JRF JOSEPH ROWNTREE FOUNDATION

INSPIRING SOCIAL CHANGE

IMPROVING DECISION-MAKING IN THE CARE AND SUPPORT OF OLDER PEOPLE

This evidence review considers how to improve decisions made by and for older people about their care and support. It investigates how formal, semi-formal and informal relationships can work together to best effect, and the relationship between risk, trust, and good decision-making.

Key points

- Making decisions about older people's care is a complex social process. It includes the older person needing care, formal care providers, informal carers and the wider community.
- The traditional view that decisions are made on the basis of logic and rationale is outdated. Many factors influence the 'players' in decision-making: among them, negative stereotypes of older people, risk avoidance, cultural perceptions and the need to feel they are 'doing the right thing'.
- Older people rely more on gut instinct, feelings and experience than deliberative cognitive processes when making decisions but this does not lead to poorer decisions.
- A high level of trust between the older person and others involved in the decision appears to be a major factor in making good decisions.
- Concern tends to be centred on the risk of physical harm, at the expense of less obvious risks to autonomy, identity, self-esteem and sense of control, which are as important for older people as avoiding physical harm.
- 'Blame culture' has led to a growth in procedures to minimise risk but this approach undermines trust, and underpins risk aversion.
- Narratives – the stories we hear and tell – play an essential part in building trust, developing a sensible attitude to risk and making positive decisions about an older person's care and support. An emphasis on overall psychosocial well-being and a shift towards positive risk-taking play a part in making good decisions about older people's care and support.
- There should be less emphasis on blame if things go wrong. Genuine partnerships between care providers and care recipients, with shared responsibility for decision-making, is the way to establish trust and improve the likelihood of making good decisions.

The research

By a team from the RSA
Action and Research Centre

DECEMBER 2012

BACKGROUND

In the next 30 years the proportion of the population in retirement is likely to rise significantly. Excessive risk-aversion can harm older people's wellbeing, but the rise of a culture of blame in society has heightened the need for practitioners to protect their own interests. How can decision-making – by formal and informal carers – be improved in order to promote a more effective and rewarding environment for older people and those who care for them and support them?

Reconciling respect for older people's autonomy with a recognition of their vulnerability is particularly problematic in the management of risk and decision-making affecting the care of older people.

Using what the authors call the 'decision-making ecology' this study exposes underlying tensions in the interactions between different people making decisions about support for older people – formal, semi-formal, informal and older people themselves.

How decisions are made

Conscious rationality is the exception rather than the rule in confident decision-making in an ageing society: the role of habit, the influence of social norms and the need to feel like we are 'doing the right thing' all play a part. The classic assumption that more choice leads to better outcomes has also been rejected by some commentators. Too much choice, combined with the lack of support in forming strategies for choosing, can be a source of stress for older people and those associated with their care.

The decision-making ecology

The many influences on decisions about risk and trust in an ageing society can be termed a 'decision ecology', encompassing the context and the interlinking issues that bear on decision. In this ecology there are broadly three types of decisions made: by older people about their own care; by older people and their carers about levels of independence; and by non-formal carers about whether to provide care and/or be kind to older people. There are four relevant categories of individual: older people needing care; formal, paid carers; informal carers providing regular unpaid care; and the wider community including neighbours. People may have multiple and changing roles.

Key features of the decision ecology include:

- older people get help from others to make better decisions;
- neighbours play a distinctive role;
- non-kin support of independent people and volunteers is important;
- community networks contribute significantly to decision-making and care;
- different relationships provide different types of support for older people;
- the support provided by different people is fluid;
- the motivation of formal workers and semi-formal volunteers in caring professions is based on strong values;
- formal carers can make the wrong decisions and tend to be overly risk averse;
- informal connections do not necessarily result in better decisions;
- older people's well-being can be compromised by conflicts in relationships
- older people make valuable contributions to society.

Influences on caring decisions

Many factors may influence people involved in caring decisions, including: negative stereotypes of older people; a hardening of attitude towards those in need; attitudes to risk; mood; gender.

Older people rely more on affect – gut instinct, feelings and experience – than deliberative cognitive processes but their accumulated knowledge and experience appears to compensate for a decline in effortful thinking. Factors such as attitudes to risk, changing priorities in old age and security affect decision-making. Older people often underplay their susceptibility to risk, seeing risks in terms of external factors, rather than their own frailty. Social factors also influence decision-making.

High-trust relationships increase the likelihood of formal carers making good decisions about care. For example, older people generally trust doctors and allow them a major role in decisions about health. However, for good decision-making in a medical context, doctors need to build and maintain a good relationship with older patients. Factors that undermine trust (e.g. high staff turnover, perceived professional incompetence) reduce the likelihood of good decision-making.

The rise of a culture of blame in society as a whole has heightened the need for practitioners to protect their own interests. Risk-avoidance may outweigh a person's autonomy and this can lead to depersonalisation and a breakdown in trust. Organisational and professional cultures are an important influence on approaches to decision-making. The degree of trust in colleagues and their support is an important factor, and different styles of decision-making are found in different professional groups. The context in which decisions are taken is significant. Some caring decisions are taken at times of crisis, and the type and scale of the crisis is an influence on decision-making.

When making decisions that crop up in the course of caring, informal carers (like formal carers) have interests of their own which may influence decision-making. The involvement of the wider community in caring decisions made about individuals reflects the nature of support they give. Typically friends and neighbours give social support and help with tasks such as shopping and gardening. The support they give is limited by factors such as time, other commitments and what feels socially acceptable.

Caring decisions are complex. People in different roles see situations differently and bring different needs and interests to the decision-making process. However, there is evidence that high-trust relationships are a major factor in making good decisions. Acknowledging different points of view helps to build trust.

The role of narrative

Stories – written or verbal – appear to have an important role in helping older people take control, and helping carers to better understand their needs; narrative communication techniques are better at holding attention than the presentation of technical material. 'Risk statistics' often do little to change people's perceptions, but narratives of risk can change attitudes and behaviour because they tap into non-rational, values-based, more emotional factors. Professionals have the choice to help older people structure and tell their own stories as a means to gain autonomy and make decisions with confidence. Narratives are therefore essential in understanding how individuals and organisations understand risk, developing strategies for engendering trust and making positive decisions.

Risk and trust

In organisations providing services to older people concern tends to be centred on the risk of physical harm, at the expense of less obvious and measurable risks to autonomy, identity, self-esteem and sense of control. However, for older people these things are as important as avoiding physical harm. Distressing losses of life skills and mobility often result from restrictions intended for their protection. Defensive practice leads to frustrating rules and restrictions for older people and eats into staff time. This has adverse effects on personal and emotional relationships with clients. Older people's trust in organisations and the people who work for them is undermined as a result. Unpaid carers may also become over-protective of those they care for, usually as a result of the stress, anxiety and exhaustion associated with informal care. Again, this can have consequences for the well-being of those they care for.

The authors advocate a shift in approach from risk aversion to positive risk-taking. The principles of the 2005 Mental Capacity Act are relevant to all older people who need care. The evidence indicates that trust built through relationships cannot be replaced by trust built through regulation-based risk

management procedures. Effective care for older people relies on trust, and trust requires an attitude to risk management which has the psychosocial well-being of older people at its heart.

Responsibility

Given the large number of different players in the decision-making ecology, it is not obvious who should take decisions and who should have responsibility if things go wrong. Countering the paternalistic culture of care that has grown as a result of state intervention, there are initiatives to pass more responsibility to service users, with involvement, choice and control emerging as key themes.

There are good reasons for vulnerable older people to have prime responsibility for their care. Both formal and informal carers tend to have difficulty in fully appreciating the perspectives of those needing care, and their judgements can be biased by their own interests. However the value of paid practitioners' knowledge and experience in helping older people to make appropriate choices should not be overlooked, nor should the effect on family and other unpaid carers of decisions about care. The authors suggest there should be shared responsibility, with a distribution that takes account of the different players' capacities and relevant expertise.

Conclusion

Effective decision-making requires constructive partnerships between older people (carers and cared-for), and informal and formal carers that understand their value, potential shortcomings and strengths. Professionals and the wider public must recognise that *risk elimination* is a myth. The well-being of older people requires positive risk-taking, and things will sometimes go wrong. Informal carers also have special expertise, and there is no substitute for personal relationships and responsibilities. However, informal support can be misinformed, and is not always kind, loving, or helpful.

Effective decision-making through partnership requires mutual appreciation of the different nature of risk and trust in formal and informal care and support. We must go beyond the cognitive 'fit' between older people and decisions about their care, to consider also the ethical, psychological and political 'fit' amongst attitudes to risk, willingness to trust, and daring to be kind.

About the project

The review included material that might usually be excluded from systematic reviews, including anecdotal evidence from practitioners and non-academic literature. The research team searched several electronic databases using an iterative search strategy, and searched for non-academic literature and anecdotal evidence. They used databases, search engines and networks of professional contacts.

FOR FURTHER INFORMATION

This summary is part of JRF's research and development programme. The views are those of the authors and not necessarily those of the JRF. The main report, **Improving decision-making in the care and support of older people: Exploring the decision ecology** *by the RSA Research and Action Centre*, is available as a free download at www.jrf.org.uk

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ISSN 0958–3084

Joseph Rowntree Foundation
The Homestead
40 Water End
York YO30 6WP
Tel: 01904 615905

email: publications@jrf.org.uk
www.jrf.org.uk
Ref: 2815