

ORIGINAL REPORT

## WOMEN'S EXPERIENCES OF DAILY LIFE AFTER ANTERIOR CERVICAL DECOMPRESSION AND FUSION SURGERY: A QUALITATIVE INTERVIEW STUDY

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**Objective:** To explore and describe women's experiences of daily life after anterior cervical decompression and fusion surgery.

**Design:** Qualitative explorative design.

**Subjects:** Fourteen women aged 39–62 years (median 52 years) were included 1.5–3 years after anterior cervical decompression and fusion for cervical disc disease.

**Methods:** Individual semi-structured interviews were analysed by qualitative content analysis with an inductive approach.

**Results:** The women described their experiences of daily life in 5 different ways: being recovered to various extents; impact of remaining symptoms on thoughts and feelings; making daily life work; receiving support from social and occupational networks; and physical and behavioural changes due to interventions and encounters with healthcare professionals.

**Conclusion:** This interview study provides insight into women's daily life after anterior cervical decompression and fusion. Whilst the subjects improved after surgery, they also experienced remaining symptoms and limitations in daily life. A variety of mostly active coping strategies were used to manage daily life. Social support from family, friends, occupational networks and healthcare professionals positively influenced daily life. These findings provide knowledge about aspects of daily life that should be considered in individualized postoperative care and rehabilitation in an attempt to provide better outcomes in women after anterior cervical decompression and fusion.

**Key words:** daily life; cervical spine; research interview; content analysis.

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### INTRODUCTION

Individuals with cervical radiculopathy present with radicular pain in one or both upper extremities (1, 2). This is frequently associated with sensory and motor disturbances, and neck pain (1, 2). The incidence of cervical radiculopathy is approximately 83 per 100,000, with a peak at 50–54 years of age (3). In 2013, a total of 983 surgical procedures to treat patients with cervical spine disease and radiculopathy were registered in the Swedish Spine Registry (Swespine). Half of these patients were women (4). Anterior cervical decompression and fusion (ACDF) is an established method of treating radiculopathy caused by degenerative cervical disc disease (5) with the main goal of providing pain relief and preventing further neurological symptoms. However, how patients experience their daily life after ACDF is currently unknown.

Studies evaluating the effect of ACDF traditionally include surgical variables, neurological function, pain intensity, disability and global outcome of surgery, with good surgical outcome, including reduced pain intensity and disability (2, 5). A limited number of studies have focused on clinical functional outcomes (6–8) and psychosocial status after ACDF (9–11). Earlier studies reported gender differences in functional and psychosocial outcomes after surgery, with women reporting worse outcomes than men (9, 12). Studies focusing on the individuals with worse outcomes can provide valuable information for improving care, rehabilitation, and outcomes after surgery.

Questionnaires and functional outcome measures consist of structured questions and/or measures in which the researcher uses predefined categories and limits the responses. The clinician or researcher also decides the important aspects of outcome. In the *Swedish Health and Medical Services Act* (13), the need to unite the perspectives of healthcare professionals and patients is stated explicitly. Exploring the views of the patients may provide new insights into the complex reality of the patients' own situations (14, 15). Results from such a study could help healthcare professionals understand important

aspects of daily life that may need to be considered in postoperative care and rehabilitation. To the best of our knowledge, no previous studies have explored how individuals describe their daily lives after ACDF.

Thus, the aim of this study was to explore and describe women's experiences of daily life after ACDF surgery.

## METHODS

A qualitative explorative design was chosen with data collected through individual semi-structured interviews. An explorative design was chosen because it can provide insight into a research area that has not previously been investigated. Semi-structured interviews provide a rich understanding of informants' experiences of the world expressed in their own words (14).

### Informants

Informants were recruited from an ongoing randomized, controlled, multicentre trial (RCT) in south-eastern Sweden investigating the effect of a structured rehabilitation programme on outcomes after ACDF for cervical disc disease (16). The participants in this RCT were randomized to either customary physiotherapy treatment or customary physiotherapy treatment plus a structured rehabilitation programme.

A purposive sampling strategy was used to obtain rich descriptions of how individuals experience their daily lives after surgery. The sampling procedure aimed to establish maximal informant variation by including informants differing in age, county council, postoperative rehabilitation, family and work situation, and being from rural or urban settings.

The inclusion criteria were: (i) individuals 18–36 months after ACDF surgery; (ii) female sex; and (iii) participation, either currently or previously, in an ongoing multicentre study evaluating the effect of a postoperative rehabilitation programme after ACDF (16). The exclusion criteria were: (i) presence of musculoskeletal pain (not originating from the neck); and (ii) other medical conditions that would substantially influence the informant's daily life. The timeframe was chosen based on a previous study of pain and neck disability after ACDF, which showed that outcomes were unchanged after 1 year of follow-up (17). Also, 3 years after surgery, the informants were expected still to relate their current experiences to daily life after neck surgery. The focus of the present study was women's experiences due to the observation of worse outcomes in women after surgery compared with men (9, 12).

Fourteen women aged 39–62 years (median 52 years) agreed to participate in the study. Time from surgery to follow-up varied between 18 and 33 months (median 27 months) (Table I).

This study was approved by the Regional Ethics Review board in Linköping, Sweden (Dnr 2012/416-31). All informants provided written informed consent prior to the interview. The recorded and transcribed material was stored in a locker/safe that was accessible only to the first author. The transcripts were anonymized, and only coded data was discussed among the researchers/authors. If problems that required professional attention were detected during the interviews, the informants were to be referred to an appropriate primary healthcare professional. However, no such problems were identified during any of the interviews.

### Data collection

Socio-demographic information was collected using a structured interview prior to the semi-structured research interview. The Neck Disability Index (NDI) (18, 19) was used to measure and categorize (19) self-reported disability in order to describe the characteristics of the informants (Table I). The NDI was completed at the end of each

Table I. Characteristics of the women (n = 14)

Characteristics	n
Treatment	
Surgery with standard care	5
Surgery with standard care+structured rehabilitation	9
Education	
Primary school (1 <sup>st</sup> to 9 <sup>th</sup> grade)	2
High school	7
College education ≤2 years	2
College education >2 years	2
Community college	1
Employment status	
Employed full-time	4
Employed part-time	6
Unemployed	1
Retired	0
Sick-leave	2
Student	1
Family status	
Married/cohabitant	12
Single	1
Divorced	1
Informants with in-house children	6
Profession	
White-collar	6
Blue-collar	8
NDI <sup>a</sup>	
No disability	4
Mild disability	6
Moderate to severe disability	4

<sup>a</sup>Cut-off values for NDI: no disability: (0–8%) mild disability (10–28%), moderate to severe disability (≥30%) (19).

NDI: Neck Disability Index (0–100%).

interview session in order to minimize the influence of the structured questionnaire on the informants' responses during the interviews.

The semi-structured research interview was based on an interview guide, starting with one open question "At this time after your neck surgery, please tell me about your experiences of daily life." Additional questions were asked about the following underlying content areas: experiences of factors influencing daily life after surgery, thoughts and feelings related to daily life and to the future with regards to their surgery, possible remaining impairments, and descriptions of any behaviour-related changes in daily life after surgery or strategies related to any remaining symptoms. Throughout the interviews, informants were encouraged to talk about private, occupational, domestic and social/recreational areas of daily life.

The interview guide was developed based on previous research on the patient group and research on health, illness, and care, as experienced by patients with other chronic diseases. The content areas were chosen in an attempt to broaden our knowledge of the patient group by exploring multiple dimensions of daily life after ACDF surgery. The interview guide was discussed among the authors and peer reviewed by doctoral students in physiotherapy. The interview guide was pilot tested in 3 individuals (included in the study). This resulted in a minor revision, including one additional probe to more thoroughly explore how the important factors in daily life, as described by the individual informants, were affected by the surgical procedure.

The interviews were performed at a location chosen by the informant. All interviews were performed by the first author (AH), who has previous experience of working with neck patients as a treating physiotherapist and in research with patients after neck surgery. The

Table II. Examples of the analysis of interviews with women after anterior cervical decompression and fusion surgery

Quotes	Codes	Sub-categories	Category
...before surgery um the last six months I only worked part time because of the pain, so it's really a big improvement, so I was at home for two months and then I started working again...	Work was hindered by pain before (surgery) but not now	Daily life being restored or improved	Being recovered to various extents
... it's no ordinary life this for me it's not ... I have been used to working you know and get to work on things so that um it's a big difference ...	There's a difference from ordinary life because used to working	Experiencing own life as limited despite improvements	

interviews were conducted from October 2013 through March 2014, and each lasted 40–80 min. The interviews were recorded and transcribed verbatim by the first author.

#### Analysis

Collection and analysis of data proceeded simultaneously. The inclusion ended when no new information emerged from additional interviews. The transcripts were analysed by the first author using qualitative content analysis with an inductive approach (14), which allows patterns, variations, and categories to emerge from the text (i.e. from the informants' own stories). Only the manifest meaning of the text was analysed according to the aim of the study, which was to describe the informants' experiences from their own perspective.

Initially, each transcript was read thoroughly to get a sense of that informant's story. During additional readings, statements in the text (quotes) that responded to the aim of the study were identified. These quotes were coded as closely to the transcribed text as possible and given a label that represents and describes each individual statement. The next step consisted of systematically comparing the codes to find regularities and variations. Similar codes were sorted into subcategories, and finally into categories (14) (Table II).

No differences were found between the 2 RCT groups, and the analysis proceeded with all informants as 1 sample. The content within each category should be homogeneous and separate categories should be mutually exclusive. The process of sorting codes into sub-categories and subsequently into categories involves working back and forth between the categories and the data/text to verify the meaningfulness and accuracy of the categories (14). The consistency of codes and categories was checked by, and discussed with, all co-authors during and after completion of the analysis, with high agreement between the authors.

## RESULTS

The informants' experiences of daily life were described in 5 different ways, as outlined in Table III.

#### *Being recovered to various extents*

The informants' experiences ranged from being recovered and improved, being able to live a close to normal life despite disabilities in daily life, to being limited although improved compared with before surgery. All but one informant experienced improvements in daily life after surgery. One informant had been able to live a close to normal life shortly after surgery, but her symptoms had recurred, and she now experienced the same difficulties in daily life as before surgery. Positive feelings, such as happiness and thankfulness for being improved or recovered after surgery, were also experienced. Informants were able to do things at home, at work and/or in social situations that they could not do before surgery:

*I can do everything you know, shovel snow, walk to the store, carry heavy bags ... without any pain so that, well, it is extremely positive it is ... (I:7)*

Some informants described that they were able to perform most daily activities despite symptoms:

*Right now I'm on a roll (laughs) ... it's unbelievably fun at work and I ... things are smooth at home and, well it works*

Table III. Overview of categories describing women's daily life after anterior cervical decompression and fusion surgery

Category	Sub-categories
Being recovered to various extents	Daily life being restored or improved Positive feelings related to surgical outcome Functional everyday life despite symptoms Experiencing own life as limited despite improvements Being a different person with symptoms or without
Impact of remaining symptoms on thoughts and feelings	Describing remaining symptoms Negative or positive feelings related to symptoms Thoughts of causes of remaining symptoms – medical and own behaviour Expectations and hopes of a future without symptoms
Making daily life work	Making adjustments to and in activities to make life work Behaviours and techniques to reduce neck-problems Choosing strategies of the mind A need for new treatment or altered behaviours
Receiving support from social and occupational networks	Family situation creating calm or tension Participating in social and domestic life positively affects daily life and well-being Conditions for return to work
Physical and behavioural changes due to interventions and encounters with healthcare professionals	Medical and rehabilitation interventions have positively influenced physical recovery The actions, competence, and approach of surgeons and physiotherapists have influenced recovery, activities, and behaviours Surgery-related complications affecting heart and throat negatively affecting daily life

very well ... I haven't really reflected on it, but the neck is where it is and the arm is just coming along ... (I:8)

I live my normal life because ... uhm ... I have, live with what's remaining if you say so ... the pain and the other [neurological symptoms in the arm], mm so I live like I used to ... (I:11)

Activities in daily life were also experienced by informants as being limited by symptoms, including necessary activities such as work, driving, and cleaning the house, as well as recreational activities.

It's no ordinary life this for me it's not...I've been used to working you know ... (I:4)

Daily life was described as positive at some times and limited at others depending on the variability of symptoms. Both spirit/mood and behaviours were described as being dependent on symptoms:

On days when I'm in pain I don't do so much and I'm not especially nice ... at all when you're in real pain... (I:9)

#### Impact of remaining symptoms on thoughts and feelings

Experiencing neck-related symptoms of pain, stiffness, weakness and sensory disturbances was a part of most informants' daily lives. These remaining problems were accompanied in some of the women by negative feelings of anger, sadness and worrying, as well as thoughts about causes of persistence and the future.

How it feels ... it's depressing, I get pissed off. Why do I have pain now, or what, why does it have to be like this ... I become sad... (I:4)

Positive feelings of happiness, joy and satisfaction were related to symptom reduction.

It's [the nerve pain] gone ... and it I don't think it bothers me now kind of... I'm really happy that it's gone ... (I:10)

Some women worried about a deterioration in their symptoms. Other women had thoughts about persistent symptoms that were focused on the operated area of the spine: and they wondered if there was something wrong with it or whether or not behaviours in daily life caused these symptoms:

It's about how well my ... how the vertebrae around [the segment operated on] ... will manage my working on the computer ... which I think may have been a part of it from the beginning, how this [the neck problems] has developed. That it may be a reason to why it [the neck] is the way it is and, uh, I try to think about how I sit and things like that ... so, I think about that and wonder whether it [the operated area] will hold up for a few more years ... (I:3)

#### Making daily life work

Within daily life, strategies and adjustments were developed to make occupational, domestic and social areas work. Adjustments were made by performing the usual activities somewhat differently or by choosing alternate activities. Strategies were also developed to control physical symptoms by reducing or avoiding triggering the symptoms in order to diminish their im-

pact on daily life. Mental strategies described by the informants were thinking positively about life or ignoring pain in certain social situations in order to increase well-being and to be able to participate. Adjustments in activities could be a balancing act between previous inherent behaviours and current needs:

I don't do it all at once like before when perhaps I cleaned the whole house at once and ... did kind of everything in one day. Now perhaps I do it over two or three days instead ... divide it some ... and I don't do it as fast, I might take a bit longer time so that I don't stress...you learn how to handle things ... (I:5)

Physical activity, training and mobility exercises were mostly used to control or prevent neck problems:

Because the more I move around, the less ... the less problems I have with my neck I guess you could say ... (I:11)

When the pain was worse, medication and relaxation techniques were used:

Much of it is about reducing the pain uh pain medicine and then lay down on the floor, relax ... further ... this meditation tape ... it has helped me very much ... (I:9)

#### Receiving support from social and occupational networks

Family was most often experienced as supportive. Participating in social and occupational activities influenced the informants' well-being and daily life by increasing positive energy, diverting attention from a tough situation, and creating a sense of belonging. The return to work conditions either facilitated or hindered a smooth work day and the ability to participate in occupational life:

It's important I think that you have the social [life] because otherwise I probably wouldn't manage ... because I'm a very social person I enjoy being with friends ... going to the movies for example like this, it happens like once a month ... and we meet ...after work and such ... think it is important to not sit at home feeling sorry for yourself but try to get out ... (I:5)

Some informants described going back to work, though with different assignments, as important for daily life:

There [at work] is the most different ... now it's not a problem because I have a job where I move around more but ... I don't think I would feel as good if I worked at the front desk again ... you're stuck in one position and you're sitting down ... (I:6)

#### Physical and behavioural changes due to interventions and encounters with healthcare professionals

The women described the treatments and support from healthcare professionals as positively influencing daily life by facilitating physical recovery, as well as providing confidence, individualized treatment, information and advice. The perceived reductions in pain and other physical impairments were attributed mostly to the surgical procedure. Physical therapy treatment and physical training were described as facilitating recovery by improving neck and arm function as well as functioning at work and psychosocial aspects of life:

*The pain ... it can't compare at all to how it was before [surgery] ... such pain I had in my arm and that has changed ... (I:8)*

*And the period after [surgery] with physiotherapy it helped as well, for sure it did, um, both strengthening the muscles and that part ... to get back in shape and that's both mentally socially and physically so it's three parts of the whole that ... I thought was helpful for me ... (I:8)*

Some women experienced a sense of security in the ability to perform activities. This was established by a trust in the competence of the surgeons and physiotherapists:

*Hearing it straight out that it is not ... this is not harmful to do, you can do this exercise ... so absolutely ... that I dare you know, ... do the exercises I had before because I did not know ... no more than I'd been told that my neck is stronger now than it was before ... (I:7)*

## DISCUSSION

This study is unique in its attempt to reach further than the standardized and healthcare-oriented outcome measures and questionnaires traditionally included when evaluating patients after ACDF. To the best of our knowledge, no previous studies have explored patients' experiences of daily life in this population. The main findings show how daily life was experienced as positive and improved, but most women were simultaneously affected and limited by remaining symptoms. New and/or altering behaviours were integrated into activities of daily life to adjust for these limitations. Participation in social and work lives, as well as the support and interventions of healthcare professionals were described as positive factors for a good daily life after surgery.

As no studies have investigated this area of research in this population, only partial comparisons with previous research are possible. One advantage of qualitative research is the possibility to describe and understand the complexity of a patient's situation (14). Some earlier follow-up studies of patients after ACDF surgery have reported good global outcomes and statistical reductions in pain and disabilities (17, 20, 21), whereas others have reported remaining physical impairments (6, 7, 22). All but one of the women in the present study described their lives as being improved after surgery. However, almost all of these women also described symptoms that affected them in 1 or more areas of daily life. The NDI provided a slightly different result, with 10 informants rating no or mild disability. These differences indicate that either the symptoms did not affect informants enough for them to experience disability, or the NDI does not capture the limitations experienced by an individual patient. Within the descriptions of improved daily life were statements of positive feelings, such as happiness and thankfulness for the reduced symptoms. These are factors that may influence frequently used outcome measures, such as a global perceived effect score, but do not necessarily describe good function or a satisfying daily life.

Cognitive and behavioural efforts to manage activity limitations and existing symptoms or prevent symptoms are examples of coping strategies (23). Coping with chronic and acute pain can be described as active (using one's own resources to control pain and to function despite pain) (24) or passive (helplessness, reliance on others for pain control) strategies (24). Active strategies tend to be used when the stressor is considered to be a challenge and possible to control, whereas passive strategies are related to an appraisal of threat or harm (25). The women in the present study described mainly problem-focused active strategies to adjust and scale down activities to fit their new level of functioning. Physical activity and exercises were the main active strategies used for control of symptoms. Informants also described cognitive strategies that can be considered active coping strategies, such as positive thinking and ignoring pain in order to be able to perform. When pain intensified, passive coping strategies, such as rest, social withdrawal, and pain medication, were used. Avoidance behaviour due to a fear of pain and re-injury was another passive strategy. Certain strategies were described as context- or activity-specific, such as ignoring pain in social situations and at work. Exercise was described as a strategy to cope with symptoms, but it is likely that exercise also improved the informant's overall health and well-being. Remaining active despite symptoms and avoiding activities expected to make pain worse were viewed similarly by patients after lumbar spine surgery (26). Informants described a number of social networks and forms of support influencing well-being and daily life. Emotional, tangible (practical), and informational are types of social support presented in the literature (27). Social support has been proposed to influence or moderate the effect of a stressor on well-being and health in different populations (27, 28). The emotional support of feeling cared for and belonging to a family, social, or domestic group; and the receipt of tangible, practical support were experienced. Thus, the type and perceived quality of support seemed to be the important factors, and the lack of perceived support from existing social networks caused sadness and frustration in a few informants.

The informational and emotional support received from healthcare professionals was experienced by the informants as being as important to their daily lives as the physical interventions. Examples were guidance and information from doctors and physiotherapists in improving informants' confidence in the treatment and future outcomes, and being seen by the healthcare professionals as an individual. Social support has not previously been explored in patients after ACDF. However, private, occupational, and healthcare arenas as supportive networks, and the importance of socio-emotional support provided by healthcare professionals, were reported previously by patients with musculoskeletal disorders (29).

Two women differed from the rest of the sample in that they did not rate or describe any pain or physical symptoms. These women were not extremes of the sample in demographics. Interestingly, these women also described altered behaviours due to the fear of pain and re-injury and the importance of social

support. Qualitative findings from information-rich samples can be applicable to other samples with similar characteristics under similar conditions (14). This study focused on women's experiences in an attempt to learn more about the sub-group with the worse outcome after surgery. The informants varied in demographic factors and in disability, which makes the findings of this study transferable to other female populations after cervical spine surgery. Additional studies of men's experiences and potential gender differences are needed.

The interviewer was a physiotherapist, which may have affected the data collection by influencing the authenticity of the informants' presentations and allowing the interview to deviate toward the functional aspects of daily life. To ensure the authenticity of the informants' stories, they were informed that the interviewer had no relationship with the neuro-orthopaedic clinics or the RCT. In addition, both the interview guide and the analysis were discussed between authors, one of which is a highly qualified qualitative researcher in nursing science and experienced in patient evaluations. All authors checking the codes increased trustworthiness through analyst triangulation (14). Furthermore, trustworthiness was established by following rigorous methodology for inclusion, data collection, and analysis.

The dual nature of experiencing reduced pain and neurological symptoms while dealing with symptoms affecting all areas of daily life is a phenomenon not explicitly identified in quantitative studies on the outcome of ACDF surgery. A thorough dialogue with these patients is needed to identify any remaining difficulties, understand individual strategies for managing daily life, and understanding the support received by their social networks. When patients are struggling to manage daily life, healthcare professionals need to guide these individuals toward effective coping strategies. Healthcare professionals also need to reflect on their roles in providing social support. Future research could focus on how well traditional outcome measures cover the patients' experiences of daily life after surgery.

In conclusion, this interview study provides insight into women's daily life after ACDF. While improved after surgery, most informants also experienced remaining symptoms and limitations in daily life. Active coping strategies were used to manage daily life after ACDF, but when symptoms intensified, the informants could turn to passive strategies. Social support received from family, friends, occupational areas, and healthcare professionals, were important factors positively influencing daily life. These findings provide knowledge about aspects of daily life that should be considered in individualized postoperative care and rehabilitation in an attempt to provide better outcomes in women after ACDF.

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