Take Back Your Health: Power Tools for People with Chronic Illness, Their Caregivers, and Healthcare Providers

A Summary Paper

Presented to

The Faculty of the Adler Graduate School

In Partial Fulfillment of the Requirements for the Degree of Master of Arts in Adlerian Counseling and Psychotherapy

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November 2012
Take Back Your Health: Power Tools for People with Chronic Illness,
Their Caregivers, and Healthcare Providers

People with chronic illness and their care providers frequently feel disempowered – even helpless – when facing an ongoing medical condition or pain. The purpose of this project was to provide a workshop in which people with chronic illness or physical disability, their caregivers, and healthcare providers gained empowerment and practical tools to manage any health condition, utilizing the Adlerian concepts of social interest and encouragement.

Chronic disease can be defined as illnesses that are prolonged, do not resolve spontaneously, are rarely cured completely, and may involve some type of long-term disability that is irreversible. The health problem can be stabilized and controlled, but the affected individual cannot expect return to the level of health enjoyed before the onset of the illness. The most common chronic diseases in the United States are arthritis, cardiovascular disease, cancer, chronic obstructive lung disease (COLD), and diabetes (National Center for Chronic Disease Prevention and Health Promotion, 2000).

Forty-five percent of Americans has at least one chronic disease (Wu & Green, 2000), and chronic diseases cause major limitations in daily living for more than 10% of Americans (Centers for Disease Control and Prevention, 2004). As our population ages, the need to address these issues increases (Wu & Green, 2000).

**The Relationship Between Chronic Physical Illness and Mental Health**

Chronic physical conditions are significantly associated with depressive and/or anxiety disorders (Scott et al., 2007; Spearing & Bailey, 2012; Walters, Schofield, Howard, Ashworth, & Tylee, 2011; Lin, Zhang, Leung, & Clark, 2011). Chronic pain deprives individuals of their independence, confidence, quality of life, and often their primary support groups while leaving
them with depression, anxiety, and uncertainty regarding a cure or a treatment for their pain condition (Dewar, White, Posade, & Dillon, 2003; Lame, Peters, Vlaeyen, Kleef, & Patijn, 2005; Paulson, Danielson, Larsson, & Norberg, 2001; Sullivan & Stanish, 2003).

The Holistic Approach to Treatment

Holism is the belief that all aspects of life are interrelated (Smuts, 1926/1961). There is a connection between the mind and the body, where each affects the other. A biopsychosocial approach, addressing a variety of interconnected factors including biomedical, cultural, and personality, helps us understand their influence on the subjective experience of chronic illness (Sperry, 2006). "The biopsychosocial model is an integrative, comprehensive, and systemic perspective for understanding the person and the relationship of the system outside and inside the person that influences both health and illness (Sperry, 2008, p. 370)." Psychosomatic medicine is a comprehensive, interdisciplinary approach based on a biopsychosocial model integrating psychotherapy in the treatment of physical illness (Fava & Sonino, 2010).

Research results have consistently indicated that therapies dealing with the psychosocial issues of chronic pain patients improve outcomes, reduce distress, improve return-to-work status, and decrease the individual's reliance on the medical and social services system (American Academy of Pain Medicine, 2005; Gatchel et al., 2003; Lemstra & Olszynski, 2005; Loeser, 1999; Pizzi et al., 2005; Sullivan & Stanish, 2003; Trunks, 2008; Turk, 2005). Many chronic diseases could be prevented, delayed, or alleviated through simple lifestyle changes. Emotional symptoms can exacerbate physical pain (LaFountain, 2011).

Adler & Holism

Sperry (2011) found "that Adler is recognized as the founder of modern psychosomatic medicine and that his view of mind-body interaction has been empirically validated (p. 1)."
Noncompliance with treatment is a major obstacle to positive outcomes for people with chronic illness. Sperry (2009) describes a link between situational beliefs of illness and Adlerian lifestyle convictions, and he felt that psychotherapy could address treatment noncompliance by working with the lifestyle.

**Self-efficacy & Outcomes**

Walker & Watts (2009) found a link between self-efficacy and chronic pain disability. Self-efficacy is a person’s belief that he or she can handle the challenges that life throws at him or her (Bandura, 1977; 1997). Multidisciplinary programs addressing self-efficacy reduce disability for patients with chronic pain (Arnstein, 2000; Flor & Turk, 1988; Keefe et al., 2000; Wells-Federman, Arnstein, & Caudill, 2002).

**Methodology**

**Design of the Project**

This project included a presentation at a public workshop at the Adler Graduate School (AGS), an institution offering graduate degrees in Adlerian Counseling and Psychotherapy. The AGS Alumni Association sponsored the workshop and provided marketing and logistical support.

**Target Population**

The presentation focused on providing resources to students, alumni, and faculty of AGS and other graduate psychology programs; medical and mental healthcare providers; people with chronic illness and physical disability; and caregivers. I chose this broad population with the intent of focusing on foundational concepts that would be universally useful to everyone coping with illness, either directly or indirectly, with the goal of having the broadest impact possible. To maintain a manageable scope, I focused on the issues of coping with physical illness or
disability, though many of the concepts taught could easily be translated into useful tools for managing mental illness.

**Project Development**

In the development of this project, the most difficult challenge was settling upon an appropriate scope for my goal of applying psychological interventions to chronic illness and physical disability. My interest in the topic contains breadth and depth, and could easily result in a textbook (or three). A useful approach offered to me by Dr. David Mathieu was to settle upon which chapter of that book I wanted to write first (personal communication, June 6, 2011).

My topic finally crystallized in vivo, when I saw a client in my office just a few hours after having a medical appointment of my own. With the client, I spontaneously pulled my personal healthcare journal from my backpack, explaining to her that it was a tool I had developed for chronic illness management, which she could also adopt. In that moment, I realized that I could channel my identities as a mental health provider, a patient with chronic illness, a caregiver, and a former healthcare administrator into helping people apply concepts and techniques that I have learned to their own situations.

Even with this focus, in the final days of preparing my presentation, I concluded that I could easily have spent a great deal more time reviewing all the materials I had gathered, let alone everything else I still had on the horizon of my mind – articles, presentation recordings, and entire volumes that I had collected – even though I already had more than enough for my presentation.

**Description of Project Implemented**

Participants received invitations to the workshop through the Adler Graduate School newsletter, posts made on various online communities, email, and personal networking. Thirty-
five participants attended the workshop, including approximately 20 mental health providers, two nurses, about ten caregivers, and roughly 20 people with chronic illness. As anticipated, many of the participants fell into more than one category.

**Introducing Adlerian Concepts**

Participants with no prior exposure to Adlerian concepts were introduced to some of the basic tenets of Adlerian psychology, with an emphasis on practical application of those principles as solutions to the challenges of living with a chronic illness or disability – or caring for people with a chronic illness or disability. The Adlerian concepts most emphasized were social interest and encouragement.

**Social interest.** Social interest, or social feeling, or community feeling, is about one’s sense of belonging in the community. Adler describes this as the ability, “To see with the eyes of another, to hear with the ears of another, to feel with the heart of another” (Ansbacher & Ansbacher, 1956, p. 135). People who do not feel this community feeling are usually discouraged and dealing with feelings of inferiority. Feelings of discouragement and inferiority could also describe the experience of coping with chronic illness or disability, as it is easy to get depressed or feel disempowered when doing anything hurts or is difficult.

Workshop participants learned why social interest can contribute to their empowerment. For example, research shows that lack of social support is predictive of long-term disability (Johansson & Lindberg, 2000), and access to social support increases the likelihood of positive outcomes when dealing with health issues (Cohen, 1988; Gentry & Kobasa, 1984). The adequacy of social support and the quality of the relationship between patient and healthcare provider increase confidence, and therefore ability to achieve positive outcomes (Sperry, Lewis, Carlson & Englar-Carlson, 2005).
We also addressed the special challenges to social interest faced by people with chronic illness. Managing social relationships can be made more difficult by illness-related behavioral limitations, such as an inability to go for a day of shopping with friends.

Cultural context presents another special challenge to social interest. The dominant United States culture emphasizes individualism instead of communalism. A typical White American values individualism, independence, and self-reliance. Other worldviews in other cultures, including some ethnicities in the United States, emphasize community, the family unit, the clan or village. They believe that if one person is sick, then the community is sick, and everyone is responsible for each other.

Using one’s team. To overcome these special challenges to social interest and to take advantage of the empowering effects of community feeling, workshop participants learned how to identify and engage their team. One’s team is defined as caregivers, including partners, family, friends, etc.; healthcare providers; patients; and social support, including partner or spouse, family, friends, and society/community/culture.

People with chronic illness and their caregivers were encouraged to communicate effectively with their healthcare providers, expressing their needs directly, ask questions, repeat instructions received, and being candid. I also encouraged them to get social support for their goals and changes, taking advantage of the impact of social influence, increasing the likelihood of success of change.

We also discussed various techniques of working with social relationships. Applying the Adlerian concept of feeling with the heart of another, etc., is useful through imagining what it is like to be in the role of others in one’s life, such as one’s caregiver, or patient, or loved one with an illness. Others have their own concerns and cannot always share or understand ours. It can
be difficult to hear about struggles with pain or be around someone who focuses primarily on the challenges of illness. Sometimes we talk about ourselves and our problems, occasionally overmuch, because we are seeking validation from other people, but we may not be able to get their validation, and we may have to validate ourselves.

People with chronic illness must also be careful not to drive others away. It might even be tempting to, unconsciously, push those people away so that they do not have to deal with them or be rejected by them, to prove they do not need others or so they can be justified in feeling even more discouraged. But none of these is helpful, so it is more helpful to remember the reasons above why social support is necessary.

It is helpful to demonstrate reciprocity by showing interest in others’ lives, problems, needs, and goals. Expression of gratitude and returning kindness however possible, even if this means finding creative ways to reciprocate, are valuable. It may be necessary to accept the reality of changes in existing social networks, including coping with the loss of people who no longer fit into the new reality. It is important to make time for social time with the people who remain by finding ways to work them into one’s life, communicating what works. With the behavioral limitations, one may need to be creative to find something in common.

Another significant element to working with one’s team is getting appropriate help for one’s needs. It is most effective to let others know, directly, what kind of help one needs, and to avoid the temptation to be passive or manipulative in communicating needs.

Patients also must work together with their spouses or partners as a team. It is important to see the illness is a mutual challenge, and to nurture the relationship and keep it solid. Partners must encourage each other and acknowledge each other’s efforts, saying please and thank you.
To be most successful, it is helpful for partners to consider treatment a joint effort. Family support is an important component in recovery (Roback, 1984; Turk & Kearns, 1985, Friedman & DiMatteo, 1989), and the family’s success in adapting to the challenges of the disease may have a major effect on the individual’s success with self-treatment (Hendrick, 1985).

The patient’s partner should come with the patient to healthcare appointments as much as possible. This allows the partner to hear for him or herself from the professional what the patient’s limitations are with things such as housework, exercise, and the challenges of self-care. The loved one can help the patient remember which questions to ask and what the doctor said. The patient’s partner can ask his or her questions and participate as both consider options for treatment and make decisions, giving him or her more ownership in the process. Also, the partner can provide encouragement and support. If one does not have a partner, one can ask a close friend or family member to be a teammate at appointments.

**Social interest for providers.** It is important for healthcare providers to work with patients to establish trust, to increase compliance and improve outcomes. It is the provider’s responsibility in the treatment room to create a space that facilitates healing and change. Providers can use their patient’s learning style and ensure that their patient is able to listen and learn. Instead of talking at a patient, it is important to engage them. It is also helpful to understand resistance as a misalignment of goals between the provider and the patient, which requires realignment between the provider and the patient. Providers can also demonstrate social interest by building relationships with other providers for case management and teaching their patients to use all of the applications of social interest discussed.
Encouragement. The aim of encouragement is “to increase an individual’s courage to meet the problems of life” (Ansbacher & Ansbacher, 1956, p. 20). Discouraged people are discouraged because they lack social interest or that community feeling. Encouragement is not praise or reward, but instead is positive feedback that focuses primarily on effort or improvement rather than outcomes. Praise perpetuates a discouraging superior-inferior relationship in which one must please an authority and get good results, whereas encouragement can be given at any time, even when things go poorly (Evans, 1989).

It is useful to understand the sick role and illness behavior and its relationship to encouragement. The sick role is a kind of discouragement. When playing the sick role, the sick person feels helpless, as if they cannot contribute or take care of themselves. They solicit attention for their illness behavior by acting helpless or complaining to find significance and attention through playing the role, sometimes using illness, pain, or disability as an excuse to avoid something unpleasant. It is possible for caregivers and social supports to actually contribute to this discouragement by being overly helpful (Sperry et al., 2005).

People can avoid or overcome the sick role by finding more useful avenues to significance and meaning. Caregivers can provide encouragement for their loved ones, giving them support, but being careful not to unintentionally reinforce sick-role behavior, instead giving attention and social reinforcement for wellness behavior. Healthcare providers should avoid recommending excessive tests and treatments, as this can unintentionally reinforce patients’ perception that they are unwell. People with illness can make it clear to their team that they want encouragement and to be reinforced for wellness behavior. If feeling unable to get one’s needs met, one might be tempted to use illness behavior to control situations and solicit attention, but it
is more encouraging and effective to practice assertive communication, problem-solving, and other relationship skills (Sperry et al., 2005).

**Self-efficacy.** Related to the concept of encouragement is self-efficacy: a person’s belief that he or she can handle the challenges that life throws at him or her (Bandura, 1977; 1997). Self-efficacy is related to the feeling of being in control of the situation (Sperry et al., 2005). If one feels like one can do it, one is more likely to achieve it than if one feels like one cannot (Ajzen, 1988; Bandura, 1977). Higher feelings of self-efficacy are related to less disability, less pain, better outcomes, and better functioning (Jensen, Turner, & Romano, 1994; Turk, 1996; Silverman, 2001; Turk & Feldman, 2000; Gatchel & Turk, 1999). Higher efficacy decreases stress, and lower stress is better for the body (Sperry et al., 2005).

There are a few ways to increase one’s feeling of self-efficacy. It is useful to count one’s resources or blessings, focusing on what one has rather than what one does not have. It is also helpful to exercise power over what one thinks and feels, such as managing self-talk, remembering achievements, and practicing gratitude. Self-efficacy can also be increased through self-management, discussed further below.

**Apperception.** Adlerians believe that reality is subjective, and the meanings we give to situations determine our experience more than the situations themselves do (Ansbacher & Ansbacher, 1956). We can choose our thoughts and emotions. Finding useful meaning in our experiences, including our illnesses, is useful. It is helpful to establish the new normal by leaving behind the life one once had and accepting the reality of living with chronic illness. Patience and a sense of humor also go a long way, and realistic expectations of oneself and others are helpful. Instead of focusing on whether one still has the problem, focusing on whether one can manage the problem is more useful.
Self-Management

Additional methods of increasing self-efficacy include managing one’s illness. I introduced workshop participants to two tools that I personally developed to manage my own chronic illnesses.

**Personal Healthcare Journal.** The first of these tools is the Personal Healthcare Journal, a diary or notebook in which one can document one’s own healthcare appointments. Before the appointment, at home or in the waiting room, one can write down questions and comments for the healthcare provider. With the provider, the patient can write down the date and who he or she is seeing and record any important information, like the diagnosis, the provider’s plan for treatment, and answers to questions. If necessary, the patient’s partner or other helper can assist with documentation. This record can be referred to in the future. Healthcare providers can encourage their patients to keep such a notebook and write down important information.

**Flareup protocol.** A flareup is when illness or pain suddenly becomes worse than usual. It is often difficult in that time to make good decisions, due to feeling discouraged, being in denial of the flareup, being short on time or energy, or not feeling prepared to handle it. However, when a flareup comes, often there is much that we need to do to cope with it and properly care for ourselves. So exactly when we need to do the most, is when we have the least resources.

For this reason, I developed a written protocol. In medicine, a protocol is a guideline for treatment. In the case of a personal flareup protocol, it is a kind of personalized instruction sheet written for oneself, when one is healthier, so that it is there for one when one becomes sicker. The protocol can include elements such as treatment, e.g., “take medication,” “drink water,” “call the doctor.” Other useful elements may include ways to manage time while sick, whether
more productive activities (e.g., “work out,” “light cleaning/organizing,” “call a friend or family member”) or more relaxing activities (e.g., “play with pets,” “reading,” “journaling,” “watching TV”) are called for.

**Being proactive.** Another way to increase one’s feelings of control and self-efficacy is to take steps managing one’s illness (Sperry et al., 2005). Fully investing in problem solving, welcoming challenge and change, gives one more power to cope and achieve positive outcomes (Kobasa, Maddi, & Courington, 1981). Instead of the negative cycle of “I feel bad because I can’t do anything about it because I feel bad,” one can engage in a positive cycle of “I feel better emotionally because I’m taking positive steps to help me feel better physically.” By doing a little, one encourages oneself to do even more.

As an active participant in managing one’s life, one can take responsibility for what happens in life and relationships. If dealing with job dissatisfaction, substance abuse, relationship problems, depression or anxiety, or other personally difficult issues, it is useful to start taking charge of these, with professional help if needed. People in psychological pain express more physical pain (LaFountain, 2011). Facing the things in life that one would prefer to avoid will change one’s pain (B. A. Schumacher, personal communication, September 27, 2012). People with chronic illness can also look after their health by engaging in prevention; changing health risk behaviors such as smoking, high-cholesterol diet, and lack of physical activity; and being an active participant, educating themselves about their illnesses. It is also useful to improve coping skills, as stress and the way people cope with stress play important roles in health outcomes (Sperry et al., 2005). Additional resources were provided to help workshop participants take further steps.
Experiential Exercises

Participants had an opportunity to practice the newly-learned concept of social interest through three experiential activities. The overall goal of these activities were for the participants to practice listening, have an opportunity to feel heard, give and receive encouragement, and support each other with resources.

Sharing and listening. In the first activity, participants were asked to pair up with another person. They were encouraged (but not required) to choose someone that they did not know well, in order to gain a fresh perspective. For five minutes, one member of the dyad was designated the Talker, and the other was designated the Listener. Talkers were encouraged to share their own personal stories of caregiving or coping with chronic illness, including the challenges faced. Listeners were instructed to listen attentively and supportively, but not offer advice or try to solve the problem for the Talker. After five minutes, participants were instructed to switch roles, so that each would have a turn as Talker and Listener.

Setting your goals. In the second exercise, participants were instructed to pair back up with their partners from the first activity. They would take turns again as Talker and Listener, but with new instructions. In this exercise, Talkers were instructed to develop goals and plans for making changes and overcoming present challenges, and they were encouraged to use the workshop content and their partner for goal brainstorming. Listeners were instructed to help their partner create goals and provide encouragement, both verbal and written. After a few minutes, they again switched roles.

The purposes specific to this exercise were twofold: Participants would be able to leave the workshop with concrete goals, developed with the aid of concepts learned in the workshop;
and they would have an opportunity to receive and practice giving encouragement, a skill meant to empower them and increase their sense of self-efficacy.

**Discussion.** The third interactive portion of the workshop was the question-and-answer/discussion segment at the end. Participants had an opportunity to ask questions and get further information to help them cope with their challenges. For example, one participant, whose husband has major depression, asked for further resources, such as support groups, for herself as a caregiver; in response, another participant, a mental health professional, suggested the National Alliance on Mental Illness as a good resource – further demonstrating social interest in action.

**Summary of Outcome**

Twenty-four workshop attendees completed feedback surveys (69% response rate). One hundred percent of respondents indicated that they agreed or strongly agreed that "The workshop delivered what it promised." Ninety-six percent of respondents agreed or strongly agreed that "The presenter impressed me as knowledgeable," "I believe the workshop will enrich my personal growth," and "I would recommend this workshop to others." Ninety-two percent of respondents agreed or strongly agreed that "The workshop kept my attention."

Seventy-one percent of respondents agreed or strongly agreed that "I believe the workshop will enrich my professional development," with the remaining 29% indicating no opinion. This result may be explained by the fact that several of the workshop attendees were not healthcare professionals.

Additional comments offered by survey respondents included:

- Thank you! I hope to implement many of these suggestions.
- Great job-thank you!
- Sherry’s humor kept the talk moving at lovely pace.
• Sherry was a wonderful presenter!

• Thank you for hosting this!

• I would love to get a copy of the video.

• I was floored by all the great and thorough insight!

• Thanks Sherry—very helpful!

• Sherry is very engaging as a speaker and you can see her enjoyment in showing her information.

• Great job! Good luck with everything and congratulations!

• Thank you.

• Great organization and detailed presentation. I liked the way how the presenter incorporated Adlerian concepts into effective management of chronic illness. She shared her personal experiences with her own chronic illness and insight with the workshop participants.

• One improvement to suggest; a sound system. I have excellent hearing and heard her fine but not everyone does. Excellent, interesting, personal but clinical in the best way. I, as a person with a chronic disease, found this presentation very encouraging. This also incorporated some very intelligent social analysis to put all of this in context. Really, really important.

After the workshop, a participant, who is a mental health professional, emailed me with additional feedback:

I was so impressed with your presentation. You would have been so much more helpful than what I received when I first became ill than the many therapists I tried at that time (I couldn't find a therapist who specialized in this). I also want to work with the chronically
ill population and your ideas were so helpful! . . . Thanks! (S. Utter, personal communication, October 15, 2012)

I was very pleased with all of the positive feedback. By the time I gave my presentation, I had been so immersed in my research for so long, that I was starting to worry that the concepts I would be offering were neither novel nor helpful, because they were so familiar to me. I tried to attribute these fears to typical pre-presentation jitters, but the glowing reviews were immensely encouraging. And so the cycle of social interest and encouragement continues!

**Future Plans for Use of the Project, Summary and Conclusion**

The North American Society for Adlerian Psychology (NASAP) accepted my proposal to give this presentation at the NASAP 2013 meeting in San Diego, California. It will be interesting to slightly retool some of the information for the NASAP audience of Adlerian counselors, therapists, and educators. The only main difference that comes to mind is that I could leave out or abbreviate some of the information for healthcare providers about building an effective treatment relationship with patients, because I believe that most mental health providers are likely to receive effective training on this as part of their training programs. However, I will still want to touch on it, especially as I discuss what kinds of expectations for communication patients should set for their providers. It will also be interesting to see how this different audience responds to the information and the dyadic exercises.

In the future, I believe it will be helpful and interesting to ask participants after the dyad exercises for a few examples of what the experience was like and what they learned from it. These responses could demonstrate that the participants achieved the workshop goal of empowerment through encouragement and increased social interest, and could provide constructive feedback to improve further presentations.
A workshop participant made a comment during the group discussion that could yield further exploration. She commented that it is important to remember that not everyone has people on their team, social supports that they can draw on. I felt that my response to this comment at the time was inadequate, which suggests an opportunity for additional discussion on how people in this position can identify or acquire a team.

Avenues are available for further exploration of Adlerian approaches to chronic illness. For example, Alfred Adler originated the concepts of organ inferiority and organ jargon, which were based, in part, on his experiences as a sickly child (Sperry, 2011).

In conclusion, it was a valuable learning experience to research and present this project. I enhanced my understanding of key Adlerian concepts through the lens of coping with chronic illness, and I was pleased to practice social interest by teaching others these skills.
References


Additional Sources Consulted


