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Pain, Coping and Health Care Utilization in Younger and Older Adults with Sickle Cell Disease

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Abstract

Sickle cell disease is characterized by acute pain crises. Pain, chronic medical problems, utilization and coping were compared in younger vs older patients using questionnaires and medical record review. Groups reported similar pain intensity and medical conditions. The pattern of utilization differed such that older patients attended outpatient clinic, and younger patients went to the Emergency Department. Younger patients were more likely to cope by ignoring pain, or by using heat, cold or massage. Older patients were more likely to pray and hope. We conclude that age plays an important role in the utilization and coping of sickle cell patients.

Keywords

- coping
- health care utilization
- pain
- sickle cell disease

SICKLE cell disease (SCD) refers to a group of inherited blood disorders that includes sickle cell anemia, SC hemoglobin disease and sickle beta thalassaemia. Over 250,000 children are born worldwide with SCD each year (Serjeant, 1997). SCD affects over 12,000 people in the UK (Howard & Davies, 2007) and over 50,000 in the USA (Sickle Cell Disease Guideline Panel, 1993). It can be a devastating disease, as it is associated with recurrent painful vaso-occlusive crises, serious medical complications, developmental delays, poor educational attainment and underemployment (see Barrett et al., 1988; Harris, Parker, & Barker, 1998). Powars, Chan, Hiti, Ramicone and Johnson (2005) reported median survival of female sickle cell patients at 36.3 years, and 38.7 years for males. An earlier and larger study by Platt et al. (1994) reported the median age of death at 48 years for females and 42 years for males. In either case, patients with sickle cell disease have a shortened lifespan compared to individuals who are disease free (see also data on a Jamaican sample in Wierenga, Hambleton, & Lewis, 2001).

In addition to physical complications, SCD patients have higher levels of psychological maladjustment compared to other illness groups, however, coping strategies predict psychological adjustment beyond demographic and illness severity variables (Midence & Elander, 1996). Further, passive and negative coping responses were associated with greater pain intensity, more frequent episodes and poorer psychological adjustment. Anie, Steptoe and Bevan (2002) found that greater use of affective coping (e.g. catastrophizing, anger and fear self-statements) was associated with poorer quality of life (QOL).

Health care utilization (HCU) is a variable of great importance in the SCD population because, in addition to pain, patients experience many associated medical problems, for example, acute chest syndrome, anemia, infections, stroke (Platt & Sacerdote, 2002). These complications range in severity across patients, but may lead to frequent emergency room visits and hospitalizations. While pain severity is a fairly consistent predictor of HCU across several studies (Anie et al., 2002; Gil et al., 2004; Porter, Gil, Carson, Anthony, & Ready, 2000; Porter et al., 1998), psychosocial factors such as stress and negative affect have also been found to play a role (Gil et al., 2004; Porter et al., 2000; Reese & Smith, 1997).

Coping strategies may be an additional variable that influences HCU, although results in this area are mixed. Gil, Abrams, Phillips and Keefe (1989) reported that negative thinking and passive adherence coping were associated with greater utilization. In contrast, others have reported that coping is not a significant predictor of health care utilization (Anie et al., 2002; McCrae & Lumley, 1998). Folkman, Lazarus, Pimley and Novacek (1987) have discussed age differences in coping with stressful events, and have reported differences between younger (30s and 40s) and older (late 60s) adults. Specifically, younger adults in their study used more active coping strategies (e.g. confrontational coping) while older adults used more passive (e.g. distancing) and interpersonal strategies. They discuss possible interpretations for these age differences in coping, and find most support for a developmental interpretation of the results, that is, that people grow in their coping as they mature throughout their lives. Coping with sickle cell disease is likely to be similar. That is, one might expect older adults to be more adaptive in their coping, as they have had a longer time to develop adaptive coping skills.

The research on sickle cell patients above was done with young adults, typically with an average age of 30 years (e.g. Anie et al., 2002; Gil et al., 1989). No reports have yet addressed adjustment to SCD across the lifespan, even though advances in medical management have extended the life expectancy of these patients. Further, no studies have examined adaptation to pain across the life span. Several studies have examined pain related variables in older populations (i.e. Barry et al., 2004; Reid, Guo, Towle, Kerns, & Concato, 2002b) and at least one study (Reid, Crone, Otis, & Kerns, 2002a) has compared younger and older patients on various pain-related variables, including coping. Reid et al. (2002a) compared younger (<65yrs) and older (65+) veterans with chronic pain, and reported little evidence that patients adapt to pain over their life span. Specifically, while younger and older patients reported a similar duration of pain (10 years), younger patients reported significantly greater pain intensity versus older patients. The groups reported similar use of pain medications. There are several factors that limit generalizability of the Reid et al. (2002a) study to the SCD population. SCD patients represent a unique pain patient as pain began at a very young age. In addition, most SCD patients who live into their 60s may be a select group that is different from other 60 year olds.

Thus far, the literature contains no information about changes in pain experience, coping or health care utilization that might occur as sickle cell patients now live longer lives than in the past. Most of the research in pain, coping and HCU included only young adults with an average age of 30 years (e.g. Anie et al., 2002; Gil et al., 1989). The purpose of this study was to examine group differences in pain, coping and health care utilization in younger and older adults with SCD.

Methods

Participants and procedures

Participants were recruited sequentially from adults attending outpatient clinic appointments in a large urban Comprehensive Sickle Cell Center. The study was described and informed consent and authorization for medical record review were obtained. One hundred thirty adult patients were approached, and 70 consented (54%).

Of the 70 participants, 48 were women and 22 were men. The average age was 34.9 years (range: 18–62). The sample was divided into ‘younger’ vs ‘older’ adults based on survival data presented by Powars et al. (2005). Specifically, Powars et al. reported median survival for sickle cell patients is 36–39 years (depending on gender). Our younger group was comprised of individuals aged 18–36 ($X = 26$ years; $N = 38$) and our older group was 37–62 years old ($X = 45$ years; $N = 32$). X^2 analyses yielded no significant age group differences in marital status or employment; most patients were single (80%), and many were unemployed or disabled (75.7%). The older group had more education overall ($X^2(5) = 13.43, p = .02$) (many in the younger group had not yet completed their education); 47 percent of the entire sample had attended some college. The type of sickle cell disease did not differ by group; overall 81 percent of the participants had sickle cell anemia (HbSS).

Measures

Sickle cell variables Participants completed questions about the number of pain crises, emergency room visits, hospital admissions and clinic visits in the past year. A summary of health care utilization (HCU) was derived by summing the number of reported clinic visits, emergency room visits and the number of hospital admissions (at our center and also outside hospitals) in the past year.

Participants were provided with a list of 13 typical complications associated with SCD (e.g. leg ulcers, kidney problems, stroke, joint pain) and were asked to indicate which of these they had experienced at any time. The total number of complications is used in the analyses below as an index of the extent to which individuals have had chronic, ongoing medical problems. Participants reported pain intensity on a typical day and also during a typical pain crisis, using a 10-point Likert scale (1 = not bad, 10 = very bad). Medical records were reviewed to confirm type of SCD, clinic and emergency room visits, admissions and complications.

Brief Symptom Inventory (BSI; Derogatis, 1993) The BSI is a 53-item measure of psychological distress. Items are rated on a five-point scale from 0 (not at all) to 4 (extremely). The measure has nine subscales (e.g. depression, anxiety, paranoid ideation) and three summary indices of distress. This measure has shown good reliability and validity, with internal consistency alpha coefficients ranging from 0.71 to 0.85 for the nine symptom subscales and test–retest reliability coefficients ranging from 0.68 to 0.91 (Derogatis & Melisaratos, 1983). Based on Derogatis and Melisaratos’ (1983) recommendation, the Global Severity Index (GSI) was used as an overall measure of psychological distress; it is the average of distress ratings on all symptoms (test–retest reliability coefficient was 0.90 for this scale). Higher scores indicate greater psychological distress.

Coping strategies questionnaire for SCD (CSQ-SCD; Gil et al., 1989) The CSQ-SCD is a modified version of the Coping Strategies Questionnaire developed by Rosenstiel and Keefe (1983). Gil et al. (1989) added items to assess coping strategies relevant to SCD (i.e. taking fluids, heat/cold, massage). The measure consists of 80 items; individuals rate the degree to which they use each strategy to cope with SCD pain on a scale of 0 (never do that) to 6 (always do that). The final two items ask for overall ratings of the patient’s perceived ability to control and decrease pain. The measure produces 13 subscales describing cognitive, behavioral and physiological coping strategies (i.e. Diverting attention, Reinterpreting pain sensations, Calming self-statements, Ignoring pain sensations, Increasing behavioral activities, Heat/cold/massage, Catastrophizing, Fear self-statements, Anger self-statements, Isolation, Taking fluids,

Praying and hoping, Resting). This measure has high internal consistency (subscale alpha coefficients 0.69–0.91) and is commonly used in research investigating coping in adults with SCD (e.g. Anie et al., 2002; Gil, Williams, Thompson, & Kinney, 1991).

The MOS Social Support Survey (Sherbourne & Stewart, 1991) The MOS Social Support Survey was developed as part of the Medical Outcomes Study. It consists of 19 items on which participants rate how often support is available when they need it on a 1 (none of the time) to 5 (all of the time) scale. Items assess tangible support, affectionate support, positive social interaction and emotional/ informational support, and are summed to yield an overall index of social support. Higher scores indicate more availability of social support. Previous research indicates the overall index is a valid measure of available support across all domains and shows reliability coefficients (Cronbach’s alpha) of all scales are greater than 0.91 (Sherbourne & Stewart, 1991). The total number of supports is determined from one item asking the number of close friends and relatives a person has. Both the overall social support score and the total number of supportive others were used.

Results

Participants

Mean scores on the major sickle cell variables (pain, utilization, complications) and also on the questionnaires for the younger and older adult groups are in Table 1. The number of pain crises, emergency room visits and inpatient admissions

varied considerably, with some participants reporting almost no problems with pain in the past year, and with others reporting a high frequency of pain and high use of medical services.

To evaluate potential age differences in pain, complications and health care utilization, *t*-tests were run comparing the younger and older age groups. Table 1 shows the results. It is notable here that the younger and older groups did not significantly differ on the number of pain crises, typical pain intensity or pain ratings during a pain crisis. Nor did they differ on the number of self-reported complications – or on their overall utilization. However, the *pattern* of health care utilization differed, such that younger patients had significantly more emergency room visits and hospital admissions, while older patients had significantly more outpatient clinic visits. There were no significant differences in psychological distress, or social support between the age groups (Table 1).

To assess differences in coping, a MANOVA was performed comparing the two age groups, with the number of pain crises and number of complications as covariates (to control for acute and chronic medical issues) with the 13 CSQ subscales as dependent measures. Results indicated a significant multivariate effect of age ($F(13, 47) = 2.34, p = .017$). Univariate analyses yielded significant effects for Ignoring pain sensations ($F(1, 60) = 5.44, p = .023$), Praying and hoping ($F(1, 60) = 3.82, p = .055$) and Heat/cold/massage ($F(1, 60) = 5.58, p = .021$). Specifically, the younger age group reported more Ignoring, greater use of Heat/cold/massage and less Praying and hoping than the older age group.

Table 1. Younger vs older adults, mean (standard deviation) pain and utilization scores

	Total	Younger	Older	<i>t</i>	<i>p</i>
Number of pain crises, past year	6.97 (9.21)	8.38 (11.32)	4.96 (4.35)	1.46	NS
ER visits for pain, past year	3.29 (4.57)	4.47 (5.54)	1.88 (2.50)	2.45	.02
Pain on typical day	4.81 (2.75)	4.76 (2.85)	4.87 (2.66)	.16	NS
Pain during pain crisis	8.90 (1.97)	9.03 (1.55)	8.74 (2.44)	.59	NS
Hospital admissions	1.49 (2.52)	3.97 (3.75)	1.43 (2.13)	3.27	.01
Clinic visits, past year	7.9 (8.99)	4.84 (4.04)	9.56 (12.16)	2.25	.03
Complications, ever	4.16 (2.23)	3.82 (1.94)	4.58 (2.50)	-1.43	NS
HCU summary score	13.07 (11.60)	13.29 (10.49)	12.81 (12.97)	.17	NS
Psych distress (BSI-GSI)	61.56 (10.44)	61.58 (12.15)	61.53 (8.15)	.02	NS
Social support total score	3.75 (0.93)	3.93 (0.80)	3.55 (1.04)	1.73	NS
Number social supports	9.42 (13.16)	8.81 (10.44)	10.15 (15.99)	-.41	NS

Discussion

Our sickle cell patients tended to be single, unemployed or disabled and about half had attended some college. Participants reported a significant pain crisis about seven times in the past year, with significant pain intensity. Associated with the painful episodes were visits to the emergency room, hospital admissions and a variety of additional medical problems.

While most research has focused exclusively on a young population, our study analyzed differences in pain variables and utilization between younger and older adults. Our younger group is comparable to sickle cell patients in earlier studies of pain, coping and utilization (e.g. Anie et al., 2002; Gil et al., 1989), and our older group represents patients who are close to or beyond the median life expectancy. It is interesting that the number of pain crises, pain ratings on a typical day and also during a crisis and the number of complications associated with sickle cell disease did not differ between the two groups. So while both acute and chronic markers of disease did not differ, the *pattern* of utilization of health care resources did. That is, younger patients were more likely to get treatment through emergency room visits and hospital admissions, while older individuals were more likely to attend the outpatient clinic. It is possible that there is a survival bias that accounts for the age differences obtained. It is also possible that the individual's approach to pain and chronic disease changes with age, or that these findings reflect a change in the health care culture that encourages young adults today to deal with their medical issues in the emergency room rather than the outpatient clinic. Clearly there are many societal and individual variables that influence health care utilization. As noted by Andersen and Newman (1973), age plays a role in health care utilization, as an older person likely has more illness and also different ideas and beliefs about health care that results in a pattern of utilization that differs from that of a younger person. Different utilization patterns were obtained in our study, and while the older and younger groups did not significantly differ on the sickle cell variables measured, the older group may have had a higher frequency of additional medical issues, unrelated to sickle cell. Further research would do well to examine these hypotheses and other contributors to differences in coping and health care utilization with age in adults with sickle cell disease.

There were no differences between the age groups in terms of psychological distress or social support, but there were differences in the frequency with which they utilized various coping strategies. The younger group was more likely to ignore pain, and to use heat, cold or massage to manage it. Older adults were more likely to cope using prayer and hoping. The two age groups did not differ on their use of coping strategies such as calming self-statements, catastrophizing, fear and anger statements or isolation. Specific coping mechanisms for sickle cell pain, such as taking fluids and resting, also did not differ between the two groups. Our results were somewhat consistent with those of Folkman et al. (1987) described earlier. That is, our older participants did use more passive coping than the younger participants. However, our groups did not differ in their use of active coping strategies. It should be noted also, that the coping measures in the two studies differed, as did the ages of the 'younger' and 'older' groups.

It was surprising that, even on days when participants were not reporting a 'pain crisis' they still reported a significant level of ongoing pain. These results add to a growing body of evidence indicating that pain is commonly experienced by sickle cell patients, and that the acute painful episodes (i.e. pain crises) occur in a context of chronic pain (see also Smith et al., 2008). The complexity associated with the acute on chronic pain likely accounts for some of the difficulty in managing the pain of sickle cell disease, as well as the emotional aspects of this disease experience.

This study is the first to report on pain, utilization and coping in SCD patients who have lived beyond their expected lifespan. Limitations include a convenience sample and a cross-sectional design. Further research should delineate additional changes in psychological factors as sickle cell patients age, to enable us to better serve this population as they outlive their predecessors.

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