

A Better Life – what older people with high support needs value

Findings
Informing change

November 2011

Finding the best way to develop and fund support for the increasing numbers of older people in society is a political priority. Understanding, measuring, improving and monitoring their overall quality of life (not just the quality of their care) will be the main challenge. This study presents the views of older people with high physical and mental support needs who have described what they want and value in their lives, and proposes a model to assist policy-making, research and practice.

Key points

- The views of older people with high support needs have rarely been sought. Reasons for this include their invisibility, communication issues and the lack of a collective voice.
- Participants in the study wanted and valued different things in their lives, but all expressed common human needs for social, psychological and physical well-being.
- People valued their close emotional relationships, though some expressed concerns about ‘imposing’ on family and friends. Many had made new friends as a result of their increasing support needs.
- Having control over their lives was important but meant different things to different people. Adjusting well to change was also central to psychological well-being, and this might require support.
- Participants valued getting out and about, keeping mentally and physically active and having contact with nature.
- Care, support and other people’s time were key factors that enabled or prevented people doing things that mattered to them.
- Participants faced various challenges and difficulties, some a result of illness, disability and ageing but many because of lack of access to information, money, technology, equipment and transport.
- The study proposes a model (see p. 3) of what older people with high support needs value in their lives.

The research

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Background

This study is part of JRF's *A Better Life* programme. It aims to provide a framework for understanding what older people with high physical or mental support needs want and value in their lives.

The experiences and wishes of this group have, until very recently, not been sought. The authors suggest five explanations for this, linked to:

- communication issues, reliability of data and ethics, especially in relation to people with cognitive impairment;
- undue focus on health and care needs at the expense of wider quality-of-life issues;
- assumptions about older people that ignore social roles, individuality and choices;
- stereotypes, language barriers and assumptions of homogeneity that ignore diverse voices;
- failure to encourage older people with high support needs to get involved in campaigning for their rights.

What older people with high support needs value

Older people with high support needs value similar things to everyone else. However, many have had to adapt the way they meet their needs, or come to terms with unmet needs, as a result of illness or disability and other issues, such as money or information. The things that older people value can be divided into three (sometimes overlapping) aspects of well-being: social, psychological and physical.

Social

Participants valued their relationships and social interaction very highly, though some worried that they might be 'imposing' on people. Many participants described new friendships resulting from increasing care needs – through moving into housing schemes or residential homes, meeting care staff (including home carers) or attending day centres. The prospect and reality of meeting new people seemed to bring a number of psychological benefits.

I like meeting with people. When I came to the day centre, I felt like a new person ... I relax and I'm comfortable here.

Gertrude, 74, who lives alone

Participants' cultural lives included music, art and crafts, theatre, religious observance and watching television. These brought benefits including social interaction, relaxation, a sense of achievement, mental stimulation and continuity with the past. Others valued the roles they played or wanted to make more of a contribution to their community.

I want to do some more work ... some voluntary work ... helping out with tea or something like that or serving customers.

Jack, 73, with learning difficulties and a heart condition, living in sheltered housing

Psychological

Self-determination, or being in control of their lives, mattered to everyone but it meant different things to different people. 'Independence' might be about staying in your own home, being self-sufficient, keeping the house in order or keeping yourself clean, not imposing on family, making your own decisions or being able to pursue your own interests. Many participants seemed happy to delegate key decisions or take advice from those they trusted.

My daughter does all my banking for me ... because I'd made a muck of things ... but everything's been sorted out now ... It's fine,

I don't bother, as long as she's able to do it,

it's fine.

June, 85

Whilst continuity was valued, many participants demonstrated considerable adaptability to a wide range of changing circumstances. However, some wanted more support to help them adjust to change.

You begin to wonder in your moments of depression, have you got any time left to do anything? Where am I going? Because up until now there's always been a sense of purpose.

Jimmy, 89

Physical

Living in a safe, secure and pleasant environment was important, though many people described compromises they had made on housing. Despite having multiple health problems, getting out and about was still very important to many participants and some took great risks to go out, given sensory impairments or risk of falling. Some wanted to take physical exercise, but lacked opportunities to do so. Contact with nature was valued, outdoors in the garden, if possible, or viewed through a window, on the television or through the internet.

It's lovely to go outside, and I've got the [electric wheel]chair, that's where it's made the difference. I can go outside now and get some fresh air, it's wonderful ...

Millie, 89, who has dual sensory impairment

Factors that help or hinder quality of life

Care and support

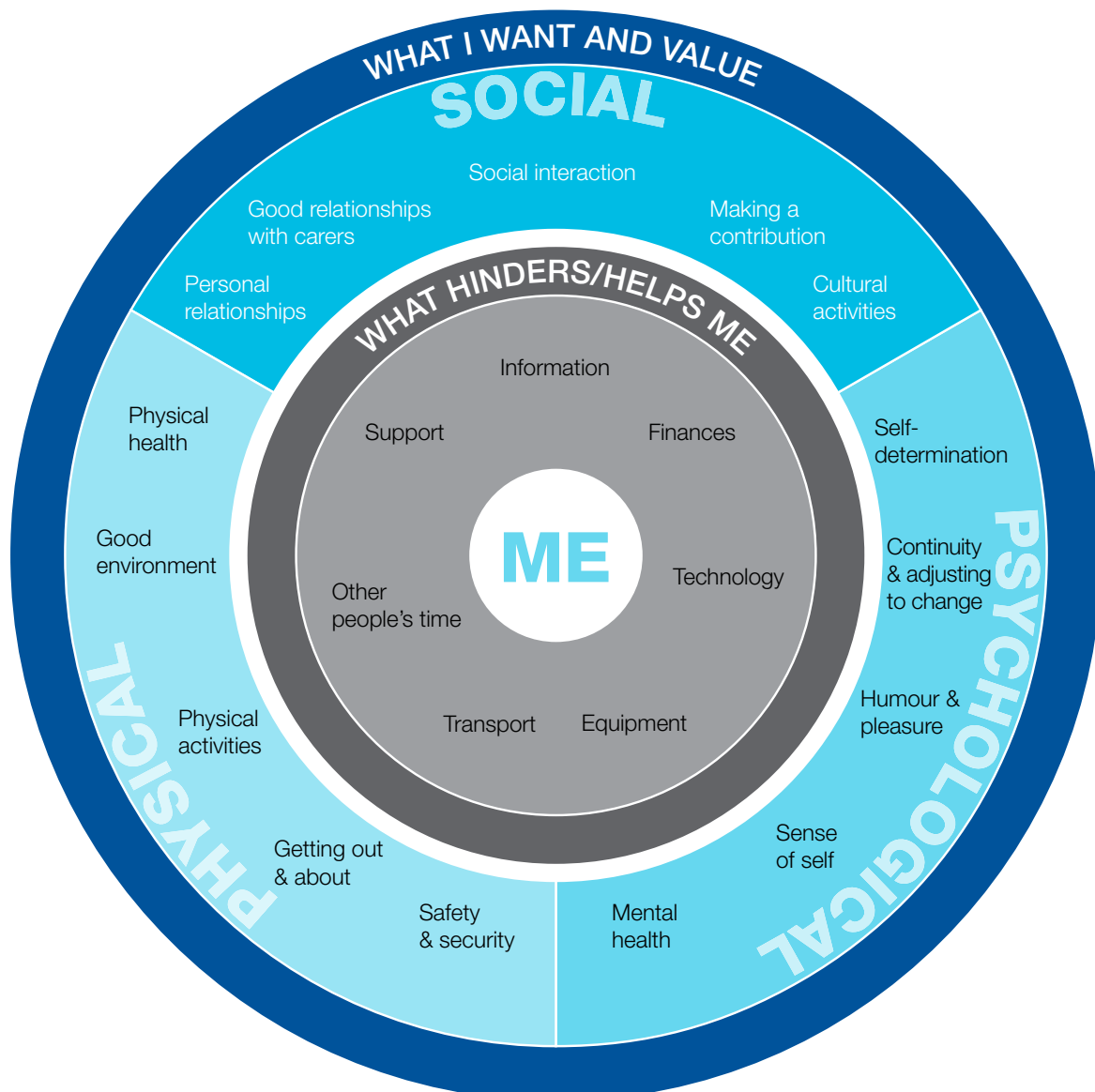
People valued friendly carers who give appropriate and respectful support. Continuity of care from familiar people was very important. Specific examples were given of over-stretched carers, inflexible or badly timed support and poor staff attitudes.

Other people's time

The quantity and quality of time spent by formal carers and others made a significant impact and helped paid carers to understand the person and how they wanted tasks to be done.

Other issues

Lack of money was a recurring theme and the provision of information about services seemed to be haphazard. Some participants were missing out on (or had waited for some time to receive) suitable mobility or communication equipment or access to basic technology, such as the internet or a loop system.



A model to explore what people want and value

The model (below) distinguishes between what people want and value across different aspects of their well-being (shown in the outer circle) and the factors that help or hinder them to access these needs (inner circle). The older person is at the centre of the circle, a reminder that this is about diverse individuals and what they want from their lives, not what services and policies decide they can have. The older person is represented as 'me' to give ownership to people who use the services and to remind others using the model that this is – or will be – about them too.

Implications

The study shows that older people with high support needs, including those with dementia, can, and want to, articulate the things that matter to them. There may be scope to develop a stronger collective voice for this group, possibly using the internet as a means of communication for some.

The model can be used in a number of ways:

- as a prompt to identify and explore what individual older people with high support needs want and value in their lives, to be used by older people, their families and professionals;
- as a tool in the education and training of professionals working with older people;
- as a framework for commissioning services, based on outcomes for older people rather than on the input of services;
- as a tool for understanding the trade-offs individual budget holders are (or are not) willing to make; and
- as an aid for researchers who are exploring quality-of-life issues for older people with high support needs and assessing the impact policies and services have on their well-being.

About the project

The study involved a review of the literature on what older people and/or people with high support needs value in their lives, followed by qualitative fieldwork to verify the emerging themes. Twenty-six people with high support needs, aged between 40 and 93, were identified through the Open University's networks. The participants were diverse in terms of their gender, ethnicity, geographical location and type of disability or health condition, and they had not previously been consulted. The researchers adapted an existing tool, 'The Facets of Life Wheel', as a prompt for in-depth, individual conversations with the participants about what they valued in their lives. They analysed the interview data to explore how participants' experiences confirmed or differed from those of previous studies.

About the programme

This study was commissioned as part of the Joseph Rowntree Foundation's 'Better Life' programme of work, which aims to improve quality of life for older people with high support needs. It is the first paper in a package focusing on direct and diverse experiences and voices. In January 2012 we will publish papers that explore the perspectives of diverse groups of older people, and launch a microsite called the 'The new old age', which will provide a digital platform for older people's words and images.

For further information

The full report, **A Better Life – what older people with high support needs value** by Jeanne Katz, Caroline Holland, Sheila Peace and Emily Taylor (edited by Imogen Blood), is published by the Joseph Rowntree Foundation. It is available as a free download from www.jrf.org.uk

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