

# **When Social Workers Have Serious Physical Illnesses: A Mixed Method Exploration of Changes in Use of Self and Ethical Dilemmas**

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## **Statement of the Research Problem**

Serious physical illness causes suffering and disruption to one's life story (Brody, 2003; Kleinman, 1998). For social workers, the impact of illness can affect the therapeutic process and alter clients' experiences (Bula, 2000; Friedman, 1991; Guy, 1987; Morrison, 1997; Silver, 2001). Serious physical illnesses can have a profound impact on a primary social work tool: the use of self (Baldwin, 2000; Chapman et al., 2003; Satir & Baldwin, 1983; Woskett, 1999).

Advances in medicine have significantly changed the lived experiences and management of illness states (Kleinman, 1998). Once debilitating treatments for serious physical illnesses have improved, enabling people to accommodate interventions for both chronic and acute illnesses while remaining employed. Social workers, an aging population, are increasingly vulnerable to serious physical illnesses (National Association of Social Workers (NASW) Center for Workforce Study, 2005). Those professionals who remain employed while affected by serious physical illness have to consider the ways in which their conditions might impact their interventions and roles, as well as the potential for ethical violations and professional impairment.

The purpose of this mixed method research study was to explore the circumstances of serious physical illness in social workers. The intention was to examine alterations in professional use of self that might occur while remaining in practice and the potential of such changes to be associated with behaviors identified with ethical dilemmas and violations. Under the umbrella of social ecological theory, multiple explanatory theories informed the inquiry, including the health beliefs model, contemporary psychoanalytic theory, narrative theory, and ethical theories regarding ethical dilemmas, dual relationships, maintenance of boundaries, and professional impairment. The study was designed to address the following research questions:

1. What is the impact of serious physical illness on social workers' use of self?
2. Do social workers who have been seriously physically ill encounter associated ethical dilemmas, and if so, how are they managed?

3. Do social workers who have been seriously physically ill report behaviors that are associated with ethical violations or professional impairment, and, if so, which behaviors?

## Research Background

The term “use of self” covers a broad range of attributes, self-knowledge, relational qualities, and self-disclosures the clinician brings to the therapeutic relationship. Some consideration has been given to the effects of alcohol and substance abuse (Fewell, King, & Weinstein, 1993; Siebert, 2003, 2005), pregnancy (Ashway, 1984; Fenster, Phillips, & Rapoport, 1986; Gerson, 1996), and depression (Siebert, 2004) on social workers’ use of self. However, the link between serious physical illness, changes in use of self, and impact on therapeutic process and clients’ experiences has never been considered in the social work literature.

Most of the discourse concerning serious physical illness in mental health professionals has been informed by psychoanalytic theory and written by analysts (Schwartz & Silver, 1990). These reports use single case designs to illustrate the author’s personal response to illness, how patients were managed, and the decision whether or not to disclose their illness to patients (Abend, 1982; Dewald, 1982). There are few self-reports offered by social workers with no empirical evidence to suggest which theoretical models or practice wisdom influence the decisions social workers make regarding management of serious physical illness. Outside of a contribution by Morrison (1997) offering insight into the potential of the therapist’s serious illness to enrich and inform the therapy, a preponderance of the literature concerns counter-transference issues emerging and shifting throughout the course of diagnosis, treatment, and recovery. The obvious limitations with the literature are that contributions are only made by practitioners who have opted to share the narrative of their experience, often an indicator of resolution of the impact of illness (Brody, 2003)—and only with the degree of detail they have chosen to share. While the focus of this study is on serious illnesses, defined as those that are life-threatening, changes in use of self could also occur under less dire conditions, including transitory illnesses that cause serious physical impairment while they are treated but never reaching the level of being life-threatening (e.g., retina tears and certain orthopedic injuries).

Each person’s response to serious illness is unique, influenced by social norms, cultural and parental models of sick role behavior, and stigma (Kirmayer & Looper, 2006; Kleinman, 1998). Threats to body integrity, to life goals and to one’s sense of immortality coupled with the unpredictability of serious physical illness can create incoherence and significant challenges to a person’s sense of self (Goodheart & Lansing, 1997). The potential changes in roles, relationships, employment, family life, and finances can compound loss of body integrity and shake the foundation of the self. For many it is essential to maintain employment, reinforcing a sense of normalcy, and minimizing the financial losses caused by time off, diminished workloads, and the increased medical expenses that intensify the burden of illness (Goodheart & Lansing, 1997).

Chronic illnesses, such as diabetes, cardio-vascular disease and lupus, may exacerbate without warning, creating uncertainty (Frank, 1991). Other illnesses, such as various cancers, present ordeals linked with coming in and out of remission. Serious illnesses associated with aging can be accompanied by the co-morbid burden of loss of acuity of the senses, as hearing, sight, and cognition decline. Buffeted by exhausting, anxiety-provoking symptoms and medical treatments, people suffering serious illnesses are vulnerable to losing their senses of humor, flexibility, and playful spirits (Goodheart & Lansing, 1997). They are susceptible to scattered thinking, lack of depth and clarity, and limited attention span and perception. Cognitive alterations, mood swings, profound anxiety, preoccupation, and self-absorption may contribute to a disorganized and shifting sense of self. Frustration, anger, and blame can be difficult to contain, impairing judgment as these feelings frequently are projected onto others (Goodheart & Lansing, 1997). The potential for depression, self-pity, and spiritual crisis in an otherwise mentally healthy, well-functioning person is high, considering the fortitude it takes to retain a stable sense of self in the face of such difficulties (Maramaldi, Dungan, & Poorvu, 2008).

On the other hand, Frank (1991) asserted that the experience of serious illness can also result in renewed strength and value clarification. For seriously ill people, connecting to others in a caretaking role, such as through social work, can be stabilizing. Continuing to help others may refocus people's core values; reasons for living can become clearer when one faces the potential for death. Frank contended that with the re-evaluation of life principles and increased desire to accomplish cherished goals, people often use periods of remission and wellness with re-invigorated enthusiasm and wisdom.

If the diagnosis of an illness emerges over time, clinicians have opportunity to prepare for absences, preoccupation, and emotional responses that might interrupt their work. Most often, acute illnesses do not offer the possibility for carefully considered reactions or time to explore best evidence practices. Therefore, many serious physical illnesses have the potential to create ethical dilemmas for social workers who continue in direct practice (Reamer, 2001).

It has been argued that the personhood of the clinician is so vital that the disorganization in sense of self caused by the physical, cognitive, and emotional manifestations of serious illness cannot be kept out of the therapeutic relationship (Baldwin, 2000; Brothers, 2000). Guy (1987) pointed to the question of self-disclosure as the main quandary that therapists of all disciplines confront when faced with a serious illness. Yet serious illness can result in other ethical dilemmas associated with threats to the therapeutic alliance, transference and countertransference disturbances, boundary crossings, and violations and behaviors that are indicative of professional impairment (Guy, 1987; Reamer, 1992; Seibert, 2004).

Ethical dilemmas occur when a worker has to choose between two competing values or two or more contradictory but relevant ethical alternatives, and they may occur in several facets of social work (Reamer, 2001). Ethical problems force the question: What is the right choice for a worker to avoid unethical behaviors in a given situation?

Certainly not all clinicians who suffer from serious physical illnesses will ever experience boundary violations or become professionally impaired. Several factors can

create resiliencies to violations and impairment: the experience of the worker, the use of theory and best practice evidence, previous training in ethics, and the availability of supervision. Further, a personal support network, financial resources, spirituality, and the presence of a spiritual community can enhance coping (Canda & Furman, 1999; Goodheart & Lansing, 1997). Yet ordinary life stressors—other concurrent life crises, job stress, alcohol or drug abuse, financial concerns, divorced or single marital status, comorbid psychiatric disorders, and aging— may exacerbate the psychosocial impact of illness.

Social workers have gradually addressed these factors contributing to professional impairment (Reamer, 1992). Currently the NASW *Code of Ethics*, (2008) places the impact of serious illness under the category of professional impairment. NASW estimates that at least 20% of all social workers suffer from professional impairment at any one time (Social Work Speaks, 2002-3), compromising client care, and affecting clients' rights and the effectiveness of the treatment provided. Social workers who practice while impaired are at increased risk of unethical conduct such as boundary violations and malpractice (Houston-Vega & Nuehring, 1997). Further, the stressors related to professional impairment can influence the essential social work skills of empathy, perception, and objectivity (Social Work Speaks, 2002-3). Such pressures can lead to insufficient record keeping or follow through, excessive dependence on reimbursement, and billing errors (Strom-Gottfried, 2000).

Although medicine, nursing, pharmacy, and dentistry fields have fitness-to-practice standards that guide them in fulfilling such an obligation, social work does not (Allen, 2005; Floyd, Myszka, & Orr, 1998; Orr, 1997; Stadler et al, 1988). The guidelines from regulatory boards and professional organizations and the *Code of Ethics* (2008) leave it up to either the judgment of the social workers themselves or their professional colleagues to recognize impairment.

Reamer (2001) advocated that social workers should be willing to approach colleagues who appear to be impaired, to discuss their concerns and possible remedies. He asserted that social workers who are aware of their own impairment have an ethical obligation to take action to remedy their situations, including consultation, professional help, and altering practices. While professional colleagues are encouraged to address and/or report professional impairment, NASW studies indicated many workers were reluctant to interfere in the lives of their troubled colleagues (Elpers, 1992). Fear of disrupting collegial relationships might result in large numbers of underreported cases and incidents where clients are continuing to be treated by social workers who are impaired (Reamer, 1992).

## **Methodology**

The study utilized the Concurrent, Convergence, Triangulation, mixed method Design (Tashakkori & Teddlie, 1998). In a single, concurrent phase of data collection, this study weighted the qualitative data, specifically text related to participants' experiences in continuing their social work employment while undergoing a serious physical illness. The quantitative data, derived from an online survey instrument

completed at the end of each interview, offered an additional means of exploring questions theoretically linked to the qualitative segment.

Participants included social workers licensed to practice independently (LICSWs) in Massachusetts who had experienced a serious physical illness within the past three years, but not less than one year ago, and remained employed. The sampling technique used was non-random, purposeful sampling, employing a combination of convenience and snowball sampling.

Each participant's illness narrative was explored in detail in the qualitative portion of data collection. The semi-structured interview guide had seven questions related to health beliefs, including the perceived susceptibility to illness, the need to plan for the potential for serious physical illness, and responses to the perceived threat of the illness. The quantitative survey portion that included a nine-item Impact of Illness Scale (IIS) (Devins et al., 1993) supported the answers these questions. Responses indicated the participants' perceptions of their limitations in nine areas of daily functioning, including involvement in satisfying relationships, capacity to work or study, involvement in enjoyable recreational activities, ability to fulfill social and religious obligations, capacity to meet family obligations and expectations, capacity to conduct routine chores, ability to attend to personal daily needs, general mobility, and the capacity to think about or attend to other things than the illness (Klimidis et al., 2001). The instrument has been evaluated favorably for reliability, validity, and cross-cultural applicability (Klimidis et al., 2001).

One section of the survey, developed by the researcher, explored participants' perceptions of the changes in their use of self with clients. The measure retained the same four-point Likert scale and used the same language and question structure as in the IIS (Devins et al., 1993), which would be familiar to the participants. To increase validity and reliability, in May 2009, this part of the survey was piloted by email to all full-time and adjunct faculty who had taught Practice at the Simmons College School of Social Work in the past two years ( $n = 15$ ). Eight people responded to the email. Based on the feedback of the faculty, the questionnaire items were revised to enhance clarity of the terms.

A choice was made to limit the number of questions around ethical dilemmas during the qualitative portion of the data collection. Siebert (2004) developed an operational definition of professional impairment that was examined as part of a descriptive survey of North Carolina social workers' work and wellbeing. Permission was obtained to use Seibert's survey instrument question, employing a five-point Likert scale to explore the behaviors associated with professional impairment in the quantitative portion of this exploration (personal communication, D. Seibert, August 21, 2009). Pope, Tabachnick, and Keith-Spiegel (1987) successfully tested this question in a study of psychologists' ethical behaviors. Sixteen items that might relate to the situation of social workers experiencing serious physical illnesses were utilized. The question began with "Have your health problems EVER caused you to..." The entire protocol, including both the interview and the survey portions, was piloted with a faculty member Simmons College School of Social Work who met the criteria for the study.

Results were analyzed simultaneously and converged by comparing data during the analysis to gain a fuller understanding of the variables: changes in use of self, ethical dilemmas, and the potential ethical violations, including professional impairment (Creswell & Clark, 2007). Embedded within the Concurrent Triangulation Design, the researcher utilized a combination of both Narrative and Case Study approaches to qualitative data analysis, as described by Creswell (2007). These approaches allowed the researcher to create and organize the data files, describe the data, identify the stories and establish themes and patterns (Creswell, 2007). Peer review with a research assistant who coded the data separately and created memos containing her own responses to each interview, was indispensable in confirming the validity of both the codes that were derived from the theoretical framework and the in vivo coding.

As the coding neared completion, the researcher began to create case summaries. Concurrent with the qualitative data analysis, quantitative data analysis occurred. The material and information from the surveys, particularly the demographic and impact of illness scales, were woven into the introductions to the case summaries.

## Results

The sample was made up of 16 participants: 15 females and 1 male between the ages of 43 and 79, with a mean age of 53.12. The participants experienced a wide range of illnesses, including four cancers, one heart disease, and ten other illnesses. The findings support the literature in that social workers are a population vulnerable to vicissitudes of aging, including increases in major medical illness and the onset of chronic illness (Guy et al., 1989; Seibert, 2004). Half of the study's sample ( $n = 8$ ) was diagnosed between 45-55, confirming that this age bracket is a particularly vulnerable time of life. The majority of the participants were diagnosed with their illnesses between the ages of 45-55, with the largest number, ( $n = 5$ , 31.3%) between ages 55-60.

Seven participants (43%) reported learning about social work ethics through continuing education courses, four (25%) had courses in their graduate school programs, one (6%) reported some training on the job, and four (25%) reported no ethics education or training at all.

Participants spoke of the increased resiliency that comes of surviving a serious physical illness. Several mentioned an increased ability to recognize medical problems in clients. Many participants felt that their illness experiences would make them more sensitive, empathic clinicians in the future.

The primary result of this study indicated that most of the participants who had serious physical illnesses underwent challenges and changes to their sense of self from the moment of diagnosis. While results confirmed both a tendency to deny this impact of illness and a wish for things to remain the same, accommodating the presence of illness ultimately required accommodations that altered the sense of self. Illness behaviors, such as monitoring, appraising, and worrying about illness are time consuming and preoccupying (Frank, 1991). 14 participants (87.6%) found their capacity to think about or attend to issues other than their illnesses or problems had been reduced either "a little" or "very much" by their illnesses or problems (Figure 1). Sarah described feeling alone,

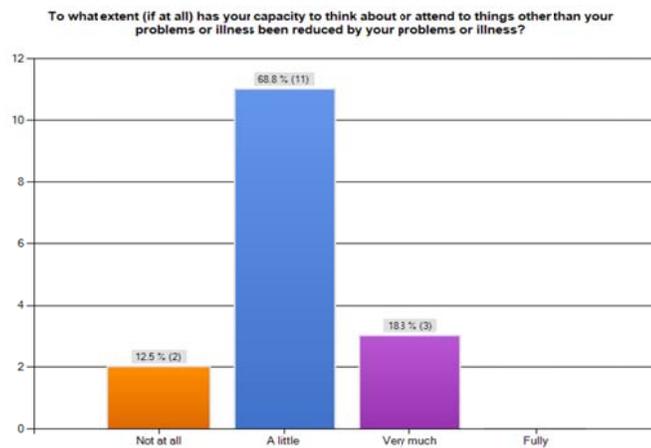
as her colleagues moved away from her, and she struggled to maintain her private practice. She lost a much of her referral base.

What comes to mind, and I don't know how it fits in or not, is how unbelievably isolated I felt. And how isolated I felt from my collegial community. I felt, at the end, there is no collegial community. I feel like my colleagues kind of got sick of hearing about it, even though they didn't really say that. (Sarah)

Such changes in sense of self led to changes in the participants' use of self with clients, as the stress of serious physical illnesses was difficult to keep out of the clinical arena. The overarching concern for participants was how to find the energy to take care of themselves and still take care of others. This difficult balance speaks to the ethical tensions around whose needs—the client's or the social worker's—are primary, and how the clinician maintains the focus on clients.

For example, Alison, sandwiched between multiple familial obligations and her professional responsibilities, reported being too busy to “think straight”. Busyness fostered a denial about her illness, making it easier for her to “not remember things” and avoid the symptoms of MS she could not bear to address. Sarah, was diagnosed with 3 cancers in 3 months, on top of several recent personal losses and changes. She described herself as feeling very strong and “even more astute and present in my practice because I was trying so hard to be that way.” Then she admitted, “So I was whackadoodle. In 2006, I was just whackadoodle and still working.”

*Figure 1. Capacity To Think about Or Attend to Other Things Reduced by Illness*



Almost half the clinicians ( $n = 7$ ) who participated in the study did not have any emergency backup plan. Four participants had loosely formed plans that would have not have been adequate in the case of the worker being rendered unconscious or unable to participate in offering further instruction. In seven cases participants reported fully formed emergency back-up plans. The numbers add up to more than the total  $n$  because in some cases participants had emergency plans at their agencies but not for coverage of their private practices. Jane's situation highlights the plight of social workers who piece together employment through various part-time jobs to have the flexibility to remain available to their children and to raise their families. At age 52, when she was diagnosed with Guillian Barré syndrome, she had worked as a social work clinician for 35 years and

had 2 part-time positions: a part-time faculty advisor to 15 students for the field department of a local graduate school of social work and a consultant for a senior care company, where she was assigned to two nursing homes. Jane had no plan for back-up or someone to cover her clients with whom she had regular communication about them. When Jane was ill she was out for months and her clients had no communication about where she was or what had happened to her. Only that they could see the psychiatrist on call until she returned.

Barb had a seizure and found she had a brain tumor. From the emergency ward she assigned her 18 clients to four colleagues. The others were divided depending “on the clients and who they were”. Barb states she wrote out a script for her husband to give to her colleagues, telling them what had happened and what she wanted her clients to hear, and her clients learned about her absence through her colleagues.

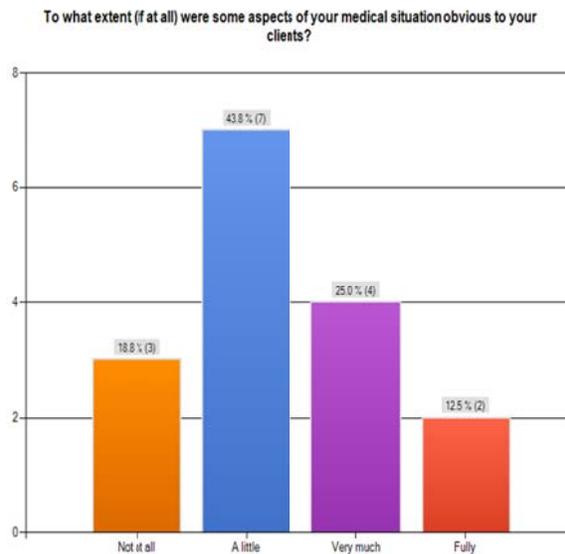
I didn't know how much to tell them. Because nobody tells you how to deal with stuff like this. And I thought, what do I tell them? What do they need to know? (Barb)

The issue of what to tell clients in when one has a serious physical illness can interfere with the aspect of use of self that involves authenticity. The alternative of lack of full disclosure was terribly upsetting to Melissa, whose agency advised her strongly against self-disclosure.

I said I had a family emergency and I had to stay out, because I was advised not to say anything. So I felt like I was telling a lie, and it felt really—I was being inauthentic with people that I had been really straight with and honest with. (Melissa)

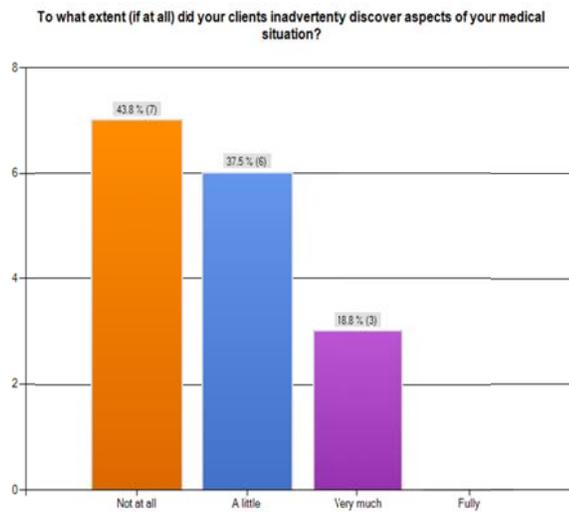
Self-disclosure, a key component of use of self, often created an ethical dilemma for participants. Some participants became stricter about boundaries and some became more open in their use of self. Decisions about self-disclosure were not always within the workers' control; many participants reported inadvertent or inescapable self-disclosures. It is important to note the decisions workers make are based on their own self-assessments at a time when the need to see oneself as “well” is often critical to “doing well” and fighting illness. (81%) reported obvious physical markers of illness such as extreme fatigue, weight loss of 20 pounds (or more), pallor, hair loss, wigs, or the use of assistive devices such as canes or walkers that clients could not help but notice. These markers are considered inescapable self-disclosures. In contrast, only 37.5% acknowledged that aspects of their medical situation were either fully or very much noticeable to their clients (Figure 2).

Figure 2. Extent Medical Situation Obvious to Clients



Thirty-one percent of the participants reported incidents of inadvertent self-disclosures (Figure 3). Inadvertent self-disclosures may be unintended and occur out of the clinician's control (Pizer, 1997). Sarah reported being cared for in the post-surgery recovery room by her client's partner, and she then assumed her client knew about her illness. Such inadvertent self-disclosures were all linked with ethical dilemmas.

Figure 3. Extent Clients Inadvertently Discover Aspects of Medical Situation



For example, Allison, who worked with teens in a school and had not yet faced her increasing symptoms of MS, shared,

... but this particular day it had, um, I went down to the cafeteria with my student, with the stairs, we came back up, and I couldn't walk. And we weren't at my office yet. And so I needed to go into the copy room, which is right by the stairs, and he had to hold the food I had gotten for myself; he held my food while I went through this process of trying to be able to stand up, and I scared the life out of him.

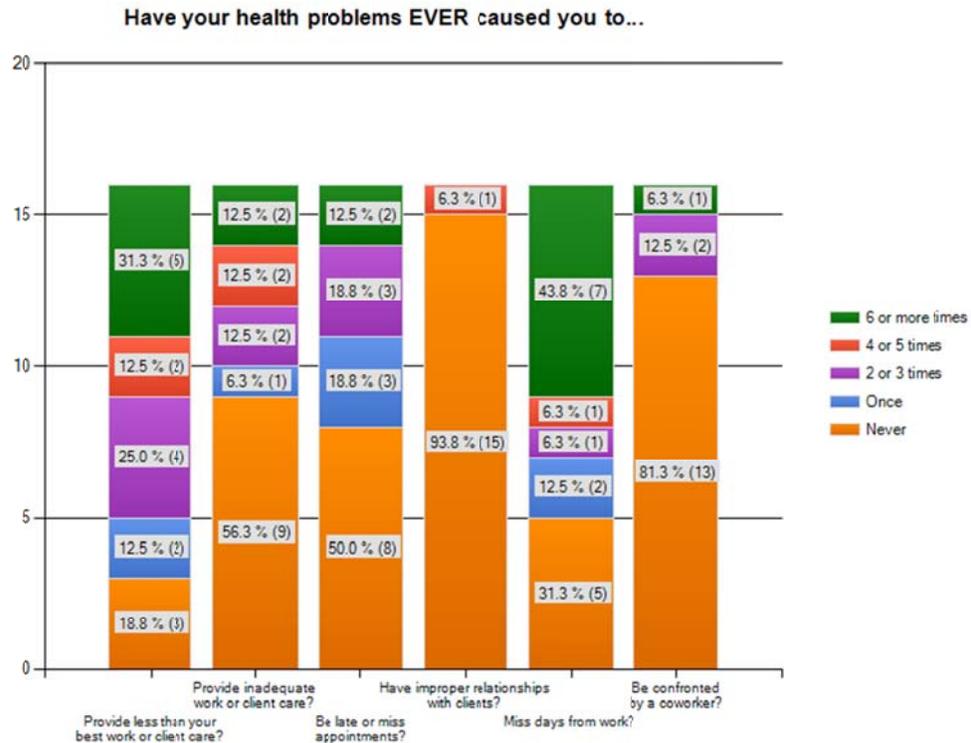
Participants also reported negative changes in their use of self due to illness, including diminished energy levels that interfered with clinical work, and becoming less tolerant of clients who participants felt were wasting precious time. For many, this balance of taking care of themselves and others was challenging, and led to transferring clients who were burdensome or took too much energy, were insufficiently responsive, or required outreach. Countertransference feelings heightened for many participants. Diverse work environments contributed to some of the stress of adjusting to serious physical illness while remaining employed. Compelled by financial situations, several participants in private practice returned to work before they were physically ready.

I had to tell people that. Like, you know, “I’m not able to smile. I’m not mad at you. I may look like I’m mad at you, or I’m not—I’m disinterested, [evidence of lingering speech difficulties] but I can’t smile, or I can’t—my mouth doesn’t move the way it used to move.” (Jane)

The most important finding of this study was that usually reasonable, prudent, ordinary social workers, under the condition of serious physical illnesses, experienced ethical dilemmas that could impair their judgment, even for a moment. There was only one example of a participant being confronted by coworkers regarding her impairment. The results of this study indicated that some participants were working while clearly impaired. Further, participants engaged in boundary crossings, dual relationships, conflicts of interests, and interruptions of services.

In several instances, competent clinicians, whose narratives illustrated they had managed their illnesses quite well while remaining in practice, seemed to have at least a single case that left them wondering whether they had been “good enough” for their clients. Workers felt confused about what was good enough. The stories highlighted the dilemma of when a clinician is feeling too compromised to be of value to the client; Some narratives reveal the ethical dilemma of paternalism and clinicians’ urges to protect clients versus the NASW *Code of Ethics*’ mandate for self-determination, alluding to clients’ rights to know and choose whether to participate in treatment with a therapist who is ill. Others highlight instances in which the participants found clients they no longer felt they could work with, those persons who sapped the participants’ strength, and for whom the clinicians lost the energy to stay with the work. Twenty five percent of the sample stated that they had provided inadequate client care 4 or more times, 12 % said 6 or more times. 43% said they had provided less than their best work 6 or more times. One person admitted having been confronted by a co-worker 6 or more times and 2 said 2 or 3 times (Figure 4).

Figure 4 Evidence of Professional Impairment Caused by Health Problems



The stress of coping with illness made it tough for several workers to place their clients’ needs before their own consistently, meeting the criteria for 1.06(a) Conflicts of Interest (NASW, p. 5). The narratives elicited stories of clients who felt abandoned, such as Jane’s clients in the nursing homes, or forced into early terminations or transfers. These cases are violations of 1.15 Interruption of Services (NASW, p. 8). They reflect the overarching theme of workers feeling they could not take care of certain clients and still practice self-care. These decisions were not made easily; at times they came with gut-wrenching analysis of the workers’ physical and emotional needs. The workers in rural areas were particularly vulnerable to dual relationships with clients, in which clients were known in multiple contexts, another form of 1.06(c) Conflicts of Interest (NASW, p. 5), ( $n = 2, 12\%$ ).

And then when I went back, you know, I’d be, like, you know, propped up. And so [the clients] would be very caring, I think. You know there would be periods where I’d have to lie down in the session. And they wouldn’t miss a beat. They just kept talking about themselves. (Lois)

### Utility for Social Work Practice

Social workers need to take the necessary precautions to secure emergency backup plans for their practices. The study’s results showed only 50% of the participants had an emergency backup plan. This statistic makes sense using the health beliefs model

(HBM), which indicates that people take preventative actions based on their perceived susceptibility to an illness (Janz et al., 2002). Almost all of the workers reported a low level of perceived risk of illness. Even social workers who are employed in agency settings need to ensure their superiors have thoughtful emergency plans in case of emergency illnesses or sudden death. Records should be kept up to date and be accessible to the person covering in case of an emergency.

Social workers who experience serious physical illnesses and remain employed must receive formal supervision. Peer supervision and informal arrangements with like-minded colleagues appear to be inadequate to process the complex personal responses, transference and countertransference feelings associated with this phenomenon (Dewald, 1990). Ideally, social workers who recognize a colleague's professional impairment would responsibly address the problem through direct communication with said impaired colleague or by reporting it to professional organizations or regulatory boards. However, most workers would not do follow-through without instruction, mandate, or civil protection, in part due to reluctance to interfere in the lives of their troubled colleagues or fear about disrupting collegial relationships (Reamer, 1992). Civil immunity laws that would protect potential reporters of professional impairment do not exist. While social workers receive training in how to report child and elder abuse there is no training available for the reporting of professional impairment. Practitioners have then been burdened with the enormous responsibility for their own actions, to recognize their difficulties, adhere to professional standards of care, and to take the initiative to resolve the impact of impairment—all on their own.

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