

Stigma-handling among women with dysmelia*

INTRODUCTION

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), a form of *congenital limb deficiency* (CLD). The incidence of CLD is 2-7/10 000, with a slight male dominance. Approximately two-thirds have an upper limb affected.

METHOD

A grounded theory method was chosen because 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.

Sources of information are nine interviews with four participants and three supplementary conversations with two of the interviewees. The women interviewed are 20 to 30 years old and all lack a hand. *A* is an active, full-time user of a myo-electrical prosthesis; *B* is a user of a myo-electrical prosthesis, although passive since the battery broke down about a year before the first interview; *C* does not use any prosthesis; *D* uses a cosmetic prosthesis.

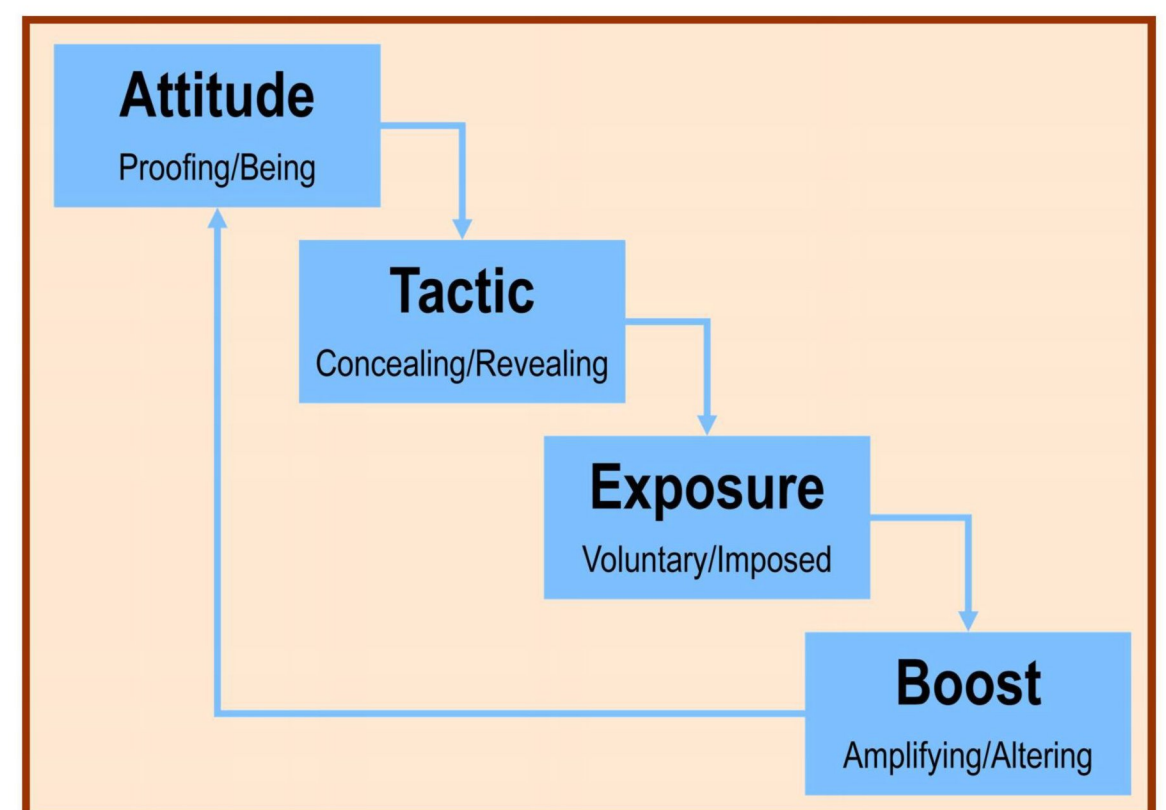
Other sources of information are e.g. participation in camps, articles from the newsletter *Dysmeli-bladet* (the *Dysmelia Newsletter*), an educational film and visits to an orthopaedic technician. The combination of sources resulted in the collection, coding and analysis of 37 separate pieces of data.

RESULTS

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)
4. *Boost* (amplifying/altering)

A proofing or being attitude constitutes a contextual adaptation understood in terms of a concealing or revealing



Construction of strategies

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.

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.

FURTHER RESEARCH

Although this study focuses 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.

* Krantz, O., Bolin, K. & Persson, D. (2007) Stigma-handling strategies in everyday life among women aged 20 to 30 with transversal upper limb reduction deficiency. *Scandinavian Journal of Disability Research* (Accepted).