

lifepsychol[®]

Bringing life to medicine[®]

A new initiative empowering patients to communicate
and track their quality of life



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Quality of Life

Quality of life means different things to different people. It encompasses the social, emotional and physical wellbeing of a person and can reflect an individual's capacity to achieve their desired goals. Therefore when managing a long-term condition, supporting and where possible improving quality of life is regarded as the desired patient outcome.

Why monitoring quality of life is important

Research shows that taking a more holistic approach to patient care delivers considerable long-term cost savings and benefits:

77.9% reduction in the average length of stay in hospital

66.7% reduction in hospitalisation

47.1% reduction in physician office visits

*4% reduction in the number of prescriptions received*¹

Other studies consistently reveal that when the interpersonal relationship between patient and provider evolves from the predominant dependent model to a co-manager partnership between patient and provider, with clear roles and responsibilities, patient health outcomes improve².

People with chronic or life-threatening conditions can feel overwhelmed and unable to prioritise their concerns when consulting a health professional. By monitoring, tracking and addressing changes to their quality of life, patients and health professionals are able to better understand where management and care needs to be focused.

Given the extended duration of chronic illness, a plan of care developed collaboratively by patient and provider is a useful tool in defining objectives and essential elements of care. Subsequently this helps lead to a joint understanding of the respective roles and responsibilities of the patient and provider.

(1) The Cost Effectiveness of Mind-Body Medicine Interventions, Sobel DS, Progress in Brain Research 2000;122:393-412

(2) Managing Chronic Conditions, Optimising Health Throughout Life, Leine Stuart PhD, ACRN 2008 Family Health International

Lifepsychol[®]

Lifepsychol is a new healthcare initiative which focuses attention on supporting and improving the quality of life of people living with a chronic and/or life-threatening condition.

The Lifepsychol initiative consists of three elements:

- Lifepsychol QoL profiling and monitoring system
- Lifepsychol Survey
- Lifepsychol 2010 Conference

Introducing lifepsychol[®]QoL



“ This gives the opportunity for the patient to talk about what really matters to them ”

Quote from patient/GP

Lifepsychol[®]QoL is an easy-to-use, patient-driven system consisting of a handheld dial, an electronic dial and a website. It enables patients to record and monitor how their quality of life is affected by their life-threatening or chronic condition, and empowers them to discuss these issues with their health professional. As well as providing structure and focus for the consultation, the system also provides patients with direct access to relevant resources.

Benefits to patients

Patient-driven

- Focuses attention on areas of concern to patients
- Allows patients to monitor and address life changes

Empowers patients

- Provides tangible evidence, helping to legitimise concerns and giving 'permission' to raise these with the healthcare professional
- Aids autonomy and self-care
- Provides a visual representation to help patients express their difficulties
- Helps to overcome the barrier of articulation
- Can be customised to meet patients' individual needs

Benefits to health professionals

Efficient and time-saving

- Provides focus and structure to consultation
- Easy to use and interpret
- Shows patients' concerns at a glance
- Potential to reduce healthcare use by patients
- Quantifies qualitative issues
- Illustrates changes over time

Builds trust and improves concordance

- Helps build relationships and trust
- Helps health professionals promote and support patients' self care
- Encourages a collaborative approach between health professionals and patients
- Aids goal-setting and care planning

Lifepsychol® QoL - a profiling and monitoring system

Lifepsychol QoL provides a very simple and highly visual approach to monitoring quality of life. Patients begin by completing a handheld dial, given to them by their health professional.



Fig 1.1: The Lifepsychol® dial and a completed insert

The handheld dial enables patients to monitor the following areas:

- Anger and frustration
- Domestic tasks
- Energy levels/fatigue
- Financial situation
- Independence
- Mobility/Physical Function
- Mood (anxiety and depression)
- Pain
- Relationships
- Sleep
- Social life/hobbies
- Working life

The selection of areas is based on research which indicates there are particular issues that patients frequently discuss when talking about how their illness interferes with their life (see *Lifepsychol® Survey* on page 9 for more information).

The user completes their Lifepsychol® by placing a cross in the box that they feel best describes how their condition affects each area, rotating the dial to complete each segment. Once completed the dial is taken out of the sleeve, to give the health professional a quick 'snapshot' of how the person's life is affected by their chronic condition.

In essence, the further from the middle of the dial, the more affected that area is as a result of the patient's chronic condition. The strong visual nature of the completed dial helps the health professional to tailor the consultation and helps highlight to the patient specific areas of concern.

Once the consultation is concluded the user can take their dial home. On the reverse of the dial they will have details of how they can access and set up their online Lifepsychol® account, hosted at www.lifepsychol.com.

Lifepsychol® QoL Online

The Lifepsychol.com website is an online extension of the Lifepsychol system. After setting up a free online account, users will be able to: complete an electronic version of the dial at any time; customise their lifepsychol to monitor different areas of their life; view and compare previously completed Lifepsychols; use charts to track changes in any area they are monitoring; set reminders and add comments using an online diary and access further resources tailored to their condition or areas of concern.

It is quick and simple to set up a free lifepsychol.com account using the secure online registration process. During the registration users will be given the option to personalise their Lifepsychol®. The default dial includes the same 12 areas shown on the handheld version, but the user can deselect any of these and choose from a list of areas they feel are more appropriate to their current circumstances.

Fig 1.2: lifepsychol.com homepage



Once their account has been set up, and every time the user subsequently logs in, they will be presented with their Profile page, which presents them with notifications and reminders and allows them to change any of the settings entered during registration.

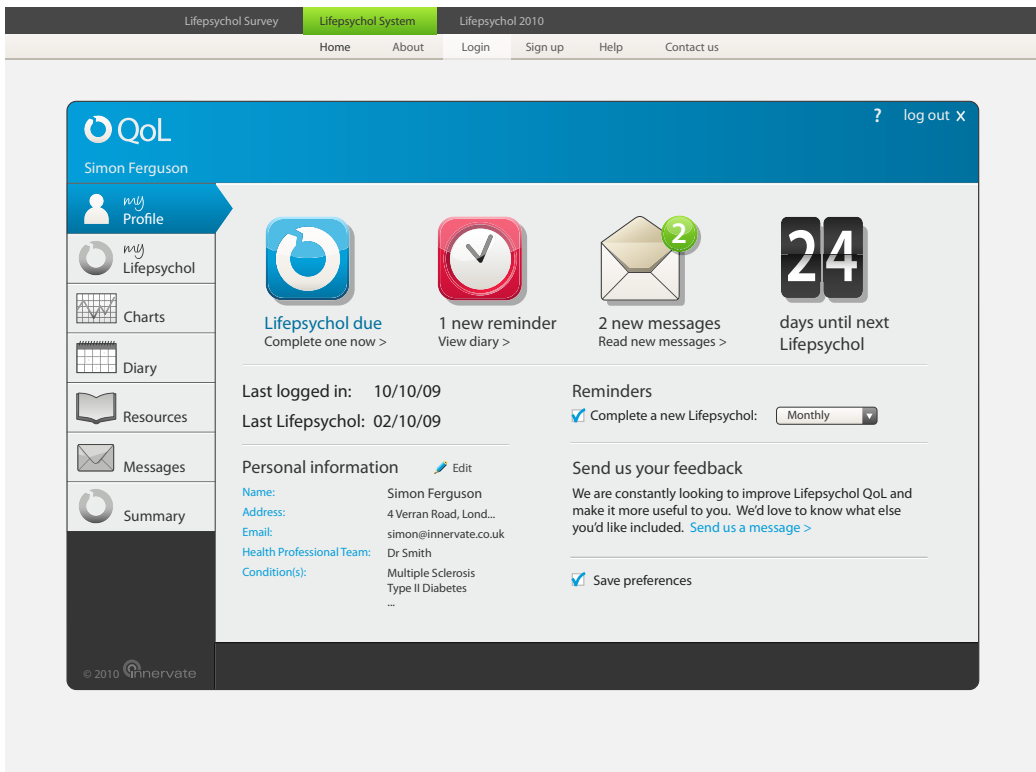


Fig 1.3: 'My Profile' page

Provides useful reminders, notifications and shortcuts to regularly used sections.

After completing the online registration, the user completes the electronic dial. This is done very simply by clicking the mouse on the appropriate segments of the dial. The dial will then automatically rotate after each entry.



Fig 1.4: 'Update My Lifepsychol' page

The online dial replicates the interactivity and ease-of-use of the handheld version.

The user can log in and complete a new Lifepsychol® at any time, and reminders can be set to prompt the user on a regular basis. Every completed Lifepsychol® is stored for the user to view and compare in order to see how a particular aspect of their life has changed over time.

Fig 1.5: 'Lifepsychol History' page

Users are able to view and compare any previously completed dials.

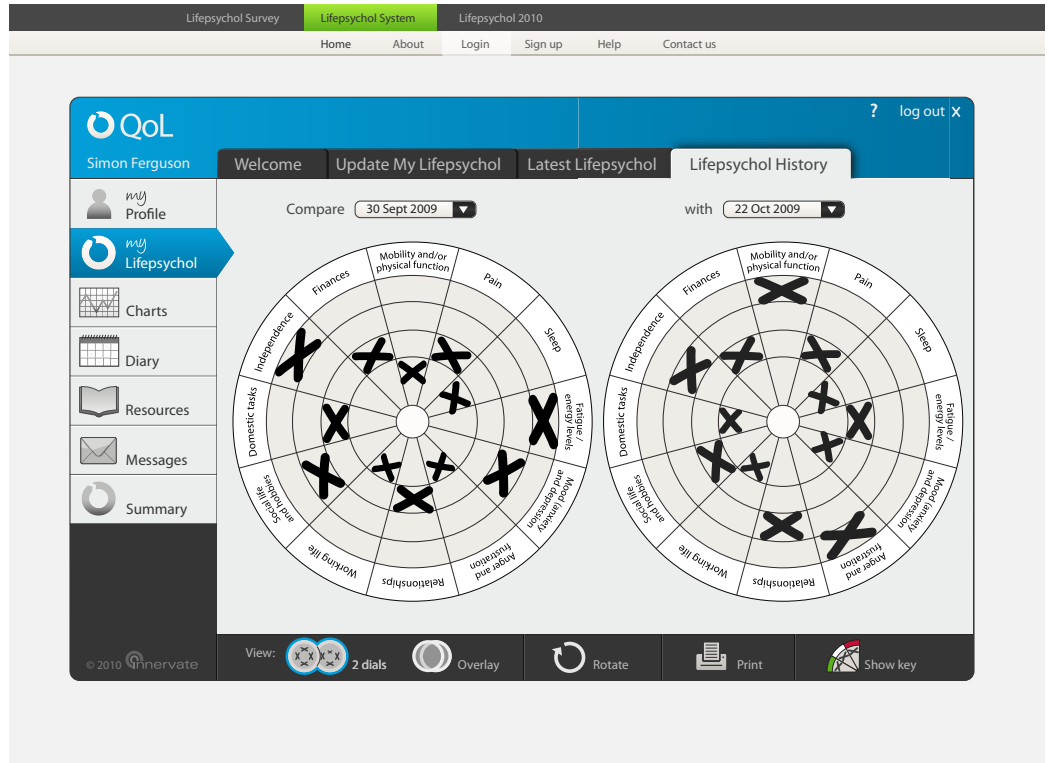
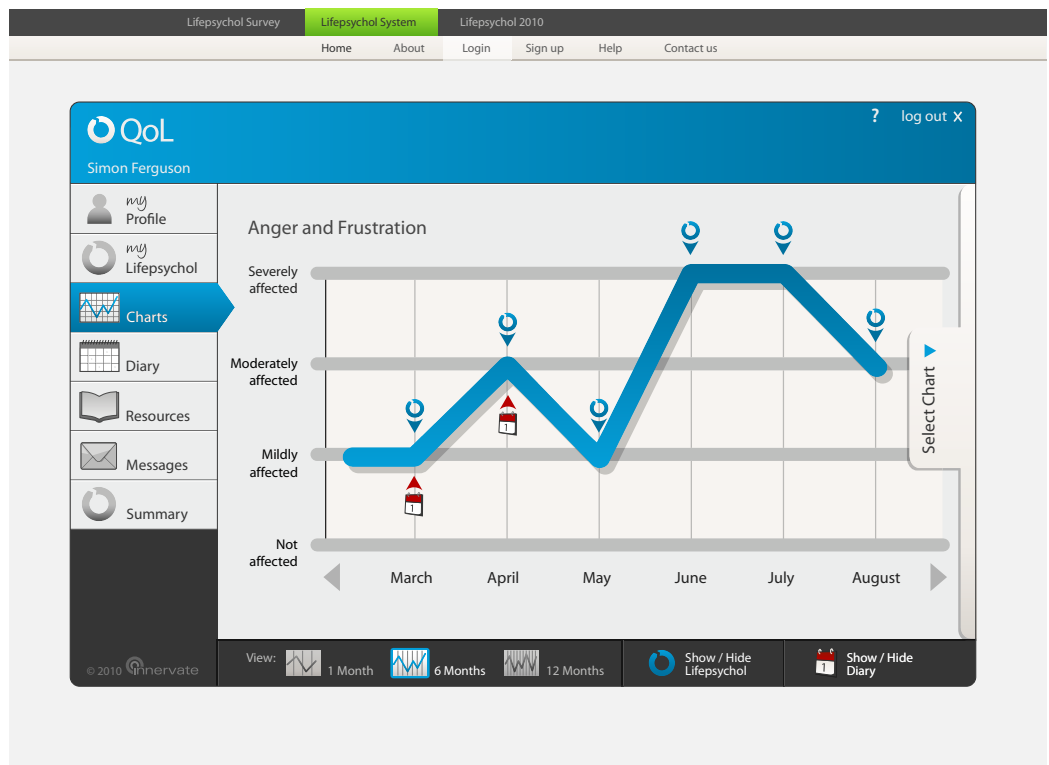


Fig 1.6: 'Charts' page

Data from every completed Lifepsychol is plotted onto charts, allowing the user to track changes in their QoL over time.



The online Lifepsychol® has been developed to help the user manage their quality of life by providing links to relevant resources.

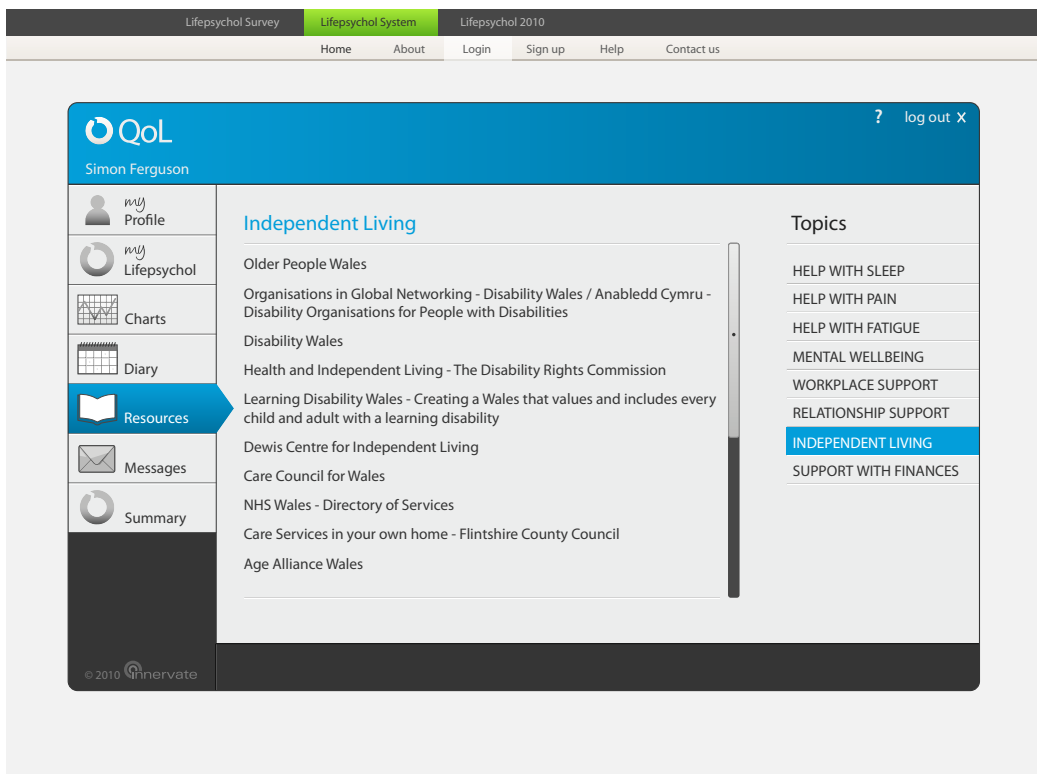


Fig 1.7: 'Resources' page

The resources available are tailored to the user's condition and areas of concern

Applications of Lifepsychol® QoL

- Can be used by the patient to monitor the impact of any changes in his or her life
- Can be used in consultation with health professionals to discuss ways to improve a person's quality of life, and to track the impact of introducing or modifying treatment/therapy
- Can be shared by the patient across all members of a healthcare team to ensure continuity of care
- Can provide clinics/hospitals and Trusts access to a considerable source of anonymised data. This data will help to show how services are impacting upon patients' quality of life and to inform healthcare service development

Summary

Lifepsychol®QoL offers a person suffering from a long-term or life-threatening illness with a simple but engaging communication tool which also helps them to keep a detailed record and analysis of how key aspects of their quality of life change as a result of living with the illness. It also provides key data to assist with goal setting and promoting and supporting self care. It gives patients access to resources in areas where support is needed as highlighted on the Lifepsychol®.

Lifepsychol®QoL helps to generate quantitative data from what is usually perceived to be a qualitative issue. It also gives clinics and hospitals access to a system that helps them assess the impact their services and products are having on the quality of life of their patients.

Pilot Project

The first pilot of the Lifepsychol® system is scheduled to start in the second quarter of 2010 and is being run with the National Leadership and Innovation Agency for Health in Wales. This pilot will involve running the Lifepsychol® system alongside 'Lifestyle advisors'.

For further information, or if you would like to enrol as a pilot please contact Neil Bindemann at:

email: info@innervate.co.uk

tel: 020 7554 4044

or visit: www.lifepsychol.co.uk

What does Quality of Life mean to Patients?

lifepsychol[®] Survey

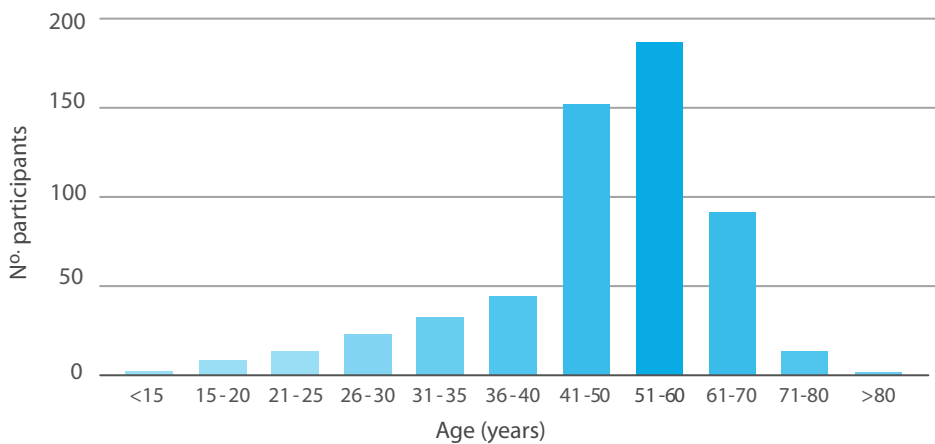
In June 2009 Innervate Ltd launched a new survey inviting people's views on quality of life. The purpose of the survey is to gain a better understanding of what the phrase 'quality of life' means to people living with a long-term or life-threatening illness, and what they believe affects their quality of life.

The Lifepsychol[®] survey is ongoing and can be accessed at www.lifepsychol.com. It is open to anyone with a long-term or life-threatening illness, as well people in good health.

Here we report some of its early findings:

Demographics

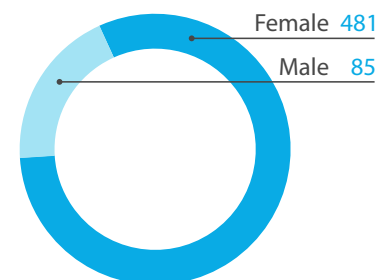
Fig. 2.1 Age of participants



“ To be able to do what I want, when I want to, not when my illness lets me ”

All quotes are from patients in response to the question: "What does quality of life mean to you?"

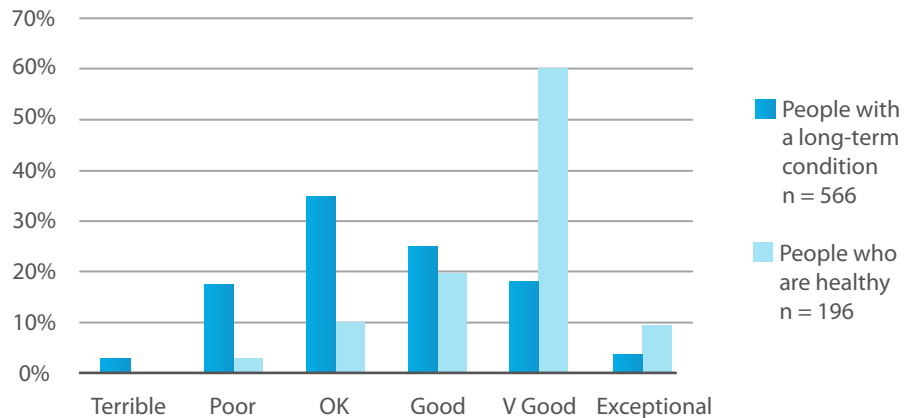
Fig. 2.2 Gender



“Being of real support to and with others”

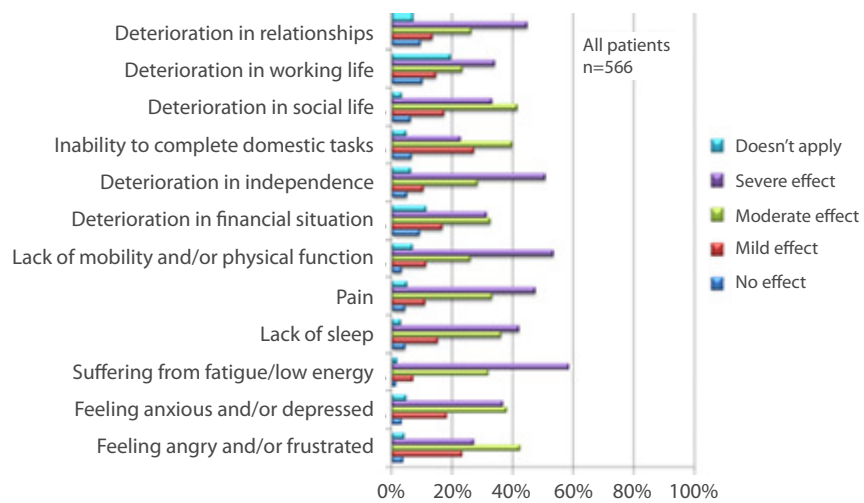
State of quality of life

Fig. 3 State of quality of life



To what extent do you believe the following would or does affect your quality of life?

Fig. 4.1 All People with a long-term or life-threatening condition



“To wake up in the morning and look forward to the day”

Fig. 4.2 People with arthritis

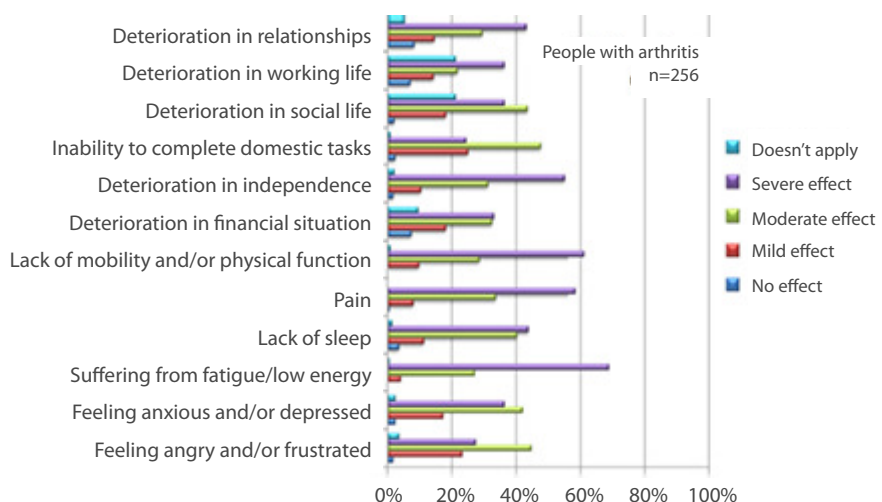
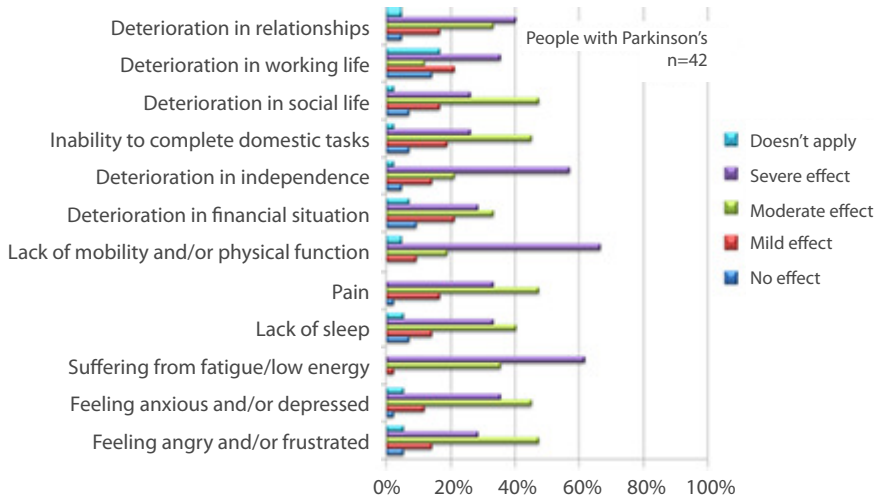
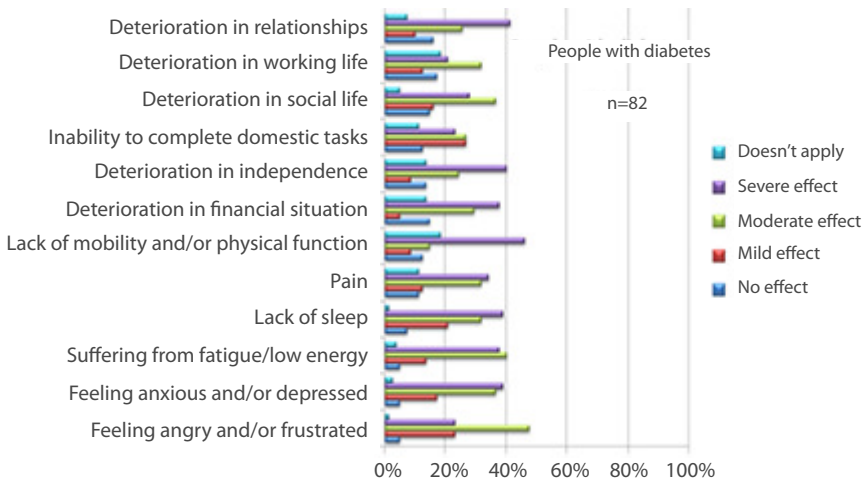


Fig. 4.3 People with Parkinson's



“ Having enough money to do the things you want to without having to save ”

Fig. 4.4 People with diabetes



“ Being able to get down on the floor to play with my children ”

Fig. 4.5 Healthy people

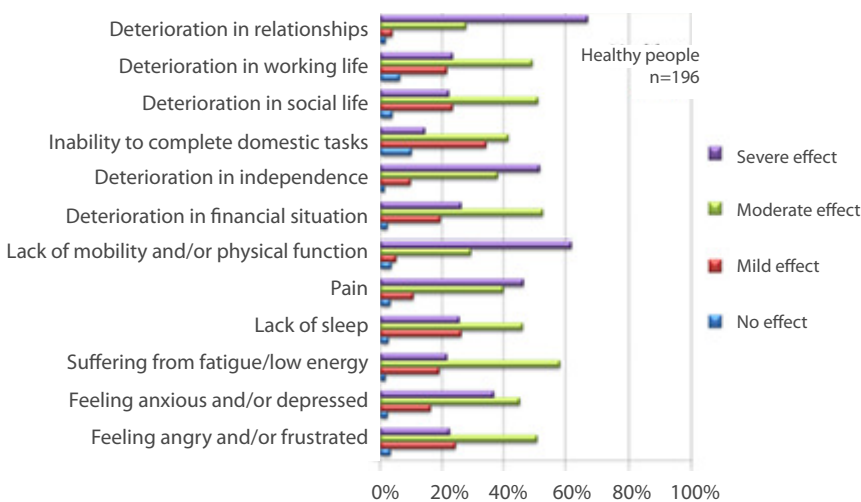
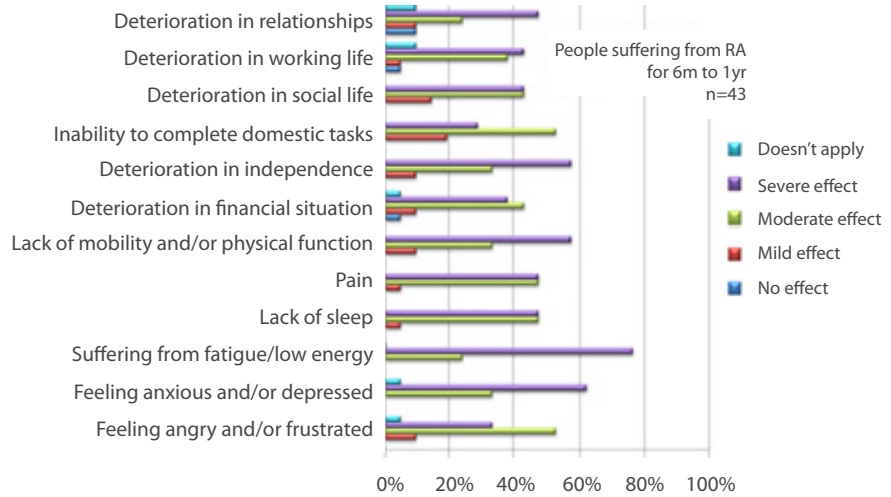
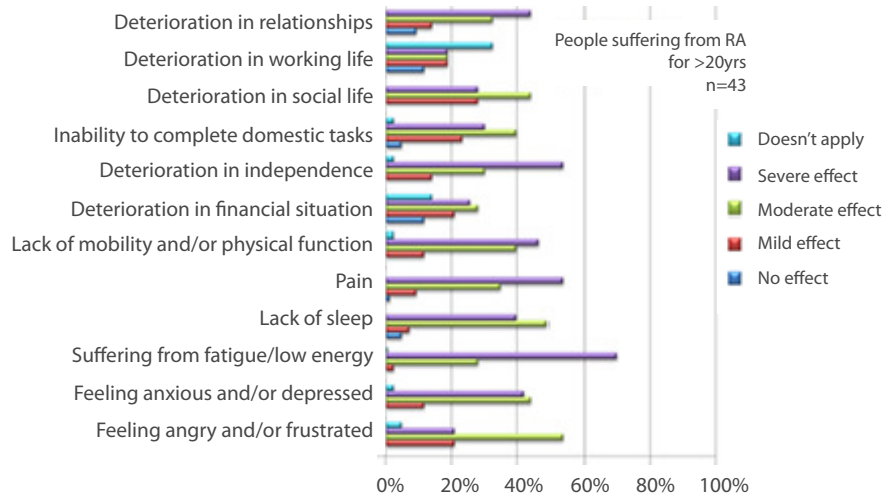


Fig. 4.6 People suffering from RA for 6 months to 1 year



“Having a life you want to have and which makes you happy”

Fig. 4.7 People suffering from RA for over 20 years



Observations from the Lifepsychol® Survey

Across all long term conditions, *fatigue* is the most frequently selected factor that is rated as severely affecting quality of life

People with RA select *fatigue* more frequently than pain as an issue which severely affects their quality of life

People with Parkinson's Disease most frequently select *lack of mobility and/or physical function* as severely affecting their quality of life

People with diabetes also most frequently select *lack of mobility and/or physical function* as severely affecting their quality of life

Healthy people selected *deterioration in relationships* more often than any other item as severely affecting their quality of life

Fatigue is less frequently selected by healthy people (compared with people suffering from a long term condition) as severely affecting their quality of life

People who have suffered with RA for 6 months to 1 year score *feeling anxious or depressed* as severely affecting their quality of life more often than the general population of RA sufferers, and those who have suffered from RA for over 20 years.

Summary

The preliminary findings show that people's definitions of quality of life and the factors most affecting it are extremely diverse, highly personal and liable to change over time. Various factors including age, how long a person has been living with the condition and the particular condition itself can greatly influence a person's perspective of quality of life.

Given these findings, it is clear that when addressing the quality of life of a person with a long-term or life-threatening condition, it is essential first of all to elicit what quality of life means to that individual.

“Don't ever make assumptions about what others may value in their quality of life - ask them!”

Patient comment taken from the Lifepsychol® Survey

To take part or learn more about the Lifepsychol® Survey, please visit:

www.lifepsychol.co.uk

or contact:

info@innervate.co.uk

020 7554 4044



A two-day conference putting quality of life at the heart of patient care

“ *The underlying concept for this study meeting was inspired. Excellent conference – passionate speakers, broad topic range, great organisation* ”

Lifepsychol2009 delegate

“ *Fantastic refreshing event* ”

Lifepsychol2009 delegate

Lifepsychol®2010 is a unique event bringing together leading professionals with expertise in long-term and life-threatening illnesses. The programme explores various aspects of quality of life and examines why understanding and supporting patients’ quality of life is crucial to delivering an effective and efficient healthcare service.

Lifepsychol®2009 was voted an outstanding success, with 100% of delegates rating the event as good or excellent. We anticipate good attendance once again from various professional groups including:

Who will attend Lifepsychol® 2010

Consultant nurses and physicians

General Practitioners

Psychiatrists

Psychologists

Practice Nurses

Specialist Nurses

Therapists

How delegates rated Lifepsychol®2009

36% Good

64% Excellent



Learning outcomes for delegates

- Essential practical advice on caring for patients
- Network with like-minded colleagues from across the UK
- Develop new research ideas
- Fulfill professional development requirements

Topics include

- Reaping the socioeconomic benefits from monitoring quality of life
- Do complementary therapies improve patient reported outcomes?
- Care planning for a better quality of life
- Pain as a long-term condition
- Parkinson's disease and sleep disturbances
- Rehabilitation after stroke - the impact of sleep disturbance
- Dementia - protecting patients without impairing quality of life

Speakers include

Professor Edzard Ernst
Laing Chair in Complementary Medicine

Professor Sarah Hewlett
ARC Professor of Rheumatology Nursing

Margaret Kitching
Director of Nursing Professions

Dr Roger Bullock
Clinical Director, Older People's Strategic Business Unit

See the full programme overleaf.

For up to date information about the event, venue and speakers, please visit:

www.lifepsychol.co.uk/conference

or contact:

email: info@innervate.co.uk

tel: 020 7554 4044

“ A brilliant
experience ”

Lifepsychol2009 delegate

“ Very
refreshing and
inspiring ”

Lifepsychol2009 delegate

“ Fantastic to
be with
professionals
from such
different
backgrounds ”

Lifepsychol2009 delegate

“ Can't wait for
next year's! ”

Lifepsychol2009 delegate

- 09.15 **Chairperson's Introduction**
Prof Glennys Parry, Professor of Applied Psychological Therapies, University of Sheffield
- 09.30 **Reaping the socioeconomic benefits from monitoring quality of life**
Speaker tbc
- 10.05 **Do complementary therapies improve patient reported outcomes?**
Prof Edzard Ernst, Laing Chair in Complementary Medicine, Peninsula Medical School
- 10.40 Tea/Coffee & Exhibition
- 11.10 **Focus on Sleep**

Parkinson's Disease and sleep disturbances - Managing the consequences
Prof Marjan Jahanshahi, Consultant Clinical Psychologist, UCL Institute of Neurology
- Rehabilitation after stroke - the impact of sleep disturbances**
Prof Annette Sterr, Head of Psychology, University of Surrey
- TBI and managing the sleep disturbance consequences**
Dr Mike Dille, Consultant Neuropsychiatrist, Honorary Senior Lecturer, National Hospital for Neurology & Neurosurgery
-
- 12.40 Lunch
- 13.40 **Focus on Pain**

Pain as a long-term condition - What really matters to patients, with experiences from the front line!
Dr Frances Cole, GP, Pain Rehabilitation & Cognitive Behavioural Therapist, Bradford Teaching Hospitals
- Chronic pain and sleep - a reciprocal and dynamic relationship**
Dr Neil Stanley, Former Manager, Clinical Research and Trials Unit, Norfolk and Norwich University Hospital
- Assessing sensitivity to pain**
Dr Sarah Barker, Consultant Clinical Psychologist, INPUT Pain Management Unit, Guy's and St Thomas' NHS Foundation Trust
-
- 15.10 Tea/Coffee & Exhibition
- 15.40 **Focus on Fatigue**

Learning from experiences with RA patients
Prof Sarah Hewlett, ARC Professor of Rheumatology Nursing, Honorary Consultant Nurse, University Hospitals Bristol
- Fatigue and cognitive function**
Dr Anita Rose, Clinical Psychologist, Walton Centre of Neurology and Neurosurgery, Liverpool
- Fatigue and the workplace**
Dr Diane Playford, Senior Lecturer, Institute of Neurology; Honorary Consultant Neurologist, National Hospital for Neurology and Neurosurgery
-
- 17.10 **Detection and treatment of anxious depression in general medical practice**
Prof Sir David Goldberg, Emeritus Professor, Health Services Research Dept, Institute of Psychiatry, King's College London
- 17.40 Summing up and close

- 09.15 **Chairperson's Introduction**
Dr Stephen Allen, Consultant in chronic pain management, the Oxford Pain Relief Clinic
- 09.30 **Understanding quality of life - the impact of cultural beliefs and ethnicity**
Dr Tasneem Irshad
- 10.05 **Is routine monitoring of quality of life realistic?**
Speaker tbc
- 10.40 Tea/Coffee & Exhibition
- 11.10 **Focus on Relationships** _____
Cognitive impairment - addressing the emotional impact on the carer
Sally Askey-Jones, Mental Health & Research Nurse, The Institute of Psychiatry, Kings College London
The parent/young person relationship: an important step in supporting medicines management
Dr Jennifer Newbould, Analyst, Health and Healthcare, RAND Europe, Cambridge
Taking a human needs approach
Dr Ian Walton, GP, Tipton
-
- 12.40 Lunch
- 13.40 **Quality of Life at Home** _____
Stroke rehabilitation - the impact of the home environment
Dr Avril Drummond, Associate Professor of Rehabilitation, School of Community Health Sciences, Institute of Neuroscience, University of Nottingham
Dementia - protecting patients without impairing quality of life
Dr Roger Bullock, Clinical Director, Older People's Strategic Business Unit, Avon & Wiltshire NHS Partnership
-
- 15.10 Tea/Coffee & Exhibition
- 15.40 **Supporting Self-care** _____
Care planning for a better quality of life
Kathryn Padgett, Assistant Director of Nursing and Professions, Barnsley Primary Care Trust
Self-care of healthcare professionals - learning from the experience of palliative care professionals
Dr Inigo Tolosa, Lead Consultant Psychologist, Pan- Birmingham Cancer Network, University Hospitals Birmingham NHS Foundation Trust
- 17.10 **Could monitoring quality of life lead to improved adherence to treatment?**
Prof Rob Horne, Director, Centre for Behavioural Medicine, Department of Practice and Policy, The School of Pharmacy, University of London
-
- 17.40 Summing up and close

For full information visit www.lifepsychol.com/conference