

**“You Look So Well”
The Multiple Facets of Hidden Disabilities**

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When people say, “You look so well,” it can be one of the most frustrating things a person with a hidden disability can hear. When the external facade does not match the internal reality people enter into internal dialogs that deal with issues of personal, cultural, and psychological competency. How can I look so well and feel so bad? Should I tell this person that what they see is not what they get, that how I look and how I feel are quite different? If I tell will they believe me, think I am just trying to get attention or sympathy or decide I must be crazy? What will the other person think of me? But if I do not tell then how will they judge me when I behave as my body dictates and not as I appear I should behave? Maybe none of this is real, maybe I am crazy? The doctors certainly treat me like I am. Maybe they are right.

The above reflects the kind of inner dialogs people with hidden disabilities (hypoglycemia (Singer, Arnold, Fitzgerald, Madden & Voight von Legat, 1984; Singer, Fitzgerald, Madden, Voight von Legat & Arnold, 1987), temporomandibular joint syndrome (TMJ), hidden multiple sclerosis (MS) (Fitzgerald & Paterson, 1995; Fitzgerald, Paterson & Azzopardi, 1997; Paterson, 1994), chronic fatigue syndrome (CFS) (Watson, 1996; Watson & Fitzgerald, 1997), chronic back pain (Ashby, 1998), mental illness¹, etc.) have been reporting to us. This paper is about one development trajectory of the concept hidden disability based on such reported dialogs and a variety of other kinds of data and experiences. As this work demonstrates, this concept of hidden disability is an important and useful one; it has significant explanatory power. There is, however, further testimony to its importance. The fact that it developed independently in several arenas suggests that it has great saliency. Finally, the very existence of this issue on hidden disabilities is testimony to its utility.

As noted elsewhere, my use of the term initially evolved out of interviews with people with TMJ conducted in 1989-90 (Fitzgerald & Paterson, 1995). These people talked in ways that reminded me of the way people in the study on the experience of living with hypoglycemia talked. They talked about how even they knew that they appeared healthy and robust, that it was not as if they were in a wheelchair or had a cast on an arm or leg. They did not have anything to mark them as having a disability so they could understand why people might not believe there was a problem, and that made things hard for them. In fact, as the women in the MS study also noted, the fact that they did not have an obvious disability and could often get around without obvious difficulty and could, in fact, do some essential tasks most of the time without assistance, made them look and feel like fakes. Maybe they did not have a “real” disability if no one could see it and no tests could confirm it - they certainly were not as deserving of attention as those people with MS who did need wheelchairs.

What was not noted in that 1995 publication was an event that made me realise just how important this concept was and that there was a need to consider it more earnestly. The event happened at a Society for Disability Studies meeting around the time I was collecting data with people diagnosed with TMJ. A colleague and I had been having a quiet, private discussion about our hidden disabilities, although obviously we were not using that term at the time. We were talking about how our conditions affected our lives, and they clearly had significant impacts on our lives even though we were both successful and productive in our fields. Both of us had developed generally useful strategies that allowed us to “sort of work around” the problems, symptoms, and limitations. In fact, my colleague, whose condition had a far greater impact on her life than mine did, was just describing to me in some detail how

she managed when she had a serious exacerbation of her symptoms when the timbre of the general discussion in the room dramatically increased. With this we turned our attention to this discussion.

Shortly thereafter, a woman with clearly visible disabilities made a comment to which my colleague, a health professional, responded. The other woman became incensed and shouted: "You able bodied people!" and went into a tirade about how we, my colleague and I and others "like" us, could not possibly understand anything about having a disability and, therefore, we had no right to say anything - we had no right to a voice in discussions about living with or responding to disabilities. Because my colleague did not have a visible disability people assumed she did not have one.

In this SDS meeting context this response had a powerful impact. In essence, whether she meant to or not, this woman and those who shouted support for her comments, reinforced the idea that in this society, even among people with disabilities, only disabilities you can "see" (measure or identify in some way) count as "real." If you can not see it, it does not exist. People assume people are disability free if they cannot see some evidence of a disability. Kathy Paterson (1994, p. 31) later described this as a "doubting Thomas" or "seeing is believing" phenomenon. This event highlighted the kind of problems that hidden disabilities can present, in particular the problem of having one's experience legitimized. This led me to developing a research proposal to specifically explore people's experiences with living with a hidden disability. It was in this successful grant application submitted in 1992 that I first formally used the term "hidden disability" (Fitzgerald, 1992).

As noted in an article that resulted from that research (Fitzgerald & Paterson, 1995), as of 1992 my student colleagues and I could find no similar uses of the term in the literature. Our searches included a very extensive search of all the CD ROMs available to us at the time. Later, a colleague drew our attention to a work by Weiss published in 1985 that we had not identified or been aware of.

Thus, by 1992 I was using the term "hidden disability," as, apparently, others were as well. However, at this point, although I recognized that the concept was important, I did not fully understand the power or the ramifications of using the term "hidden." In this paper I discuss why my colleagues and I believe the term "hidden" has significant and important explanatory power and seems more appropriate than any other term (e.g., Goffman's (1959; 1963) invisible) used to describe this phenomenon, that hidden disabilities are hidden in multiple ways and each hidden nature presents different, sometimes additive, consequences for the person living with such a disability.

Understanding the nature of hidden disabilities is critical in modern societies because increasingly more and more disabilities are hidden or are becoming hidden. Most chronic diseases, in particular those that involved debilitating pain and fatigue, are hidden and with modern technology many previously visible disabilities are now less obvious. Understanding hidden disabilities and what it is like to live with such a disability is important because so many of these disabilities are difficult to diagnose and treat and, as a result, many are "controversial" (Singer et al., 1984) and, thus, the lives and experiences of people with such illnesses are too often delegitimized. Furthermore, far too often the needs of these people are not identified, let alone addressed, and, thus, people often suffer needlessly - and one of the greatest forms of suffering is their self-doubt. I also believe, as I have noted elsewhere (Fitzgerald et al., 1997), that by understanding behaviours associated with hidden disabilities we can better understand a whole range of health and illness related behaviours better and in this way we can better understand them as sociocultural phenomena.

When I speak of hidden disabilities I speak of them as hidden in several ways. First, it means "those disabilities (impairments or handicaps) which are not easily seen, measured, or objectified. They are those which lack external features or visible signs" (Fitzgerald & Paterson, 1995, p. 15). Second, many of these disabilities are hidden in the

sense that they are hidden from the currently available and legitimized diagnostic tests and, therefore, not only is the illness and the illness experience placed into question (e.g., TMJ, CFS, back pain), but the very legitimacy of the condition is cast into doubt. There are no widely accepted tests to demonstrate the kind of tissue damage some associate with TMJ and other chronic pain conditions. The tests for hypoglycemia and CFS are highly contentious and MS can often only be diagnosed if the MRI is appropriately timed. In other words, many conditions are hidden from diagnostic scrutiny. Third, by the very nature of being hidden, hidden disabilities can be kept hidden, "people with hidden disabilities can choose whether or not to keep them hidden; they can manage their illness identities" (Fitzgerald & Paterson, 1995, p. 15). They can choose when and to whom to disclose. However, choosing to keep the disability hidden can present a variety of dilemmas. If they do not disclose they cannot expect to be given the kind of accommodations they might need to function at an optimal and safe level. For example, women with MS often told us of engaging in behaviours that presented them to others as super competent, but such behaviours often resulted in an exacerbation of their illness. People with CFS tended to "overdo" on good days and then had to spend days in bed trying to recover. People with TMJ also overdo on "good" days and suffer the consequences: an exacerbation of pain and the fatigue and poor concentration that can result from the use of pain medications and pain related sleep disruptions. Students and others with mental illness who do not disclose can not take advantage of the special accommodations in place to address some of their particular needs.

Furthermore, if people choose to keep their disability or condition hidden they risk being labeled with a label that may be less acceptable than the one associated with their condition, although in some cases the alternative diagnosis was more acceptable. Thus one woman told us that for a long time she would rather have people assume she might have had a bit too much to drink than to have to disclose that she had MS, but for others being viewed as lazy or incompetent was far less acceptable than being labeled as having MS or CFS. Others would rather have bosses and colleagues think they were a bit lazy than to disclose that they had MS or CFS and thus risk losing their jobs or a promotion, despite legislation that would make such an action illegal. People with more than one hidden disability often chose the one associated with a more positive identity or less stigma. For example, a student in the disclosure of mental illness study preferred to cite her arthritis rather than her mental illness in order to obtain special accommodation in regard to assignments.

Others engage in partial disclosure. "I have a chronic pain problem" rather than I have TMJ. This serves not only to manage one's identity and avoids having to disclose a potentially more devalued identity, but it also means the person does not have to engage in long explanations about the condition itself. People with hypoglycemia, MS, CFS, and TMJ all reported that they grew tired of trying to explain these conditions to people. They knew that people needed to learn about them to understand people with them, but constantly engaging in explanations was both tedious and drew attention towards the condition and away from the issue that required the disclosure in the first place.

Thus hidden disabilities have implications for the management both one's identity and one's opportunities. Some felt that the longer they could keep the disability hidden the better, but others felt it was more important for people to know, to fully disclose. Most often people engage in selective disclosure. They tell people close to them, people they trust, and people who "need to know," like family, partners, and close friends.

People who choose to not disclose (in general or in particular situations) engage in all kinds of behaviours to hide (keep hidden) their condition. Such actions range from developing alternative explanations for their behaviour to avoiding interactions where they might have to disclose. These people can engage in elaborate schemes so they can get through a situation without revealing that they have a disability. Thus people with conditions that cause significant fatigue (e.g., MS and CFS) may spend days resting before the event or develop

schemes so they can obtain periods of rest during or after the event. These people, and those who expect a particular event to exacerbate symptoms, rearrange or reschedule their lives to both hide the disability and to deal with its consequences. People with TMJ who know that going to a party with all the laughing and talking will result in a significant headache will arrange things so they can have one or more days of rest afterwards - or they just do not go. People with hidden disabilities manage their activities in ways designed to avoid symptoms or exacerbation of symptoms. People with TMJ will get to a room early so they can choose a seat where they can look straight on to the primary speaker. To be stuck in a seat to the side where the person is forced to look to the "bad side" for too long can be enough to make the person leave the situation rather than contemplate the pain that will result. For some people, such actions are not only attempts to avoid unpleasant, even debilitating, consequences, but some use such actions to try to hide the condition from themselves.

Controlling the condition is one way to hide it, even from oneself. Acting as though the condition does not exist is another way, but one that often results in unwelcome effects, like an exacerbation of symptoms. Not talking to others about the condition can help to establish a kind of psychological distance from the condition (cf. Felton et al., 1984). It may also mean that the person has to deal with the condition and its consequences alone, without medical or social support.

There is another important way in which the word hidden comes into play with such disabilities. As Watson (1996) and Watson & Fitzgerald (1997) note, many of the conditions that can be classified as hidden also serve to "hide" what the person believes is their "real self." The condition and living with the condition has transformed them into a different self, a person with a "different personality." In a few cases this is a more valued self, a more mature self as a result of overcoming adversity. More often, however, people want to bring out the previous, more valued image of self - the self that was physically, psychologically and culturally competent in their own eyes and the eyes of others. They want the inner image of self to be consistent with the external image. They do not want their valued image of self to be hidden from others. But more importantly, they want to feel as good as they look when people say to them: "You look so well."

To see that the term "hidden disability" is beginning to gain some serious recognition is encouraging because it may mean that the experiences of this hidden group of people might be given serious recognition and many of their needs might be better addressed. At the same time, this recognition of the phenomenon provides a forum that may help people better understand all the facets of this rather complex phenomenon, a complexity that has only gradually revealed itself.

Over the years, people with hidden disabilities have taught us that having a hidden disability is not always a bad thing, but it is certainly not a good thing either. It is an experience that is replete with paradoxes and conundrums, many of them hidden. Gaining a greater understanding of hidden disabilities and the lives of those with them should help us come to a better understanding of many the physical, cultural, psychological, and social experience aspects of health, illness, and disability. We have much we can learn from those people who look so well and yet so often feel so bad.

Acknowledgements

On behalf of all the people involved in The Hidden Disability Project at the University of Sydney I would like to thank the people with hidden disabilities who have helped us begin to understand the nature of hidden disabilities. The Hidden Disability Project has been supported in part by School of Occupation and Leisure Sciences Internal Grants; a University of Sydney, University Research Grant; and a University of Sydney, Faculty of Health Science, Cumberland Research Grant.

Endnote

1. This project, "Supporting Tertiary Students Who Have A Mental Illness: The Dilemma of Disclosure," is being conducted in collaboration with Laurence Bathurst and Julie Grove with a grant from the DETYA/Universities Disabilities Co-operative Project NSW.

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