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### ORIGINAL RESEARCH

# Personalizing protocol-driven care: the case of specialist heart failure nurses

Tom Sanders, Stephen Harrison & Katherine Checkland

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Correspondence to T. Sanders: e-mail: kath.checkland@manchester.ac.uk Tom Sanders BA MSc PhD Senior Research Fellow Arthritis Research UK National Primary Care Centre. Primary Care Sciences, Keele University, UK Stephen Harrison BA MPhil PhD Professor of Social Policy National Primary Care Research and Development Centre, Division of Primary Care, University of Manchester, UK Katherine Checkland MBBS MA PhD Walport Clinical Lecturer in Primary Care National Primary Care Research and Development Centre, Division of Primary Care, **1** University of Manchester, UK

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#### Abstract

Aim. This paper is a report of a study conducted to explore how specialist heart failure nurses negotiate treatment advice with patients, in the context of an increasing expectation that clinical staff in the National Health Services will follow guidelines in their daily work.

**Background.** The development of specialist nurse roles has given rise to questions about their compatibility with patient-centred care. However, research has revealed little about how specialist nurses balance clinical guidelines with traditional caring tasks.

Methods. Semi-structured interviews (n = 10) were conducted with specialist heart failure nurses in northern England recruited from a heart failure specialist nursing contact list. In addition, non-participant observations were carried out on nursepatient consultations (n = 16) in one regional nurse-led heart failure clinic. Data were collected between 2003 and 2005, and analysed using a variation of grounded theory. Findings. Heart failure nurses sought to combine traditional caring work with the wider goal of improving patient outcomes by 'personalizing' their advice to patients and presenting their heart failure as 'typical'. They accommodated protocol-driven care into their daily routines, and perceived no disjuncture between evidence-based practice and patient-centredness. However, their approach allowed little space for the exploration of each patient's own priorities about their illness.

**Conclusion.** There is a need both to re-examine the appropriateness of traditional caring concepts, and to reflect on the need to incorporate patients' own values into the consultation process.

**Keywords:** clinical guidelines, decision-making, evidence-based medicine, patient choice, personalization, protocol-driven care, specialist heart failure nurses

#### Introduction

Evidence-based medicine (EBM), from its origins in British public health and Canadian clinical epidemiology, has2 become an international social movement (Daly 2005, Pope

2003). Its prominence in contemporary United Kingdom (UK) health policy is evidenced by the central role of such institutions as the National Institute for Health and Clinical Excellence (NICE), the Health Technology Assessment research and development programme, National Service

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Frameworks, and the Quality and Outcomes Framework (QOF) incentive scheme in primary care (for an overview, see Harrison & Checkland 2009). In contrast to the aspirations of EBMs early proponents that clinical practice should be informed by critical appraisal of scientific evidence, integrated with patients' preferences (Sackett et al. 1996), UK health policy has largely taken the form of 'scientific bureaucratic medicine' (Harrison 2002), in which clinical care is increasingly governed by close adherence to formal guidelines, with clinicians and patients exercising little or no choice (beyond basic consent to treatment) over decisions about therapeutic interventions (Stromberg et al. 2003). This approach facilitates clinical decision-making that is grounded in scientific evidence but, as such evidence relates to populations (Byrne 2004), it is not axiomatic that individual patient preferences will, or should, concur with it. There is a possibility that clinicians may be impelled towards a more paternalistic style of practice (Berg 1997, Edwards & Elwyn 2001, Janicek 2006), and some research has shown that it can lead to the provision of care that is more standardized and consequently less patient-centred (Landsman 2006, Harrison & Checkland 2009).

Emphasis on the systematic application of scientific evidence has spread beyond the clinical practice of physicians and into that of other clinical professions, so that nursing work is also affected. Internationally, evidencebased nursing has gained considerable momentum, particularly in the United States of America (Landsman 2006), with many training opportunities interwoven into the undergraduate and postgraduate curriculum, emphasizing the need to integrate evidence into teaching and practice (Richardson & Dowding 2005, Dowding *et al.* 2009). These developments paint a picture in which the systematic application of 'the evidence' has become a customary feature of nursing work, with significant implications for the development of UK nursing.

Nursing has a traditional discourse of caring for the whole patient, long formally recognized in official policy statements (Department of Health and Social Security 1977, Department of Health 1994) and by the profession itself. Even now, the need to 'treat people as individuals' is placed much earlier in the current Nursing and Midwifery Council Code than is the need to use the 'best available evidence' (http://www.nmc-uk.org/aArticle.aspx?ArticleID=3056, accessed 3/12/09). However, this traditional discourse now exists alongside a more recent one that associates professional roles with 'evidence-based' care, in which nurses are expected to account scientifically, rather than intuitively for their decisions (Greenwood 1993, Royal College of Nursing 1996, p. 3). There is some evidence that patient-centred care can be compromised by pressures associated with this new conception of the nursing role, such as the need to meet performance targets (Tyler 2000, Manias et al. 2005), to conceptualise care as a series of tasks (Greenwood 1993), and to take over aspects of work formerly undertaken by physicians (McDonald et al. 2009). Although there is a 'soft' side to specialist nursing, clinical guidelines are central to the role. To take the example of heart failure, Jolly (2002) makes it clear that the role includes the responsibility for ensuring that any 'suboptimal' treatment regimes are brought into line with evidence-based guidelines (Koelling et al. 2005). Moreover, whilst increased specialization risks narrowing a practitioner's clinical focus at the expense of breadth of competence and of knowing the personal and social circumstances of patients, there is some evidence that specialist nurses still appeal to patient-centredness as one element of their espoused identity (Sanders & Harrison 2008).

Although the conjunction of discourses of patient-centredness (or holism) and evidence-based practice is potentially uncomfortable for specialist nurses, such analyses of contradictory logics tell us little about their daily work. In this paper, we show how at least some nurse specialists deal with this issue within the workplace, using data from a qualitative study of the treatment of heart failure patients in two English hospitals.

#### The study

#### Aim

The aim of the study was to explore how specialist heart failure nurses negotiate treatment advice with patients, in the context of an increasing expectation that clinical staff in the National Health Services (NHS) will follow guidelines in their daily work.

#### Design

The data reported here relate only to the work of specialist heart failure nurses, and are drawn from a study that also included the work of doctors; findings in relation to the latter have been published elsewhere (Sanders *et al.* 2008). The data were collected by TS. The study was in two parts. First, interviews were conducted with practising specialist heart failure nurses and with physicians involved with the care of patients with heart failure. This was followed by observation at two NHS heart failure clinics, both in a hospital setting, allowing contextualization and further exploration of the issues discussed in the interviews.

#### Participants

The interview sample of specialist heart failure nurses was obtained using a combination of snowball sampling and a nursing contact list obtained from a regional heart failure nursing forum. The list contained the contact details of all practising specialist heart failure nurses in the North West of England. All nurses on the list were contacted by letter inviting them for interview. A total of 10 specialist nurses agreed to participate from a total of 15 who were approached. Interviews were audio recorded and transcribed verbatim. Second, the observational part of the study was conducted at two NHS heart failure clinics in Northern England between 2003 and 2005. Non-participant observations were conducted of consultations between specialist registrars and patients (24) in both settings, and subsequently a proportion of nurse-patient consultations were observed at one of the clinics (the other clinic was run by a single registrar with no nursing support). A 'purposive' sampling strategy was adopted for the nurse-patient observations (new presentations), to achieve a broadly representative mix of patients on the basis of age, social class and sex. More men than women attended the clinic and our sample reflects this difference. We also sought to observe both nurses conducting the consultations. Observations of repeat consulters included patients whom we had not previously observed; they were also recruited using a 'purposive' sampling strategy. In total, 16 nurse-patient consultations were observed, with 10 newly diagnosed and 6 follow-up patients, led by two specialist heart failure nurses. The majority of patients consulting with a nurse were aged between 60 and 80 years. Five were female and 11 male. The clinic list was obtained prior to each observation episode, and patients were approached for permission to conduct the data collection.

#### Data collection

The topic guide for the interviews with the nurses included approaches to patient care; perceptions of nursing work; patient choice and patient-centredness; attitudes towards clinical guidelines; problems with communication; and perceptions of decision-making and adherence to treatment advice. Consultations were audio recorded and later transcribed verbatim. Additional field notes were made on consultation style, body language of the participants, and level of interaction between nurses and patients. Data such as age, sex, marital status and co-morbidity were also recorded. Informal discussions with staff and patients during the course of the fieldwork were written up as field notes to inform the ongoing data analysis. Following some of the consultation episodes and during lunch breaks, clinic staff freely engaged in brief discussions with the researcher about specific patients or other issues such as the organization of the clinic. Brief conversations with patients about their experiences of the consultation and treatment also took place.

#### Ethical considerations

The study was approved by the appropriate ethics and governance committees.

#### Data analysis

Interview and observation data were analysed together so that emergent findings from each could be compared, providing triangulation (Murphy *et al.* 1998). The data were subsequently coded using Atlas-ti and analysed for connections and thematic links between the individual codes. Data were analysed using an inductive approach derived from grounded theory to identify emergent themes (Strauss & Corbin 1994). Following initial coding, analytical memos were written and meanings, patterns and relationships emerging from the interviews and observations were identified.

Our findings are presented below as verbatim excerpts from consultations and quotations from interviews with nurses, selected as representative of the major analytic themes, with italics used to highlight key points. All personal characteristics have been removed from the quotes to protect participants' identity. We report the analysis of interviews and observations in separate sections, prior to a discussion of the findings as a whole. In the subsequent sections, we refer to 'compliance' with recommended treatments. We recognize that 'compliance' has been superseded in the literature by the term 'concordance'; however, the nurses we studied repeatedly referred to 'compliance' (see quotes below), and therefore this term has been used in the text.

#### Rigour

Findings were discussed and examined for consistency and credibility with (SH) and (KC).

#### Findings

Overall, we identified three themes, each highlighting key strategies used by specialist heart failure nurses to personalize the treatment and advice offered as part of the NICE guideline for heart failure. 'Outcomes driven nursing work' depicts the nurses' attempts to achieve the desired clinical outcomes in patients through the provision of health educa-

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tion. This strategy, combined with a 'personalized' approach enabled them to tailor key health education messages to patients' specific personal circumstances. Finally, our nurses also adopted a 'normalizing' discourse where the symptoms and side effects of treatment were presented as 'normal' and therefore more acceptable to patients.

#### Interviews: outcomes driven nursing work

The nurses expressed the need for healthcare professionals to adopt a caring 'bedside manner' when looking after patients with heart failure. However, this patient-centred discourse was deployed in the service of a biomedical and managerial agenda concerned with improving health 'outcomes'. The aim was to build an effective interface with patients through which compliance with clinical advice might be better achieved:

I would say the luxury of heart failure nurses I suppose it's building the relationship with your patient so that they feel that they can talk about things and they have an opportunity to ask questions...At [Hospital X] they've been followed up quite closely and regularly so hopefully that *reduces the readmission rate*.

This outcomes-driven approach was perceived to be entirely consistent with traditional nursing work. It demanded, however, willingness on the part of nurses to reach a compromise with patients:

I've got patients who love salt, can't eat food without salt, and we have to reach a compromise. Now, it might be that the compromise to start with [is] that the patient will put it in the cooking...Then you've got a partnership, a two-way partnership. And you're much more likely to get the patient leaving and discharged from your clinic complying with everything that you spent three months setting up, than if you just lectured them.

Specialist nursing work was informed, on one hand, by a desire to improve patient outcomes through maximizing compliance with medication and, on the other, by engaging with person-specific issues that could potentially affect such outcomes:

They didn't take anything on board what I said last time, or it hasn't sunk in. So a lot of it is reinforcing, maybe because they don't understand what I am saying or they've got communication issues that I haven't necessarily picked up on.

I always try and tell them that when we are putting them on medication, why we are doing it, not that it's going to prolong your life but it's going to help the severity of your symptoms. It's going to get rid of your breathlessness if you're compliant with it...and I try and go over the research that has recently come out that yes you may feel worse when you start them, you may well for a couple of weeks feel really lousy, but if you persevere, the benefits for being on it far outweigh the initial lousiness that they feel.

Participants typically reinforced the main lifestyle and health education messages to patients in the hope of improving compliance and subsequently reducing avoidable hospital admissions:

I go over the reason that they have heart failure, ask if the doctor has sorted their tablets out and explain that they will help your heart and help improve symptoms hopefully and that there are things that they can do at home and that is when I go through the weighing, the salt intake, the fat in their diet the normal things; the blood pressure, being compliant with your medication mainly.

#### Observations (1): personalizing the clinical protocol

The heart failure clinic where the observations were conducted for this part of the study was nurse-led. Typically, patients were referred by their GPs to the clinic, where the diagnosis was confirmed. They then had a first consultation with a cardiology specialist registrar, who explained the diagnosis and the treatment options. All patients then saw one of two specialist heart failure nurses, who explained the treatment process in more detail and advised patients on recommended lifestyle changes. Each patient received a standard set of 'instructions' on how to detect and identify early symptoms of heart failure using self-assessment. Thus, patients attending the clinic were in receipt of a highly standardized package of care reflecting the National Institute for Clinical Excellence (2003) clinical guideline, which stipulates that all patients with a diagnosis of heart failure should receive the optimum treatment, which includes medication and health education advice and support. Far from representing personalized care, the same package of treatment was given to all patients seen.

Consultations were highly structured encounters at which the desire to implement the standardized care package seemed to override other concerns. However, this approach operated alongside attention to the individual patient, through which the clinical protocol for heart failure was delivered by specifically tailored and personalized health education and advice. Close support and individualized attention seemed to be equated with greater patient-centredness by the nurses:

Nurse: Be compliant with your tablets as well we know it's difficult sometimes when you're on water tablets and you want to go out like today coming to the clinic...Don't completely miss them out, it's quite flexible that if you were going out in the morning and you didn't want to take them that's fine, but obviously we would want

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you to take them when you get back home...One of the main reasons for re-admission to hospital is people that don't take the tablets, so we want to make sure that you take all your tablets [New patient].

One of the techniques used by the nurses to personalize care was to emphasize to patients the close support available. This approach emphasized that the nurses' primary responsibility was to the patient rather than simply their condition. In the following consultations, the nurse emphasizes the need to prevent admission through regular weight monitoring, and offers support in interpreting the results. The nurse here is closely adhering to the clinical guideline, but is also making the patient feel cared for:

Nurse: So it's very important, daily weight is the most important sign of any problems. And I want you to phone us if it's constant. If [only for] one day, it doesn't matter, but two or three days, just give us a ring and we'll chat to you on the phone [New patient].

Nurse: So if you weigh yourself everyday and your weight suddenly increases, you'll know you're putting on fluid and your heart is not pumping properly, and in that scenario we'd ask you to ring us [New patient].

Patients were routinely made aware of the close supervision and support available to them, with direct telephone access to the clinic for advice at all times:

And the fact is if the drugs are wrong that [we've given you] give us a ring immediately. If there's anything on it you don't understand there will be things you don't understand just give us a ring and I'll try and explain it over the telephone to you [New patient].

#### Observations (2): normalizing patients

Nurses routinely used a normalizing discourse which presented the patient's heart failure, its treatment and the associated symptoms as typical or common. We inferred that the intention of such a strategy was to make patients feel comfortable with, and maximize adherence to, the clinical advice. Again, this approach seemed to personalize the clinical and lifestyle advice provided by nurses. It also seemed to demarcate quite clearly to patients not only what they might expect from their illness and its treatment, but also what was considered to be both 'normal' for their condition and 'normal' patient behaviour:

Nurse: That's it with heart failure, if you speak to a hundred patients with heart failure what they say is some days they have wonderful days when they can get up and do what they like, other days as soon as you get out of bed you know you're knackered and you just want to go back to bed again, so that is *normal* for your condition and you'll find that when you mix with patients here or with us, the *things that you're experiencing are all the same things that everybody else is experiencing* [New patient].

Nurse: We have two thousand patients that come to this clinic so you're not in the minority [New patient].

In the following extracts, treatment for heart failure is described as both safe and routinely administered to patients:

If you get down [depressed], go back on [Beta Blockers] because it's one of the safest drugs and *we use it all the time*, we've got lots of patients on it. With heart failure you know you get very, very depressed anyway; a lot of it is because *patients get* frustrated because they can't do what they want to do [follow-up consultation].

If you're on water tablets *I always say to everyone* it can fluctuate up and down, a couple of pounds here, a couple of pounds there; as long as it drops back down and you're feeling well, that's fine [follow-up consultation].

An exercise class was an integral feature of the treatment regime offered to patients, supported by the National Institute for Clinical Excellence (2003) clinical guideline for heart failure. The nurses not only emphasized the positive health-related outcomes resulting from this intervention, but also stated that others had benefited in the past. Again, couching the advice in the context of other patients' experiences introduced a more human or personal dimension, encouraging new patients to take up the offer:

Now most people find it extremely beneficial...A lot of patients find they have a lot more exercise capacity afterwards...I mean most patients tolerate it no problem, what happens is it dilates your vessels so the blood can get through...Really, so many people use it. I think you'll be fine [New patient].

We run a rehab programme, an exercise programme run by a physiotherapist down in the gym, 'Claire', who is specifically employed to train our heart failure patients ok. *Most patients find it extremely beneficial*; it's for one hour a week for seven weeks. I don't know whether you'd be interested in that [New patient].

The nurses' emphasis on the largely positive collective experience of the entire group of patients may have made patients feel more comfortable about the treatment plan, but at the same time left little space for patients to explain what they wanted, either from the clinic or from their overall care. In particular, there was little opportunity to resist or even discuss the clinical recommendation.

#### Discussion

#### Study limitations

Qualitative research can uncover rich insights about human behaviour that are not normally available to survey researchers. However, such studies offer less scope for generalization in the statistical sense to other settings and populations. In this study, the interviews were limited to clinicians working in northern England, and we recognize that it is possible that their working practices may be different from those in other settings. Nevertheless, occupational roles in the NHS are highly interdependent, with doctors (particularly more junior staff) being relatively mobile, and specialist nurses forming part of wider support networks (Cherry & Sokolovs 2008). It would therefore be unusual for working practices in one mainstream clinic to be markedly different from those elsewhere. Further research could usefully investigate how the approach taken by specialist nurses varies across specialities and between different patient groups.

#### Specialist nurses' strategies

Our specialist nurses routinely adopted two highly structured core strategies with heart failure patients. They sought to 'personalize the protocol' by undertaking intensive efforts to educate patients about the recommended treatment and desirable lifestyle changes. They also sought to 'normalize' patients' condition and their experiences of it as typical or common. We found that both these strategies were employed instrumentally, with the aim of securing adherence to medication and to lifestyle advice, with the longer-term aim of reducing hospitalization and increasing life expectancy (National Institute for Clinical Excellence. 2003). We also found that specialist nurses cited this close support and extensive advice to substantiate a claim to practice 'patientcentred' care.

What are the implications of these findings? First, our nurses' claim to 'personalize' care was not wholly without foundation. They did indeed make considerable efforts to help patients make connections between their condition, their lifestyle, and their medication, adopting the 'intensive, systematic, tailored and planned education and support' approach that has been shown to improve patients' self-care behaviour (Jaarsma *et al.* 1999, p. 673); significantly reduce hospital admissions (McAlister *et al.* 2004); and increase compliance with treatment (Martje van der *et al.* 2005). Furthermore, the technique of 'normalization' that they employed has been shown to improve patients' ability to cope with their illness (Krause 2003). Nevertheless, this is somewhat different from the traditional model of holistic care. Nursing work has in the past been defined by a selfless concern with patient wellbeing and delivering holistic care, with 'care' valued for its own sake rather than as an instrument to produce health outcomes. Yet the kind of 'human' discourse implied by this was notably absent from our nurses' interactions with patients; they articulated a desire to provide personalized care, yet for the most part 'a personal approach' involved the offer of close supervision and the delivery of standard advice. It did not involve discussion of the patient's own agenda or personal definition of what 'successful treatment' might look like. Whilst evidence from randomized controlled trials demonstrates that the interventions offered to patients in the clinics can prolong life, reduce hospitalization and reduce symptoms (National Institute for Clinical Excellence, 2003), they can also lead to significant side effects (Lonn & McKelvie 2000). In our study, building a relationship with patients was a means to an end. The nurses' caring related to professionally desired outcomes of symptom control and avoidance of hospital admission, whilst the consequence seemed to be that patients were often deprived of the opportunity to negotiate treatment options.

Second, our nurses seemed to see no disjunction between evidence-based practice and personalized care. The model of care that they delivered was frequently equated with a 'patient-centred' approach (Tarrant et al. 2003). As a new occupation whose very function was defined (at least in our study sites) as 'implementing' treatment protocols, it is perhaps unsurprising that influencing patient behaviour was seen as the core task. The rhetorical force of appeals to 'evidence', and the institutional authority invested in clinical guidelines through bodies such as NICE, may have made it more difficult for healthcare professionals to engage in open negotiations with patients to facilitate choice, particularly nurses, who may have subscribed to the principle of protocoldriven care more readily than their physician colleagues (Gerrish & Clayton 2004, Plost & Nelson 2007). Our findings thus raise the question of whether substantive clinical practice (not just in nursing) is increasingly drifting away from traditionally espoused values of patient-centredness and patient autonomy.

Third, the 'patient-centred' discourse and 'evidence-based guideline' discourse as practised by the participants in our study are in tension with each other; the first privileges the individual and their wants whilst, unlike the original conception of 'EBM' as the means of integrating evidence with patient needs and preferences, the second privileges evidence about a population. The normative implications of this are problematic, as there are compelling arguments for

#### What is already known about this topic

- Specialist nurses have to balance their knowledge, which is increasingly dependent on the latest scientific evidence, with the traditional caring role.
- The recommended treatment for heart failure is known to improve patient survival, although quality of life may be compromised.
- The United Kingdom National Institute for Clinical Excellence has published a guideline for the recommended treatment to patients.

#### What this paper adds

- Specialist heart failure nurses implemented the National Institute for Clinical Excellence guideline for heart failure by using 'strategies' intended to maximize patient compliance with the treatment advice.
- Nurses 'personalized' the treatment protocol to patients and seldom engaged in discussions about their preferences, which we define here as 'outcomes-based caring work'.
- Nurses adhered to a 'standard', structured script in their discussions with patients, offering similar advice to every patient and thereby perhaps moving away from their traditional 'patient-centred' role.

#### Implications for practice and/or policy

- Definitions of what it means to offer 'holistic' care may shift as the environment in which specialist nurses work changes around them.
- Routine implementation of clinical guidelines by nurses may lead to the standardization of care where patient choice could be 'diluted'.
- There is a need both to re-examine the appropriateness of traditional caring tasks in the context of evidence about healthcare interventions, and to reflect on the need to incorporate patients' own values into the consultation process.

both discourses. Most patients may well share the objectives of such guidelines; in our case of heart failure, it seems unlikely that many patients would prefer poor symptom control or hospitalization. At the same time, however, they may have a wider conception of the relevant outcomes than the narrowly biomedical. For instance, some patients may prefer not to experience the side effects of medication, and may take at least immediate pleasure in elements of an unhealthy lifestyle. Moreover, it is not possible to deduce probabilities of individual patient outcomes from research into population probabilities (Byrne 2004), so that, strictly speaking, a clinician cannot logically tell a patient that adherence to medication and lifestyle advice offers the best personal prospects.

We do not suggest that patients were necessarily cajoled into accepting the recommended treatment against their wishes. The tensions between evidence-based practice and patient-centredness that we have identified above present a problem requiring a practical solution, which our nurses sought to resolve by working hard to translate the evidence-based guideline into a personally meaningful 'package' of care for their individual patients (Gabbay & Le May 2004). This strategy incorporated some elements of the traditional 'nursing as caring' discourse into the evidence-based elements of nursing care, but what was missing was any consideration of the patients' own values and treatment goals.

#### Conclusion

The devil of evidence-based nursing care is in the detail of translation between research and practice, and our findings suggest that the practical meaning of concepts of patientcentredness and holistic care may be in the process of shifting away from the traditional focus on individual patient needs and preferences towards a more instrumental concern with persuading patients to adhere to evidence-based care. The strong evidence-base underpinning the management of heart failure (stronger than that in many other specialities) implies that specialist nurses such as those studied here may be at the forefront of attempts to amalgamate evidence-based care with traditional holistic approaches. There is a need both to re-examine the appropriateness of traditional caring concepts in the context of the contemporary availability of evidence about healthcare interventions, and to reflect on how patients' own values can be incorporated into the consultation process.

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#### Conflict of interest

The authors declare no conflict of interest.

#### Author contributions

TS was responsible for the study conception and design. TS performed the data collection. TS, SH and KC performed the data analysis. TS, SH and KC were responsible for drafting of the manuscript. TS, SH and KC made critical revisions to the paper for important intellectual content. TS and SH obtained funding. TS provided administrative, technical or material support. TS and SH supervised the study. TS, SH and KC

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