Fatigue in Developmental Coordination Disorder: an exploration of the risk factors among adults

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Background: The reporting of fatigue in the clinical management of Developmental Coordination Disorder (DCD) is increasingly being acknowledged. This is particularly relevant for adults with the condition. However, until now, no research has explored the nature of the fatigue experienced by adults with this disorder.

Purpose: Based on our existing model of fatigue, this paper aims to examine fatigue in DCD within the context of a range of psychosocial measures such as mood and everyday functioning. Adults with DCD are compared to a group of adults with Chronic Fatigue Syndrome (CFS) – a condition characterised by excessive, prolonged fatigue – as well as a typically developing/ non-fatigued group.

Method: Fifty-three adults with DCD, 84 with CFS and 52 typically developing/ non-CFS adults completed all questionnaires. A range of established measures were administered to participants via an online data collection tool. This was similar to work carried out previously involving CFS patients in a longitudinal study.

Results: Findings demonstrate clear differences between the DCD and TD groups for all measures administered, including fatigue (p<0.001). When compared to the CFS group, the adults with DCD showed several similarities in their profile.

Conclusions: Of particular importance in the current study was the capture of data that corroborated anecdotal evidence of heightened levels of fatigue in adults

with DCD along with impairments relating to key indicators of well-being such as depression, anxiety, cognitive functioning, self-esteem and sleep. In addition, the comparison between DCD and the existing model of fatigue in CFS provided overlaps which might indicate commonalities in the psychophysiological mechanism underlying both conditions.

Introduction

A great deal of research focuses on developmental disorders in children and adolescents, yet these conditions may not disappear with age. Our understanding of how these conditions impact on the lives of adults and older adults is unclear. This paper focuses on one particular developmental disorder, Developmental Coordination Disorder (DCD), and examines the role of fatigue in the development and maintenance of this condition in adults. Clinicians have reported anecdotal evidence to indicate that fatigue in DCD is a real issue. However, this is the first paper to examine this in an adult sample. There is a substantial literature on the role of fatigue in a number of conditions, including chronic fatigue syndrome (CFS), and it is clear that acknowledgement of fatigue, if present, is vital to the clinical management of these conditions.

DCD is a neurodevelopmental disorder which is diagnosed, for the most part, on the basis of poor motor coordination. The current edition of the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM-5)[1] describes the motor difficulties in DCD as significant when considering the individual's age and level of pre-existing skill. Indeed, the impairment experienced is at a level which impacts on daily activities and academic achievement and is evident in early development.

Prevalence of DCD

Although initially considered to be a childhood disorder, there is increasing evidence that the difficulties associated with DCD (sometimes referred to as *dyspraxia*) continue into adulthood. In children, prevalence rates vary around the world. For example, a population-based study of seven-year-olds in the UK reported prevalence

rates ranging from 1.8 and 4.9%[2], whereas a similar Swedish study reported higher prevalence ranging from 4.9 to 8.6%[3]. The discrepancy has been attributed to both the stringency of the criteria used to describe the sample and the assessment tools and their clinical cut-offs chosen for the measurement of impairment. To add further confusion to measuring the prevalence of DCD, it is commonly acknowledged that overlap between the developmental disorders frequently occurs[4].

When considering the transition into adulthood, again taking the caveats mentioned above into consideration, prevalence rates vary from 30—87%[5-9]. However, despite the increasing evidence suggesting that DCD continues beyond childhood, diagnostic pathways and service provision for adults seeking a diagnosis of DCD are inconsistent across the UK.

Defining DCD in adulthood remains a challenge. Factors such as past intervention, strategies employed by the individual to avoid tasks which cause them difficulty, and the presence of co-occurring conditions should be taken into consideration. As a consequence, research in this field has tended to present this group in a number of ways. Some studies describe adults with motor difficulties as opposed to specifically DCD as a diagnosis of DCD had not been made in childhood[4]; others included those who self-reported they had DCD or a motor coordination difficulty (no formal diagnosis)[10]. These studies did, however, use recognised screening tools as part of the inclusion criteria process such as the Adult DCD Check-list[11] and the Adolescents and Adults Coordination Questionnaire[12].

Fatigue in DCD and chronic fatigue syndrome

Although not viewed as a typical symptom in the classification of DCD, anecdotal evidence exists of individuals with DCD reporting high levels of fatigue when

presenting to General Practitioners (GP) and other healthcare professionals. This is true for both children and adults. Apart from clinical practice, there has been a wealth of research conducted into the fatigue experienced in childhood DCD. This has been attributed to a number of causes such as inefficient patterns of movement leading to higher energy expenditure[13]. However, DCD in adults has not been formally studied, as far as we are aware. This initial study will provide preliminary data on fatigue in adult DCD.

Apart from fatigue as intrinsic to DCD, the fatigue could also be linked to the high rates of comorbid depression and anxiety reported[4, 14]. Furthermore, anxiety and depressive disorders are associated with somatic cardiopulmonary symptoms, musculoskeletal symptoms, and gastrointestinal symptoms[15]. Consequently, when measuring fatigue in those with DCD, one approach is to also assess levels of these associated symptoms. Understanding the nature of the fatigue experienced by individuals with DCD will have valuable implications, both for clinicians managing the condition, and for those with the diagnosis.

An area of fatigue that has been extensively researched is the illness of Chronic Fatigue Syndrome (CFS). CFS is characterized by excessive fatigue (plus several secondary symptoms) lasting at least six months which is unresolved by rest or sleep.[16] The illness has no known aetiology or distinctive biological diagnostic markers. The condition has a higher prevalence in middle-aged women and those who are diagnosed with it experience measurable cognitive impairment[17] and high levels of somatic symptoms, anxiety, and depression[18]. Together with decreased personal, occupational, and social activities which impact negatively on their quality of life, individuals with CFS are more likely to be unemployed than their peers[19].

When comparing CFS and DCD, one can see distinct similarities in terms of how problems manifest. Both are heterogeneous in nature and associated with a comparable pattern of symptomatology, including fatigue, somatic symptoms, as well as impairments in both cognition and mood[4, 17]. In both conditions adults report difficulties gaining and maintaining employment[17, 20]. Furthermore, there has been an increase in the number of cases presenting at specialised clinics where individuals have received a dual diagnosis of DCD and CFS. Given the detrimental impact of fatigue on one's quality of life, it is important to understand the extent and nature of fatigue in this group.

Based on the absence of research exploring the fatigue reported by adults with DCD, the present study adopted a model used previously to investigate the impairments associated with CFS[17, 18, 21]. This work was conducted in response to recommendations made by the UK CFS consensus meeting which aimed to seek agreement amongst research workers for the conduct and reporting of future studies of patients with chronic fatigue[22]. The CFS model was chosen as the syndrome which, much like DCD, does not have an established aetiology or known mechanism for the fatigue experienced.

We aimed to compare the level of fatigue and associated symptoms experienced by adults with DCD with that of a group of adults with CFS and a typically developing (TD)/non-CFS group using established self-report measures outlined below. It was hypothesised that the DCD group would report both greater levels of fatigue and psychosocial impairments than the TD/non-CFS adults. It has not yet been determined whether the impairments in DCD are similar to those reported in CFS, although, as already stated, DCD/CFS dual diagnoses are occurring. It is not the remit of this preliminary study to assert any direct link between the two conditions, rather the aim

here is to quantify the level of fatigue and impairment experienced in adults with DCD using measures previously used in CFS research.

Methods

Design

A cross-sectional group comparison between the DCD, CFS and TD/non-CFS was used.

Participants

Adults with DCD were recruited via advertisement on the Dyspraxia Foundation's webpages and via email to international organisations and support groups. The CFS participants were recruited via advertisement on the Action for ME webpages and via email to international support groups. The TD/ non-CFS group was invited to participate in the research via an advertisement on an institutional staff website and by referral from individuals with DCD participating in the study.

Cases were excluded if: 1) there was no evidence of a diagnosis of DCD or CFS by a relevant healthcare professional / Centre of Excellence / NHS service and 2) participants did not complete the full questionnaire set.

A total of 189 adults completed the online questionnaire – 53 had a self-report diagnosis of DCD, 84 had a diagnosis of CFS, and 52 were TD/non-CFS (referred to hereafter as the TD group). Table 1 describes the age and gender data for the three groups. When exploring these data, 14 adults with DCD reported also having a diagnosis of CFS. Due to the small number with both diagnoses, these data were not included in the final analysis.

Insert Table 1 about here

Materials and apparatus

Online questionnaires required participants to first state their diagnostic status (i.e. DCD, CFS, TD). To do this, participants were asked: 1) if they had a diagnosis of DCD or CFS, 2) who made the diagnosis and 3) when was the diagnosis made. Demographic information including age and gender was also collected. This was followed by a number of established measures used previously to assess levels of fatigue and psychosocial impairments.

Profile of Fatigue Related Symptoms (PFRS)[23]

The PFRS is a 54-item self-report measure designed specifically to assess fatigue and related symptoms in those with Chronic Fatigue Syndrome. Each item consists of a statement (e.g. *feeling physically tired even when taking things easy*) along with a seven-point Likert scale on which the participant rates the extent to which they have experienced the symptom during the past week from 1 (not at all) to 7 (extremely). The PFRS consists of four subscales: emotional distress, fatigue, cognitive difficulty, and somatic symptoms. Each subscale demonstrated high internal reliability, with alpha coefficients ranging from 0.88 to 0.96. Higher scores indicate greater levels of emotional distress, fatigue, cognitive difficulties or somatic symptoms.

State-Trait Anxiety Inventory (STAI-T)[24]

The State-Trait Anxiety Inventory is a widely used 40-item measure of trait and state anxiety. The trait scale (STAI-T) consists of 20 statements relating to the persons

general propensity to experience anxiety (e.g. *I lack self-confidence*). Participants report the degree to which they feel each statement describes them on a four-point Likert scale from 0 (not at all) to 4 (very much so). The STAI-T has been found to have a high test-retest reliability (0.73-0.86) and concurrent validity with other measures of anxiety (0.73-0.85). Higher scores indicate greater levels of anxiety.

Centre for Epidemiological Studies Depression Scale (CES-D scale)[25]

The CES-D scale is a brief self-report scale which measures symptoms of depression in the general population. The measure contains 20 items, each asking subjects to report on the frequency of their symptoms (e.g. *I had crying spells*) during the past week along a scale from 0 (rarely or none of the time) to 4 (most or all of the time). A higher score (*>15*) is indicative of greater morbidity. High internal consistency (coefficient alpha) with both clinical (0.90) and general populations (0.85) and a moderate test-retest correlation (0.45 -0.70) of the measure has been found. Higher scores indicate greater levels of depression.

Positive and negative affect[26]

This 30-item scale produces measures for both positive and negative affect. Participants are asked to rate how they have felt in the past week (e.g. *how attentive have you felt this week* or *how distressed have you felt this week*) on a scale from 0 (not at all) to 4 (extremely). The alpha reliabilities for Positive Affect are from between 0.83 to 0.90 and for Negative Affect are from 0.85 to 0.90[27]. High scores on the Positive Affect sub-scale indicate greater positive mood, whereas high scores on the Negative Affect sub-scale indicate a more negative mood.

Perceived Stress Scale (PSS)[28]

The PSS is a self-report measure designed to assess the extent to which a person views situations in their life as stressful, uncontrollable, or overloading. The measure asks participants to rate along a four-point scale from 0 (never) to 4 (very often) how often they have felt or thought a certain way during the past month (e.g. *how often have you been upset because of something that happened unexpectedly*?). PSS scores have been found to correlate with biological indicators of stress, such as cortisol[29, 30], suggesting the PSS is a valid measure of stress. Higher scores indicate greater levels of perceived stress.

Cognitive Failures Questionnaire (CFQ)[31]

The CFQ is a self-report measure designed to assess failures in perception, memory, and motor function. The 25-item measure asks participants to rate how often certain things happened over the past six months (e.g. *do you bump into people?*). Participants can rate each event from 0 (never) to 4 (very often). The test-retest correlation for this measure has been calculated between 0.80 and 0.82. Higher scores are indicative of greater cognitive failures.

Self-Esteem[32]

This self-report measure was designed to assess factors of social confidence, ability, and self-regard. Fourteen items (or situations) were posed to the participants (e.g., *I often dislike myself*) who were asked rate their response along a six-point scale from 1 (agree very much) to 6 (disagree very much). The test-retest correlation for this measure has been reported as 0.83. Higher scores indicate greater levels of self-esteem.

Symptoms checklist and sleep behaviour measure[21]

A symptoms checklist and sleep behaviours measure used in previous research[19] was also included in the questionnaire. The symptoms checklist presented participants

with 28 physical (e.g. *legs feeling heavy*) and psychological ailments (e.g. *anxiety/panic feelings*) from which they could select symptoms they were currently experiencing. A brief four-item measure of sleep behaviour was also included. The first item asked participants how many hours (on average) per night they sleep. The remaining three items required participants to respond to questions regarding the quality of their sleep (e.g. *how often do you feel rested from your night's sleep*?) using a four-point Likert scale from 0 (never) to 4 (very often).

Procedure

The questionnaires described above were transcribed into the Survey Monkey™ online data collection tool and checked by an independent researcher for accuracy. An information sheet advising individuals about the purpose of the study and the requirements of participation and a consent form were included at the beginning of the questionnaire batch. Access to the questionnaire was only allowed once participants had provided consent. If consent was not given, the data collection tool prevented further participation. The study was approved by the local Research Ethics Committee.

Data analysis

Data from the questionnaires were downloaded directly into the Statistical Package for Social Sciences (SPSS) Version 22. Chi-squared cross-tabulations were used to compare the demographic nature of the three groups and multivariate analysis of variance was used to compare group data across the questionnaires used.

Results

There was no significant difference between the DCD and TD groups in terms of gender or age. However, the CFS group was significantly more likely to be female

(x=19.109, df=2, p<0.001) and were older than both the DCD and TD groups (F=8.162, df=2, 161, p<0.001).

The DCD data revealed that 19 participants had received a diagnosis in childhood and 34 had received a diagnosis in adulthood. Comparisons between those who were diagnosed in childhood versus those diagnosed in adulthood uncovered no significant differences across individual measures used. For the purpose of the current study the two diagnostics group were, therefore, considered as a whole for the analysis.

There was an overall group effect for each of the measures used. When compared to the CFS and TD groups, adults with DCD reported significantly higher levels of cognitive difficulties (p<0.001), fatigue (p<0.001), emotional distress (p<0.001), and somatic symptoms (p<0.01). The DCD group also showed higher levels of anxiety (p<0.001), depression (p<0.001), stress (p<0.001), cognitive failures (p<0.001), total symptoms (p<0.001), and negative affect (p<0.001). In addition, the DCD group presented with lower levels of self-esteem (p<0.001) and positive affect (p<0.05) than the CFS and TD groups.

When comparing the DCD and CFS groups, a slightly different picture emerged. Adults with DCD report significantly lower levels of cognitive difficulties (p<0.05), fatigue (p<0.001), somatic symptoms (p<0.001), and total symptoms (p<0.001) than the CFS group. However, there was no significant difference between the DCD and CFS groups in terms of levels of anxiety, depression, stress, emotional distress, cognitive failures, negative and positive affect, or indeed self-esteem.

Insert Table 2 about here

On examining measures of sleep behaviour in the three groups, there was no difference between them in terms of the average number of hours slept. However, when the quality of sleep was considered, the CFS group was significantly less likely to feel rested by sleep than both the DCD and TD groups, and were significantly more likely to have difficulty falling asleep and waking early than the TD group. The DCD adults were also significantly less likely to feel rested by sleep than the TD group. There was no difference between the DCD and TD group in terms of difficulty falling asleep or waking early.

Insert Table 3 about here

Discussion-need more subheadings

Fatigue is a difficult symptom to accurately assess and quantify. This is especially true in cases where the cause of the fatigue and mechanisms which perpetuate it, are unknown. In order to address this, we adopted an established model of fatigue and associated symptoms used in previous CFS research[17, 18, 21]. In this study, which appears to be the first of its type in the developmental literature, data collected from a DCD group were compared to both a group of adults with CFS as well as to a TD/non-CFS group in a cross-sectional study.

The CFS group recruited to the current study reported a significantly greater impairment for each measure than the TD, with performance being comparable to those recruited to previous studies. This also acted to replicated findings by Thomas and Smith[17]. In addition, the TD group data used here were comparable to that reported in the same previously published CFS study[17]. Given this, it was possible to more confidently assess fatigue and functioning of the DCD group in relation to both TD and CFS data. Previous studies had ruled out gender and age among other things as confounding factors in the outcome measures[17].

It was clear the CFS group recruited here was comparable in profile to previous samples, showing similar levels of impairment[17]. However, the important finding in this study was the presence of marked fatigue in adults diagnosed with DCD when compared to a typically-developing group. This finding gives credence to clinical observations that have been hitherto unexplored in the research literature. The impact of the experienced fatigue is widespread, affecting a number of key indicators of well-being, such as mood, cognitive function, self-esteem, and sleep.

It was interesting to note that the DCD group produced a pattern of impairment that was comparable to the CFS group yet also distinct. Levels of anxiety, depression, and negative and positive affect were very similar, as were overall levels of stress and emotional distress. Indeed, our findings of significantly increased self-reported anxiety and depression in adults with DCD - when compared to TD controls - are in keeping with those by Kirby et al[4]. This is indicative of issues with emotion regulation. Fluctuations in mood and perceived distress have a detrimental effect on everyday function which may contribute to day-to-day cognitive deficits[33] as well as fatigue and tiredness[34]. These issues are explored further in Thomas and Christopher[35].

Self-esteem was also significantly lower in the DCD and CFS groups compared to the TD group. Previous research has shown low self-esteem in children with DCD[36], so this finding appears to be replicated in our adult group. Low self-esteem is linked to anxiety and depression. A meta-analysis of longitudinal studies[37] found that low self-esteem both contributes to and is caused by anxiety. In the case of depression, low self-esteem appears to feed the cycle of depression rather than be caused by depression.

In addition, the level of overall self-report cognitive difficulties across a range of everyday activities was comparable in the two clinical groups.   Such difficulties may reflect the mental fatigue associated with these conditions. As explored later, physical fatigue and tiredness through a lack of feeling rested may also contribute to the cognitive problems experienced. Although cognitive difficulties, fatigue, and symptoms (somatic and total) are lower in DCD as compared to CFS, these symptoms are higher in DCD when compared to the TD and should be considered for intervention.[37]

Sleep plays a vital role in resolving fatigue and, as such, is a major consideration when diagnosing such conditions. Findings from the current study suggest that, although those with DCD are sleeping about the same number of hours per night as the TD group (6-7 hours), and are not having problems falling asleep or waking early, they are in fact not feeling rested by sleep. Such subjective feelings are likely to contribute to the daytime fatigue experienced by this group. In addition, poor sleep contributes to poor concentration, and physical and emotional fatigue. It also acts to lower mood[38]. Lowered mood and poor physical health may further degrade sleep quality[39].

In terms of the participants, the demographics of each group were consistent with expectations. The DCD sample was matched appropriately to the TD group such that there were no significant differences in either age or gender. Although DCD is thought to be more predominant in males, a previous online study recruited participants with a similar profile to the groups described here[4]. The CFS sample was directly comparable to those recruited to previous studies such that it consisted predominantly of females in their forties[17].

There are clear practical advantages to better understanding the fatigue experienced by individuals with DCD both in terms of their quality of life and with regard to clinical management. Prolonged fatigue is likely to have a detrimental impact on an individual's willingness to engage in, as well as ability to sustain, both physical and mental activities. The focus of research on DCD to date has been on children. However, this study offers a number of findings pertinent to adults.

Several theories for the fatigue experienced by children with DCD have been postulated, such as higher energy expended due to poor movement control[13, 15]. One area of clinical relevance to be negatively affected by fatigue is physical exercise and

physical health, both of which are major risk factors for poor health as we age[39].

Physical exercise is of primary importance in either improving or sustaining overall

health and life expectancy in adults[40]. Obesity and cardiorespiratory fitness are vital for

this, especially when one considers metabolism slows with age, as does the general

level of exercise[39]. Barriers experienced as children continue to plague the adult. It is

important then to raise awareness that fatigue is a fundamental element of DCD, and in

doing so, help facilitate the performance of key physical activities. Consequently,

investigating the fatigue experienced by those with DCD will advance our

understanding of how to re-engage them in important daily activities, thereby improving

long-term health outcomes.

Limitations

The current study was a preliminary investigation into whether it would be

possible to in some way quantify the fatigue being reported anecdotally to clinicians by

adults with DCD. Information around medical history, heath status and medication /

intervention history were not collected. Also, survey data collection is limited by self-

selecting sample bias and inability to definitively ascertain diagnosis and medical status.

Having said that, data from both the CFS and TD group matched data collected from

previous studies. This adds some confidence in reporting the findings indicating a

significant problem of fatigue in adults with DCD. Future studies would also add an

objective element by including measures of performance to further explore the

behavioural impact of fatigue experienced in this population.

Conclusions

Fatigue is an increasingly reported problem in primary care, one that is

associated with other chronic conditions as a secondary chronic symptom[36]. However,

there is currently no generalisable intervention to alleviate fatigue across a range of conditions. Future research will focus on the using objective and subjective measures[17] to monitor interventions for fatigue[19] associated with a range of conditions in the primary care setting.

The current study is the first of its kind to quantify the level of fatigue experienced by adults with DCD. The comparability of symptoms with CFS may perhaps indicate a common psychophysiological mechanism underlying both conditions. The level of significance of our findings warrants further investigation when one considers the potential impact in terms of clinical management and intervention. The socio-economic implications of fatigue, mood, and psychosocial impairments in conditions such as CFS have been well documented[17, 21, 41]. There is now some evidence to indicate that these factors may be exerting similar effects in adults with DCD, which perhaps may impact the ability to be employed.   The challenge for future studies will be to unravel some of the inter-relationships reported above and establish the mechanisms at play in DCD that result in fatigue.

Disclosure

There is no conflict of interest.

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Table 1:   Gender and age data for the three adult groups

	DCD (n=53)	CFS (n=84)	TD (n=52)
Male (%)	23 (43)	9 (11)	14 (27)
Female (%)	30 (57)	75 (89)	38 (73)
Mean age: years months (s.d.)	35 yrs 11 mths (12yrs 1 mth)	43 yrs 5 mths (14yrs 11 mths)	33 yrs 6 mths (10 yrs 5 mths)

Table 2: Measures of fatigue and related symptoms for the DCD, CFS, and TD groups (scores are the means with s.e.m. in parenthesis)

	DCD	CFS	TD	Group effect (df = 2, 161)
PFRS:				
Cognitive difficulties	45.20 (2.33)	51.48 (1.79)	24.13 (2.31)	$F=44.903$, $p<0.001$
Fatigue	49.32 (2.56)	70.36 (1.96)	28.47 (2.53)	$F=87.108$, $p<0.001$
Emotional distress	59.43 (3.71)	57.96 (2.84)	37.16 (3.67)	$F=12.339$, $p<0.001$
Somatic symptoms	44.27 (3.01)	64.37 (2.30)	30.38 (2.97)	$F=43.060$, $p<0.001$
Anxiety	55.20 (1.90)	54.49 (1.45)	40.71 (1.87)	$F=20.398$, $p<0.001$
Depression	48.52 (2.12)	48.73 (1.62)	35.31 (2.09)	$F=14.766$, $p<0.001$
Positive affect	25.95 (1.89)	23.99 (1.45)	32.27 (1.87)	$F=6.262$, $p<0.01$
Negative affect	29.39 (2.06)	28.75 (1.58)	16.22 (2.04)	$F=14.231$, $p<0.001$
Perceived stress	33.95 (1.59)	32.55 (1.22)	24.29 (1.57)	$F=11.572$, $p<0.001$
Cognitive failures	64.98 (2.75)	59.37 (2.11)	42.38 (2.72)	$F=19.118$, $p<0.001$
Self-esteem	40.04 (2.71)	45.81 (2.08)	56.91 (2.68)	$F=10.263$, $p<0.001$
Symptom check-list - total	9.23 (0.79)	16.49 (0.06)	2.93 (0.78)	$F=96.511$, $p<0.001$

Table 3: Measures of sleep behaviour ('Fairly often' and 'Very often')

	DCD Frequency (%)	CFS Frequency (%)	TD Frequency (%)	Sig df=2
Rested from sleep	11 (20.8)	4 (4.8)	26 (50.0)	χ=38.731, p<0.001
Difficulty falling asleep	23 (43.4)	45 (53.6)	15 (28.8)	χ=7.980, p<0.05
Waking up early	22 (41.5)	41 (48.8)	14 (26.9)	χ=6.391, p<0.05