

An invisible disability: Qualitative research on upper extremity disorders in a university community

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Abstract: *Objectives.* To understand how upper extremity disorders related to computer use affect graduate and undergraduate university students; and, to develop hypotheses for prevention and management of these disorders.

Methods. Focus group discussions concerning upper extremity disorders were conducted among sixteen symptomatic undergraduate and graduate students at a private university in the US. Discussions were tape recorded, transcribed, coded for themes, and analyzed qualitatively.

Results. The findings point to four main themes: 1) the essential role of computers in academic, social, and personal activities; 2) the negative impact of upper extremity disorders on students' physical and emotional well-being, including their career aspirations; 3) students' expectations and perceptions of medical care providers; and 4) recommendations for interventions.

Conclusion. Students with upper extremity disorders experience numerous adverse consequences on a college campus. Effective strategies for prevention, and treatment of upper extremity disorders in young adults in universities are needed. Based on this research, an educational and skills development intervention would appear to be appropriate for preventing disability due to upper extremity disorders.

Keywords: Upper extremity disorders, repetitive strain injury (RSI), college and university

1. Introduction

Upper extremity disorders occur frequently in office settings and include nerve entrapments such as carpal tunnel syndrome, tendon disorders about the wrist and elbow such as epicondylitis and wrist ten-

donitis, and shoulder disorders such as rotator cuff tendinitis [11]. Upper extremity disorders are the fastest growing source of disability in the American workplace [2,8]. Industries characterized by forceful and repetitious upper extremity activities, such as poultry and meat processing, lumber, and manufacturing, have the highest rates of upper extremity disability [3,4]. Computer operators are also at risk, as computer use for more than four hours per day appears to double the risk of upper extremity disorders [10]. The prevalence of upper extremity symptoms in workers who use

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computers intensively ranges from 20–40% [1,9].

Information technology is diffusing rapidly across colleges and universities. This trend, coupled with scientific evidence of potential health hazards of computing [10], suggests that upper extremity disorders may be an emerging health problem on campus. The limited literature on this topic suggests that half of students experience upper extremity discomfort with extensive use of computers and one sixth of students have symptoms after using the computer for just an hour at a time or less [6].

There is currently little published information about college students' perceptions of the impact of upper extremity disorders, use of health services for these conditions, beliefs about the efficacy of health care, and strategies for prevention. The objective of this formative research is to conduct and analyze focus groups in which students discuss the impact of upper extremity disorders, describe patterns of health service utilization and suggest strategies for prevention.

2. Methods

2.1. Sample

The study took place at a large private university in New England that has an undergraduate college as well as a graduate school and numerous professional schools. Participants for each of the focus groups were recruited with fliers, e-mail trees, advertisements in the student newspaper, announcements made at campus health promotion workshops, and through contact with student-run social and upper extremity disorder support groups. Students were told that the University Health Services was conducting a study of the issues faced by students with upper extremity disorder symptoms, and that dinner and \$20 compensation would be provided to each student who participated.

2.2. Eligibility criteria

Our goal was to recruit undergraduate and graduate students who had experienced (currently or in the past) an upper extremity disorder. We reasoned that these students would be best able to discuss the impact of upper extremity disorders on the quality of students' lives and on their academic performance and career plans. Therefore, we developed the following eligibility criteria: To be eligible to participate a student had to be at least 18 years of age, report current or past

upper extremity symptoms, and use a computer four or more hours a day. All participants were screened for eligibility via telephone and e-mail, using a standard screening instrument. The instrument asked about the students' age; graduate, professional or undergraduate status; whether they had ever experienced upper extremity symptoms; and, whether they would be available to participate in a focus group.

2.3. Sample characteristics

One focus group was comprised of undergraduates, the other of graduate students. The undergraduate group had seven participants (5 males, 2 females) and the graduate group had nine participants (3 males, 6 females). In both groups, the students had a wide range of academic concentrations and extracurricular interests.

2.4. Focus group procedures

The focus groups were held during the summer and fall of 1998. Each focus group was led by a moderator, who was a health educator with a background in social marketing and considerable experience leading focus groups. All four investigators had prior experience conducting qualitative research and/or analyzing qualitative research findings. One of the authors (BCA) has extensive experience in all aspects of qualitative research (design, development of moderator guides and other materials, conduct and analysis of focus groups).

The research team developed the moderator's guide (Table 1) using standard methodology [5,7]. The guide is intended to elicit participant perceptions and behaviors about upper extremity disorders. The moderator used open-ended questions and specific probes in six areas (Table 1). These included: 1) the role of computers in everyday life; 2) factors involved in the development of upper extremity disorders; 3) resources that were helpful in dealing with the symptoms and disability; 4) recommendations regarding types of treatment and advice that is helpful; 5) the impact of symptoms on students' lives; and 6) the impact on future plans.

At the beginning of each focus group, the students were informed of their rights as participants and that the data would be confidential. The institutional human subjects committee approved the project and all students provided informed consent.

Table 1
Substantive aspects of the moderator guide

<p>(1) Use of Computers and Behavioral Aspects</p> <p>a. How would you describe the current role of the computer in your life? Probes: Is it essential/non-essential? What about in your academic work; enjoyment; social; information seeking?</p> <p>b. How often do you use the computer? Probes:</p> <ul style="list-style-type: none"> – Time spent on computer daily/weekly – What about breaks or variations in activities? – How often do you type for long periods of time? How long on average? <p>c. How difficult would it be to give up computer use as practiced now? Why?</p> <p>d. What are your feelings regarding changing students' behaviors with regard to computer use?</p> <p>(2) Risk Factors</p> <p>a. Looking back, what were things that may have contributed to the development of repetitive strain injury (RSI)? Probes: Workstation characteristics; personal work style; academic demands; posture; extracurricular exposure.</p> <p>b. Why seek help? Probe:</p> <ul style="list-style-type: none"> – If participant had symptoms, even mild ones, what made them finally decide to act, e.g., seek clinical care? <p>c. If participant did not seek help, what was the reason(s) / barrier(s)?</p> <p>(3) What Helped?</p> <p>a. What resources (e.g., organizations; persons) have been most or least helpful? Probes: Health providers; other university organization(s); educational material; peer support; alternative healers; the web; books.</p> <p>(4) Recommendations Regarding Help</p> <p>a. What treatment(s) has been most helpful, and what has been least helpful? Probes:</p> <ul style="list-style-type: none"> – Physical therapy <p>b. What advice would you give someone beginning to have symptoms of RSI? Probe:</p> <ul style="list-style-type: none"> – Identification of early symptoms and/or limited function <p>(5) Impact</p> <p>a. How has having an RSI affected your way of life? Probes:</p> <ul style="list-style-type: none"> – Academic performance – Social – Emotional – Extracurricular <p>(6) Future</p> <p>a. Does your RSI affect your plans for the future? Probes: Academic and/or career plans; expectations of self; health care.</p> <p>b. How do you feel about this (these)?</p>	
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2.5. Analysis

The focus groups were recorded on audiotape. A secretary transcribed the audiotapes with all personal identifiers removed. Two investigators (MCC, CH) reviewed the transcripts independently and identified salient themes. These themes were based primarily on the content of the moderator's guide, and modified during review of the transcripts. The two investigators de-

veloped written records of specific student comments that represented themes. They compared each other's written documents to ensure uniformity in coding of themes (although no formal inter-rater reliability testing was performed). The entire research team then discussed and synthesized the themes and quotations to develop major, general themes. These themes are presented in the Results section, with illustrative quotes.

The themes were also examined across the two focus groups to identify contrasts between undergraduates and graduates.

3. Results

Four major themes were identified from the two focus groups: 1) the essential and almost omnipresent role of computers in academic, social, and personal activities; 2) the negative impact of upper extremity disorders on physical and emotional well-being, including the negative impact on students' life and career aspirations; 3) the expectations and perceptions of primary care providers; and 4) recommendations that focus on a) primary prevention, b) proactive approaches in seeking treatment, and c) psychological and social ramifications of upper extremity disorders. There were also some important differences between graduates and undergraduates in terms of the personal impact of and response to upper extremity disorders.

3.1. Role of the computer in everyday life

Both undergraduates and graduate students stressed that computers are essential to routine academic and job-related work, as well as for social and personal activities. They suggested it is hard to imagine functioning as a student without using a computer. Undergraduate and graduate participants stated that almost all of the students they know own computers and use them on a daily basis. In addition, both undergraduate and graduate participants reported that young people start using computers as early as age five, and that this habituation has a cumulative effect, both in terms of computer competency and in exposure to upper extremity disorders. The ubiquity of computers in students' lives is captured in the following statements from students:

The computer is an essential homework device, . . . and it is also our fundamental communication device. (undergraduate)

You'll probably find that when most . . . students are writing a paper, when they want to take a break they check their email. They don't walk away from their computer. (undergraduate)

3.2. The impact of upper extremity disorders

Several participants in both the undergraduate and graduate student groups emphasized their fear of living with an upper extremity disorder. In general, graduate students were most concerned that their long-term career goals appeared to be compromised by an upper extremity disorder. In contrast, undergraduates were generally more concerned with current academic performance. Few undergraduates mentioned career goals, but both undergraduates and graduates discussed how the symptoms of upper extremity disorders limited their ability to work at the computer long enough to perform well academically. Furthermore, undergraduates were concerned that the impact of reduced computer time would have a negative effect on their academic performance and would limit their graduate study opportunities.

Several graduate students indicated that their upper extremity disorder had already had a severe impact on their career choices. Two students were forced to settle for entirely different careers – that would either pay significantly less or have less prestige – in order to accommodate the limitations imposed by their upper extremity disorder. Another graduate student said that accomplishing less academic activity because of an upper extremity disorder would mean lowered career expectations. The fear associated with the impact of upper extremity disorders on the students' futures is reflected in the following statements:

[It was] very devastating because I was a musician and there were two years that I couldn't play . . . I would never tell a recruiting firm that I had had this medical problem, because I felt they would say, "Oh, take him out to the back and shoot him like a broken horse . . ." because I might re-injure myself. (graduate)

Participants also discussed the influence of upper extremity disorders on their quality of life. Many of them noted that it became difficult to do simple yet essential things such as driving, eating, washing dishes, opening doors or jar lids, buttoning their clothes, holding newspapers or grocery bags. Others said they often dropped things, and that upper extremity pain disturbed their sleep. At least three undergraduates found exercise such as biking and weight lifting difficult.

These physical limitations have emotional consequences. Many students voiced fear and frustration. Both undergraduates and graduates described a feeling of isolation associated with living with upper extremity disability. Some students observed that having an up-

per extremity disorder is like having an “invisible disability”, which seemed to complicate their process of getting assistance and support. The statements below show some of the fear, stigma and emotional consequences.

... it's an enormous self-esteem blow, particularly [when] ... you've been trying to work hard and you still can't do a lot of stuff or have a more normal life. (graduate)

I don't want to stigmatize myself as having RSI. ... this place teaches us to be very risk adverse in how we are perceived by other people in terms of dealing with our weaknesses ... As students we are all competing, ... and so anything that would make us stand out in a negative way, you would try to keep as quiet as possible. (undergraduate)

How does anybody who is disabled feel? I don't know, you feel like an outcast, you're no longer part of what used to be the 'best people', now you're part of the people who need help. (graduate).

Given the computer's prominent role in their lives, students perceived it to be indispensable. Consequently, it was difficult for respondents to comply with what they considered to be simplistic recommendations from clinicians that they discontinue computer use. All students felt that this was not realistic, given the university's academic demands and their own career goals.

I've had people tell me that “you can't use the computer anymore”, and that's basically saying “drop out of grad school”. There is no alternative that was presented so that's really been hard to take. (graduate)

3.3. Expectations and perceptions of medical care

For both undergraduate and graduate participants, the major reasons for seeking health care were pain, fear, or the advice of friends. In both groups, some students mentioned that they had taken a long time to seek help, either because they did not feel their symptoms were serious enough, or because they were concerned about the quality of the medical treatment they would receive. Some students did not seek care because they were “busy” doing other things they considered more important, or because they did not want to be seen as a “hypochondriac” or a complainer.

In general, graduate students sought care late in the course of the problem. Some students said they decided to seek treatment when they heard about others who had surgery for an upper extremity disorder. Sev-

eral graduate students agreed that only continuous pain “made me take it seriously”. Despite continuous pain, some waited until they were incapacitated before seeking care. These different views on when to seek care are captured in the following statements:

I waited [to seek medical care] until my right hand and arm swelled up ... (undergraduate and graduate)

... it was really just physically being unable to use my hands for anything. This was the point I had to be at before I was willing to seek medical attention. (undergraduate)

In contrast to the graduate students, some undergraduates revealed that their friends at the university advised them to see a physician early, when they had mild pain. Several expressed concern about delays in getting appointments, especially with specialists or physical therapists. Some participants felt their primary care physician did not take their symptoms seriously.

In general, participants appeared to want answers and constructive advice from their clinicians. Most participants expected that there would be tests or a hands-on examination. They felt these would lead to a description of what was wrong and advice about what steps they would have to take to get relief, followed, if necessary, by referrals to other specialists. Several participants in both groups noted that their primary care physicians did not provide enough information and/or treatment recommendations to help them address their symptoms. Students who had diagnostic tests and a more thorough examination expressed greater satisfaction with their care. Similarly, participants felt better about their care if their physicians had touched them, tested them, and spent time explaining things. Several participants commented that physical therapists provided more detailed physical examinations and gave more thorough instructions than their primary care physicians on activity limitations and other aspects of treatment. The statements below reflect a range of views about the medical care these students received.

[I] ... figured if I had pain and it was something that's going to affect my career, not only in school, but my performing career, that it should be taken a little more seriously [by the physician I went to]. (graduate)

[I had gone to the doctor] to hear the answers. But then of course the more often you see them the more you realize they really don't have those kind of answers for you. It is almost like the doctors are learning about you with you, and so you end up knowing probably more than they do because

you know your symptoms the most and you know they have to learn from you . . . You know you just have to learn from your own mistakes sometimes because they really can't tell you. (graduate)

[I was satisfied with my clinician because that person] did more concrete tests to give me a diagnosis, to suggest behavior that was more consistent with everything that I heard about RSI, . . . he gave me some braces to use. He explained exactly what was causing the RSI . . . but also explained what was behind that. (graduate)

3.4. Recommendations for prevention and management

Participants stressed that campus-based interventions should focus on primary prevention rather than restricting attention to those who had already developed symptoms. They also stressed the need to raise awareness about the potentially chronic nature of upper extremity disability if it is left untreated. The participants supported a proactive approach to implementing prevention activities, seeking treatment and addressing risk factors.

It's important to show people know how to recognize the early warning signs. (undergraduate)

Both groups also stressed the importance of addressing the negative psychological and emotional impact of these disorders. Some participants mentioned that talking with a mental health counselor and participating in support groups had been helpful for them. The graduate student focus group participants suggested that physicians integrate into routine office visits a simple screening question about upper extremity disorder symptoms. The students suggested that physicians routinely provide students with information on the risk factors related to these disorders, especially regarding computer use.

Participants also felt that ergonomic analysis of workstations should be more accessible to students. They discussed the possibility of using peers to do ergonomic site checks for the undergraduate students who lived on campus. In addition, both groups discussed how to inform incoming students about risk factors related to computer use. Some suggested that ergonomic training should be provided during orientation for new students and at programs held for all students (new and continuing) throughout the Fall semester. The suggestion that peers provide some of the education is captured in the following statement:

Well, I think seeing other people and hearing their experiences is what would do it for me. Who knows? (graduate)

Other suggestions included the development and support of a computer technology laboratory, where students could try out ergonomically designed computer technologies such as keyboards, pointing devices, and voice recognition software. The laboratory could also provide general information about ergonomic adaptations such as reading stands, adjustable chairs, and work habits, such as appropriate rest breaks, postural improvement and stretches.

4. Discussion

These focus groups provide new and valuable information about the impact of upper extremity disorders in a university community. Four main themes emerged. First, computers are essential to academic, social, and personal activities among the student community. Second, upper extremity disorders can disrupt and degrade students' quality of life and career aspirations. Third, medical care providers should become more facile with the recognition and management of upper extremity disorders and their functional and psychosocial consequences. Finally, the students recommended primary prevention, proactive approaches to treatment, and attention to the mental health consequences of upper extremity disorders. These themes are critical to framing policy recommendations that can improve overall management of these disorders among college and university students.

There are fifteen million undergraduate students in the US [12] and many more graduate and professional students. Approximately half of the undergraduate students experience upper extremity symptoms with computer use, and 10–15% experience symptoms after computing for as little as one hour at a time [6]. There is little data currently available on the short and long term consequences of these symptoms. Our focus group research suggests that upper extremity disorders may threaten students' school performance, career choices, and earnings trajectories.

The study has important limitations. We studied a convenience sample of students with symptoms. Caution should be exercised in generalizing the results of these focus groups to the broader student population. In particular, data on the functional consequences in a less select sample of symptomatic students would enhance our understanding of the broader impact of these

disorders. Further, the views of asymptomatic students would be useful, particularly for developing strategies for primary prevention. Our work focused students' attention on computer associated symptoms, but other activities, including musical performance and sports, may also give rise to or exacerbate upper extremity disorders and need to be included in any discussion of activity modification and prevention. We did not perform formal reliability tests to assess the accuracy of coding. Finally, as with all qualitative research, our work should be viewed as hypothesis-generating and validated in more comprehensive surveys.

If the perceptions and experiences offered by these focus group participants are confirmed in additional research, they should be integrated into the design of quality improvement efforts in student health services. These findings should also prompt controlled trials of educational plus skill-building interventions for prevention of upper extremity disorders in university students.

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