Patients’ experiences and perceptions on support to self-manage their long-term condition

Executive summary

This report presents the findings from one focus group discussion involving people with various long-term conditions, registered with a single general practice in Sheffield.

Objectives:
- To explore the perceptions and needs of people with long-term conditions with regards to their experiences of annual reviews and support for self-care and managing their health.
- Gain feedback on the ‘care planning’ approach and associated proposed documentation / patient information

Methods:
- Focus group, consisting of 8 patients (6 male and 2 female), lasting approximately 3 hours
- All participants had one or more chronic health problem
- Facilitated using a semi-structured interview schedule (Appendix 2)
- Discussion was recorded and later transcribed verbatim
- Thematic analysis - inductive, exploratory approach

Results:
- There were two predominant themes: the ‘process’ of support for self-care / management and the personal impact of having a long-term condition.
- Key points:
  - passivity – treatment is “done to them”
  - taking control based on how people think about their condition
  - possible links with level of ‘patient activation’.
- Feedback on sample written patient information was mixed and may be related to knowledge and perceived capacity to self manage or how ‘activated’ the patient is.

Conclusions:
A limited number of themes or key points have resulted from this small focus group. However it has offered a useful starting point and insight into the patients’ perceptions and experiences with regards to managing their long-term condition.
- Suggestive of low ‘activation’ levels, and may reflect lack of knowledge about their condition and the potential impact on their ability / confidence to self management, despite positive satisfaction with services
- An element of expectation that the health care professional (HCP) would provide solutions
- Impact of condition on social, psychological and physical well-being
- Medication issues and polypharmacy were also important concerns for these patients

Recommendations:
• Ensure findings from report are available to the practice and those developing and implementing strategies to improve self-management of people with long-term conditions and
• Recommend that self-management implementation plans to include interventions that improve patients’ level of ‘activation’
• Explore the potential for using the Patient Activation Measure (PAM) tool to guide consultations. See: http://www.slideboom.com/presentations/404469
• Review aspects of PAM to identify existing resources / skills already available to support patients and gaps

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1. Introduction
Year of care - Yorkshire and Humber developed a diabetes and subsequently a long-term conditions template to support ‘care planning’ in particular goal setting. In Sheffield we have adapted this template to include existing local clinical templates. A number of practices in Sheffield have expressed an interest in using this template and would like to consider ways of improving support for self-management with patients who have long-term conditions. Support for self-management can include various tools and strategies, including patient education, patient orientated goal-setting, motivational interviewing, different consultation styles and shared decision-making. The outcome of these strategies aims to support patients to become ‘activated’, i.e. knowledgeable, confident and motivated to manage their health and long-term condition. (See Appendix 1)

With a view to implementing a ‘care planning’ approach to long-term conditions management it was decided to gain an understanding of patients’ experience with current annual reviews and their views on proposed documentation pertaining to effective goal setting. This report presents information gathered from one focus group discussion involving people with various long-term conditions, registered with a single general practice in Sheffield.

1.1 Objectives
The overall objective of this report is to inform the implementation of effective self-management support to individuals with long-term conditions. To achieve this aim the focus group objectives were to:

• To explore the perceptions and needs of people with long-term conditions with regards to their experiences of annual reviews and support for self-care and managing their health.
• Gain feedback on the ‘care planning’ approach and associated proposed documentation / patient information

1.2 The ‘Research’ Team
The two authors of this report are Lead Primary Care Development Nurses (PCDN) with clinical backgrounds in cardiovascular disease and older people. Both are currently employed by NHS Sheffield and were asked to undertake the focus group on behalf of the general practice as part of the development of long-term conditions management in the primary care setting. A third PCDN with a clinical background in respiratory disease observed the focus group and supported the summary of findings at the end of the focus group discussions. The chairperson from NHS Sheffield’s Clinical Audit Patient Panel who has a clinical nursing background and personal experience of neuro-vascular disease
facilitated the focus group discussion. Support with methods and analysis was provided by Dr Lerleen Willis, Research and Development Facilitator, NHS Sheffield, (now Sheffield City Council). The practice team identified and invited the potential participants and provided the accommodation, resources and refreshments during the focus group session.

2. Methods

2.1 Data Collection

Twenty two patients, who all had at least one long term condition (Diabetes, Cardiovascular and/or respiratory disease) registered with a single general practice in Sheffield, were invited to discuss their views and experiences of their annual review of their condition and what they personally think their needs are with particular reference to a proposed ‘care planning’ approach. Eight patients (6 male and 2 female) attended the focus group lasting approximately 3 hours on 5th December 2011. All participants had one or more chronic health problem, including chronic obstructive pulmonary disease (COPD), diabetes and cardiac conditions.

Consent was implied by agreement to attend. Permission was sought to record the conversations and no objections were raised. Assurances were also given regarding confidentiality; access to data was limited to the two researchers and stored safely within a ‘safe haven’ at NHS Sheffield and that all data would be destroyed on completion of the analysis/report. A semi-structured interview schedule (Appendix 2) was used to elicit views. The focus group was undertaken on the general practice premises.

2.2 Data Analysis

The focus group discussion was recorded and later transcribed verbatim. Initial data analysis was undertaken using Microsoft Excel to support the organisation of the text to particular themes. The analysis was undertaken by both nurses individually and discussion took place to agree on developing themes. The transcript was first read and descriptions applied to relevant sections of the text. These descriptions were then interpreted to suggest possible meanings and finally grouped into themes.

Post focus group de-briefing highlighted the difficulties experienced with facilitating the group using the semi-structured interview schedule. This appeared to arise from difference in perceptions regarding what constituted a ‘review’, ‘self-care’ / ‘self-management’. General first thoughts were that the group was very positive about the service they received from the practice.

Given the resulting conversations, analysis took an inductive, exploratory approach rather than a confirmatory approach driven by specific questions and ideas. Therefore we present a rich description of patient experiences and perceptions around the topic area, although not specifically answering questions initially posed in the focus group. We do however summarise some specific feedback on the written information provided in other areas.

The patients’ responses were then considered within the context of existing self-management theory, in particular the patient activation model (See Appendix 1)

3. Results

There were two predominant themes:

I. the ‘process’ of support for self-care / management and

II. the personal impact of having a long-term condition.

I. Support Self-Care / Management of Long-term Conditions
There were differing views about what a review was and how often it took place. Some considered each visit to see a HCP was “a review”; others saw their review as their “annual MOT”.

“What do you mean by review it? Do you mean sit down and talk about your condition?”

“You don’t get it that regular”
“...a six monthly or a 12 monthly review. I think this is very, very important”
“some get good reviews but sometimes end up with about four a year so it can be a bit, coming backwards and forwards and that can sometimes feel a little bit..”

Similar confusion was expressed around other terminology:
“....I’ve got this chronic thing and I don’t know what chronic means!”

Although this group was very positive and complimentary about the support they got from the practice team to manage their condition, what they actually described was a process of “things being done to them” and a degree of “passive compliance” to instructions and treatments usually initiated by the HCP:

“....prescribed tablets and you take them religiously....”
“I’m happy with the situation as it is with treatment and... medication.....”
“....test blood and urine and sugar.....start metformin tablets....”
“The practice actually initiated the review.”
“....sometimes we get management ‘instruction’ which goes beyond…”
“I feel that I’m being very well reviewed “
“You’ve only got to ring and nurse comes up.”
“They tell you not to do this and not to do other”

Yet patients expressed a wish to be treated holistically and not as a condition:

“... condition actually belongs to a person.”

However, in contrast to this ‘passive compliance’, there appeared to be some comprehension of what self-care / management was, including the importance of knowledge / understanding of their condition and responsibility for their own health:

“We want to move that step beyond, instead of them wagging the finger and saying this is what you should do you, say this is what I want to do.”

“....all the doctors are involving you.... “
“....responsibility for your condition does stay with the person who has got the condition, as you said, at the end of the day it’s me that’s got to live with it....”

“If you know a lot about your condition and you work together with your healthcare professional....”

“Understanding makes it a lot easier to manage.”
“....try to keep myself ...fit...activities... eat wisely....”
“....supporting you to manage your condition....I want to do ‘this’ to help myself and they suggest something.”
“....part of the review process is .... helping you to be able to make the decisions for yourself.”
There was some reference to effective communication that patients considered important and enhanced their trust in the health care professional: listening skills, trust and confidence in HCP:

“…listened and picked out … a lot that were wrong… not only physically … but mentally…”

“You want to come out of a review … feeling that they know how you feel.”

“…speak language which we can understand…”

**II. Personal Impact of Long-term conditions**

The personal impact of long-term conditions was very evident in the conversations, in particular the financial implications and psychological effects:

“I’d got two kids, mortgage to pay, wife to keep and it was like somebody had chopped my hands off”

“…anybody … who’s just starting off … to quell their fears, ‘cause that’s biggest part of it. When you first got any serious illness …biggest fear is … I was working… plenty of cash … confidence… then all of a sudden, bang, it’s done. That’s when it wants catching.”

“…incapacity from last year…”

“You take so many tablets…”

“….when you look through … list of conditions that could occur through taking this tablet ….This is a big worry.”

**Feedback on sample written information**

Part of the session included asking the group their opinion on getting their test results prior to their review and taking summary information away following a review.

With regards to communicating test results prior to review, some felt it would be beneficial,

“Yes, before you saw nurse, I think if you got your test, you know what’s going to happen.”

“People have got to know haven’t they? “

But others raised concerns about understanding results and possible anxiety this may cause, particularly if it was ‘bad’ news:

“Obviously, if there is anything seriously wrong … (they do ring you up) you’ll be advised immediately to come in and I think that that system works quite well.”

“Too much information can do more harm than good and you might start to worry about things you don’t need to worry about “

“… we might not understand what the results mean. It might cause you worry.”

“If there’s any bad news I like it to come from a sympathetic doctor, I wouldn’t want it by a letter.”

These concerns may be addressed by increasing the individual’s knowledge about conditions and associated tests and improving their confidence to manage their condition.

When considering the summary information that could be given to patients to take away at the end of a consultation:

“Yes, it would be a good idea to have a record of your cholesterol results and your blood pressure every time you came in, but certainly I think also for something like diabetes it looks very, very good.”

“Useful to have a written copy”
4. Conclusion
4.1 Discussion and Future Considerations

This was a small group of patients with long-term conditions, who appeared satisfied with the services currently provided to manage their condition / health. However, it was interesting to see how they perceived this management. There was clearly an element of expectation that the HCP would provide solutions (e.g. medication, health advice) and a degree of ‘passive compliance’. When considering the ‘patient activation model’ (See appendix 1) the patients present at the focus group appeared to be at level 1 or possibly 2. Medication issues and polypharmacy was also an important concern for these patients.

The theory suggests that the way patients think about their condition can determine whether they take responsibility/control. There is also a link between awareness and knowledge of condition and a sense of taking control or passivity. In hind sight, it would have been useful to assess the participant’s level of activation and relate this to individual knowledge, attitudes and responses.

Tailoring support and coaching to the patient’s current level of activation can help to move the patient along the continuum, improving their ability and capacity for behaviour change and self management.

A limited number of themes or key points have resulted from this small focus group. However it has offered a useful starting point and insight into the patients’ perceptions and experiences with regards to managing their long-term condition.

The results are suggestive of low ‘activation’ levels, and may reflect a lack of knowledge about their condition and an impact on their ability / confidence to self management, despite positive satisfaction with services. Specifically there was:

- An element of expectation that the health care professional (HCP) would provide solutions
- A significant impact of their condition on social, psychological and physical well-being
- Medication issues and polypharmacy concerns for these patients

5. Recommendations

- Ensure findings from report are available to the practice and those developing and implementing strategies to improve self-management of people with long-term conditions and
- Recommend that self-management implementation plans to include interventions that improve patients’ level of ‘activation’
- Explore the potential for using the Patient Activation Measure (PAM) tool to guide consultations. See: [http://www.slideboom.com/presentations/404469](http://www.slideboom.com/presentations/404469)
- Review aspects of PAM to identify existing resources / skills already available to support patients and gaps
Appendix 1

Patient Activation Model

Coaching for Activation

Tailoring support to activation levels recognizes that individuals possess differing levels of knowledge, skill and confidence in managing their health. Coaching for Activation meets the individual where he or she is, allowing for education, health goals and action steps to better engage and move individuals along a path toward higher activation.

Source: http://www.insigniahealth.com/solutions/coaching-for-activation
Appendix 2
PURPOSE & INTERVIEW SCHEDULE

PURPOSE:

- To find out what patients think about long-term condition “reviews”
- To establish what they want from a review
- To explore what would help them manage their health better
- To explore patient views on receiving written information – personal goals and test results
- To establish if patients would like a more collaborative care planning approach

WELCOME & INTRODUCTION:

*Introduction to the session*

*Ice-breaker: Name and how long people have had their condition*

W1. What does ‘self-management’ or ‘self-care’ mean to you?

QUESTIONS:

*You should all have been invited at some time in the past for a review of your long-term condition…*

Q1. What information were you given about the review before it happened?
Q2. What did you expect to happen at the review?

*Think about a review that you have had recently (FLIPCHART SUMMARIES: Q3, 4, 7, 8, 9 12)*

Q3. What do you think went well?
Q4. What do you think didn’t go well?
Q5. How much were you able to talk about your ideas about managing your condition / health? Or How much were you able to join in and contribute to the discussion?
Q6. How much do you feel your views were listened to and taken into consideration?
Q7. What would you like to get out of the review?
Q8. Is there anything about the review that needs to change?
Q9. Is there anything about the review that should stay the same?
Q10. How did the review help or not help you to manage your own health?
Q11. In what way?
Q12. What would help you to manage your condition?

BREAK

DRAFT RESULT SHEETS / GOALS TO SHOW THEM

Q13. Would you find it helpful to get your test results before you see the nurse / doctor?
Q14. How would this be helpful?
Q15. How might this not be helpful?

Q16. Would you find it helpful to get a written copy of things you had talked about and agreed together to do?
Q17. How would this be helpful?
Q18. How might this not be helpful?

Q19. What do you like about the example copies you have seen?
Q20. What don’t like about the example copies you have seen?

Q21. What information would you like to take away from the review?

Q22. Is there anything else that you would like to change or definitely see continue:
   a. About the way your condition is reviewed?
   b. About the way you manage and are supported to manage your condition?

SUMMARY:

Oral presentation of brief summary / key points for confirmation and further clarification