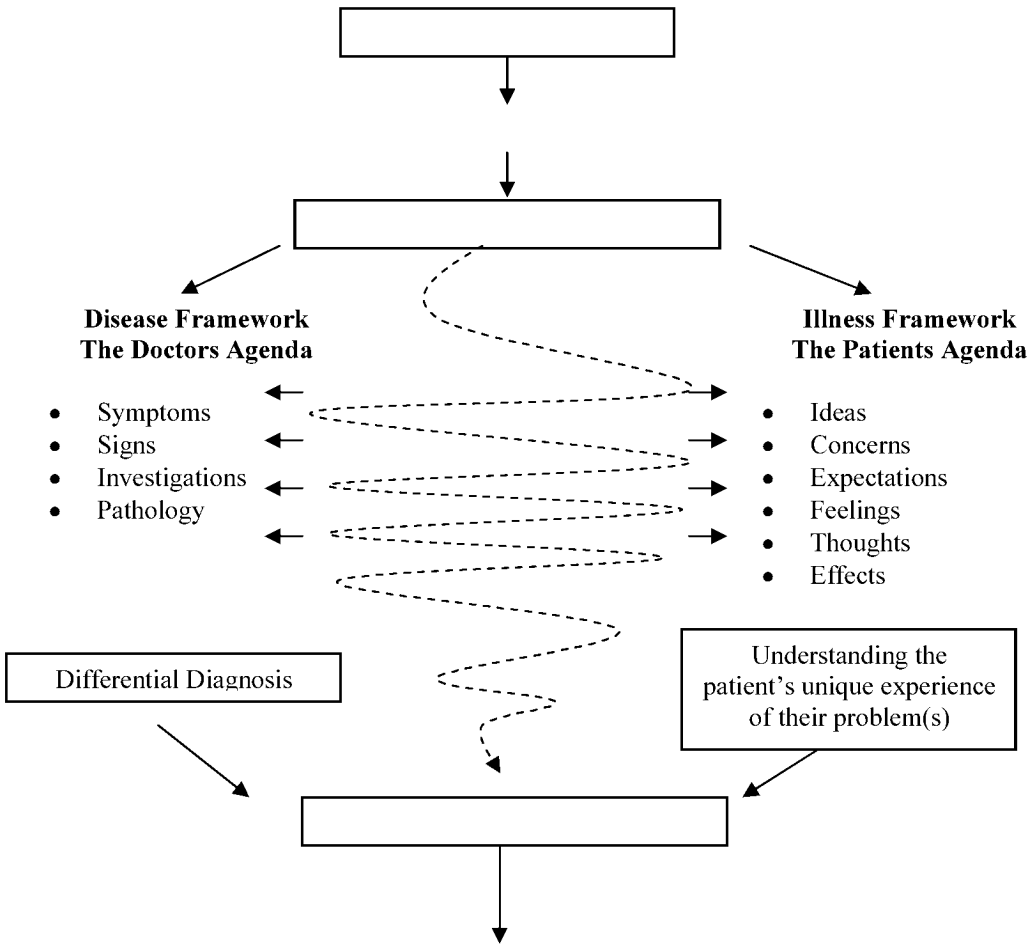
The Disease - Illness model

Integrating the clinical or biophysical content with an understanding for what symptoms mean to the patient within their own 'life-world' remains the ultimate goal for this part of the consultation. It helps to explain why, and when patients present - as well as how they subsequently behave.

This is known as the Disease-Illness model and is based on the work of Professor Ian McWhinney and colleagues at the Ontario University, Canada in 1990. Readers are strongly recommended to read a fuller account of the Disease-Illness model on pages 35 – 42: Chapter three of 'Skills for communicating with patients'.

In practice there is a gentle meandering between the disease and illness content throughout the information gathering section of the consultation. You are not only listening and probing openly for biophysical symptoms that might reveal evidence for underlying disease – but consciously using your awareness and senses to 'listen out' and discover clues for the patient's illness perspective that tends to 'leak out' at any time.

The skills that help uncover both these perspectives as well as the process by which both are integrated are discussed below.



For a variety of reasons, it is fundamental to discover the patient's perspective if we want to practise as effective clinicians

- We can't always make a diagnosis of disease (in fact we do so in rather less than 50% of patients problems)
- There is plenty of evidence that we never reach a diagnosis even after many consultations. Numerous presentations are eventually labelled in retrospect as 'functional' or 'non-organic'. Research shows this applies to common problems of chest pain, tiredness, abdominal pain, headache and many others.[1]
- Exploring the illness perspective early on will help to uncover a significant number of presentations where their roots lie more in the emotional or personal domain.
- Even if there is co-existent disease an understanding of why the patient has presented at this stage often after a long period of time will not be easily understood without exploring the factors that initiated it.
- Alternatively, a patient who repeatedly appears to 'make light' of their symptoms may in fact be concealing an underlying fear of a diagnosis that might affect their livelihood or ability to function within their family unit.
- Diabetes may stop them driving - and a diagnosis of cancer may be denied to protect a worried and dependant partner.

We are likely to use time and resources more efficiently

It may be easy to make a straightforward diagnosis of asthma in a child, but without an understanding of what this means to the mother (who may have totally different ideas about causation and management) constructing an effective management plan is likely to fail.

This not only wastes our own time - but taxpayer's money on expensive prescriptions too. Even when doctors are confident that the symptoms are functional repeated visits with the same problems usually result in us feeling forced into investigation or referral, unless the person's world is explored and symptoms related to it. Doctors who conduct patient centred consultations and spend time exploring patients concerns have fewer follow-up appointments, perform fewer investigations and refer patients less often.[2]

A large study that looked at the outcome of chronic headache and which factors were most closely related to resolution found that the most significant aspect that lead to it's resolution was the time given to explore the patient's concerns about their symptoms at the initial interview.

Resolution of the headaches did not seem to be related to the severity or type of the presenting symptoms, nor to the way it was managed including the type and complexity of any investigations, referral or treatment offered.

Uncovering the patient's perspective improves our chances of making a correct diagnosis

Asking for the patient's own ideas about causation may bring up all sorts of unlikely but helpful information which might otherwise have not been discovered. A recurrent vaginal discharge in a happily married woman may sound innocuous and common enough.

However when a patient's mentions that her mother had a similar discharge followed by a diagnosis of Crohn's disease and a bowel resection - suddenly puts previous vague bouts of diarrhoea and a prior assumption of 'irritable bowel' into a different diagnostic category.

It helps us plan the next stage of managing the problem

Frequently the acceptance of treatment by the patient depends on their personal beliefs. We are more likely to succeed by using appropriate negotiating skills to get across our preference for prescribing an antidepressant first if we are aware that this is likely to meet initial resistance beforehand. Discovering the patient's own beliefs that they think it is due to a hormonal imbalance will give us prior warning before blundering in first with our own agenda.

Discovering the patients own expectations about what they had hoped would result from the consultation can save a lot of time. Discovering a sick note is all they require instead of a presumed demand for tablets, physiotherapy or referral will make the management much clearer and efficient.

Equally discovering patient's expectations may sometimes help and even protect us during situations where uncertainty is normal. To discover that the person had hoped to be *"sent straight into hospital…"* with their mild abdominal pain - will not only give a clue as to their underlying level of concern and tolerance (as well as probably prompt us one extra last search for potentially serious features) it will allow us to incorporate this option objectively during our discussion of management and during the course of 'safety-netting' at the end.

Apart from engendering confidence in the patient and indicating that you are taking them seriously - if unexpected things do arise - it might help prevent criticism – even when an unexpected disastrous outcome could not have been reasonably.

Further exploration of symptoms relating to possible illness

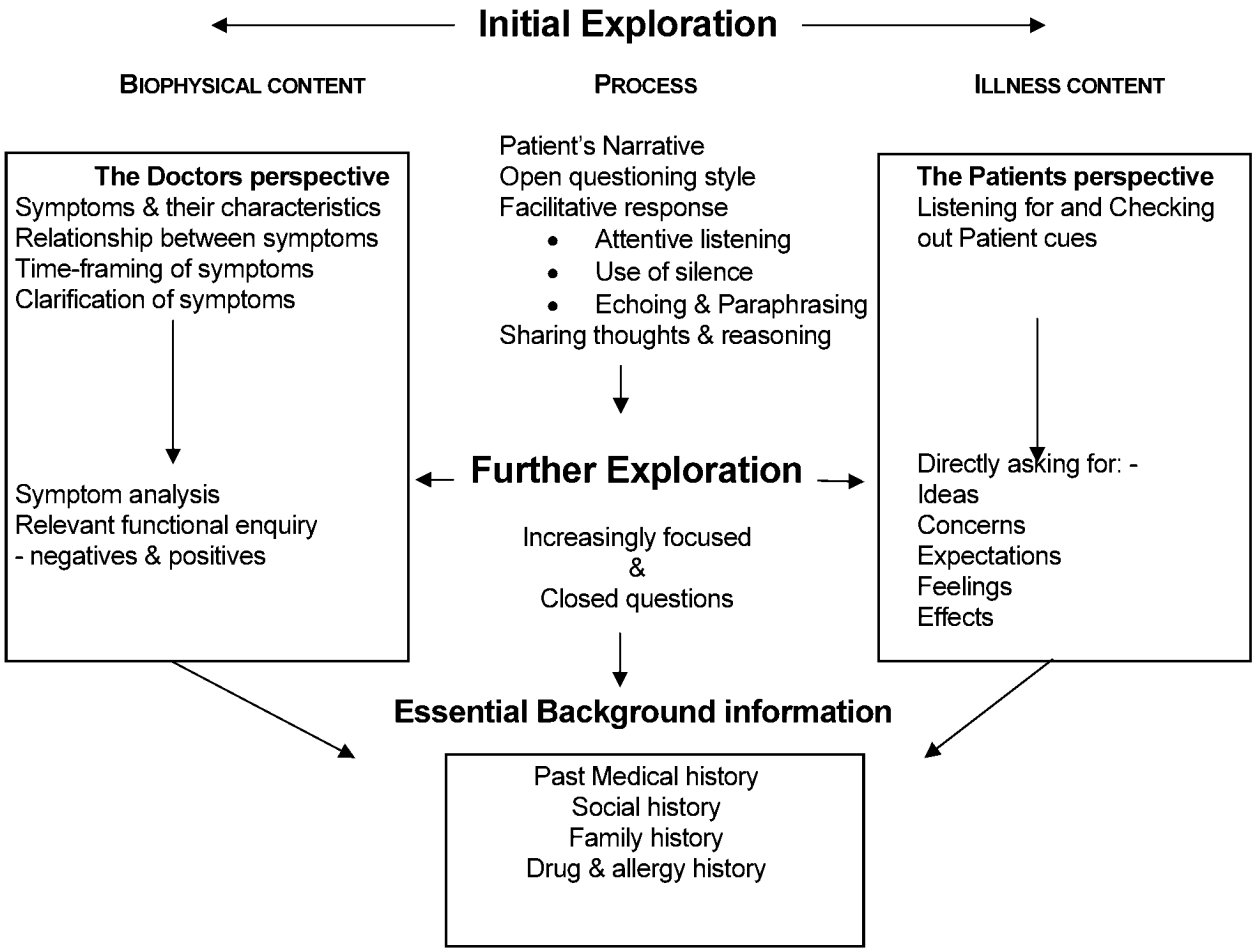
Most patients do not volunteer their concerns openly or at least not at first! Despite our best efforts as doctors to be patient-friendly and approachable there is still a natural power gradient that prevents equal discourse of ideas. There are many reasons for this that range between patients feeling unsure or being afraid of doctor's reactions to fear of the truth. This is more fully discussed on pages 109 –110 Chapter five of Skills for communicating with patients.

The Skills

Before the skills are individually discussed it is helpful to expand the framework of this part of the consultation into the different areas of content and process.

There are skills that discover the **disease** or **biophysical content** and those that help determine the **illness** or **patient perspective**.

The process skills help make the transition between the **initial** and **further** exploration of the patient's problems.



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During the initial exploration of the patient's problem the aim should be to cover four aspects of the biophysical content: -

1. The range of symptoms and their characteristics
2. The relationship between symptoms
3. Clarification of symptoms used by the patient
4. The timing of these (Time-framing) – their onset, duration, development over time, and where present – their pattern or variation.

It is often how we phrase our initial exploratory questions, to search for medical content, to cause most of the problems with clinical reasoning. Instead of moving straight into a traditional mode of inquiry - we need to rephrase the questions we use to facilitate the patient's story without interruption - and change our instinctive style for using closed questions - to an open-ended questioning approach instead.

The Narrative thread

This has the dual effect of discovering both content and starting the process of gathering information. It is a little like encouraging the patient to start telling their story from the beginning and often acts as a catalyst to encourage the patient to recount a more coherent and logical form of their story. This is something they may have rehearsed in some detail beforehand – yet it is liable to 'fall apart' as a result of anxiety during a confrontation with a doctor in the consultation.

Asking them to start at the beginning helps them to develop a better story or narrative that is less disjointed, fragmented or full of things that previously mystified them.

> *Doctor: "Perhaps you start at the beginning and tell me how this all began...?"*

Interestingly, it allows the doctor a certain amount of interference without damaging the flow of information from the patient.

> *Doctor: "So the headaches came on first, then you started to feel faint...I see... go on..."...?"*

However, the doctor must be careful to direct them exactly back to the point where they interrupted them so that the patient is able to continue telling their story without disturbing its flow or their concentration and end up deflecting the story 'off-course' onto something else.

This is reminiscent of the way a child asks for clarification during the process of reading a story at bedtime!

> *Doctor: "Go back to the headache again...."*
>
> *Patient: "Oh Yes... that's right...the headaches...then my hands started shaking and the room went dim...?"*

The narrative thread also has another important function. The doctor can use an adaptation of the 'Narrative thread' perhaps called 'Returning to the Narrative' as a powerful skill or technique to help regain structure and control of the consultation's direction and content. This is especially helpful when the patient wanders 'off course' and steers away from important lines of exploration or enquiry. This is discussed further below.

Using Open-ended questions first – within the open-to closed cone of questioning

The more open the type of question used at the start, the more it encourages patients to elaborate and widen their story.

Using open-ended questions at the beginning are also the best way of discovering the patient's perspective and interpretation of their story as well as being the most efficient and effective way of gathering information in general. (See below)

Open questions often start with the What, Why, How and When… format, but can also start by using directive statements that encourage the patient to 'tell their story'.

> Doctor: "So tell me more about the dizziness...?"

Clarification

It is also important to encourage patients to clarify and describe their symptoms and perceptions accurately. What is meant by 'dizziness' or 'tummy upset'?

What do they mean when they say they are 'a bit low'? How does a patient characterise their pain – what sort of quality do they ascribe to it? We need to be sure that what they are describing is close to what we think.

Time-framing

This is one of the most important characteristics often left out in haste that leads to poor diagnostic evaluation of symptoms. The timing and mode of onset for a severe headache can be crucial - as is the pattern and timing of abdominal pain in many circumstances. Failure to appreciate the development of pain over time may also leads to diagnostic and management errors.

Phrasing opening questions during the initial exploration of the patient's problem

It is the way we instinctively start asking questions at the beginning that causes so much trouble. Frequently doctors start using closed types of questions they were trained with at the beginning - to start interrogating symptoms.

After perhaps using the 'Narrative thread' and one or two broad 'open-ended' questions to screen for the range of symptoms - it often falls to the doctor to direct the patient to each of the symptoms possible characteristics whilst continuing to use an open ended style.

The exact phrases below are only suggestions using a mnemonic to help remind you of one possible way of expressing these.

You need to develop an individual repertoire of phrases rather than use the same one each time that is comfortable and becomes part of our own personality and style.

Using Open style questions Mnem	Using traditional closed approach (Macleod 1964)
When did it first START?	Duration
HOW did it come ON?	Onset
WHAT were you doing at the time?	
Can you describe how it has VARIED over time? How has it developed over time?	Frequency & Course
How INTENSE has this become?	Severity
Have you noticed any PATTERN to it?	Periodicity
Can you DESCRIBE it in more DETAIL? (What does it feel like?)	Site, Radiation, Character
What ALTERS it?	Aggravating factors, Alleviating factors
Have you TRIED/TALKED to anyone else about it?	What have they tried or been influenced by
Have you noticed anything ELSE?	Associated Phenomena
How SERIOUS do you think this is?	Perhaps a good 'lead into' their personal perspective & concerns

Further exploration of the biophysical content or perspective

Using closed questions to fill in the 'gaps' and determine important physiological function

The objectives here include asking for remaining important and missing information that is vital to 'rule in' or 'rule-out' clinical disease.

Relevant areas of the functional enquiry need visiting as well as any characteristics for symptoms not already mentioned.

This is where closed questions are more helpful and designed to allow only a limited response when it is your intension is to seek specific important data.

It should therefore be realised that both open and closed questioning styles are essential – it is the order that is important.

Open questions should be used first since they are the best way of screening for information in general and picking up the early clues as to the patient's perspective discussed below.

Closed questions act as a precise and selective tool that serves the doctor's agenda. They can be used to 'fill in' the holes quickly and efficiently by directing the patient that this is about to happen – and why.

Doctor: "I'd just like to ask a few quick questions about this pain to make it clear to me whether you have an ulcer or gall-stones causing your symptoms ...then I'll ask you a few more questions on how the rest of your digestive system might be working...if that's Ok with you?"

This type of statement not only clearly 'signposts' your intent for the consultation to enter into a new and more interrogative style (and why) – it also shares your diagnostic reasoning with the patient.

The initial exploration of the patient's perspective

Most patients do not come out openly with their concerns and worries - and for various reasons hold back unless given encouragement or opportunity. However research shows that after consultations over three quarters of patients wanted to ask questions or express doubts of one sort or another.[3]

Most commonly this was to do with feeling hurried or uncertain about how to ask questions, or feeling that their view was unlikely to be unconsidered and unimportant - as well as remaining frightened of getting a negative reaction from the doctor. Less than 10% cited their fear of the truth as a reason.

Furthermore over 85% of patients do make some attempt to become involved and express themselves in the consultation though they tend to do this in covert or indirect ways by giving out various non-verbal 'cues' or by dropping hints and vague suggestions or expressing doubts. Even if they are picked up - 80% of doctors make no effort to listen or deliberately interrupt them; 13% of doctors listen passively but don't pursue their concerns – and only 7% becoming actively engaged.

The importance of developing and maintaining rapport

This underlines the importance of developing and maintaining an atmosphere of collaboration and trust between the doctor and patient in the consultation – allowing patients to feel confident about being involved in its process. The emphasis should be on partnership rather than patients being made to feel submissive and subservient within a traditional doctor-centred approach.

Some of the skills of developing rapport have already been covered in the first chapter and others that help maintain it - will be discussed further on below.

Using Open ended questions

The skills used during the process of Gathering information are important here. As already mentioned open-ended questions are more likely to gain access into the patient's perspective or illness framework than closed questions. Doctors are more likely to pick up the vital 'cues' that frequently leak out at this stage in the consultation. By 'handing over' control to the patient to tell their story – the doctor encourages a patient centred approach.

Picking up 'cues' that underline the patient's perspective

Clues to the patient's perspective frequently occur early on in the consultation either in their opening statement or during the opening stages of gathering information. They are often also the strongest clues to the patient's underlying concerns and expectations - but because they are often vague and covert - are easily missed or ignored by the doctor's selective concentration on clues that screen for disease.

Picking up cues is also the most natural way patients indicate their views. It is important to either check them out immediately or at least to acknowledge them and 'flag up' that you will return to them shortly.

The only way is for doctors to be constantly alert and actively think about picking up 'cues' that 'leak-out' during the consultation.

Doctor: "...you said you were very worried about that... can you tell me a bit more about your concerns...?" *or...*

Doctor: "...you said you were very worried about that... I can see that there is something here you are very concerned about...but can I come back to that in a moment to explore this with you?"

"First - can I just make sure I've finished understanding some of the other things you've been telling me...so I don't loose track?"

The patient's perspective may present from verbal or non-verbal behaviour.

Nonverbal behaviour

- Patient looks anxious or worried from expression, tone of voice, posture and body tone
- Persistent poor eye contact

Verbal behaviour

- The use of emotionally laden terms by the patient:

"Worried, upset, frightened, serious, dangerous, important..."

- Repeating words or continually returning to phrases are a patients attempt to give a 'wake-up' call to the doctor who misses their hints the first time round.
- Speech censoring - which indicates a person is holding back from saying soothing important or sensitive:
- Hesitating in mid-sentence
- Deletions – deliberately omitting information that allows understanding:

"It's no better" (what's no better?)

"Something will have to be done" (What and who should do this?)

As the patient's perspective is explored - there are three important rules to follow.

Sensitivity: Enquiring about people's inner feelings needs a certain amount of tact because many people recognise that their fears may be seen to be signs of neuroticism or personal weakness and if wrong will be made to look silly. The doctor needs to be empathetic (see below) or use the Accepting response when exploring patient cues.

Doctor: "When you said 'serious'...I wonder what was going through your mind when you said that...?"

Patient: "Well... you know...(embarrassed pause followed by silence)...."

Doctor: "I know that many patients might be thinking of something as grave as a Brain tumour...especially when they are so severe...I think that can only be both understandable and natural..."

In some situations where particular sensitive issues are being discussed or when the patient appears very nervous talking about a subject – the doctor may need to ask permission before being sure the patient is ready to reveal them.

Doctor: "...You look really upset when you said you had fears about going mad...can you bear to go on and tell me a little more... or do you want to just sit for a minute?"

Tentativeness: You need to give the patient chance to reject or at least defer owning a certain emotion or feeling – particularly if they are embarrassed to provoke a defensive reaction that blocks further exploration

Doctor: "...I may be wrong but you seemed to look upset when you talked about your mother just then..."

Accuracy: It is also very important to check that your interpretation is correct.

Doctor: "...When you said 'serious'...I know many patients might be thinking of something as grave as a Brain tumour... especially when they are so severe...I think that is only understandable and natural...would I be right in thinking this?"

Patient: "I hadn't specifically thought that...but you see my father complained of headaches just before he died of a brain haemorrhage... and I did wonder if my headaches meant I was at risk of having a stroke?"

Because someone simply looks anxious may not be the case out and misunderstanding will take place.

Doctor: "...you look worried...?"

Patient: "...Oh no... sorry doctor...I was just concentrating on what you had just said...I'm afraid I always tend look like that when I'm thinking!"

Further exploration of the patient's perspective

Asking directly for the patient's perspective

Even if early cues have been elicited previously - direct questions are often needed to explore the patient's perspective further to get a comprehensive picture of how the patient is feeling and what their expectations about this consultation are. This is the counterpart to filling in any essential medical content left out during the initial exploration.

The types of questions asked can be thought about under the headings of - Ideas, Concerns, Expectations, Feelings and Effects.

Ideas

What do you think is causing it?

Why do you think that might be happening?

Have you had any ideas about this yourself?

Have you got any clues or theories?

You've obviously given this some thought; it would help me to know what you might be thinking it might be?

Concerns

What are you concerned that it might be?

Is there anything particular or specific that you were uneasy about...?

What was your worse fear or thoughts about this?

In your darkest moments... what had been going through your mind?

Expectations

How were you hoping I might help you with this?

What were you hoping we might be able to do for this?

What do you think might be the best plan of action?

You've obviously given this some thought, what were you thinking might be the best way of tackling this?

Feelings

How has all of this made you feel?

How has this left you feeling?

How have things seemed to you?

Effects

How has this affected your life?

When should doctors attempt to discover the patient's perspective?

Using phrases that are sensitive is important. Asking what they thought was wrong can receive a curt reply.

Patient: "...You're the doctor... you tell me!" or

Doctor: "...What are you worried about?" ...is likely to be somewhat defensively replied with

Patient: silence... "... nothing.. or... I'm not worried!".

'Concern' might have be a better term than 'worried'.

GP Registrars need to try out and practice various phrases that are sensitive and sound natural when eliciting such areas. There are several examples from Skills for communicating with patients Chapter three; page 63.

The use of direct questions designed to explore the patient's perspective further has to be timed carefully and sensitively.

Asking too early on in the part of the consultation can give the impression that you are possibly evading making a diagnosis – leading to the patient 'closing down' and becoming reluctant to contribute further.

On the other hand, too late an attempt to ask patients directly for their perspective risks wasting time on issues unimportant to the interview. Suggestions may have been made that have to be retracted. It is better to leave this towards the end of the information-gathering phase unless a 'cue' comes up.

Just like we fill in missing medical facts by asking a series of more direct closed questions an attempt to find their thoughts and feelings can be signposted as follows.

Doctor: "Before I ask some questions about your past medical history... it often helps to know how all of this has seemed to you..."
pause...
"I wonder if there had been any particular areas that had concerned you..." pause...

"Had you had any thoughts as to what might be the best way forward here?"

Getting essential background information

Traditionally the medical interview started off with the doctor interrogating the patient about personal details concerning things like age, social status and occupation before taking a presenting history.

This had the effect of being unsupportive to the patient and promoting a doctor-centred start to the consultation.

Much of the patient's past medical, family, social, drug and sometimes even their allergies may come out spontaneously during their story. These essential areas that haven't can be filled in later on.

Again, signposting your intent helps focus the patient to an area of the consultation that hasn't previously been discussed.

Doctor: "Perhaps I could fill in on a few more details about your about your...(past medical, family history, social history, allergies etc...) as well as make sure I have a list of all the drugs you are taking at present... is that Ok?

The Narrative Thread and 'open-to-closed cone' of questioning

The most important skills that facilitate the process of gathering information have already been discussed – the Narrative thread and open-to-closed cone of questioning.

They have dual properties that act as the 'cornerstone' for exploring both the content of disease and illness and starting the process of gathering them.

There are other important skills that are based on encouraging the patient to expand their story further.

Facilitation

Facilitation contains skills that are similar in some respect to the Active listening phase proposed during initiating the session. It consists of encouragement, use (and tolerance) of silence, repetition (or echoing), and paraphrasing.

However, there are some important additional differences.

Facilitation may involve tolerating longer periods of silence when the patient is having difficulty in describing themselves or reflecting upon painful emotional areas. Whilst there is a balance between comfortable and uncomfortable silence - it probably only needs to be broken when there are signs from the patient (rather than the doctor) that they feel uncomfortable.

The continuing use of appropriate non-verbal behaviour from the doctor is often enough. Occasionally there is a need to give reassurance that you are comfortable and respect their need for a pause in communication. Permission can be verbalised for them to carry on using silence for thought, or to gather 'strength'.

Repetition (or echoing) the last few words or sentence is a powerful way of encouraging patients to both carry on and elaborate further.

Patient: "I'm not sure I will cope very well if things get much worse..."

Doctor: "...if things get worse...?"

Patient: "It keeps reminding me of what happened when my mother had breast cancer – the pain and all that..."

Paraphrasing

This goes one stage further by the reflecting back both what has been said and also the interpretation and meaning of what was said. It is a useful way of detecting if there are hidden feelings or emotions behind what the patient has said.

Patient: "I have always said I would stand by him how ever much he drinks - because of my religion...and there's the children – but I really don't know how this will affect our marriage this time"

Doctor: "You mean you are not sure whether you can live with John anymore?"

Patient: "I don't even mind his awful language – but the children are now growing older and asking questions and I don't know what effect it' having on them"

Doctor: "Am I right in thinking things have changed...and you now feel you are letting the children down more than your beliefs by staying with John?"

Sharing clinical reasoning with the patient

One of the most powerful ways of combining patient collaboration with the doctors own problem solving is for the doctor to openly feed back to the patient what they are thinking and how they are forming their opinions.

This enables various ideas to be 'floated' or theories tested out with the patient - without making any assumptions or decisions. It is a particularly good method to bring up sensitive issues that may not be initially accepted by some patients such as symptoms that are likely to have psychological rather than physical origins.

The key again is to raise your thoughts sensitively and retain a certain amount of tentativeness before checking for accuracy and acceptance by the patient.

A useful ploy is to de-personalise symptoms from being personally owned by the patient until they accept and acknowledge them as possibilities. Equally, generalising symptoms or experiences away to others as being common and normal maybe helpful.

Doctor: "One of the ways tiredness can come about is through sheer exhaustion over worry and pressure at work and home. Whilst this might not apply to you...I just wondered if this could be a factor in all of this... what do you think?"

Doctor: "Whilst we still may need to consider whether tests are needed...on occasions I've known abdominal pain like this to be brought on by stress...?"

Doctor: "Although indigestion like this is certainly very real and severe - the cause may lie with how many of us constantly live with worry and nervous tension in our lives...do you think this might possibly explain why - after all the tests - you still have such bad pain?"