

**'Listening to my body' to 'Look after my body': a theory of information use for self-management of chronic obstructive pulmonary disease**

**Author**

Ehrlich, Carolyn, St John, Winsome, Kendall, Elizabeth

**Published**

2010

**Journal Title**

Journal of Nursing and Healthcare of Chronic Illness

**DOI**

[10.1111/j.1752-9824.2010.01067.x](http://dx.doi.org/10.1111/j.1752-9824.2010.01067.x)

**Rights statement**

© 2010 Blackwell Publishing Ltd. This is the pre-peer reviewed version of the following article: 'Listening to my body' to 'Look after my body': a theory of information use for self-management of chronic obstructive pulmonary disease, Journal of Nursing and Healthcare of Chronic Illness, Volume 50, Issue 7 October 2010 , pages 652 - 669, which has been published in final form at <http://dx.doi.org/10.1080/03630242.2010.520250>

**Downloaded from**

<http://hdl.handle.net/10072/35884>

**Griffith Research Online**

<https://research-repository.griffith.edu.au>

**'Listening to my body' to 'Look after my body': Self management of Chronic Obstructive  
Pulmonary Disease (COPD)**

**ABSTRACT**

**Aims:**

To report how people with COPD gather, interpret and apply health affecting information.

**Background:**

Some people with COPD manage more effectively than others, presumably because they have better coping skills, life skills and self-management strategies. A considerable amount of health care time and money is invested in delivering information and self-management training to people with COPD, based on an assumption that education effectively and efficiently promotes positive self-management behaviour. This assumption is not based on sound knowledge about how individuals acquire and use information to guide their self-management behaviors.

**Method:**

A grounded theory design was used to gather and analyse interview data collected from people with COPD in 2007. An iterative theory-building approach, was used to develop a model that represents how participants used information in their daily self-management.

**Conclusions:**

Everyday self-management decisions for people with COPD are more than simple treatment choices or compliance with medical regimens. Rather they result from intricate and purposeful interactions between cycles of 'Listening to my body' and 'Looking after my body' within the context of their daily lives.

Relevance to Clinical Practice:

Understanding individual information use patterns will assist health professionals to tailor effective and supportive health care information. Health professionals need to consider not only the health-care needs of an individual, but also the social context within which that person acquires and uses information.

Key words: Chronic illness, chronic obstructive pulmonary disease, decision making, health-related information, personal beliefs, person-centredness, self-management

## **INTRODUCTION**

Chronic Obstructive Pulmonary Disease (COPD) is a major cause of disability and death in Australia (McKenzie et al. 2006), and the fourth highest disease-related cause of death globally (World Health Organisation 2008). People with COPD manage their condition 24 hours a day, every day. Some people with COPD manage more effectively than others, presumably because they have better coping skills, life skills and self-management strategies. Individuals actively self-regulate when adjusting to living with chronic disease. This self-regulation depends on an ability to observe and make judgements about one's health, based on observations rather than on personal habits, fear, and tradition (Clark et al. 2001). The ability to self-regulate is particularly important for people with COPD, because rapidly changing symptoms can make it difficult to determine clinical significance. Although health professionals play a vital role by providing information and support, individuals ultimately maintain control over their own condition and treatment. The purpose of this study was to identify and understand the mechanisms people use to gather, interpret and apply health information to manage their COPD.

## **BACKGROUND**

Self-regulation, including the choice of self-management strategies, is thought to be determined by the nature of information that is available to an individual. As a consequence, health professionals focus heavily on the delivery of information and self-management training as a primary method of influencing behavior (see for example, Lorig 2003, Arnold et al. 2005, Boxall, 2005, Chodosh et al. 2005, Patterson 2007). At a system level, a considerable amount of health care time and money is invested in designing and delivering information and education to

people with COPD, based on an assumption that these are effective and efficient mechanisms for promoting positive self-management behavior. This assumption, however, is not based on sound knowledge about how individuals acquire and use information to guide their self-management behaviors.

Instead of investing in better understanding of information use among people with COPD, considerable effort is expended on improving sources of information. It is generally believed that clearer, better, and more information will eventually translate into improved health outcomes. Health professionals frequently refer to concepts such as health literacy (see for example, Baker 2006, Johnson et al. 2010) when engaging with individuals who have COPD. Although these perspectives are valuable, they fail to attend to evidence that printed materials promoting patient self-education do not significantly improve Health Related Quality of Life (HRQoL) (Harris et al. 2005). Indeed, research has found that health professional-led self-management interventions may only lead to short-term outcomes, suggesting that, in isolation, the provision of education and information is insufficient to produce sustained change (Kendall et al. 2004, Kendall et al. 2007).

## **AIM**

To explore how people with COPD gather, interpret and apply health affecting information.

## **METHOD**

A grounded theory design was used to gather and analyse interview data. An overarching assumption was that people with COPD actively interact with and use information to self-manage and are able to recognize and describe the process. The research question necessitated an interpretive inductive approach to explore the dynamic creation and maintenance of meanings underpinning human conduct (Hewitt, 2007), in this case COPD. Because grounded theory research is concerned with the way in which participants' create and respond to experiences and generate order in their social world, it was selected as an appropriate method for this research study (Morse, 2001; McCann & Clark, 2003).

## **PARTICIPANTS**

In 2007, nine people with diagnosed COPD agreed to participate in the study: four males and five females aged between 56-77 years ( $\underline{M}$ =68.88;  $\underline{SD}$ =7.88). All participants lived in south-east Queensland, Australia and experienced moderate to severe COPD. All reported breathlessness when walking up hills or one flight of stairs. Most (78%, n=7) were breathless when bathing or dressing, and one-third (n=3) reported breathlessness even when sitting or lying still. The duration of their disease ranged from 5 to 30 years ( $\underline{M}$ =11.89;  $\underline{SD}$ =7.91).

Participants were initially recruited from a COPD-specific community-based nursing service (n=5). It was thought that information use may be different in different settings. To explore the information use of those who were not using services in the public health system, participants were the accessed from a COPD-specific support group (n=2); and a general practice surgery

(n=2). Thus theoretical sampling was used to explore the limits and boundaries of information use across a range of settings and potentially different populations.

## **ETHICAL CONSIDERATIONS**

Ethics clearance was obtained from the University and relevant Health Service District human research ethics committees. Ethical considerations included actively ensuring that participants were self-determining, protected from discomfort and harm, treated with privacy and dignity and guarantee anonymity, confidentiality and fair treatment. Additionally, the values and principles of the National Health and Medical Research Council, namely “respect for human beings, research merit and integrity, justice, and beneficence” (2007, p.11) were considered individually and actively managed to ensure neither participants nor the researcher were compromised during the study.

## **DATA COLLECTION**

Data were collected in 2007 through face-to-face interviews, which lasted an average of one hour and were conducted in the privacy of each participant’s home. Each participant was asked a primary question: ‘Tell me about what you have done to learn to look after your COPD?’ Adopting this approach allowed participants to share their personal understanding about the information they interacted with and used rather than imposing external constraints on their experiences. This method generated rich and textured data and facilitated the use of probing questions to explore emerging concepts and categories.

## **DATA ANALYSIS**

The discussion was recorded using a digital recorder and transcribed verbatim. Field notes were made before and after interviews. Transcriptions were checked for accuracy and data were analysed with the assistance of QSR NVivo7™. We discussed and agreed upon the initial coding definitions and then used constant comparative analysis to explore meanings and identify concepts that required further clarification in subsequent interviews. Using an iterative process, our analysis used the following three theory-building activities to develop a representative model of information use in the daily self-management activities of these participants.

- (a) Identification of categories. Open, axial and selective coding was used to identify the conceptual properties and dimensions within the data (Glaser 1992, Strauss & Corbin 1998). During coding and data analysis participants' actual text was used to describe results wherever possible (Chiovitti & Piran 2003). Transcripts were read and reviewed several times, and concurrent coding memos were used to capture thoughts and ideas about what was happening in the data (Glaser 1992, Strauss & Corbin 1998).
- (b) Retention and rejection of categories. Through ongoing discussions, we reflected on, questioned and reviewed our interpretations throughout the entire process. Ongoing participant interviews provided opportunities to explore the relevance of categories to other participants, thus building the boundaries of particular concepts and identifying the overlap between processes.
- (c) Development of core processes and relationships. Diagrams were used to assist our interpretation of the data and to visually represent the relationships between categories.



Relationships between categories were further explored using theoretical sampling in that the interviews were revisited repeatedly to investigate the utility of each concept and relationship in particular cases. This process was continued until the model was internally consistent and minimal gaps in the logic could be found (Strauss & Corbin 1998). In developing visual representations of the findings, questions included ‘What is the nature of the relationship between these categories?’ ‘Does this relationship extend to other categories?’ ‘Is the relationship unidirectional?’ ‘Is there a beginning and ending point, or is the relationship cyclical?’ The process of questioning, reviewing, and refining occurred until a model emerged from the data that was able to account for all the categories that had been identified across all the participants and their different circumstances.

## **FINDINGS**

Two core self-related processes were generated in this study, labelled ‘listening to my body’ and ‘looking after my body’ (Figure 1)

[insert figure 1 about here].

These processes underpinned the self-management information use model that emerged through the analysis. The two processes described how participants integrated internally generated information (e.g., how I am feeling) with externally available information (e.g., health

professional advice) into overall self-management cycles. Internal information was derived from participants' own meaning they attached to their sensations and experiences, but was often validated through their social networks. Externally available information was most frequently sourced from relationships, including those with health professionals.

Both self-generated intrinsic information and externally available information was processed through an interpretive filter aimed at determining the relevance and plausibility of that information in participants' own lives. Two specific actions occurred when new or unfamiliar information required integration of new information into existing self-management cycles, namely 'trial and error' and 'risk taking'. Successful integration of information resulted in the creation of new routines, contingency plans, and active self-management behaviors. In most cases, a 'critical event' significantly changed the nature of internally generated information, and was a major trigger for a different behavioral process. Significantly, at the time of a critical event, participants were more receptive to externally available information provided by health professionals. This was the only time during which external information was likely to independently result in behavior changes that were not subjected to the trial and error processes described in all other situations.

### **Listening to my body**

Listening to my body incorporated the sub-processes of physical self-assessment and applying a personal filter through which to interpret that information. Participants' personal filter represented a process of individualized reasoning about symptoms and was based on intimate

knowledge and personal theory about the meaning of the symptoms in the past or for others. For all participants, the process of 'Listening to my body' in this way was essential to the second process of 'Looking after my body'.

The purpose of 'Listening to my body' was to interpret 'how I am feeling?', so that decisions related to 'looking after my body' could be enacted in a useful and personally relevant way. As part of the process of 'Listening to my body', participants might make the decision to use existing strategies, particularly if no feelings of concern or alarm or if these symptoms were not perceived to be personally meaningful or relevant at the time. If, however, concerning and relevant physical symptoms were identified, participants were likely to seek ways of making sense of those symptoms, often by seeking out social comparison and validation from others in their social network. As one participant stated, 'I listen to my body... because if you don't, you're in trouble'. Participants continually 'scanned', 'monitored', or 'listened to their body' to determine the presence or absence of physical symptoms. They used this information as a basis for taking action, 'If I don't feel right, I go back to see my GP'.

#### *Sub-Process 1: Making sense of how I am feeling*

Personal understanding was a unique filter each participant used to make sense of how their disease made them feel and why. This personal understanding ranged from simplistic acceptance of a disease state: '...about every three or four months, I'm in hospital because I get chest infections, and I don't know why' to deeply held theories of disease that had been developed over time: 'I've tried a lot of things over the years, ... and with me, things tend to work in the

short term rather than the longer term because my body tends to get used to things...'. Participants used their personal understanding to justify their treatment choices: '[Complementary therapy] gives me a lot more energy, because I lack energy without these things'. The choice to ignore advice was also based on their personal understanding and a desire to remain true to their own theories: 'I ignored it [health professional advice] for twelve months... you don't like to let yourself down...'.

Although participants' understanding could be counter-intuitive to health professional understandings of disease, it was intrinsically linked to the meaning they constructed about their disease and its impact on their lives. In this context, their decision to reject health advice was understandable. For example, 'It [the 'flu vaccination] sent me blind the last time I had it, so I'm not going back for it'. Even though influenza vaccination is recommended for those with respiratory disease, the firm belief based on previous experiences that this treatment resulted in undesirable symptoms resulted in a rejection of its use.

#### *Sub-Process 2: Social comparison – validating personal understanding*

Engaging in comparison is a common mechanism to test and validate personal understanding and was commonly used by these participants. For example, participants described how they compared their symptoms to those of other people, or identified a benchmark against which they judged their own performance. 'When my wife's in bed, and I'm in bed, I can hear my breathing. And I'm getting further and further ahead and I just don't catch up with her rhythm of breathing'. Participants also compared themselves with strangers:

...I used to see one lady... she'd puff away on one of those ventolin [aerosol medication] things. And I thought... do your breathing woman... And you only need to do it two times... I do it twice in the morning and twice at night [use ventolin]... but she was puffing away at the thing as if it was a lifesaver, and that's silly... You should do as they say. You should do it in the morning... and then try and cope yourself... You've got to help yourself, don't you?

The behavior of other people in the local community was also an important source of validation for the actions that could or should be taken:

When I go in [the bird aviary] and birds are flying all over the place... that can't do my breathing any good... so I wear a mask... And I think I might do the same when my grass grows. My mate across the road, he is as fit as a fiddle, but every time he cuts the grass, he wears a mask.

Thus, participants observed and interpreted others' health behaviors and used that information to reinforce or adjust their own beliefs and behaviors.

### **Looking after my body**

The process of 'Looking after my body' represented the goal-oriented health behaviors that arose from the process of 'Listening to my body'. Central to this process was a sense of personal responsibility for taking actions that prevented symptoms, 'I just have to accept it... There's no use crying over spilt milk... What's done is done'; and 'Before [prior to disease], I used to be a bit bombastic; get stuck into anything and just do it. But now, I can't do it, so you just ease up a bit'. Participants actively sought information from their external sources that responded to how they were feeling and their personal understanding of that information. They actively used two important behavioral processes to integrate extrinsic information into their existing routines, namely 'trial and error', and 'risk taking'. The personal filter continued to play a role in interpreting the outcome of these sub-processes. For instance, in the following example, the participant's goal was to use trial and error to produce a routine that prevented harm, but the

eventual behavior remained reliant on whether or not the participant was feeling 'alright' about this routine.

'They said to me in the hospital... you can go on that nebulizer as many times as you like... I go on it before I go to bed... and in the morning... But if I'm feeling alright during the day, I don't go on it. If you keep going on it and you don't need it, I think you sort of get into that routine and you could do yourself more harm than good'.

### *Sourcing information – the role of relationships*

Responding to feelings that were identified by the process of 'Listening to my body' sometimes required the use of extrinsic information, usually that arising as a result of relationships with key people. The way in which external information was used influenced the goal-orientated behaviors associated with the process of 'looking after my body'. Extrinsic information had the potential to moderate personal understanding and support self-management behaviors by providing an impetus for change. Family members were the most significant and common sources of extrinsic information that could motivate behavior change:

I used to do all the work on [my] car... and [my] son had his car down... I was feeling pretty good and... I got down and got underneath and gave him a hand, but I couldn't do that after a while... He could hear [the way I was breathing] when I was helping him ... and he said 'Dad get out of here'. I had to get up. And he said 'You can't do that anymore', and I thought to myself, 'yeah, you're right.' I won't attempt it any more.

Participants also identified health professionals and health related groups as sources of information: '[My General Practitioner] has always been there for me', and 'they're [community nurses] a godsend'. Support groups provided broader opportunities for information exchange: '...we'd sit around and talk... That's where we learnt a lot of stuff...'.

Sometimes, however, conflicting information from external sources created dilemmas for participants: ‘...You get conflicting answers to the same questions from doctors, naturopaths, whatever’. As a result, this participant needed to: ‘...sit and I think about it. I do believe what [my General Practitioner] says... [But] I like the more natural thing to go into this body...’

### *Integrating information – trial and error and risk taking*

Trial and error was the main process used for integrating and testing new information and changing health behaviors. Participants spoke directly about using trial and error as a source of learning: ‘through trial and error I suppose... finding out things I should do, and shouldn’t do’. Sometimes, through trial and error, it became apparent that further change was required: ‘I tried to do a couple of things... I thought I was alright, and all of a sudden I’m sitting down and I’m nearly back to square one...’. Trial and error was an important process for learning to self-manage: ‘...you make your mistakes, you learn as you go’. Trialling ways of doing things and learning from them was not always straightforward or easy: ‘...didn’t I suffer a lot before I learnt them [ironic tone]’. Health information sourced through the media was also trialed, because: ‘...not everything suits a particular person... So, if something’s on [television], I think I’ll try that, but there again it might not work for me’.

Sometimes trial and error was associated with risk-taking behaviors that contradicted medical advice and would be labelled as non-compliance. Inconsistent medication usage was one example: ‘I was told years ago that I have to take them [medication] or risk my life. I’d take them. I might take two a week (instead of one per day)... You look for shortcuts’. Learning

from risk-taking behavior and trial and error processes allowed participants to be clear about the limits of their capability: 'I suppose by realizing that different things I did... I was putting my life at risk'. Acknowledgment of risk-taking often occurred with the benefit of hindsight: '...you know, the things you do when you're young and stupid'. However, the behavior was rarely identified as risk-taking at the time and appeared to play an important role in the process of gathering information to guide future behavior.

#### *Applying information— routines and contingency plans*

All participants developed routines based on their personal understandings of their disease. These routines could be very detailed or quite simple, but they all provided participants with a sense of control over their COPD and its symptoms: 'If I get a cold, I'm quite unwell. But if you keep looking after yourself, make sure you don't get your feet wet, or you don't go outside in the rain [then you don't risk developing a cold]' and 'I always wear a singlet (chest covering undergarment). I don't know why, but if I don't wear a singlet, I'm inclined to get a bad back'.

Contingency plans were equally important for managing activities of daily living that were associated with an increased risk of breathlessness or exacerbation of symptoms: 'I go and have a shower, maybe an hour and a half or two hours before I have to go out. [Then] I'll just take it easy so I calm down again'.



*The 'Critical Event' – an unexpected and unique opportunity for change*

COPD sometimes resulted in a 'Critical Event', usually defined as a period of acute illness or an unexpected hospitalization. A 'Critical Event' had several identifiable characteristics. Specifically, it was able to be recalled in great detail, and it elicited strong emotions. For example:

... I used to get a bit breathless ... but then in April I had a cold and I come indoors, sat at the table and I started coughing, and then for the life of me I couldn't breathe... I was gasping for air... That's the first attack I ever had.

The strong emotions associated with the 'Critical Event' were usually so significant that they remained strong and salient during these interviews many years later: The impact of a Critical Event was best illustrated in the story of one participant who described an episode of semi-consciousness 'One time... I ended up with triple pneumonia... I slowly went to sleep until I couldn't get out of bed...' The critical event was always frightening: 'When you've had an experience like I had when they rushed me to hospital and that really frightened me... I think that makes you sit up and think'. While talking about this event, participants were visibly affected. During the interviews, they frequently revisited their emotive descriptions of the event and how it impacted on them. The 'Critical Event' triggered an ongoing sense of vulnerability and distress that required urgent attention.

A 'Critical Event' could occur despite the best efforts to self care: 'It was just that the cold was too far gone... I was doing everything normal'. In these cases, the event helped participants to

understand that normal care was insufficient and that they were sometimes vulnerable despite their best actions.

Of most importance to health professionals was the fact that the occurrence of a ‘Critical Event’ represented an important motivational point in the disease trajectory when the standard processes of listening and responding to information were temporarily suspended. On some occasions, there was evidence that the opportunity provided by the Critical Event had been taken up by health professionals, enabling them to contribute to positive health-related behavior change. For example, ‘I just thought well that’s it. I’ll just do as I’m told’ and ‘The doctor at the hospital told me... Your trouble is smoking – unless you want any more sessions like this [critical event], I’d give it up..... So I did’. However, in most cases, the Critical Event triggered a change in participants’ personal understanding about the impact of their disease. This process enabled the integration of new information from a different source or facilitated the transformation of existing information into a new routine. It also provided a new or broader social network for comparison and external information, often one that reflected healthier norms and standards.

## **DISCUSSION**

Although providing information is a fundamental component of health care provision, knowledge about how information is used in daily self-management by people with COPD is scarce. Our findings show that people with COPD use information in an interactive manner that includes two core interrelated processes of ‘listening to my body’ and ‘looking after my body’. The current study has identified how people with chronic disease use personal understanding to

make sense of a complex array of information and then utilize trial and error and risk-taking behaviors before integrating information into the personalised knowledge that underpins how they actually look after their bodies. This finding is not surprising, given that similar research has identified the importance of listening to one's body in this way among pregnant women experiencing pregnancy-related pain (Fredriksen et al. 2008).

After testing the utility of information in their personal context, participants created new knowledge, which then contributed to the establishment of routines and contingency plans. Development of strategies, routines and contingency plans for everyday management of living with COPD is also not a unique finding. Indeed, Kralik et al. (2004) found that people with arthritis frequently used boundary monitoring and resource mobilization to create order in their life with a chronic illness. A phenomenological study of the experience of living with emphysema also described a process of 'conscious body management' whereby people developed strategies that allowed them the greatest chance of effectively functioning within the limits of their breathlessness (Gulick & Stainton, 2008). The current study has developed a greater understanding of the mechanisms by which information is integrated into a personal theory and how that personal theory translates into practical strategies and actions.

When working with clients, health care professionals are required to integrate current evidence with the preferences of individuals (Barratt 2008). Understanding how mechanisms of trial and error, risk taking, and personal understanding impact on information use and self-management in COPD clients provides health professionals with evidence about the circumstances under which

clients are likely to be receptive to the provision of information. This research also highlights the importance of relationships and context to the behavioural preferences of individuals when self-managing their disease. Thus, it is important for health care professionals to develop appropriate and targeted educational and information sharing opportunities that accommodate, complement and capitalise on the contexts, relationships, previous experiences, and personal knowledge of their clients.

Importantly, in this study, it was found that people with COPD engaged in a process of looking after their bodies that was unique, dynamic, mutable and not necessarily consistent with professional opinion about best practice. Thus, when providing information, health care professionals need to explore clients' beliefs and perceptions about their disease and its management. Perception has the remarkable property of assisting individuals to make sense of complex sensory input (Jones 2003) and is essential to self-management. This study revealed that underlying belief systems, which can be deeply entrenched and socially reinforced, have a significant influence on self-management activities through their effect on the way in which individuals interpret information, integrate it with their own personal knowledge systems and then apply it to their own context.

A 'critical event' provides health care professionals with a significant opportunity to motivate and support rapid change in health-related behaviors. During a 'critical event', individuals are vulnerable and are confronting a frightening situation in which normal behaviours have not been successful and seeking information about strategies that will work quickly and effectively. This study provides some evidence that during a 'critical event', people are ready to adopt strategies

with only limited reflection about their credibility. By changing behaviour, people were seeking control over their symptoms, which supports the early assertion of Bandura (1997) that the gap between internal beliefs and actual coping efficacy determines whether or not detrimental health habits will be changed. Thus a 'critical event' creates a predictable 'teachable moment' (Lawson & Flocke, 2009) at which time the interaction between the health professional and individual can prompt behavior change. Non-critical times during the self-management cycle seemed to offer less opportunity for health professionals, but greater opportunity for family and broader social comparison processes.

### **Strengths and limitations**

This study has been limited by time, scope and participant numbers. However, a cycle of information use has been derived from, and is consistent with, the data obtained from people who are living with COPD. While the cycle of information was not resubmitted to participants to ascertain their view regarding accuracy, consistent with grounded theory approaches, each component of the cycle was comprehensively tested against existing data. Although this research was relevant to information use during individual self-management, no assessment was made regarding how well people with COPD were living with and self-managing their disease. Subsequently, it cannot be assumed that engagement in the processes identified in this study will equate to living well and optimally self-managing COPD.

### **Relevance to clinical practice**

Specifically, this study has suggested that, in practice, health professionals need to take time to understand their clients' personal interpretations, theories and routines, to capitalize on informal sources of information and processes such as social comparison, to provide information at timely points based on an understanding of the personal disease journey, and be sensitive to points of vulnerability when information may be most useful. Any intervention by health professionals should aim to contribute to the client's understanding of the connections between symptoms and personal consequences as defined within the context of their own social environment. By attending to the cycles of information use identified in this study, health professionals will be able to tailor effective and supportive health care that is responsive to the personal knowledge that underpins the unique experience of living with COPD.

## **CONCLUSION**

This study has identified cycles of information use derived from in-depth interviews with a small sample of people living with COPD. Despite the small sample size, the participants all reflected a similar process of self-management. Everyday self-management decisions represented much more than simple treatment choices; or compliance with and adherence to medical regimens. Rather, self-management was the result of an intricate and purposeful interaction between the processes of 'Listening to my body' and 'Looking after my body'. All information was passed through a central filter based on personal understanding. This filter was constructed on the basis of interpretation of one's feelings and experiences within one's social context. The presence of this personal knowledge base ensured that information became purposeful, structured and intensely individualized. Thus, the process of delivering educational and information-sharing interventions must respond to this complexity.



## REFERENCES

- Arnold R, Ranchor AV, Koëter GH, de Jongste MJL, Wempe JB, ten Hacken NHT, Otten V, & Sanderman R (2005) Changes in personal control as a predictor of quality of life after pulmonary rehabilitation [Electronic version]. *Patient Education and Counselling*, 60(2006), 99-108. [doi:10.1016/j.pec.2005.02.015](https://doi.org/10.1016/j.pec.2005.02.015)
- Baker DW (2006) The meaning and the measure of health literacy. *Journal of General Internal Medicine*, 21, 878-883. doi: 10.1111/j.1525-1497.2006.00540.x
- Bandura A (1997) *Self-efficacy: The exercise of control*. New York: W.H. Feeman and Company.
- Barratt A (2008) Evidence based medicine and shared decision making: The challenge of getting both evidence and preference into health care. *Patient Education and Counseling* 73, 407-412. [doi:10.1016/j.pec.2008.07.054](https://doi.org/10.1016/j.pec.2008.07.054)
- Boxall A, Barclay L, Sayers A, & Caplan, GA (2005) Managing chronic obstructive pulmonary disease in the community. *Journal of Cardiopulmonary Rehabilitation* 25, 378-385.
- Chiovitti RF, & Piran N (2003) Rigor and grounded theory research. *Journal of Advanced Nursing* 44(4), 427-435. doi: 10.1046/j.0309-2402.2003.02822.x
- Chodosh J, Morton SC, Mojica W, Maglione M, Suttrop MJ, Hilton L, Rhodes S, & Shekelle P (2005) Meta analysis: Chronic disease self-management programs for older adults. *Annals of Internal Medicine* 143(6), 427-438.
- Clark N, Gong M & Kaciroti N (2001) A model of self regulation for control of chronic disease. *Health Education and Behaviour* 28 (6), 769-782. DOI: 10.1177/109019810102800608



Fredriksen EH, Moland, K.M., & Sundby, J. (2008) "Listen to your body" A qualitative text analysis of internet discussions related to pregnancy health and pelvic girdle pain in pregnancy. *Patient Education and Counseling*, 73, 294-299.

doi:10.1016/j.pec.2008.02.002

Glaser, B.G. (1992). *Basics of grounded theory analysis*. Mill Valley, CA: Sociology Press.

Gulick, J. & Stainton, C. (2008). Living with chronic obstructive pulmonary disease: developing conscious body management in a shrinking life-world. *Journal of Advanced Nursing*, 64 (6), 605-614. doi: 10.1111/j.1365-2648.2008.04823.x

Harris, M., Smith, B., & Veale, A. (2005). Printed patient education interventions to facilitate shared management of chronic disease: a literature review. *Internal Medicine Journal*, 35, 711-716. doi: 10.1111/j.1445-5994.2005.00955.x

Hewitt, J.P. (2007). *Self and society: a symbolic interactionist social psychology*. Boston: Allyn and Bacon.

Johnson, V.R., Jacobson, K.L., Gazmararian, J.A., & Blake, S.C. (2010). Does social support help limited-literacy patients with medication adherence? A mixed methods study of patients in the Pharmacy Intervention for Limited Literacy (PILL) study. *Patient Education and Counselling*, 79,(1) 14-24.[doi:10.1016/j.pec.2009.07.002](https://doi.org/10.1016/j.pec.2009.07.002)

Jones, K. (2003). *Health and human behaviour*. South Melbourne, Australia: Oxford University Press.

Kendall, E., Catalano, T., Kuipers, P., Posner, N., Buys, N., & Charker, J. (2007). Recovery following stroke: The role of self-management education. *Social Science & Medicine*, 64(2007), 735-746. [doi:10.1016/j.socscimed.2006.09.012](https://doi.org/10.1016/j.socscimed.2006.09.012)

Kendall, E., Hunter, B., Foster, M., Chaboyer, W. & Gee, T. (2004). The Sharing Healthcare Initiative: A better approach to managing chronic conditions. PWC & DoHA.

Kralik, D., Koch, T., Price, K., & Howard, N. (2004). Chronic illness self-management: taking action to create order. *Journal of Clinical Nursing*, 13 259-267. doi: 10.1046/j.1365-2702.2003.00826.x

Lawson, P.J., & Flocke, S.A. (2009). Teachable moments for health behavior change: A concept analysis. *Patient Education and Counseling*, 76, 35-30.  
[doi:10.1016/j.pec.2008.11.002](https://doi.org/10.1016/j.pec.2008.11.002)

Lorig, K. (2003). Self-management education: More than a nice extra. *Medical Care*, 41(6), 699-701.

McCann, T.V., & Clark, E. (2003). Grounded theory in nursing research: Part 2 – critique (grounded theory). [Electronic version] *Nurse Researcher*, 11(2), 19-28.

McKenzie, D.K., Frith, P.A., Burdon, J.G.W., & Town, G.I. (2006). *The COPD-X Plan: Australian and New Zealand guidelines for the management of chronic obstructive pulmonary disease*. Retrieved September 3, 2006, from [www.copdx.org.au/guidelines/documents/COPDX\\_April06\\_2006.pdf](http://www.copdx.org.au/guidelines/documents/COPDX_April06_2006.pdf).

Morse, J.M. (2001). Situating grounded theory within qualitative enquiry. In R.S. Schreiber & P.N. Stern (Eds.), *Using grounded theory in nursing* (pp. 1-16). New York: Springer Publishing House.

National Health and Medical Research Council. (2007). *National statement on ethical conduct in human research*. Retrieved February 7, 2008, from [http://www.nhmrc.gov.au/publications/synopses/\\_files/e72.pdf](http://www.nhmrc.gov.au/publications/synopses/_files/e72.pdf).

Patterson, E. (2007). Health teaching. In W. St John & H. Keleher (eds.), *Community Nursing Practice: Theory, skills and issues* (pp.157-170). Crows Nest, NSW: Allen and Unwin.

Strauss, A., & Corbin, J. (1998). *Basics of Qualitative Research*. (2nd ed.). Thousand Oaks, CA: Sage Publications.

World Health Organization (WHO), (2008). The global burden of disease: 2004 update.

Retrieved from

[http://www.who.int/healthinfo/global\\_burden\\_disease/GBD\\_report\\_2004update\\_full.pdf](http://www.who.int/healthinfo/global_burden_disease/GBD_report_2004update_full.pdf),

24<sup>th</sup> April 2009.

We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Figure 1: The COPD personal intelligence information use cycle

