

# Stigma-Handling Strategies in Everyday Life among Women aged 20 to 30 with Transversal Upper Limb Reduction Deficiency

OSKAR KRANTZ\*, KRISTIAN BOLIN\*\* &  
DENNIS PERSSON†

\*The Vårdal Institute, Lund University, Sweden; \*\*Lund University Centre for Health Economics, Lund University, Sweden; †Division of Occupational Therapy, Lund University, Sweden

**ABSTRACT** *This grounded theory study shows an adaptation of stigma-handling strategies to situations in everyday life by women aged 20 to 30 with dysmelia, i.e. transversal upper limb reduction deficiency (TULRD). Strategies are comprehensive patterns of action aimed at controlling information about one's status as deviating from an ad hoc normality. Strategies consist of: (1) attitude (proofing/being); (2) tactic (concealing/revealing); (3) exposure (voluntary/imposed); and (4) boost (amplifying/altering). A proofing or being attitude constitutes a contextual adaptation understood in terms of a concealing or revealing tactic, aiming at delaying or promoting exposure to contextual attitudes and possible prejudices. If exposure is delayed, a person with dysmelia blends in. Exposure may be voluntary or imposed. After exposure, the relative importance of TULRD in the specific context may decrease, thus a boost of an amplification or altering of the attitude, i.e. boost is the interactional outcome enforcing the choice of strategy in another context.*

**KEYWORDS:** Body-image, congenital limb deficiency, dysmelia, gender, transversal upper limb reduction deficiency

## Introduction

Many persons with disabilities encounter biased attitudes among people without disabilities (Rybarczyk, Nyenhuis, Nicholas, Cash & Kaiser 1995). Psychosocial wellbeing is closely associated with attitudes towards the body, often influenced by comparing appearance and functional capabilities to others (Breakey 1997). For women, physical disability may imply lowered self-esteem (Hermansson 2004b), and “a physical disability enforces a view on young women's bodies as not ‘up to scratch’” (Barron 1997). Persons with disabilities may be exposed to values and attitudes of a society that sees them

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Correspondence: Oskar Krantz, Department of Health Sciences and The Vårdal Institute, Lund University, PO Box 187, SE-221 00 Lund, Sweden. Email: oskar.krantz@med.lu.se

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as less valuable, and inferior to those considered to uphold the embodiment of normality (Edwards & Imrie 2003), i.e. stigmatized (Goffman 1990a). One form of what may be referred to as a disability (stigma) is the congenital absence of a hand. This absence can draw attention, lead to depressive symptoms and lower self-esteem, i.e. cause stress and affect, for instance, social inclusion, coping and body-image (Hermansson 2004b).

The aim of this study is to develop a grounded theory regarding stigma-handling strategies used in everyday life by women aged 20 to 30 with transversal upper limb reduction deficiency (TULRD). The basic question of this study is: what strategies (patterns of behaviour) are used by women with TULRD between 20 and 30 in everyday life, and how are these strategies constructed?

### *Definition of terms*

In this article, the following terms are used:

- *Body-image*: a person's mental picture of her/his body, a dynamic construction based on internal and external stimuli (Desmond & MacLachlan 2002). Body-image constitutes the compatibility between actual and mental pictures of the body (Breakey 1997).
- *Coping*: cognitive and behavioural efforts undertaken to manage specific internal and/or external demands appraised as taxing or exceeding personal resources (Folkman & Lazarus 1980; Lazarus & Folkman 1984).
- *Everyday life*: "a series of 'methodic appearances' through which 'doing being ordinary' is mundanely, methodically and reflexively accomplished" (Sandywell 2004), i.e. daily occurrences where social relations are (re-)produced, activities performed or desisted from (Burkitt 2004).
- *Micro-stress*: the result of unwanted attention drawn from others based on physically deviating from normality (Hermansson 2004b).
- *Normality*: a set of (ad hoc) generally accepted norms (Edwards & Imrie 2003).
- *Stigma*: a distinguishing attribute that makes a person deviate, thus less desirable (Goffman 1990a), reflects "discrepancy between individuals' virtual (assumed) and actual (real) social identities", located outside the natural or typical (Taub, McLorg & Fanflick 2004).
- *Strategy*: comprehensive course of action, used to manage thoughts and feelings associated with threats or challenges (Melnyk, Cash & Janda 2004).

### *Background*

Congenital limb deficiency (CLD) is the congenital absence of a limb. Transversal upper limb reduction deficiency (TULRD) is the transversal congenital absence of an upper limb (Hermansson 2004a). In the Scandinavian countries and Germany, *dysmelia* is used synonymously with CLD and

as a general description of TULRD. The term *dysmelia* comes from the Greek language, where *dys* means abnormal, and *meli* means limb (Svensk Dymeliförening 2006). Henceforth in this article, TULRD will be referred to as dysmelia, as it is the term used by the respondents in this study.

The incidence of CLD is 2–7/10,000 according to a review by Ephraim, Dillingham, Sector, Pezzin and MacKenzie (2003). Källén, Rahmani and Winberg (1984) report 6.3/10,000 in Sweden, with a slight male dominance. Approximately two-thirds have an upper limb affected (Hermansson 2004a).

Persons with dysmelia may use prosthetic devices (Dudkiewicz, Gabrielov, Seiv-Ner & Zelig 2004). This can extend the user's body-image to include the external object (Breakey 1997). A prosthesis can mask dysmelia, although camouflaging can prove harder for females than males, due to societal images of perfection (Taub, McLorg & Fanflik 2004). Any given prosthesis may for one user embody disabling attitudes and prohibition of functions and roles, and for another user ability, i.e. enable functions and roles (Desmond *et al.* 2002).

A potentially stigmatizing “physical imperfection” can be referred to as a “minor bodily stigma” (Ellis 1998). Stigmatization refers to situations rather than categories of individuals, although lifelong attributes may be typecasting (Goffman 1990a). A person with a stigmatizing attribute may be discredited (there is an easily noticeable attribute, and an attempt to manage tensions involved in social interactions); or discreditable (there is a concealable attribute, and a striving to control exposure) (Taub, McLorg & Fanflik 2004). According to Pinel (2002), stigma-consciousness may be (1) high – ascribe the stigma a major role in out-group person's behaviour; or (2) low – “barely give their stereotyped status a moment's thought”.

### *Previous research*

Previous research regarding stigma and coping has concerned e.g. older caregivers (Kristensson Ekwall, Sivberg & Rahm-Hallberg 2007), obesity (Puhl & Brownell 2003), and African-American gay and bisexual men (Della, Wilson & Lin Miller 2002).

Coping can be problem-focused, where the problem causing the emotions is addressed, i.e. behavioural (taking action); or emotion-focused, where the emotions emerging from the problem are addressed, i.e. cognitive (mental strategies) (Folkman & Lazarus 1980). Efforts may be complementary, referred to as “coping functions” (Lazarus 2006), and exercised proactively (before a potential stressor); or reactively (after a stressful experience) (Mallet 2003).

Coping goals can be higher order, e.g. preservation of identity (i.e. a strategic goal); or lower order – a means to achieve higher order goals, e.g. conceal a stigma (i.e. a tactical goal) (Lazarus 1991).

Melnyk, Cash and Janda (2004) found three tactics concerning body image coping: (1) avoidance (e.g. withdrawal); (2) appearance fixing (e.g. conceal-ing); and (3) positive rational acceptance. Avoidance may consist of social withdrawal from entire contexts, e.g. public places, or situational withdrawal,

e.g. from stressful situations (Letkemann 2002). Appearance fixing, e.g. concealing, as a method of coping may enable a person to “pass” (Goffman 1990a) as non-deviating. Positive rational acceptance can be for example empowerment via peer-to-peer networks, i.e. with persons exposed to similar stigmatization (Kaufman & Johnson 2004, Shih 2004).

A person’s coping skills repertoire (pre-defined set of tactical dispositions) is a dynamic construction based on previous experiences (Chia & Holt 2006). A given form of coping may be effective in one context but ineffective in another (Lazarus & Folkman 1984). Functions changing over time and contexts can be regarded as a process, and relatively stable functions as a trait or a style (Lazarus 2006).

### *Gender aspects*

Women and men may cope differently. Women may use social coping, e.g. by seeking social support and reacting emotionally, whereas men may use more direct responses (Puhl & Brownell 2003).

In general, women are more often than men judged by appearances. Combined with a physical disability, this can lead to self-doubt, shame and lower self-esteem (Barron 1997, Taub, McLorg & Fanflik 2004), i.e. disabled women are not only forced to cope with societal images of perfection, but also stigmatized due to having a disability (Fine & Asch 1988). Furthermore, “disabled women are either attractive in spite of their impairment or unattractive because of their impairment” (Morris 2001). Women with disabilities face more disadvantages than men with disabilities (Thomas 2006). They are exposed to multiple oppressions due to “discrimination and oppression against women and against disabled people in society” (Reinikainen 2004:257).

Men with disabilities are ascribed traditional male positions, e.g. strong, independent and active (Fine & Asch 1988, Reinikainen 2004), partly due to more relaxed and flexible male cultural norms (Strahan, Wilson, Cressman & Boute 2006). For women with disabilities, on the other hand, “being disabled” is emphasized: “disability neutralises the disabled woman as a Woman, and makes her instead and above all Disabled” (Reinikainen 2004:259).

Stigma related to CLD “have to be considered differently in boys and girls” (Hermansson 2004b). However, experiences among women with disabilities, e.g. of coping, has been neglected, as men with disabilities have been considered representative of the disabled population (Thomas 1999).

### *Arguments for the study*

As seen in previous research regarding women, coping or disabilities, dysmelia in women imposes an additional disadvantage, i.e. stigmas intersect. Although men with dysmelia may experience stigmatization as well, this can be different due to relaxed and flexible cultural norms of masculinity. Thus, compared to men with dysmelia, women with dysmelia can risk lower self-

esteem and more self-doubt. However, this is only an assumption as a majority of previous research has focused on other stigmas or predominantly male perspectives on disabilities. Thus the aim of this study is to develop a grounded theory regarding stigma-handling strategies used in everyday life by women aged 20 to 30 with TULRD.

### **Method and population**

This study uses grounded theory for data collection and analysis. Grounded theory aims at conceptualizing patterns of behaviour engaging people. In grounded theory, categories and their respective properties are allowed to emerge from the data. These categories are later integrated into hypotheses resulting in a theory, i.e. a statement of conceptual probability explaining the patterns of behaviour regarding the main concern of the participants (Glaser & Strauss 1967, Glaser 1978, 1998). A grounded theory method was chosen because, as shown earlier, constructions of actual coping methods in everyday life among women with dysmelia are seldom considered in earlier research, in contrast to attitudes, male perspectives or other forms of stigmatization. Furthermore, there may be relatively few studies focusing stigma, coping and women using an inductive approach in the form of grounded theory.

#### *Data and population*

Sources of information are:

1. nine interviews with four participants and three supplementary conversations with two of the interviewees;
2. participation in two camps organized by *Svensk Dymeliförening* (Swedish Association of People with Dysmelia), where conversations were held with five participants during the first camp;
3. articles in 10 issues of *Dymelibladet* (*Dysmelia Newsletter*, produced bi-annually by *Svensk Dymeliförening*);
4. the dysmelia (educational) film entitled “*Precis som alla andra ... nästan*” (“*Just like everyone else ... almost*”) produced by *Svensk Dymeliförening*;
5. the website of *Svensk Dymeliförening*;
6. two reports from conferences arranged by the Scandinavian dysmelia organization;
7. conversation with the chairman of *Svensk Dymeliförening* (Stig Jandrén);
8. two visits to an orthopaedic technician, the first with one of the interviewees (to adjust her prosthesis), the second as an informative meeting with an orthopaedic technician;
9. an essay by Maria Gardsäter (2004), written from a personal perspective of growing up with dysmelia, thus used as a primary data source.

When referring to the sources (2–4, 6, 8), the following abbreviations are used in running text: summer camp – SC; *Dysmelibladet* – DB; the educational movie – EM; conference reports – CR; orthopaedic technician – OT. Field notes were made on all the occasions mentioned above. The combination of sources resulted in the collection, coding and analysis of 37 separate pieces of data.

The women interviewed are 20 to 30 years old. The reason for focusing on a specific age group is that different periods in life involve different strategies, and the period in focus may be signified by a broader span of activities in a larger variety of contexts than other periods in life (Persson, Erlandsson, Eklund & Iwarsson 2001), e.g. education, moving, getting a job, meeting a partner, having children, etc. However, comparisons between age groups are matters beyond the scope of this study, thus are not explicitly addressed.

The four interviewees all lack a hand, i.e. transversal single-sided upper limb reduction deficiency between elbow and wrist. They were selected based on gender, dysmelia and age. To avoid revealing their true identities, they are called Mia, Maja, Nora and Cora, respectively. Mia is an active, full-time user of a myo-electrical prosthesis; Maja is a user of a myo-electrical prosthesis, although passive since the battery broke down about a year before the first interview; Nora does not use any prosthesis; Cora uses a cosmetic prosthesis. All interviews were face-to-face, and field-notes were made concerning mostly non-verbal aspects of the interaction. Each interview was followed up through e-mail and telephone before continuing with the subsequent interview, a process aiming at increasing the reliability by minimizing possible misunderstandings. All interviews tape-recorded were transcribed verbatim. The interviews and the analysis have been conducted in Swedish; the quotations appearing in this paper have been translated into English, focusing on the meaning of what was said, rather than a more literal translation. Consent from the interviewees was obtained in accordance with valid ethical guidelines.

### *The research process*

The formulation of this grounded theory began with open coding. After an initial search on the Internet, where the website *Svensk Dysmeliförening* was found, two interviews were performed. Thereafter, the data selection was guided by theoretical sampling, i.e. the process of collecting data aimed at generating a theory. During the sampling process data was collected, coded and analysed, thereby guiding the decision of what subsequent data to collect and where to find these data. The aim was to develop the emerging theory by checking and refining emerging conceptual categories by gathering further data (Glaser 1978). The chronology of the data collection process can be seen in Figure 1.

Following the first two interviews, contacts were made with *Svensk Dysmeliförening*. This was in line with the concept of theoretical sampling, as one of the interviewees emphasized this organization regarding empowerment. The contacts with *Svensk Dysmeliförening* proved helpful in gaining a



Figure 1. Chronology of the data collection process.

more thorough understanding of e.g. prosthetic technology, growing up with dysmelia, and empowerment; i.e. the beginning of a thematic understanding of strategies. In the first contacts with *Svensk Dysmeliförening*, the chairman had the function of gate-keeper, granting access to *Dysmelibladet*, the dysmelia film, the essay (Gardsäter 2004) and the first visit to the summer camp. Thereafter, interviews were performed with two more respondents. The first interview with each respondent began by asking “what is it like to have dysmelia?” During each interview, ideas emerged about what to ask next. This is one ingredient in theoretical sampling (Glaser 1978). For the subsequent interviews, more specific questions were also generated aiming at increasing saturation, e.g. concerning the function and use of prostheses, and specific situations and activities. This was to some extent based on ideas emerging from *Dysmelibladet*, as well as the conference reports and the dysmelia film.

Finishing each interview, a question was asked about whether something needed to be supplemented, aiming at giving the interviewee more control of the content of the interview (Beazley, Moore & Benzie 1997). Main sources of information were the interviews as they gave a deeper understanding of strategies in everyday life, but also due to the natural reciprocity of the interviews providing possibilities to follow up on specific matters. However, the other material contributed largely to the emerging understanding, i.e. generating ideas of what to ask in the subsequent interviews. It can be assumed that the emerging theory could have been less substantial without this material, as it contributed to the thematic understanding of main issues within the dysmelia community.

Validity may in grounded theory be less of an issue than: (1) fit (i.e. that concepts fit the represented incidents); (2) relevance (i.e. that the real concerns of the participants are captured); (3) workability (i.e. that how the problem is solved is explained, with variations); and (4) modifiability (i.e. that there is a possibility to alter when new data are added) (Glaser 1998). Parts of the latter interviews served as a form of discussion regarding the emerging core. The respondents expressed an interest in this as a way of understanding how the interviewer understood dysmelia, i.e. the emerging theory was thus discussed involving e.g. fit of the theory, its relevance and workability.

Consistent with the grounded theory concept that “all is data” (Glaser 1998), every component in the data collection process – pertaining to the process itself or to the informational content – was used in the analysis, i.e. no

data was excluded. A comparative approach was used together with a conceptual analysis, the latter by continuing memo-writings and open coding of the material. Transcripts from the interviews, the film, the articles in *Dysmelibladet*, the conference reports, etc., were coded line-by-line, as well as the memos from visits to the summer camps and the orthopaedic technician. This was done by asking a set of questions about “what is happening here”, “what category could this be”, etc., thus maintaining the theoretical sensitivity. Memo-writing contributed to the development of codes and categories based on the transcribed material. Line-by-line coding was done by sorting and categorizing events in the data, thereby assisting in generating concepts representing underlying patterns. Each piece of data was coded and analysed separately before continuing to the next part of the process, a “circular methodological cycle” (Chicchi 2000). This functioned as a continuing review process, since comments were received from the respondents within every segment of the process. Furthermore, fit, relevance, workability and modifiability may thus have increased, as the emerging themes were constantly compared to each other, i.e. a process of constant comparativeness. Concepts were then compared with other concepts, continuing through the process, thus leading to the core *adapting stigma-handling strategies to situations in everyday life*. After this, selective coding was performed in a search for variables relating to the core concept. As such, the core concept served as a major factor in further data collection and theoretical sampling, e.g. the latter interviews. To deepen the understanding of the material, it was coded once more searching for categories relating to the core.

Theoretical memos in the form of both text and figures were produced during the data analysis. Memos were written when anything substantial concerning the analysis emerged. As such, a large collection of memos were created. During the sorting and systematization of these memos, relationships between categories and core were sought and noted. In the final stage, the memos were formed as an emerging grounded theory. After the formulation of the substantive theory, a search for, and review of, relevant literature was performed. This was done in line with Glaser’s (1978) advice to try to avoid reading the literature until a framework of understanding has been formed. The literature formed another source of data, thus integrated into the process of constant comparativeness. The literature added an understanding of the theory in relation to a social relational model of disability (Thomas 1999). Collection of data ended when saturation had increased significantly, i.e. when the most recent data were generating a less substantial contribution to the emerging theory (Glaser 1978).

## Results

The core in the proposed model of understanding is: Women aged 20 to 30 with dysmelia *adapt stigma-handling strategies to situations in everyday life*. Strategies are understood as comprehensive patterns of action based on both contextual demands and (habitual) expectations of interactional response, i.e.

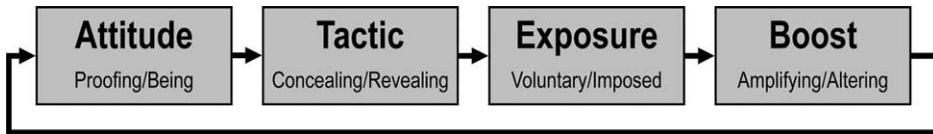


Figure 2. Model of understanding.

as means to achieve higher order goals. “Habitual” implies that the expectations may be based on earlier experiences. A strategy that minimizes micro-stress and, consequently, maximizes personal wellbeing, is chosen. Strategies may vary between contexts as well as over time and phases in life. Categories within the core, i.e. the construction of a strategy, are shown in the model, Figure 2, and will be discussed below.

- *Attitude* constitutes expectations based on previous experiences of contextual reactions to a stigma, i.e. lower order goals, thus a starting point for choice of tactics. *Proofing* is striving to be recognized by emphasizing other factors of self as more significant; *being* is striving to be recognized with dysmelia as a part of normality.
- *Tactic* refers to specific patterns of behaviour. *Concealing* aims at delaying exposure by blending in, thus not being noticed as deviating from the contextual normality. *Revealing* is promoting, or not bothering about, exposure.
- *Exposure* is the *voluntary* or *imposed* outing as deviating from the contextual normality, thereby being exposed to interactants’ attitudes and possible prejudices. After exposure, the relative importance of dysmelia in a given context may diminish, although rarely completely vanish.
- *Boost* is the interactional outcome, i.e. experiences had during the process, *amplifying* or *altering* attitudes.

In the following sections these terms will be discussed more extensively.

### *Attitude*

Individual awareness of deviating from an ad hoc normality can imply an accentuation of proofing or being, i.e. the attitude is based on previous experiences of contextual reactions, thus is a starting point for choice of action in a given context. Proofing is striving to be recognized (despite dysmelia) by emphasizing other factors as more significant, e.g. by over-achieving, thereby not giving interactants an excuse for seeing one as deviating. Being is striving to be recognized with dysmelia as a part of normality. Thus, proofing can imply higher stigma consciousness than being. A proofing attitude might imply concealing, although nothing hinders a person with a proofing attitude from emphasizing revealing, and vice versa, due to choice of tactics also being based on contextual input, as will be discussed later.

In many contexts, the person with dysmelia is alone as being different; “already as children we are forced to manage situations such as questioning and looks that most people are not exposed to” (DB). However, regarding activities, “you develop ways to do things your own way” (Cora).

None of the interviewees considered themselves disabled; they did not need assistive devices and managed all desirable activities, although sometimes with an alternative *modus operandi*. Explanations were similar: “and no, I cannot pick something from the floor with my left hand, there are quite a lot of things I surely cannot do if I think about it, but nothing I miss being able to do!” and “If I decided that it is negative to be different I might as well lie down and die right away, the hand will not grow out, and I will always differ from normality” (Nora); “The hardest part is not missing a hand; the hardest part is the reactions among people around you” (Mia); “I have never known anything else and I am a whole and complete human being the way I am” (Cora); “We all know that a hand more or less is unimportant in most situations, things tend to work out anyway” (Nora). Thus, physical limitations may be a smaller problem than a non-mainstream body-image.

One arena in empowering a being attitude may be the camps arranged by *Dysmeliföreningen*: one annual summer camp, a few shorter regional camps, and camps for teenagers. The purpose of the camps is empowerment and increasing knowledge for persons with dysmelia and families with children with dysmelia (DB, EM, SC, Mia, Nora). “It is great to go to the camps because no one takes any notice of me missing a hand” (EM). Articles in *Dysmelibladet* about teenage camps are frequent. A common theme is hesitation as the dominant feeling before, and a strong sense of relief and empowerment afterwards. “By meeting others in the same situation, you get the courage to be as you are” (Nora). “There is such an enormous need to talk with the ones you do not have to explain to, everyone understands and recognizes” (DB). This is another common theme: everyone is different, and you are allowed to be the way you are. Activities arranged by *Dysmeliföreningen* can be a back region (Goffman 1990b), an arena where matters regarding dysmelia can be openly discussed among peers.

According to Gardsäter (2004) and Stig Jandrén (chairman of *Dysmeliföreningen*), there are three combinable solutions, or treatments, for a person with dysmelia: (1) surgery; (2) prosthetics and other technical aids; (3) do nothing. The latter is often the choice if the dysmelia is minor (OT). Medical professionals consider dysmelia as treatable, implicitly telling the person with dysmelia that “your body is not good enough as it is”, experienced as negative feedback upon one’s person, boosting a negative body-image and lower self-esteem (Nora).

### *Tactic*

Two interactional tactics were found among the interviewees: (1) concealing the missing hand by the use of long sleeves, prostheses for cosmetic reasons, body-language and choice of activities; (2) revealing the absence of a hand, although this has a higher cost in terms of self-esteem in many contexts.

Revealing may be more common in contexts where the relative importance of dysmelia has faded or where the attribute is not a stigma. Choice of tactic (behavioural) may be induced by habitual expectations (proactive cognitive coping) combined with interactional response, i.e. a dynamic construction based on previous experiences. Thus, attitudes can be thoughts before and during interaction (and after, affected by the interaction, thus reactive). Attitudes may constitute a starting point and a re-shaping reference, although not necessarily the actual course of events, as attitudes affect tactics in the actual appearance, which in turn affect attitudes – an assumption supported by Goffman (1990b).

Concealing a deviation from an ad hoc normality is not being obliged to explain, as concealing assists in focusing abilities, not disabilities. Prosthetics may conceal dysmelia and facilitate activities. However, none of the interviewees using prosthetics say they really need them; activities are often more easily performed without. A prosthesis may work as a tool in establishing a status as non-deviating in a new context; however, when the status has been established, the prosthesis may be abandoned since the need to conceal per se fades away. A woman (CR) concludes why she does not use prosthesis: “it is rough, heavy and it itches”.

Today, concealing is important for Maja and Cora, as Maja uses her prosthesis in combination with long sleeves, etc., and Cora wears a cosmetic prosthesis. Mia uses a myo-electric prosthesis, and occasionally a cosmetic prosthesis. “My self-esteem is better with the cosmetic prosthesis . . . I do not change to the cosmetic for my own sake, but for others, it will look better”. Mia underlined that she does not see camouflaging her dysmelia as primary, but does not feel comfortable without prosthesis. This may imply that a person with dysmelia can have one body-image when using a prosthesis, and another when not; and the body-image can be altered when wearing different types of prosthetic devices. The contrary can be: “I have never had the prosthesis on when I have been out partying. The prosthesis is not a part of me, it is a tool” (DB). Dysmelia may be concealed in order not to be a constant topic of conversation, reducing the person to something that is not there, i.e. the missing body part. Cora’s choice to wear a cosmetic prosthesis is understood as concealing a part of her that is mostly unimportant, yet has the potential to become the centre of every new interaction.

Today, Nora regards concealing as negative and destructive. However, she also tells about her own fears and how she got quite sweaty and almost paranoid after the first times wearing a t-shirt in public. “The truth is of course that most people do not care at all, and if they care, it does not have to be in a negative way.”

### *Exposure*

Exposure occurs when the interactants become aware of a deviation from an ad hoc normality. However, it may be hypothesized that exposure exists in two forms: voluntary, when a person is emphasizing a revealing tactic; or imposed, when a person is emphasizing a concealing tactic and is exposed

unintentionally. The first is an example of individual choice; the latter is a contextual effect. However, both result in contextual reactions, thus the proposed model of understanding focusing exposure per se.

When a person with a disability is exposed, the person is in many contexts stigmatized, i.e. discredited (Taub, McLorg & Fanflik 2004). Concealing can delay exposure and (temporarily) grant a status as discreditable, thus establish a contextual status not based on deviation.

Generally speaking, after the point at which interactants become aware of the dysmelia, they do not think of the person with dysmelia as like everyone else. The earlier in life this is accepted, the earlier it is possible to understand these reactions as socially constructed prejudices and fears of something unknown. It is then possible to develop one's own ways to meet these reactions (DB). "Some people have dropped coffee-cups and screamed, but sometimes the reaction is almost nothing, like 'OK', and that is it!" (Cora). Maja recalls when she began in a new school, and a classmate screamed "you only got one hand!" over the whole schoolyard whereupon what felt like 50 people turned around and stared. None of the interviewees said that they could predict how anyone is going to react. Maja gives an example from a nightclub where she was dancing with a man who, when incidentally touching her prosthesis, reacted with an odd look on his face, turned around and left. "I just hate it, I hate it" (Maja). However, none of the interviewees spoke of any bullying due to dysmelia.

Persons with dysmelia can find it difficult telling someone they are dating about their dysmelia. Mia says it feels positive when someone continues their interest after discovering her prosthesis: "if someone does not like me, it does not have to be because of that". Maja tells about a date when they decide to meet at a pizzeria. His reaction to her dysmelia was just "OK", after being asked to slice up her pizza. "He did not care at all and after a while we became a couple."

Many persons who meet someone with dysmelia for the first time respond with questions of pain. "They try to understand by relating to themselves, as if they would suddenly wake up with just one hand it would be something trauma-related and they would have 'lost' a body part" (Nora). "They never think of how it would be to grow up and never have had any hand at all, their imagination does not stretch that far" (Mia).

Maja tells of an airport where the security check forced her to remove her prosthesis in public. "It felt like everyone was staring at me, although I suppose it was only a security guard and an older woman". "We know that it does not hurt to be physically different, that we are normal in our own way" (Gardsäter 2004). Cora says many people cannot understand that she is not broken, and she does not miss anything and has not lost anything.

### *Boost*

Boost is the interactional outcome, i.e. experiences had during the process, enforcing attitude and choice of tactics in another context. Boost may exist in

two forms: (1) strengthening the present attitude, i.e. amplifying; (2) enforcing a change in attitude, i.e. altering.

Gardsäter (2004) tells of earlier periods of grief because of the non-existent hand: "Today I know that the self-image I had was false . . . it was very rarely confirmed by anyone else." However, to constantly be exposed to the valuations of others is a major component; dysmelia constitutes something interactants feel obliged to relate to. "People around you see you as either 'abnormal', 'deformed' . . . or, on the contrary, 'cool', 'amazing', 'capable' . . .; you are always special, very seldom neutral, and very rarely left alone" (Gardsäter 2004).

Nora withdrew from activities where she risked being treated differently. In other situations she became an over-achiever: "I was overly sensitive to criticism, extremely self-criticizing . . . I had high grades and was popular among friends". She should at least manage what others did, and if not, she thought everyone would presume it was because of her missing hand. The other interviewees have similar explanations. Mia thinks it is because many persons with dysmelia have a low self-esteem, and over-achieve to prove that they really can do it, or on the contrary desist from desirable activities.

A young woman (DB) describes how she during puberty gradually withdrew from activities where she risked exposure. The turning point was when a friend told her "your disability should not hinder you from living!" After this, she went to a teenage camp with *Dysmeliföreningen*. She concludes: "now I do not care if I have one or two arms, I have the same dignity as everyone else". Here, the teenage camp may be seen as an altering boost.

After exposure, interactants gradually re-emphasize other aspects – the contextual importance diminishes, although rarely vanishes: "when the first kind of critical moments are over, most things tend to sort out quite well" (Cora). However, it can be hard to "constantly be half inside, half outside the group, to get looks and comments and possible negative attitudes and prejudices aimed at you" (Nora).

As stated earlier, to be exposed is to be looked at based on deviation and not on other aspects, that are perhaps more relevant. The contextual reactions focuses on deviation, thereby stigmatizing by accentuating an aspect of self and identity the deviating person sees as less important. This can be a boost underlining a more proofing attitude. To be exposed can also boost the opposite: the context does not regard the deviation as a stigma, or even as a deviation. For a person with a more proofing attitude, the latter may imply an altering boost. This can be in a back region (Goffman 1990b) or in any context that not deem a person discreditable as an automatic consequence of dysmelia.

## **Discussion**

The results of this study indicate that dysmelia among women aged 20 to 30 involves an adaptation of stigma-handling strategies to situations in everyday life. Strategies are understood as patterns of behaviour based on internalized experiences and expectations regarding interactional reactions to the stigma;

i.e. a proofing or being attitude constitutes the basis of contextual adaptation understood in terms of a concealing or revealing tactic aiming at controlling exposure. If exposure is delayed, the person blends in. After exposure, the contextual importance of dysmelia gradually diminishes, thereby boosting a proofing or being attitude.

A grounded theory method was chosen based on the possibility of achieving the desired closeness to a broad spectrum of emerging data. This approach has also served the purpose of gaining a thorough understanding of strategies used by females with dysmelia in everyday life, as grounded theory aims at conceptualizing patterns of behaviour (Glaser 1978). Another approach could have been phenomenology, with a similar intention; i.e. to catch the life-world meanings of the informant. However, a deepened understanding in the form of an emerging theory may then have been lost. Furthermore, phenomenology may be a less adequate tool in handling such a different flora of data sources as shown to be necessary in the current study. The use of grounded theory made it possible to explore the underlying patterns of behaviour, which may have been de-emphasized by a less thorough analysis of e.g. the interviews, as saturation increased substantially through the process.

Using co-analysts might have further increased the reliability of this study. However, when the analysis was conducted, neither the resources nor the time were available. Instead, the circular methodological cycle (Chicchi 2000) was emphasized and served as a constant reviewing process in data collection and analysis. This proved to function in the interview process with Nora and Maja; a deepened understanding was gained through the recurring process. It would, however, have been desirable to implement this approach fully in the interviews with Cora and Mia as well, but this proved impossible since both interviewees emigrated (employment reasons). This resulted in a relative lack of data from the interviewees, compensated by a more thorough search for data from other sources (DB, EM, etc.). No additional interviewees could be found at such short notice. However, the interviews with Cora and Mia were very thorough, and only minor needs for further explanations remained. This was solved by telephone and e-mail contact, resulting in increased saturation. The total effect is considered minor, since additional data were obtained from other sources, thereby extending the width and depth of the theoretical sampling and analysis.

One surprising finding to one of the authors (OK) was based on personal experiences as a wheelchair user. A wheelchair, seen in relation to an upper limb prosthesis, is by nature more difficult to conceal. The stigma associated with wheelchair use may be more obvious than with dysmelia, since a wheelchair to some extent draws more immediate attention. Despite this, the energy invested in concealing dysmelia (if concealing was chosen) was in some cases major. This implies that the concealability of a specific deviation from an ad hoc normality is a factor regarding choice of strategy.

Data in this study indicate that dysmelia can promote creativity in terms of finding alternative ways of performing activities, and that some activities may be more easily performed without prosthetics. A part of the explanation may

be that prosthetic training aims at teaching the person with dysmelia to perform tasks in a two-handed manner – despite prosthetic devices being quite rough imitations of the human hand in terms of dexterity and sensorial feedback. Nevertheless, prosthetic usage was in many cases maintained. This indicates self-image to be valued higher than operational factors regarding useworthiness; the latter defined as the importance of a technical aid in the life situation of the user, i.e. worth using or not (Eftring 1999). One reason may be that experiences of stigmatization are the reference, not the practical implications. This assumption is underlined as women with dysmelia in this study want to be seen on the same terms as everyone else, i.e. without prostheses, concealing, etc., as dysmelia is something mostly unimportant, but at the same time has a potential to become the centre of every new interaction.

Furthermore, findings concerning a concealing tactic may be discussed from a perspective of a medical or social model of disability. A medical model implies that disability is a problem of functioning based on personal shortcomings, whereas a social model implies that disability emerges in the discrepancy between individual functioning and contextual construction, thus based on physical and social barriers of society (Lutz & Bowers 2005, Thomas 1999). One emerging question is whether dysmelia constitutes a disability, a priori seen as restricting activities as a result of impairment. Data suggest that practical performances of activities implicated by the impairment per se are of less importance. Therefore, it can be argued that dysmelia may be a social disability: it is something interactants relate to as a deviation from an ad hoc normality, a stigmatizing construction of the body. However, unwanted attention may also be curiosity from an interactant, experienced by the person with dysmelia as stigmatizing. Nonetheless, the unwanted attention to which persons with dysmelia are exposed may constitute a disability.

Thomas (1999) argues for a social relational definition of disability. This is based on both personal and contextual factors and sees disability as “oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing” (Thomas 1999). Lutz and Bowers (2005) describe disability as “a multifaceted, complex experience”, not solely as either limitations based on function, or barriers of the social and/or physical environment. According to Thomas (1999), personal experiences of living with impairment are shaped by the interaction between (and accumulation of) impairment effects and disability. As such, the social relational model is a tool with which dysmelia can be explained as a form of social oppression requiring the person to adapt a certain strategy in order to handle the undermining of the psycho-emotional wellbeing. Performance of activities is a smaller problem than contextual attitudes. With this in mind, it can be proposed that dysmelia implies less of a disability than it is a construction of the body that draws attention from others, i.e. a stigma.

Although this study focuses on women with a specific form of concealable stigma, applicability and modifiability may be discussed regarding gender and

other concealable stigmas based on differently constructed bodies. One example of a concealable deviation, i.e. constituting a discreditable status, is *Alopecia Areata*, autoimmune loss of hair, concealable with a wig. It is assumed that hairlessness may be experienced in a similar way as dysmelia – both constitute a (potentially) discreditable deviation and are both concealable. Hairlessness may be more stigmatizing for women than men due to: (1) cultural norms regarding femininity are narrower than masculinity; and (2) women, more often than men, are judged by their appearances. Thus, in a possible wider application of the model, it may be hypothesized that applicability depends on a stigma to be concealable and to intersect with gender. A concealable stigma can make the person discreditable, whereas a non-concealable stigma can make the person discredited. Thus, to cover non-concealable stigmas, the proposed model may need comprehensive modification, e.g., hypothetically, tactics as concealing or revealing may be less relevant, and exposure regulated via social or situational withdrawal.

A comparison between male and female experiences of dysmelia is a matter beyond the scope of this study. Nonetheless, it may be assumed that experiences differ due to the more relaxed and flexible male cultural norm. The latter includes strength, activity and independence, whereas women are judged by their appearances, e.g. as dependent victims. This implies that men are defined more by what they do and women by what they are and how they appear, however this is only an assumption. Nevertheless, it may be speculated that the proposed model can be made applicable to men, possibly with modifications. Thus, this indicates a need for research focusing concealable stigmas and individual strategies in everyday life among both females and males. The proposed model of understanding may be a starting point.

## Conclusions

This grounded theory has shown that transversal upper limb reduction deficiency (dysmelia) among women aged 20 to 30 implies an adaptation of stigma-handling strategies to situations in everyday life aimed at controlling the distribution of information about one's status as deviating from an ad hoc normality. Strategies are means to achieve higher order goals, e.g. to minimize micro-stress and maximize personal well-being. Strategies consist of: (1) attitude (proofing/being); (2) tactic (concealing/revealing); (3) exposure (voluntary/imposed); and (4) boost (amplifying/altering). A proofing or being attitude (lower order goal) constitutes a contextual adaptation understood in terms of a concealing or revealing tactic, aiming at delaying or promoting exposure. If exposure is delayed, a person with dysmelia blends in. After exposure, the relative importance of TULRD, when interacting with others in the specific context may diminish, thus amplifying or altering attitude.

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