



University of Brighton



Well-being in old age: findings from participatory research

Executive Summary



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Addendum

This research was conducted in collaboration with Age Concern Brighton, Hove and Portslade. At the time of going to print the organisation was on the point of joining Age UK and changing its name to Age UK Brighton & Hove. Any references in the report to Age Concern should be understood as Age UK Brighton & Hove.

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Executive Summary

Introduction

Well-being has become an important focus for health and social policy in general, and in relation to older people in particular. Well-being has been linked to ideas about 'active ageing' (The National Framework for Older People DH, 2001) as well as independence (Opportunity Age DWP, 2005). The connection between well-being and independence was reinforced in the social care Green Paper, Independence, Well-Being and Choice: Our vision for the future of adult social care in England (DH 2005).

But what is well-being? Can it be measured? Does it mean the same to everyone? And what produces well-being? Researchers have come up with different definitions and 'indicators' to be used in measuring well-being and these sometimes produce rather different results. Some research and policy appears to assume that well-being is a quality of individuals and can be produced through individual effort.

Others have argued that an emphasis on the individual does not sufficiently take into account the importance of relationships between people and that, rather than measuring individual well-being, we should focus more on how to generate caring relationships that can enhance well-being.

This project was designed to develop our understanding of what well-being means to older people, and of how it is produced. An important aim of this project is to make a contribution to thinking about policy and practice and how this might enhance or detract from the way people experience well-being in old age. Our aim was not to measure, but to develop insight into how older people sought to maintain a sense of well being, often in circumstances where this was difficult; what helped them do this and what got in the way of 'being well.'

As we describe in section 3 our approach soon became one that understood well-being as profoundly affected by the nature and quality of different types of relationship, rather than an individual characteristic or quality. Thus, as well as looking at other work on well-being, we have also drawn on work exploring an ethic of care in order to understand what affected older people's experiences. This work starts from the recognition that human beings need others in order to survive and flourish. It identifies the universal need for care and explores the ethical as well as practical meanings of care giving and care receiving.

Our approach: co-producing knowledge with older people

The well-being project was carried out between 2008 -11 in Brighton and Hove by a team involving university researchers, a voluntary sector manager and older co-researchers. Our aim was to develop participatory research with older people which would foreground lived experiences of ageing and co-produce knowledge about what well-being means. We developed a process that enabled older people (both those who took part as research participants and the co-researchers) to engage in reflection and dialogue about what well-being meant to them and what both contributed to and detracted from being well as they grow older.

We recruited eleven co-researchers who were at the time aged between 60 and 87. A key part of the project has been learning how to work with a group of older people at different stages of later life, as well as from different backgrounds, and trying to ensure that they were able to contribute their own particular strengths. We also aimed to ensure that their involvement as co-researchers was personally worthwhile and rewarding. Right from the beginning we emphasised

the importance of older people as narrators of their own stories and interpreters of their own lives. By working together on the design, delivery and realisation of the research we also aimed to break down barriers between 'expert knowledge' and 'lay knowledge' - between academic expertise and community expertise.

Research relationships

We needed to develop inclusive ways of working that were attentive to the different needs and circumstances of our colleagues. We recognised that involving older people is not just a matter of good design, but of ethical practice. We worked with ideas deriving from care ethics to develop our approach to ethical relationships within the research team, as well as in our relationships to the older people who took part as interviewees or participants in focus groups. Involving our team of older people in research was not just a matter of including them in a set of activities, but was also about the nature of the relationships we developed during the process, and how these were connected to our subject matter and our developing understanding of well-being and ethical research practice. It involved being attentive not only to the different contributions that team members felt comfortable with making, and to the practical support necessary to enable them to work with us, but how we could ensure and hopefully promote well-being through the ways in which we worked together.

Research design, analysis and dissemination

The project was carried out in four phases. The first phase sought the perspectives of those working within Age Concern on what contributes to or detracts from older people's well-being. The values of the organisation emphasise person-centred practice and we wanted to explore how workers and volunteers sought to embody these values in their work, and what aspects of practice they thought contributed to well-being.

The second and third phases captured older people's perspectives. During early discussions on the research design the team rejected using a structured questionnaire to measure well-being and opted for an approach which would capture lived experience in all its contextualised and relational aspects. We developed a topic guide for individual interviews and focus groups to explore what older people themselves consider important. Interviewees and focus group participants were able to shape what they talked about; to reflect on issues that the team themselves might not have identified as likely to be important; and to discuss why things were important to them and what precisely it was about issues that made a difference in terms of their well-being.

The co-researchers carried out one to one interviews with 30 older people and seven focus groups in which another 59 older people took part. Half of those who took part in one-to-one interviews were aged 85 or older, including 5 who were in their 90s. Twenty were women and ten were men. Fifteen interviewees were users of Age Concern services and the others were recruited using snowballing methods to include older people in a diverse range of circumstances.

Co-researchers used the topic guide to help structure the interview and respond to what interviewees talked about. A similar approach was adopted in focus groups where participants were invited to explore and discuss what they felt was important to well-being.

To help us make sense of what older people had told us we identified themes within the interviews and focus groups by developing a coding framework and coding the transcripts. The coding process was undertaken collaboratively by some members of the team. The coded data was then organised into thematic sections and brought to team discussions for reflection and interpretation. The presence of the team's experience, particularly in the thematic analysis, was really important. They were able to resonate with the data bringing an authenticity and an understanding of the meaning of the material from their own lived experience.

The final phase of the project was designed to begin a process of engagement with practitioners and other service providers. When we set out we envisaged the exchange of knowledge and skills as an interactive process, involving developing tools and resources relevant and useful to those working with and providing services for older people, as well as creating links to the wider strategic and policy agenda. As the research was drawing to a close we were successful in securing funding from the Economic and Social Research Council to disseminate our findings to a wider audience and we started this phase of work in November 2011. Older members of the research team have produced a booklet for older people drawing on the research findings and their own experiences.

Thematic findings: Age Concern staff and volunteer perspectives

Ten interviews were carried out with Age Concern staff and volunteers. They explored the main issues for service users and what Age Concern services and culture of practice may contribute to older peoples' well-being. The main points identified by those working with Age Concern were:

- Different levels of care needs tend to relate to age and those over 80 may need higher levels of care. There can be a loss of confidence, lower expectations and a feeling of not wanting to be a burden within the older group of service users. Those aged 50 – 70 are generally more active and have higher expectations around being engaged, participating in activities and being independent.
- Isolation and loneliness are major issues for those accessing care and rehabilitation services. Lack of social contact can be a result of loss of mobility and/or confidence to go out; bereavement and the gradual loss of friends and family can result in an increasing sense of isolation and feeling cut off from the world. For people who are unable to get out, having regular social contact makes a big difference to well-being.
- Needs for support can be difficult to acknowledge and people may be reluctant to ask for help. Staff reflected that often this is linked to a sense of pride and/ or embarrassment. They highlighted the importance of listening and responding to what people say and allowing people to make their own decisions about the services they receive.
- Time was identified as an important factor in being able to work in a person-centred way. 'Being present' with the person, acknowledging their situation and feelings, and building trust, being consistent and reliable were also considered crucial. Staff reflected that the quality of relationships can impact on the intervention and being attentive to small things can make a difference to the person's well-being.

Thematic findings: older people's perspectives

The thematic analysis has been organised in four sections: **people; health, care and support; resources; places and environment.**

People

- Relationships of all kinds emerged as significant in many different contexts - within families, friendships and with neighbours, as well as casual interactions with people in everyday encounters.
- Families can be a source of support and security, but for some can also involve difficult and painful relationships, distance and estrangement.
- Good relationships with adult children can contribute to well being and maintaining satisfactory relationships was recognised as important. This involves learning to relate

- to adult children in different ways. Accepting help from adult children and recognising the role reversal between parents and children is a major shift older parents face. A reluctance to be 'a burden' on children was common.
- Role reversals within relationships between husbands and wives where there is a need for care, impacted on identity and maintaining a sense of self.
- Friendships are important and the meaning of friendship may change with ageing. Ill-health and physical distance may make it harder to sustain friendships and the loss of long term friends, with shared experiences and history, was felt very strongly.
- Good neighbours can play a vital role in emotional security and support. A move to a new area or housing situation meant that some did not know their neighbours.
- Everyday interactions with others, such as conversations struck up in shops or on buses can contribute to a sense of being connected with others and the outside world.

Health, Care and Support

- Health featured as an important factor in well-being, but poor health is not necessarily directly related to an absence of well-being. Ill health and managing long-term health conditions impact on relationships and experiences of loss and can cause instability and uncertainty due to fluctuations. It requires adapting, coping and adjusting to the need for help and assistance. Fears of ill health in the future and being taken ill can impact on the present.
- Deteriorating health and disabilities can change the capacity to engage in social life and impact on relationships, particularly on those affected by communication difficulties, such as hearing and speech loss.
- Acute or chronic ill health has not only physical effects, but also emotional and psychological impacts. These include a loss of confidence and self control which can generate a degree of fear, for example of going out alone, crossing roads, and negotiating public space and places. Managing the psychological aspects of ill health, such as fear, anxiety and vulnerability can be difficult if there is no one these can be shared with and are shouldered alone.
- Access to health services and GPs are important. This includes location, appointment times and systems and being properly listened to by practitioners. The quality of the interaction and relationship with the member of staff (whether GP, nurse, receptionist or consultant) is key. Poor services and relationships can feel disempowering for older people who may be fearful of having a service withdrawn or asked to leave a surgery.
- Care can encompass a range of activities and relationships, from having someone watching out for you, help with household tasks, to nursing and personal care. The ways in which care contributes to well-being depends on the ways in which it is given and experienced. Knowing that care is there in the background if needed is important and gives security and comfort.
- It can be difficult to acknowledge needs and accept help. People may be reluctant to ask for help because of not wanting to be a burden or fearing a loss of independence and control. For some there was also a fear of rebuff or rejection. If the request for help and the support received is positive, it lessens the sense of feeling a burden and people can experience well-being from the experience of being well cared for. The availability of information and advice about sources of help, and people's feelings about asking for help often combined to make it hard to find the help needed.

- Both giving and receiving care involve significant emotional aspects, such as changes in self identity, sometimes involving a reversal of a previous role in a relationship and can be difficult to adjust to. Taking on a caring role can have conflicting emotional impacts, for example feelings of guilt and duty as well as satisfaction and love. People can experience well-being through caring for others.
- Those caring for others also need support for themselves. Their own health problems cause concern about being able to continue in the caring role. Carers can find it hard to ensure their own needs are met.
- Participants found that information about services or local authority support was not easy to access and there was some uncertainty about rights and entitlements in relation to social care services.
- Many participants were worried about the cost of care services and expressed anxiety about meeting eligibility criteria, and feared expenses may be beyond their control.
- Concerns about future care needs related not only to cost, but also to the quality of care provided within residential homes.
- When health and care services were underpinned by values such as respect, reliability and reassurance, and where trust was present, the person receiving the support does not feel disempowered or de-humanised as a result. The quality of the service was identified by many participants as important and this included staff skills; time given; flexibility and sensitivity.

Resources

- Being able to draw on experiences gained over a lifetime, learning from past mistakes, or reflecting on the benefit of hindsight, informed present attitudes and was a personal resource for some. Memories and reminiscing can generate a sense of pride at past achievements and positively contribute to self-identity and resilience.
- Faith and spirituality can be important resources which extend beyond attending church and religious affiliation. For some, spiritual and religious life helped make up for loss of other relationships and provide a sense of belonging.
- Learning to adapt to change, making the most of the present and focusing on the 'here and now' were identified as important personal resources.
- Being able to think about the future and looking forward, without anxiety and fear, particularly in relation to health and social care needs can be important. Planning for practicalities and having things to look forward to can help.
- Volunteering, having interests and hobbies or belonging to social groups or church communities can help people feel involved in wider society. Having opportunities to be 'active' and join in were clearly important, but this may become increasingly difficult with age and frailty.
- Financial resources are important and 'having enough' without having to worry both in the present and the future was a common theme. Most people indicated that they managed on their current income (whatever level it was), but for some receiving benefits was crucial in achieving this. The necessity of planning ahead and careful management of income was something learned early on in life by many.
- The increased use of technology creates both opportunities and barriers. New technologies can be a means of communication when physical activity and travel become problematic, and can be valuable for keeping in touch with family and friends living

- abroad. Difficulties in learning to use technology and not knowing what to do when things go wrong can create anxiety and contribute to people feeling out of touch or left behind. Many experience frustration with the assumption that everyone feels comfortable with using ICT and some felt at a disadvantage and even penalised if they did not move to online payments methods.

Places and environment

- Feeling safe at home is important and having someone, like a neighbour who will notice if anything is not quite as it should be, added to people's sense of security.
- Keeping the home in good order, often in the face of increasing difficulty due to mobility or health problems, is also important. Older people want to have a degree of control over their living environment. Managing the maintenance of the home was a source of anxiety, particularly for those who live alone. This included difficulty in finding trustworthy trades people to carry out repairs and the costs involved in structural work that might be needed. Concerns about not being able to manage the home and garden may shape decisions to move to a more manageable home.
- Local buses and free bus travel were greatly appreciated. For those with limited mobility or without a car, and who were able to use buses, being able to get to places with relative ease was important for accessing services and keeping connected. Some parts of the city are not easily accessible by bus, particularly the seafront which is a popular area for many.
- Some areas of the city were avoided, due to difficulties in negotiating the crowds, or at night time. Many people are reluctant to go out at night which restricts social life and many highlighted the importance of accessible day time activities.
- Some of the difficulties in getting around the city can be attributed to the physical landscape with its steep hills. This creates difficulty in accessing many areas of the city, particularly for those with mobility problems. But one advantage of the hilly landscape is the views it offers which are important to some.
- The ways in which people spoke about the sea and seafront and other public places, like parks and gardens, indicate that having access to outdoor space can positively contribute to well-being.
- Many described Brighton and Hove as a lively place and enjoyed the cultural life it offers. Being able to go out and enjoy public spaces and facilities as an older person was affected by practical considerations, such as availability of public toilets and seating.
- Having a 'place' in the world as an older person depended on the extent to which needs were recognised and acknowledged on an everyday level, on the ways other people treat them and how they see themselves as older people. How people feel about ageing is not only related to self perceptions, but wider societal attitudes towards ageing and older people.

Narrative analysis

In addition to the thematic analysis seven interviews were selected to undertake a narrative analysis looking at each interview as a whole and the nature of the stories that run through them. This offers ways of understanding how issues such as people's experiences of poor health – their own or that of close relatives; their feelings about Brighton and Hove as a place to live; or their

responses to the social changes taking place around them, interact in the context of their lived lives. They offer an account of well-being that highlights the significance of being able to make sense of life changes over time and thus the need to understand well-being not as a steady state, but as a dynamic process of responding, adapting and negotiating.

Being well through change and loss

- Different narratives emphasised both loss and disruption, and adaptability and resilience.
- The significance of loss of different kinds: those associated with physical capacity; loss of valued activities; the loss of people who have been very important, were key issues. People were learning they could not always 'be the person you used to be'.
- The capacity to adapt, develop new skills and find ways of 'getting through' can themselves be sources of well-being. While this requires hard work in a practical sense of maintaining the circumstances that might be capable of sustaining things that are important to people's sense of well-being, this work of adaptation also involves a substantial amount of emotional labour.
- Changing cultural and social norms are important and the way in which these impact on subjective well-being affect older people in different ways (eg attitudes towards gay men and people with learning disabilities).
- Material circumstances can make it easier to mitigate losses (eg being confident that it will be possible to retain a home that is not only comfortable but enables contacts with the kind of physical environment that is a source of well-being)
- Particular historical moments and events can be significant in providing a benchmark against which to assess current circumstances and experiences (for this generation of older people, their war experiences are often significant).

Caring, being cared for and other relationships

- Care is vital to well-being, but can be a highly ambivalent experience for both care givers and receivers. This is affected by the extent to which care is supported and valued both personally and socially.
- For carers the experience of giving care to, or securing good care for, a spouse, can be fundamental to the carer's own well-being.
- The significance of care to well-being is not restricted to relationships identified as caring relationships. Human interaction, face to face contact and friendship are highly significant.
- The importance of reciprocity and the capacity to care for others remains important even for those with in difficult personal circumstances such as ill health.
- Narratives of relationships and care are both highly personal and reflect important social and cultural influences on well-being. They reinforce the way in which it is not possible to understand well-being as an individual state, but rather how it can be produced in and through relationships.

Recognition, respect and identity

- Being respected and treated properly can positively contribute to well-being.
- Old age and the way it is perceived can bring about a loss of recognition or respect.

- The people who spoke most explicitly about the importance of recognition are those whose identities may have been most threatened by others' attitudes towards them.
- Negative perceptions and experiences of loss can lead to internalized feelings of having outlived usefulness in old age.

Discussion: Learning to be 'well enough' in old age

Our analysis has revealed the very different experiences that constitute old age and the varied factors that affect well-being at this stage of life. We know that relationships of different types are important and we know that the resources and capacities that people have to adapt to personal and social changes can make a big difference to people's sense of being well in old age. We know that security, feeling like you 'belong', and being confident that help is there if you need it are all important.

There is a danger that definitions that emphasise physical health, people's capacity to plan and set goals, and to be active within their communities, may exclude from any hope of being well those people for whom old age is accompanied by illness, a reduction in their physical horizons because of mobility problems and who, because of advanced old age, are focused on being well in the present rather than planning for the future. We suggest it is useful to talk about being 'well enough', rather than setting a standard against which to measure older people's well-being.

The stories that people told of their personal experiences of growing older has led us to reflect on the 'work' that ageing entails, and the learning that is necessary to be well enough at different stages of older age. These are processes that require change and adaptation over a period that may be longer than that from birth to adulthood. Both the work and the learning that is required need to be done not only by older people themselves but by us all if the ageing of the population is to be experienced collectively as a positive development, rather than a 'problem' to be managed.

Older people learning to be 'well enough'

- Learning to be 'well enough' involves both emotional and organizational labour during the processes of personal, interpersonal and social change that accompany ageing. Changes are not only physical, but also involve changes in roles and expectations, in the way people are viewed by others, and changes amongst those other people who constitute sources of companionship, friendship and love.
- Emotional labour includes things such as: learning how to ask for and accept help; responding to changes in close relationships; dealing with a sense of declining visibility, a lack of recognition of one's strengths and experience and, in some cases, identity. The capacity to do this emotional work can be substantially enhanced by the support of others – including other older people.
- Planning and organization form a considerable part of labouring to be 'well enough'. This can involve the everyday work of planning routes to the shops to avoid hills and ensure use of services close to bus stops; or reviewing the availability of public toilets, seating and other practical supports to make the experience of going out a source of well-being rather than something that reinforces a sense of loss. It can also involve 'bigger' planning, including difficult decisions about making changes in one's life.
- Older people have to make many difficult decisions that can be experienced as emotionally and organizationally draining, rather than a source of empowerment. The way in which they are cared for and supported through these processes makes a huge difference to their well-being. The emphasis on individual choice, rather than collective attentiveness to the impact of public policies on older people's lives, and on individual attentiveness to need, is insufficient to enabling well-being.

Learning to be well with older people

- To be well enough in old age requires a supportive culture in which to grow old. Thus the learning that is required to maximise well-being is learning that we all need to do because the capacity of older people to experience well-being depends in part on the actions, attitudes and behaviours of younger people.
- This learning includes: how to give care that does not make the care receiver feel demeaned or a 'burden'; how to respond to people who may have changed in important ways because of physical frailty, memory loss, or because they are no longer able to do many of the things they used to do; learning to be sensitive to the tensions that exist between different values and to make good judgements about which should take priority in different circumstances.
- It is not only family and friends, but service providers, policy makers, urban designers and strangers who encounter older people in their daily lives who need to recognize how their actions, behaviours and decisions can enhance or undermine well-being.
- The quality of health and social care services can impact on the well-being not only of those who are actively making use of such services, but on the confidence of those concerned that they may need to in future. Whether people are prepared to ask for help when they need it may depend on the response they think they will get if they do so.
- If 'care' is considered less important than choice, if the message is that 'independence' is the most important thing to aim for, then this can undermine efforts to promote the importance of caring relationships to well-being.
- This learning can best come from maximising opportunities for people of different ages to interact personally, socially and politically, i.e. within the public spaces of everyday life, as well as the private spaces of family and friendship networks, in collaborations such as the one that generated this report, in the spaces of policy and political decision making.

Cultures, structures and resources

- Well-being is not directly related to wealth or the material circumstances of people's lives, but anxiety about having enough money can detract from well-being as well as reduce the options available to people. Older people do worry about having enough money to pay for the care they need, now or in the future. In the current economic climate fears around future financial security and cuts in health and social care budgets may exacerbate older people's anxieties.
- Understanding that well-being in old age is affected by differences that people have experienced at different stages, and sometimes throughout their lives, is important.
- Well-being in old age is not solely a function of individual choices and capacities to adapt. We need to think of how collective decisions about the way social life is organised, policies are made, particular characteristics are valued or de-valued and places are designed can all affect individual and collective well-being.
- Older people need to feel that both the physical places in which they live, and the social worlds they inhabit, are ones that recognise and include them. 'Age-friendly' communities are needed and made possible by prioritising: good public transport, accessible public buildings, and good quality health and social care services; and overcoming barriers, such as a lack of public seating, lack of public toilets, crowded streets, busy traffic, the decline of small shops / high streets, and the depersonalisation of services through increasing reliance on technology.

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Whilst the losses that often accompany old age can reduce resources to be well, survival and adaptation can also generate resources not available to younger people. Well-being is not something that can be achieved solely by being active in old age, but nor is it restricted to those who are able to maintain a high level of activity. It requires action by all of us, older people and those who hope to and will become old, to create the conditions in which our success in living longer is also a success in terms of ensuring old age is a time of well and not ill being.