to withdraw caused by the physical exhaustion of living with an impaired body, the loss of habituated body-self images, and pervasive societal barriers to community participation. Another is the reversal of cultural chains of reasoning, such as feelings of guilt, shame and pain from physical disfigurement in the absence of personal culpability. He points to the impact of disabilities on the person’s sense of a continuity of personal meanings and of limited futures for the self. These dimensions are prominent features in the following study.

THE OTHER IN SELF-REPRESENTATIONS OF DISABILITIES: A CASE STUDY OF SELF-REPORT IN CLINICAL RESEARCH TESTS DIALOGUE

The labeling of impairment as negotiated between a clinical research psychologist–Other and a research subject are described. An on-going longitudinal study of mood among the elderly offered an opportunity to observe five consecutive research diagnostic interviews with one subject. In that project 12 standardized questions were used to rate pain, health and five positive moods (e.g. happy) and five negative moods (e.g. sad). Subjects were instructed to answer the question, ‘how are you feeling today’ by telling the researcher their choice from among five possible answers that ranged from ‘not at all’ to ‘extremely’ (see Table 2).

The project researchers and subject agreed to allow audiotaping of five consecutive sessions for this study, starting on the 61st day with one subject. No further observations of this or other subjects were possible due to restrictions imposed by the facility and concerns related to research involving human subjects. Each visit began with a greeting and small talk, for example, about the weather. Then the researcher started the formal test, asking, “Now I want to ask about how you are feeling today.” Each occasion lasted about 20–25 min. The researcher ended by thanking the subject and saying “see you tomorrow.”

A case study: Mr Vetch

Mr Vetch (pseudonym), the research subject was 78 year old man with no cognitive impairments. The cancer deaths of his sister, father and wife remain keenly felt. He described a great deal of current family strife between his daughter, son and himself. A mild stroke two years earlier left him with residual weakness in one arm. Due to continuing symptoms of depression he had been given a consensus diagnosis of Dysphoria.[†] The interviewer was a Ph.D. level researcher in her mid-thirties who had worked for two years at the facility where he lived. These interviews took place in Mr Vetch's room at a large teaching hospital and long-term care facility with 1100 elderly, ranging in age from 60 to over 100. At this facility healthier residents live independently in private apartments and others in the nursing-home.

Verbatim transcripts of the five occasions were prepared noting speech overlap, pauses and emphases.[‡] Texts were reviewed with the interviewer to clarify background information to the interviews. Next, two independent raters identified topic initiations and closures, discourse cycles, themes, turn-taking and statements of personal identity.[§] Analyses were conducted by systematically comparing the contexts and contents of each topic segment for each test occasion. The analyses built upon the view that discourse is a problematic interaction where participants pursue competing interests and goals and so the actual talk is the resulting solution to those problems [45, 46], as attested to by the quote at the start of this article.

RESULTS

Comparison of the verbatim transcripts with the computerized results of the test show two very different pictures of Mr Vetch. The computerized record suggests a rapid, nonproblematic test using identical questions each day that captured facts about the subject's state. In contrast, the texts depict lively discussions about the interview questions and answers. An overview of three main findings is presented followed by illustrations of each finding.

First, the interviewer repeatedly instructs Mr Vetch to report his "feelings at the moment" since the researchers intended to report on subject's daily mood. But, Mr Vetch tries to switch the topic on many occasions to assert a personal identity and self-image rooted in his past. He also redefined the meaning of the question or the allowable answers prior to

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[†] Diagnoses were drawn from mental health assessments records. These were conducted using established multidisciplinary clinical procedures performed independently by physicians, psychologists and psychiatrists. A consensus diagnosis is arrived at by combining these findings during case conferences. Depressive symptoms were assessed using the Geriatric Depression Scale and clinically defined Major Depression was judged by DSMIII-R checklist criteria. Symptoms of depression (e.g. sadness, appetite loss) are part of the normal spectrum of affect over the life course. Clinically defined depressive disorders range from 6 to 15% [79] and are *less* prevalent among the elderly than among other ages. Depression is more prevalent in old age homes [80]. At the study site 40% of residents exhibit depressive symptoms; 12% meet clinical criteria for Major Depression [81].

[‡] Transcription conventions [82] indicate, respectively: bracket at the start of a line, overlapping speech; question mark, rising tone; period, falling tone; bold face, emphasis.

[§] Texts were verified by replaying the tape and correcting the transcripts. Two independent coders read the texts and identified: topics sequences, topic initiation and closure sequences, discourse cycles, and summarized the contents of narratives [83–85]. Texts were studies from the perspective of speech acts [86] to understand the intensity of the conversations as purposive strategies. The goal was to sample for meaning and qualitative clarity [87]. Themes were analyzed according to the dual criteria of frequency and explicit salience to the speaker [88].

indicating his answer. For example, Mr Vetch ignored instruction to report his feelings at the moment by making assertions about his whole life, “I never knew a dull moment,” and “[I] always had a lot of energy.” It is only on such occasions that he indicates having “some” rather than “no energy at all” while being depressed. These redefinitions of the questions and the answer categories are analogous to the concepts of double voicing [47], double indexicality [48, 49] and semantic networks [50]. He labels his experience in terms of personal frames of meaning instead of the preset answer categories of the test, but his intended meanings are not encoded in the research record. Thus, important aspects of the intended self-representation may be routinely neglected, or ‘forgotten’ in the preparation of scientific models. Note that these processes in behavioral science are pervasive elsewhere, including ethnography [51–57].

Secondly, a count of the discourse cycles indicates that Mr Vetch introduces fewer topics than the interviewer and that he struggles to maintain topics across the multiple test questions. That is, the discourse cycles were distributed asymmetrically marking the unequal power relations between the subject and the research interviewer.

Thirdly, Mr Vetch’s replies were extremely consistent across the five occasions, as were his statements for the entire clinical study. Other large surveys suggest that affect is relatively stable over time and that the intensity of high and low emotions diminishes with advancing age [58–60]. For Mr Vetch, answers to four items never changed. The items were questions about feeling sad, depressed, happy, or content as can be seen in Table 2. On the occasions when his answers varied, the conversational contexts appear to include features that are absent when the answers did not diverge from his usual reply. The variations can be interpreted as related to the situational factors of discourse, personal identity and cultural meanings.

Self-report in context: discourse, identity and cultural meanings

A systematic comparison of each discourse cycle in each interview identified the content of each reply and the context of the reply. Context is defined as the discussion topics prior to and after the discourse of each interview question. Variations in Mr Vetch’s replies were identified with three contextual dimensions:

1. attention to language and discourse;
2. personal identity and self-image management; and
3. situated meanings emergent from the flow of the conversation.

One or more of these dimensions was observed when the self-report differed from previous replies. Such factors were *not* present on the other occasions for that item.

After illustrating these findings, the discussion will concentrate on six replies which shifted three or more categories on the five point scale from Mr Vetch’s usual response to that item. These included the questions about: ‘energetic,’ ‘warm,’ ‘interested,’ ‘irritated’ and two replies that were split in opposite directions on the scale: ‘annoyed,’ ‘worried.’

(1) Language and the flow of discourse—Social conventions and pragmatics for *talking* entered into Mr Vetch's labels for his feelings. He voiced concerns concerning: appraisals and negotiations related to prior (and subsequent) discussions and to "side talk" [46]; the jarring topic switches built into the fixed sequence of test questions that interrupt the coherence of the conversation; and emotionally abrasive juxtapositions of a topic in the sequence of questions.

Abrasive pairing of topics are built into standardized behavioral tests. Mr Vetch was just asked if he feels sad:

Researcher:	David?! **Right now** I want you to think about how you feel **at THIS MOMENT**
Mr Vetch:	[I feel lousy
Researcher:	[Does that mean that you are feeling sad?
Mr Vetch:	My—If I were able to go to the bathroom I may feel better but I can't go
Researcher:	Are you feeling very sad or just a little bit?
Mr Vetch:	[Very sad. My stomach is like a rock and I can't move my bowels…
Researcher:	Are you feeling content right no::w?
Mr Vetch:	NO.

Complaints about stomach pains and inability to make his bowels function are met with a question about contentment. Behavioral research tends to treat impairments and moods as abstract traits, isolated from each other and from the individual's lifetime. To answer a question, resondents often introduce a topic or narrative explanation, but these justifications are not allowed by the researcher script. Here, Mr Vetch gives a concrete reason (stomach pains) to explain his sadness. The reason establishes a context that, in informal discussion, makes the researcher's next question a harsh, even silly interruption. In essence, test questions may not be interpreted identically by each subject because the content of answers to earlier questions reframes the meaning of subsequent questions. In the context of the discussion each question acquires multiple nuances and implicit meanings [61–63] not part of the test as it was designed.

The behavioral science research tradition follows a stimulus–response model where each test question evokes only one meaning (stimulus) that causes a direct self-report (response) on internal states unmediated by other influences. Knowledge is constructed by the researchers who aggregate the separate answers and determine what is important. Similarly, the research event is largely treated as a one-sided interrogation by an authoritative researcher of a dutifully compliant naive subject [64, 12]. It is not conceptualized as a situated dialogue with, for example, turn-taking and topic negotiation. North American clinical researchers have yet to incorporate the growing literature on how language conveys and shapes information on internal states. Cultural conventions for narrating personal experience, for conversation and self-representation shape reports of well-being, as do social interactional factors. These contextual dimensions introduce multiple frames of reference into subjects' evaluation of their state.

For example, even highly structured depersonalized tests call for social adeptness by the interviewer to smooth topic incongruities, or to manage subjects' perceptions of links between test items that are intended to be treated as unconnected.

Researcher: Are you having pain today?

Mr Vetch: [I've been having pain, yeah

Resaercher: Is that extreme, a little bit

Mr Vetch: [Extreme.

Researcher: Extreme

Mr Vetch: I have a great pains in the heart, in the arm. Even the fingers. Even my fingers I am in extreme pain. Even my stomach. I'm having extreme pains. My father died from that …

Researcher: Are you feeling very pleased with yourself today?

Mr Vetch: No. **How can I feel pleased when I—when uh—when my stomach hurts me?**

Mr Vetch's angry reply hearkens to the fact that his father died after a painful stomach surgery, and he is now suffering these same stomach pains; his father lived in this same facility. Self-reports should be conceptualized as the outcomes of complex interactions and contexts instead of the simple unalloyed reports of internal states. The webs of meanings within which Mr Vetch's reply are meaningful do not enter the scientific record which remains at odds with his stated meanings.

Trained to stick to the questions, the interviewers pejoratively label Mr Vetch's actions as non-compliance or perseveration because the researcher sees no need to hear more once she gets an answer. In contrast, the subject believes he is entitled to continue talking in order to justify his answer, or if the interviewer seems not to grasp his point. Breaches of conversation customs (e.g. interrupting, topic coherence, acknowledging prior statements) are intrinsic to standardized tests. The interviewer's task is to adeptly manage the many violations without inciting the subject to quit or to become apathetic and stop giving honest answers. The standardized test ideal of having subjects speak only when spoken to is only sometimes achieved by interviewers.

(2) Personal identity and self image—The conversations accumulate their own history as the clinician presses from question to question; but the subject views the 'items' and his replies as connected along a second dimension. Mr Vetch was sensitive to the tenor of the composite image of himself implicated by the succession of questions and answers. He expresses unease and tries to change the emerging image of himself. That is seen where he asserts personal traits or features rooted in past, present or idealized future states. For example, “I am the kind of person who never quits,” or “I am a giving person.”

At least two kinds of identity statements are apparent in the talk. The one is an *idealized* ageless identity [65] founded upon past virility and mastery. The other identity emerges from his current experience of feeling *obsolete*, incapacitated, unable to master either his body (arms, bowels), environment (sleep and eating schedules), social relationships, daily activities or future. Idealized identity statements in these texts occurred prior to positive self-reports; their absence was associated with reports of being in pain and depressed. The clinical researcher ‘Other’ controls the entry of these topics and statements into the conversation.

On just one occasion he stated feeling “no irritation.” That occurred inside a segment of talk about his personal identity, “I was always on the go …” “I would’ve known to do everything a man can do.” He asserts a continuous personal biography linked to earlier life which for him cannot be disconnected. He replies to a question about how much energy he feels,

Mr Vetch:	Did you know a dull moment? I never had a dull moment I was always on the go
Researcher:	But right now do you feel energetic, extremely energetic, a lot, somewhat?
Mr Vetch:	[a little
Researcher:	a little bit
Mr Vetch:	I have always had.
Researcher:	A lot of energy?
Mr Vetch:	Lot of energy I could of done anything in the world. I would’ve known to do everything a man, a mechanic can do and that a man can do
Researcher:	you could do it
Mr Vetch:	Yeah
Researcher:	OK … right now are you feeling annoyed by anything?
Mr Vetch:	Nooo.

Mr Vetch diverts requests about his feelings ‘at the moment’ by reframing the discourse to encompass a lifelong idealized image of health and affect. In this segment he communicates a sense of the ‘true’ self, one which the present-day self only opaquely reflects. The true self is hidden by his decrepit body, living conditions and by the discourse. The disjunction is exacerbated by the limits on self-expression imposed by the standardized tests [66, 67]. Again, these confrontations and adjustments to meanings are erased in the clinical research record. Notably, the four occasions when he stated being more irritated occurred in the absence of talk about his personal identity. They focused exclusively on mundane daily events and pain.

MURPHY’S BODY/SELVES REVISITED: DISCOURSE AND SELF-REPORT

On all the occasions, *positive* reports of well-being occur within narratives of personal experience and are framed by identity claims, whereas *negative* well-being reports occur in talk about body dysfunctions and social losses. As the previous example illustrated the only occasions when he stated feeling very energetic were preceded by identity claims rooted in his earlier life. A detailed example may make this clearer. The dialogue is outlined due to space limitations.

On one occasion when he stated that his pain was only ‘moderate’ he explains that the pain from a recent fall was less severe compared to a terrifying fall from a roof many years ago. The interviewer replies, “you’re lucky to survive falling off the roof,” thus validating his central life theme that he is a tough man. That exchange sustains a self-image of strength and mastery, linking together his past and present. The question and reply about his energy level is defined in the bigger picture in which reliving an epic past event enhances his self-conception.

Next, when asked about having any energy, Mr Vetch replies with a global (not situated or contingent) identity claim, “I am always energetic even though depressed” which is linked to an idealized, enduring self. That self-portrait of himself is intensified by contrasting these robust internal traits (mastery, toughness, uniqueness) invisible to others today, with present day experiences of depression, and life in an institution that stymies his ability to enact an identity consonant with his real self. The talk continues across several test questions, each of which validates his claims to the global identity asserted and corroborated earlier by the researcher’s talk. The interviewer persistently tries to elicit answers set in the present day. Mr Vetch replies with global assertions about his whole life such as, “I never knew a dull moment,” “always had a lot of energy and could of done anything …” Mr Vetch’s report of “a little energy” as scored for the interview used in this example is best interpreted as the outcome of a complex interplay between life concerns [68], identity management and the two speakers’ interaction.

In contrast, during the other interviews the question of ‘energy’ occurred before a broader conversation was established. Thus, identity claims or nuances of past self-images had not emerged, nor were concerns with conversational coherence yet exerting an influence. These other reports of energy are situated in the time frame of the interview itself and focus on physical pain and health.

To review, these examples illustrate how self-reports of personal experience are bound-up with the interaction and contexts of the conversational setting, self-image and identity. These transcripts question the validity of a clinical research paradigm that treats the items as unsullied reflections of inner states, with each item as a discrete fact isolated from other items and the interviewer as a neutral party. The texts illustrate how replies are negotiated within both wider personal and cultural frames of meaning, and the immediate sequence of discourse topics in the history of the interview setting. Mr Vetch asserts alternate meanings for the questions and idealized lifelong identities which are not encoded in the research data. These processes reduce the standardization of the survey instrument.

Monitoring for corrosive self-images: situated vs decontextualized selfs

Mr Vetch closely monitors the whole discussion for potentially corrosive images of himself emerging across the span of the test as clarified in a previous example.

Researcher:	You answered you felt sad. Is it extremely sad, a little bit?	146-5 147-5
Mr Vetch:	[It ain't bad. You know when you, you ask me questions but, but **when something hurts you how could you feel happy?**	148-5 149-5 150-5 151-5 152-5
Researcher:	It depends on the person. It is such a personal thing.	153-5 154-5
Mr Vetch:	**Must be you are a stupid person to feel good.**	155-5 156-5
Researcher:	Not necessarily, there are different reasons. Some people have a lots of reasons to feel bad.	157-5 158-5 159-5
Mr Vetch:	**You know I am not stupid!**	160-5 161-5

His retort is effective at three levels and echoes

Robert Murphy's points. First, it conveys the brute reality that he is "in pain every day," too sick to go out, and "don't feel well." Second, he rhetorically shifts the stage to ridicule the researcher for posing the question. At the same time, he challenges the basic reality and suggests that any other reply would be irrational or "stupid." Knowing of the pain, no reasonable person could feel warm to other people or interested in doing things. In TBS, Murphy repeatedly points out that able-bodied people consistently underestimate how the act of completing a routine day leads to sheer exhaustion by people with impairments. Mr Vetch is compelled to give the only sensible answer, that of "not at all" content or happy. His answer is categorical about the world, not about immediate feelings. The cultural propositions guiding his evaluation [69, 61, 63] of well-being are revealed in this commentary about the research process itself.

Mr Vetch's heated retorts parry a more serious attack he perceives on his core being. For elderly residents living in an institution verbal performances are salient as one of the few remaining pragmatic means of normalization [70–72]. The reply, "You know I am not stupid," demonstrates that he is mentally competent and can even judge the expert professionals who might try to trick him with a neuropsychological test. Adept performances of argumentative repartee pragmatically serve to exhibit that he is mentally intact. "Having your marbles" and managing a public visage as cognitively intact [*cf* 70, 17] are crucial social boundary markers where he lives. More than to bodily functioning or age, these elderly look to mental functioning to demarcate within their community between intact apartment dwellers and the decrepit elderly who reside in the nursing home.

A second aspect of monitoring for corrosive self-images was identified. The standardized questions decontextualize meaning-making from the person and obscure the subject's intended meanings. These processes lead the researchers to conjecture about fixed personality traits rather than personal meaning and situational influences on data about personal experience.

Mr Vetch expresses ‘warmth’, and ‘interest’ only during talk about his second wife’s maliciousness. To dramatize her unsavory character, he intensifies the comparison to his own ‘goodness’ by claiming he is perpetually warm towards people and interested in things.

Researcher:	you stayed with your second wife for three months	226-1 227-1
Mr Vetch:	we couldn’t handle it together because **she was insulting my children**	228-1 229-1 230-1
Researcher:	**she was insulting the children**	231-1 232-1
Mr Vetch:	My Rhoda, even my Rhoda, Rhoda is very very smart—she won scholarship after scholarship. **She was jealous of her**	233-1 234-1 235-1 236-1
Researcher:	I see, I see	237-1
Mr Vetch:	Yah … I	238-1
Researcher:	[Can we get back to the questions and then you can tell me what happened. OK? Are you feeling warm towards other people this morning?	239-1 240-1 241-1 242-1
Mr Vetch:	**I al:ways** feel warm	243-1 244-1
Researcher:	you always, do you feel	245-1
Mr Vetch:	always friendly	246-1
Researcher:	Do you feel moderately, quite a bit	247-1
Mr Vetch:	I don’t, I am always friendly	249-1 250-1

The researcher recorded the ‘fact’ that he is feeling ‘very warm’ to others that day. That record of his self-report is wrestled from the webs of signification that made the reply meaningful. The decontextualized clinical data is incomplete as a portrait of the subject’s experiences. This example suggests, in part, how the clinician’s statistical analyses of fixed choice answers quoted in the preface is driven to speculate about ‘underlying proneness’ and ‘idiosyncratic patterns.’

Contested and substituted meanings for self-representation

In a last variety of discourse actions Mr Vetch completely subverts the intended meanings of the formal test items and the answer categories prior to answering. Mr Vetch ignores the frames for experience embodied in the test’s generalized abstract reply categories (e.g. a lot, somewhat, a little, not at all) and substitutes an alternate semantic scale of his own. Such reduction of standardization is a serious concern for quantitative analyses. Mr Vetch’s discourse highlights key dimensions of his understandings about the questions missed by the test records.

For example, Mr Vetch distinguishes questions that pose existential issues (e.g. death or achieving change in life) from those that appeal to daily mundane things. In Murphy’s lexicon, ‘worries’ tap deep beliefs about his own future. For Mr Vetch discussions about the question ‘worry’ center on mortality and the meaning of life. The implications of ‘worry’ for Mr Vetch spread to judgments of whether a situation has only mundane implications and is controllable. That is, ‘worry” is appropriate only for earthly things and those which he sees as being amenable to change. In contrast, anger, depression, and resignation to fate—*not worry*—are valid stances towards forces he views as being beyond his control. For example, neither the institution (surgical treatments) nor the universe (death and burial) incite worry since they are beyond his control. This personalized construction is consonant with a theme in the interviews in which he asserts that he is a man of mastery, action and competence who is only temporarily handicapped by external superior forces. An example of such an incident is when he is denied surgery to correct weakness in his arm after a stroke. In the discourse segments when he abandons hope for and claims to an alternate present and future state, or ‘potentials,’ then he reports no worry in the face of fate.

The following example is one of the two times Mr Vetch said he is not worried at all; on the other occasion he stated he was very worried.

Mr Vetch:	No. I am just worried about myself, will I make it.	84-5 85-5
Researcher:	Does that worry you a lot or a little bit?	86-5 87-5
Mr Vetch:	No.	88-5
Researcher:	It doesn’t worry you a lot?	89-5
Mr Vetch:	Nothin worries me a lot. I just, I am basically going to go down in a hole. You know a hole they make it, they make a big hole.	90-5 91-5 92-5 93-5 94-5
Researcher:	So you are worried, but you are worried a little bit, or a lot?	95-5 96-5 97-5
Mr Vetch:	They make a hole six feet deep.	98-5
Researcher:	Uhm-hmm.	99-5
Mr Vetch:	According to Jewish law it must be six foot.	100-5 101-5
Researcher:	Does that worry you a lot?	102-5 103-5
Mr Vetch:	No.	104-5
Researcher:	A little bit?	105-5
Mr Vetch:	Each hole that they make in the ground must be six foot, then …	106-5 107-5 108-5
Researcher:	Are you feeling content right now?	109-5 110-5
Mr Vetch:	Hnn. How could I feel con:tent when my leg hurts me so?	111-5 112-5 113-5

The topic ‘worried’ is connected to existential dilemmas and to his present life. He makes explicit the reason for the shift in his reply on this occasion by indexing his ideas about the meaning of ‘worry’. In one segment (lines 84–90) he expands the meanings by repetitively playing on the word ‘thing’. The repetition serves to emphasize that he is not “worried about *anything”* as the researcher has asked. The talk is shifted from “any [particular] thing” to a gestalt view of his whole life. He declares that the word ‘anything,’ equated with material things and the cares of daily life (“no thing bothers me”), are irrelevant to loftier preoccupations with his whole existence and impending death. The words ‘worried’ or ‘irritable’ for him do not encompass the magnitude of his concern.

When the item ‘worry’ is set in talk about broad existential concerns, Mr Vetch asserts that the term pertains to earthly things (4: 257–260) potentially within his control, but not to larger issues concerning his identity as a fully functional person. Adamantly refusing the physical therapy the hospital ordered, he demands surgery which the hospital refuses to authorize because it would not help according to the doctor.

Researcher:	Are you worried about anything right now?	237-4 238-4
Mr Vetch:	You know what I want? What—What kind of a doctor is Doctor Jet. Psychiatrist?	239-4 240-4 241-4
Researcher:	Yes he is.	242-4
Mr Vetch:	He is no good to me =	243-4
Researcher:	= yes he is	244-4 245-4
Mr Vetch:	I need a—a neurosurgeon. Say “David! We are going to operate right here and clean you out, clear the blood out, clear that damage you got there =	246-4 247-4 248-4 249-4 250-4
Researcher:	= Ok =	251-4
Mr Vetch:	= you know. Clear the blood off of. off of the ner:ve. That is what I want.	252-4 253-4 254-4
Researcher:	Are you worried about anything right now?	255-4 256-4
Mr Vetch:	[No I am not worried about nothing right now. I want a Doctor, a good Doctor who—would —“David! I will. Clear the nerve so you, you, your arm will come back and your leg.”	257-4 258-4 259-4 260-4 261-4 262-4

In the other interviews when the evaluations occur during talk about daily minor irritations and things he believes he may control, then he reports being extremely worried. Those irritations include being able to visit his grandchildren. Stein [27] suggests that people may externalize stigmatizing physical impairments that are experienced as negative personal attributes by projecting them into negative malicious features of the environment as a way to avoid integrating them as part of the self. Here, Mr Vetch depicts the institution as the villain responsible for his pain and disability, and will not recognize how his own refusal to accept rehabilitation exacerbates his disability.

SUMMARY AND DISCUSSION

To summarize, the representation of impairment experiences by people with disabilities and the influences of Others on the report was examined here. Two sources of expertise on experiences of disability provided insights, Robert Murphy in *The Body Silent,* and a 78 year old man speaking during a series of clinical research interviews. How far can the observations of these two individuals be generalized to people in other settings and of different ages, health and backgrounds clearly remains an open question. With the insights contributed by these examples, and by case studies in general, many new questions arise that are clearly beyond the scope of the present paper.

Substantively, the cases starkly illuminate the multiplicity of contextual influences and time frames that shape self-labeling. One contribution is the identification of aspects of the social situations and cultural contexts that add to variations in self-reports, and to the documentation of their role in specific question–answer sequences. These aspects need to be more adequately incorporated into the research data which are used to construct authoritative scientific models and social images of people with impairments. Simultaneously, a practical message for the behavioral researchers is to redouble their efforts to train interviewers to stick closely to the survey questions and to limit informal talk.

The paper identifies multiple frames of meanings that people with impairments use for interpreting their current conditions, whether for a research test or for themselves. In the clinical research interview, salient focuses of attention included: the management and pragmatic use of discourse; personal identities, self-image and lifetime biography; fundamental cultural meanings and practices for meaning-making; and the actions of the interviewer. That is, the standardized questions and the abstract answer categories (e.g. none, some, a lot) are polysemic, not monosemic as intended by the researchers.

An example of the multiplicity of meanings shared by Mr Vetch and Robert Murphy is the description of how the experience of present day impairment is infused with a sense of being seamlessly connected to experiences and identities from the past, present and future identities, both actual and idealized or expected. They were attentive to the potential obsolescence of cherished identities and habituated routines of engagement with the world through ‘able-bodies,’ and of desired or intended personal futures. Analogously, research on life stories has identified how concerns and conflicts in the present and Others shape the contents of the life history [73, 74, 68, 42, 53]. Here we saw the past and future figured prominently in labeling present conditions. For Mr Vetch and Robert Murphy, caustic and affirmative feedback from others adumbrated their own conception of their functioning and disability, as well as the representations Others hold of them. Additionally, the ways the customs of standardized behavioral research may transform and rend the subject’s intended self-representation [53] were identified. The process was seen in the negotiation or translation between genres for representing experience, shown here between clinical research measurement and subject’s narrative and dialogic forms of telling. The power of the researcher–Other reaches beyond shaping subjects’ replies, it shapes the formulation of scientifically authoritative models of disability experience used to construct social policy and popular images.

A trenchantly contested point was the researcher's direction to 'forget' (prior answers and discussion, earlier life events) as well as to remember. For example, the researcher urged the subject to answer each question as if it were unrelated to previous ones or the next one. Further, the clinician strove to decontextualize self-appraisals from lifelong personal meanings and the local context of the test questions. Yet the subject spoke of that as corrosive to his being a sensible, intelligent, mature man. Two different influences were produced by this clinical behavioral research practice of knowledge building. On several occasions the research process and the interviewer seemed to instill self-ratings of more positive moods and less impairment. For example, some of these were observed when the conversation enabled Mr Vetch to construct a continuity of personal meanings connected to idealized life-long self-images. The confluence of talking about the body and self-identity in the dialogic production of some replies is linked with better health. Yet, survey questionnaires seldom include items to assess a person's sense of continuity and future prospects. Perhaps they could profit from including such topics.

Alternate explanations for the subject's replies may be suggested. Most simply, perhaps the subject just felt differently when he said he did. Serendipidity may be the reason for the association between speech and action in his answers. However, the succession of five transcripts each provide compelling, richly detailed cultural and sociolinguistic evidence for why the subject's replies are most parsimoniously and fully explained as being a thoughtful and well-reasoned reply in the contexts of the interview. Or again, perhaps, on other days when he is not being interviewed by the clinician Mr Vetch may create similar patterns of interactions with other people that lead to similar supportive and non-supportive responses, thus fostering the same mood. Such possibilities can not be ruled out from the transcripts at hand.

The points of contention raised by Mr Vetch and Robert Murphy are very understandable as those of Americans whose culture idealizes achievement, self-determination, hope, change and rejection of fate. Their cases show a core of the burden of 'being-disabled' is the challenge to their ability to pursue these motivations for 'becoming.' Given the cross-cultural variability in the social definition of disability [75], the constellation of concerns for people aging with disabilities may fundamentally differ in relation to those culture-specific local conceptions of history, social and personal development and the self.

Robert Murphy's conception of the potential body-self draws attention to the sense of isolation from meaningful, desired social interactions, an obsolete relationship between the body and self-defining daily activities and the grinding burden of utter exhaustion. More importantly, the ability to obviate [76], that is to transcend the researcher–Other's supplied frame of meaning for the self (being tied to the immediate moment) and infuse the interpretation of present conditions in the wider horizon of idealized past self-images, and future potentials for being are an important tension between the researcher and subject, and for Robert Murphy and his community. It is these aspects of the experience of *being* and *becoming* as a person with disabilities to which behavioral science is inimicable. The research and analyses are conducted as if the observer is cleansed of influencing the subject; even the subject is cleansed from the 'data' as illustrated in the introductory quote. This approach to understanding disability experiences serves to erase the sociocultural contexts from the data and scour the embeddness of the self-report from the human lived experience of multiple pasts, presents and potential futures. Robert Murphy's enduring legacy in *The Body Silent* is the identification of these new arenas for the continuing work to humanize the ways we all build understandings of, and, ultimately, engage in living with, people with disabilities.

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Table 1

Murphy’s schema of the experience of disability

• Urges to withdraw and to engage at the level of:	
being:	*becoming*:
body experiences	personal development
body and self awareness	social life course
self and society	
• Reversal of cultural logics for defining the person	

Table 2

Responses to the research interview questions

Question topic	Subject reply by interview number answer categories				
HEALTH	**5**	**2, 3, 4**	**1**		
	very poor	poor	fair	good	excellent
PAIN	**3, 4, 5**		**1, 2**		
	extreme	quite a bit	moderate	a little	no pain
ENERGETIC	**5, 3, 4**	**1**			**⟨2⟩**
	none	a little	moderately	quite a bit	extremely
ANNOYED	**⟨4⟩**		**2**	**5**	**⟨1⟩, ⟨3⟩**
	extremely	quite a bit	moderately	a little	not
WARMTH	**2, 3, 4, 5**			**⟨1⟩**	
	no	a little	moderately	quite a bit	extremely
INTERESTED	**3, 4, 5**	**2**			**⟨1⟩**
	none	a little	moderately	quite a bit	extremely
HAPPY	**1, 2, 3, 4, 5**				
	not at all	a little	moderately	quite a bit	extremely
IRRITATED	**2, 4, 5**	**3**			**⟨1⟩**
	extremely	quite a bit	moderately	a little	not at all
DEPRESSED	**1, 2, 3, 4, 5**				
	extremely	quite a bit	moderately	a little	not at all
WORRIED	**2, 3**	**1**			**⟨4⟩, ⟨5⟩**
	extremely	quite a bit	moderately	a little	not at all
CONTENT	**1, 2, 3, 4, 5**				
	not at all	a little	moderately	quite a bit	extremely
SAD	**1, 2, 3, 4,5**				
	extremely	quite a bit	moderately	a little	not at all

Key: numbers indicate the interview when that answer was given ⟨_⟩ = major shift across the entire study period.