IV. SOCIALINIS DARBAS SU RIZIKOS GRUPĖMIS

HOW SOCIAL WORKERS UNDERSTAND “PERSON IN SITUATION”: RESEARCH CONCERNING MOTHERS WITH HIV

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Summary

In the process of assessment, it is important for social workers to understand the normative characteristics and social processes that are likely to happen when people confront social and medical problems. It is at least as important to work in partnership with people to construct a shared understanding of the person in his or her situation. This study presents an example of how practitioners developed this type of understanding from the literature and their own practice. It was begun in the early days of the HIV epidemic in the USA. The results contrasted with the findings in the literature, both in substance and in form. This finding is important to illustrate how practitioners can put assessment into action in the rapidly developing social work profession in Lithuania. The increase in HIV infections puts the region at a point where the USA was at the time original data were collected. Thus, there are parallels that can be helpful in beginning to understand and to find ways to work with people affected by the virus and related social phenomena.

Keywords: HIV, assessment, theory, qualitative, social construction

Most practitioners and teachers of social work share the idea that some kind of “assessment” is involved in practice. Sometimes assessment means comparing individuals to a set of criteria of normality or pathology, and arriving at a statement that describes specifically what the problem is and how it keeps operating. This can be a “diagnosis” in some cases. Much of assessment, however, involves not so much a comparison to norms, but a description of a situation and how it operates, with the positives included. This happens jointly between social worker and client, largely through the client’s describing what she or he feels and wants, and working towards how much of it is possible to achieve. It is particularly important in situations in which the problems are unfamiliar to social workers to be open to various ways of understanding and finding ways to move towards desired ways of being with clients. This paper illustrates how this process occurred for a group of American social workers in the early days of work with mothers who had the human immunodeficiency virus (HIV) and whose children also had HIV. While perinatal medications have drastically reduced this particular situation in the USA, it remains problematic in many places where the medicines and awareness of prevention are less prevalent.

Despite nearly two decades of professional experience, social workers are still looking for ways to enhance the quality of life of the many women and children who have HIV. Practitioners and researchers have produced several excellent reviews noting the problems women and children face when they must deal with HIV infection. They also discuss the need for better understanding of how professionals might help (e g, Corea, 1992; Lewert, 1988; Schneider, 1991; Wiener, Moss, Davidson, & Fair, 1992). Nevertheless, there has been very little systematic study of practice and its effects. This article reports on a qualitative study of practitioners' reflective understanding of the nature and effects of their work.

Septimus (1989, 1990), Wiener at Septimus document the problems that any family dealing with chronic illnesses might encounter, and the "unique social stresses associated with this disease, including difficulty in sharing with relatives and friends their child's diagnosis, isolation, social stigma, depression, grief, disorientation, and inability to sustain their normal routine" (Wiener & Septimus, 1991, p 577). The structural characteristics of society that lead to homelessness, poverty, prostitution, and drug abuse often impinge on families affected by HIV. This situation makes practice research difficult. Misogyny and scientific neglect have made matters worse (Corea, 1992) and clouded popular and professional perceptions of the realities of family life with HIV. At the mention of HIV infection a certain ineffable hopelessness and sadness still befalls many workers who might otherwise have been more optimistic about their prospects for helping.

Background

Social workers must be innovators. While elements of the human condition are timeless, the contexts and details that make social work social are ever-changing. Knowledge of how a situation might be improved may be extremely ambiguous even when the assessment of the situation is clear. As Lewert noted, "Few guidelines exist for the treatment of these children and their families. To a large extent, practice is being created on an ongoing basis by practitioners who are involved with this population." (Lewert, 1988, p 354).

This article describes practice as it is created. The research "surfaces" tacit practice knowledge to share it for practical purposes and to make it amenable to study. It derives from the practitioners' open-ended accounts, and thus, the work derives from the "local world" (Kleinman, 1992) and "local knowledge" (Geertz, 1983) of the practitioners. This type of knowledge comes from the professionals' viewpoint, which should be compared to the viewpoints of people who have HIV (Borden, 1991; Lamendola & Newman, 1994). To put these new dimensions of knowledge into context, it is important to understand the major themes that were prominent at the time of the study. These would constitute the main sources of information from "outside" their practice that the practitioners in the study might have used to build their understanding.

Psychosocial distress and depression

Accounts of depression, alienation, and a downward trajectory of social functioning were common in the literature on persons with HIV or AIDS (e g, Atkins & Amenta, 1991; Belfer, Krener & Miller, 1988; Dubik-Unruh, 1989; Frierson & Lippman, 1987; Septimus, 1989; Spiegel & Mayers, 1991). Most published accounts concerned men, not the women who were the primary clients of the workers in the present study. Schwartz (1987) reviewed studies of the psychological needs of persons with AIDS for a National Association of Social Workers publication. He concluded that "All studies have agreed that the persons with AIDS respond to their fate as others have responded to life-threatening illnesses —with anxiety, distress, and depression—and that they go through the same stages of anticipatory grief (denial, anger, bargaining, depression, and acceptance) noted by Kübler-Ross" (Schwartz, 1987, p 20, in Leukefeld & Fimbres, 1987, citing Kübler-Ross, 1969). In contrast, Borden (1991) reported a study of 15 HIV-positive young men, 14 of whom reported at least some beneficial aspect of their adjustment to learning that they had the HIV. Similarly, Lamendola and Newman (1994) reported another qualitative study of nine gay men in which “expanding consciousness” and “meaningful connectedness” apparently came with awareness of having HIV. It is quite likely that the social contexts of the men in these studies are quite different from those of the women with whom the practitioners in the current study worked. No counterpart of Borden’s and Lamendola and Newman’s studies was known to exist in the professional and scientific literature concerning mothers with HIV at the time of this study. These early studies are notable for their theoretical grounding in studies of adaptation to illness and other extraordinary adversity.

Publications by clinicians often shared certain themes concerning women who have HIV. One theme was about the differences between men and women who have HIV. Many women with HIV are from minority groups, or are dispossessed or powerless. Whether overtly discussed or not, gender, racial, and political or social status themes converge in clinical and other descriptions (Fullilove & Fullilove, 1993; Worth, 1990). For example, Septimus discussed the “staggering set of conditions” facing poor women before they encounter HIV. She asserts that “In addition to the reactive depression resulting from learning about their own or their child’s HIV infection, parents may have a complicated depressive state triggered by a multitude of problems that contributed to the single parent’s initial resort to intravenous drug abuse or other substance abuse” (1990, p 96). Wiener and Septimus (1991) provided an excellent overview of the combined chronic and reactive depression that likely results from “...the stress of single parenthood, substance abuse, socioeconomic problems, rejection of family and friends, emotional isolation and illness.” They also clarified the effects of hopelessness that are “particularly germane for poverty-stricken single mothers who may be barely coping with existing problems. Their perception of hopelessness precedes the acquisition of HIV and is compounded by the suffering and fatality of infection” (p 581). Septimus (1989) bases much of her recommended approach to practice on the notion of instilling hope.

Persons with HIV are likely to experience many problems and paradoxes of identity management. For women who are at most risk of transmitting or acquiring HIV through drugs or sexual relations, there is an extraordinary paradox. The more isolated they become, the less at-risk they become for getting or transmitting HIV, but they become more at-risk for many other stressful situations (Suffet & Lifshitz, 1991). These include problems in child rearing and difficulties in negotiating sexual and other intimate relations through which identity is formed and experienced. American subcultures often make it difficult for many women to deal with these problems. For those who see themselves at-risk for HIV infection or who already have HIV, matters are even more difficult. The “passage” (Glaser & Strauss, 1971) from the social status (social role and sense of self) of an uninfected person to that of a woman or child with HIV is likely to be a particularly important transition. Disclosure and secrecy are two ways to deal with social relations and stigma, but each path can be distressing in its own right (Tasker, 1992).

Studying local worlds of practice

Attempts to help people to deal with the wretched results of macro social structures and processes led to the creation of the social work profession in the West, and subsequently in other regions of the world. Practitioners have always been concerned with the individual experience of social forces. But never before have the conjunctions of the social and the medical been more compelling and potentially overwhelming as with women and children with HIV.

Consider the challenge of engaging in practice (the behavior and ideas about the behavior) that focuses on problems that seem new and intractable, or for which existing practice seems feebly matched. This is the situation that many Lithuanian social workers face daily. What is needed to make a start at conceptualizing and testing knowledge in an uncharted area? First is the recognition that something new is happening. For example, in a 1987 interview, a worker from a pediatric setting discussed the unknown she faced when the problem of practice with the first generation of children with AIDS was made more complex by the first generation of HIV-positive parents:

"…actually when I first came here we did not know a lot of sick parents. The parents we knew were not sick and the child was seen, and then it started to happen, after a while some of the parents got sick. That's when it really hit me; we had not really run into this situation so up-front before… So now what can I do with him? I thought my role with him was to try and get him to open up, because he obviously must have feelings in dealing with his kid's death. Now, what am I going to do? I really did not know what to do…"

A body of professional literature had begun to relate experiences and reflections that practitioners had made public about practice with women and children with HIV. Examples include works by Anderson (1990); Boland, Tasker, Evans & Kerestzes (1897); Lewert (1988); Septimus (1989, 1990); Tasker (1992); Wiener, Moss, Davidson & Fair (1992); Wiener & Septimus (1991). These works excelled in portraying the problems faced in medical and child welfare settings. Some emphasized therapeutic clinical functions, some coordinating services, and some were more oriented to organizational relations.

Methods

This study sought to understand the symbols, phenomena, and perceptions that social workers in the field of family and children's HIV-related practice deemed meaningful in their work. Several studies have undertaken this inductive task in recent years in different fields (e g, Benner, 1984; Chenitz & Swanson,1986; Harrison, 1987, 1989, 1991; Schön, 1983). For example, Elks and Kirkhart (1993) reported a study of practitioners' approaches to evaluating practice, the methods and strategy of which were similar to those used in the current article. In each case, the design aimed to find and to make explicit the tacit principles of practice that are regularly expressed. As Lithuanian social work research develops, this type of study will assume its rightful place among the types of systematic inquiry that inform practitioners and policy-makers.

The goal of capturing a culture's understanding of a phenomenon is often accomplished by ethnographic observation methods. However, owing to the difficulties of observing social work practice, these methods were of necessity merged with a process of grounded theory development and constant comparison that Turner (1981) articulated and a more interpretive approach than would occur in purely descriptive ethnography. The study design strategy was to probe and listen to accounts of practice and workers' understanding of it, then to analyze the texts of tape-recorded interviews and field notes in detail in line with constant comparative principles, starting with many descriptive categories, and eventually evolving these into conceptual and propositional ones. The analytic procedures were simplified with the HyperResearch computer program (Hesse-Biber, Kinder, Dupuis, & Tornabene, 1992).

In 1987, 11 practitioners participated in research interviews in the New York metropolitan area. These workers were in the first generation of practitioners to deal with pediatric-HIV problems. They were identified as experts largely on the basis of having the most experience with what was then a relatively small number of children who had AIDS. Participants were selected from those presenting accounts of their experiences in national media and professional conferences, and then by following up their suggestions of other potential participants. This "snowball" sampling process led throughout the study to practitioners who had either published work or had earned local reputations for reflective, innovative work. Since so many family-HIV workers know each other, there were many referrals of specific people to participate.

The dominant themes from the 1987 interviews were as follows:

a) There was no other widely known medical entity in which a parent was notified that her/his child had a fatal condition, and simultaneously told that therefore the parent probably also carried the lethal germ;

b) The picture of double-diagnosis of child and parent set into motion a cycle of denial and grief that even experienced medical social workers found extraordinary;
c) Conventional chronic illness approaches to social work were relevant, though inadequate;
d) Concerns about stigma and socio-economic deprivation were inevitably involved in the practice, but that not all workers chose to consider them directly in their coordination and mental health roles; and
e) Workers were in awe of where the epidemic was going or of what the future of practice held. Workers were increasingly seeking ways to attend to families, but especially to mothers.

As noted above, the situation has changed considerably in the USA with medical advances and social intervention and support, but many elements of the picture are extremely relevant in both the USA and other countries and regions.

In 1991 a second phase began. The research strategy was to conceptualize inductively practice principles more fully by working in more settings, with more workers than had occurred in the earlier phase of the study. Meanwhile better understanding, earlier detection and treatment, longer lives after diagnosis, and the voices of people with HIV led to the idea that AIDS was just one part of the HIV disease picture. There was a return to examinations of chronic disease approaches.

In 1991 and 1992, 38 more interviews were held with practitioners who were working directly with families in which children or parents had HIV. Most of the research interviews occurred in medical settings, but the practitioners were not limited to inpatient or even medical services. Just as the epidemic spread through more sectors of the community, the thoughtful practitioners were now found in an increasing variety of settings, including a number in major cities of the Midwest and the South. They were still most likely to work in special clinics and inpatient units, but participants also practiced in pharmacological clinical trials units that also provided comprehensive care, specialized African-American community agencies, public and private child welfare settings, and in private practice. In contrast to most of the 1987 New York-area interviews, feminist, ethnic, conventional child welfare and community-based advocacy themes were evident in some agency programs and in many workers' understanding of HIV phenomena and how to work with them. Since there were so many suggestions for informants, it was possible to do a good job of "theoretical sampling," (Glaser and Strauss, 1967) by which participants could be recruited deliberately on the basis of their being able to address emerging constructs and propositions. Favorable responses to invitations to participate occurred more than 10 times as often as did turn-downs. Six workers were interviewed at home, and five were interviewed at schools of social work or public health. The others were on-the-spot at the practice setting. Forty of the participants were female. Several workers were re-contacted or sent transcripts of their interviews for further discussion. Four participants sent manuscripts, letters, and other materials related to the topics that had been discussed in the interviews. Several others initiated contact by telephone.

Almost all participants were accomplished professionals. Their ages and experiences varied, but the majority was between 30 and 50 years old. They usually endorsed the value of sharing professional experience and of the need to further the profession by conceptualizing practice. Similarly, the sampling process resulted in what was perceived to be an extraordinarily intelligent and reflective group of workers, ranging in experience from three months to eight years of work with people with HIV.

Participants were told of the general topics that the interviews would cover: their professional backgrounds, the types of clients and services that they work with, any practice principles and processes that they identified as guiding their work, what they see as happening when they practice, how the practice and services work, how they evaluated their practice, whether or how they use ideas from professional education, and what work in the field meant to them. They were encouraged to detail examples of when practice had gone particularly well or had not. These examples often provided particularly valuable data. The interviews were tape recorded in most cases. In the cases in which workers declined to be taped, all of which occurred in New York City, notes were taken during and especially after the interviews. Several interviews involved small groups of professionals where this conformed to the patterns of work in the agency or interdisciplinary clinical setting.

Findings

The participants consistently showed that their understanding of practice rested on understanding clients and what they faced. This is one of the possible definitions of “assessment” and it is instructive for how Lithuanian social workers frame their own practice processes. Participants dealt frequently with well-defined practice concerns such as supporting women who were struggling with the issue of whether to tell a child about her own or the child’s HIV; or about the need to advocate with primary care physicians to carefully include HIV-related studies in their gynecological examinations of clients; ways to try to avoid domestic violence; and, reported especially often, the many challenges of teaching about “safer sex” and disinfecting needles and syringes. The conceptualization extended to what had often been a subjective and tacit enterprise for most of them. Many principal themes and constructs in the study came from questions about the meaning of the practice phenomena that participants described and why they presented the ideas that they did. It was not unusual for workers to speak with intensity of intellect and emotion, and for them to relate their emotion to their commitment.

Core themes and propositions

HIV may not be the most pressing problem. Study participants differed in their views of whether families or individuals with HIV were very different from other clients, and whether their work differed in corresponding ways from the work of other practitioners. Several workers discussed the fact that many people they worked with were much more concerned with immediate matters of shelter, safety and hunger than with asymptomatic HIV. Many believed that work on today’s immediate problems frequently led to help later with the developing HIV-related stressors. The link between one’s understanding of people and how one practice came up often. For example, one participant discussed practice heuristics that she had evolved:

“When I interview someone, if I focus on risk behaviors, which is what you are taught to do, I immediately rouse up the defenses of my clients who live amid great risk, much greater risk than HIV, daily. They run the risk of being shot or, you know, taking an overdose of drugs, or being beaten up by somebody, all the time. Those risks are much higher. The way they live with those risks, they use their most powerful coping mechanisms, denial and avoidance.”

Participants asserted that HIV is typically something added to a person’s prior list of significant problems. In this view, too much attention to HIV can contribute to patronizing and stigmatizing stereotypes, and to an increase in resistance to further attempts to help: de-emphasizing HIV and emphasizing other, pressing concerns and needs might be more helpful, especially soon after diagnosis. One community medical worker expressed the point clearly in response to a question about work with mothers as a type of innovation:

“I think that’s one of the biggest problems that social workers have, that they tend to not look at what they can do, what they have learned. [They should understand] this approach [to practice] that they have, and to value it. They think that each thing that comes is something new—and when somebody tells me that they are interested in HIV work, I immediately cross them off my list, because if they’ve got to be “drawn” to it, if they are drawn to it as something that’s “Oh, new, innovative,” then they’re going to run into trouble working with my patients. First of all, I got into this work because I’m committed to working with the population that I've worked with now for many years... I've only worked with HIV for [a few] years, because HIV became part of this community... and that's not surprising because of the social vulnerability of the community. So they suffer the worst ills of social vulnerability, and HIV happens to be associated with the behaviors that are sometimes the outgrowth of social vulnerability, so that's why this population has that. There's nothing that I do that I didn't do before! Nothing! There's no experience that I'm having now that I didn't have before. There's a new body of knowledge, okay, but that's a bunch of medical knowledge that could be in any area."

Practice with mothers with HIV was, for many, a particular application of a general helping process. The focus of practice was not so much the configuration of causative factors and pathological results that is so prevalent in professional literature, as on the process of "living with HIV and everything else."

Other workers participating in the study saw work with people with HIV as very distinctive. Whatever the participant's emphasis, the common message was almost always about relationship and emotion shared between worker and mother in a professional context. Workers who practiced in hospitals were most likely to see HIV-oriented work as a distinct specialty. This correlation was particularly evident for workers directly involved with children, complex medical situations, and mortality issues.

Practitioner: I think there's a clique. I have argued with colleagues who've worked in cancer and other kinds of chronic illness, but I really think that AIDS, when you work intimately with people, not just HIV prevention, when you work with people who live with this disease, it somehow affects you in such a way that it makes you different. Not to be elitist or anything, but my husband and I argue about this all the time, but there is something different about working with HIV than any other disease up to this point in time, that brings people together, both from a client standpoint, but also from a professional standpoint. I guess it's kind of like going through a war together. There is this bonding that takes place that I haven't really seen in other areas of social work.

Interviewer: Why, do you suppose?

Practitioner: I think it has to do with the level of tragedy that is involved in working with HIV. On some level, whenever anybody has a terminal illness, the emotions are the same. But, on another level, they are different, because you are dealing with a stigmatizing disease, you are dealing with something that is transmissible, where I have seen entire family systems, not just father, mother, baby, but father, mother, sister, uncle, cousin, relative decimated because of this disease.

Many women experience enhanced "well-being" after an HIV diagnosis. Even the participant just quoted clearly identified this central theme which stands out against the literature about women and children with HIV, which emphasizing guidelines for recognizing and treating despair and depression. Borden's (1991) report of "beneficial outcomes" of seropositivity and Lamendola and Newman's (1994) description of "expanding consciousness" were consistent with this paradoxical finding, though both studies concern men. Practitioners observed that many families, and particularly many mothers, improved in their social role functioning and mood over time. When asked what proportion of women did better, they often reported that the phenomenon was more likely to occur than not, but that the changes were part of a trajectory or process. Consider one practitioner's response when challenged as to whether she could document improvements:

Practitioner: I have seen people deal with their HIV. I've seen them make that transition to being very fearful, weeping, very angry, and [then] being able to begin to cope and deal with their situation. That's some measure, to come to some understanding. It seems impossible at the beginning. (Holds her mouth open and shakes her head apparently to convey the difficulty of finding words to communicate her observation.)

Interviewer: Does it seem that many people use this [HIV situation], or after this diagnosis that they sort of get their act together in a way? You're nodding 'yes'--.

Practitioner: Yes, absolutely. I usually hear this sort of comment from those who have hit the deepest bottom. Those who have been ongoing, long-term, substance abusers.

Perhaps they lost their children to the foster care system, etcetera. My worst stories... and I've seen this: I've sat in my office and they've said "If I'd only known sooner." It's like they're trying to get a last chance to turn things around. "If I knew a year ago what I know now, if I knew two years ago what I know now." They really get their acts together. Sometimes you see them go the other way; usually the patients I work with, it's been much more positive experience, more often than not. Sometimes I hear about them going back to their drug life style, etcetera.

Interviewer: Do you have any guess about what proportion of people go those two routes?

Practitioner: Which way they go? The people I've worked with, most of them go in a more positive direction. This has really gotten their attention.

This theme became clear when many workers spontaneously referred to it, usually in discussing examples of their work. After the researcher identified the regularity with which the theme was expressed, in each subsequent interview (about 30) the interviewer listened specifically for it. When it was not voiced (in only about five interviews, according to the sometimes necessarily arbitrary coding scheme), the matter was initiated by the interviewer. In only two cases did the participating practitioner not recognize the phenomenon as part of her work.

Three factors facilitate psychosocial well-being. Three intertwined factors constitute a conceptual model of how practitioners understood the tasks and processes that constituted their professional work. The first factor was the mother's ability to face the reality that life will be shortened by HIV. This factor was usually described as an acknowledged but nonverbal change that results from the social worker's patient focusing and the mother's mobilization of her strengths over time. The second factor was relationship. It referred to the worker's ability to engage mothers emotionally in tasks and responsibilities oriented to the mother's or, frequently, her child's well-being. Often social workers were the engaged professionals, but frequently there were several relationships ongoing at once, perhaps with case managers, nurses, physicians, and community members. Participants sometimes discussed teamwork, but always with some one-to-one relationship present. While few workers used the language of psychotherapy, many of their examples were very similar to processes of alliance-building, appreciating and using "resistance" constructively, and evolving interpersonal solutions to problems with practitioners that could be extended to relationships with others. Examples integrating nurturance and confrontation were common.

The third factor was the use of concrete services. Very often these services were either unavailable, or were not used, until the mother or child was diagnosed as having HIV. Some workers remarked on the many new resources that one may become eligible for when one has HIV or AIDS diagnoses. Doubtless, the ability to use new services was linked to the other two factors.

This set of factors depended on the assumption that contextual social forces do not become much more problematic than ever. Workers discussed the importance of clients having the good fortune not to be so severely harmed, oppressed, or stigmatized as to blunt or erase any progress. They often noted that esternal social forces posed barriers, but that sometimes the most progress occurred in coping with or avoiding troublesome circumstances or people. These are the same social forces that often led to HIV-infection. Workers reported advocacy as an aspect of their work, but more often they reported difficulty in advocating on the case-by-case basis against such difficult social problems.

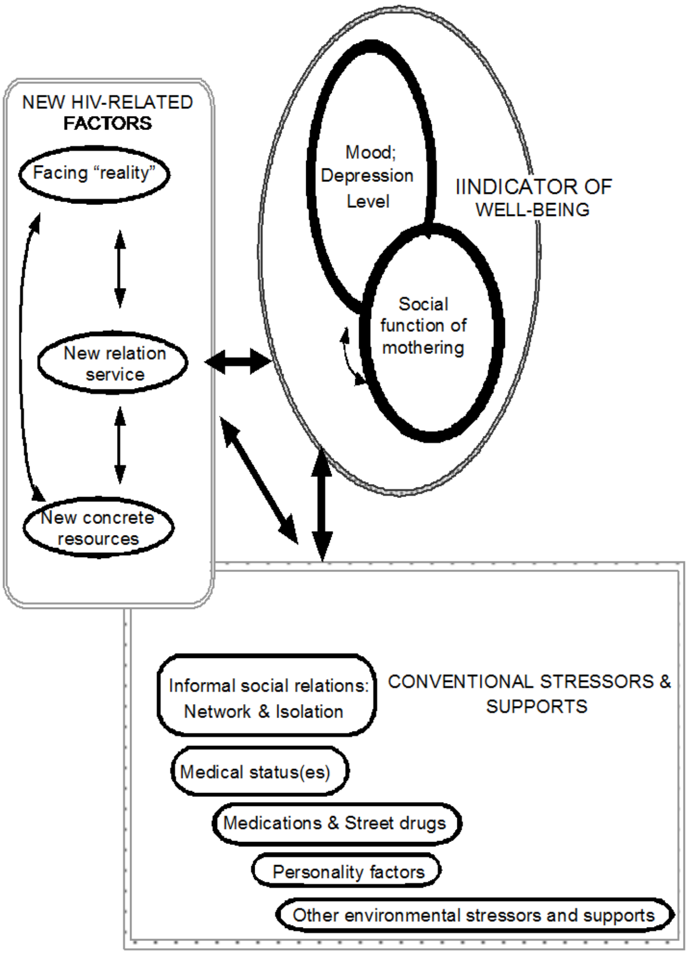

Figure 1. **Factors affecting whether mothers „get better“ with HIV**

As the interviews progressed, this conceptualization of practice was developed and tested with practitioners. Consistent with the study methodology, it developed in propositional form. The core of the idea was labeled "the practitioner's hypothesis": *To the extent that a mother who has HIV can a) face the fact of a shortened life, b) engage in new relationship services, c) gain needed new concrete resources, and d) avoid or overcome new environmental stresses, she will improve in e) mental health (especially depression) and f) social functioning (especially mothering).* Note that this proposition was developed with practitioners who dealt primarily with women whose lives had been characterized by deprivation, neglect, and, in some senses of the term, oppression.

Often the three main predictive components of the practitioner's hypothesis lie significantly within the control of practitioners. However, these motivational elements had rarely been offered to many mothers before their HIV-positive findings. The idea of a "wake-up call," or facing the reality of a shortened life, was inextricably connected not only with having HIV, but also with the notion of a new, caring relationship or set of relationships. Rarely, participants asserted, had anyone entered a serious relationship and made the commitment to these young women before the HIV diagnosis. HIV became the concrete reality that served as the focus for discussions of how to live one's life. The process of focusing may have been widespread, but it was not reported as a fast or easy milestone to master. Social workers, support groups, professional and semi-professional case managers, and other professionals often worked to establish this focus. According to many practitioners, it occurred most often in the context of care, which is shown by dependability, giving (food is sometimes provided in clinics), and a combination of directness, honesty, and practicality.

Workers also thought that staying with a mother through referrals for concrete services and preparing her for what she may encounter advance the process. Participants often spoke forcefully about the importance of planning for children who might survive parents or for parents who might survive children. Whatever the specific focus, or the specific person engaging in the relationship, the crucial ingredient of having HIV and facing it came through repeatedly, as shown by one respondent who was angered by the social implications of the problem:

Practitioner: ...we really have all these women who say, “It’s the best time in my life! I didn't want to get HIV, but I've never been so together; I’ve never been so motivated; I never cared so much; I never connected so much!”...There has to be something that’s measurable there.

Interviewer: I’ve seen it, and I’ve heard it almost every time I talk to people.

Practitioner: So it’s that sense of things. Really, I think it’s a total condemnation of our society that this is [the mothers’] statement. They had to get the virus for society to notice them! I don’t mind doing research that allows that to be an issue.

One worker recalled a case situation [here disguised] that shows an example of how these factors may unfold, and the fact that they did not fall into place quickly. The participant had discussed the importance of helping a mother find better housing and to begin substance abuse treatment (concrete resources), and how facing these needs was coupled to facing HIV (the wake-up call). The worker-client relationship is implicit.

Interviewer: On the subject you mentioned people who seem somehow to get their lives together in a new way, or find a new option, what might you have done in the case with this person to help that happen?

Practitioner: Well, I think in the case of one person, I was often there for her as a support… I think that being non-judgmental, and helping her not to feel like she was just kind of a “no-good individual,” because she couldn’t, for a while, really put things together, and she continued to use drugs. I think that being available and non-judgmental were important and I think so because… she always kept coming back, and it was never like I made her feel that she had failed, and that I couldn’t do any more or we couldn’t work together anymore. I think that was useful. I think I helped her to recognize what she could do, what her strengths were, that she did have a great deal. She wanted to like hurry up and do it all. We had to talk at times about the fact that “You haven’t been with your daughter for some time and just because you now have her back, doesn’t mean that everything is going to be wonderful. You have to work at this. You are going to have to talk with her and think of new ways to do things besides screaming at her.” …I was the one who suggested that she go and talk with other people in her community about her HIV illness. But this only happened after she started to deal with it. Being able to use herself in that way and share something about what had happened, I think this made her feel very good. She would come back and tell me how it had been and she didn’t want to go anyplace where she would know anybody and know her family might get upset about this, but as time went on she was willing to do more and more of these things. Eventually, she... was able to go back and transfer some things and think of a new way to deal with some difficult problems with her own mother and sister. I think in some way I supported what she was doing and I helped her look at what she had in herself that she could use to work with her family or change some of the ways things had been in her family.

Implications for practice and research

Social forces shape both practice and research. Many minority group members, women, and others do not have services of the sorts that these practitioners found useful. Sometimes these resources become available only after people are identified as victims of an epidemic or as threats to society. Major health care reforms and cost containment policies should recognize the social aspects of service delivery and the fact that the sociosomatic course of HIV infection and illness is at least somewhat amenable to improvement by social workers and others. These policy-level possibilities merge with the concerns of the individual practitioner who works largely on an individual-by-individual basis. Social workers face very difficult questions about efficiency and efficacy of their work, especially now that so much practice is thought of as a form of quasi-medical treatment in which specific behavioral objectives and measured units of service become prevalent. Questions of how long it is reasonable for social workers to work with distressed individuals, and towards what ends, are increasingly prevalent (Meyer, 1993). For the individual social worker, the "practitioner's hypothesis" might hold widespread applicability as an example of the importance of time as a dimension of practice. It is particularly important to recognize that time was a central part of the local worlds of the social workers dealing with this newly identified phenomenon, and that much of their understanding was tacit. These participants used the construct of time limits and "uncertainty related to time until milestones on the course of HIV processes" (one of the categories used for coding study data) a great deal, they often spoke of these ideas indirectly. For example, many emphasized the problem that medical and social work practitioners did not take, or felt unable to take, the time necessary to provide the interpersonal and concrete resources that even severely deprived and drug addicted people might use with great benefit. Practitioners' consciousness and awareness of time as a practice dynamic certainly merit more study. It is possible that the greatest area of social work client advocacy in the coming years will have to do with financing time spent with social workers, which would also imply the need for more social workers.

This study was similar to Borden's (1991) and Lamendola and Newman's (1994) in seeking to develop new research questions about practice from the participants' frames of reference, rather than testing too many of the wrong hypotheses based on the researcher's a priori assumptions (Tyson, 1992). Research should be done to chart objectively and specifically the phenomena reported in the earlier studies, as well as to make plain to professionals the phenomenological worlds of both people with HIV and practitioners. In particular, it is important to ask the question of what proportion of clients change and in what ways, judged by their own and by external criteria. Is improvement common, but short-lived, or trivial? It is possible that workers appraise cases differentially, and magnify success to compensate for the overall difficulty of the work. Other research questions are highlighted. Do practitioners perceive improvements because they need to justify their value and to motivate themselves? Would improvements occur if less skillful practitioners were involved?

Practitioners and clients alike must have mental representations of current situations and of alternative ones towards which practice flows, even if in zigzags and fits and starts. The beneficial side-effects that sometimes accompany medical and other crises are certainly not new discoveries, although there are specific psychosocial and "sociosomatic" (Ware & Kleinman, 1992) trajectories characteristic of different illnesses and cultures. Many workers in this study found images of people having a better life than ever, after they had been diagnosed with HIV. These images can inform other practitioners who are facing the grimmer aspects of AIDS and oppression and may serve to improve practice, focus research, and further enhance the well-being of mothers who have HIV.

More broadly, these practitioners offered an example of how they went beyond the surface level of understanding, beyond the prescriptions for how to "deal with" people with a specific sort of situation and disease or infection, and into the world of reality understood in collaboration with clients. This approach stands in contrast to many of the prevalent ways to understand practice, in which a classifiable condition is linked to a "best" solution or professional response. In fact, the best practice may be to work with individuals with "open minds" to develop ways to understand, to find strengths to build upon, and to formulate representations of reality. In Lithuania, a country with new social work traditions developing now, this approach to collaborative partnership work would seem to be particularly relevant, with people with HIV, or with anyone. All social work education and policy should allow time for students and practitioners to develop this ability and to formulate practitioners' hypotheses and to further test them through further research.

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SOCIALINIŲ DARBUOTOJŲ POŽIŪRIO Į MOTINAS, SERGANČIAS ŽIV, TYRIMAI

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Santrauka

Vertinant socialiniams darbuotojams svarbu suprasti normatyvines savybes ir socialinius procesus, būdingus žmonėms, susiduriantiems su socialinėmis ir medicinos problemomis. Todėl svarbu: 1) Partnerių bendradarbiavimas, asmenybės, esant įvairioms gyvenimo situacijoms, kūrimas. 2) Partnerių bendradarbiavimo ir sąvokos „asmuo situacijoje" kūrimo procesas ir analizė. Šios studijos pateikia pavyzdį, kaip praktikantai išplėtojo šią sąvoką remdamiesi literatūra ir savo praktika. Tai buvo pradėta daryti JAV pradėjus plisti ŽIV epidemijai. Rezultatai skyrėsi nuo literatūroje rastų duomenų. Tai svarbus atradimas siekiant iliustruoti praktikantų vertinamąjį darbą ir sparčiai besiplėtojančią socialinio darbuotojo profesiją Lietuvoje. Pagal ŽIV viruso plitimo greitį Lietuvą šiuo metu galima palyginti su ta JAV stadija, kai buvo pradėta rinkti duomenis apie šią ligą. Galima teigti, jog esama būdų dirbti su žmonėmis, užsikrėtusiais ŽIV.

Pagrindinės sąvokos: ŽIV, vertinimas, teorija, socialinis vertinimas (socialinė interpretacija)