ELSEVIER

Social Science & Medicine 65 (2007) 1619–1629

SOCIAL SCIENCE & MEDICINE

www.elsevier.com/locate/socscimed

The passing dilemma in socially invisible diseases: Narratives on chronic headache

Cristina Lonardi*

Department of Education, University of Verona, lungadige porta vittoria 17, 37129 Verona, Italy

Abstract

This contribution concerns the experience of chronic diseases and how it disrupts the trajectory of a person's biography, undermining his/her identity, self-reliance and social relationships. The study focuses particular attention on those diseases which have not yet been fully acknowledged and can, therefore, be considered a socially invisible disease: chronic headache is one of these. Thirty-one life stories were collected from patients attending a specialized headache centre in Northern Italy, and selected in order to include all common varieties of chronic headache. Following the principles of grounded theory, interviews began by adopting a minimal theoretical framework which consisted of asking people how they became aware of the objective (disease), subjective (illness) and social (sickness) aspects of their condition. The analysis highlighted particular points in the patients' life trajectories: first, the biographical disruption that takes place because of the disease; second, how people succeed or fail in identity negotiation, which is vital for developing an acceptable social representation of the disease. Results show that patient's choices follow a vicious circle, where a partial social representation of the disease is produced. People who suffer from chronic headache face a dilemma in social relationships: should they conceal their disease, or make it evident? If they conceal, any possible social representation of the disease is denied, which could lead to carrying the burden of the disease alone, with no social support. On the other hand, making chronic headache visible could result in stigma.

Keywords: Italy; Narrative; Chronic illness; Sociology of health and illness; Chronic headache; Stigma

Introduction

Chronic disease has an impact on daily life, interferes with work and social activities, puts strain on future perspectives, and has a dramatic impact on the social and economic condition of those who are affected (Herzlich & Adam, 1994). Many authors regard the experience of chronic disease as a social construction, resulting from interaction (Frank, 1993, 1995; Herzlich & Pierret, 1984; Williams, 1984). As a consequence, most chronic diseases produce shared social representations that allow us to address social expectations, triggering coping activities and requesting social and welfare support.

Some of these diseases, however, have not achieved social acknowledgment yet (Madden & Sim, 2006). This is the case of "socially invisible" diseases, of which headache is among the most emblematic ones. It is a very common disease (Breslau & Rasmussen, 2001) that in mild form

---

*Tel.: +39 3334371266.
E-mail address: cristina.lonardi@formazione.univr.it

0277-9536/$ - see front matter © 2007 Elsevier Ltd. All rights reserved.
doi:10.1016/j.socscimed.2007.07.007

can be experienced by most people (Blau, 1990, 2005). Some of its forms, however, such as tension-type headache (the most common one), migraine (with or without visual aura), cluster headache (typically a male headache) and chronic headache are very painful and even disabling, especially when they are chronic.

The difficulty of univocally assessing the causes of headaches is due to the fact that they can be seen as symptoms of different pathologies. Primary headaches are not associated with any other disease, while secondary headaches are associated with other diseases or accidents, i.e. cranial traumas (International Headache Society Classification Subcommittee, 2004). In primary headaches (tension-type, cluster headache, etc.) mechanisms triggering attacks may be of a different nature, though the origins of most of them are still under discussion.

Several studies have shown that chronic headache can limit or disrupt one's capability to manage family and work (Edmeads et al., 1993; Fishman & Black, 1999; Frediani, Martelletti, & Bussone, 2004; Lerner et al., 1999; Lipton, Hamelsky, Kolodner, Steiner, & Stewart, 2000; Monzon & Lainez, 1998; Peters, Huijer Abu-Saad, Vydelingum, Dowson, & Murphy, 2005; Pryse-Phillips et al., 1992; Ruiz de Velasco, Gonzàlez, Etxeberria, & Garcia-Monco, 2003; Santanello, Davies, Allen, Kramer, & Lipton, 2002; Smith, 1998). It can also trigger poorer quality of life (Niero, 2002) and increase healthcare expenses (Roncolato et al., 2000). Repeated headache attacks, together with the worry of future attacks, have a serious impact on family and marital life, as well as on social and work relationships: in the worst circumstances the sufferer's routine completely stops because of the pain. This means that the impact of the disease goes far beyond the individual patient and has disrupting effects on the family and the community (Dueland, Leira, Burke, Hillyer, & Bolge, 2004; Dueland, Leira, & Cabelli, 2005; Lipton et al., 2000; Ruiz de Velasco et al., 2003; Smith, 1998).

Nevertheless, people who are affected look exactly the same as physically healthy people and adopt outwardly normal behaviour in public. This is due to the fact that chronic headache is experienced as a private suffering, where the rise of social representations of the disease is inhibited and dramatically underestimated.

This study is dedicated to the narrative reconstruction of chronic headache experience as an invisible disease. Its main queries are the following: firstly, how the disease as a biomedical event is faced by the person at the rise of the headache; secondly, how different aspects of the disease are represented by others, be it in a narrow or in a wider environment; thirdly, what kind of actions are undertaken by the sufferer in reply to a possible failure in identity negotiation during social relationships.

Method and concepts

The study was mostly exploratory and followed the principles of grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Qualitative open-ended biographic interviews (Atkinson, 1998; Bertaux, 1981; Bichi, 2002, p.53) were conducted with 31 people from all over Italy, all of them diagnosed with primary chronic headache, recruited in a Northern Italian Headache Centre (University of Modena and Reggio Emilia) (Ferrari et al., 2004), and then randomly selected. All interviews lasted between 45 and 90 min and were conducted in a headache centre at a university hospital; they were tape-recorded and transcribed verbatim.

The interview guide included general topics that emerged from the review of the sociological literature on chronic disease (Bury, 1982; Frank, 1993, 1995; Herzlich & Adam, 1994; Herzlich & Pierret, 1984; Williams, 1984). In accordance with the grounded theory approach, the guide was revised after each interview and integrated with the emerging conceptual research frameworks (i.e. the passing strategy).

Among the various options of purposeful sampling (Glaser & Strauss, 1967; Miles & Huberman, 1994; Patton, 1990), a convenience sampling technique was adopted and patients were recruited in consecutive order as they attended the centre. Table 1 shows that types of primary headache were

Table 1
Sample of patients by type of headache: taxonomy from the International Headache Society, 2004

	Male	Female	Total
Cluster headache	2	/	2
Migraine	1	7	8
Tension-type headache		3	3
Other primary headache (daily persistent headache)	4	14	18
Total	7	24	31

represented in patients ranging from 23 to 74 years in age. Recruitment ceased as the main concepts started to show redundancy along the various stories, and trajectory models started to show clear shapes according to the criterion of theoretical saturation (Glaser & Strauss, 1967). Although concepts were kept open during the whole study, the clues collected during preliminary contacts with the patients were used to construct a loose interview guide.

Common to all stories was the finding that the disease brought about a significant change in people's lives. It was found that this corresponded to Bury's (1982) proposal, that the rise of a disease would introduce sharp discontinuity in people's personal trajectories. This is what he calls "biographical disruption", the idea that the onset of chronic illness affects daily life, individual identity, self-reliance and social relationships (Conrad, 1987; Corbin & Strauss, 1987; Williams, 1984).

As interviews were collected, it was observed that patients tended to refer to discrepancies between their experience of the disease and the way it was accepted by others. We thought Kleinman's (1988) suggestion to be particularly suitable; according to him, a disease could give rise to three kinds of different representations: (a) a biomedical event (disease); (b) a personal experience (illness); and (c) a socio-cultural one (sickness).

The stories were analysed one by one ("vertical analysis") to find out the diachronic personal story of every single patient, the illness trajectory (Glaser & Strauss, 1965), possible experiences related to biographical disruption and disease/illness/sickness dimensions, and, finally, "passing" strategies. Each story was compared with the others ("horizontal analysis") in order to extrapolate social recurrences of the above-mentioned phenomena.

Materials were, therefore, organized to see how people with chronic headache struggled in their search for consistency among the aforementioned representations, in an attempt to stabilize biographical disruption. This will be reported and commented on in the first section of this paper. When focussing on the social representation stories, we realized that most of the social representations (sickness) were produced and managed within the restricted family environment or a network of close friends. Nevertheless, for most of the patients a central concern was how to negotiate social representations and identity in public as well as in non-family surroundings. Hence, the problem of the social invisibility of (chronic or episodic) headache will be dealt with in the second section.

This introduces another important milestone from the theoretical point of view, since it refers to what Erving Goffman (1963) called "passing" (which is particularly suitable for chronic headache that shows no evident physical signs). The person has therefore two possible decisions: (1) keeping total secrecy on stigma that is, therefore, invisible to others and known only by the owner; (2) disclosing all information on stigma by making it visible to all (Goffman, 1963; Joachim & Acorn, 2000a, b).

Both solutions include advantages and shortcomings, as will be seen later. The risk is a moral trade-off that can lead the person being "discredited". Sometimes such an attempt can be successful and a compromise reached whereby personal and social identity become compatible; in some other cases they could fail. The topic of invisible disease and "passing" strategies will also be the content of Section 2.

It would be helpful here to recall that the concepts chosen so far, focussed as they are on the content of the stories, are well known in sociological literature. By using the same procedure, consecutive adjustments linked these concepts to the model shown in Fig. 1. It includes a typical chronic-headache-affected life trajectory, with possible cross-roads corresponding to the biographic disruption, and possible attempts related to the passing strategies.

Suggestions for that model are clearly derived from clinical as well as sociological, medical and anthropological literature, its main linchpin being the concept of trajectory as proposed by Glaser and Strauss (1965). The authors used this concept for describing the different death trajectories related to the main fatal diseases. From the methodological

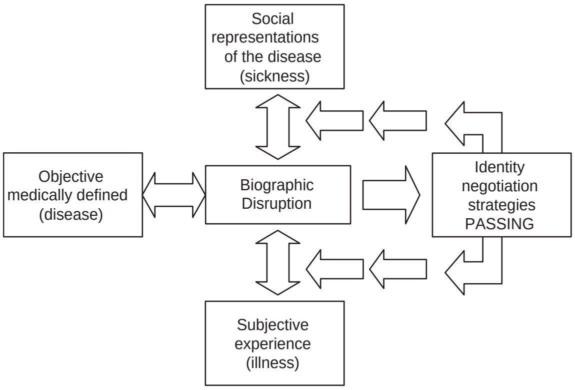

Fig. 1. Model of chronic headache trajectory.

point of view, this concept is particularly sound with the biographic approach that was adopted here for the collection of the stories. Indeed, it allows us to picture the development of life events as well as its critical points; naturally, in several studies, this concept was applied to other subjects, not necessarily related to death (see, for example, Strauss & Corbin, 1997).

However, it cannot be said that in the present work this concept was defined in advance. Rather, it took shape instead as the story collection went along, in the typical spirit of grounded theory. The literature provided a concept which was shown to be appropriate to the data as they were collected. The nature of the model is therefore mainly empirical and its conceptual articulation was derived from the data.

The trajectory followed by the patient with headache, in its relationship with the disease and its chronic characteristics is, therefore, elicited as a sort of conceptual map (Fig. 1). It highlights the rise of the disease (as a bio-medic event: disease) and its subsequent influence at subjective (illness) and social level (sickness), which ends by triggering the biographic disruption.

The passing strategies are attempts that a person implements in order to confirm his own identity. They can be successful or they can fail. Failure can bring about a new definition of the personal or social representations of the disease, by implementing what in the psychological literature (and more seldom in the sociological one) is defined as coping in all its varieties (Skinner, Edge, Altman, & Sherwood, 2003).

Each of the conceptual dimensions of the model also represents a source of critical experiences, that give rise to a variety of queries:

- how the person faced the rise of the disease as a biomedical event (doctors, drugs, etc.);
- how the disease was represented by people or groups surrounding the person (family, work, etc.);
- how the person coped with pain and the related limitations; and
- which strategies of passing were adopted.

This last point is crucial for the headache sufferer. Indeed, it entails the ways of managing his or her own identity from the social point of view, because of both the relative social invisibility of the disease and the possible behavioural alternatives (concealing or disclosing the information about the disease).

Naturally headache as a chronic disease can be analyzed also by using other conceptual models. Some of these, for example, can be drawn from the Freudian or post-Freudian tradition (Sperling, 1952) as well as from theories that take into consideration the personologic features associated with migraine sufferers (Sacks, 1986; Wolff, 1937). In addition some contributions in clinical literature highlight how stressful events can foster the rise of the primary headaches, trigger their worsening as well as accompanying their development. Some other studies have been dedicated to the psychological variables including coping mechanisms and strategies of affective regulation (Venable, Carslon, & Wilson, 2001).

Headaches involve several medical specialities (from neurology to psychiatry, from pharmacology to general practice). Nevertheless they may dramatically entail psychological as well as social and economic aspects, and this is why interdisciplinary approaches show them to be more suitable. This last concern is at the basis of the explanatory model in Fig. 1 that describes social and psychological distress, as well as the worsening of quality of life that epidemiological and clinical research make evident (Lerner et al., 1999; Smith, 1998).

Illness, disease and sickness: headache representations

People with chronic headache live in a grey zone that includes the alteration of biography concerning their body, the loss of self, and the ‘‘combined effect of the disabling symptoms and the cultural milieu which surrounds a particular kind of symptom’’ (Bury, 2000). Identity is harmed because of the lack of possible viable perspectives. Planning ahead is made impossible as shown by the next few sentences:

> I have given up a lot of things… my freedom to plan ahead… what I can’t do because I don’t know how I will be the day after […] I lost my freedom to plan what to do tomorrow… [int.30] (woman, 74, pensioner)

People with chronic headache are bound to give up several things, such as having a normal social life (e.g. going out with friends and staying in noisy and crowded places) or enjoying leisure time with others (family members or others), and they live with a constant worry of interfering with or limiting other people's lives, together with the fear of not being understood completely. When everyday life falls apart, a regressive choice leading to self-exclusion is easily made. In short, biographical disruption could be defined as erosion of reference points; harm towards identity, or loss of identity; depression; incapacity and impossibility to act; accustoming one's self to giving things up. In such conditions, the person sets out on a quest for consistency in his/her identity and this is achieved by moving through the aforementioned analytical triad: illness, disease, and sickness (Kleinman, 1988) and by producing congruous representations.

The subjective representation of the disease, the "illness dimension", is what people experience first through the painful symptoms of chronic headache, which strike both day and night, as illustrated by the following sentences:

> …it is an agonising pain… not even comparable to the pain of giving birth. The head affects everything else. You lean your head on a pillow and it feels as if your eye is coming out … light, smells, perfume, it is years since I've worn perfume because nine mornings out of ten I wake up with nausea… sometimes I dream of unscrewing my head and resting it on the night table it hurts so much …you don't know where to put it, you just don't know… [int.15]
> (woman, 55, pensioner)

> …I don't know when the headache will come either, so I start panicking about where I'll be feeling pain next, so maybe the pain increases because of that [int.5]
> (woman, 43, housewife)

During this phase of subjective experience and imagery, there is an initial feeling that is commonplace among people with chronic headache. It is the search—and this is true for any disease—for a rational explanation. For many, having cancer is the most rational explanation for such a terrible pain:

> … an NMR, another in 2004, and one now because I'm scared that something uglier is there, but there's nothing, nothing… my worry is always the same, but when I see that all the tests are negative, then I wonder why I have a headache. If the doctors can't explain to me, then how can I? [int.3]
> (woman, 74, pensioner)

The need for a technical and rational representation of the "disease" often entails changing specialist on a number of occasions. By doing so, the patient is in search of an official statement for his/her disease and undertakes the risk of facing several possible explanations, each with its own treatment.

But this experience does not affect patients when they first meet a single specialist. Once a new specialist is in town, patients tell themselves "why not?" and decide that it is worth a visit. Here are some experiences and results of such attempts:

> I had dizzy spells when I used to go to one Professor who tried by putting sounds in my ears and tubes up my nose… the dizzy spells went away, but the headache came back much worse [int.28]
> (woman, 61, pensioner)

> I've seen so many doctors… including doctors outside this hospital… I don't even recall their names… [int.6]
> (woman, 50, shopowner)

The representation of the "disease" dimension comes to light when, under simpler or more complicated circumstances, the patient finds that a certain medical diagnosis is acceptable and coincides with his/her subjective perceptions.

At times, judging by some of the comments from the interviews, one has the impression that patients absorb the technical jargon and attempt to diagnose their condition themselves, often using appropriate language:

> …a vasomotorial headache… [int.31]
> (male, 45, craftsman)

> …migraine… chronic migraine… everyday… I have it every day, heavier or lighter [int.7]
> (woman, 55, housewife)

> …they diagnosed it as being chronic… daily… all days, there is no day I am free… if it does not come in the morning it comes later… it lasts 15–16 h a day [int.1]
> (woman, 36, skilled factoryworker)

Needless to say, not only is the language appropriate, but patients also manage to provide highly accurate descriptions. Pain, anamnesis and drugs are all mentioned to introduce primary personal perceptions into the medical history of the disease. A correct diagnosis, by making the problem objective from the medical point of view, allows patients to start moving to the next step, the "sickness" dimension, which is the social representation of the disease.

Such a crucial dimension needs a social environment to emerge. For most of the patients, it coincides with the family. This is obvious, since the ideal place for developing a disease representation that will be accepted by others should be supportive, cooperative, and full of affection. In this surrounding, social relationships include helpful social benefits, defined by Bourdieu (1980) and Coleman (1990) as social capital. This includes cultural–symbolic, logistic, and practical support to the weaker person.

Although a social representation of the disease provides important support which enables the various pieces of a fragmented identity to be put back together, this does not mean that the subsequent situation will be considered fully satisfying. To clarify this point, it will be helpful to outline here below four options (scenarios) that emerged in the stories.

Scenario 1. The patient is fully accepted into the inner family network. Nevertheless the more the family is self-conscious, the more external risk and harm are envisaged. The family may become so watchful and hyper-protective that this would be more or less the equivalent of a sort of label, which often goes together with stigmas. The following sentences indicate how patients refer to this type of scenario:

> Fortunately I have a child who helps me in caring about the other children, my husband comes back from the office and then he cooks until the drug takes effect [int.5]
> (woman, 43, housewife)

> They used to help me often… yes… they saw when I change colour on my face, there was vomit, just a nasty disease [int.7]
> (woman, 55, housewife)

Scenario 2. What might happen is that although the social representation of the disease is managed within the family, it is nevertheless incomplete. A residual kind of acceptance may also take place: the patient is recognized as having problems due to a disease, but this is a reason for constant and explicit under-evaluation. Under such circumstances the family circle reduces progressively. It is like living a sort of half-life:

> … as my child says the family eco-system jams, falls apart, no one does anything any more [int.5]
> (woman, 43, housewife)

> People who don't suffer from headache do not understand. When my brother comes to see me on Saturday afternoon he finds me in bed… and he complains because he doesn't understand my condition [int.20]
> (woman, 23, administrative clerk)

> People who do not have headaches cannot understand. When I married there were quarrels with my husband and relatives because that wife (me) was always moaning, because of her head: My sister-in-law even had a go at me once…[int.7]
> (woman, 55, housewife)

Reading the stories, one factor (perhaps the most important) that can explain such a scenario is a shared stereotype about headaches. Everyone has experienced headaches that are generally mild, periodical, and provisional, and go away after taking a tablet.

> …it is headache, it passes, just take a tablet [int.19]
> (woman, 49, factory worker)

> back in the 50's a headache was a headache. It was considered as a normal pain [int.30]
> (woman, 74, pensioner)

> once I called the doctor on duty who told me that headache was there because I brought it about by moaning [int.30]
> (woman, 74 pensioner)

This is the current true social representation of headache; this way severe headache becomes a private experience and its social representation is undermined and denied.

This dominant stereotype discredits the headache sufferer because the disease's invisibility disrupts the main components of experience: ordinary people are usually tied to the sick-role perspective, which is rooted in the perception of the disease as an objective event. Possibly, here lies the main obstacle in the construction of a correct social representation of headache. The fact that anyone could experience a mostly mild headache episode makes severe forms of the disease even more invisible. This is radically different from what happens with other chronic severe diseases (Dawn, 2003) such as, for example, multiple sclerosis, psoriasis, Alzheimer, epilepsy, diabetes, etc. Indeed, healthy people cannot experience anything comparable in their daily life, while the contrary is true of headache. This has to be added to the fact that headache is a chronic disease that can worsen, but certainly does not lead to a fatal conclusion.

Scenario 3. Though none are optimistic, the above scenarios are by no means the worst. When the lack of sickness dimension cannot be recovered, a person may risk being the victim of social death. This means feeling useless, being refused by others and by social surroundings (school, work, home), experiencing expulsion from the productive world, losing personal value as a human resource, experiencing related feelings of exclusion, isolation, and loneliness:

> I tend to isolate myself in the sense that I don't even want them to ask me how I am, you see? I go into the darkness, close my shutters. I left them closed for years in the afternoon [int.7]
> (woman, 55, housewife)

In this scenario the patient is alone with his/her own "disease" and the corresponding "illness" dimension. Just because he/she has poor possibility of communication, he/she could be seen as a heavy burden to others.

Scenario 4. There is also a situation in between, when the inner family network accepts the person as ill, but, the wider or external network refuses him/her: employers or colleagues can in fact stigmatize the person with headache as unreliable, lazy, listless, while neighbors and friends tend to trivialise the condition.

> …not totally unappreciated at work, but perhaps not taken into consideration for what I am… I had to go to the emergency room, this is the only way they understand… but I get angry because you are taken as someone who tells stories [int.23]
> (female, 39, nurse)

> I don't feel… inferior in certain moments that I had to hang on from work… some colleagues kept on taking care of my work and this was very humiliating… then I decided (to change job and start my own business) [int.31]
> (male, 45, craftsman)

It is a situation that verges on something nastier; the family knows and understands, and cushions the burden of the disease when possible, while the others do not give enough importance to the person's sorrow. These are circumstances for patients who try to mediate between their own pain and a lack of acknowledgment by others.

Nevertheless, once one's own conditions become non-communicable and non-explainable to others, relationships are jeopardized.

Invisible disease and the passing dilemma

So far this paper has illustrated what can happen when social identity is produced and negotiated within a close family network. This corresponds to the immediate surroundings, where a social representation of the disease can take place and there are real chances to provisionally mend disruption.

Nevertheless, managing the disruption process in such a restricted social network may not always be desirable. Indeed, in the words and concepts of Granovetter (1985), it corresponds to bonding social capital, which relates to a high density network: while this close network provides protection, it also contributes to the creation of a tight, but almost impervious social network, a sort of protective shell, like living in a fishbowl. Is it possible to leave such a circle? Furthermore, what happens when identity is negotiated in external networks or in public? As seen above , this leads to the relational scenarios described by Goffman as "passing".

The dilemma between absolute secrecy vs. total disclosure of information about stigma and the possible outcome of choices in terms of risk ("discredited/discreditable") (Goffman, 1963) lead directly to the decision-making solution for those who have chronic headache and are deeply affected by the invisibility of the disease.

By saying that chronic headache is invisible, we mean that the disease is actually visible only through its outcomes (family and working-life disruption), and mainly in hindsight. Some of these physical symptoms have some amount of visibility, such as vomit and nausea; others, like photophobia and aura, are such that people cannot understand them (Lipton et al., 2000; Ruiz de Velasco et al., 2003; Smith, 1998). Nevertheless, the main symptom of chronic headache, i.e. pain, is hardly describable and does not provide any form of exterior stigma. It does not spread symbols that could be taken as scars (Goffman, 1963) of what affects or has affected the person.

But why should this necessarily be considered a shortcoming? For several patients, invisibility is the reason why absolute secrecy seems viable. Pretending to be normal, therefore, is the first strategy that the patient with chronic headache tends to experience. Silence and secrecy seem to be a very promising choice, though this does not mean that success should be taken for granted. Above all, success comes at a price.

Firstly, the choice of pretending to be normal can prevent others from knowing about the disease. Nevertheless, in this case, the person has to learn to live as if he/she did not have a disease when he/she actually does. People who adopt the strategy of secrecy, either by choice or by compulsion, conceal their condition, their difficulties, pain, and suffering, sometimes even to the members of the family network. This is an inconvenience that affects the very identity negotiation practices he/she wanted to avoid.

Secondly, as Goffman argues, masking one's own identity allows the person to be neither obliged to show nor say anything about stigma. Nevertheless, once undertaken, this strategy is very demanding for the person, who must always be in control of the situation in order to avoid letting slip information that may give away the secret. Tips for avoiding disclosure go together with tricks for controlling pain and discomfort: there is no way to disclose it in the form of complaining, giving up or getting tired.

> When you are in company, telling them that you feel bad because you have an attack is hard. They would say that you are a burden, and I suffer agonising pain in order to conceal my nausea … [int.28]
> (woman, 61, pensioner)

> I pretend not to have it because in certain places, for example at work, nobody helps you and the only way to live with others is to pretend to have nothing… But how do you make them understand what it means to have a migraine 24 h day…? I never complain, I don't say anything, otherwise I would be penalized … for example they could say: you can't do that job because you take headache drugs, while I am able to think clearly enough to do the job properly …[int.1]
> (woman, 36, skilled factory worker)

Thirdly, because of the shortcomings seen above, a person could decide to differentiate the risk. In that case he/she could divide his/her daily world into segments and decide what strategy to adopt and with whom. With family members, for example, patients could be totally sincere, and this could also happen with close friends, while the secret could be kept with others. Nevertheless this strategy is also costly. This fragmented way of conceiving interpersonal strategies, in fact, contributes to raising the threshold of attention in managing information and all the aspects of communication that make one's own identity explicit. Here identity negotiation sometimes takes place in terms of other events or of other people: for example, in order to keep a job on which a lot of effort has been spent; or in order to meet the expectations and needs of both the family circle and a network of friends.

All in all, one has the impression that the strategy of passing is really a very complicated one with the constant risk of failure that would expose the person to discredited moral judgement. The impossibility of expressing what it means to have the disease in a clear manner could put the person in the ambiguous situation of being viewed as devious, equivocal, ambiguous, and dishonest.

Certainly, passing can be successful and a social condition which can be considered as normal is reached; the person is healthy in everyone's eyes, because he/she does not declare his/her problem; he/she succeeds in keeping the information confidential. Metaphorically speaking, the disease disappears and, as a consequence, the need for any sickness dimension fades away. Moreover, absolute secrecy could even delete the dyad disease/illness in social relationships, except for the close family circle or those places where there is acquaintance about it.

But, as shown above, this scenario also has several shortcomings: a person might have to bear a situation with which he/she is completely unfamiliar; he/she might exert enormous effort in order to avoid information leaking out and to control the pain as well as the effects of the disease. What happens if the passing attempt fails?

It is easy to see that failure in keeping absolute secrecy could, first and foremost, worsen the initial condition. Consequent burden and consequences of failure are added to a situation of instability, where the sense and meaning (Garro, 1994) of the disease are sought. Secondly, absolute secrecy could compromise one's own credibility, since failure could oblige a person to move to the opposite end of the spectrum, namely to total information, by making one's situation totally public. Thirdly, absolute secrecy may increase discredit: behaviour could be interpreted as cheating and help would be denied because the person is believed to be affected by a disease that does not actually exist.

At this point we should wonder what happens if a person does not make any decision to pass. By considering the cases seen during the research, the decision to disclose all information is made by people who can adapt positively by moving through the rise of the disease, cope with biographical disruption and reach a satisfying condition. In their life accounts, some of the patients showed that being able to bring biographical disruption to a positive end also meant being in the best position for acquainting others with their disease, as shown by the following sentences:

> My friends go and I stay at home… nevertheless they understand my problem and they are sorry about it … they know that I'm not making excuses, they know I tell the truth … [int.29]
> (woman, 40, factory worker)

> My colleagues are always so nice, they always ask how I am …I've never met people who were not able to understand and because of this I've not had to give up anything really… [int.8]
> (woman, 47, factory worker)

Some stories tell us that there are also those who do not adopt any particular identity strategy. Some inform about their disease all those with whom they are in contact: families, friends, neighbors, employers, and colleagues. Such patients can bear such a choice because they receive positive feedback by spreading information about the disease. In this case, they reap the benefits of biographic disruption from an environment which assimilates the presence of the disease. This is possible because their social networks are able to understand them and avoid creating stigma. In other words, social environment is able to assimilate the presence of the disease. Through this, the disease gains a social dimension that otherwise would have remained hidden.

Conclusions

It is reasonable to maintain that the trajectory outlined in Fig. 1 can explain how the headache patient either moves across negative and discreditable social representations of the disease or avoids any social representation by pretending to be healthy and so denying the disease. Whatever the choice, the strategy of passing feeds a vicious circle of identity negotiation which is repeated over and over again as a sort of Sisyphean myth, or better, an identity paradox. In Luhmann's view, a paradox "rises when conditions that make a situation possible are at the same time those that make it impossible" (Luhmann, 1990); when finalized at rescuing sickness related to an invisible disease, this identity negotiation is a source of paradox. If the problem arises because social representation is missing, the impossibility of social representation makes the quest all the more awful and meaningless. A satisfying social representation of the disease has no chance of being produced and the person tumbles back to square one, making biographic disruption all the more heavy because of mechanisms of discredit. This means that if a socially acknowledged representation of the disease cannot be reached because of its invisibility, those who are affected do not even find social assets that take their problem into account; furthermore, they are morally discredited if they do not perform normally, and cannot seek help because the reason is not understandable. But does this necessarily lead to a negative conclusion? Are there possible means for rescuing a social representation which is viable for social networks and acceptable for sufferers? There is no one way to answer this. It is argued above that sickness representations can be achieved in close and protected networks such as the family. This phase should be consolidated and here self-help groups could be useful, both by playing an important role when the family is not there and by seeing that the family is not left isolated. Nevertheless, as we saw, this does not prevent the risk of a fishbowl existence, where social representations may be protected but are private and isolated. The true problem is how to open wider networks to the information by avoiding the risk of setting discrediting mechanisms in motion, since the biologic representation of the body and disease by headache sufferers is not completely integrated into the cultural and social dimension (sickness).

The challenge for health professionals and support organizations is to offer information to those who do not suffer from chronic severe headache, starting from the main social institutions. Laws that protect people who have chronic headache at work as well as in other environments are of crucial importance and are adopted throughout the western world (examples can be found in some Italian NHS districts). At the international level, in its annual report "Mental Health: New Understanding, New Hope'' (2001), the World Health Organization (WHO) identified migraine as the 19th among all causes of years lived with disability (YLDs). In the same period WHO promoted the Global Campaign to Reduce the Burden of Headache Worldwide, a joint action between WHO and the World Headache Alliance, International Headache Society and European Headache Federation. With this global campaign WHO and its partners aim to raise awareness of these burdens by making the associated global public-health actions imperative. WHO remark clearly that the key is education, which first should create awareness that headache disorders are a medical problem requiring treatment.

By this the WHO shows that the main fight is to be directed against the beliefs of daily life that cloud people's perceptions of the devastating effects of chronic headache in its most severe forms. These are important agenda items both for governments as well as for health educators, and could possibly be fostered by empowering those afflicted by chronic headache through self-help associations. As long as people believe that a headache is normal and that it goes away with a tablet, there is not much hope for building understanding social networks.

Acknowledgments

The author thanks the doctors and nurses of the Toxicology and Clinical Pharmacology Section, Department of Internal Medicine and Department of Biomedical Sciences, Section of Pharmacology, University of Modena and Reggio Emilia, Italy, for allowing her access to the department, and Professor Mauro Niero, University of Verona, for his revisions, assistance and support.

References

Atkinson, R. (1998). *The life story interview*. London: Sage.

Bertaux, D. (1981). *Biography and society: The life history approach in the social sciences*. London: Sage.

Bichi, R. (2002). *L'intervista biografica. Una proposta metodologica*. Milano: Vita e Pensiero.

Blau, J. N. (1990). Common headaches: Type, duration, frequency and implications. *Headache*, *30*, 701–704.

Blau, J. N. (2005). Feeling and seeing headaches. *Journal of Headache and Pain*, *6*, 10–19.

Bourdieu, P. (1980). Le capital social. Notes provisoires, in *Actes de la Recherche en Sciences Sociales*, 3, 31.

Breslau, N., & Rasmussen, B. K. (2001). The impact of migraine: Epidemiology, risk factors and co-morbidities. *Neurology*, *566*(Suppl 1), S4–S12.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, *4*(2), 167–182.

Bury, M. (2000). On chronic illness and disability. In C. Bird, P. Conrad, & A. Fremont (Eds.), *Handbook of medical sociology* (Fifth ed). New Jersey: Prentice-Hall.

Coleman, J. (1990). *Foundations of social theory*. Cambridge: The Belknap Press of Harvard University Press.

Conrad, P. (1987). The experience of illness: Recent and new directions. *Research in the Sociology of Health Care*, *6*, 1–31.

Corbin, J., & Strauss, A. (1987). Accompaniments of chronic illness: Changes in body, self, biography and biographical time. *Research in the Sociology of Health Care*, *6*, 249–281.

Dawn, A. M. (2003). Headache and other types of chronic pain. *Headache*, *43*, 49–53.

Dueland, A. N., Leira, R., Burke, T. A., Hillyer, E. V., & Bolge, S. (2004). The impact of migraine on work, family, and leisure among young women—A multinational study. *Current Medical Research And Opinion*, *20*, 1595–1604.

Dueland, A. N., Leira, R., & Cabelli, S. T. (2005). The impact of migraine on psychological well-being of young women and their communication with physicians about migraine: A multinational study. *Current Medical Research And Opinion*, *21*(8), 1297–1305.

Edmeads, J., Findlay, H., Tugwell, P., Pryse-Phillips, W., Findlay, H., Murray, T. J., et al. (1993). Impact of migraine and tension-type headache on life-style, consulting behaviour, and medication use: A Canadian population survey. *Canadian Journal of Neurological Science*, *255*, 946–952.

Ferrari, A., Pasciullo, G., Savino, G., Cicero, A. F. G., Ottani, A., & Bertolini, A. (2004). Headache treatment before and after the consultation of a specialized centre: A pharmacoepidemiology study. *Cephalalgia*, *24*, 356–362.

Fishman, P., & Black, L. (1999). Indirect costs of migraine in a managed care population. *Cephalalgia*, *19*, 50–57.

Frank, A. (1993). The rhetoric of self-change: Illness experience as narrative. *The Sociological Quarterly*, *34*, 39–52.

Frank, A. (1995). *The wounded storyteller. Body, illness and ethic*. Chicago: The University of Chicago Press.

Frediani, F., Martelletti, P., & Bussone, G. (2004). Measure of negative impact of migraine on daily activities, social relationships and therapeutic approach. *Neurological Science*, *25*, S249–S250.

Garro, L. (1994). Narrative representations of chronic illness experience: Cultural models of illness, mind and body in stories concerning the temporomandibular joint (TMJ). *Social Science & Medicine*, *38*(6), 775–788.

Glaser, B. G., & Strauss, A. L. (1965). *Awareness of dying*. Chicago: Aldine.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of the grounded theory: Strategies for qualitative research*. Chicago: Aldine.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. NJ: Englewood Cliffs,.

Granovetter, M. (1985). Economic action and social structure. The problem of embeddedness. *American Journal of Sociology*, *91*, 481–510.

Herzlich, C., & Adam, P. (1994). *Sociologie de la maladie et de la médecine*. Paris: Nathan.

Herzlich, C., & Pierret, J. (1984). *Malades d'hier, malades d'aujourd'hui: De la mort collective au devoir de guérison*. Paris: Payot.

International Headache Society Classification Subcommittee. (2004). International classification of headache disorders, 2nd ed. *Cephalalgia*, 24 (suppl 1), 1–160.

Joachim, G., & Acorn, S. (2000a). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, *32*, 243–248.

Joachim, G., & Acorn, S. (2000b). Living with chronic illness: The interface of stigma and normalization. *Canadian Journal of Nursing Research*, *32*, 37–48.

Kleinman, A. (1988). *The illness narrative: Suffering, healing, and the human condition*. New York: Basic Books.

Lerner, D. J., Amick, B. C., Malspeis, S., Rogers, W. H., Santanello, N. C., & Gerth, W. C. (1999). The migraine work and productivity loss questionnaire: Concepts and design. *Quality of Life Research*, *8*, 699–710.

Lipton, R. B., Hamelsky, S. W., Kolodner, K. B., Steiner, T. J., & Stewart, W. F. (2000). Migraine, quality of life and depression. A population-based case-control study. *Neurology*, *55*, 629–635.

Luhmann, N. (1990). *Die wissenschaft der gesellschaft*. Frankfurt/M: Suhrkamp.

Madden, S., & Sim, J. (2006). Creating meaning in fibromyalgia syndrome. *Social Science & Medicine*, *63*, 2962–2973.

Miles, M. B., & Huberman, A. M. (1994). *An expanded sourcebook. Qualitative data analysis*. London: Sage.

Monzon, M. J., & Lainez, M. J. A. (1998). Quality of life in migraine and chronic daily headache patients. *Cephalalgia*, *18*, 638–643.

Niero, M. (2002). *Qualità della vita e della salute*. Milano: Franco Angeli.

Patton, M. Q. (1990). *Qualitative evaluation and research method.* Beverly Hills: Sage.

Peters, M., Huijer Abu-Saad, H., Vydelingum, V., Dowson, A., & Murphy, M. (2005). The patients' perceptions of migraine and chronic daily headache: A qualitative study. *Journal of Headache and Pain*, *6*, 40–47.

Pryse-Phillips, W., Findlay, H., Tugwell, P., Edmeads, J., Murray, T. J., & Nelson, R. F. (1992). A Canadian population survey on the clinical, epidemiologic and societal impact of migraine and tension-type headache. *Canadian Journal of Neurologic Science*, *19*(3), 333–339.

Roncolato, M., Arpinelli, F., Fabbri, L., Manetta, F., Visonà, G., Brignoli, O., et al. (2000). The cost of migraine patient in Italy. *Journal of Headache and Pain*, *1*, 173–177.

Ruiz de Velasco, I., Gonzàlez, N., Etxeberria, Y., & Garcia-Monco, J. C. (2003). Quality of life in migraine patients: A qualitative study. *Cephalalgia*, *23*, 892–900.

Sacks, O. (1986). *Migraine: Understanding a common disorder*. Berkeley, CA: University of California Press.

Santanello, N. C., Davies, G., Allen, C., Kramer, M., & Lipton, R. B. (2002). Determinants of migraine-specific quality of life. *Cephalalgia*, *22*, 680–685.

Skinner, E. A., Edge, K., Altman, J., & Sherwood, H. (2003). Searching for the structure of coping: A review and critique of category systems for classifying ways of coping. *Psychological Bulletin*, *129–2*, 216–269.

Smith, R. (1998). Impact of migraine on the family. *Headache*, *38*, 423–426.

Sperling, M. (1952). A psychoanalytic study of migraine and psychogenic headache. *Psychoanalytic Review*, *39*, 152–163.

Strauss, A. L., & Corbin, J. (1990). *Basics of qualitative research. Grounded theory procedures and techniques*. Newbury Park: Sage.

Strauss, A. L., & Corbin, J. (1997). *Grounded theory in practice*. Thousand Oaks, CA: Sage.

Venable, V. L., Carslon, C. R., & Wilson, J. (2001). The role of anger and depression in recurrent headache. *Headache*, *41*, 21–30.

Williams, G. (1984). The genesis of chronic illness: Narrative reconstruction. *Sociology of Health and Illness*, *6*, 175–200.

Wolff, H. G. (1937). Personality features and reaction of subjects with migraine. *Archives of Neurology and Psychiatry*, *37*, 897–921.

World Health Organization. (2001). *The world health report 2001. Mental health: New understanding, new hope*. Geneva: WHO.