Health-related quality of life, illness perception, coping strategies and the distribution of dependency in autoinflammatory diseases

Sirs,

Systemic autoinflammatory disorders (SAID) are a recently-defined group of rare rheumatic diseases characterised by recurring episodes of inflammation of specific tissues, in particular joints, skin and eyes, and often manifested by fever (1). Given the recent conceptualisation and the rarity of these diseases, studies into SAID are still ongoing. Little attention has been paid to the psychological and social dimensions of SAID. The aim of the present study was to evaluate the health-related quality of life (HRQOL) and the levels of anxiety and depression in SAID, and to investigate if illness perception, coping strategies and the distribution of dependency, impact on the way the patients under consideration evaluate their health and psychological well-being.

The participants were 31 patients (21 females and 10 males) aged between 19 and 59 years (mean±standard deviation = 38.4±12.1), diagnosed with SAID from the age of 1–9 years (mean ± standard deviation = 3.11±1.87), in care at a clinic specialising in autoinflammatory diseases at a public hospital in Northern Italy. The participants were asked to complete the SF-36 Health survey (2), the State-Trait Anxiety Inventory (3), the Beck Depression Inventory-II (4), the New Italian version of the Coping Orientation for Problem Experiences (5), the Illness Perception Questionnaire – Revised (6), and the Dependency Grids (7). The study protocol was approved by the ethics committee of the School of Psychology at the University of Padova, and a written informed consent form was signed by all participants.

Correlations and multiple regression analysis were carried out, and the results showed that patients with SAID have a lower HRQOL than the general population, in particular in the physical dimension. They tend to evaluate their health as being particularly reduced, and frequently feel tired and exhausted. Unexpectedly, levels of anxiety and depression in the study sample are comparable to the ones with regard to the general population, with the exception of women who had higher levels of depression. SAID patients tended to perceive their illness as mainly caused by medical factors (genetic mutations and alterations in their immune system) but also by stress. The dependency percentage concentrating on self was higher than the dependency concentrated on anybody else, thus suggesting that these patients tend to rely mainly on themselves.

As shown in Table I, the use of avoidance strategies was positively correlated to levels of anxiety and depression. Impaired HRQOL was associated with a strong illness identity, beliefs in the serious consequences of the autoinflammatory disorder, and a perception of poor control over the disease and its treatment. Better mental HRQOL and less anxiety and depression were associated with a greater sense of personal control with regard to the illness, and a greater number of resources in whom patients could confide for help. In the regression analysis, illness coherence and the amount of resources used in the dependency grid were significant predictors of mental HRQOL (R^2=0.507, β=0.425, p=0.005 and β=0.464, p=0.002 respectively), highlighting that making sense of the illness and the possibility of relying on a large support network plays an important role in the adjustment to chronic diseases such as SAID (8-10).

To conclude, SAID has an impact on HRQOL, and the way in which these patients evaluate their health and psychological well-being is linked to psychological factors such as illness beliefs, coping strategies and the distribution of dependency. All these aspects should be taken into account in the long-term treatment of patients with SAID. In particular, this study showed how promoting a better understanding of the illness, and the possibility of relying on a good social network, could help these patients to adapt to the chronic illness and improve their quality of life.

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Table I. Correlations between IPQ-R subscales and SF-36, STAI-Y2 and BDI-II components.

	Physical QOL	Physical functioning	Physical Role Limitations	Pain	General health	Mental QOL	Vitality	Emotional role Limitations	Social functioning	Mental health	Anxiety	Depression
COPE												
Social support	-0.395*	-0.510**	-0.364*	-0.400*	-0.132	-0.078	-0.252	-0.227	-0.238	-0.076	-0.052	0.048
Avoidance strategies	-0.004	0.056	-0.256	-0.228	-0.115	-0.342	-0.193	-0.370*	-0.351	-0.254	0.364*	0.467**
Positive attitude	-0.105	-0.181	-0.063	-0.175	0.090	0.184	0.010	-0.122	0.115	0.332	- 0.399*	-0.288
Problem solving	-0.078	-0.053	0.022	-0.069	-0.084	0.062	-0.169	0.219	-0.002	-0.015	-0.101	-0.206
Transcendent orientation	-0.234	-0.356*	-0.019	-0.187	-0.037	0.169	0.052	0.118	0.003	0.049	-0.024	-0.032
IPQ-R												
Identity	-0.335	-0.394*	-0.092	-0.353	-0.459**	-0.078	-0.272	-0.027	-0.288	-0.085	0.071	0.081
Acute/chronic	-0.340	-0.225	-0.161	-0.109	-0.382*	0.024	-0.337	0.275	-0.181	-0.167	0.031	0.018
Consequences	-0.322	-0.457**	-0.280	-0.307	-0.413*	-0.291	-0.451*	-0.225	-0.625**	-0.243	0.237	0.054
Personal control	-0.097	-0.128	0.020	-0.039	0.345	0.554**	0.511**	0.289	0.339	0.542**	-0.438*	-0.425*
Treatment control	0.165	0.188	0.285	0.177	0.437*	0.516**	0.544**	0.270	0.618**	0.511**	-0.626**	-0.206
Illness coherence	0.011	0.129	0.135	-0.068	0.367*	0.528**	0.535**	0.382*	0.553**	0.378*	-0.393*	-0.321
Emotional representations	-0.085	-0.219	-0.132	-0.060	-0.336	-0.440*	-0.404*	-0.375*	-0.505**	-0.375*	0.286	0.129
DEPENDENCY GRIDS												
Resources indicated	-0.136	-0.183	0.180	-0.129	0.182	0.540**	0.317	0.454*	0.354	0.394*	-0.346	-0.372*
Resources used in the grid	-0.091	-0.120	0.128	-0.052	0.208	0.549**	0.368*	0.444*	0.347	0.432*	-0.423*	-0.402*
Dependency on self	0.102	0.041	-0.006	-0.003	-0.211	-0.440*	-0.331	-0.434*	-0.369*	-0.215	0.271	0.322
Dependency on a significant other	-0.055	-0.025	-0.114	0.043	-0.075	-0.262	-0.193	-0.249	-0.013	-0.306	0.113	0.110
Uncertainty index by column	-.161	-0.120	-0.111	-0.139	-0.013	0.319	0.174	0.239	0.049	0.210	-0.208	-0.255

Significance *p<0.05. **p<0.01

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