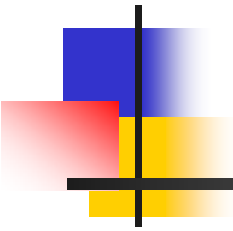


What Are The Information Needs Of
Patients With Primary Systemic
Vasculitis? Development of an Educational
Package.



Janice Mooney 2007





Aims of the study

- 1) To explore the educational needs of patients with PSV.
- 2) This information will be used to guide the second part of the study, which is the development of an educational package



Background

- PSV (Wegener's Granulomatosis, Churg Strauss Syndrome, Microscopic Polyangiitis and Polyarteritis Nodosa)
- Are rare conditions characterised by inflammation and necrosis of blood vessel walls (Watts & Scott 2003)
- Modern treatment has changed these diseases which once had a poor outcome, to chronic diseases, which relapse and remit



Background

- There is considerable literature on the educational needs of patients with SLE and RA
- It has been shown to be an important part of the management of these patients (Ramos-Remus et al, 2000)
- Active patient involvement in disease management such as RA improves outcome, reduces the need for professional input (Ward et al 2003)



Background

- But there has been very little work specifically devoted to patients with PSV
- There is little published literature on the specific informational needs of patients regarding their disease (Herlyn et al 2001)
- Prognosis, treatments, and management of disease symptoms and coping strategies



Sources of Information

- Can be hard to find
- Need to know where to look / who ask
- Magazines, articles, books, information leaflets, internet, support groups, medical journals
- Rare disease
- Often not disease specific
- Not everyone has access to the internet



Information

- Provision of high quality information, empowers patients to become active partners in the management of their condition (Coulter 1997, Opie 1998, Spalding 2000)
- Information sources, which have been developed with active participation of patients, are likely to be more acceptable and relevant to patients (Kennedy et al 2003)



Study design

- The study will collect and analyse qualitative and quantitative data through a four-stage process.
- Initial focus groups
- Face: face interviews
- Prioritisation of identified themes by patients
- Development of education programme



Focus Groups

- Each focus group 8-10 people
- Wegener's Granulomatosis, Churg Strauss Syndrome, Microscopic Polyangiitis or Polyarteritis Nodosa
- Aged >18years
- Agreed to participate



Focus group members

- Male
 - CSS 2
 - I male carer
 - Age (48-61)
 - Anca positive
 - Disease duration 2 - 13 years)
- Female
 - CSS 1
 - WG 3
 - Age (56-69)
 - All Anca positive
 - Disease duration (9-15 years)



Focus Group

- The researcher manages the group, ask questions, encourages active participation within the group
- Important in order for patients to share their experiences, opinions and attitudes
- The meeting is tape recorded and transcribed



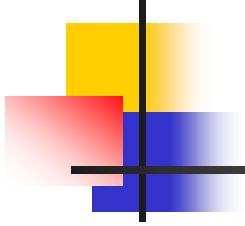
Vignette (Story)

- 'I had been feeling unwell for sometime and no-one really knew what was wrong with me, I had various tests and investigations. I was seen by several doctors and I was given this diagnosis of Vasculitis, I didn't want to bother the doctor with questions as he / she was too busy. I was worried, I had never heard the name of it before, I wanted to find out more about this rare condition and didn't know where to start'

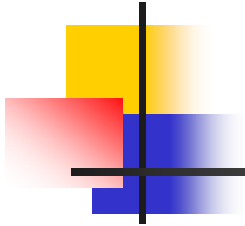


Initial Reaction After Diagnosis

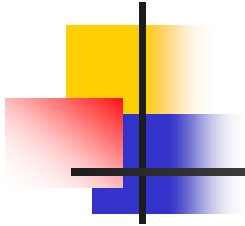
- ' When I was diagnosed I was quite frightened. But on the web I found people who had been living with the disease for 15 years which was quite reassuring '
- 'It took about 3 years to diagnose me, a long long time a lot of tests, and a lot of other things went on, and I was just going downhill all the time, so a lot of it went over my head I do not remember,



-
- Well I must have had a different sort of reaction because I was elated because I was being fed anti-depressants and treated like I was mental going off my head'
 - When they finally did a kidney biopsy that was the way they found it, so it was nice to know what it was in a way someone knew what it was and it was not, not something untouchable.



- And I thought I just have to try again, and I went down and I said look I'm not depressed, there's nothing wrong with my marriage, nothing wrong in the family, I'm ill. Please do something, Then they . He said. I think I know what this is, it is but it's rare'



- 'I would go backwards and forwards to the dr. last time I crawled in to the dr's'
- I've got a suggestion, I know what it is, and then eventually a dr came to me one morning and said, I think I know what you've got , it's very rare, very unusual, he said but I'm going to ask then to test for Wegeners, I had never heard of it, didn't mean anything to me, I felt so relieved,



Patient Information Experiences

- I think I was lucky because while even on the ward I was given a paper with lots of information (produces leaflet)
- Now I got a general book on vasculitis, which has a paragraph of Wegeners about ... that's all I got
- Well I don't remember any leaflets on Churg Strauss, I was handed a lupus leaflet, and that was it'



Access To information

- My doctor gave me something off quite a good website, em sort of summary, which , I can't remember which one, of the top of my head, but I kept moaning to him I don't know enough about...and he did print me something off which I haven't been able to find again, it was something like the BMA, which was couple of pages which was basic but good , if you were first diagnosed , you know in a way I almost knew it all , but I wouldn't haven't have minded having it 2 years ago or something it was a good basic level of information, and was quite useful.



Accessing Information

- 'And I must be one of the few who have not got a computer '
- 'You're not the only one '
- 'Are you, don't worry, your probably better off, sometimes it's quite frightening, sometimes I just think I wish I had never looked this up'
- 'I don't agree with that, I have found it invaluable myself'



Knowledgeable Practitioners

- There was a doctor in our practice who was unhelpful. I broke my ankle and he said I don't know why you're coming to see me because I don't know anything about your condition and I said, just as well because I've come about my ankle. After that experience I never go to that doctor about Wegeners.
- It's that rare they don't know about it.



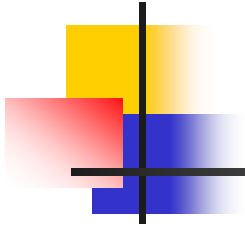
Knowledgeable Practitioners

- Now the rheumatology helpline, the few times I've been frightened for whatever reason legitimate or perhaps just psychosymptomatic or whatever you know I've found them really good'
- ' I think you need access to someone who is knowledgeable about you're condition'

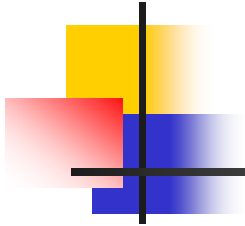


Information Delivery

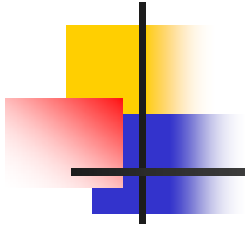
- 'I think a good leaflet – a well written leaflet, is essential, it has to be written down, I don't know what the rest of you felt like'
- 'Yes'
- 'The talk went over my head'
- 'Yeah' from group
- 'in one ear and out the other, I just couldn't remember things'



- 'My wife heard things but it's different for her, than it is for me I need Myself. I prefer it to be written down, so I can refer back to it , perhaps with contact numbers' 'yeah' from group
- 'I felt that I wanted someone to reassure me I would be all right, but then I needed to get a little bit better before I wanted all the information'



- I'd like to look at the leaflet and then be given the opportunity to discuss it because if someone came saying something to me, something in the conversation will stick in my head and I'll be thinking about that, the rest of the conversation will go past me there so I think you need both
- yeah so do I
- people are different aren't they and react differently to situations



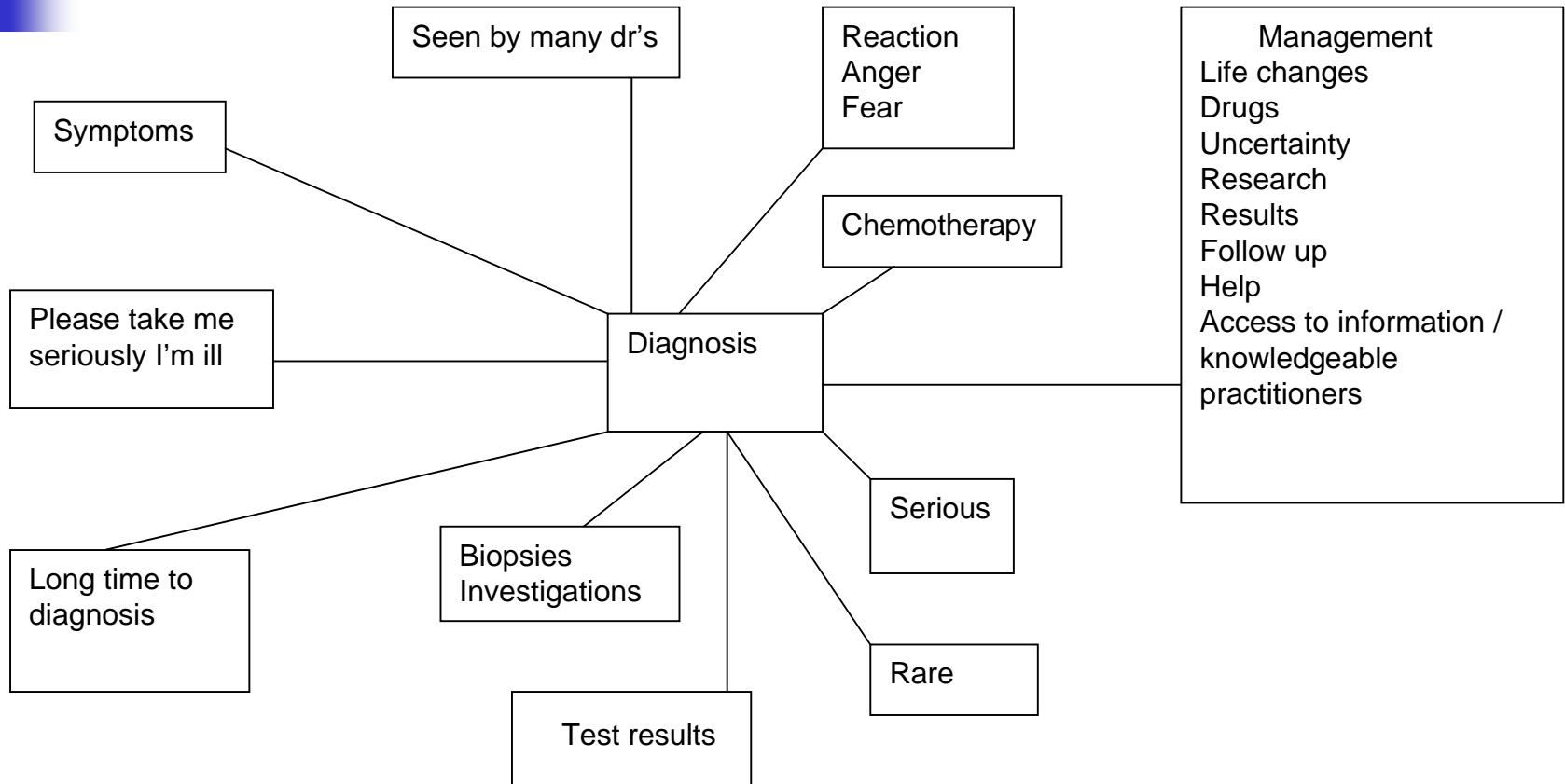
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- I'm satisfied I had really good information'
 - I'm happy with a leaflet because you can sit and absorb it and then ask questions
 - I think I prefer the other approach where, somebody talks to you, and goes through the leaflet
 - Yes, it gives you time to ask questions



Support Group

- 'A support group would make a real difference'
- Are you all in Stuart Strange
- How to you get that then, how come you're on their mailing list
- Well I have heard of it yes. Did a sponsored walk for it
- 'Taking part in today's discussion made a difference'

Contextual Model of Road to Diagnosis of PSV



Acknowledgements

- ARC



- Dr R Watts and Prof DGI Scott
- Most of all the Patients