An exploration of the experiences of rheumatology nurses counselling patients on Methotrexate therapy

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Introduction:

Educating patients prior to starting Disease Modifying Anti-Rheumatic Drugs (DMARDs) for inflammatory arthritis is a central role of rheumatology specialist and monitoring nurses (RCN, 2009). In most rheumatology units, once the decision is made by a clinician to commence Methotrexate, the patient is then referred to a rheumatology nurse to receive counselling regarding the commencement of treatment (RCN 2009). Patients need to understand how to take the drug and what side effects to look out for in order to take it effectively and safely and improve concordance (Hill et al, 2009).

Methotrexate is the most widely prescribed DMARD for Rheumatoid Arthritis and Psoriatic Arthritis (Bird et al 2014) and education is particularly important because of its delayed effect and the significant risk of side effects, which can occasionally be fatal (NPSA 2004; Harrison and Jones 2014). There are also tolerability problems in more than half of regular takers, which may affect adherence (Robinson et al 2015).

No studies have been conducted as to how rheumatology nurses are taught to carry out specialist roles. Latter et al (2001) recognized that nurses make an important contribution to the education of patients, and carried out a survey of student nurses to identify drug knowledge and attitudes towards patient education. They concluded that students expected to learn on the job in order to gain knowledge and experience. A survey of diabetic nurses demonstrated that they had not received any formal training to carry out their role (Courtenay and Carey 2008).

Robinson et al (2017) carried out the first survey of rheumatology nurses regarding the training they had received to educate patients on Methotrexate. The aims of the survey were to identify knowledge, confidence and perceived requirements for training; the findings demonstrated an historic lack of formal training and variable confidence in the role. Confidence in the role developed over time and was significantly correlated with knowledge. The survey demonstrated that there was little accredited and standardized training for nurses in Rheumatology regarding the education of patients on Methotrexate. The aim of the current study was to explore the experiences of rheumatology nurses counselling patients regarding the commencement of Methotrexate therapy, partly as a means of exploring the educational needs of these nurses.

Method:

A qualitative phenomenological approach was used (Ritchie and Lewis 2003) because the lived experience of nurses counselling patients on Methotrexate were being explored. Phenomenology looks to examine real experiences of participants, recognise the qualities of those experiences and therefore identify what is at the core of that experience. The goal of phenomenological research is to accurately describe a ‘lived’ experience in relation to what is being studied (Ball, 2009). Further, one of the characteristics of the phenomenology approach is purposive sampling (Connell et al 2014), this ensures that the research question will have a common significance to the research participants. Semi-structured interviews were performed with a purposive sample of six nurses from two rheumatology centres in the United Kingdom. The participants were identified by the authors who were known to them, the only eligibility criteria was that the participants were involved in the education of patients about to commence Methotrexate. This small sample size is in keeping with comparable in depth qualitative studies where the objective is to gain an in-depth understanding of the experience of particular individuals (Greenhalgh and Taylor 1997; Connell, et al 2014). A letter of invitation and study information was emailed to all participants. Informed consent was obtained prior to conducting the interview. Ethical approval was obtained from Sunderland Research Ethics Committee.

The interview schedule (figure 1) was developed by the steering group (which consisted of two rheumatologists, two nurses and an academic psychologist) who have expertise in this area. The interview schedule was also informed by current research which identified the training, confidence and experience of nurses in this role (Robinson 2017).

Figure 1 The Interview Schedule

Nurse Interview Schedule

1. Can you describe a recent education session?

* Do the sessions vary?
* If they do, in what ways do they vary?

2. Do you use any written information or prompts?

* Can you describe what you use?

3. Are there some key areas you try to cover when educating patients?

* Can you describe these?

4. Do patients express their views during these sessions?

* What are their views?
* What sort of things do patients talk about?

5. Do you have adequate time to do the education sessions?

* How much time does it normally take?

6. After the education sessions, do you monitor these patients yourself?

* How does the monitoring/follow up system work in your department?

7. What preparation did you have before you started educating patients starting

 Methotrexate?

* Did you have any supervised practice?
* What did it consist of?
* How useful did you find it?

8. In an ideal world what training would you like?

9. How do you feel now about educating patients starting Methotrexate?

* How confident are you with this role?

Demographic details, including the length of time participants had worked in Rheumatology and the duration of years participants had been involved in educating patients on Methotrexate, were collected. The interviews were conducted by the lead researcher (SMR). At the beginning of the interview, participants were invited to describe a recent education session that involved counselling a patient on Methotrexate. Their views and experience were sought on: written prompts used during the consultation; key information needed by the patient; patient engagement in the session; duration of the session; training received to counsel patients on Methotrexate and their confidence in counselling and making arrangements for subsequent monitoring appointments. The interviews took place in a quiet room within the hospital in which the participants worked and lasted between 45 to 60 minutes.

Interviews were recorded and transcribed verbatim. Analysis was carried out using a thematic analysis approach which systematically identifies, organises and offers insight into, patters of themes across a dataset (Braun and Clarke 2012). In order to control personal bias with regard to analysing the data, the interviews were analysed independently by two researchers (SMR and DW) and themes extracted. SMR is a specialist Rheumatology Research Nurse and DW is a Consultant Rheumatologist. The transcripts were read to obtain an understanding of the whole experience. Then significant statements that were related to the education of patients on Methotrexate were extracted from the interviews and the significant statements were then grouped into themes.

Results:

The duration of time the rheumatology nurses had been educating patients on Methotrexate varied from 25 years to 0.5 years. Three of the nurses educated patients immediately following the consultation in which they were recommended methotrexate by a rheumatologist. Whilst the remaining nurses conducted dedicated clinics with 30 minutes appointments to conduct the methotrexate education. Three of the nurses had attended a degree level rheumatology course and three nurses had received practical training in the workplace by their nurse colleagues.

The demographic details of the participants are contained in table 1.

Table 1.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Participants | Age  | Years working in rheumatology | Duration of interview | Previous Training |
| P1 | 65 | 25 | 45 | Self taught |
| P2 | 55 | 1 | 50 | Watched colleagues |
| P3 | 48 | 6 | 60 | Watched colleagues |
| P4 | 51 | 8 | 45 | Mentored by senior colleague |
| P5 | 58 | 14 | 45 | Mentored by senior colleague |
| P6 | 35 | 0.5 | 50 | Mentored by senior colleague |

Four main themes emerged from the data analysis :

1. Using standard written information to structure the content of the consultation

2. Patients have different information needs

3. Time pressures

4. Training and evolution of practice

Theme 1: Using standard written information to structure the content of the consultation.

Some participants would commence the consultation by explaining what the purpose of the consultation was:

 *“I always start off by having the patient reflecting….how they feel their everyday life has been affected by the arthritis and then try and put in context why we are starting methotrexate….. (P5)*

*“…when they go to see the doctors they don’t know what they are expecting from us…so we have to discuss why they’ve come to see me” (P6)*

Whilst other participants tended to start straight away by explaining what Methotrexate is:

*“I usually explain to them that this is a medication that does require blood monitoring” (P3)*

*“I basically go through the booklet” (P2)*

*“I would say, talking about DMARDs, particularly methotrexate…we do follow a chart that we use” (P4)*

All participants had developed a dialogue using specific information to guide the consultation to ensure that the information that they felt was necessary to give to the patient was provided:

 *“….the purple booklet (*local patient information*), the methotrexate……and that’s…I use that as my prompt..….and using it to guide me through and keep me on track and I seem to have my own little like speech and if I get thrown off my speech it sort of throws me a little bit”* (P2)

*“I usually use one of the ARUK leaflets about the…about methotrexate…..so that we’ve got a plan to follow.”* (P4)

All of the participants used standard written information and they described underlining or referring to important sections of the information booklets:

 *“I normally put a little star by what I think are for them to take away important things to be read back…”* (P4)

“*I go through the purple booklet* (local patient material) *and use it to guide me through…it keeps me on track” (P1)*

It was apparent that the literature given to the patients often acted as a check list for the nurse which acted as a prompt during the consultation:

 *“I use the headings (*of the booklet*) and then talk around that subject”* (P5)

*“I go through it you know …. so I know I’ve said everything I should and then on the back of our.…checklist, …and it’s got everything there like a tick so I go through that as well as I am going along.”* (P6)

Sub-theme: Overloading patients with information

Participants volunteered that patients were “bombarded” or “overloaded” with information and patients were described as being “dazed”, “shocked” and “frightened”. So patients were encouraged to take the information booklets and read them again at home in their own time.

 *“..all the information I’ve just given you is written in this book, go home and read it again’……… because it is, ‘it’s all there for you to read again, if you…you know’ because it is a lot to take in…….. you know in 10 minutes ….you can’t possibly take it all in so…… ‘you know it’s there so go and read it”*(P3)

 *“I find that they’ve been totally bamboozled by the consultant they come out to me and they are a bit sort of dazed you know shocked at what they’ve been diagnosed with and then I feel as If sometimes I am telling them stuff but they are not actually taking it all on board”* (P2)

..”*they get a little bit frightened…when you talk about it and some patients just don’t want to take drugs”.* (P1)

Sub-theme: Asking questions

It also emerged that patients did not always ask questions during the consultation with the nurse:

 *“I would say the majority don’t, no they just sit and take it all in…”*(P3)

*“I just didn’t have enough time because I thought that she still had questions that she wanted to ask but didn’t…”* (P1)

But on some occasions the patients did ask questions:

 *“..sometimes they want to know everything in that one sitting and you can’t possibly do that..”* (P4)

*“I think the people who interrupt are the…the sort of the more, it sounds terrible….but the more intelligent people tend to interrupt and ask more questions”* (P3)

 *“How often will I have to come to have for me to have my bloods done…that’s a main one….I think that’s it really..”* (P6)

Sub-Theme: On-going support

All participants provided patients with the telephone helpline number to use for any follow up queries following the consultation:

”*…but there is always a helpline and help at the other end of the phone”*(P1)

 *“And we also offer them..…the rheumatology advice line number and explain how and when they need to use that..”*(P4)

And one centre offered an outreach clinic:

 *“… they’ve got the option of going to an afternoon appointment to one of the outreach clinics but it’s still our staff that do them..”*(P4)

There were also opportunities for patients to have further counselling when they returned to the monitoring and escalation clinics:

*“and it’s the sessions that they come for monitoring afterwards that they start to get a bit more involved and ask questions there.”*(P2)

*“But quite often they do come back to the DMARD escalation clinic”*(P3) *“When you come for your first monitoring if you remember anything just write it down and who ever does the monitoring with you, you know you can ask them.”* (P6)

Theme 2: Patients have different information needs

It was noted that there were important variations between patients with respect to their need for information as perceived by participants:

*”…go into it a little bit deeper than …than others, others just want treatment and no matter what it is as long as they can get rid of their pain…”* (P1)

 *“…I think particularly if they are new patients and they’ve never been on anything before they have a lot more concerns..”* (P5)

The participants described the challenges encountered when counselling patients commencing multiple therapy:

 *“Because triple therapy has come out that’s a problem we find…….I don’t like to bombard people with too much so doctors like us really to start the triple therapy but you might start methotrexate and hydroxyzine then come back to the sulfasalazine it’s bombarding people and going out and saying ‘What ever has that nurse said to me..”* (P5)

 *“I do find it hard on the ones who have maybe got...two sets of drugs….you bombard them with two lots..” (P2)*

The amount of information given to patients varied if they already had some knowledge of their disease and treatment:

 *“..I talked to… about methotrexate they’d already been on a few DMARDS before so it was loads easier because they already know the ins and outs of the disease and their condition.”* (P6)

 *“sometimes you can fly through….because they seem to have grasped everything you take in..”* (P2)

Theme 3: Time pressure

Pressures of time were apparent for all participants and appeared to influence how they conducted the consultation:

 *“….. because we are under pressure you know if you’ve got a queue of 10, 15 people waiting you know”* (P3)

 *“I mean for example if you got a patient that’s newly diagnosed and methotrexate is the first DMARD that they’ve ever come across that they are going to go on to it I do think you have….you need more time really with that patient..”* (P4)

The participants also said that patients required different amount of time.

 *“My honest answer is I take as much time as it takes..…if the patient I feel needs that extra time to go over it and over it they get it, simple as because if there is anybody waiting outside, tough they wait but I know that we are under that pressure ‘Come on you know there’s a queue”* (P2)

There was general agreement that most patients need information spread over several appointments.

 *“..so it becomes an on education all the time follow on all the time, or it should be it should be.”* (P1)

 *“Don’t worry, we will go week to week and we will get there”* (P5)

One participant also acknowledged that the patients themselves understood the time pressure and believed that the nurse’s time was precious.

*”I just didn’t have enough time because I thought that she still had questions that she wanted to ask but didn’t”* (P1)

The participants understood that sometimes patients needed time to decide to take the drug:

 *“..so we leave it open that they can contact us to start it before the review..”* (P5)

Or may not take it at all:

*“some patients just don’t want to take drugs…they just don’t want them…they just think well I will just master on with some herbal remedy….but we try to spend time educating them and telling them the safe side….it is a good drug for rheumatoid arthritis”* (P1)

 Theme 4: Training and evolution of practice

Most participants felt that when they first started counselling patients on Methotrexate it was an unsettling experience a:

 *“..at the beginning it might frightened you ……..*(P5)

*“Yes. I mean a lot of the time I’ll check with somebody else something that I know I am doing the right thing but it’s just that added reassurance…”*(P6)

*”..and although I’ve had lots and lots of patients….and done lots and lots of monitoring clinics with Methotrexate and the other DMARDs, I am still not 100% satisfied that I know enough about that drug for to educate a patient.”* (P1)

 Training to provide education on Methotrexate varied between the participants. Some participants had not received any training.:

*“….my training was when we were first started using Methotrexate……..after using things like..…drugs like Gold and penicillin mainly and sulfasalazine was none, I didn’t have any training what so ever.”*(P1)

Other participants described their training as consisting of observing the doctor or nurse:

*“..I even tried to get sessions where I could go in with the doctor and sort of listen to what they were saying”* (P2)

*“It got more clearer when I got on the outpatients because...I didn’t start doing the counselling sessions straight off …I sat in with* (Name of person) *a few times..”* (P6)

All participants described how their practice had evolved with experience and time:

 *“..but then, I think as time goes on you do, you learn more because you know when you are sitting and monitoring you can…..you can hear what other people are telling the patients and so you pick up little snippets”* (P3)

 *“..and to me it’s like driving, you can have your lessons, you take your test but you don’t really learn to drive until you are behind that wheel on your own do you?”* (P4)

There was agreement between the participants that there was a need to keep up to date as practice evolved:

 *“..and even to this day I would still say I need to be educated in it further.”* (P1)

 *“It’s like the shingles vaccine there’s been a lot of talk around that.”* (P5)

One participant described learning about side effects from patients::

 *“..but you still don’t learn as much, I don’t think, as you do from patients coming in and saying ‘Well I’ve got this side effect, I’ve got that side effect”* (P3)

All of the participants agreed that there should be formal training available in order to carry out this role effectively and offered some suggestions around what they thought could be the content of a training module for nurses new to this role:

 *“…. like maybe in house training on the computer that I could maybe read and get a background on.…”* (P2)

 *“I think it’s good to have formal session so that the nurse knows exactly what she is supposed to say and then as a backup I think the….that role play thing would be good ...”* (P4)

Discussion:

This study explored the experiences of rheumatology nurses educating patients commencing Methotrexate. The majority of the consultation focused on nurses imparting information with little opportunity for patient interaction. Participants recognised that patients had different information needs which could be challenging to respond to within a time bound consultation. No standard training was available regarding the knowledge and skills required to perform this role.

 The commencement of any medication requires to be accompanied by some education to enable the patient to know how to take it, how and when it is expected to work, what side effects to look out for and what, if any, monitoring is required.  Hill et al (2001) demonstrated that educating rheumatology patients on their medication improved concordance. Zhao et al (2015) carried out a survey of 159 patients with Coronary Heart Disease (CDH) in a hospital in China. They assessed medication adherence with the Morisky Medication Adherence Scale (Morisky et al 1986) and disease knowledge with a Medicine/Disease Related Knowledge Test (MDKRT) The MDKRT was developed by the researchers with guidance from an expert panel and a systematic literature review (Al Hamarneh et all 2011). Zhao et al concluded that whilst the majority of participants had little knowledge of drug treatment, those participants that had a greater knowledge of CDH were more likely to be drug adherent. Despite the paucity of evidence guidelines uniformly recommend education (NICE 2013) and the Department of Health (DoH 2012) advocates that health professionals promote self-care and shared decision-making, enabling patients to make choices. This will require the patient to be sufficiently educated, which, in the case of commencing Methotrexate, commonly is dependent upon education by nurses who may not necessarily have received education in this area.

During the counseling of a patient on Methotrexate participants reported discussing the purpose, administration, contra-indications and side effects of the treatment; patients then have to make sense of the information given within their own context. The meanings that patients develop will vary, influenced by factors such as their beliefs, past experience, education, culture and intelligence (Goodacre and Goodacre 2004). It is therefore necessary to check the patient’s understanding at frequent intervals.

It was clear that the nurses interviewed understood the purpose of their consultation, but their practice of using a checklist approach to inform the content of the consultation reduces the opportunity for the patient to ask questions and issues that are important to patients and which might impact on concordance are unlikely to be discussed. Macdonald et al (2013) video recorded 35 consultations between 10 nurses and 18 patients who had Type 2 Diabetes Mellitus. The initial consultation involved the extensive use of checklists and was driven by the nurse’s clinical agenda rather than what the patient already knew or wanted to know. Whilst checklists can be helpful for the nurse by ensuring that important information has been delivered to the patient, they might prevent the patient asking the questions that will influence their decision whether to commence the medication being advocated. The Calgary Cambridge Model is used in many medical schools to teach students how to carry out a consultation (Kurtz et al 1998) and is widely practised amongst GPs (Burt et al 2014). This model emphasizes the need to provide information in manageable chunks and to use the patient’s response to guide the consultation (Kurtz et al 2003). Whilst this model was developed for the medical profession, some attempts have been made to apply it in the nursing context (Munson et al 2007). Whilst nurses who counsel patients about Methotrexate do not necessary need to apply the full model, elements of it could enhance their consultation skills for this particular role (Munson et al 2007).

Patients also have different preferences for communication (Macdonald et al 2013) and, to optimize concordance, the nurse needs to be able to identify the patient’s information preference and meet it. In this study nurses were aware of the different needs patients have but the reliance on the checklist and the time constraints acted as a barrier to responding to the patient’s individual needs.

Patients also require information on their condition to put the treatment into context. Thompson (2011), in a study of patients with Ankylosing Spondylitis, found that at disease presentation before drug therapy commenced patients wanted responses to a series of questions which included: Why have I got it? What will happen to me and my family? What can I do about it?

The nurses’ perceptions of the limits of time for their consultations appeared to have an impact on their willingness to encourage questions from the patients. Participant 3 used the word “interrupt” which could indicate that this nurse was under time pressure to deliver the Methotrexate counselling to the patient and therefore did not engage in encouraging questions. There was general agreement between the participants that patients did not ask many questions but there appeared to be little opportunity for the patients to ask questions. The nurses described patients as being “bamboozled” or appearing “dazed” and “shocked”. Patients in this state would probably find it very difficult to absorb any new information regarding their medication, which appears to be reflected in participant 3’s account of patients sitting and “taking it all in” without asking any questions.

Nurses need training to allow them to develop the skills to engage in effective consultations with the patients and to increase their confidence in moving away from a check list consultation. But it can be difficult to secure study leave and funding for any training (Haywood et al 2013). As drug counseling/education is regarded as a key role of a rheumatology nurse (RCN survey 2009) then a training programme could be developed which would include effective consultation skills to maximize the time-bound consultation and increase confidence to enable a two way communication process where a guide is no longer required to structure the consultation and the encounter can be patient-led.

It is difficult to know how representative of the Rheumatology nurse community the sample interviewed in this study is and therefore how generalisable the findings are, but there is a compelling argument to research further the nature of consultations between nurses and patients. Such research might include direct observation through video recording and post recording interviews with the participants using Video stimulated recall (VSR). This is a method whereby participants are shown video recordings of their own behaviour in order to stimulate enhanced recall and understanding. This could generate a more meaningful and critical response of that particular consultation event (Paskins et al 2017) thus enriching the data and analysis of the research.

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