Review

The role of information in supporting self-care in vascular conditions: a conceptual and empirical review

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Accepted for publication 28 October 2010

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Abstract

Self-care has the potential to make a significant contribution to vascular conditions, but engagement with self-care support has been limited. Lack of relevant information is highlighted by patients and policy-makers as an important barrier to effective self-care, and information provides a potentially efficient platform for changing behaviour. However, work within the social sciences has generally seen information as a necessary but insufficient driver of health behaviours. Furthermore, some groups (such as the socially disadvantaged) are expected to be less amenable to information interventions. We conducted an integrated conceptual and empirical review on information-based interventions for people with vascular disease (diabetes, heart disease and kidney disease). We reviewed conceptual and empirical work concerning the role and impact of information in self-care support to generate an explanatory framework to determine why information was effective or ineffective in encouraging self-care in patients with vascular conditions. This involved mapping relevant theories and models linking information and self-care. We also explored published systematic reviews of educational interventions in diabetes, coronary heart disease and chronic kidney disease to examine the role of information and evidence concerning its effectiveness and impact in different patient populations. The conceptual review identified variation among information interventions in terms of type, function, and their relationship to behaviour change techniques and psychological mediators of behaviour change. Key moderators of the effect of information included types of disorder, and patient capacity and resources. A wealth of educational interventions exists for diabetes and heart conditions, but the precise components of these interventions that are effective are difficult to identify. There is little evidence concerning optimal ways of tailoring interventions for socially disadvantaged groups other than ethnic minorities. A focus on printed information may not provide access to effective methods of information delivery (e.g. tailored information, use of narratives and user generated content). Developing a framework for the effective use of information needs to take account the full range of the factors identified.

Keywords: chronic illness management, diabetes, heart disease, kidney disease, information, interventions
Introduction

The global burden of disease is shifting to long-term conditions and vascular conditions such as diabetes, heart disease and chronic kidney disease are highly prevalent (Murray & Lopez 1996). NHS policy bases care for long-term conditions around three tiers: case management for patients with complex conditions; disease management for patients at medium risk and self-care support for patients at low risk (Department of Health, 2006). Self-care is defined as ‘care taken by individuals towards their own health and well being; it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition and to prevent further illness or accidents’ (Barlow et al. 2002). Support for self-care is defined as ‘increasing the capacity, confidence and efficacy of the individual for self-care by providing a range of options’ (Department of Health 2005b).

Self-care has the potential to make a significant contribution to vascular outcomes. A variety of mechanisms have been developed to support self-care, including information, new technologies, training for patients and professionals and support networks (Department of Health 2005b), but there are concerns that the potential of self-care is not being realised.

The United Kingdom government surveyed public attitudes to self-care to explore barriers (Department of Health 2005a). In addition to a lack of time and money, lack of information was perceived as a key barrier, with 8% reporting a lack of knowledge about health and 5% blaming complex or contradictory information. When asked what would improve their self-care, 26% suggested better knowledge of conditions and their treatment and 19% more information. Another recent report focussing on long-term conditions reported that:

Information provision is central to helping people take a greater role in the treatment of a long-term condition. Around one in five say that information about the condition (22%), about the treatment (20%) or about how to avoid worsening the condition (19%) would help (Ipsos MORI 2009).

According to the above report, the preferred source of information and advice about long-term conditions in the future is the GP (80%). Other preferred sources included practice nurses, pharmacists and hospital doctors.

These findings suggest that information should play a key role in supporting self-care for people with long-term conditions and this is reflected in the policy focus of the Department of Health. Information has the potential to be an efficient intervention (especially using the internet as a platform) and using a low-cost intervention to improve self-care and reduce utilisation of health services is likely to be attractive to policy-makers in times of economic difficulties. However, it is not clear to what extent this focus on information is supported by current theoretical and empirical work in the behavioural and social sciences. This review aimed to synthesise evidence concerning the role and effectiveness of information in self-care support in vascular conditions.

Methods

The work was conducted as part of the NIHR CLAHRC (Collaboration for Leadership in Applied Health Research and Care) for Greater Manchester (http://cla hrc-gm.nihr.ac.uk/) research programme on patients with long-term conditions. The collaboration is focussed on improving care for diabetes, heart disease and chronic kidney disease.

We conducted an integrated conceptual and empirical review on information-based interventions relevant to self-care for people with diabetes, heart disease and kidney disease. Our approach extends beyond a conventional Cochrane style systematic review as it is designed to explain how interventions work or why they fail, as well as judge their effectiveness. Our approach is thus in line with the Medical Research Council framework for evaluating interventions (Medical Research Council 2000, Craig et al. 2008) which highlights the importance of determining how interventions might work (through theoretical work and piloting) prior to definitive trials of whether they do in fact ‘work’ and produce effective and cost-effective outcomes.

Given this explanatory focus, a conventional systematic review has limitations with its focus on measuring outcomes rather than explaining how and why outcomes were achieved (Pawson et al. 2005). In terms of aims, our approach has significant similarities with the ‘realist review’ method (Pawson et al. 2005), but whereas Pawson’s approach is based on a model which sees outcomes as an interaction between context and mechanism, we adopted the mediation–moderation model from psychology as the conceptual basis of our review (see Figure 1), (Baron & Kenny 1986, Kraemer et al. 2002).

In psychological terms, a mediator refers to ‘transformation processes’ by which the effects of stimuli impact on behaviour. In statistical terminology, a variable is said to function as a mediator ‘to the extent that it accounts for the relation between the predictor and the criterion’ (Baron & Kenny 1986) For example, information may impact on self-care behaviour because it increases knowledge about a condition and its treatment, and changes in knowledge enable patients to engage in effective self-care behaviour. In this example, information achieves its
effects through the mechanism of change in knowledge, and thus knowledge is the mediator. Mediators have also been described as ‘behavioural determinants’ (Michie et al. 2008).

A moderator is defined as ‘a qualitative (e.g. sex, race and class) or quantitative (e.g. level of reward) variable that affects the direction and/or strength of the relationship between an independent or predictor variable and a dependent or criterion variable’ (Baron & Kenny 1986). For example, if an information-based intervention is used in a trial (for example, access to a health information website), the benefits of the intervention may be higher in patients who have more formal education than those with more limited educational attainment. In this example, education moderates the effectiveness of information.

The review was conducted in two stages.

Stage 1 – conceptual review
The initial stage of this review involved identifying theories and models relating to the ways in which the intervention of interest (i.e. information) might work. This stage was designed to answer three research questions:

Question 1: What is information in the context of self-care?
Question 2: What are the mediators of the effect of information on self-care?
Question 3: What are the moderators of the impact of information on self-care?

The search for theories and models used a combination of structured search strategies and ‘snowballing’ from those initial searches. Unlike a conventional review this phase is not designed to be comprehensive in nature, and there is no standardised assessment of quality for such studies (Pawson et al. 2005). The aim was to provide an overview of relevant theories and models that could illuminate policy in self-care, and the core criteria were relevance and coherence.

Stage 2 – evidence review
Following the conceptual review, a structured review was conducted to examine empirical evidence concerning two research questions.

Question 4: How effective is information in encouraging self-care?
Question 5: How can information interventions be modified to improve their effectiveness?

This involved a review of published reviews on a topic. A search was conducted of the Cochrane Database of Systematic Reviews and the Database of Abstracts of Reviews of Effects, searching for reviews of the effect of information or educational interventions on the self-care behaviour and outcomes of patients with diabetes, heart disease and kidney disease (the list of search terms can be obtained from the first author). To ensure rigour, reviews had to be restricted to controlled outcome research (i.e. randomised controlled trials or non-randomised quasi-experiments) and had to involve systematic review techniques (defined as the use of explicit searches of multiple electronic databases, with assessment of the quality of studies included in the review).

Where information was provided as part of interventions included in the reviews, we extracted data within the reviews which explored the relative contribution of information, either through narrative analysis of the results, or more formally through techniques such as meta-regression, which quantifies the relationship between characteristics of interventions in a review and outcomes (Thompson & Higgins 2002).

Results

Stage 1 – conceptual review: What is information in the context of self-care?
There are a number of perspectives on ‘information’ in self-care which are relevant in the current context. Most patient information is based on a traditional patient education model where information is communicated in a mechanistic way with patients as passive recipients (Dixon-Woods 2001). However, such a model has been criticised as being ‘information for compliance’ (Henwood et al. 2003). An alternative perspective is set within the patient empowerment agenda with information being targeted at the affective as well as the cognitive needs of individuals (Harland & Bath 2008).
The positivist perspective on information views its role as reducing uncertainty and bias associated with decision-making as part of a rational process (Kennerley & Mason 2008). In contrast, the relativist perspective sees information as something created through a social interaction which can only be applied to a specific context. Knowledge results from social activity, sense-making and interaction, and is therefore constantly adapted. Access to resources (including information) and the creation of knowledge reflects power imbalances, where certain groups have the ability to legitimise their knowledge.

A similar dichotomy of information types concerns system-centred and user-centred approaches (Harland & Bath 2008). The former have failings because of excessive assumptions about the type of information required, the way it is provided, the timing and individual preferences. The system-centred paradigm views information as an objective entity and the goal of this approach is to deliver the ‘best’ information (as decided by an authoritative body) to the user with minimal distortion. In contrast, user-centred approaches recognise individual uniqueness and subjective needs. The user-centred paradigm argues that information does not exist independently of human constructions and must be understood ‘through the eyes of the user’.

Developments in information technology and the rise in the web as a source of health information has meant that some of the traditional restrictions on information (such as the need for it to be standardised) have been removed. There is some evidence to suggest that ‘tailored print communication’ is more effective than non-tailored information, in that it may have an enhanced ability to attract notice; be better remembered, read and/or perceived as relevant; and may be more effective for influencing behaviour change (Skinner et al. 1999). Tailored print communications have included personal letters, brochures or newsletters with a varied use of graphic styles, mode of delivery (waiting room, mail shots) and message source (health providers, peer, university). They can vary in message combinations, style (e.g. lay or professional, narrative) and language and studies suggest that tailored content and not just personalisation enhances impact.

Another important distinction concerns the difference between factual and narrative based information. As highlighted above, much health information is concerned with presenting facts and appealing to logic. In contrast, narrative has been defined as ‘a cohesive and consistent story with an identifiable beginning, middle and end that provides information about scene, characters and conflict: raises unanswered questions or unresolved conflict; and provides resolution’ (Hinyard & Kreuter 2007). Narrative may have advantages in the presentation of health information, and has been used in diabetes education of ethnic minority patients (Greenhalgh et al. 2006). Studies have found that narratives, particularly first-person narratives, can be more influential than traditional forms of information but can bias decision-making leading to patients making poor health choices (Winterbottom et al. 2008).

Finally, it is important to consider the function of information in self-care. Data from research on internet use has suggested that patients use internet information to prepare for discussion elsewhere (with a friend or health professional); assist with initial decision-making and the testing of personal hypotheses (e.g. investigate specific concerns such as ‘could I manage with a lower dose?’); and for improving confidence (Silence et al. 2007). It has been found that a majority of patients seek information about how to cope with health problems (Coulter & Ellis 2006), to become ‘empowered’ (Edwards et al. 2009), to increase knowledge and to provide strategies for behaviour change (Skinner et al. 1999).

Stage 1 – what are the mediators of the effect of information on self-care?

As noted above, mediators are ‘transformation processes’ by which the effects of stimuli (such as information) impact on behaviour (such as self-care). There are a number of psychological theories which outline possible mediators, including the information-motivation-behavioural skills model, theory of reasoned action, theory of planned behaviour, social-cognitive theory, control theory and operant conditioning theory (Elder et al. 1999, Conner & Norman 2005, Abraham & Michie 2008). Each theory highlights a range of different mediators. One review identified eight core mediators (strong positive intention to perform the behaviour; minimum of barriers to performing the behaviour; perception of having requisite skills; belief that reinforcement will follow the behaviour; belief in normative pressure to perform the behaviour; behaviour consistent with self-image; positive affect regarding the behaviour; and cues or enablers to engage in the behaviour) (Elder et al. 1999) while a second reported 11 (social/professional role and identity; knowledge; skills; beliefs about capabilities; beliefs about consequences; motivation and goals; memory, attention and decision; environmental context and resources; social influences; emotion; and action planning) (Michie et al. 2008).

Linking interventions such as information with mediators requires identification of particular ‘behaviour change techniques’ (Michie et al. 2008). Despite this being an obvious focus of health research, it remains unclear how particular interventions relate to particular behaviour change techniques, and which behaviour change techniques are optimal to influence particular mediators.
A recent study outlined a list of 26 behaviour change techniques (Abraham & Michie 2008). Although a number could relate to the use of information, some are more clearly linked. The core techniques would include: providing instruction; providing information about the behaviour-health link; providing information on consequences; providing information about others’ approval. Other techniques that might be linked to information would include: prompting intention formation; prompting barrier identification; providing general encouragement; setting graded tasks; and providing feedback on performance.

The link between information as an intervention, behaviour change techniques and mediators is potentially complex. For example, information may lead to enhanced understanding of the need for a self-care behaviour (such as exercise), by providing information about the link between the behaviour and health outcomes. Abraham & Michie’s (2008) analysis of behaviour change techniques suggests that such an effect would cohere with the tenets of information-motivation-behaviour model (Fisher & Fisher 1992). However, the information-motivation-behaviour model and others also highlight the importance of motivational issues, which highlights the role of other mediators such as self-efficacy. One of the potential methods of changing self-efficacy is via persuasion, which could be achieved through information by ‘providing general encouragement’ (Conner & Norman 2005), although that is unlikely to be critical compared to other sources of self-efficacy such as modelling or mastery (Michie et al. 2008).

Linking information interventions with specific behaviour change techniques and relevant mediators provides greater clarity in understanding the likely causal pathways and thus should allow greater specificity in terms of intervention effects, as well as allowing exploration of the relative effectiveness of various types of information in achieving certain goals. These benefits are highlighted as significant in a review which found that socially disadvantaged groups benefit from interventions which contain fewer techniques and which are more clearly targeted at changing certain behaviours. This suggests that interventions which are too dilute (because they involve too many behaviour change techniques) or try to impact on too many mediators are less likely to be effective (Michie et al. 2009). Therefore clearer, theoretically supported intervention objectives are recommended together with more robust inclusion criteria for types of information. However, the potential of such detailed analyses is limited by the lack of clarity in published reports concerning the content of interventions, which are instead characterised as being based on ‘an informal blend of logic and practical experience’ (Fisher & Fisher 1992).

Stage 1 – conceptual review: What factors moderate the impact of information on self-care?

The effect of information on self-care may be moderated in a variety of ways.

Clinical conditions

The type of disorder may be important in moderating the impact of information. A recent synthesis of qualitative studies examined patient engagement with and use of information in the management of long-term conditions (Protheroe et al. 2008). Five key concepts were found to influence engagement:

- Perception and awareness of alternative self-care possibilities. Information was more likely to impact in medically unexplained conditions.
- Prior extent and nature of engagement with information. Patients are less likely to seek out information on certain conditions (such as those that are stigmatised).
- Extent of and ability to self-care. Some conditions are highly suited to self-care, whereas others require more interaction and brokerage with a health professional.
- Opportunities for use of the information and stage of illness career. Certain conditions may benefit from information at an earlier stage than others (episodic conditions may utilise information when necessary).
- Congruence and synergy with the professional role. Professional support is necessary to encourage the use of self-care in some conditions.

Table 1 shows how these relate to diabetes, coronary heart disease and chronic kidney disease. There are many similarities between conditions, in terms of the way that they are managed medically, and the fact that management in the UK is encouraged through the Quality and Outcomes framework which sets clinical standards and financial incentives for UK general practitioners (Campbell et al. 2009). All are potentially manageable through self-care, and the self-care behaviours of relevance to each are similar. This might suggest that aspects of information interventions could be generic, to take advantage of these synergies. However, there are core differences. Chronic kidney disease is a relatively ‘new’ disorder, with a more uncertain status (both among patients and professionals), and the synthesis suggests that such a status may heighten the role of information compared to better established disorders such as diabetes and coronary heart disease.

The effects of a relatively passive intervention such as information may be weaker where the severity or burden of disorder is high and the effects of self-care are less important. Co-morbidities may moderate the impact of information, one reason being that most information is disease specific and thus may not be useful for patients
whose disorders interact (Detweiler-Bedell et al. 2008) or where information is contradictory (Bayliss et al. 2003, 2009). Physical conditions with associated mental health problems such as depression may have an additional effect, through effects on motivation and concentration and the consequent ability of patients to engage with information (Detweiler-Bedell et al. 2008).

**Resources and environment**

Even when information is understood and changes attitudes and intentions, implementing behaviour change may be more difficult when patients living in certain circumstances have less access to relevant resources and face a greater number of perceived barriers to self-care (Dutta-Bergman 2005). For example, certain areas may not be well resourced with NHS services, exercise facilities or community-based healthy living groups. Alternatively the financial implications of accessing these resources may restrict their availability to people with low incomes. There are charges for services such as eye tests, dental services and prescription medicines which may limit access. Other cost implications such as time lost from work or travel may also discourage uptake (Gulliford et al. 2002).

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**Table 1** Characteristics of conditions and their relationship to information

<table>
<thead>
<tr>
<th>Experience of condition in everyday life</th>
<th>Diabetes</th>
<th>Coronary heart disease</th>
<th>Chronic kidney disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recognised definitive diagnosis, with few outward symptoms (unless associated with complications). Involves diet restrictions, personal discipline and monitoring, fatigue and may be associated with obesity</td>
<td>Collection of ‘diseases’ (including myocardial infarction, angina, atrial fibrillation, heart failure), although the underlying disease process is similar. Symptoms differ (chest pain, palpitations) and may be symptom-less (e.g. following MI). Associated with older age groups.</td>
<td>Relatively new ‘label’, diagnosed by blood test, and symptomsless in most cases. Many patients may not be aware that they have the condition, but in a minority progression may lead to need for dialysis and/or kidney transplant. Associated with older age groups.</td>
<td></td>
</tr>
<tr>
<td>Routine check ups required. Education classes, specialist services and nurses available. Managed in primary care.</td>
<td>Routine check ups required. Cardiac rehabilitation exercise classes available. Often managed in primary care, but likelihood of hospital admission</td>
<td>Close medical monitoring to check on compliance with medication. Usually managed in primary care, with more advanced stages referred for specialist opinion.</td>
<td></td>
</tr>
<tr>
<td>Information provided at diagnosis, reinforced at face to face encounters with medical staff. Potential for confusion about shopping and dietary restrictions</td>
<td>General exposure to healthy lifestyle messages. Information for behaviour change likely to be engaged with at a crisis point (e.g. following hospitalisation for myocardial infarction)</td>
<td>General exposure to healthy lifestyle messages around reducing cardiovascular risk.</td>
<td></td>
</tr>
<tr>
<td>Encouraged to make marked changes in diet, exercise and attempt to stop smoking. Blood tests will detect if not following diet</td>
<td>Encouraged to make marked changes in diet, exercise and attempt to stop smoking. Patients need to adhere to medication regimens and to self-monitor symptoms</td>
<td>Encouraged to make marked changes in diet, exercise and attempt to stop smoking.</td>
<td></td>
</tr>
<tr>
<td>At diagnosis often overwhelmed with information, followed by later reaching the point of acceptance to change behaviour</td>
<td>Healthy lifestyle changes important early in illness career. Possibly crisis point needed before information about future risks leads to behaviour change.</td>
<td>For a minority, kidney failure a constant threat. Dialysis imposes severe lifestyle changes. Kidney transplant may be a cure and symptoms may go.</td>
<td></td>
</tr>
<tr>
<td>Growing problem at national level, seen as a key condition for national health promotion targets. Management is a target for Quality and Outcomes Framework</td>
<td>Serious and growing national health problem. Management is a target for Quality and Outcomes Framework</td>
<td>Risk of other long-term conditions (major cause of death is cardiovascular problems) with emphasis on reducing risk (blood pressure, diet, smoking and exercise). Management is a target for Quality and Outcomes Framework</td>
<td></td>
</tr>
</tbody>
</table>
Personal capabilities and learning styles

Theories of information processing focus on the notion of ‘bounded rationality’. Information processing requires effort and the cognitive burden required may lead to failure to use information. The burden may be greater in those with lower levels of education and low levels of literacy and health literacy (World Health Organisation 2008). The World Health Organisation states that:

Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus health literacy means more than being able to read pamphlets and make appointments. By improving people’s access to health information, and their capacity to use effectively, health literacy is critical to empowerment (World Health Organisation 2008).

Health literacy (alone or in combination with other factors) may place a limit on the ability of patients to engage with self-care. There is some evidence that interventions targeted at groups with low-literacy can be effective (Coulter & Ellis 2006).

Tailoring information to recipients’ psychological characteristics has been proposed as a way to enhance the impact of information on health behaviour. The C-SHIP model describes how people process information cognitively and emotionally and how this motivates health behaviour. The assumption of this model is that matching health information to the processing style of individuals is likely to have a more positive impact than non-matched information. The model defines two processing styles: monitors and bluters. According to this model, monitors experience greater anxiety about health risks and amplify threatening cues. Hence, they require detailed health information with strategies on how to reduce risk. Bluters can become overwhelmed by information they perceive as threatening; therefore short, simple and succinct information is preferable in terms of positively influencing health behaviour (Miller et al. 1996, Williams-Piehota et al. 2005).

Stage 2 – evidence review: How effective is information in encouraging self-care?

In diabetes, face to face individual and group education are common approaches to improving self-care. Published reviews suggested that individual education has only a limited impact on glycated haemoglobin (HbA1c) and other outcomes (Loveman et al. 2003, Duke et al. 2009) although the evidence was stronger in relation to group education (Deakin et al. 2005). However, comparisons of the two tended to demonstrate no difference in effect (Gary et al. 2003, Duke et al. 2009). Reviews of group-based education also highlighted that educational interventions ‘based on therapeutic patient education using the principles of empowerment, participation and adult learning have proved to be efficacious’ (Deakin et al. 2005) and highlighted the limitations of didactic interventions focusing on knowledge (Norris et al. 2001). Another review which explored non-pharmacological treatments for diabetes also explored treatment factors related to outcomes. Educational interventions had a significant impact on glycaemic control, and the effect was increased through the use of face to face delivery, cognitive reframing and exercise (Ellis et al. 2004). Another review found that the only significant determinant of the effect of self-care education on HbA1c was the amount of contact time between educator and patient (Norris et al. 2002). The reviews in coronary heart disease also suggested that non-pharmacological interventions and self-care support can lead to changes in healthcare outcomes. As with the diabetes interventions, most of the interventions (such as cardiac rehabilitation) were multi-factorial, with the bulk of education delivered via meetings with health professionals, and many interventions were poorly described, making it difficult to distinguish the nature of health education and other interventions (Linden et al. 1996, Dusseldorp et al. 1999). One review in heart failure suggested that more intensive education was more likely to show benefits, although only a limited number of studies were included (Jovicic et al. 2006). The review protocol in chronic kidney disease is yet to report, but personal communication with the authors indicates that the evidence base is limited at present (Wu et al. 2008).

Stage 2 – evidence review: How are self-care interventions modified to take account of barriers to the use of information?

Several reviews have explored the role of education and self-care interventions in specific groups which may face barriers to the use of information, although it is difficult to disentangle the effects of information and other service delivery strategies. Reviews focussed mainly on ethnicity (Eakin et al. 2002, Glazier et al. 2006, Peek et al. 2007, Hawthorne et al. 2008), although one review explored studies of patients of low socioeconomic status (Glazier et al. 2006) and one included a single study of low-literacy patients (Eakin et al. 2002). Didactic teaching aimed at improving diabetes knowledge was least successful with disadvantaged groups (Glazier et al. 2006). Tailoring of health education for ethnic minority patients was generally successful in improving outcomes of patients in the short-term (Glazier et al. 2006, Hawthorne et al. 2008) Key aspects of tailoring related to the provision of information were culture and health literacy, but successful interventions were multi-faceted and required
multiple contacts over a prolonged period (Glazier et al. 2006), rather than being based on simple information provision. Other positive strategies included the use of community educators or lay people leading interventions, one-to-one delivery and assessment and behavioural focus (Glazier et al. 2006).

Discussion
This study aimed to synthesise evidence concerning information in self-care, and to consider the mediating processes by which information might impact on behaviour change and the factors that might moderate that influence. The results are summarised in Figure 2.

It is noteworthy given the focus in policy discussions that information is only linked to a few of the known behaviour change techniques and its relationships with core psychological mediators of behaviour change are poorly specified. Psychological models generally view information as being only one factor among many which accounts for behaviour, and there are those that criticise even these broader psychological models for their excessive focus on the individual and failure to recognise the impact of structural, contextual and cultural factors (Crossley 2001, Dutta-Bergman 2005). This is borne out by the evidence review. Although few of the included reviews could provide a detailed assessment of the intervention components which were responsible for change, the findings that were reported tended to highlight that didactic, low-intensity interventions were least effective, compared to multi-faceted and tailored interventions which adopt a range of methods aimed at increasing knowledge and changing behaviour. However, it is possible that interventions based on information are cost-effective because these modest effects are achieved at very low cost, although empirical evidence on this issue is lacking.

Evidence is also lacking on what specific aspects of tailoring are successful, although there has been some progress in attempts to identify which behaviour change techniques are present and effective for certain populations (Abraham & Michie 2008). It should be noted that mediators at the level of individual psychology represent only one level of interest (Baron & Kenny 1986), and they function in concert with mediators at other ‘levels’, such as health services, family, wider community and the physical and sociocultural environment (Fisher et al. 2005).

There is some limited evidence that socially disadvantaged groups may benefit from interventions which are group-based, community-located, and led by lay people who have the condition (Glazier et al. 2006), which may link with a companion review which indicates the relevance of understanding the role that social networks play in self-care support outside formal health services, in terms of shaping adaptation to the illness and sharing the additional work associated with a long-term condition. Changes in existing practices and the introduction of new ones is a complex process of negoti-

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Figure 2 Final integrated model.
ation with others within personal networks. These negotiations can include considering what is desirable to be done, why it is done in a particular way and how responsibilities are shared (Vassilev et al. 2010). Therefore, the role of social networks in self-care in long-term conditions needs to be considered when developing interventions as these new practices must be negotiated and normalised not just by the individual with the condition but also by their wider social network.

The limitations of information outlined in the evidence review may reflect the fact that patients can find it difficult to relate to standardised interventions which can feel disconnected from their everyday lives. Therefore, tailoring techniques which use lay language and lay understandings that are reflective of the lived experiences of certain groups may have greater potential for engaging these communities to improve their health. ‘Authentic’ narrative accounts may be a useful device in these circumstances because of their ability to contextualise the challenges and barriers to lifestyle change which can be particularly difficult for disadvantaged groups.

It has been suggested that the predominant model of rational choice in the health and social sciences is ‘instrumental rationality’, described as a consequentialist rationale that causally relates an action to an objective (Baker 2006). An instrumental rationale is focussed on outcomes and the best means of achieving those outcomes. A problem with health promotion campaigns is that they often assume an instrumental rationality, whereas patients may operate in a different mode. ‘Procedural (bounded) rationality’ involves choices that are often the result of settling for an acceptable outcome in order to limit the search for further information. In this model of rational choice it is also important to recognise social norms, the ‘web’ of shared rules and structures, cultures and institutions within which individuals operate (Baker 2006).

Baker (2006) offers a third model of rational choice in an effort to describe those individuals who appear unreachable using current methods of health promotion. Baker calls this third model ‘expressive rationality’ and describes it as an ‘inner conflict’ where choices convey meaning and are based on judgements which reflect questions and uncertainties about the self and the world. These choices may not be based on calculations and may reflect an ambiguous or highly subjective decision-making process which reveals inconsistencies where the ‘right’ answer may not be known (Baker 2006).

There are links between this concept and the self-construction perspective (Burton & Hudson 2001) which suggests that the construction of self plays a fundamental part in the decisions people make regarding their health. This moves the focus towards needs and goals which are individually constructed and based on maintaining the patient’s construction of self. Burton suggests that this focus on self-image and identity will allow for medical goals to be more consistent with individual goals as they are more likely to be aligned with an individual’s sense of self. Medical goals which are more relevant to a patient’s identity will encourage greater adherence to medical treatment and promote long-term, self-sustaining health behaviours (Burton & Hudson 2001). Crossley (2001) also agrees that the idea of ‘healthy’ and ‘risky’ behaviours are connected to issues of self and identity and that health behaviours can be understood in the context of ‘lay rationalities’ in which values other than health take priority.

Timing may be important in the impact information has on the ability of people to engage with self-care or self-care support provided through health services. The differential effect of the disorder may be relevant here as well. For example, people with diabetes may be overloaded with information and self-care support options soon after diagnosis and it may take some time for them to come to terms with the need for behavioural changes. In contrast, people with heart disease may only start to relate to self-care at a crisis point. In our other exemplar condition, kidney disease, most people may never be aware they have this label and early information may cause unwarranted distress or anxiety.

It is important to understand the complexity of individual circumstances which can influence health behaviours in order to provide sensitive and appropriate resources for people living with long-term conditions. This review has demonstrated that there are a numbers of factors which can influence health behaviours which range from: the nature of the disease and the stage of its development; cultural beliefs; socioeconomic circumstances; literacy levels and different ways of making sense of information. It is therefore important to provide a framework for a more effective use of information as part of a broader strategy for self-care support which takes into account the complexity of issues influencing health behaviours in order to develop more effective self-care strategies for people with long-term conditions in underserved populations.

**Acknowledgements**

This project was funded from the NIHR Collaboration for Leadership in Applied Health Research and Care for Greater Manchester. The views expressed in this article are those of the authors and not necessarily those of the NIHR.

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