(1.5%). For 57 patients (3.0%) without caregiver a health professional was identified. An interview was conducted with 1289 (67.8%) of the 1900 identified caregivers at an average of 234 days after the patients' death (range 103–374). Six patients whose cause of death was not cancer and 12 without a terminal phase of disease were excluded from all the statistical analysis, leaving a total sample of 1271 valid interviews. Based on the ISDOC study several end-of-life care issues were discussed in different papers: e.g. on actual and preferred place of death, on diagnosis and prognosis disclosure, on the impact of terminal disease on family and caregiver; on the multidimensional problems experienced by patients and families; and on the unequal distribution of Palliative Care Services across the country.

Conclusions

Overall, the results of this survey can be interpreted as representative of the experience of the population of cancer patients during their terminal phase of disease.

H.5. Workshop: Supporting self management of the chronically ill

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Since medical treatment and adaptation to chronic illness is mostly taking place at the patient's home, self-management can be considered the most important part of chronic care. Self-management comprises a variety of tasks such as managing physical symptoms and treatment, life style changes, adapting life goals and roles and dealing with the emotional and social consequences of the disease. Given the multiplicity of self-management tasks that make high demands upon the patient, it is not surprising that many chronically ill have difficulty performing successful self-management. This is why appropriate self-management support—by healthcare professionals as well as family members—is so important.

During the past decades, a large amount of self-management support programmes have been developed, most of them targeting the person with the chronic condition and choosing a disease-specific approach. Little attention has been paid to more generic aspects of self-management in chronic illness and the role of family members. In this workshop, we will address some important challenges in improving self-management of the chronically ill:

- which personal beliefs and competences contribute to successful self-management?
- how can family members be involved in self-management activities?
- what is needed to implement self-management support in chronic care?

Self-management in rheumatoid arthritis: the role of social support in adjustment to disease

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Background

In chronic diseases, patient and his family are the principal caregivers; therefore, patient's self-management is considered to be an essential part of chronic care. Adaptive tasks in chronic disease often require help from others. Social support from family members and friends may positively affect the adaptive process to a chronic disease through physiological, emotional and cognitive pathways. The aim of this study was to explore whether social support has a beneficial effect on overall adjustment to rheumatoid arthritis (RA) when controlling for relevant clinical and psychological variables.

Methods

The data were collected annually via a structured interview over a 4-year period in the European Research on Incapacitating Diseases and Social Support (EURIDISS). The sample consisted of 124 patients with recently diagnosed RA (85.5% women; mean age 48.1 years; mean disease duration 21.9 months). Pain (NHP), functional disability (GARS), depression (GHQ-28) and social support (SSQT/SSQS) were the independent variables. In the analysis, the mean score from the first three measurement points was used for these independent variables. Adjustment to disease, as the dependent variable, was measured by the general adjustment to RA (GARA) at the fourth measurement. Data were analysed using multiple linear regressions.

Results

Significant correlations were found between all independent variables and adjustment to disease. The total explained variance of adjustment to disease in the regression model was 41%. Pain explained 27%, functional disability another 7% (both $P < 0.001$), depression 4% and social support transactions additional 4% (both $P < 0.05$). Satisfaction with social support failed to explain any variance in this model.

Conclusions

Social support transactions were positively related to the adjustment to disease even after controlling for pain, functional disability and depression. The results of this study imply that social support measured by the amount of supporting transactions may play a protective role in the process of adjustment to RA.

The importance of self-efficacy beliefs and family influences for asthma and COPD self-management and outcomes

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Background

Secondary prevention of adverse outcomes in patients with asthma and COPD requires that patients become actively engaged in self-management efforts such as participation in physical activities, medication adherence and stop smoking. However, despite assiduous efforts to find strategies that help asthma and COPD patients to adopt and maintain such behaviours, many studies of interventions designed to improve self-management have shown disappointing results. In this presentation, the importance of self-efficacy beliefs and family influences for self-management are explored as these concepts might have potential application for the development of interventions to support asthma and COPD patients' self-management.

Methods

In 2007, 295 patients with COPD and 477 patients with asthma filled in a questionnaire on self-management, quality of life, disease severity, self-efficacy and family influences. Self-management behaviours assessed were physical activities, medication adherence and smoking behaviour. All patients were medically diagnosed with asthma or COPD and are representative for the population of asthma, and COPD patients in the Netherlands.

Results

Patients who scored low on self-efficacy reported more daily symptoms and a worse quality of life in all aspects. When disease severity was controlled, patients who scored low on self-efficacy engaged less in physical activities, were less adherent to medication prescriptions and smoked more often than patients high on self-efficacy. A stimulating family environment was associated with more physical activity, better adherence, less smoking and a better quality of life.

Conclusion

Improving self-management by enhancing patients' self-efficacy and learning families to stimulate and support patients' self-management efforts may prevent adverse outcomes and improve quality of life in asthma and COPD patients.

Self-management in diabetes: the result of efforts of both patients and partners

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Background

Characteristics of the treatment, of patients and their social context are all associated with self management of type 2 diabetes. The social context has however hardly been studied. The need for adaptation to diabetes is significant for both patient and partner. This study evaluates how differences in beliefs about diabetes between partner and patient influence patient's self-management behaviour. It is hypothesized that diverging illness perceptions of spouses interfere with coping with chronic illness.

Methods

One hundred patients with type 2 diabetes and their partners were recruited via general practices and a diabetes research centre. Patients and partners administered a questionnaire about illness perceptions, spousal support, self-management and coping. Measures of glycaemic control were obtained via general practitioners. Multilevel analysis with three levels (patient, couple and method of recruitment level) will be used to identify factors that lead to positive outcomes in terms of patient's self-management.

Results

The data collection was finished in July 2008. Preliminary results show that patients and partners do not differ in their perception about what diabetes means in terms of treatment and duration. However, patients more often feel that the illness has an influence on their mood. Taking medication and changing life style have a great impact on daily life, even when the partner is supportive. Partners more often judge diabetes as a more serious disease and attach more value to tight glycaemic control than the patients.

Conclusions

Self-management behaviour and compliance to the care regime are not individually driven, but the result of the efforts of both patients and partners. Patients and partners have different perceptions about the consequences of diabetes. Spousal beliefs about the importance of disease control are thought to be a predictor of patients' self-management. This will be evaluated by glycaemic control measures as well as patients' coping strategies.

I.5. Session: Hospital care

Development and impact of distribution of inpatient hospital outcomes data in New York

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Background

During the past several years, hospital outcome indicators based on discharge abstract data have been widely distributed in the United States and Western Europe. The outcomes data distributed included risk adjusted hospital inpatient mortality and readmissions for two major services and three diagnoses. It also included Potentially Preventable Complications data for 32 categories.

Methods

This project described the development and impact of these data across four hospitals Syracuse, New York. These hospitals generate approximately 70 000 inpatient discharges annually based on a service area population of approximately 575 000. Development of inpatient mortality data was based on the All Patients Refined system developed by the 3M Corporation. Potentially Preventable Complications data was based on logic and software developed by the 3M Corporation.

Results

For adult medicine, the difference between the combined mortality rate and the risk-adjusted national rate for the Syracuse hospitals declined from 1.1% to 0.4% between January–February 2006 and January–February 2007. For adult surgery, the difference between the combined mortality rate and the risk-adjusted national rate for the Syracuse hospitals increased from 0.1% to 0.3% between the same periods.

Potentially Preventable Complications data indicated that the Syracuse hospitals performed at or better than severity-adjusted comparison populations for 20 of the 35 Potentially Preventable Complications categories during 2007. The data also demonstrated that a majority of the hospitals performed worse than comparison populations for categories including acute pulmonary oedema and respiratory failure, pulmonary embolism, acute anaemia, decubitus ulcers, accidental punctures and iatrogenic pneumothrax during this period.

Conclusion

The study demonstrated that standardized hospital outcomes indicators were useful in tracking specific measures of inpatient performance among hospitals. The impact of these data on inpatient mortality and inpatient complications was mixed. The availability of standardized data should contribute to improvement of outcomes for these indicators among the hospitals in the future.

Characterization of non-urgent cases admitted in emergency departments of Lazio region (Italy): a 1 046 957 patients 1-year cohort study

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