It keeps me going’ – older people’s perception of wellbeing and use of complementary and alternative medicine (CAM)

Ava Lorenc¹, Angela Clow², Denise Forte³, Nicola Robinson¹

1. Faculty of Health and Social Care, London South Bank University, 103 Borough Road, London, SE1 0AA; telephone: (0)207 7815 7940; fax (0)207 7815 8490; email: lorenca@lsbu.ac.uk

2. Department of Psychology, University of Westminster, 309, Regent Street, London, W1B 2UW. Telephone (0)207 911 5000

3. Faculty of Health & Social Care Sciences, St George’s University of London Campus, Cranmer Terrace, London SW17 0RE, Telephone (0)2087250146
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ABSTRACT

Purpose

To explore older peoples’ decision-making regarding CAM use and their perceptions and experiences of well-being.

Methods

Qualitative focus groups with 37 volunteers aged over 61 years explored health and well-being decision making were held at a community centre in southwest London. Data was content analysed.

Findings

Five themes emerged; physical well-being, impact on activity, emotional issues, community and health services, and keeping positive. A range of CAM was used, most commonly mind/body or physical therapies. The main reason for CAM use was to ‘keep going’ and maintain well-being. Conventional medicine was perceived as central to well-being, with CAM used to address its limitations. Decision making was rarely systematic; anecdotal information dominated, and disclosure to conventional practitioners was uncommon.

Conclusions

‘Keeping going’ is important for older people and often promoted by CAM, including manipulative and exercise therapies. Concurrent CAM and conventional medication use, unreliable information or and insufficient discussion with conventional providers may have safety implications. Nurses should consider exploring CAM use with older people and facilitating access to CAM information.

Practical implications
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Asking older people about CAM use may be integral to providing holistic, safe care. CAM use may provide an opportunity for health promotion in older people by encouraging self-management and responsibility for health.

Originality/value

Although up to half of older people in the UK may use complementary/alternative medicine (CAM), there is little information on their decision-making process.

Key words

Older people; complementary and alternative medicine (CAM); well-being
Background

The proportion of the UK population aged over 65 years rose from 15% in 1984 to 16% in 2009 and is projected to be 23% by 2024 (Office for National Statistics, 2010). Older people are likely to suffer from chronic ill health (Wolff et al., 2002) and functional impairment (Brayne et al., 2001) which increases pressure on health and social care systems.

Complementary and alternative medicine (CAM), healthcare usually defined as health care approaches outside of conventional medicine, includes natural products, mind-body medicine and manipulative practices (NCCAM, 2007). Although research is contradictory, significant proportions of older people appear to use CAM (Willison et al., 2004) and prevalence is thought to be increasing (Flaherty and Takahashi, 2004). Figures vary between 28% to 87% in national USA surveys (McMahan and Lutz, 2004; Ness et al., 2005) and between 9.9% and 14.6% in Australia (Tilden et al., 2004). CAM use may decline with age (Wellman et al., 2001), but end of life CAM use has been estimated at 50% (Adams et al., 2009a). Consistent with research on other age groups, CAM use is more likely for those who are female (Adams et al., 2009a), better educated (Votova and Wister, 2007) and have higher income (Kelner and Wellman, 2001).

Common CAMs used by older adults include; nutritional supplements, herbal medicine, spiritual healing and chiropractic (Evans et al., 2009), acupuncture and relaxation (Bowling, 2002). Research has demonstrated associations between older peoples’ CAM use and physical health problems (Cherniack et al., 2001), especially long-term conditions (Buono et al., 2001), thyroid (Wellman et al., 2001), depression (Wellman et al., 2001), anxiety (Adams et al., 2009a), arthritis (Cheung et al., 2007), respiratory diseases (Kelner & Wellman, 2001), neuropsychiatric disorders (Votova & Wister, 2007), musculoskeletal and emotional problems (Cheung et al., 2007). CAM is often used for general health maintenance (AARP, 2007 3074 /id) or more sporadically (Kelner & Wellman, 2001), for example for pain relief (Wellman et al., 2001). Older people may also seek CAM for problems which impact their
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daily activities and relationships (Buono et al., 2001). They may also use CAM due to a
desire for control and responsibility regarding their healthcare (Willison et al., 2004; Evans et
al., 2009). CAM has the potential to promote successful ageing, independence and quality
of life, and reduce frailty (Brown, 1999; Bloor et al., 2001). However, to inform policy and
practice, more research is needed on older peoples’ use of CAM (Andrews, 2002; Adams et
al., 2009b). It has been found that older people may be more likely to rely on conventional
medicine than CAM (Rabiee, 2004). If the safe use of CAM is to be facilitated amongst older
people it is necessary to explore how older people make decisions about their health and
well-being.

This study explored the decision-making processes of older peoples’ use of CAM and how
this related to their perception and experience of wellbeing.

Methods

This study was part of a larger project on older peoples’ wellbeing (Evans et al., 2009; Evans
et al., 2011). Participants were volunteers from community voluntary organisations (Evans
et al., 2009). This article reports data gathered at a ‘participant engagement event’ in
November 2008 held at a community centre. The event was part of a series of similar
events convened over the previous 3 years, all of which were part of the same research
project, and meant that many of the participants had got to know each other and were
comfortable discussing issues together. Attendees were divided into three groups. Each
group was separately involved in two focus groups. The first focussed on perceived
meaning of wellbeing, changes in wellbeing since the group last met (3 years previously),
and factors influencing wellbeing. The second explored complementary and alternative
medicine (CAM) use, health care decision making and discussion with their conventional
healthcare providers.
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Focus groups are recommended for exploring beliefs and opinions, as well as understanding and reasons behind these beliefs and complex behaviours (Cartwright, 2007). They are particularly suitable for marginalised groups such as older people (Coreil et al., 2001) and for accessing normative understanding (Wellman et al., 2001), which is thought to be important in CAM use. The focus group facilitator was experienced in focus group methodology and encouraged group discussion and a natural flowing conversation, while ensuring every participant contributed. A second researcher acted as a scribe and made notes, particularly observing non-verbal communication. A topic guide was used, which included questions on participants’ understanding of what CAM is, use of CAM for themselves and family members, decision making regarding healthcare use, and their experiences communicating with healthcare professionals about CAM.

The groups’ discussions were digitally recorded and transcribed verbatim. Data were content analysed to identify data on a number of topics informed by the literature and the data, facilitated by Atlas.ti qualitative analysis software. A series of themes and subthemes were identified and all text was coded with one or more themes. Quotes from each theme were analysed for similarities, and the results for each theme summarised.

Results

A total of 37 people attended the event: 73% were over 70 years, mean age 75 years (table 1); 68% (25) female, 35% (13) married, 30% (11) widowed and 87% (32) reported suffering with chronic medical conditions (table 2).

<table>
<thead>
<tr>
<th>Age range</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>61 - 65</td>
<td>2</td>
</tr>
<tr>
<td>66- 70</td>
<td>8 (21.6%)</td>
</tr>
<tr>
<td>71- 75</td>
<td>9 (24.3%)</td>
</tr>
<tr>
<td>76 – 80</td>
<td>12 (32.4%)</td>
</tr>
<tr>
<td>81 – 85</td>
<td>4 (10.8%)</td>
</tr>
<tr>
<td>86+</td>
<td>2</td>
</tr>
</tbody>
</table>
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Table 2: Medical conditions of sample

<table>
<thead>
<tr>
<th>Condition</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>High blood pressure</td>
<td>13 (35%)</td>
</tr>
<tr>
<td>Arthritis</td>
<td>11 (30%)</td>
</tr>
<tr>
<td>Digestive problems</td>
<td>7 (19%)</td>
</tr>
<tr>
<td>High cholesterol</td>
<td>5 (14%)</td>
</tr>
<tr>
<td>Cardiac</td>
<td>4 (11%)</td>
</tr>
<tr>
<td>Sight problems</td>
<td>4 (11%)</td>
</tr>
<tr>
<td>Endocrine</td>
<td>4 (11%)</td>
</tr>
<tr>
<td>Asthma</td>
<td>3</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>3</td>
</tr>
<tr>
<td>Other musculoskeletal</td>
<td>2</td>
</tr>
<tr>
<td>Cancer</td>
<td>2</td>
</tr>
<tr>
<td>Other\a</td>
<td>8</td>
</tr>
<tr>
<td>a. allergies; epilepsy; gout; immobility; skin</td>
<td></td>
</tr>
</tbody>
</table>

Predictors of well-being and changes in well-being

Five common themes emerged from participants' discussions of wellbeing: physical wellbeing; impact on activity; emotional issues; community and health services; and keeping positive. Wellbeing was described by one participant as 'relief and reassurance'.

Physical wellbeing was important to most participants. Most had chronic health conditions (see table 2) and 31 (84%) were taking prescribed medication, and often expressed concern with medication, including side effects. Table 3 shows significant life events in the past 2 years which were reported to impact upon well-being over that time span. –Family issues and illness featured highly, as did finance, illness and housing issues. Examples of negative events included developing arthritis, having a stroke, a bad fall, and wellbeing deteriorating due to stress or age. Positive ‘events’ were either reported as activities which participants chose to take part in such as physical activity, gardening, voluntary work and artwork or events which involved interaction with the family. Eleven people (30%) did not report any significant changes in their wellbeing over the past 2 years.
Table 3: Significant events affecting wellbeing in past 2 years

<table>
<thead>
<tr>
<th>Positive events</th>
<th>Frequency</th>
<th>Negative events</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family issues (positive) e.g. birth, job</td>
<td>6</td>
<td>Income decreased</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Aggravation of condition</td>
<td>4</td>
</tr>
<tr>
<td>Improved treatment</td>
<td>4</td>
<td>Family /friend/pet illness</td>
<td>4</td>
</tr>
<tr>
<td>More physical activity/gardening</td>
<td>2</td>
<td>Bereavement</td>
<td>4</td>
</tr>
<tr>
<td>Music practice</td>
<td>2</td>
<td>New condition</td>
<td>3</td>
</tr>
<tr>
<td>Improved income</td>
<td>1</td>
<td>Moved house</td>
<td>2</td>
</tr>
<tr>
<td>Voluntary work</td>
<td>1</td>
<td>Family issues (negative)</td>
<td>2</td>
</tr>
<tr>
<td>Marriage</td>
<td>1</td>
<td>Loss of social support</td>
<td>2</td>
</tr>
<tr>
<td>Weight loss</td>
<td>1</td>
<td>Renovation to house</td>
<td>2</td>
</tr>
<tr>
<td>Artwork</td>
<td>1</td>
<td>Lack of medical treatment</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less exercise</td>
<td>1</td>
</tr>
<tr>
<td>Unspecified</td>
<td>1</td>
<td></td>
<td></td>
</tr>
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</table>

Wellbeing was strongly related to participants’ ability to be involved in physical activity with health problems which prevented physical activity being considered as more serious. Keeping active was perceived as important for health maintenance and wellbeing, e.g. going out every day, keeping busy, charity work, playing the piano and exercise (keep fit, yoga, bowls, tai chi and walking).

The negative impact of stress on health and well-being was the main emotional factor identified, for example stress arising from family problems, caring for family members who had health problems, and voluntary work. However, most believed that these stresses were temporary and they were ‘through the worst of it’. Many participants also mentioned finance negatively impacting their wellbeing.

Community and health services were important, with concern expressed about the future of community services such as post offices and libraries and their ability to access them in the future. Confidence in and feeling cared for by their conventional medical provider created a feeling of wellbeing though perceived quality of health services varied.
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Keeping positive was important for many participants, for example one participant reported focusing on their remaining abilities after having had a stroke. Some participants were ‘inspired’ by others with severe health problems who still continued to live rewarding lives.

Use of complementary and alternative medicine

A range of CAM was used, most commonly mind/body or physical approaches, often to tackle mobility problems, including yoga, tai chi, Alexander technique, osteopathy, chiropractic, acupuncture and exercises. These tended to be used long term, perceived as supportive and for ‘keeping them going’. Acupuncture was used for musculoskeletal problems and reflexology, aromatherapy and massage used for ‘relaxing’.

“it [osteopathy] sort of keeps me going”

“I’ve used acupuncture for a specific complaint, a frozen shoulder, and that certainly worked”

Some participants mentioned the use of psychological or religious approaches but this was less common, while having faith (“in something”) was generally felt by some to improve wellbeing.

“I do everything I can to support my health…by changing attitudes”.

Some used dietary supplements, including cod liver oil, glucosamine and vitamin C as well as traditional herbs and spices, which they found effective e.g. clove oil for toothache, ginger for digestion, feverfew for arthritis or turmeric for wound healing.
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Other CAM perceived as helpful were music therapy which was perceived as helping memory, breathing for general wellbeing, magnet therapy for knee pain and homeopathy for toothache.

**Varied effects**

Perceived effectiveness of CAM varied and was based in personal experience, anecdotal reports and to a lesser extent research evidence. The most common reported positive effects were on improving joint mobility and pain, followed by positive outcomes on stress and mood.

“it’s [playing the piano] bloody marvellous!...my memory is better, I’m more alert, my breathing is better”

“I am still an AT [Alexander Technique] student, I swear by it...my temper improved immeasurably as a result of not being in pain”

“osteopathy, yes I’m a great believer in that”

There was some disagreement in the group on the effectiveness of supplements and acupuncture but scepticism mainly focussed on homeopathy and reflexology. One person reported CAM (reflexology diagnosis and homeopathy for toothache) effective despite his scepticism and another was very sceptical due to trying to understand the mechanism of action and the evidence-base.

“something I’ve always, not despised, but thought ludicrous, where you dilute and dilute and dilute [homeopathy]”

“the science of reflexology, which I just cannot tolerate, that rubbing your big toe for instance will cure a headache. As a logical person, which I hope I am, I just cannot accept it”.
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Although a few were aware of adverse effects - including pain from acupuncture, blood clots from feverfew and St Johns wort interacting with conventional medicines – few had experienced these and most felt CAM was safe.

Deciding to use CAM – the limitations of the conventional approach
CAM was most commonly used to overcome conventional medicine limitations, such as for stress or musculoskeletal problems.

“doctors - I don't think they offer much help for stress”

CAM was also used to ‘get to the root of the problem’, compared to symptomatic conventional ‘quick fixes’.

“far better than the prescription from the doctor because the osteopath actually gets to the bottom of the matter”

Also, as identified in the wellbeing discussion, many participants were concerned about the side effects of conventional medication so used CAM instead.

“sometimes the side effects are worse than the actual illness you’re taking them for!”

“I won’t take anything at all, not a painkiller or anything; I think they’re all poisons”

The relationship between CAM and the NHS varied - most did not talk to the conventional healthcare providers about their CAM use. However, many accessed CAM via conventional medicine, from their doctor, hospital or pharmacist and reported that availability of NHS CAM affected their decision making, due to financial cost and accessibility.

“at one stage you could get it [CAM] on the National Health Service….but with the cutbacks I think it’s not available”
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“My local chemist… has complementary medicines”

“How would you decide what sort of treatment you would use?
Participant: I think you would have to ask your doctor wouldn’t you?”

Lack of communication about CAM between medical practitioners and the patient was often due to the perception that consultations could only focus on one thing, due to both lack of time and the symptomatic focus of conventional medicine.

“well I could talk [to the GP] about anything but he’s always got somebody waiting”

“I don’t think they [conventional healthcare providers] want to know [about CAM], they’ve got a vested interest and they’re supported by the pharmaceutical drug companies”

The main reason for not using CAM was not having considered it.

Information from other people
The two main sources of CAM information were conventional healthcare providers and friends/family, some of whom practiced CAM. Participants exchanged information during the focus group itself.

“I think this sort of conversation [the focus group] is incredible, because people tell you things you haven’t thought and you think of new avenues to explore, it’s brilliant.”

Very few used published sources of information, with only three people mentioning the internet and two, newspapers/magazines. Information seeking was generally not proactive,
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with most people relying on information that they ‘happened upon’ such as adverts and word of mouth, and there was little awareness of books, specific websites or journals.

Discussion

Many participants currently or previously used CAM, mainly mind/body and herbal approaches. Other studies have found the most popular CAM for older people to be reflexology (Buono et al., 2001), massage (Buono et al., 2001) acupuncture (Cheung et al., 2007), chiropractic (Leontowitsch et al., 2010) and herbal medicine (Wellman et al., 2001).

Cartwright (2007) reported older people in London using CAM as part of ‘getting on with life’. This was the main issue regarding wellbeing in general, as well as for CAM use, particularly manipulative and exercise therapies. ‘Keeping going’ was mainly related to keeping active, which defined and maintained ‘wellbeing’. This was primarily mobility and physical wellbeing, but also ‘keeping positive’ and reducing stress (Wellman et al., 2001). The preventative and health-management qualities of CAM are well suited to such health maintenance (Adams et al., 2009b) and are a key aspect of the Department of Health QIPP agenda on self-care for those with long-term conditions (Department of Health, 2009).

‘Keeping going’ is commonly a central concept in older people’s health (Willison et al., 2004; Cartwright, 2007), including daily functioning, ‘the freedom to do what I want’, having energy, thinking positively and an absence of symptoms/pain (Cartwright, 2007). Stress was also an important issue in wellbeing, not felt to be adequately addressed by conventional medicine, with relaxation techniques commonly used (Adler et al., 2009). This emphasis on empowerment and personal responsibility for health and well-being has previously been identified as an aspect of older peoples’ CAM use (Adler et al., 2009). CAM use may therefore provide an opportunity for health promotion in older people by encouraging self-management and responsibility for health.
The perceived effectiveness of CAM in this study varied widely, with the effectiveness of acupuncture and supplements debated, as found previously (Buono et al., 2001). Another study has found a high satisfaction with CAM, although this may be subject to response bias (Cheung et al., 2007). We also found a range of attitudes to CAM in general, as expected in any population.

Conventional medicine appeared to play a central role in wellbeing and CAM use, with most participants conferring conventional medicine with considerable respect, and using it as a ‘safety net’ to allow experimentation with alternative healthcare (Leontowitsch et al., 2010). However the fear of negative side effects from prescribed medication was a significant factor with participants using CAM to address or avoid the limitations of conventional medicine, including ineffectiveness and side effects, (Wellman et al., 2001; Arcury et al., 2005; Leontowitsch et al., 2010). This use of CAM as a self-care approach echoes the UK Department of Health focus on patient choice and empowerment (Department of Health, 2009). Self-care support including information provision has the potential to save money and social capital, particularly for those with chronic illnesses, prevalent in an older population (Department of Health, 2007; Department of Health, 2009). Health care practitioners may have a central role in facilitating this self-care (Department of Health, 2009), particularly in this population who place trust in conventional care providers.

In this study some participants used CAM in a more decisive manner, usually due to scepticism and dissatisfaction with conventional medicine and this pluralistic healthcare ‘shopping around’ is known to be common amongst older people. This complementary use may have implications for safety and particularly drug-CAM interactions, exemplified by the adverse effects cited. Potential safety implications are another important reason for health care practitioners to discuss CAM with older people.
Limited income was identified as a negative impact on wellbeing, and may be a barrier to older people’s use of CAM, particularly given their access to conventional medicines free of charge in the UK. Information on affordable sources of CAM may be valuable for older people but requires the provision of an evidence based resource which will provide the potential user with confidence in accessing various CAM options. A subsidised CAM service for older people in London has previously been shown to be highly valued and users were confident in using CAM, despite initial scepticism (Cartwright, 2007).

Decision making processes identified during the focus groups were not particularly systematic, and based on mainly anecdotal and opportunistic information. However participants were generally keen to learn more, but unaware of where to find information. Health and community services played a central role in participants’ lives, with some accessing CAM in NHS settings. Although participants rarely mentioned nurses, studies comparing differences between health professions have shown that, compared with doctors, nurses may be more comfortable discussing these CAM approaches (Brown et al., 2007), have more positive attitudes to TCA (Easthope et al., 2000; Chez et al., 2001; Bourgeault and Hirschkorn, 2008) and be more likely to recommend (Sohn and Loveland Cook, 2002; Song et al., 2007; Bourgeault & Hirschkorn, 2008; Robinson and Lorenc, 2011). The nursing setting may therefore be the best location for older people to source CAM information, though community centres, post offices and libraries may also be useful.

Despite a reliance on conventional healthcare in general, older people may not raise the issue of CAM due to perceived time constraints and perceived lack of interest from conventional healthcare providers, particularly given the complex health needs and multiple morbidities in this population (AARP, 2007 3074 /id}{Montbriand, 2000 46 /id}. Conventional providers may also have differing perspectives to patients regarding CAM, including definition of CAM and perceived effectiveness (Lorenc et al., 2010). Reliable information in books, magazines, newspapers or the internet may also be useful, as older patients wish to manage their own healthcare.
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The participants were volunteers, which limits the generalisability of the findings to older people in general. Unfortunately data on individual participants was not available, so analysis of data according to demographic variables was not possible.

Conclusion

‘Keeping going’ is important for older people, and a range of CAM is used to promote this, including manipulative and exercise therapies to maintain activity levels. CAM use reflects pluralistic healthcare, often addressing perceived limitations of conventional healthcare. This complementary use may have potential safety implications given that older people overwhelmingly rely on friends and family for information on CAM and are unaware of the evidence base. Clear and consistent sources of CAM information are needed so that older people can make an informed decision. Few discuss CAM with their conventional healthcare providers, despite a heavy reliance on conventional health settings for routine care, information and referral. We recommend that conventional practitioners recognise the prevalence of CAM use and the role CAM has in promoting health and wellbeing and are open to discussing CAM with their patients. Supporting safe access to CAM will promote and empower self-care by older people, in line with government guidance for people with long-term conditions.

Implications for practice

- Older people should be supported and empowered to access safe CAM as part of their self care. CAM is often perceived as ‘separate’ to conventional care by both older people and health care professionals, restricting discussion of CAM within the healthcare consultation. This occurs despite older peoples’ trust in health care professionals, and may be a barrier to preventing the provision of holistic, patient-centred care.
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- Concurrent use of CAM and conventional medicine (often polypharmacy) is common amongst older people, and may have safety implications. Health care professionals may need to discuss this as part of their duty of care to patients.

- Health care practitioners should be aware of reliable sources of information on CAM to facilitate onward referral.

Word count: 3319 (including quotes and references in text)

Funding

This study was funded by WestFocus, a collaborative partnership between several universities whose projects are supported by the Higher Education Funding Council of England (HEFCE).

Acknowledgements

We are very grateful to the participants and to those that helped organise the focus groups including Elizabeth Aitchison and Cathrine Fredhoi.

Contributions

AL and NR conducted the focus groups and analysed the data. AC and DF designed the study and organised recruitment. All authors contributed to writing the paper.
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