

Background

Families are changing in ways that affect how they might care and support older members. The Oldest Generation project (TOG) studied a sample of families with at least one member over 75, in order to assess the impact of these trends on the lives of older people and their family relationships.

Methods

We called for volunteer families through the extensive UK-wide Open University network. In each family, one member over the age of 75 years, 'the senior', was to be interviewed in 2007 and again 18 months later, and another person, 'the recorder', was to keep a diary and to take photographs.

Forty families responded to our call, and we were able to select a sample that included a minimum number of families or seniors in each of a set of categories based on age, sex, location, living arrangements, marital status, children, class, place of birth and ethnicity (see Bytheway and Bornat, 2010, for details). Although diverse, the sample was not statistically representative and those who responded tended to be from middle income families. Moreover the volunteers nominated the 'senior' member of their family on the basis of their ability and willingness to participate. It should be noted that older people who have little family, a lone life style or who are dependent on means-tested statutory services for care are under-represented.

Only one family dropped out, shortly after the first interview, and was replaced by another. Over the course of the 18 months, two seniors died and a son and two daughters were interviewed in their place at the time of the second interview.

Key points

- The oldest generation has a key role in sustaining a family's sense of who they are.
- Within each family, there is a continuing and complex history of how care is negotiated between people of different generations.
- Families develop ways of caring for and supporting each other as family circumstances change when people move through life-stages and change location. These patterns continue into later life.
- Relationships with siblings and friends are some of the most enduring and most important in older people's lives.
- People continue to face major challenges in later life particularly when their health and wellbeing is threatened. Families expect to be partners in care with the NHS and care services
- Older people who are not using health and care services, draw on personal experience and family resources, when responding to needs and risks.
- This study using in depth interviews over time, provides insights into how people make choices over the course of long lives.

Our data derive from 24 life history interviews, 3,873 diary entries and 824 photographs. This material looks both to the past and future, including accounts of pre-war events and circumstances, and information about current activities and future expectations. The seniors were the focus but the research casts light on the unfolding histories of relationships between generations within the twelve families. The families' names have been changed for this paper.





Findings

Family identity

Identities within the families were defined largely by generation and relationship. So the twelve seniors were variously great grandparents, grandparents, parents, brothers or sisters, cousins, and aunts or uncles. As such they were central to the ways in which each family sustained a sense of shared identity. For example, Alan Shaw, one of two seniors with children living in Australia, and his wife were planning to visit their son even though their daughter thought they might need assistance in making the journey. They were, however, prepared to travel in order to sustain family links. All twelve families sent us photographs of family gatherings, and the seniors provided detailed histories of how they and their families had coped with major historical challenges over the course of the last century.

Family care over time.

The involvement of the seniors with younger generations was both practical and emotional, and had changed as each had moved through various life stages, and as family ties extended, in some cases over considerable distances, sometimes across nations. Regarding the changing economic climate, we found that the oldest generation feared more for younger people than for themselves.

Several families had experience of providing longterm care. For example, Alice Watson described not only how she had cared for her father and her husband when they were terminally ill, but also how she was still supporting her younger brother who, since his birth in 1935, has had both physical and mental impairments.

Currently he was living with a local family through an adult placement scheme and she continued to visit him regularly. Similarly, Angela Rammell had a middle-aged daughter who has serious learning difficulties and was living in a nearby group home. Angela visited her regularly and preferred to stay close by rather than to move nearer her other two daughters who lived some distance away and had professional careers. They recognised the part that their mother was playing in supporting their sister.

Siblings and friends

The relationships which older people have with siblings, cousins and old school friends, are often the longest lasting, and in the twelve families there was evidence that they continue to be important both materially and in terms of individual meaning. Often distance prevented face-to-face contact but, through the telephone, email, the post and go-betweens, mutual affection and support was sustained. Marion and Adam Arthur each have one sibling. Marion's sister, widowed and without children, regularly visited them. Meanwhile Adam's sister, Daphne, who had never married, was living in a care home in a distant part of the country. She was unhappy there and, through the telephone, the internet and visits to Daphne by his daughter, Adam was trying to find a more satisfactory home for her. Another senior, Albert Rice, was born in Jamaica and, in addition to maintaining regular contact with his sisters there and in the USA, he kept in touch with friends who, like him, had emigrated to Britain in the 1950s and 1960s. Although he



had friends who had retired to Jamaica he was not tempted to follow them, given that his own children were living in England with their own families.

Life transformations

The seniors were continuing to face major decisions and challenges that had the potential to transform their lives. Over the course of the project, we followed bereavements, house moves, cross-national reunions and personal decisions such as to give up driving. Some of these related to health and wellbeing and, in particular, to statutory services including the NHS. Wilma Frame had moved from south Wales to Yorkshire to live with her daughter and family. In the interviews she was able to talk about how, given increasing health problems, she had come to decide she could no longer manage on her own. The diaries, kept by her daughter, illustrate not only how Wilma was coping to living with others, but also how she was adapting to different health services.

Some challenges had major consequences not only for close family relationships but also the wider network. Marie Rees for example lived on a Scottish island and had been a volunteer for the Red Cross. Her husband now had a serious chronic condition and Marie travelled with him when he required hospital treatment on the mainland. This took several weeks and she was able to be with him, staying in a Red Cross hostel. Whilst there, she renewed links with other relatives living on the mainland.

Care and support

Among the twelve families, some members of the oldest generation needed regular care and support. This was provided by partners, family, neighbours and occasionally, formal services. There was a commitment to family-based care. The seniors and their families were alert to signs of change and there were examples of how they sought to forestall sudden crises.

When the person needing care was married, the spouse played a critical part. The wife of Geoff Roberts for example had dementia and, although they received support from their four children (all living close by) and from their local authority, it was Geoff who provided the bulk of her daily care.





Regrettably Geoff died during the course of the 18 months, and it was left to the children to provide the support that their mother needed. At the time of the second interview they were looking at options for full time care in a residential setting.

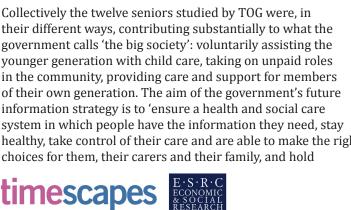
Recommendations for Practice

The government puts personalisation at the forefront of current policy (DH, 2010). However, it recognises however that, in exercising choice, older people may need support in managing their care. Moreover it is promoting a range of person-centred approaches for rehabilitation. The findings of the TOG project have implications for these developments:

- When an older person is first referred to a service providing care, this follows an acceptance by them and their family that there is no alternative, even so this may possibly convey a sense of personal or family failure. Practitioners should recognise this in discussing and agreeing a way in which the service can support the family whilst meeting the individual's needs.
- In assisting them to make 'the right choice', practitioners should ask older people about their past experiences in order to ensure that interventions and new situations support their family and friendship networks. This will ensure that older people remain actively involved in decision-making about their continuing lives.
- Family and friends are of great significance to the quality of the everyday life of older people, particularly when they are receiving routine treatment or care. Through close contact and regular communication they are alert to small changes and the risk of crises developing. Those practitioners providing routine or short-term treatments should periodically check whether carers might welcome the support of other care services. They should however take full account of the expressed choices of the older
- We have found that asking older people to recount stories about health and wellbeing within their families has provided them with the opportunity to reflect on values and knowledge, and to express their conflicting emotions regarding available options. If practitioners were to follow this practice, then the choices that followed would be all the more effective in ensuring high quality care.

Recommendations for Policy

their different ways, contributing substantially to what the government calls 'the big society': voluntarily assisting the younger generation with child care, taking on unpaid roles in the community, providing care and support for members of their own generation. The aim of the government's future information strategy is to 'ensure a health and social care system in which people have the information they need, stay healthy, take control of their care and are able to make the right choices for them, their carers and their family, and hold





the system to account' (DH 2011). Recent UK debates however, relating to personal income, education, employment and the NHS, have fostered divisions which undermine the real and symbolic value of ties between the generations. To continue to play their part in family and wider social relationships, older people need to be able to draw upon an adequate income, health care free at the point of need and ready access to affordable public transport.

Our findings relate to the personalisation agenda and the need to strike a balance between preferences and effectiveness in ensuring a good quality of care. In order to move beyond the current rhetoric and make personalisation work, research must inform policy and we offer the following recommendations:





- In collaboration with professionals working with reliable agencies (whether statutory, voluntary or commercial) personalisation should be achievable for those left to organise their own care as a consequence of means-testing policies. Strategies should be identified whereby help required at a personal level is equitable, safe and affordable with the older person actively involved in the decisions that are taken
- Through ready access to appropriate housing, transport, health, learning, education, communication and income, policy should help older people to continue to play their part in family and community life as active citizens
- The training and development of professionals who engage with older people social workers, nurses, doctors, therapists, welfare rights workers, care workers and others – should include modules on age and ageing in C21 UK society
- Care settings and the wider social environment should be made more sensitive to the needs and contribution of older people through the promotion of age awareness and non-discriminatory policies
- Policy should recognise that exposés of poor care practice (e.g. PHSO, 2011) do not inspire the oldest generation or their families to be confident about the future, and so should prioritise good quality care for the individual with a complex mix of needs
- This kind of study, using qualitative longitudinal data about older people, is potentially of great use in assessing the long-term impact of policy and practice and in implementing the 'personalisation' agenda effectively, and so we recommend that policy should pay close attention to such research.

References and Further Reading

Bornat, J & Bytheway, B (2008) 'Tracking the lives of the oldest generation', *Generations Review*, vol 18, 4. Accessed online at: http://www.britishgerontology.org/08newsletter4/research.asp

Bornat, J & Bytheway, B (2010a) 'Perceptions and presentations of living with risk in later life', *British Journal of Social Work*, 1-17, doi:10.1093/bjsw/bcq001

Bornat, J & Bytheway, B (2010b) 'Late life reflections on the downturn: perspectives from The Oldest Generation', 21st *Century Society*, forthcoming

Bytheway, B., Bornat, J., Edwards, R. and Weller, S. (2008) *Sisters and Brothers: Results of a UK-wide postcard exercise*, ESRC Festival of Social Science 2008, http://www.lsbu.ac.uk/families/brothersandsisters/

Bytheway, B. and Bornat, J. (2010) 'Recruitment for 'The Oldest Generation' Project', in F. Shirani and S. Weller (eds) *Conducting Qualitative Longitudinal Research: Fieldwork Experiences*, Timescapes Working Paper Series No. 2.

Bytheway, B. and Bornat, J. (forthcoming) 'Family images of the oldest generation', in Ylanne, V. (ed), Age, Image, Identity, Palgrave.

DH (2010) A vision for adult social care: capable communities and active citizens, Department of Health.

DH (2011) Transparency in outcomes: a framework for adult social care, Department of Health.

PHSO (2011) Care and compassion? Report of the Health Service Ombudsman.

Sheldon, R. (2009) 'Breaking "a strange silence", Public Policy Research, 16.2, 98-102.





