

The nursing contribution to chronic disease management: a case of public expectation? Qualitative findings from a multiple case study design in England and Wales.

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ABSTRACT

Background

The global response to the rise in prevalence of chronic disease is a focus on the way services are managed and delivered, in which nurses are seen as central in shaping patient experience. However, there is relatively little known on how patients perceive the changes to service delivery envisaged by chronic care models.

Objectives

The PEARLE project aimed to explore, identify and characterise the origins, processes and outcomes of effective chronic disease management models and the nursing contributions to the models.

Design, settings and participants

Case study design of seven sites in England and Wales ensuring a range of chronic disease management models. Participants included over ninety patients and family carers ranging in age from children to older people with conditions such as diabetes, respiratory disease, epilepsy, or coronary heart disease.

Methods

Semi-structured interviews with patients and family carers. Focus groups were conducted with adolescents and children. A whole systems approach guided data collection and data were thematically analysed.

Results

Despite nurses' role and skill development and the shift away from the acute care model, the results suggested that patients had a persisting belief in the monopoly of expertise continuing to exist in the acute care setting. Patients were more satisfied if they saw the nurse as diagnostician, prescriber and medical manager of the condition. Patients were less satisfied when they had been transferred from an established doctor-led to nurse-led service. While nurses within the study were highly skilled, patient perception was guided by the familiar rather than most appropriate service delivery. Most patients saw chronic disease management as a medicalised approach and the nursing contribution was most valued when emulating it.

Conclusions

Patients' preferences and expectations of chronic disease management were framed by a strongly biomedical discourse. Perceptions of nurse-led chronic disease management were often shaped by what was previously familiar to the patient. At a strategic level, autonomous nursing practice requires support and further promotion to wider society if there is to be a shift in societal expectation and trust in the nurse's role in chronic disease management.

KEY WORDS

- 1. Chronic disease**
- 2. Delivery of health care**
- 3. Disease management**
- 4. Nurse's practice patterns**
- 5. Patient-centred care**

What is already known about this topic

- Chronic care models have been widely adopted in response to the rise in prevalence of chronic disease.
- The role of nurses has rapidly expanded to play a central role in chronic care models.
- There is evidence that nurse led chronic disease management is as safe and effective as medically led chronic disease management.
- Patients value the psychosocial skills and ease of access to nurses working within chronic disease management models.

What this paper adds

- A multi-site case study evaluation of the nursing contribution to chronic disease management included a qualitative exploration of service users perceptions of the shift to chronic care models;
- Despite the shift to chronic care models often located within primary care, patients perceived a monopoly of expertise to exist within acute hospital based care.
- Patient perceptions of expertise within chronic disease management were influenced by what was familiar; care framed by a strong biomedical discourse.
- There is a link between patient expectation of nurse-led chronic disease management, trust in the competencies and skills of nurses, and patient expression of satisfaction with the model of chronic disease management.

Introduction

The global policy response to the rise in prevalence of chronic disease has been a focus on the way services are managed and delivered, with the Chronic Care Model influential (Wagner and Groves, 2002, World Health Organization, 2005a). Drawn upon to inform the Long Term Conditions model in England (Department of Health, 2005a), the aims of the model include creating empowered and informed patients, and proactive health and social care teams. In order to develop practitioners to be effective members of these teams there has been a concurrent international focus on skills required for chronic disease management (World Health Organization, 2005b). The breadth of the nursing role means that nurses are seen as being at the forefront of these teams (Bodenheimer et al., 2005, Department of Health, 2005b, Department of Health, 2008), and have a significant role within any part of the long term conditions model ranging from community based public health practice to individualised care for those with highly complex needs. However, while nursing is changing in order to meet the challenges of chronic disease there is relatively little known on how service users perceive the changes to service delivery envisaged by the chronic care model. This paper reports results from an evaluation of the nursing contribution to chronic disease management in England and Wales suggesting that despite nurses' role and skill development in chronic disease management (CDM), there is a belief by service users in the superiority of acute and medical-led care. Drawing on sociological and social psychological frameworks on trust and the relationship between expectation and satisfaction, this paper will argue that patient's expressed approval with some nursing roles is influenced by patient expectation and preferences.

Background

Nursing has long been recognised as having a key role to play in helping people to manage long term conditions (Audit Commission, 1999, Kratz, 1978), and the shift from acute to chronic care models brings sharper focus on a care process where the patient is recognised as an active participant in care (Wilson, 2001). Nursing has acknowledged new ways of working with patients within models of chronic care (International Council of Nurses, 2003), and an emerging range of models to deliver CDM over the last decade has provided nurses working within the UK National Health Service (NHS) significant opportunity to develop roles and skills aimed at effective delivery of CDM. These models have emerged through a number of policy drivers aimed at developing the nurses role (Department of Health, 2003a, Department of Health, 2005b), enabling joined-up services for people with long term conditions (Department of Health, 2005a, Department of Health, 2005c), and providing incentives for CDM within general practice (Department of Health, 2003b). In addition, a number of models developed elsewhere such as the Evercare model of case management (Department of Health, 2004) have been piloted and adapted for use within England.

An evaluation of the Evercare case management pilot indicated patient and carer preference for the model compared to previous service arrangements (Boaden et al., 2006, Sargent et al., 2007). Overall, nurse-led case management may have a positive impact on clinical outcomes, quality of life and functionality (Sutherland and Hayter, 2009), and is seen by patients, carers, health and social care professionals and the case managers themselves as an effective role in meeting health and social needs of the patient (Brown et al., 2008, Chapman et al., 2009, Dossa, 2010).

In Canada, high quality chronic disease management was found to be associated with the presence of a nurse practitioner (Russell et al., 2009), and an evaluation of nurse-led shared

care in the Netherlands (Irmgard et al., 2002), where generalists and specialists work together with the focus on the patients needs, suggested that many participants preferred the treatment by the nurse practitioner in the GPs office to traditional care by the medical specialist at the outpatient clinic. However, patients felt it was important to maintain a direct link with the medical specialist, and the nurse practitioner model had limitations such as the requirement for the nurse to contact the medical specialist in case of a complication as this was felt to be too time consuming. In the UK, primary care (practice) nurses have expressed concerns about the amount of preparation they have received for taking on extended roles within CDM (Hansford et al., 2009).

Overall, while the literature suggests an appreciation of the psychosocial skills, availability and ease of access to the nurse working within CDM, there is less evidence on the service user's perception of the increasing nursing role within CDM.

The study

In response to the emergence and focus on models of CDM, in 2005 the National Institute of Health Research in England called for proposals that would evaluate the nursing contribution to models of CDM, and in particular examine the origins, processes and outcomes of CDM models. The authors as part of a mixed discipline research team (nursing, health visiting, medical sociologist and health economist) were awarded a grant to undertake a three year study commencing in 2006. The study was approved by the NHS National Research Ethics Service and local NHS research governance departments.

Aim of the study

The PEARLE study (**P**revention, **E**nabling self care and **cARe** in **L**ong term conditions **E**valuation) aimed to explore, identify and characterise the origins, processes and outcomes of effective CDM models and the nursing contributions to such models using a whole systems approach.

Methodology

A whole systems methodology (Kendrick and Conway, 2003) was selected to reflect that as illustrated in the chronic care model and long term conditions model (Department of Health, 2005a, Wagner and Groves, 2002), public provision of health and social care and other support services need to be integrated. Four principle perspectives were focused on to produce a whole systems analysis (figure 1). The causal system focuses the research on an exploration of the unfolding of slow, gradual processes over time, enabling an analysis of the origins of the CDM models. The data system recognises that for many of the most important aspects of the whole system there is little data available. Therefore, whilst the PEARLE study collected data that were available, areas with a dearth of data were also identified to illuminate the analysis. The organizational whole system is most commonly identified as the main feature of the whole systems approach and is concerned with how health and social care systems may or may not function together rather than as parallel systems. Finally, the patient experience of the whole system recognises that the whole system comes together and is embodied in the experience of individual users of the health care system. Hence, while the organizational system may suggest a unified health care system, data from patient experience may contradict this by indicating a fragmented service.

The PEARLE study employed a mixed methods approach to enable a whole systems perspective, including consensus methodology and a survey, however, the bulk of the study employed a qualitative design. It is beyond the scope of one paper to report all the findings and the purpose of this paper is to focus upon the qualitative data from patients and service users. Data from health professionals will also be drawn upon to contextualise the findings.

While a whole systems approach provides a methodological guide towards data collection and synthesis, it is not sufficiently developed to provide methodological rigour in qualitative data analysis. A thematic approach (Fereday and Muir-Cochrane, 2006) was therefore adopted to guide data analysis and data saturation.

Participant selection

Identification of potential case studies was via a systematic search of UK practice focused websites and a national consensus conference on the nursing contribution to models of CDM. Forty seven nurses and service managers participated in the conference and within small workshops presented an overview of their CDM model. Using a sampling frame based on the Long Term Conditions model (Department of Health, 2005a)(figure 2), post conference the models were reviewed by a project working party and a purposive sample of 15 nurses and managers were invited to a further workshop. Seven case studies were finally selected to reflect a range of models in terms of delivery systems, population served, geographical spread, and organizational willingness to participate in the study.

In total 32 nurses and 19 service managers, doctors and other health professionals participated in interviews (n=51). Depending on caseload size in each case study site, a questionnaire was distributed to either a census or random sample of patient/service users

(n=1635). The questionnaire included a response form to be sent directly to the research team if respondents were interested in participating in an interview (adults and younger people) or focus group (children and younger people). A total of 84 adults, younger people and family carers agreed to take part in an interview, and 6 children and younger people agreed to take part in focus groups.

Case studies setting

A summary of the seven case study site characteristics is provided in table 1. Whilst selected to provide a range of models, populations served and geographical spread, the case studies also reflected a continuum of autonomous practice which, as presented later, impacted on the patient perception of the nurse's role within each model of CDM.

Data collection

Data was collected during 2008 and 2009. Semi-structured interviews were conducted following informed consent with adult service users and family carers/parents usually in their home, or if preferred in a private area at their place of work or via the telephone. Members of the research team (PW, SK) and an experienced research assistant (JM) carried out the interviews using a semi-structured guide and the interviews lasted for approximately 90 minutes. Focus groups with children and younger people were carried out at their schools. Focus group methodology has been used extensively in research with young people and has been found to be a safe and ethically sound method for children aged from 7 (Morgan et al., 2002). The focus groups were run by members of the research team (FB, EM) and a facilitator (JMa) experienced in working with this age group. Using a semi-structured guide the discussion lasted for approximately 45-60 minutes depending on the

age group. Focus groups were held separately with younger children (8-10 years old) and adolescents (11-16).

Interviews with health staff involved with each CDM model were conducted face to face or by telephone where this proved more convenient for respondents. Using a semi-structured guide the interviews were conducted by experienced members of the research team (PW, SP, SK, FB, SA) and lasted up to 45 minutes.

All interviews and focus groups with participants' permission were recorded, transcribed and anonymised.

Analysis

Transcripts were entered onto NVivo software (QSR International Pty Ltd, 2006) and open coded by members of the research team experienced in qualitative analysis (PW, SK, SP, FB, JMa). Interviews and focus group transcripts were analysed separately, but as guided by the whole systems framework (figure 1), were drawn together to further illuminate the patient experience. Regular team meetings occurred to enable a common understanding of the open codes and development of tree nodes. Researchers outside of the team cross-checked coded transcripts (MC, SR) and coded transcripts independently to aid inter-rater reliability. A sub-group of lay service user representatives from the project advisory group coded a sample of transcripts to enable vicarious respondent validation (Cresswell, 2007). Any variation in interpretation was checked with the respondent. Development of themes and categories was facilitated by a series of summative analysis meetings of the research team.

Findings

Analysis of the data from service user respondents cross checked with data from service providers revealed a number of themes (Kendall et al., 2010). For the purpose of this paper themes will be presented that illuminate how service users located, articulated and evaluated the nurse within CDM.

When and how is the nurse most needed in CDM?

It was clear that the nurse's contribution in CDM was particularly valued by service users at specific stages of their chronic illness, particularly when they felt most vulnerable such as initial diagnosis or an acute exacerbation:

"I was in complete shock and I had no idea what was going on because I have no family history, I have nothing that is diabetic-related at all in the family...lots of crying and then lots of reassurance... she (diabetes nurse specialist) even went as far as giving me her home telephone number so that I could call her initially, just those first couple of days..."

Female, type 1 diabetes, condition specific nurse specialist model

However, because of increased confidence in self-management skills, during stable phases of the long term condition service users were less likely to articulate a key role for nurses in CDM:

"I think once you've settled down and you know what you're doing yourself, you feel able to pull back from things like that"

Female, type 2 diabetes, condition specific nurse specialist model

The importance of continuity of care for service users within CDM was recognised by all clinicians and was often one of the goals the CDM model was working towards:

“She (primary care nurse) has become essentially a mini GP in diabetes within the surgery. She’s been able to provide the experience, the expertise and the continuity which is what a GP provides in all the other illnesses... I think that anything that provides continuity within primary care is valued by patients.”

GP, primary care nurse model

However continuity, while desired by service users, was rarely achieved consistently in CDM models comprising of a team of nurses and other practitioners. Frequently respondents spoke of their strategies to ensure continuity:

“I keep meaning to take her name because I think yes, when I go to see her again I say “you know I want to see that one.”

Female, CHD, primary care nurse model

In CDM models characterised by a lone nurse at its centre, service users clearly valued the relationship and rapport they had with the nurse:

‘I’d been in touch with [Epilepsy Nurse], after those two very nasty falls. Got in touch with her, because you can ring her any time... she’s obviously more knowledgeable than your GP, being a specialist nurse, and at the end of conversation she said she’ll increase the dosage...

Female, epilepsy, condition specific nurse specialist model

In contrast to the high visibility of single nurses within a CDM model it was also evident that in some of the case study sites the nursing contribution to CDM was invisible to many of the service users. Although nurses were still functioning to improve care, there was not a direct face to face input in the way that traditionally nurses have worked with and alongside

patients. This was particularly noticeable in the public health model where many of the children, young people and parents were unaware of the school health advisors, because they were operating in a coordinating and leadership role to create a model of care that was delivered by others

“...I don’t know of any school nurse really. I mean, I presume there is one, but I don’t think the girls have actually seen her”

Mother of two girls with asthma, public health model

Even within CDM models facilitated by a single nurse some service users chose to continue accessing the doctor rather than the nurse. For example, one respondent who was recruited via the primary care nurse’s diabetes review database refused to see the nurse:

“...I’d rather see the doctor than see the nurse... you know, I very rarely ever go to see the nurses. I’ve been there once to get my ears syringed...”

Female, diabetes type 2, primary care nurse model

However, although many respondents stated a preference to seeing a specialist or doctor for their CDM, in many instances this preference was offset by the ease of access to the nurse within the CDM model. Ease of access was defined in two different ways. First, it was described in physical terms such as the ease of contacting the nurse, less waiting times for appointments and more rapid response. Secondly, ease of access was described in psychosocial terms as nurses being more accessible through their communication style. Service users particularly valued the less formal relationship they had with the nurse when compared to the patient-doctor relationship. Many respondents, particularly those with

diabetes, perceived nurses as less likely to be judgemental and hence easier to discuss the difficulties and realities of living with the condition:

"I suppose you tend to think of the doctor as the one that's going to, not tell you off, but it's just that, oh gosh I'm going to get it now from the doctor, whereas the nurses probably are that softer person to kind of talk to, just that bit more friendlier..."

Female, type 1 diabetes, condition specific nurse specialist model

Equally, service users often described the nurse as being more skilled at explaining, providing information, and increasing the patient's self-confidence:

"Oh she's been a great help, just her coming it gives you confidence, you can talk things over with her and there's nothing they can do for me, I know that and she has told me there's nothing at all, only that thing to keep me going on, so as I say it's somebody, when you're on your own you've got nobody to talk things over..."

Male, diabetes type 1 & COPD, community matron model

The monopoly of expertise within acute/secondary care and limited role of primary health care

Service user respondents frequently spoke about the importance of having access to a specialist for on-going management of their condition:

"You know you've got it from a specialist, so you're alright really."

Young person, asthma, public health model

Specialist or expert care was generally seen to be a characteristic of acute or secondary rather than primary care, with the latter often being seen as just a gateway to specialist secondary expertise in CDM:

“...you know you look at her (epilepsy nurse) for more the expert...she’s more in tune with it really. I mean all my doctor’s going to do is send me to her. So you’re just cutting out the middle man really.”

Male, epilepsy, condition specific nurse specialist model

In contrast many clinicians and managers described a shift of CDM expertise, particularly diabetes care, into primary care:

“We are finding that we need to refer less and less patients now into the secondary care route, because we can actually deal with the condition entirely in primary care...”

Diabetes nurse specialist, primary care model

However, there was an acknowledgement certainly born out in the service user data that there was some resistance to this shift:

“I’ve been going there (hospital clinic) for years and years but then suddenly the doctor (GP) said “your annual review” and I had to go there (GP clinic) but I don’t like it.”

Female, diabetes type 2, primary care nurse model

This perception of the monopoly of expertise being within secondary care was further compounded by service user reservations about the level of autonomy nurses have or should have:

“But her (primary care nurse) understanding or her willingness to actually come up with a sort of medical diagnosis or to venture into those areas which are quite clearly the doctor’s professional concerns, I don’t have a problem with the nurse giving me injections...to some degree it’s useful being able to get that lower level of care rather than going to the doctor every time...”

Male, diabetes type 2, primary care nurse model

Not only was specialist expertise seen by many service users as being located in secondary care, but also seen as being a hallmark of medicine:

“...prefer the doctor because from the doctor I’m going to get an answer...”

Male, diabetes type 2, primary care nurse model

In some of the CDM models the nurses were valued due to their clinical expertise and ascribed the same value as medical input. These nurses were often described by respondents, both service users and clinicians, in terms traditionally reserved for the medical profession:

‘I think she takes on enormous responsibility which is... I mean she is very experienced and she is actually extremely able and I think if she weren’t there I think we would miss her terribly... I mean she’s the Consultant for Epilepsy in this area really.’

GP, condition specific nurse specialist model

Levels of autonomy were perceived to be greatly enhanced by both nurses and service users if the nurse was an independent prescriber; indicative again of role aspects traditionally the province of medicine from the service user's perspective. Service users clearly valued nurses who were able to practise autonomously and also maintain a person centred approach. However, the data suggested that in a number of instances more mechanistic care approaches were evident. This was most apparent in primary care where many patients had co-morbidities and yet were attending single disease review clinics:

"...because I'm looking for them to check me out for diabetes, for angina and for the prostate, I sometimes find that they're quite happy to push the cholesterol business and the prostate business to one side and they're not concerned. I don't want that, if I'm going to go and have a check-up, I want them to check me for every concern that I have..."

Male, diabetes type 2, primary care nurse model

Many service users stated that arthritis was the chronic condition that impacted on their life most but the clinician emphasis was on a concurrent condition such as diabetes or heart disease, with the patient defined most pressing need often ignored.

Service users also spoke of the regular review clinics being seen as a test or being a "tick box" focused activity:

"Sometimes I feel with the nurse that it's just very robotic what she does, you know I don't feel that there's any intimacy, not intimacy but any, it's a job, she's not really interested she's just asking the right questions that are perhaps on a form...she would have a form and ask these questions no matter what.

Female, COPD, primary care nurse model

This more mechanistic approach to care also impacted on the amount of information given at the review and subsequent service user understanding of the disease management:

“...what goes on when you see her (practice nurse)? What does she do? Well just the general health check and just blood tests.. and that’s it...nothing about diet or anything like that...”

Male, diabetes type 2, primary care nurse model

The origin of primary care nurse led CDM clinics was clearly traced back by clinician respondents to changes in work practices as the result of the new GP contract (Department of Health, 2003), which linked payments to the recording of CDM activity as part of the Quality Outcomes Framework (QOF):

“...QOF came along so they had to be developed further. But yes, I think really initially it was to try and take, well to try and absorb the work that was necessary but also protecting, as I say, doctor time, doctor consulting time”

GP, primary care nurse model

Service user’s responses to the nurse in CDM

It was clear from the data that service users within the primary care case study sites often perceived the nurse’s role as limited to a protocol driven review of a singular chronic disease, and patients were unlikely to consult the nurse for more proactive care:

“Yes, it’s easier for me to see the doctor. The times that I see the asthma nurse and the heart nurse are usually at predetermined appointments, check up appointments as opposed to any other kind of appointment”

Male, CHD, primary care nurse model

Often access was limited to nurses due to the structure of the health care service; however it was also apparent that access was limited because of service user’s reservations about the nurse’s ability to deal with problems as they arose in CDM:

“...he’d (doctor) give you more confidence with your illness, a nurse will do that, I mean she is qualified but not as much as a doctor...the skill level will be different... they can’t move things on if there’s a problem but the doctor would do that..”

Male, diabetes type 2, condition specific nurse specialist model

“I just think I would sooner see the doctor probably yearly or just because they are the doctor and always are in that role...not because I have an issue with the nurses, but just kind of because he’s the doctor”

Female, diabetes type 1, condition specific nurse specialist model

Other service users were more receptive to the developing role of nurses within CDM seeing it as evolutionary:

“...it’s almost like the plumber apprentice because when the plumber in effect suddenly learns how to do that joint so it doesn’t leak, then that plumber is a bit more than an apprentice isn’t he, he’s an apprentice plus one and it’s the same with a nurse ...”

Male, diabetes type 2 & chronic renal failure, condition specific nurse specialist model

Furthermore, on questioning a number of respondents felt their reluctance to nurse-led care was due social conditioning rather than anxieties about outcomes:

“It would be quite strange not to have a doctor, but mainly it’s just from conditioning really, it would feel odd. I don’t think it would be anything.”

Female, diabetes type 1, condition specific nurse specialist model

However, a number of service users within the condition specific nurse specialist and community matron models indicated that they had fully accepted the nurse as the key clinician:

*“...would you call your GP instead of the Community Matron or vice versa? We don’t call him (GP) do we now... ...would she (community matron) **always be your first port of call?** ‘Oh yes.”*

Family carer, community matron model

In the public health model many respondents were unaware of the nurses’ contribution to that model of CDM and this invisibility, as described earlier meant that service users were unlikely to perceive the nurse as lead clinician.

These different responses to nurses working in CDM are mapped in figure 3 and suggest that service users were likely to respond to the nursing contribution to CDM in three distinct ways. If patients had experienced the nurse within first contact care (Bonsall and Cheater, 2008) particularly when most vulnerable, and had observed the nurse as either diagnostician, prescriber or autonomously taking on the medical management of the

condition, then the patient was likely to view the nurse as the expert who had necessary clinical skills to support management of their condition. These patients were most likely to state that their whole experience of care was good and saw the nurse as the lynchpin of CDM. However, if the patient was experiencing the nurse in a way they perceived as being the doctors assistant, or had changed from a doctor-led to nurse-led review and management process, then the patient was unlikely to see the nurse as expert and were more likely to continue to consult a GP or hospital specialist. A third perception stemmed from the invisibility of the contribution of nurses in the public health model, or where the patient was stable and self-managing. These service users were less likely to comment specifically on their experience of the nurse's role. However, the apparent invisibility of nursing did not mean the health care was inadequate. Within the public health model, the health outcomes for children and young people were very good, with hospital admissions for asthma being one of the lowest in the country. The perception that the nurse was not in the foreground contributed to a complex interpretation by service users of what nurses actually do and the roles and responsibilities they adopt in CDM. This raises some critical questions about the relationship between the experience of health and illness and the experience and satisfaction with health care.

Discussion

The majority of service user respondents often spoke in terms emphasising the biomedical management of their chronic disease and hence used patient-clinician interactions focused on this aspect as a benchmark to judge consultations with practitioners. Previous research examining medical interviews suggests that the more biomedical tasks are emphasised in management of long terms conditions, then the less psychosocial components are

perceived as important by both patient and clinician (Gallagher et al., 2005). The work of Bury (1991) and Armstrong (1995) draws attention to the active and adaptive role of patients in managing long term conditions and the difficulties of demarcating the sick role within society. However, the findings from this paper suggest that an emphasis on the biomedical management of the chronic disease reflective of the sociological perspective developed by Parsons (1991) not only provides status and focus for the clinical role but also brings a sense of legitimacy which is strongly associated with patient engagement and consequential satisfaction (Staniszewska and Henderson, 2005).

As an exemplar of a nursing role encompassing extended biomedical skills, the nurse practitioner role has developed rapidly in the UK over the past 15 years. However, whilst the wealth of research on service user's responses to nurse practitioners indicates a positive response (Bonsall and Cheater, 2008, Horrocks et al., 2002, Kinnersley et al., 2000), the data from PEARLE suggests that this positive response does not always increase with extended nursing roles within CDM. All the nurse respondents in the PEARLE study had undertaken significant further training and were experts in their field of CDM including the biomedical aspects (table 1), and yet a significant number of patients had reservations about some of the roles and the changes within CDM. On probing, the reservations stemmed from previous experiences or expectations of what the nurse could provide, with the findings suggesting that seeing a doctor regularly for CDM is perceived by patients as normal standard practice. As found in previous research (Redsell et al., 2007), expectations were strongly linked to the trust the service user had in the practitioner and social status of the practitioner, with social status a strong predictor of influence an individual has over others (Oldmeadow et al., 2003). Service user reservations were particularly noticeable in the primary care nurse

model where the patriarchal division of labour was most likely to exist (Mills and Hallinan, 2009), and unlike the other models, the nurse is employed directly by the doctor reinforcing traditional patterns of power. Extension of the primary care nurse role in CDM has also resulted in a significant increase in workload for the nurse (Daughtry and Hayter, 2010). The tension between the drive for service efficiency (for example; reducing consultation time in general practice) and maintaining a holistic, patient-centred nursing perspective (Stenner et al., 2010) may influence the way nursing becomes operationalised as a task focused activity. The limited amount of previous research in this area also indicates some reservations from patients about primary care nurses' skills and competencies (Rashid, 2010).

Trust can be defined as the state of favourable expectation one has about another's actions and behaviours (Mollering, 2001). Redsell *et al's* (2007) qualitative study of patients' perceptions of the differences in nurses' and GP's roles in primary care suggested that service users had complete trust in their regular GP. This trust was built upon patient centredness, understanding and explanation, diagnostic competence, qualifications and experience. However, the sociologist Georg Simmel argued that trust has a further element of faith; a quasi-religious feeling of certainty about another that is not based on any concrete fact (Simmel, 1964). This faith in another is based more on cultural rather than personal knowledge, hence it could be argued that service users' articulate more trust in doctors than nurses because of societal norms. The relationship between trust and expectation is important as trust leads to a state of favourable expectation (Mollering, 2001), thus if the patient trusts the nurse they are more likely to expect that the nurse will be able to meet all their needs .

While trust links to expectation, expectation in turn links to feelings of satisfaction, and work from business and marketing academia can be usefully applied to health care when exploring the links between expectation and satisfaction (Sixma et al., 1998). Expectation has a fundamental role in expressions of satisfaction (Oliver, 1980) and the more a clinician meets the patient's expectation, the more positive they are likely to feel with the clinician's care (Johansson et al., 2002, Sitzia and Wood, 1997). A US study of the impact of what type of practitioner undertook call-out visits to patients in primary care suggested that patient approval of care was at least as high when a nurse practitioner or physician assistant visited than a doctor. However, patients were clearly informed of the role of the nurse practitioner and physician's assistant and to expect them for call-out visits (Roblin et al., 2004). Ross *et al* (1987) suggest a cyclical process (figure 4) between experience, preferences, expectation and satisfaction. It is also suggested that as a belief, expectation can be changed over time thus changing the nature of this cyclical journey (Giese and Cote, 2002, Oliver, 1980, Ross et al., 1987). While expectations can be defined as the beliefs about a practitioner's attributes and performance at some time in the future, preferences are the evaluation of the extent to which attributes, benefits and outcomes of the practitioner's care will contribute to meeting the patient's self-defined needs (Spreng et al., 1996). Thus, for the patient there is a complex interplay between what they expect of the practitioner (such as what interventions they can provide), and what they desire of the intervention (such as relief of symptoms). This is further complicated by the nature of chronic illness, with our data suggesting that many patients continued to desire approaches more aligned to the acute care model; hospital-based, biomedical, and providing a rapid answer to the problem. The nurse specialist model was meeting the expectation of visibly skilled technical and empathetic care, and the desire for immediate therapeutic interventions such as a drug

prescription. There was also a high level of satisfaction with the primary care based community matron model and, as a much older population, there was evidence to suggest that these patients had accepted the intractability of their condition but also valued the highly visible technical skills. However, for many patients chronic disease management delivered by primary care nurses did not appear to meet expectations or desired input. It would appear that patient's expectations were often based on previous experiences of CDM located in the acute sector and delivered by clinicians unhampered by the constraints of structures such as the QOF.

Limitations

As with all qualitative methodology, the findings reflect the views of a particular population at a particular time, and although meaning was checked with service user representatives, the analysis is subject to interpretation. While the sample size was reasonably large for a qualitative study it should also be acknowledged that the sample was spread across 7 case study sites. However, the case study sites were theoretically sampled to ensure geographical spread and typicality, and hence should be transferable and meaningful to other similar settings (Chiovitti and Piran, 2003). The merging of interviews and focus group data loses sight of, for example, the influence of group processes on focus group data (Kidd and Parshall, 2000), but allows for a gestaltic overview of the whole system (figure 1).

Conclusion

Service users' expressions of experience of the nursing contribution to CDM ranged from positive approval and a preference for nurse-led CDM, to perceptions of care characterised by a mechanistic approach. Service users' preferences and expectations of CDM were often

framed by a biomedical discourse alongside the desire for an empathetic approach. Drawing on sociological and social psychological theoretical frameworks, this paper has suggested that service users' expectations and preferences influenced their experience of the nurse's input in CDM. In many ways this is unsurprising as the extended roles of nurses within CDM are relatively new, and with time service user's expectations and preferences are likely to change if they experience quality care delivered by nurses working within CDM. Meanwhile, the challenge for nursing, health care organizations and policy makers is to listen clearly to service users' preferences in CDM and to enhance the process of increasing service user trust, expectations and preferences for nurses (Maben and Griffiths, 2008) to play a key role in CDM. Some potential ways of doing this include addressing how the nursing workforce can be developed clinically and more strategically in line with globalised health care concerns with long term conditions (Piot and Ebrahim, 2010). The World Health Organization (2005) have outlined the key ways that the health workforce can be prepared for the challenge of chronic conditions in the 21st century and this includes patient centredness, partnership, use of information technology and quality improvement. The nursing workforce needs to be prepared in all these aspects through education, professional development and the development of positive practice environments (Bryar et al., in press). There is also recognition that at a strategic level autonomous nursing practice in CDM requires support and further promotion to the wider society (Department of Health, 2011), thus enabling in time a shift in societal expectation and trust of the nurse's role in CDM.

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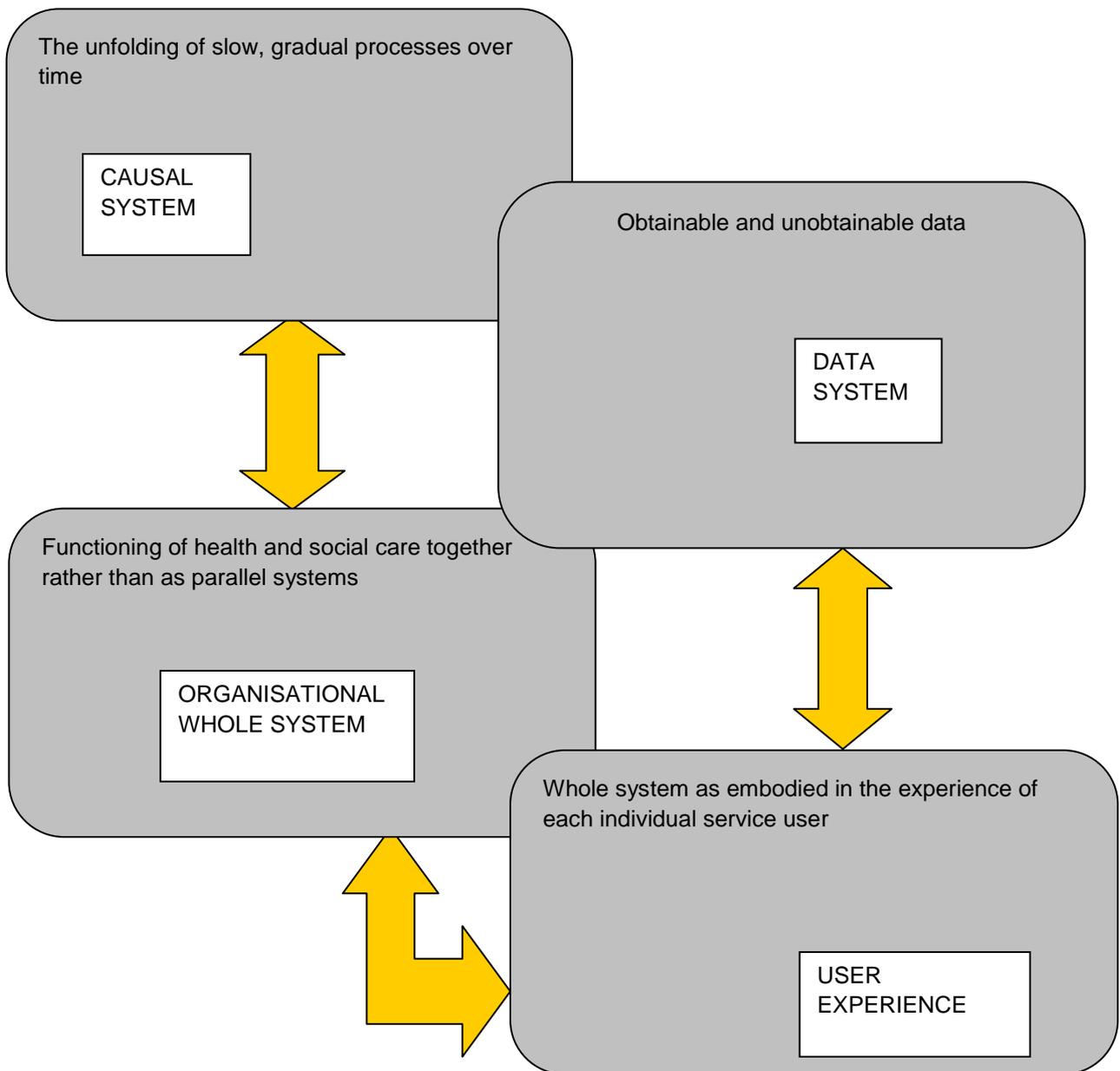
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Figure 1 Whole systems approach (Kendrick and Conway 2003)



Case study site description	Population served by model	Main focus of CDM delivery system ¹	Nurse/nursing team	Training & preparation
<p>Community Matron Model:</p> <p>Site 1 Largely rural but there are highly urbanised areas with much higher population density. Wide variations in mortality rates and pockets of extreme deprivation.</p> <p>Site 2 Inner city with 50% of population belonging to a minority ethnic group. A lower life expectancy than average and higher than average prevalence rate for diabetes.</p>	Older person with complex needs	Case management	<p>Community matrons managed within adult community nursing services alongside district nurses.</p> <p>Nurse-led case management delivered via community matrons who work alongside NHS employed case managers with a social care background.</p>	All community matron's had undertaken advanced nursing practice preparation and were independent prescribers
<p>Condition specific nurse specialist model</p> <p>Site 3 District General Hospital in a mainly rural area but with several large towns with deprivation.</p> <p>Site 4 Three teaching hospitals in a large city with diabetes prevalence</p>	Adults Condition specific high risk	Disease management	<p>Sole epilepsy nurse specialist, headed a larger neurological nursing team in secondary care with out-reach and hospital based clinics and worked highly autonomously in collaboration with a consultant neurologist to support people with epilepsy.</p> <p>Consultant nurse led team of nurse</p>	<p>Epilepsy Nurse Specialist not an independent prescriber at the time of data collection. Educated to Masters level in epilepsy care.</p> <p>The consultant nurse and nurse specialists were independent prescribers. All had undergone extensive</p>

¹ All CDM models within the study included elements of disease management, self-care support and promoting better health.

rates higher than national average.			specialists and other practitioners who provide a comprehensive service for people with diabetes, particularly those with type 1 diabetes. Strong emphasis on structured education programmes for people with type 1 diabetes.	training in diabetes care.
<p>Primary Care Nurse Model Site 5 General practice with an urban/rural mix. Pockets of deprivation.</p> <p>Site 6 General practice within a highly urbanised area.</p>	Condition specific high risk	Disease management	<p>Practice Nurse-led service for people with type 2 diabetes. The nurse managed the care of the majority of patients with type 2 diabetes running a weekly clinic for diabetes patients.</p> <p>Practice nurses leading primary care chronic disease management clinics (COPD, asthma, CHD, diabetes). The team consisted of a nurse practitioner, 2 practice nurses, and 1 Health Care Assistant.</p>	<p>The practice nurse had undertaken training in diabetes care but was not an independent prescriber.</p> <p>The nurse practitioner and practice nurses had undertaken training in specific disease management. The nurse practitioner was an independent prescriber.</p>
<p>Public Health Model Site 7 Primary Care Trust in mainly urban borough. Much higher population density than national average.</p>	Self-care support	Supporting self care	The coordinator based in a Primary Care Trust and led a team of school health advisors on a Trust-wide strategy for management of childhood asthma in schools.	The lead coordinator was a registered nurse, sick children's nurse and school nurse. Had completed a diploma in asthma care and was currently training as an independent prescriber. The school health advisors were qualified school or children's nurses and had undertaken courses in asthma management.

Table 1 Case study sites

Figure 2 The NHS and Social Care Long-term Conditions Model (Department of Health 2005a)

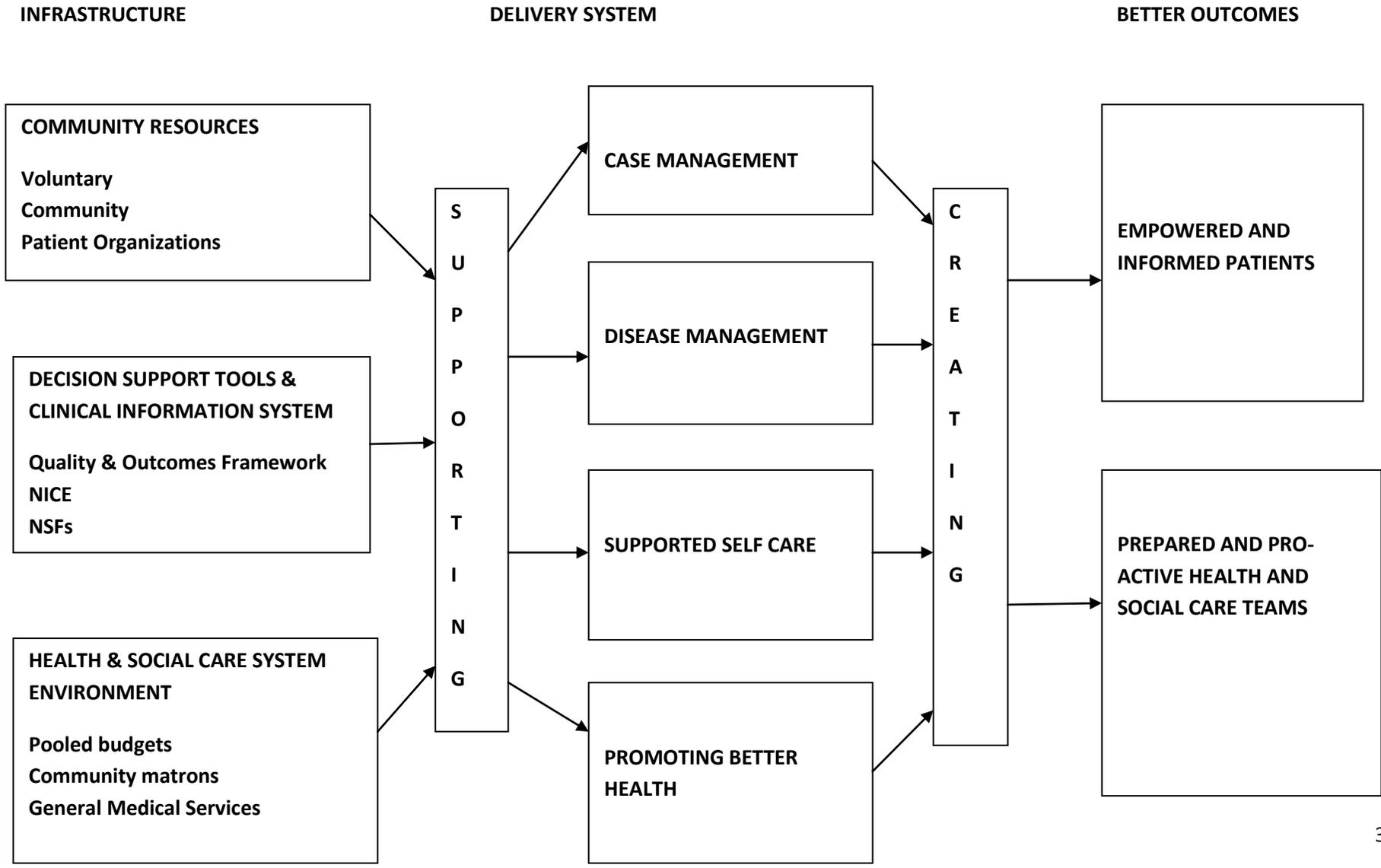


Figure 3 Patient and service user perceptions to the nursing contribution

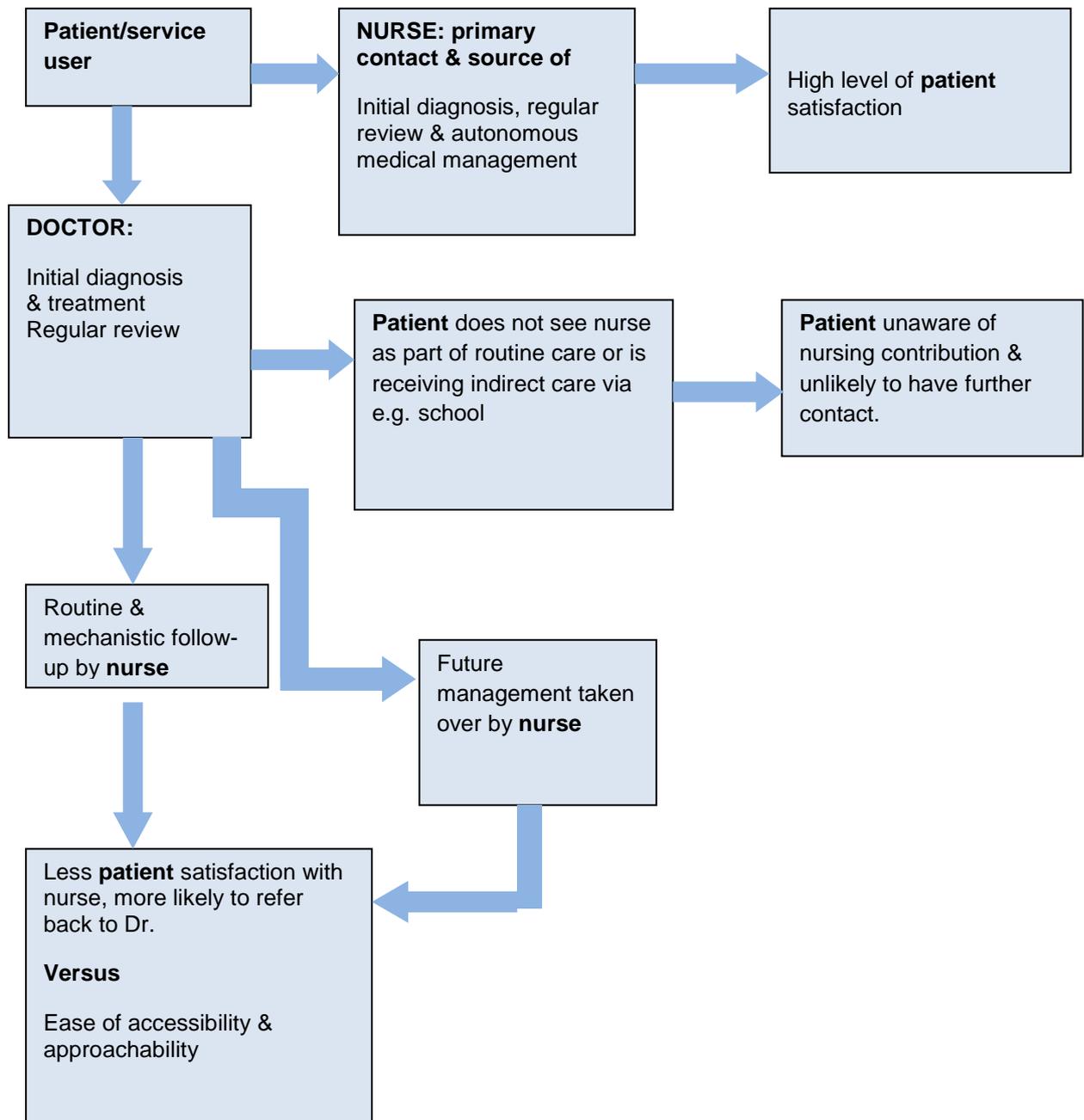


Figure 4 Preferences, expectation, experience & satisfaction cycle (based on Ross et al 1987)

