Fitting into the prevailing teenage culture: A grounded theory on female adolescents with chronic arthritis

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Abstract

The aim of this study was to deepen the understanding of female adolescents’ daily living with chronic arthritis. Tape-recorded open interviews were conducted once with six teenage girls (14–17 years), who also wrote diaries for a 12-month period. In addition, 12 interviews of female adolescents diagnosed with chronic arthritis selected from another sample in an earlier study by the authors were included in the data. The Grounded Theory (GT) method was used for analysing the diaries and the transcribed interviews. A core category, labelled Fitting into the prevailing teenage culture, and four related categories labelled (1) mastering a body in pain; (2) living one day at a time; (3) using social support; and (4) fighting for health emerged. The categories formed a substantive theory illuminating living with chronic arthritis during adolescence. The theory explains and provides a deeper understanding of the main concern of these female adolescents and their strategies in managing their situation.

Key words: Adolescents, grounded theory, juvenile arthritis, pain, teenage culture

Introduction

Juvenile idiopathic arthritis (JIA) is defined as “the inflammation of one or more joints for at least three months in a child under the age of 16 years in whom other known causes of arthritis have been excluded” (http://www.ccaa.org.uk/jia_explained.htm). Arthritis is an autoimmune disorder, where the body’s immune response is overactive. Typical symptoms include joint pain and swelling, tenderness, limited mobility and functional impairment (Cassidy & Petty, 2002). Childhood arthritis is a heterogeneous disease, and different subtypes of the disease vary in clinical manifestations, disease course, and age of onset. This makes the interpretation and comparison of studies in this area difficult. Despite the different forms of juvenile arthritis, the lives of the sufferers are challenged physically, psychologically and socially.

Chronic arthritis in childhood is one of the most common painful diseases among the paediatric population. Pain related to childhood arthritis is regarded as chronic or recurrent (Benestad, Vinje, Veierød & Vandvik, 1996) and has significant adverse effects on children and their families. Children with arthritis have to deal with a severe illness that affects the health status negatively (Schanberg, Lefebvre, Keepe, Kredisch & Gil, 1997) and controls their daily lives, resulting in restricted participation and limited activity (Sällfors, Hallberg & Fasth, 2001). Ungerer, Chaitow and Champion (1988) found that the social consequences of arthritis increase for young adults as compared with younger children. According to a study by Sällfors, Hallberg and Fasth (2004), more than half of the variation in these children's well-being is explained in terms of self-reported pain, number of pain free days and participation in physical education classes. The management of arthritis in childhood is based on pharmacological interventions, physical and occupational therapy, and psychosocial support (Hashkes & Laxer, 2005).

Health is a resource in daily life and in the Western society associated with having a youthful and active body. According to Naess (1987), well-being rises in proportion to the extent to which a person is active.
Backhett-Milburn (2000, p. 91) points out that “most dominant and recurrent theme in middle-class parents and children’s conceptualizations of the healthy body was the equation with activity”. Christensen (2000) states that children value the ability of mobility in a healthy body. To participate in games and be accepted by others a child must be able to run fast (James, 2000). The self-image undergoes major changes during adolescence and physical fitness plays a prominent role in the teenager's changing self-image (Rejeski, Brawley & Schumaker, 1996). As mentioned previously, attending physical education classes is a predictor of well-being for children with chronic arthritis (Sällfors et al., 2004), but physical fitness cannot be maintained at the same level as for non-disabled peers, if at all. Studies indicate that children with arthritis are less active physically, in general, than their peers (Klepper, Barbee, Effgren & Singsen, 1992; Henderson, Lowell, Specker & Campagne, 1995; Sällfors et al., 2004).

Despite all the new knowledge and pain research, pain in children is still not routinely recognized, evaluated, and treated (Jylli, 2004). Chronic pain in childhood affects not just present functioning but also damages the child’s future, social, physical and economic functioning (Carter, 1998; McGrath & Finley, 1999). In addition, responses to pain affect not only children’s health directly, but may also predispose them to developing chronic pain in adulthood.

Findings regarding the association between gender and reported pain in children with juvenile arthritis differ. Some studies report no differences between girls and boys (Vandvik & Eckblad, 1990; Cassidy & Petty, 2002), while others have found differences. For clinical practice, we need to know if there are clinically meaningful differences in pain experienced by boys and girls. Recent studies by Schanberg, Maurin, Anthony and Gil (2001) and Sällfors, Hallberg and Fasth (2003) indicate that it might be more disabling and painful to be a girl than a boy to suffer from chronic arthritis. The findings showed that boys diagnosed with chronic arthritis perceived greater ability to reduce their own pain than girls did. Number of days with worst morning pain affected girls more often than it affected boys. To explore this gender difference further, the aim of the present study is to explore experiences of living with juvenile arthritis in female adolescents. In a grounded theory perspective, the aim was to explore the main concern for female adolescents living with chronic arthritis and what they are doing to manage the situation.

Method

Study group

Eighteen female adolescents (14–17 years), diagnosed with chronic arthritis 1–16 year earlier, participated in the study. Six of the participants were selected from the association of “young rheumatic groups” in southwestern Sweden. Twelve of the participants were selected from five paediatric departments in the same area of Sweden in an earlier study made by the authors. Initially the informants were strategically selected on the basis of age, duration of the chronic disease, family situation and place of residence, in order to maximize variations of experiences. In addition, categories generated in the analysis of data directed further theoretical sampling that continued until saturation was reached, i.e. until new data did not give additional information or could be included in the previously developed category system. Accordingly, theoretical sampling directed by the emerging results aims at saturating categories and verifying emerging relationships between categories.

Data collection

Open interviews, lasting about 60 minutes each, together with the participant’s diaries was used as data. The tape-recorded and transcribed interviews were conducted with each participant by the first author (CS). Open interviewing permits exploration of the informants subjectively experienced lifeworld and thereby gives information from “the inside”. An in-depth interview is characterized by interaction between the informant and the interviewer, where the involved parties reciprocally affect each other. In such a process, data is constructed.

An interview guide with a few open questions, with the introductory question: “A good life—what does that mean for you?” was used. This open question aimed at opening up the interview, allowing the teenagers “to tell it as it was” in their own words and what it means to live with pain and a chronic condition in daily life. The interviews continued with questions concerning themes such as everyday life with pain and a chronic disease, thoughts and values affecting the future, attitudes of others, and experiences and thoughts about treatment. The interviewer listened actively and asked follow-up and probing questions when relevant. After the interview, six of the teenagers wrote diaries for 12 months. Initially instructions were given to the teenagers when writing the diaries, i.e. to focus on their main concern living with chronic arthritis and on what they were doing to manage their situation.
These diaries were analysed by the researchers once a month during the entire project time (12 months).

Data analysis

Collection and analysis of data (interviews and diaries) were done simultaneously according to guidelines for Grounded Theory (Glaser & Strauss, 1967) and continued until new data did not provide additional information, i.e. until saturation was reached. The aim of Grounded Theory is to generate concepts, a model or a substantive theory that is faithful and illuminates the area under study rather than testing hypothesis based on existing theory (Baker, Wuerst & Stern, 1992). The basic rules include looking for psychosocial processes, discovering existing problem and examining how the people involved handle them (Stern, 1980). The analysis generates codes, categories and concepts, in which the substantive code is the most concrete level and the core category the most abstract. According to Glaser and Strauss (1967), a grounded theory study includes quality and trustworthiness in all phases of the systematic research process. Glaser (1992) stresses that a grounded theory is not entirely right or wrong but must has as good fit as possibly and explain the studied phenomenon analytically, work appropriately and be of relevance.

In the analysis of the present data, the interview transcripts were initially broken down and conceptualised in an open coding process. Substantive codes (Glaser, 1978) were identified as significant phrases and words. Often, the teenagers’ own words were used to label substantive codes (i.e. in vivo codes), e.g. “every day is a fight”, “fighting for health and normality” and “the girl with that disease”. Each code was compared with other codes, to confirm that it was really grounded in the data rather than being generated from an implicit hypothesis or emanating from the researchers’ preconceptions. Codes with similar meaning were clustered into summarizing categories, which were given more abstract labels than the codes pertaining to it. Each category was further developed by identifying its subcategories. In a selective coding process, all the generated categories were saturated with information from new interviews, memos from the diaries or from recoding of earlier collected data (i.e. theoretical sampling). Questions like “What is this all about?” and “What is the teenager’s main problem?” were put to the data in order to find a core category illuminating the main concern in the studied area. A core category, which was central to the data, was identified and labelled Fitting into the prevailing teenage culture. Relations between the core category and the categories were sought and validated in the data. When categorizing data, the researchers tried to “hold back” preconceptions in order to find alternative interpretations, also characterized as “disciplined restraint” (Hallberg, 2006) or reflexivity (Hall & Callery, 2001).

Ethical aspects

In this study, principles from the Swedish Humanistic and Social Science Research Committee (HSFR, 1990) guided our ethical considerations. Informed consent was obtained from all the subjects and their parents. They were assured that the data would be handled in line with regulations in the law of secrecy and that anonymity would be guaranteed in documentation of the study. The local ethics committee of Halmstad University approved the study design (Dnr 90-2006-1097).

Results

In the analysis, a substantive theory was generated, explaining how female adolescents with chronic arthritis handled their main concern, which was identified as their efforts to fitting into the prevailing teenage culture (the core category). The sometimes hidden norms in the prevailing teenage culture include youthful attributes such as strength, being healthy and looking attractive. The highest wish for the female adolescents diagnosed with chronic arthritis in this study is to be seen as a “normal” teenage girl, and not being restricted by pain and illness and identified as “the girl with that disease”. Their wishes are to function normally not wanting to be defined as deviating from social norms among other teenagers, i.e. being “psychologically brand”. Partly, they lack control over their bodies and lives. This study illuminates the female adolescents’ daily struggle, which is presented as a process of fitting into the existing norms in the prevailing teenage culture. As other young ones, they want to be physically active, run fast and be able to participate in games. They want to do what other teenagers do and not be reminded of their illness all the time. Owing to their physical disease, it happens very often that they are unable to do what their friends do during the days. According to the data, the disease is experienced as a potential barrier in the female adolescents’ daily life. The teenagers suffer from their illness constantly and therefore they differ from normal teenagers in many respects.

The informants describe different strategies for managing their situations in order to avoid to deviate from other teenagers’ social norms, to be seen as “normal” and to “fit in”, or “pass as normal” (Goffman, 1963), despite having a chronic disease
with pain and illness. Four conceptual categories labelled (1) mastering a body in pain, (2) using social support (3) living one day at a time, and (4) fighting for health were related to the core category and explained the participants’ strategies for handling the situation. Each category was related to several subcategories (see Table I). The girls’ coping efforts are oriented towards avoiding stigmatisation as deviant, and finding well-being and satisfaction in their daily living. In the ongoing daily struggle to fit into the prevailing teenage culture despite living with the uncertainty related to chronic arthritis, the following strategies are used by the teenage girls: mastering a body in pain, living one day at a time, using social support and fighting for health.

Mastering a body in pain

The girls perceived their bodies as different, changed and out of control, all consequences of the chronic condition. Pain is embedded in the experiences of their bodies. Pain and related uncertainty set up barriers and could separate the teenage girls in the study from their peers. They perceived their bodies as stiff and hurting and that suddenly “the worst case” could happen. They described their bodies as “feeling like a ticking fire bomb”. Living with unpredictable pain makes the girls less physically active than they would like to be, and as prescribed by the prevailing norm among teenagers in general. Despite having a body in pain, one participant wrote in her diary: “Pain won’t keep me from doing what I want to do. It has already stopped me too much.”

Being mentally prepared for a potential negative scenario is a strategy for mastering a body in pain. The illness is often unpredictable. One of the girls said: “I prepare myself almost every day to wake up having excruciating pain.”

Worries can include pain being so severe that close friends, for example, will not or dare not plan a shared activity. According to the data, pain and illness leave the participants out of the running. They are always mentally prepared for plans to be changed and ready to make excuses and break promises. Since the qualities of pain, as invisible and unpredictable, people around the girls often distrust their suffering. It seems to be hard to gain sympathy for invisible ailment and misunderstandings appear both in relations to friends and to professionals, for which the girls were also mentally prepared.

The participants are dependent on others when it comes to health care, medicines, treatment, and techniques, and this give rise to other situations to be mentally prepared for. Sometimes they feel helpless and dare not to get angry at a person, friend or professional, on whom they are dependent. Being mentally prepared to master a body in pain also includes being prepared for occasions like the following:

“There were many blood tests to be taken, which I really hated. I was angry and tried to run away. A couple of people had to hold me down. It was very exhausting.”

Seeking information about the illness is another way to control and have influence over a body in pain. The teenage girls in this study sought information on the best ways of managing pain and illness. This resulted in their becoming active, educated consumers, empowered through access to information from health care professionals, support groups, magazines, the Internet, etc. One teenage girl wrote in her diary: “My doctor explained a lot that I did not know previously and she told me that I really can be healthy again.”

Using social support

The data describes many fears and emotional reactions related to pain and illness and to an uncertain future. Seeking support from others is essential to the teenage girls. The data also reflect the importance of receiving positive support in coping with the uncertainty. Social support seems to be an important

| Subcategories | Categories | Core category |
|---------------|------------|---------------|
| Managing feelings of concern and worry | Mastering a body in pain | Fitting into the prevailing teenage culture |
| Being mentally prepared for the worse | | |
| Seeking information | | |
| Living with certain uncertainty | Living one day at a time | |
| Planning daily routines/activities | Using social support | |
| Seeking support from family, close friends and support groups | | |
| Seeking continuity and participation in care and pain management | | |
| Compliance with treatment | Fighting for health | |
| Striving for hope and recovering | | |
resource in the teenage girls’ struggles to fit into the prevailing teenage culture. Positive support and accepting attitudes from others increase the teenage girls’ hopes for a healthy, normal life in the future. It is especially important to have support from family and close friends, which seems to have a buffering effect on coping with pain and illness:

“It is amazing to be with my brother and his child. It makes me happy. I am always so extremely tired but when we meet I forget my illness.”

The strong support perceived in the rheumatic support groups make these settings important in helping the teenage girls to strengthen their own capabilities and recourses. The data shows that support groups increase their hopes of managing a life with a chronic disease. Sharing their inner thoughts and similar problems and fears also seems to be a good strategy for strengthening their self-image. Knowing that you are not alone with a chronic and unpredictable disease gives a sense of community:

I have been at an appointment at the clinic together with girls with arthritis, all of them in my age. It makes me happy to meet them, and it is relaxing. We have a lot in common. The disease is invisible for them, too. We can learn from each other. We understand each other without saying a word. You get strengthened from such appointments.

Female adolescents with chronic arthritis have a considerable amount of experience of health care management. They know how it is to be a patient and that you can receive both exceptional and average good health care. The teenage girls feel supported and can manage their pain better when they can talk about their illness with someone they trust and who will listen attentively. Continuity and participation in health care also strengthen the teenage girls’ feelings of safety. They perceive support from health care professionals as important. The interaction between the girls and the professionals is of major importance for their compliance with treatment. The data shows that the teenagers need to have adults around them who really care about them, which is illustrated by the following note: “I can always call the nurse at the clinic. I trust her and we can talk about everything.”

Living one day at a time

Living with continuous uncertainty in daily life has a clear impact on the teenagers’ lives. The participants’ lives are largely controlled by their uncertainty related to pain and illness, which is also associated by people in general with old age: “I prepare myself to wake up having dreadful pain. For the moment I can handle it and therefore I can recharge my batteries.”

The illness varies in stability and predictability and the medical treatment is often painful and has unpleasant side effects. Some prescribed treatments also impose on and interrupt daily routines. The uncertainty is always present in the teenage girls’ daily lives, which often leads to avoidance behaviour and isolation: “Everyone wants to live life like everyone else, especially young people. To get through I live one day at a time.”

The results show that the teenage girls try to take control of all the unpleasant consequences of pain and illness by living one day at a time. This way of taking some sort of control over the situation can be seen as the girls defending their “inner selves” against internal and external strain. Living one day at a time includes day-to-day strategies for dealing with demanding challenges related to unpredictability and uncertainty. They have learnt to take things as they come and solve each problem when it appears. Living one day at a time also includes managing daily treatment, frequent clinic appointments, and frequent absence from school. The teenage girls miss a lot when they are absent from school, which they have to compensate for in some way or another: “Yet another day absent from school. I miss a lot. I have missed so much already, but I try to take one day at a time.”

According to this study, living with long-term pain and illness combined with long days at school makes the teenage girls diagnosed with chronic arthritis extremely tired. Pain has a negative influence on both quantity and quality of their sleep, and a continuous vicious circle of pain is initiated. As a consequence of a high degree of stress, the teenage girls sleep badly and are often more tired in the mornings than when they went to bed in the evenings. By taking one day at a time, they try to cope with their tiredness. Living one day at a time demands a lot of planning and prioritizing of daily routines and activities, and such thorough planning gives them some control over the uncertainty in their daily lives: “I am very careful about every step I take. I plan for one day at a time.”

Fighting for health

For teenage girls diagnosed with chronic arthritis, every day is a struggle for a healthier life. This everyday fight is interpreted as a strategy for fitting into the prevailing teenage culture. The fight involves pain reducing strategies, frequent health checkups,
strictly following schedules for medications, and keeping up with physiotherapy, occupational therapy, and other important therapeutic approaches. The participants have to take serious decisions concerning treatments and therapy processes. The results show that they have considerable responsibility for making priorities and decisions about daily activities, which are strategies for a healthier life. The teenage girls in the study seem to have a high degree of internal motivation for treatment. They are experts about their own pain and illness, and the data shows that the girls have both competence and resources: “Suddenly my joints are stiff and hurt and I need more painkillers.”

Striving for hope is an energizing and useful strategy for the teenage girls in managing their wishes to fit into the prevailing teenage culture. Continuity and patient participation are very important in health care, because they increase the experience of safety and control of the struggle for a healthy life: “I have known my nurse for a long time and been able to call her about both less serious and more important things.”

Feelings of hope are always present, especially when the teenage girls are offered new medicines. One way of coping with their life situations is to hope that better days will come: “I know that it (the disease) is always present and I need to live with it all my life, but I hope I am getting better.”

Seeking recovery is another way of striving for hope. The teenagers in the study allow themselves to be distracted from their illness and related feelings of concern and worry by, for example, listening to music, being with close friends, and travelling:

We have been skiing in the mountains, which was so relaxing. Life is much easier when you are on vacation. I feel like another person, and I have new energy, and the ongoing pain is less. Now I am fighting for good health forever.

Discussion

The analysis of data from interviews and diaries generated a substantive theory illuminating the main concern for female adolescents diagnosed with chronic arthritis and their strategies for managing this. The main concern is explored in the core category, labelled fitting into the prevailing teenage culture, showing the teenage girls’ struggle to fit into the norms of looking good and having a healthy active body, not wanting to be defined as deviating from other teenagers. This was central in the data and related to four categories, labelled mastering a body in pain, using social support, living one day at a time and fighting for health, explaining how the teenage girls handle the main concern.

Uncertainty related to pain and illness is an obstacle to live an ordinary life like healthy peers. Pain and illness are experienced as endless and unpredictable and result in limited participation in daily life, as previously described by Sällfors et al. (2001, 2003). Compared with results of earlier studies (Sällfors et al., 2001, 2003), where even younger boys and girls participated, the female participants in the present study have developed more effective coping strategies as being active and well-educated consumers. In addition, the teenage girls have achieved a greater maturity concerning making decisions related to treatment and therapy processes than their peers. One finding highlights the importance of participation in all phases of health care and pain management, which must be seen as a human right. This right also applies to teenage girls with a disability like chronic arthritis.

The participants in this study were female teenagers. Adolescence is a period of overall development in physiological, psychological and social domains. The challenge of adolescence is to achieve the desired independency and autonomy, while at the same time maintaining close and supportive ties with the nuclear family. Unique stressors are associated with chronic disease as a function of these developmental domains (Stevens, Steele, Jutai, Kalnins, Botolussi & Biggar, 1996; Wolman, Resnick, Harris & Blum, 1994). Ungerer and colleagues (1988) have pointed out the social consequences of arthritis for teenagers, compared with younger children. The results of our earlier studies clarify that those children’s (6–17 years) interpersonal relations are negatively affected by pain associated with chronic arthritis (Sällfors et al., 2001, 2002). In addition to increasing developmental challenges, pain and illness create additional challenges related to coping for teenage girls with chronic arthritis.

In the Western society, the body is important, especially for teenagers. The ideal is to have a young, thin, strong, healthy and active body (James, 2000; Christensen, 2000; Backhett-Milburn, 2000). Media focuses strongly on appearance. Teenagers, who are big media consumers, can read about the perfect body every day. Your body shows who you are and signals your happiness and success or the opposite. Wendell (2007, p. 274) points out that the problem is the norm itself, which is being constructed by the society. The norm concerns having a young, strong and healthy body. “They cannot do things that the able-bodied feel they must do in order to be happy, normal and sane”. According to Bengs (2000), girls are more displeased with and control their bodies more strictly than boys. In
Sweden, teenagers’ health is becoming even worse every year, especially the health of teenage girls. Brun Sundblad (2006) has showed that more than every second girl of 18 living in Sweden had headache and back pain every day, owing to perceived stress related to different demands.

The participants in our study were developing their identities about being women. According to our results, it is a struggle for these teenage girls to develop a positive body identity, because their stiff bodies hurt and give rise to lots of fears and worries. How does life differ from the teenage ideals of an exciting life and an attractive, physically active body for a teenage girl in chronic pain? Studies have shown that women are most often judged based on their appearance, i.e. how they look like, therefore, women have an increased risk of being identified and judged based on their disabilities (Wendell, 1997; Taub, McLorg & Fanflik, 2004). According to our findings, the teenage girls need to master their painful bodies, using social support, taking one day at a time and fighting for health in their efforts to fit into the ideal norm of looking good and being physically active. It is a daily struggle. People who deviate from the ideal, who can be regarded as less attractive, are at increased risk of psychosocial distress owing to prevailing values in the contemporary society, with its stigmatizing and stereotyping attitudes. Disabilities caused by chronic arthritis, as in this study, can be viewed as a deviation from normality, which discredits the teenage girls, i.e. stigmatization.

Visibility is a crucial factor in relation to a stigma (Goffman, 1963). Pain and illness related to chronic arthritis is invisible, but the effects of reduced activity caused by the arthritis disease are visible. Appearance is important to teenagers, and plays a prominent role in their changing self-image (Rejeski et al., 1996). Reduced physical activity is yet another deviation from the teenage ideal. According to Goffman (1963), a stigmatised person contributes to his or her own marginalisation and degradation, as he/she also has integrated social norms and expectations. Goffman (1963) states that the stigmatised person tends to find others and share ideals and views, and to feel understood by them, for example in support groups. The sense of belonging to a group of people one can identify with and join in social activities is important, as described by the female adolescents in this study and elsewhere (Accock & Hulbert, 1990; Julien & Markman, 1991).

Self-esteem and identity are developed in interaction with others. Erikson (1963) describes a person’s development of an identity as a complex coordina-

Conclusions

Based on analysis of interviews and/or diaries of 18 female adolescents with chronic arthritis, a substantive theory was generated. The main concern for female adolescents with chronic arthritis was their efforts of fitting into the prevailing teenage culture by using strategies labelled mastering a body in pain, living one day at a time, using social support and fighting for health.
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References

Accock, A. C., & Hultberg, J. S. (1990). Social network analysis: A structural perspective for family studies. Journal of Social and Personal Relationships, 7, 245–264.

Backett-Milburn, K. (2000). Parents, children and the construction of healthy body in middle-class families. In A. Prout (Ed.), The body, childhood and society (pp. 79–100). Basingstoke, UK: Macmillan.

Baker, C., Wuerst, J., & Stern, P. (1992). Method slurring: the methodology of grounded theory. Mill Valley, Ca: Sociology Press.

Benestad, B., Vinje, O., Veierød, M. B., & Vandvik, I. H. (1996). Quantitative and qualitative assessments of pain in children with juvenile chronic arthritis based on the Norwegian version of the paediatric pain questionnaire. Scandinavian Journal of Rheumatology, 25, 293–299.

Bengs, C. (2000). Looking good: a study of gendered body ideals among young people. Doctoral dissertation. Department of Sociology, Umeå University, Umeå, Sweden.

Berntsson, L. (2000). Health and well-being of children in the five Nordic countries in 1984 and 1996. Doctoral dissertation. The Nordic School of Public Health, Göteborg, Sweden.

Brun Sundblad, G. (2006). Perceived health in Swedish school students: a longitudinal prevalence study. Doctoral dissertation. Karolinska Institute, Stockholm, Sweden.

Carter, B. (1998). Children and their experience of pain. In B. Carter (Ed.), Perspectives on pain: Mapping the territory (pp. 206–230). London: Arnold.

Cassidy, J. T., & Petty, R. E. (2002). Textbook of pediatric rheumatology. In: Juvenile Rheumatoid Arthritis (4th ed.) (pp. 214–361). New York: Churchill Livingstone Inc.

Christensen, P. H. (2000). Childhood and the cultural construction of vulnerable bodies. In A. Prout (Ed.), The body, childhood and society (pp. 38–59). Basingstoke, UK: Macmillan.

Erikson, E. H. (1963). Childhood and society (2nd ed.). New York: Norton.

Glaser, B. G. (1978). Theoretical sensitivity. Advances in the methodology of grounded theory. Mill Valley, Ca: Sociology Press.

Glaser, B. G. (2001). The grounded theory perspective: Conceptualization contrasted with description. Mill Vally, Ca: Sociology Press. Retrieved May 6, 2008, from http://www.groundedtheory.com/soc14html

Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory: Strategies for qualitative research. New York: Aldine Publishing.

Glaser, B. G. (1992). Basics of grounded theory analysis. Emergence vs. forcing. Mill Valley: Sociology Press.

Goffman, E. (1963/1972). Stigma. Den avvikandes roll och identitet (Stigma: notes on the management of spoiled identity). Raben & Sjögren, Stockholm, Orginal Prentice Hall, 1963.

Guell, C. (2007). Painful childhood: Children living with juvenile arthritis. Qualitative Health Research, 17(7), 884–892.

Hall, W. A., & Callery, P. (2001). Enhancing the rigor of grounded theory: incorporating reflexivity and relationality. Qualitative Health Research, 11(2), 257–272.

Hallberg, L. R.-M. (2006). The “core category” of grounded theory: making constant comparisons. International Journal of Qualitative Studies on Health and Well-being, 1(3), 141–148.

Hashkes, P. J., & Laxer, R. M. (2005). Medical treatment of juvenile idiopathic arthritis. JAMA, 294, 1671–1684.

Henderson, C. J., Lowell, D. J., Specker, B. L., & Campagne, B. N. (1995). Physical activity in children with juvenile rheumatoid arthritis: Quantification and evaluation. Arthritis Care Research, 8, 114–119.

HSFR (1990). Etikregler för humanistisk-samhällsvetenskaplig forskning, reviserad version 1999 (Ethical guidelines for research in the humanities and the social sciences, revised version 1999). Retrieved April 28, 2008, from www.hsf.se/huksam/index

James, A. (2000). Embodied being: Understanding the self and the body in childhood. In A Prout (Ed.), The body, childhood and society (pp. 19–37). Basingstoke, UK: Macmillan.

Julien, D., & Markman, H. J. (1991). Social support and social networks as determinants of individual and marital outcomes. Journal of Social and Personal Relationships, 8, 549–568.

Jylli, L. (2004). Acute pain in pediatric patients. Aspects of pain management and pain assessment. Doctoral dissertation. Karolinska Institute, Stockholm, Sweden.

Klepper, S. E., Barbee, J., Effgren, S. K., & Singsen, B. H. (1992). Physical fitness levels in children with polyarticular juvenile rheumatoid arthritis. Arthritis Care Research, 5, 93–100.

McGrath, P. J., & Finley, G. A. (1999). Chronic and recurrent pain in children and adolescents. In P. J. McGrath & G. A. Finley (Eds.), Chronic and recurrent pain in children and adolescents: Progress in pain research and management (pp. 1–4). Seattle: IASP Press.

Naess, S. (1987). Quality of life research, concepts, methods and applications. Oslo: Institute of Applied Social Research.

Rejeski, W. J., Brawley, L. R., & Schumaker, S. A. (1996). Physical activity and health—related quality of life. Exercise Sport Science Reviews, 24, 71–108.

Sällfors, C., Hallberg, L. R.-M., & Fasth, A. (2001). Coping with chronic pain. In-depth interviews with children suffering from juvenile chronic arthritis. Scandinavian Journal of Disability Research, 3, 3–20.

Sällfors, C., Hallberg, L. R.-M., & Fasth, A. (2002). Oscillating between hope and despair—a qualitative study. Child Care Health Dev, 28(6), 495–505.

Sällfors, C., Hallberg, L. R.-M., & Fasth, A. (2003). Gender and age differences in pain, coping and health status among children with chronic arthritis. Clinical Experimental Rheumatology, 21, 785–793.

Sällfors, C., Hallberg, L. R.-M., & Fasth, A. (2004). Well-being in children with juvenile chronic arthritis. Clinical Experimental Rheumatology, 22,125–130.

Schanberg, L. E., Lefebvre J. C., Keefe, F. J., Kredisch, D. W., & Gil, K. M. (1997). Pain coping and the pain experience in children with juvenile chronic arthritis. Pain, 73, 181–189.

Schanberg, L. E., Maurin E., Anthony, K. K., & Gil, K. M. (2001). Girls with polyarticular arthritis report more disease symptom than boys. Arthritis Rheumatologica, 44(Suppl. 9), 691.

Stern, P. N. (1980). Grounded theory methodology: its uses and processes. Image, 17, 20–23.
Stevens, S. E., Steele C. A., Jutai, J. W., Kalnins, I. V., Botolussi, J. A., & Biggar, W. D. (1996). Adolescents with physical disabilities: Some psychosocial aspects of health. *Journal of Adolescents Health, 19*, 157–64.

Taub, D. E., McLorg, P. A., & Fanflik, P. L. (2004). Stigma management strategies among women with physical disabilities: contrasting approaches of downplaying or claiming a disability status. *Deviant Behaviour, 25*(2), 169–190.

Ungerer, J. A., Chaitow, J., & Champion, G. D. (1988). Psychosocial functioning in children and young adults with juvenile arthritis. *Pediatrics, 81*, 185–202.

Vandvik, I. H., & Eckblad, G. (1990). Relationship between pain, disease severity and psychosocial function in patients with juvenile rheumatoid arthritis. *Scandinavian Rheumatology, 19*, 295–302.

Wendell, S. (1997). “Toward a feminist Theory of Disability”. In L. J. Davis (Ed.), *The Disability Studies Reader* (pp. 260–274). USA: Routledge.

Wolman, C., Resnick, M., Harris, L. & Blum, R. (1994). Emotional well-being among adolescents with and without chronic conditions. *Journal of Adolescents Health, 15*, 199–204.