

Research Article

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Prototype stories of life with Chemical Intolerance – when the environment becomes a threat to health and well-being

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Abstract: We aimed to explore how individuals living with Chemical Intolerance (CI) describe the onset and progression of CI, and how they live and cope with CI. The participants were recruited via Swedish websites hosted by CI support groups. A postal survey, including a Life history calendar, was sent to potential participants. Eleven respondents fitted the consensus-based criteria for CI while not reporting comorbidity. A narrative analysis of their written replies resulted in five prototypical stories based on similarities in the onset and course of CI. All five stories contain descriptions of alienation from society and insufficient social support. Differences in participants' perceptions of the symptom onset – with regard to suddenness, the point in life and the perceived cause of symptoms – partly corresponded to etiological theories of CI related to stress or inflammation. Further differences between the prototype stories mainly concern the possible effects on health and well-being related to social support and coping. Given these differences, we recommend that medical professionals and others apply a holistic, context-sensitive approach before discouraging or promoting a specific coping strategy in relation to CI.

Keywords: coping, Chemical Intolerance, narrative analysis

Health problems associated with exposure to low levels of frequently encountered chemicals – such as perfume, car exhaust, and smoke – are fairly common. Population-based studies from the US and Scandinavia indicate a 12–33 % prevalence for mild symptoms (Berg, Linneberg, Dirksen, & Elberling, 2008, p. 886; Caress & Steinemann, 2009, p. 48; Johansson, Brämerson, Millqvist, Nordin, & Bende, 2005, p. 563; Kreutzer, Neutra, & Lashuay, 1999, p. 9) and 0.5–6.3 for disabling symptoms (Berg et al., 2008, p. 886; Kreutzer et al., 1999, p. 9; Martini, Iavicoli, & Corso, 2013, p. 1).

Chemical intolerance (CI) is an overarching concept for symptoms attributed to chemical exposure (Clauw, 2001, pp. 248-9; Dantoft, Andersson, Nordin, & Skovbjerg, 2015, p. 170). The diagnosis Multiple Chemical Sensitivity (MCS) constitutes severe CI in cases where symptoms involve multiple organ systems (Multiple Chemical Sensitivity consensus conference, 1999, p. 148). No dose-response relationship, or predictable relationship between the chemical exposure and the manifested symptoms, has been identified (Andersson, 2012, pp. 1-2; Genuis, 2013, p. 574; Martini et al., 2013, p. 7; Winder, 2002, p. 86-87). Several mechanisms have been put forward to explain the etiology of CI, and most of them involve either stress – for example neural sensitization (Bell, Baldwin, Fernandez, & Schwartz, 1999, p. 301) and oxidative stress (Pall, 2003, pp. 1461-62) – or (neurogenic) inflammation (Meggs, 1993, pp. 236-237). However, there is a lack of empirical evidence and the symptoms constituting the MCS diagnosis are categorized as Medically Unexplained Physical Symptoms (MUPS).

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CI symptoms have been reported by people of all ages, more commonly by women than men. Symptoms range from mild to severely disabling and include headaches, skin problems, airway problems and gastrointestinal symptoms (Andersson, 2012, p. 8; Hausteiner, Bornschein, Hansen, Zilker, & Förstl, 2005, p. 273). Comorbidity between CI and other syndromes categorized as MUPS, such as fibromyalgia, Irritable Bowel Syndrome (IBS) and Chronic Fatigue Syndrome (CFS), as well as between MCS and psychiatric conditions and allergies (Aaron & Buchwald, 2001, Tables 1 and 2) have been shown – some of which may be explained by an overlap between the definitions of the conditions' core symptoms. Intolerance to electromagnetic fields, noise and certain buildings (e.g. Building related intolerance, BRI) have also been shown to overlap with CI, possibly reflecting common underlying mechanisms (Palmquist, Claeson, Neely, Stenberg, & Nordin, 2013, pp. 429-430).

CI remains embedded in the same uncertainties regarding cause and treatment as when it was first described in the scientific literature in the mid-1980's. This uncertainty entails difficulties for the affected individual, his or her family and friends, as well as the medical community. As Dumit concludes: "one must have laboratory signs in order to be suffering; one must suffer in code in order to be suffering in fact, or one does not suffer at all" (2006, p. 580).

Lack of safe spaces, as well as perceived disbelief and lack of understanding from others, hinder persons with CI to form and maintain relationships, find safe housing, continue to work and consequently to make ends meet (Gibson, Sledd, McEnroe, & Vos, 2011, pp. 235-36; Söderholm, Söderberg, & Nordin, 2011, pp. 701-704). Gibson (2010) stated that people with environmental sensitivities "are denied access to community resources and made ill when forced to access them out of necessity" (p. 11). Low levels of social support among the chronically ill have been associated with comparably lower levels of physical functioning and emotional well-being (Sherbourne, Meredith, Rogers, & Ware, 1992, p. 241). This may be especially disadvantageous if the onset of CI is a stressful and life-changing event in itself, as social support is a known buffer for stress and strain (Taylor & Stanton, 2007, p. 381).

Attempts have been made to clarify what coping strategies are beneficial for persons with CI and BRI. M. Nordin, Andersson, and S. Nordin (2010, p. 2170) advocate emotion-focused coping, as avoidance may aggravate social isolation and in turn increase the severity of the symptoms. On a similar note, R. Fox, Sampalli, and J. Fox (2010, p. 27) argued that a shift towards acceptance and focus on potential, rather than limitations, is a prerequisite for health improvement in these groups. Other researchers, on the contrary, advise avoidance and suggest that exceeding their limitations may expose BRI patients to stress, which in turn could make them vulnerable to environmental stressors and perpetuate their symptoms (Edvardsson, Bergdahl, Eriksson, & Stenberg, 2013, p. 151). Persons with CI may thus encounter contradictory advice, which could potentially either benefit or harm their well-being. In general, no coping strategy is expected to be beneficial under all circumstances. When experiencing a break-up, coming to terms with chronic illness, or retiring from work respectively, persons with CI need to adopt different strategies in order to achieve successful coping (Folkman, & Moskowitz, p. 2004).

It is evident that CI entails suffering and that symptoms have severe effects on the lives of the affected (Gibson et al., 2011, pp. 235-36; Söderholm et al., 2011, pp. 701-704). Self-isolation among persons with CI, as well as lack of understanding from others (Gibson et al., 2011, pp. 325-36; Gibson, 2010, pp. 12-14; Söderholm et al., 2011, pp. 701-704) might hinder the affected persons' abilities to relate to others, put restrictions on what decisions they are able to make, and reduce their influence over their environment. In other words, it could affect in what ways, as well as how successfully, they can cope with CI. Unsuccessful coping in turn could negatively affect their health and well-being.

To further our knowledge about the processes that may lead to CI, it is important to gather data on the course of life with CI as related by sufferers themselves. Previous research on experiences among persons with CI has mainly concerned the present (Gibson et al., 2011, p. 233; Gibson, 2010, pp. 6-7; Nordin, M. et al., 2010, pp. 2165-66; Skovbjerg, Brorson, Rasmussen, Johansen, & Elberling, 2009; Söderholm et al., 2011, p. 689), so there is a lack of studies on the process and context in which a person begins to perceive him- or herself as chemically intolerant. Considering the relatively high prevalence of CI symptoms, the serious effects symptoms have on the lives of the affected persons, and the urgent need for further knowledge,

finding a less time-consuming approach while awaiting prospective, longitudinal, studies is an important step on the way. As the population in question may experience severe symptoms from exposure while traveling, and also have a hard time predicting how their relative health may change from day to day, we specifically sought an asynchronous data collection method based on self-reports that could still provide reasonably rich data.

The Life History Calendar (LHC) was developed to facilitate retrospective recall of life events in several life domains concurrently. Researchers have argued that the LHC draws on structures in the autobiographical memory – top-down, sequential and parallel retrieval cues (Belli, 1998, pp. 403-404). The calendar also provides visual feedback as the recording of events progresses – cues that facilitate more accurate recall of the temporal pattern of events and highlights temporal discrepancies (Freedman et al., 1988, pp. 60-61). The LHC has been found to help elicit better quality retrospective reports than standard question list surveys relative register data (Belli, Shay, & Stafford, 2001, p. 66) for accounts of moves, income and a number of weeks participants were missing from work for different reasons. In a qualitative study, Harris and Parisi (2007, p. 41) proposed combining open-ended questions with LHC, in order to examine how participants interpreted the transition from one status in life to another one. According to the authors, this combination provided deeper insights into the participants' struggles and choices, not apparent in the LHC data by itself. Harris and Parisi also stated that in their experience the “use of follow-up questions also helped improve the quality of the LHC data” (2007, p. 56).

The authors concluded that the LHC in combination with open-ended questions can be a valuable tool for researchers interested “in understanding how biography, history and context shape life course events” (Harris & Parisi, 2007, p. 56). Nelson (2010, p. 420), in turn, found that allowing participants to start where and with whatever event they chose within the LHC was beneficial in dealing with emotion-laden issues, as it allowed people to postpone relating difficult experiences. In all, these adaptations of the LHC show promising attempts to elicit chronological, in-depth narratives – though how well the approach works as a survey based solely on self-reported data has not been previously tested.

The aim of this study was to explore how individuals described their experiences of the onset and progression of CI, with special attention to what factors were described as affecting the experience of living with CI in a positive or negative way. This aim can be operationalized with three overarching questions: 1) How do accounts of the course of developing CI relate to the previously proposed etiologies of *neural sensitization* and/or (*neurogenic*) *inflammation*? 2) Can different coping strategies in accounts of life with CI be discerned and evaluated? 3) How can the influence of social support be understood in relation to coping and well-being in accounts of life with CI?

Method

In the present study, a retrospective design was used to collect participants' written accounts of how they perceived the onset and progression of CI, as well as the circumstances they considered meaningful in this process. In order to attain thorough accounts of the chronological sequence of events, support recall performance and encourage narrative depth, a Life History Calendar (LHC) was combined with open-ended questions (Harris & Parisi, 2007).

In previous research on, for example, coping a narrative methodological approach has proved beneficial in uncovering what people cope with in terms of stressors – especially when the research question deals with a process rather than distinctive events (Folkman & Moskowitz, 2004, p. 747). In the present narrative analysis, our ontological position leans towards (neo)realism (Smith & Sparkes, 2006, p. 178), as we assume that it is meaningful to relate our results to the proposed etiologies of MCS as well as previously published recommendations on beneficial coping strategies for those who live with CI or BRI (Edvardsson et al., 2013; Fox, R. et al., 2010; Nordin, M. et al., 2010). Our analytical approach has focused on similarities and differences in our informants' accounts so that prototypical stories emerge from our analysis – close to what Smith and Sparkes describe as “a storyteller who performs a narrative analysis and thinks with stories”(p. 185).

Participants and data collection

A collaborator of the third author introduced the second author to representatives from three support groups that he had had previous contacts with for research purposes. The third author outlined the aims of the present study, as well as the ethical rules to which the study complies (see below), and made clear that data would only be used for the stated purposes of her masters' thesis and this research paper. The second author also partook in an e-mail based dialogue with these three representatives about the study and accommodated suggested adjustments when possible.

A written consent form was compiled according to the guidelines from The Swedish Research Council [Vetenskapsrådet] (2002) in which prospective participants were informed of what participation in the study would entail: that participation was voluntary and could be discontinued at any point without explanation, that their personal information would be anonymized and that no unauthorised persons would have access to it, and that the results would be published in an academic journal. Participants were also informed that they would be sent the completed masters' thesis if they so wished. A pilot test of the material facilitated by the aforementioned contact persons resulted in changes mainly aimed at further protecting the integrity of participants.

Respondents were recruited in October 2015 via a website administered by a MCS support group and in two different online chat forums administered by support groups for people afflicted with MCS and Sensory Hyper-reactivity (SHR), respectively. At the time the MCS chat forum group had 100 and the SHR group 666 members.

We explicitly addressed persons who experienced symptoms from low concentrations of chemical or odorous exposure. Forty-two persons e-mailed their interest within our seven-day time frame and received our postal-survey. Twenty persons signed our informed consent form and completed and returned the questionnaire within the allotted two-week time frame (plus one additional week allowed for postal distribution).

Respondents who did not fulfil all six MCS criteria (Multiple Chemical Sensitivity consensus conference, 1999, p. 148; Lacour, Zunder, Schmidtke, Vaith, & Scheidt, 2005), reported comorbidity such as fibromyalgia, CFS and IBS or pregnancy (Lacour et al., 2005) were excluded, as were respondents who at the time were prescribed anti-depressants or anxiolytic medication. Since symptoms overlap between CI and other MUPS, as well as some psychiatric diagnoses, we have chosen to exclude participants who reported comorbidity as our aim was to collect narratives about CI specifically. Pregnant women may temporarily become sensitive to odors (Nordin, S., Broman, & Wulff, 2005), and were therefore also excluded. Eleven of the respondents (55%), 8 women and 3 men aged 37 to 72 ($M = 51.2$, $SD = 12.2$), met our inclusion criteria.

Questionnaire

The mail-survey contained a written consent form, a Life History Calendar (LHC [Figure 1]), open-ended questions, and a list of background questions concerning symptoms, the criteria for the MCS diagnosis (Multiple Chemical Sensitivity consensus conference, 1999, p. 148; Lacour et al., 2005), demographics, pregnancy, comorbidities and current medication (for a detailed description of the questionnaire see Ask, 2016, pp. 10-12).

The LHC contained nine life domains and – as the aim of the study was to explore the course of CI – the domain “health and symptoms” was specifically included (Figure 1). The other domains; “family and close relationships”, “social life and friends”, “living arrangements”, “school”, “work”, “spare time” and “contact with healthcare” were included based on previous research on CI (Gibson et al., 2011, pp. 234-35; Gibson, 2010, pp. 7-11; Nordin, M. et al., 2010, pp. 2165-66; Söderholm et al., 2011, p. 692). We also included an undefined domain; “other”. In all, these nine domains were chosen in order to facilitate a broad range of entries while specifically stressing the course of CI. No specific time units were pre-printed on the LHC as the study did concern the entire lifespan, though the emphasis was on the time of the onset of CI symptoms

the same number twice as one event touched on two separate life domains. Two participants chose to specify time units by adding years horizontally above or within the columns of the LHC.

In general, the open-ended questions provided more in-depth information than the LHC entries about the participants' thoughts and opinions on past events, their present situation, their views on how Swedish authorities, organizations, as well as individual members of society "deal" with them as well as with CI in general. We are therefore inclined to agree with Harris and Parisi (2007) that the LHC and open-ended questions complement each other – the first elicits a chronology, whereas the other enriches the sequence of events with the meanings that participants attached to it. Combined, the two sources of information made it possible for us to construct narratives based on the data provided by each participant.

More specifically, the reported events were arranged chronologically for each participant by the second author, who wrote and sketched a (re)constructed story and timeline with emphasis on chronology and content related to the symptoms each participant associated with his/her CI. Data from both the LCH and open ended questions were used simultaneously in this process, as data from the LCH furthered the understanding of the written answers to the open questions and vice versa. A case-based comparison between the stories revealed similarities on a structural level, and the second author sorted the material into seven tentative piles accordingly. The onset and progress of symptoms were similar for pairs or trios of participants, as were the factors they perceived to affect the course of their CI, while some stories at first did not seem to adhere to these emergent patterns. The first and second author then tested this tentative sorting against their understanding of the material. The negotiation that ensued resulted in five prototypical stories.

Finally, we presented each prototype as a coherent chronological story based on the common features we found in the written entries made by the participants we had associated with that prototype. We thus created a story that encompasses elements from more than one unique account, yet does not represent any specific account in its entirety. We have called our prototypical stories: *Our house became our enemy*, *Suddenly sensitized*, *When sensitive becomes sensitized*, *Infected with troubles*, and *Lifelong unexplained troubles explained*.

Results

Each of the five prototype stories was based on accounts from two participants, except *When sensitive becomes sensitized* which was based on three accounts. In the authentic excerpts presented below, [...] marks omissions while [text] indicates clarifying information added by the authors. Underlined words were underlined by participants, and quotation marks, " " or ' ', not marking quotes, are theirs as well. All excerpts are translated from Swedish to English by the first and second author.

1. *Our house became our enemy*

Here we present the story of a family moving to a new house when rather suddenly adults, as well as children, display new sets of unexplained, seemingly untreatable, symptoms. After a prolonged struggle of getting their own symptoms, as well as the symptoms of their child(ren), acknowledged as physical rather than psychological, they encounter a doctor who associates the symptoms with the house they live in. Though the family welcomes this explanation with relief, and the house is indeed confirmed to be infested with mold and healthier housing is found, they find themselves in a renewed struggle. They seem to have become sensitized, and symptoms are now elicited by several odors, chemicals and the like. The family tries to adjust to life with CI, but attributes many of their difficulties coping to an increasing alienation from society, and the lack of understanding and support from authorities and from their peers.

The prototypical story *Our house became our enemy* was based on data from one man and one woman, called Jenny and Hans below. They are 35-45 years of age, and both tell stories of how moving to a water-damaged house abruptly and negatively affected the well-ordered lives and good health of them and their respective families. Hans wrote: "Constant sinus infections, odd symptoms [...] the sickness took over [our lives] [...] the powerlessness in relation to the children's sickness".

The odd symptoms prevail and the families live in a prolonged state of worry and confusion. Healthcare professionals seem neither to be able to diagnose nor deal with the symptoms Jenny, Hans and/or their families' display, which increases their strain. Hans, and later Jenny, is presented with a burn-out syndrome or stress related diagnosis, but to them, their symptoms are the cause of stress, not the other way around. Eventually, each family finds a doctor, perceived as a rescuer – a health professional who comes to their aid when they had almost given up on answers to their questions or treatment for their symptoms. Their respective doctors tell them that there might be something in their homes that triggers the symptoms. This suggestion makes each of them investigate, and they find severe and widespread water damage in their respective houses which leads both families to evacuate their homes.

Jenny and Hans hope and expect that they and their families will get well after leaving their contaminated homes, and initially their health improves. However, soon enough they discover that they and/or other family members have developed a hypersensitivity to all kinds of chemical products and that the interiors of many buildings provoke painful symptoms. The relief of having found the initial trigger turns into yet another struggle: to adjust to life with chemical intolerance, to get the support they need from others – such as the Swedish authorities and healthcare system – and to find homes and schools that do not make them and/or their family members sick:

We found a healthy home and a healthy school. But we still don't feel well. We now react to perfumes, chemicals etc. It is very difficult for my middle [child] who now reacts to everything from mold to perfumes, chemicals to radiation [...] The primary care unit says it's stress and wants me to see a psychologist, but [...] I know it is not stress. I am definitely tired but not like that. (Jenny)

Their feeling of safety does increase as they learn more about what precautions they and/or other family members need to take in order not to trigger symptoms. However, they have yet to reach a point where they feel that they have a stable and bearable situation in life. They attribute many of their difficulties to the lack of understanding and support from authorities and from their peers:

I am still trying to find my feet [...] Perfumes in stores and public places [make life difficult] [...] It can take days before [the symptoms] pass [...] All those people questioning and doubting that MCS exists, that's the worst [...] The healthcare does not work, there is no knowledge [among healthcare personnel] [...] My boss has helped me by making accommodations so that I can work full time. (Jenny)

[I feel] secure about the condition now [...] [I] feel ok in a healthy environment [...] [I am] fighting the national social insurance agency and the public employment service to be able to go back to work [...] [my symptoms last for] a few hours up to several days. (Hans)

2. Suddenly sensitized

This is the story of how the settled life of a middle-aged person is abruptly disrupted by symptoms the protagonist associates with specific chemicals at work. When the initial adjustments in the workplace aren't enough, the need for further adjustments is met with little understanding or empathy from the employer, colleagues and family members. The healthcare services do not provide anything that is perceived as any real help or explanation. The suddenly sensitized person needs to quit their job and avoid some of their own family members. The situation becomes rather stressful. Over time, when the person has learned more about what triggers symptoms and finds places and people willing to adjust to the needs and limitations of someone with CI, they regain a restricted but at least functioning social and work life. However, as the triggering chemicals cannot be completely avoided, their health status remains somewhat precarious.

The prototype story, *Suddenly sensitized*, was based on the written accounts of a man and a woman between 45-60 years of age dubbed Ove and Berit. They told of lives free from problems related to chemical exposure well into their middle age. They had established themselves in the labor market early on and were married with children. Their problems began when they came in contact with specific environments and/or chemical substances in their workplace. Berit wrote: "The first time [I noticed symptoms] was when we

had gotten a printer at work, in [a specific room] where I worked. I had to leave [the room]. We moved all the printers to a storeroom nearby.” Ove records similar events: “[noticed first symptoms] while working with [a specific metal] at work. Completely free of symptoms while not working with [this metal].”

Ove and Berit describe their health as gradually declining. At first, their workplaces made efforts to eliminate specific symptom triggers. However, diffuse symptoms, such as airway problems and fatigue that they themselves attributed to chemical exposure, prevailed. Both Berit and Ove describe how they were met with lack of empathy, and that they were regarded by their employers and/or family members as being a nuisance when they asked for further provisions. In Ove’s words:

Start to demand that our home should be free from perfumed products [...] My wife and children start arguing about how it should be at home. [...] Talk about my health problems with my employer who dismisses me and demands that I continue working as before.

Their situations got increasingly difficult and stressful. They were referred back and forth between doctors/specialists receiving neither a diagnosis nor treatment and had to, eventually, quit their jobs. Finally, as they had managed to gain an understanding of what triggered their symptoms and found living and/or working conditions that better suited their respective needs, their situations slowly stabilize:

I have lost my family, work, health [...] When I am single [and living in a place of my own] and can fully control my children’s perfumes, life starts to become much better [...] Met a new woman and found a new part-time job working [within the public sector], work’s really good. (Ove)

Fix my own workplace and job assignments [...] Try to convince colleagues and [other people at work] to use as little of scented products as possible [...] [It is] a little lonely, but I meet people sometimes at workplace meetings and coffee breaks. (Berit)

Ove and Berit have managed to rearrange their lives in ways that work better for them, but they are constantly reminded of their CI as exposure to everyday chemicals is hard to avoid. They report living with painful symptoms and/or a curtailed social life. They both describe having been met with disbelief and ignorance and write that CI as an affliction needs to be better understood, and that the way people with CI are treated needs to improve. In Berit’s words: “The symptoms are invisible, but you need understanding and help from others. I try to say that I am probably a whistle-blower or a guardian angel, because what I cannot tolerate is probably not good for anyone else either”.

3. When sensitive becomes sensitized

Here comes a story of long-time mild symptoms related to everyday chemicals that escalated to what is perceived as severe CI, when symptoms worsen after a specific episode of exposure. The person reprioritizes their life and makes major adjustments in order not to trigger symptoms. These adjustments are perceived as (necessary) sacrifices. To be restricted in this way, while being met with a lack of empathy or understanding, is described as both burdensome and simultaneously feeling like a burden to others. Having reached a point in life where a fixed income (retirement or disability pension) provides some financial security, the burden eases a bit. They regain some freedom to choose what exposure to risk, rather than having to partake in a constant struggle to make ends meet in a potentially hostile (work) environment, and the burden eases a bit.

In the prototype story, *When sensitive becomes sensitized*, we combined data from three women between the ages of 60-75 called Camilla, Laila and Kristin below. They all describe experiencing mild symptoms for many years – uncomfortable but not disruptive – from different kinds of chemical triggers. Then, a specific event (like working in a house damaged by mold or suddenly being exposed to strongly scented chemicals) sets off very strong reactions that they all believe led to the onset of severe CI.

Worsening symptoms make Camilla, Laila, and Kristin reprioritize in order not to trigger debilitating symptoms and sacrifice many things in their respective lives in order to be able to control what chemicals

they are exposed to. Malls, hairdressers and even healthcare facilities become difficult or impossible to access. They also describe the grief of feeling like a burden to others, and/or being met with disbelief or a lack of understanding. In Kristin's words: "The worst part is that my family members do not reduce [their use of] perfumes [...] I often have to abstain from participating in family gatherings."

Despite their limited ability to socialize as well as access public venues, Camilla, Laila and Kristin write about feeling rather safe now, as well as in the foreseeable future. Two of them live alone, while the third one now lives with someone who has carefully considered what living with her entails, given her CI symptoms. Camilla, Laila, and Kristin have all left working life behind and receive either a retirement pension, sickness benefits or a disability pension. They are currently able to see positive aspects of their lives and experiences:

Now my economy is secure and safe and I don't have to worry about the years that I have left. I suffer with those who are affected when they have 25-30 years left in their working life! (Laila)

I focus more on my possibilities than my limitations. I see a disability, an illness or an injury as a journey. (Kristin)

4. Infected with troubles

Here the troubles begin with a viral or bacterial infection early in adulthood, which permanently affects the persons' health, and it is later perceived to be the starting point for escalating sensitivity to everyday chemicals. These CI related health problems are met with a lack of understanding and respect from others – authorities, healthcare professionals, peers, and colleagues alike. Attempts to complete an education, hold on to a job or find a place to live are unsuccessful – workplaces and housing that do not trigger symptoms seem impossible to find. Few doctors seem to understand their problems, and most contacts with authorities leave our protagonist feeling misunderstood and rejected. Colleagues and others doubt the existence of CI and are reluctant to refrain from scents or to make other adjustments. Their life has become increasingly curtailed by illness; avoiding triggers all too often means avoiding people and activities that give meaning to life. Those few relatives and friends that remain are precious: especially internet support groups and social media friends. Living on social security benefits, our protagonist persistently fights for adequate help from authorities, such as the right to housing that will not trigger symptoms and equipment to keep harmful chemicals out of their system.

The prototype story *Infected with troubles* was based on accounts from two women 45-60 years of age, hereinafter called Gunilla and Sofia, who tell of many years of ill health and/or troublesome circumstances. They also write of some brighter moments, especially in their early lives, but those events are scarce in relation to the number of events where health and/or other problems dominate. They both report having had a viral or bacterial infection as young adults that permanently affected their health. They described their lives as increasingly affected by CI related health problems and how they have been met with a lack of understanding and respect from colleagues, authorities and the healthcare system. As Sofia wrote:

My life has been eventful and I have been exposed to a lot of negative stress [...] I was bullied throughout school [...] It was very positive for me [as a child] to be out in the countryside [...] I had had chronic pains and sinus infections for about ten years [before learning about chemical intolerance].

Both Gunilla and Sofia repeatedly engaged in work and/or studies, but their health problems made most attempts to keep a job for a longer period of time and/or completing education difficult. They continue to try to find workplaces and/or homes that will not trigger their symptom, but describe how their hopes are crushed repeatedly when symptoms return. In Gunilla's words:

Worked in a bread factory but had to quit as I turned out to be allergic to [many of the products used at the factory] [...] Worked with cleaning [...], which implied environments with a lot of dust, contact with strong chemicals [...] I quit due to ill health: allergies, aching hands and arms, MCS-like symptoms/hypersensitivity [...] Lived in an apartment where the walls turned out to be moldy, suffered from many health problems due to this.

They write of seeking support, multiple times, from authorities and the healthcare system. Although they perceived some healthcare professionals – specialists such as allergists in particular – as knowledgeable, most of their contacts with primary care units and other public sector institutions make Sofia and Gunilla feel misunderstood or rejected. Colleagues at their workplaces and other people are described as unwilling to refrain from scents or adjust in other ways. They feel that people who doubt the existence of MCS make their situation more difficult. They both describe how life feels meaningless as CI makes them increasingly sick and hinders them from participating in society the way they would like to:

Chemical intolerance has hindered me from practicing my hobbies and in many respects the meaning of my life. (Gunilla)

It often feels meaningless, and almost daily I think about what I should do to be able to die [when feeling very sick] [...] It is necessary for me to believe that I will be able to feel better. (Sofia)

Their lives are increasingly curtailed, and they lose contact with some of their friends and/or relatives. Those that remain are perceived as very important, especially Internet support groups and social media contacts. At present, their income is social security benefits. They have not been able to find any occupations that they are able to pursue without falling ill, nor have their pleas for help from authorities led to the results they had wished for. They still hope for aid from authorities in order to improve their quality of life, as their current situations seem unbearable:

I cannot lead a normal life, far from it [...], I live on social security benefits [I get no] allowances to be able to buy vitally important gas masks and air cleaning equipment. (Gunilla)

I try to make plans and pull myself together to find solutions, and I am going to sue the municipality with violation of the Social Services Act [for claiming that they have no solution to the problem of finding appropriate housing] [...] I know that there is a home waiting for me, a job where I can help the world to become a little bit better, and a life to keep living! (Sofia)

5. Lifelong unexplained troubles explained

Here we find a story of lifelong poor health and strong reactions to everyday chemicals from early childhood onwards. Attending school on a regular basis was impossible while (sickness) absence was met with little understanding, and being unable to maintain friendships increased the feeling of isolation. Our protagonist nevertheless managed to complete an education and take on jobs, but was frequently sick-listed, in part as their work environment contributed to their deteriorating health. To find a home that would not trigger symptoms was hard, as neighbors smoked and cars “spewed” exhaust fumes. Prescription medicines for asthma or allergies relieved the symptoms to some extent, but a change of doctor could lead to the threat of losing medication for which they did not show the proper symptoms. Presently they have managed to find a job they can hold down, as the work environment is free from triggers and employers and colleagues accept and adjust to their needs. However, the threat still looms of debilitating symptoms suddenly reoccurring, triggered by environmental factors. They also keep getting hurt by repeatedly being met with disbelief regarding their CI, the cause they themselves have concluded lies behind their troubles.

The fifth prototypical story, *Lifelong unexplained troubles explained*, was based on the written accounts from one man and one woman between the ages of 35-40 called Jonas and Julia below. Both of them described reacting strongly to everyday chemicals, such as detergents and smoke, from early childhood onwards. They both wrote about troublesome school years, due to loneliness and/or physical symptoms such as fatigue and respiratory problems (it is not evident from the material to what extent they associate their childhood health troubles with CI). Julia wrote: I only had the energy to attend school two days out of five, many fights with teachers about me not being normal”. On a similar vein, Jonas stated “Stopped asking friends if they wanted to play after school. No one has the energy to be with me. I turned bitter – for 25 years!”

Jonas and Julia grew up, but their physical problems prevailed. They managed to complete their

education, but their ill health kept making their lives unstable and unpredictable. They took on jobs but were frequently sick-listed when their work environments made their ill health deteriorate further. Finding suitable living arrangements was difficult due to neighbors smoking and cars giving out exhaust fumes. They were prescribed different sorts of medical treatments that sometimes had positive, although limited, effects. The physicians they met could not explain their respective symptoms and/or were unwilling to provide them with prescription drugs that their symptoms did not correspond with. Julia wrote: “What the doctors’ response is, depends entirely on what kind of education the doctor has [...] Older doctors, if they are not specialists, want to remove my medication as I don’t make the typical asthma sounds.” Jonas and Julia report that they are often treated with disbelief and patronized when in contact with the healthcare system. They continue to feel more or less constantly ill.

Presently, after searching for suitable occupations throughout their adult lives, Julia and Jonas have finally found jobs that they can manage – mainly as their workplaces are free of the chemical products that make them sick. They express that current colleagues and managers respect their CI. Julia and Jonas value their jobs a great deal but still report substantial difficulties in everyday life due to physical symptoms and/or distress caused by being met with disbelief from others. As Jonas wrote:

Feel better physically, but not mentally. I often get [verbally] attacked and people complain that I am a nuisance and that it is burdening that everyone should accommodate my needs when I don’t accommodate anyone else’s. Makes me so sad when people say that [...] If I am exposed I get completely knocked out for a few hours [...] Cough for twelve hours following exposure.

Discussion

The aim of this study was to examine how individuals described their experiences of the onset and progression of CI. Our three overarching questions were: 1) How do accounts of the course of developing CI relate to the previously proposed etiologies of *neural sensitization* and/or (*neurogenic*) *inflammation*? 2) Can different coping strategies in accounts of life with CI be discerned and evaluated? 3) How can the influence of social support be understood in relation to coping and well-being in accounts of life with CI?

Our results do not necessarily fall in line with one specific etiology of CI symptoms. The course of events in both *Our house became our enemy* and *Suddenly sensitized* could be interpreted as long-term exposure as no account specifies a sudden specific event, which means that onset could be related to the theory of neurogenic inflammation (Meggs, 1993, pp. 236-237). The prototypical story *When sensitive becomes sensitized* includes the account of mild problems related to everyday chemicals followed by a critical episode of exposure to a specific environmental trigger. This sudden escalation would be in line with neural sensitization (Bell et al., 1999, p. 301). However, as it builds on accounts that include long-time mild symptoms of unclear origin related to everyday chemicals prior to the episode of exposure, we cannot discern whether this episode should be seen as an event that hit an already weakened system, i.e. neurogenic inflammation, or a distinct very stressful event, i.e. neural sensitization. In the prototypical story *Infected with troubles* the starting point of general health decline, including sensitivity to chemicals, is attributed to the aftermaths of an infectious disease – in line with mechanisms related to either neural sensitization (Bell et al. 1999, 301) or neurogenic inflammation (Meggs, 1993, pp. 236-237). *Lifelong unexplained troubles explained* seems to imply that it is possible to have been born with symptoms of CI, as no starting point or triggering event is presented. To our knowledge, no previous literature describe CI as a congenital condition, nor has this possibility been disregarded. It is possible that the initial onset of CI occurred at a very early age, without the triggering event being recognized as such, although the childhood symptoms described may have had other unknown causes. It seems that our data-gathering methods did not provide data rich enough to discern the relations between the accounts of our participants and the two main etiologies proposed for CI. It is possible that interviews could have rendered richer data. However, as no participants describe a recent onset of CI, it is also possible that what they wrote down is what each of them in retrospect has come to associate with his/her symptoms and would have said if interviewed.

A common theme, described in previous research on CI, is perceived lack of social support (Gibson et al., 2011, pp. 235-36; Gibson, 1999, pp. 278-79; M. Nordin et al., 2010, p. 2170; Söderholm et al., 2011, pp. 701-704). Previous research has also found families to be the main source of emotional social support for persons with CI (Nordin, M. et al., 2010, p. 2170). In the prototype stories 2-4 – *Suddenly sensitized*, *When sensitive becomes sensitized* and *Infected with troubles* the perceived lack of understanding and respect from family members is described as hurtful and contact with family members as restricted. In the prototype story *Our house became our enemy*, more than one core family member is affected by CI – no supporting relatives are apparent in these accounts. As the lack of support from others is mentioned, we tentatively assume the support from relatives to be negligible.

The accounts that have become the basis of *Our house became our enemy* and *Suddenly sensitized* focus more on the need and search for social support, and contain more frustration when these needs are thwarted than in other accounts. Possibly this relates to the acute predicament they found themselves in when CI symptoms disrupted their previously stable lives. Social support can act as a buffer to reduce the strain of stressful life events (Taylor, & Stanton, 2007, p. 381), which implies that social support is especially vital for those who experience a sudden onset of CI.

In *When sensitive becomes sensitized* the onset of CI might have been just as disruptive, but their present struggle appears less strenuous as it is based on accounts from individuals on fixed incomes who are able to regulate both their social and environmental contacts to a greater extent. They expressively identify positive aspects of their lives and the acceptance of their situations to a greater extent than other participants. Laila wrote that she “suffers with those who are affected when they have 25-30 years of their working life ahead”. The differences in outlook between the prototype stories *Our house became our enemy*, *Suddenly sensitized* and *When sensitive becomes sensitized* seem to relate to two different sets of timelines – time passed from exposure and time in life. We begin with a young family still close to the onset of CI, still struggling to find a way to make life work. We then have the disrupted middle-aged life that has become somewhat more stable, although triggering chemicals cannot be completely avoided – a situation the young family may reach over time. Finally, rather late in life, mild symptoms suddenly worsen and life is disrupted, but the struggle of always negotiating possibly harmful exposure is lessened by the comparable freedom of a fixed income; a situation the individuals of *Suddenly sensitized* may reach in a couple of years. It is possible that the emotion-focused strategy of acceptance and reprioritizing that has been suggested by some researchers (Fox et al., 2010; Nordin, M., et al., 2010) as the most beneficial coping strategy for people living with CI becomes more accessible for a person with CI when the threat of unwelcome exposure is less eminent and the person feels more in control.

However, contrary to M. Nordin et al.’s assumption that emotion-focused strategies would be the opposite of avoidance-based coping, what we find here is that acceptance seems to go hand in hand with the freedom to avoid. On the other hand, those who struggle to remain part of society and work-life seem to adopt a more problem-focused approach. They strive to understand their own specific needs, make others understand and respect these needs and try to find work and housing that do not trigger CI symptoms. They also seem to be struggling with what they should accept as inevitable and how to reprioritize their lives.

Further addressing how differences in the unfolding of CI over time might be understood, we find similarities regarding the major factors perceived to affect the course of life with CI. For one, there is the expressed necessity to avoid exposure to triggers. Several accounts stress debilitating symptoms that last hours or days after the perceived exposure, and how their strivings to minimize the risk of exposure restricts their social and/or work life; sometimes to the point where isolation deprives life of its meaning. The positive accounts of rearranging one’s life and/or being able to see the positive aspects that could be construed as acceptance and reprioritizing, sometimes suggested as the most beneficial coping strategy for people living with CI (Fox, R. et al., 2010, p. 27; Nordin, M. et al., 2010, p. 2170) coincides with either a reasonable amount of acceptance from others and/or perceived control over on what terms to risk exposure. Folkman and Moskowitz (2004, p. 747) pointed out that coping is context dependent, and that this relation presupposes that successful coping is dynamic and can vary with contextual changes. For example, the perceived controllability of a situation influences the choice of coping strategy (2004, p. 755). Within the framework of coping as a dynamic process shaped by contextual (pre)conditions (Folkman & Moskowitz,

2004, p. 747), the narratives in the present study could be regarded as testimonies reflecting how specific coping strategies are not only more or less beneficial but also more or less available.

A concrete illustration of this is the prototypical story of *Suddenly sensitized*. The situation was initially perceived as controllable (Folkman & Moskowitz, 2004, p. 755), which elicited goal-oriented, problem-focused coping. However, this perceived controllability declined when symptoms worsened and what triggered symptoms broadened. With an increased understanding of the limitations CI imposed on their lives, acceptance seemed to enable them to resurrect a goal-oriented, problem-focused coping strategy and move towards a way of life focused on avoiding chemical exposure. In this case, avoidance seems to be complementary rather than oppositional to acceptance, as the former seems to be a necessary first step towards acceptance, while acceptance and reprioritizing as a strategy seems to include acceptance of one's limited tolerance for exposure.

Another story, where the protagonist seems to stick to problem-focused coping, is *Our house became our enemy*. They actively seek support from authorities and strive to find safe physical environments for themselves and their family. Acceptance is markedly less manifest in this story, which is the only one that includes parents living with children who also experience CI symptoms. The quality of the relationship between parents and health professionals is an important factor in the coping strategies of parents whose children suffer from long-term illnesses (Nuutila & Salanterä, 2006). Given that our protagonist must cope not only with their own but also their children's CI symptoms, a positive relationship with health professionals may be required for them to be able to move towards acceptance. The expressed dissatisfaction with healthcare may make this protagonist keep engaging in problem-focused coping, without being able to move towards a reinterpretation of their situations the way it happens in the story *Suddenly sensitized*.

Previous studies have described a lack of physical spaces free from symptom triggering substances and perceived disbelief from other people as the two major obstacles reported by people trying to adjust to life with CI (Gibson et. al, 2011, pp. 235-36; Gibson, 2010, pp. 7-11; Söderholm et. al, 2011, pp. 701-704). Our findings are in line with these previous results. Furthermore, they add an understanding of several different possible trajectories towards a life severely curtailed by CI symptoms. The narratives also illustrate how factors, besides CI itself, influence the individual's ability to cope with their condition. They also indicate that successful coping with CI needs to be viewed as dependent on contextual factors, including but not restricted to chemical exposure.

Our aim was to complement the existing research on CI with retrospective descriptions of living with CI, from the onset of symptoms onwards. The current study shows that persons with severe CI may present diverse accounts in regard to the perceived onset of symptoms as well as well-being over the course of CI. The results also show that persons living with CI seem to cope in different ways with their situations, and that the coping strategies available are context related. The prototypical stories presented could be seen as variations, or parts, of the same process – adapting to a life restricted by CI. In this regard, the prototype stories to some extent resemble the illness narratives presented by Frank (2013) that depict experiences representative of an ill person at a given point in time; an experience that may change with altered circumstances.

Methodological discussion and limitations

We were able to gather a substantial amount of data with our chosen design. Possibly, the relatively large number of entries (11-76) was due to the participants being able to complete the material at home over a period of a few days, without the time limits of most interview situations, and without the risk of exposure to triggering chemicals.

Our time restraints may have affected data in the sense that most of the 42 participants who had signed up for the study within one week most likely were quite active in these electronic fora, and thus well acquainted with the collective lay expertise expressed, which may have limited the range of narratives available in a broader sample. It is also possible that the response rate would have been higher with one or two reminders, on the other hand, a response rate of about 50 percent is considered acceptable for a postal

survey.

The LHC provided a chronological sequence of events, while the open-ended questions seemed to encourage more subjective, emotional descriptions that were less bound to specific points in time. As one major aim was to attain the subjective meanings that participants attached to events as well as their chronological order, the combination of the LHC and open-ended questions appeared useful. The most obvious setback of our survey design, compared to traditional interviewing, was that our approach did not allow for clarifying follow-up questions since the participants completed all the material by themselves.

In conclusion, by combining two sources of information – the LHC and open-ended questions – a reasonably rich account of participants' experiences prior to, during and after the onset of CI was acquired, and the accounts were analyzed rather effectively compared to traditional interviews. Possibly, this approach can be effective in studies where the purpose is to collect personal accounts of chronological courses from a relatively large sample in a short time.

It should be noted that the participants in this study were recruited from social network sites for chemically intolerant persons, and they may thus be inclined to spread knowledge about CI. Other participants may be less motivated to invest time in completing this rather comprehensive material. Moreover, given that our participants were recruited from social networks where they interact with others who have similar experiences, the retrospective accounts may also be influenced by the accumulated experiences of others. A retrospective study could reflect the way in which the persons currently cope with what happened in the past, as well as the way in which the persons coped at the time of the event (Folkman & Moskowitz, 2004, p. 749).

Conclusion and future research

To summarize, in addition to having to live with difficult symptoms of CI, our participants seem to perceive that they are disregarded by society, which adds to their suffering. Different circumstances, as well as different stages in life with CI as sketched in this study, seem to elicit and/or facilitate different coping strategies. Given this and the competing etiologies, as well as trouble discerning a sequence of events detailed enough to discern information that would speak more clearly for one or the other, we are apt to speak against a single recommended coping strategy. We advocate instead, that medical professional and others apply a holistic, context-sensitive, approach before discouraging or promoting a specific coping strategy. Any improvement in the way people are regarded when seeking (medical or societal) help for their CI symptoms, and the possibly life-altering consequences brought on by these symptoms, may subsequently enhance the quality of life with CI. Further insights into how persons suffering from CI may be supported by, among other things, societal institutions are needed in order to facilitate their ability to cope with CI symptoms.

The LHC and open-ended questions were used as a means to elicit retrospective accounts of life with CI symptoms, and the approach proved efficient for this purpose compared to the same number of interviews. We are inclined to recommend a similar approach for studies where the purpose is to elicit reasonably rich accounts of life courses, especially when data needs to be collected from a rather large sample within a limited time frame.

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