

Engaging with information to support self-management from the patients' perspective: a qualitative synthesis

Joanne Protheroe^{1*} Anne Kennedy¹, Wendy Macdonald¹, Vicky Lee¹ and Anne Rogers¹

¹National Primary Care Research and Development Centre, 5th Floor Williamson Building, University of Manchester, Oxford Road, Manchester, UK

*Corresponding author

Email Addresses:

JP: joanne.protheroe@manchester.ac.uk

AK: anne.p.kennedy@manchester.ac.uk

WMD: wendy.macdonald@manchester.ac.uk

VL: victoria.lee@manchester.ac.uk

AR: anne.rogers@manchester.ac.uk

Abstract

Background

Patient information has been viewed as a key component of self care. However, little attention has been given to methods of dissemination or implementation of effective information strategies. Previous problems identified with the use and implementation of patient information point to the need to explore the way in which patients engage with and use information to support self management for chronic conditions.

Methods

Four published qualitative studies from a programme of research about self –management were analysed as a group; these included studies of the management of Inflammatory Bowel Disease (IBD); Self-help in Anxiety and Depression (SHADE); Menorrhagia, Treatment, Information and Preference (MENTIP) study and self help for Irritable Bowel Syndrome (IBS). Analysis entailed a combination of meta-synthesis together with a secondary analysis of qualitative data drawn from the original transcripts.

Results

The ontological status and experience of the condition in everyday life was the most dominant theme to emerge from this synthesis. This coupled with access to and experience of traditional health services responses shaped the engagement with and use of information to support self-management. Five key concepts were found which were related to influences likely to affect this. These were the perception and awareness of alternative self-management possibilities; the prior extent and nature of engagement with information; the extent of and ability to self-manage; opportunities for use of the information and the stage of the illness career; and congruence and synergy with the professional role.

Conclusions

People with chronic conditions need support from providers in both supply and engagement with information, in a way which gives legitimacy to the person's own self-care strategies and possible alternatives. Thus, a link could usefully be made between

information offered and patients' past experiences of self management and engagement with services for their condition. The timeliness of the information should be considered, both in terms of the illness career and the type of condition (i.e. before depression gets too bad or time to reflect on existing knowledge about a condition and how it is to be managed) and in terms of the pre-existing relationship with services (i.e. options explored and tried).

More considered use of information (how it is provided, by whom and at which point it should be introduced) is key to facilitating patients engagement with and therefore use of information to support self-management.

Background

Patient information has been viewed as a key component of self care and recent official policy identifies health information as important for patients “so that they are better able to care for themselves and their families”¹. This sentiment is encompassed in an initiative designed to provide information prescriptions² which envisages information being provided to service users and carers, by health professionals. The information is designed to support signposting people to relevant and personal sources of information about services and treatments needed at key points in the “care journey” (diagnosis, stages of treatment, care planning and discharge from hospital).

The enthusiasm for proliferating the use and deployment of information in health systems is supported by studies of patient information, which suggest that written information increases knowledge, and from research, which shows a demand for better information. However, evidence that information on its own promotes informed choice or leads to changes in behaviour is poor³ and little attention has been given to methods of dissemination or implementation of effective information strategies. There has been recognition in official health policy of the need to address barriers that are viewed as inhibiting the access to and use of information, for example, through initiatives aimed at improving health literacy. Low levels of literacy and numeracy are viewed as having an adverse impact on health and well-being and contributing to a growing health gap between those who are ‘empowered’ to help themselves and those that are not. The focus of action to reduce the health literacy gap is predicated on making information easily accessible and comprehensible.

Policies about patient information are also linked to the notion of empowerment and a common goal in policy statements about self-management is for patients to become active agents taking charge of their own health and their interactions with health services⁴. Empowerment in this context is used in a general sense to focus on *individual* actions in engaging with health care and in health care settings and is closely aligned to a social psychological perspective of individuals’ developing control over their own lives⁵

(e.g. as in patient activation). The latter implies that empowerment should be viewed principally as an *outcome* of patient information policies leaving the *process* of how this may be achieved under-elaborated. Moreover, terms such as ‘empowerment’ and self-efficacy have assumed an increasingly normative tone when used in the context of self-care support initiatives. It has come to mean what patients ‘should’ do rather than a neutral observation of what patients might actually do to engage with information in a given set of circumstances ⁶. A more open and less judgemental perspective toward those with a chronic condition has been suggested ⁷.

Notions of health literacy alone are unlikely to address the full range of influences impacting on information uptake and utilisation by individuals. Dixon-Woods points to a mechanistic model of communication and a dominance of bio-medical concerns in patient information and a portrayal of patients as passive and open to manipulation ⁸. The degree of complexity of living with a chronic condition and the failure to ground this in the lived experience of patients has been identified as a notable weakness in patient information leaflets designed to aid patient self-management ⁹. How and who provides information and the point at which it is introduced are likely to be salient factors in uptake ¹⁰.

Problems identified with the use of patient information point to the need to explore the way in which patients engage with and use self-management information. In particular there is a lack of understanding of the way in which people use information in health contexts relating to the self-management of specific long term conditions. Drawing on a set of four qualitative studies from a programme of research about self-management the analysis here focuses on the uptake of information for long term conditions.

Methods

Our research has focused on testing the conditions under which patients and clinicians are likely to be engaged in a shared approach to self-management within a health service organisational environment which is able to support a partnership approach. We have used mixed methodologies to develop an evidence base ¹¹. In a series of qualitative studies that had been conducted by our group in order to explore aspects of self-management the use of information and how patients engage with information to support self-management were included as a core theme and formed a key part of the self care support intervention being evaluated.

In the analysis presented here we draw on four qualitative data sets Rogers and Kennedy, Inflammatory Bowel Disease (IBD) study ¹²; McDonald et al, Self-help in Anxiety and Depression (SHADE) study ¹³; Protheroe et al, Menorrhagia, Treatment, Information and Preference (MENTIP) study ^{14;15} and Rogers^b et al, Irritable Bowel Syndrome (IBS) study ¹⁶. Drawing on the qualitative studies already published, using a combination of meta-synthesis together with a secondary analysis of qualitative data we drew from original transcripts, we discussed and analysed these as a group.

Being in the position of having four research studies which all had data to contribute to our research question, we wanted to undertake a synthesis of this work with the purpose of achieving a greater understanding and developing a conceptual framework for the use of information in self-management. Campbell et al, described this as;

synthesis of qualitative research can be envisaged as the bringing together of findings on a chosen theme, the results of which should, in conceptual terms, be greater than the sum of parts ¹⁷.

Our analysis was considered in two phases; unlike Campbell et al, we had the added benefit of access to all the raw data (including transcriptions, reflective notes and author insight about the context of the studies) so Phase I of our analysis involved a secondary

analysis; the raw data and published studies were re-interrogated by the individual authors in accordance with our new research question ‘What influences patient engagement with information to support self management for chronic conditions?’ As a group we had extensive discussions about the context of the studies and the data collection processes and discussed quotes and transcripts. This process resulted in the emergence of several key concepts relating to the research question.

Phase II of our analysis was informed by a metaethnographic approach similar to that described by Noblit and Hare, 1988¹⁸, and used by Campbell et al, 2003¹⁷. Whereas metaethnography requires key concepts to be noted down from published papers, by using the secondary analysis approach described above to develop our key concepts, we were able to return to the full data sets and therefore none of the ‘meaning in context’ was lost.

The key concepts from the secondary analysis became the raw data for the synthesis. Once these concepts were defined for each individual study, they were examined in relation to the earliest study Rogers and Kennedy, IBD study¹² and then across the other three studies, the aim of this was to translate the findings from one study to another¹⁸. The final steps in the analysis were to synthesise the translations in a ‘line of argument synthesis’ with the aim of moving from second order constructs to third order interpretations, which should represent a further level of conceptual development.

This combined approach had the advantages of both including the perspectives of the researchers who had originally collected the data and critical perspectives and distance of independent researchers¹⁹. Prolonged discussions bridged the ‘gap’ between the researchers who had collected the primary data and the other researchers involved in the secondary analysis discussions. The former process provided details and nuances about the contexts of each of the studies and the original data collections and analysis¹⁹. This collective data analysis process was facilitated by the authors sharing a similar conceptual framework about self-care support research^{11;20}. Analysis moved from the particular data

sets of each of the four studies to a more general orientation, which compared key themes and constructs across datasets.

Key questions and themes were formulated, and continually tested against the narratives about information from the original transcripts, and were subject to re-formulation as part of a constant cyclical process. Thus all the authors have been involved in discussions, refinements and final analysis¹⁹.

Results

The four studies considered in this synthesis were looking at different aspects of supported self-management in a variety of medical conditions, which were: inflammatory bowel disease, anxiety and depression, menorrhagia (heavy menstrual bleeding) and irritable bowel syndrome (see Table 1).

Phase I of the analysis, the secondary analysis, identified four key concepts relating to information: (1) type of prior information seeking, (2) timing of the provision of information, (3) role of the professional in introducing and engaging patients with information and (4) engagement with and use of self-help materials.

As described in the methods above, these concepts became the raw data for the synthesis in Phase II of the analysis. This phase is presented below and the concepts, with their origins in the papers, are described in detail, ending with a description of the ‘line of argument synthesis’¹⁷.

Phase 1: Translating the key concepts across the studies

See Table 2

(1) Type of prior information seeking

Paper 1: Rogers and Kennedy, 2005 (IBD study). This study sought to illuminate the findings of a randomised controlled trial assessing the impact of a package comprising a self-help guidebook and patient-centred consultations on disease management and satisfaction in inflammatory bowel disease. Patients were given an information guidebook by their hospital consultant, and a written self-management plan of action was negotiated during the consultation. In depth interviews were conducted with twenty-eight purposefully selected patients and eleven physicians.

In relation to prior information seeking, when participants came into the study they felt that they had already had most of the information they needed from their consultant. Thus, information seeking from these individuals was closely aligned to information previously received from consultants.

Paper 2: McDonald, 2007 (SHADE study) This study aimed to assess the clinical and cost effectiveness of facilitated self-help versus waiting list control in the management of anxiety and depression in primary care. Patients on a waiting list for conventional psychological therapy were randomised to receive self-help material facilitated by assistant psychologists or to waiting list control. Twenty-four semi-structured interviews were conducted with patients who had completed the guided self-help. In addition, six of the twenty-four were re-interviewed after they had been invited to attend for traditional therapy.

Information seeking did not seem to be a central theme for participants in this study. Only a minority of participants reported actively searching for information, and information seeking overall seemed to be inhibited due to the lack of formulation of depression as a specific condition in itself.

Paper 3: Protheroe, 2007 (MENTIP study). This study aimed to explore the findings of a randomised controlled trial comparing an interactive, computerised decision aid to written information in women consulting their general practitioner with heavy periods

(menorrhagia). Eighteen patients in the intervention group were purposively sampled and interviewed.

Within the participants in this trial there was minimal prior information seeking as the condition was not perceived as one for which treatment options were available. In other words, information was not actively sought, as there was a general feeling of accepting that 'that's my lot'.

Paper 4: Rogers^b, Lee & Kennedy 2007 (IBS Study) This study was a nested qualitative study within a three-armed randomised controlled trial of a self-help information book in the management of irritable bowel syndrome (IBS) in primary care. Patients were randomised to receive the self-help guidebook; to receive the guidebook plus attendance at a self-help group meeting or to receive treatment as usual. Qualitative data was taken from two sources: ten facilitated self-help group meetings (with a total of fifty-nine participants), and twelve interviews with patients from the intervention groups which took place after one year of follow-up.

There was a general feeling of failure of traditional services to meet needs from the participants in this study with respect to medical input, and thus there was a high level of active critical information seeking orientated to finding alternatives to the traditional medical perspective and ways to self-care.

(2) Timing of the provision of information

For both the IBD and the SHADE studies it was found that for maximum utility the timing of the provision of information should be relatively early on in the illness career. In the case of the IBD study (Rogers et al), the information was given to the patient by the health care professional (HCP). The information was then linked to the HCP and had the effect of reinforcing a pre-existing understanding and relationship between the HCP and the patient. Additionally, the information format indicated areas where patients' choice might influence treatment decisions and possibly led to improved outcomes because a written self-management plan supported earlier self-treatment of exacerbations.

With the SHADE study (McDonald et al) there were suggestions that the provision of the self-help information was likely to have most impact early in the illness trajectory. Patients felt there was a point in the illness trajectory beyond which they would struggle to engage with or use information if their symptoms were too severe or too chronic.

Conversely, due to the nature of the medical conditions in the studies, timing of information provision did not play such an important role in either the MENTIP study (Protheroe et al) or the IBS study (Rogers² et al). In the study by Protheroe et al, the episodic nature of menorrhagia led to the finding that the timing of information (in the form of the interactive decision aid) was not felt to be critical in terms of physical health, as this condition does not deteriorate over time. However, although there would be a benefit to receiving such information at any point in the illness trajectory, earlier decisions made as a result of the information could have a benefit in terms of earlier improvements in quality of life. Similarly in the study by Rogers² et al, due to the nature of irritable bowel syndrome, which also does not deteriorate with time, the timing of provision of information, with regard to the illness trajectory, was not felt to be critical. Rather, in this study patients described the episodic need for this information in times of symptom exacerbations. There was a requirement for this information to be available 'just in time'.

Looking across the four studies, Figure 1 represents how the timing of information provision is linked to the context of the nature of the medical condition.

(3) Role of the professional in introducing and engaging people with information

In the IBD study (Rogers et al), the role of the health professional, in the form of the patient's hospital consultant, was central to giving out the guidebook and the provision of primary legitimisation of self-management. Use of the guidebook was incorporated into the consultation as part of the study intervention and joint reference to the guidebook was used to re-emphasise, clarify and confirm information relating to self-management in the context of the existing relationship. Similarly, in the SHADE study (McDonald et al), a health professional, the assistant health psychologist, was the gateway into making the

self-management information both accessible and a source of emotional and self-help support. The involvement of the health professional also provided legitimization of the condition and the strategies outlined in the information guidebook.

Conversely, in the MENTIP study (Protheroe et al), there was no *direct* role for the health professional. Rather, permission was needed from a patient's GP before she could be recruited into the study and this permission gave the decision-making information package 'medical respectability' from a recognised source. In the IBS study (Rogers² et al), the role of the health professional was similar to the MENTIP study as trial participants were accessed through their GP thus ensuring permission and legitimization of the information source. The information was used by patients as a way to help them move from dependence on medical management of their condition to using an informational, self-help approach.

(4) Nature of engagement with and use of self-help materials

The nature of the medical condition was again found to be important in how patients engaged with and used information. In the IBD study (Rogers et al) the condition is a diagnosed 'main stream' medical condition. Patients engaged with the self-help materials as they identified with the experiences of others described within the materials, which also had the function for some patients of 'normalising' the condition. The materials were also seen as confirmation of the seriousness of the condition. In the SHADE study (McDonald et al) depression was a diagnosed condition and carries a stigma. The condition of irritable bowel syndrome (Rogers^b et al) is diagnosed by a process of exclusion of all other possible causes of the symptoms suffered and is experienced by the patients as medically unexplained. However, both these latter two studies also engaged with the self-help materials as sources of collectivisation of experiences and identification with other patient stories. This was less noticeable in the MENTIP study (Protheroe et al); some participants (and indeed their health professionals) had considered their condition as part of the normal range of menstrual bleeding, and something with which they just had to contend. In the case of the MENTIP study, engagement with the information was related to the 'medical respectability' of the information itself. However,

the fact that heavy menstrual bleeding was given a medical name (menorrhagia), and that treatments were discussed, conferred some legitimacy to the condition, which in turn improved engagement with the information. The severity of the medical condition was also seen as an impediment to using self-help materials. In the SHADE study this difficulty was exacerbated by the low levels of energy and impaired ability to concentrate that accompanied depression.

The guides were used in different ways by patients. In the IBD study (Rogers et al) and the SHADE study (McDonald et al), the information guides were used with family and friends to raise awareness of the condition and individually to monitor their own condition and make management changes as necessary. In the IBD study and MENTIP study (Protheroe et al) the information was used to fill in perceived gaps left by medical knowledge or to provide support not provided by the traditional approach to treatment from services. In the MENTIP study this information gave women a feeling of control and ownership of information that was used to support current or future treatment decision making; whereas in the IBD study the information was used more as a guidebook and diary to understand the antecedents of exacerbations.

In the IBS (Rogers^b et al) and SHADE (McDonald et al) studies the guides were used in an eclectic fashion used as a refresher for reference for self-action at times of relapse or for maintenance of their condition. In the SHADE study they were used as support while waiting for traditional therapy, and the depth to which the guide was used varied; democratic use of information allowed readers to skim or go to great depth (eg cognitive restructuring).

Phase 2: Line of argument synthesis

The line of argument synthesis, according to Noblit and Hare, entails the construction of an interpretation which ‘serves to reveal what is hidden in individual studies and to discover a whole among a set of parts.’

The ontological status and the experience of the condition in everyday life was the most dominant theme to emerge from this synthesis. This coupled with access to and experience of traditional health services responses shaped the engagement with and use of information to support self-management. The ‘ontological status’ of the condition refers to the nature and status (legitimacy) of the condition in terms of how individuals experienced it and the previous way it had been managed by themselves and the impact on peoples’ everyday lives. The synthesis indicated that establishing a consensus about the nature of the condition and the way it ought to be managed between patient and professional is associated with active engagement with information and its perceived subsequent utility. Such a consensus seemingly gave patients permission to engage with and use information that they felt had been sanctioned by health care

These two themes shaped engagement with and use of information by their effect on several other key factors listed below (see Figure 2):

- Perception and awareness of alternative possibilities
- Prior extent and nature of engagement with information
- Extent of and ability to self-manage influences engagement and use
- Opportunities for use and the stage of the illness career
- Congruence and synergy with professional role

This leads to a set of propositions:

Perception and awareness of alternative possibilities: Self-management information may be more likely to influence awareness of alternative possibilities in medically unexplained conditions such as IBS or menorrhagia where people have experienced little help from their HCP because there are, or they believe there to be, no medical treatments available.

Prior extent and nature of engagement with information: People with certain conditions seem less likely to search for and engage with information, for example those with menorrhagia and depression. Where there is a view that a condition has no treatment or

has a certain stigma attached to it, then people are less likely to think about searching for self-management information.

Extent of and ability to self-manage influences engagement and use: Some conditions are more amenable to patient-initiated use of self-management information than others. For example in IBS – self-management is generally the only option – for IBD and depression opportunities for self-treatment/self-management need to be ‘brokered’ by a health professional.

Opportunities for use and the stage in a particular illness career: Certain conditions may respond better to early use of self-management information – for example IBD and depression where there is a likelihood that the condition will worsen over time if nothing is done. For episodic conditions, self-management information is there when needed.

Congruence and synergy with professional role: Professional permission to use self-management information can encourage uptake by those with stigmatized or uncertain conditions such as IBS or menorrhagia. For conditions where medical treatment dominates such as IBD, uptake and use of self-management information is best achieved through a partnership approach.

This suggests that there are several key factors involved which are likely to promote the engagement and implementation of a strategy for promoting engagement with self care support information.

Conclusion

Whilst ready access to information which is easy to understand is important, our work indicates that self-management initiatives which involve information may be more successful in engaging people if an approach is used which is tailored to the type of

condition and illness stage. People with different conditions appear to respond to self-management information in different ways. It is important to acknowledge and reflect on the status of the condition, and its impact on everyday life (e.g. a condition which is traditionally bio-medical, one which is uncertain, or one which is likely to cause stigma).

People with chronic conditions need support from providers in both supply and engagement with information, in a way which gives legitimacy to the person's own self-care strategies and possible alternatives. Thus, a link could usefully be made between information offered and patients' past experiences of self management and engagement with services for their condition. The timeliness of the information should be considered, both in terms of the illness career (i.e. before depression gets too bad or time to reflect on existing knowledge about a condition and how it is to be managed) and in terms of the pre-existing relationship with services (i.e. options explored and tried).

More considered use of information (how it is provided, by whom and at which point it should be introduced) is key to facilitating patients engagement with and therefore use of information to support self-management.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

All authors participated in the conception, design, co-ordination of the study and the analysis of the data. JP drafted the manuscript. AR and AK contributed to the drafting of the manuscript. All authors read and approved the final manuscript.

References

- (1) DoH. The New NHS White Paper. 1997. London, Department of Health.
Ref Type: Report
- (2) DoH. Our Health, Our care, Our say. 2005. London, Department of Health.
Ref Type: Report
- (3) Fox R. Informed choice in screening programmes: do leaflets help? A critical literature review. *J Public Health (Oxf)* 2006; 28(4):309-317.
- (4) Roberts KJ. Patient empowerment in the United States: a critical commentary. *Health Expect* 1999; 2(2):82-92.
- (5) Kuokkanen L, Leino-Kilpi H. Power and empowerment in nursing: three theoretical approaches. *J Adv Nurs* 2000; 31(1):235-241.
- (6) Kendall E, Rogers A. Extinguishing the social?: state sponsored self-care policy and the Chronic Disease Self-management Programme. *Disability and Society* 2007; 22(2):129-143.
- (7) Paterson BL. The shifting perspectives model of chronic illness. *J Nurs Scholarsh* 2001; 33(1):21-26.
- (8) Dixon-Woods M. Writing wrongs? An analysis of published discourses about the use of patient information leaflets. *Soc Sci Med* 2001; 52(9):1417-1432.
- (9) Grime JC, Ong BN. Constructing osteoarthritis through discourse--a qualitative analysis of six patient information leaflets on osteoarthritis. *BMC Musculoskelet Disord* 2007; 8:34.

- (10) Wiles R, Kinmonth A. Patients' understandings of heart attack: implications for prevention of recurrence. *Patient Educ Couns* 2001; 44(2):161-169.
- (11) Kennedy A, Rogers A, Bower P. Support for self care for patients with chronic disease. *BMJ* 2007; 335(7627):968-970.
- (12) Rogers A, Kennedy A, Nelson E, Robinson A. Uncovering the limits of patient-centeredness: implementing a self-management trial for chronic illness. *Qual Health Res* 2005; 15(2):224-239.
- (13) Macdonald W, Mead N, Bower P, Richards D, Lovell K. A qualitative study of patients' perceptions of a 'minimal' psychological therapy. *Int J Soc Psychiatry* 2007; 53(1):23-35.
- (14) Protheroe J, Bower P, Chew-Graham C, Peters T, Fahey T. Effectiveness of a computerized decision aid in primary care on decision making and quality of life in menorrhagia: results of the MENTIP randomized controlled trial. *Med Decis Making* 2007; 27(5):575-584.
- (15) Protheroe J, Bower P, Chew-Graham C. The use of mixed methodology in evaluating complex interventions: identifying patient factors that moderate the effects of a decision aid. *Fam Pract* 2007; 24(6):594-600.
- (16) Rogers A, Lee V, Kennedy A. Continuity and change? Exploring reactions to a guided self-management intervention in a randomised controlled trial for IBS with reference to prior experience of managing a long term condition. *Trials* 2007; 8:6.
- (17) Campbell R, Pound P, Pope C, Britten N, Pill R, Morgan M et al. Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Soc Sci Med* 2003; 56(4):671-684.
- (18) Noblit GW, Hare RD. *Meta-ethnography: synthesizing qualitative studies*. London: Sage Publications; 1988.
- (19) Heaton J. *Reworking qualitative data*. London: Sage; 2004.
- (20) Kennedy A, Rogers A. Improving self-management skills: a whole systems approach. *Br J Nurs* 2001; 10(11):734-737.

Figures

Figure 1 Timing of information / illness trajectories

Figure 2 Line of argument synthesis

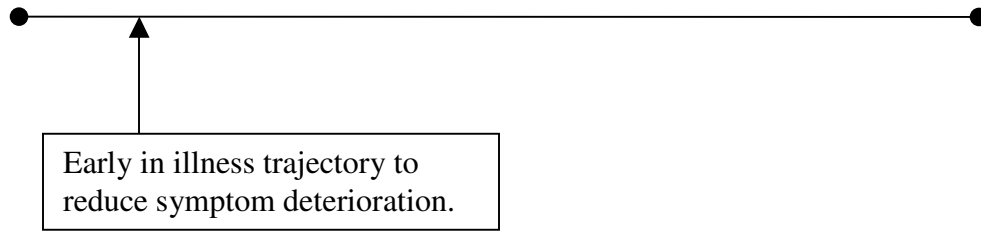
Tables

Table 1: Studies included in analysis

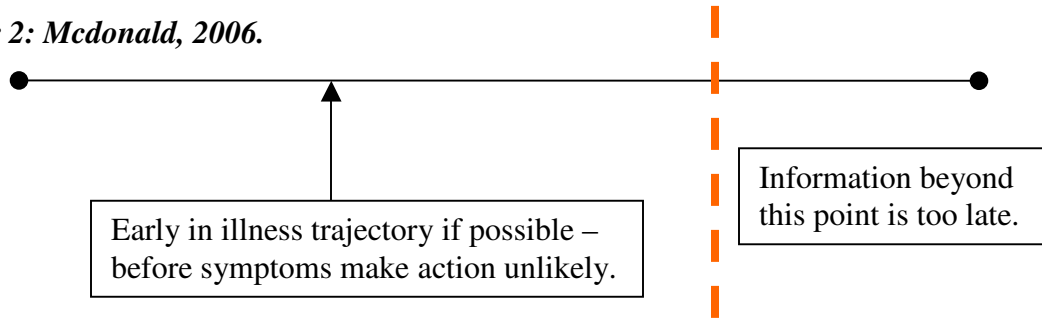
Table 2 – Translation of key concepts through the studies

Figure 1 Timing of information / illness trajectories:

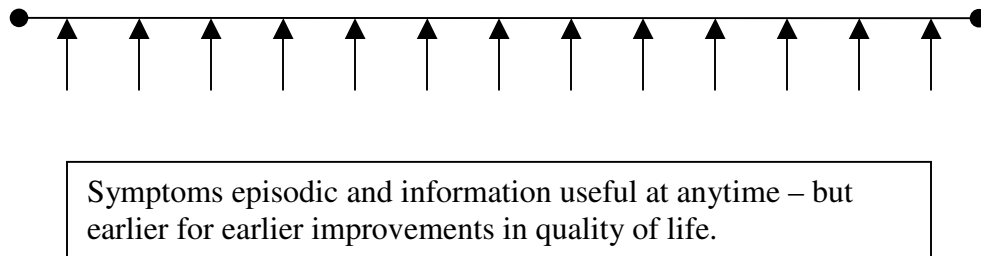
Paper 1: Rogers and Kennedy, 2005.



Paper 2: Mcdonald, 2006.



Paper 3: Protheroe, 2007.



Paper 4: Rogers, Lee, Kennedy 2007

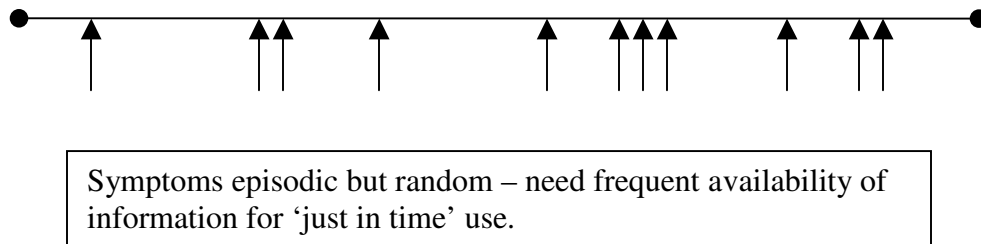
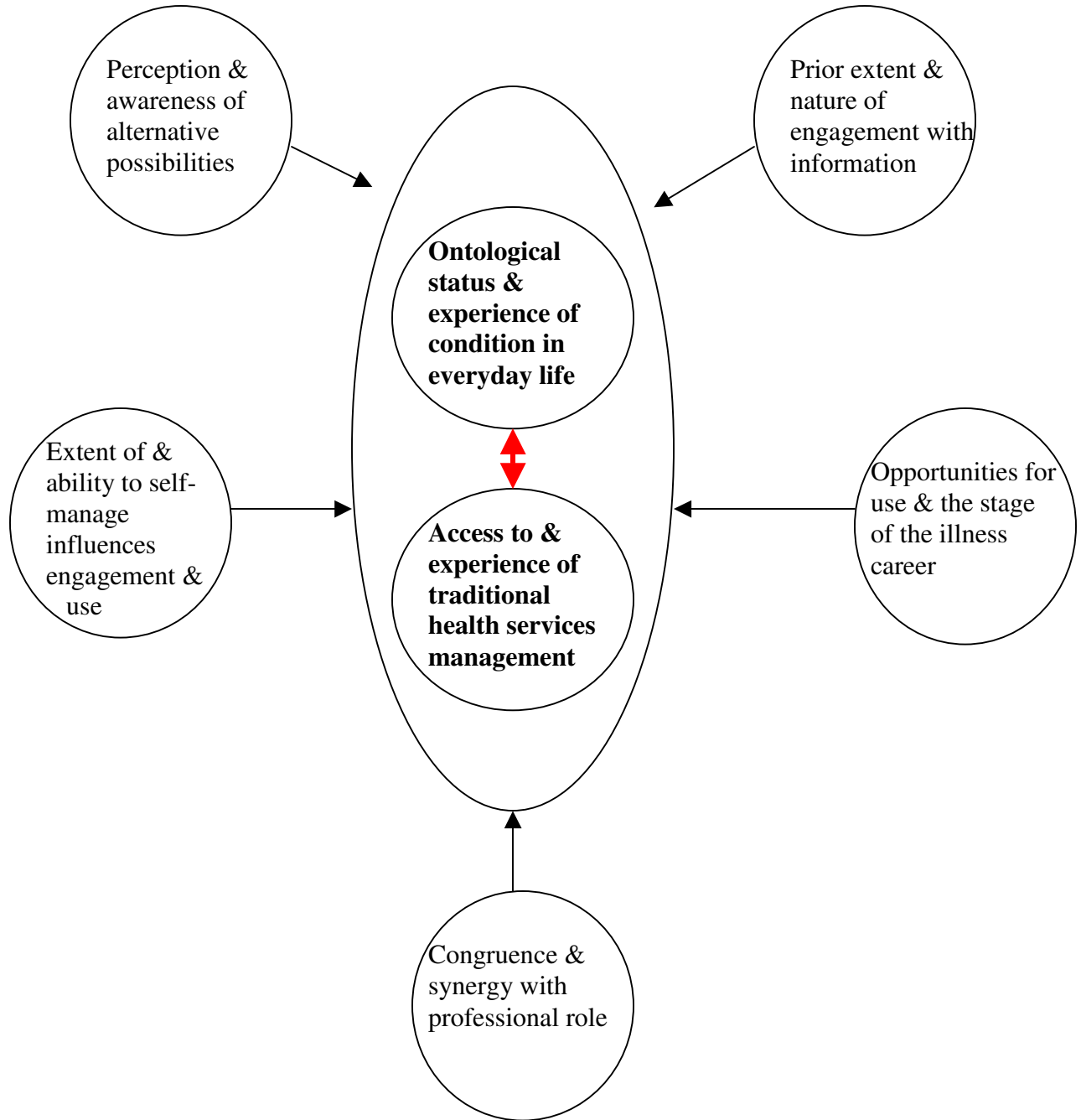


Figure 2 Line of argument synthesis



Additional files provided with this submission:

Additional file 1: table 1final.doc, 32K

<http://www.implementationscience.com/imedia/1563496825200590/supp1.doc>

Additional file 2: table 2final.doc, 28K

<http://www.implementationscience.com/imedia/9640743622005904/supp2.doc>