

Insights into the impact of clinical encounters gained from personal accounts of living with advanced cancer

Joanne Reeve¹, Mari Lloyd-Williams², Sheila Payne³ and Christopher Dowrick⁴

¹Division of Primary Care, University of Liverpool (at time of the research); current appointment: NIHR School for Primary Care Research, University of Manchester, Manchester, UK

²Academic Palliative & Supportive Care Research Group, University of Liverpool, Liverpool, UK

³Institute for Health Research, University of Lancaster, Lancaster, UK

⁴Division of Primary Care, University of Liverpool, Liverpool, UK

Aim: To describe the impact of interactions with health care professionals revealed by people's accounts of living and dying with cancer; to explore reasons for the observed effects; and thus, to consider the implications for practice. **Background:** The importance of practitioner–patient interactions is enshrined within professional values. However, our understanding of how and why the consultation impacts on outcomes remains underdeveloped. Stories recounted by people living and dying with cancer offer important insights into illness experience, including the impact of contact with health services, framed within the context of the wider social setting in which people live their lives. From our recent study of distress in primary palliative care patients, we describe how people's accounts revealed both therapeutic and noxious effects of such encounters, and discuss reasons for the observed effects. **Method:** A qualitative study with a purposive sample of 19 primary palliative care patients: (8 men, 11 at high risk of depression). In-depth interviews were analysed using the iterative thematic analysis described by Lieblich. **Findings:** Living with cancer can be an exhausting process. Maintaining continuity of everyday life was the norm, and dependent on a dynamic process of balancing threats and supports to people's emotional well-being. Interactions with health care professionals were therapeutic when they provided emotional, or narrative, support. Threats arose when the patient's perception of the professional's account of their illness experience was at odds with the person's own sense of their core self and what was important to them. Our findings highlight the need for a framework in which clinicians may legitimately utilize different illness models to deliver a personalized, patient-centred assessment of need and care. The work provides testable hypotheses supporting development of understanding of therapeutic impact of the consultation.

Key words: doctor–patient interactions; illness narratives; palliative care

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Correspondence to: Dr Joanne Reeve, Post at time of work: Clinical Research Associate, Division of Primary Care, University of Liverpool. Current appointment: NIHR Clinical Lecturer in Primary Care, NIHR School for Primary Care Research, University of Manchester, Williamson Building, Oxford Road, Manchester M13 9PL, UK. Email: joanne.reeve@manchester.ac.uk

Introduction

For many years, models of good primary medical care have emphasized the importance of consultation skills and continuing relationships (Chew-Graham, May and Ronald, 2004; WONCA Europe,

2005). Effective communication skills support accurate identification of problems, increased patient satisfaction and concordance with treatment (Maguire and Pitceathly, 2002). But the consultation is more than a communication tool to aid therapy through the correct exchange of information. Patient-centeredness, the recognition of and response to patient perspectives within clinical encounters, improves satisfaction (Kearley, Freeman and Heath, 2001; McLean and Armstrong, 2004) and concordance (Britten *et al.*, 2000; Kearley, Freeman and Heath, 2001). The consultation, including the relationship between patient and practitioner, is itself part of the 'therapy' (Hippocrates, 1923; Balint, 1955; Di Blasi *et al.*, 2001).

Despite the emphasis placed on the consultation within professional values, the evidence-base underpinning its use remains underdeveloped. Models of doctor-patient communication as a set of skills and behaviours which can be objectively observed (Saba *et al.*, 2006) and hence taught and learned (Salmon and Young, 2005), have guided development of training programmes. Yet, Saba *et al.* (2006) warned that whilst communication can 'look good' if assessed by whether doctors utilize these skills, it may still not 'feel good' for either patient or doctor. A purely skills-focused model for understanding and teaching consultation skills may be inadequate to support good clinical care (Burkitt Wright, Holcombe and Salmon, 2004; Salmon and Young, 2005; Saba *et al.*, 2006). Patient-centeredness, although valued, is not evident in many everyday consultations (Freeman, Car and Hill, 2004). The specific impact of 'therapeutic relationships' on patient outcomes is still not known (Di Blasi *et al.*, 2001). The evidence-gap perhaps arises since these core values and attitudes within clinical disciplines are often the hardest to define in a way which can be measured (Howie *et al.*, 2000).

Much research into health care interactions focuses on studying processes within the consultation itself. However, a consultation is a particular social interaction which occurs within the wider context of people's lives; health services form part of the cultural context in which people experience illness (Pierret, 2003). We increasingly recognize the importance of learning about illness by listening to the stories of people who are experiencing it (Greenhalgh and Hurwitz, 1998; Launer, 2002; Bingley *et al.*, 2008; Thomas *et al.*,

2008). These accounts have the potential to offer insights into the nature and impact of interactions with health care providers and settings.

We recently completed a study looking at the disruptive impact of illness and associated distress through an analysis of the accounts told by people with terminal cancer. A key finding was that most people were able to successfully continue to live their everyday lives despite the significant threats posed by their cancer and other life events. The processes underpinning this self-management (Foster *et al.*, 2007) of illness in the context of everyday life are summarized within the Self-Integrity Model (SIM), illustrated in Figure 1 (Reeve *et al.*, 2009a). Continuity of daily life (biographical flow in Figure 1) was dependent on managing the impacts of potentially disruptive life events, including terminal illness, on the 'core-self' – defined as that which mattered most to people. Threats caused distress; including depressed mood, anxiety, frustration and tiredness. Maintaining continuity depended on mobilizing sufficient resources to balance the threats and resulting distress. These included narrative support (creating and finding meaning in events) and emotional support (actions and circumstances which brought comfort). Occasionally, supports were overwhelmed; physical, mental and emotional exhaustion resulted in biographical fracture associated with major depression (Figure 1).

Although not a primary focus of the study, people's accounts of living and dying with cancer commonly included references to encounters with health care professionals, especially doctors. These accounts offer valuable insights into the impact of interactions with professionals as viewed from the context of people's everyday lives, rather than focusing on what occurs within the consultation itself. The aim of this paper is, therefore, to describe the impact of interactions as told by participants in this study, and to explore the reasons for the observed effects.

Methods

Our sample consisted of 19 adult patients with terminal cancer living in Merseyside, UK, all of whom were aware of their diagnosis. Purposive sampling (Silverman, 2000) selected patients from primary care practices, considering age, sex, disease

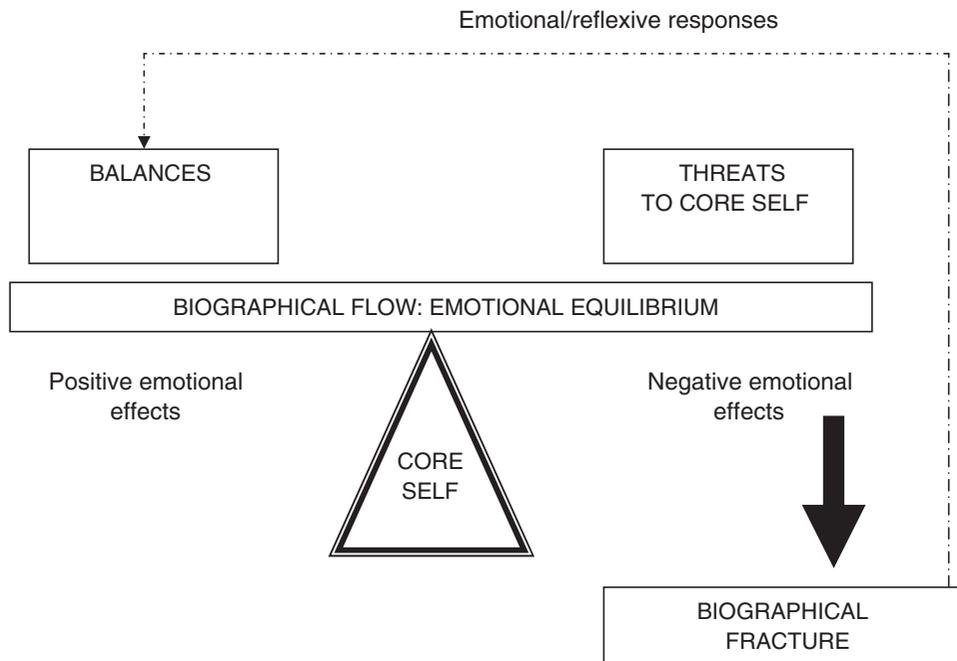


Figure 1 The Self-Integrity Model

type, socioeconomic group and risk status on the Edinburgh Depression Scale (EDS) (Lloyd-Williams, Friedman and Rudd, 2000). Table 1 summarises the participants.

Data collection was by semi-structured interview, exploring people's experiences before and since cancer diagnosis. Most participants focused on the time since their terminal diagnosis, thereby describing events that had happened in the previous weeks and months. The interview schedule asked people how they were feeling and how that had changed over time, prompting people to reflect on things that made them feel worse or better. There were no specific questions about interactions with health professionals but, where appropriate, people were prompted to reflect on how well others, including medical staff, understood the way they were feeling. All interviews took place in individuals' own homes, lasting 30–150 min. All were conducted by JR, who was introduced to participants via the study information leaflet to a local general practitioner (GP) interested in understanding people's experiences and feelings associated with their cancer. Interviews were recorded and subsequently transcribed

verbatim. In two cases, the recording equipment failed; fieldnotes covering issues from the non-recorded conversations were made within one hour of the end of the interview.

All authors contributed to the initial analysis and coding: to confirm that common areas of text were being identified as important, and to discuss the interpretation of emerging ideas. JR led the detailed analysis of subsequent transcripts, preparing analysis reports, which were discussed regularly amongst all the authors to check internal consistency and confirmability, and external relevance to existing literature.

We adopted Marton's (1986) phenomenographic approach, which seeks to understand why people experience phenomena differently; adapted to include the holistic-form and holistic-content analytical methods described by Lieblich, Tuval-Maschiach and Zilber (1998). Holistic-form analysis considers the overall structure of illness narrative, and was used to categorize accounts into those with a continuous narrative thread (biographical flow, see Figure 1) and those with evidence of significant disruption (biographical fracture) (Reeve *et al.*, 2009b). Holistic-content

Table 1 Showing participant characteristics

Reference ^a	Age range (years)	Sex	Tumour ^b	EDS ^c score	Lives alone	Attends hospice
Albert	80s	M	Resp	6	N	N
Ron	60s	M	Haemat	10	N	N
Helen	60s	F	GIT	16*	Y	N
Nora	60s	F	Resp	16*	Y	N
Marjorie	60s	F	Resp	20*	N	Y
Jenny	70s	F	Resp	17*	N	Y
Mary [§]	60s	F	Resp	18*	Y	N
Linda	50s	F	Breast	17*	N	N
Peter	60s	M	Urol	12	Y	N
Jim	80s	M	GIT	12	Y	N
Pat	60s	F	Resp	12	N	N
Bob	40s	M	Resp	5	N	N
Ruth	70s	F	GIT	7	Y	N
Stuart	40s	M	Soft tissue	**	N	Y
Joyce	80s	F	Breast	**	N	Y
John	60s	M	Urol	**	N	Y
Angela	40s	F	Gynae	6	N	N
Mark	40s	M	Resp	16*	N	Y
Joan	50s	F	Breast	**	N	Y

^a Names given are pseudonyms.

^b GIT = gastrointestinal tract; Resp = respiratory; Urol = urological; Haemat = haematological.

^c EDS = Edinburgh Depression Scale.

* = high risk scores; **selected as high risk/expressing distress by MLW.

[§] had confirmed ICD depression at time of interview.

M = male, F = female; N = no, Y = yes.

analysis identifies and explains differences between categorical groups using an iterative, thematic focus on narrative content within each category. Initial coding was supported by the use of NVIVO version 11; codes and quotes were then imported into Excel spreadsheets, allowing comparisons within and between biographical categories. As key themes emerged from the data (see Box 1), summary accounts were constructed for each participant describing the identified content for each sub-theme. Analysis of these accounts revealed encounters with health professionals as examples of both threats and balances. It is these encounters that we report in this paper. Further details of the analysis are available in Reeve (2006), and from the authors.

The processes of sampling, data collection and analysis continued until the emerging analysis demonstrated coherence: that the analytical model was adequate to explain the full range of the data set identified, within the constraints of the research question and theoretical perspectives (Radnitsky, 1968; Kvale, 1996). We used Maxwell's (2002) criteria for quality of knowledge production to assess the trustworthiness of our

Box 1 Key themes arising from the iterative analysis

Theme	Sub themes
Core self	Being & doing Competence Family
Threats	Threats to: Physical integrity Personal integrity Integrity of worldview
Result of threats	Emotional response Reflective response
Balances	Emotional Reflective

analysis; including three criteria of methodological rigour (descriptive validity, interpretive validity and theoretical validity) and two of utility (generalizability and evaluative validity).

The case studies and quotations offered in this account have been selected as the best means to illustrate the stated themes within the constraint of a publication. They are representative of concepts reflected across the complete data set.

Ethical approval was granted by the Liverpool Research Ethics Committee.

Results

Although all participants were receiving ongoing health care, descriptions of encounters with health care professionals – mainly doctors – formed only a small part of the data set gathered. People's experiences and efforts in living with advanced illness predominantly focused on aspects of their lives outside of their health care. However, there were several examples of both positive and negative impacts of these encounters on people's stories. We describe these effects before discussing the possible reasons for them, drawing on the SIM described in Figure 1.

Therapeutic interactions: narrative and empathy

Relationships were identified as a significant source of support, providing opportunities for people to talk and reflect, as well as emotional comfort.

Illness and dying posed significant threats to people's sense of who they were, and the nature of the world around them. Existential reflections on questions such as '*why me?*' (Helen), or '*why not someone else,*' were common.

Jim: Well the only simple way I can describe [it is] to say, I look at somebody that I know is not of the best, and I say, well, why did it have to happen to me?

Many sought meaning based on their pre-existing assumptions and values and their faith; occasionally doctors provided an alternative account or narrative support (Box 2).

Accounts revealed the importance of these being 'shared narratives': a shared experience with health care professionals that went beyond a narrative (cognitive) construction of events to include a non-cognitive (emotional) form of support. People described the emotional support

Box 2 Explanation and meaning identified within interactions with health professionals

Jenny: 'I'll tell you what does worry me. I went to the doctors. It sounds funny. And I said, "I think I'm getting Alzheimer's. Because my concentration's not the same. And I'll go into a room for something... and forget what I've gone in for... And she said, "No It's stress. Don't you realize you're under an awful lot of stress?" JR: 'How did you feel when she said it was stress?' Jenny: 'I felt better!'

Mark: 'The counsellor told [me I was depressed. She] turned round and said, "You've been referred to me because apparently you've been depressed."' JR: 'Did you agree? Did you think you were depressed?' Mark: 'Yes. I thought. I knew I wasn't right. I thought it's not right this... I was talking to my Doctor and he told me about the counsellor. And I thought – yeah, I see where you're coming from.' JR: 'And how did you feel when [the counsellor] suggested that maybe you were depressed?' Mark: '...How did I feel? I felt depressed! [laugh] No I felt elated! Not elated – that's wrong. I felt a bit happier – it was depression and it was getting sorted. Does that sound Irish?'

from contact with health care professionals in terms of being made to feel cared for, or special, gaining a sense of warmth or trust (Box 3).

Non-therapeutic (noxious) interactions: incongruent accounts

Other interactions were less supportive, the effect being more than simply dissatisfaction with a 'sub-optimal' service, but revealing a noxious impact on people's efforts to maintain biographical flow.

Peter was a 62-year-old man with metastatic prostate cancer, who lived alone and whose entire interview-narrative was underpinned by his account of being a fell-walker. Although no longer able to partake in the sport, his sense of 'being' a fell-walker, and of having that recognized, was a crucial

Box 3 Emotional support from doctor-patient interactions

Mary: 'It does help to talk about it with somebody like you [to JR]. I'm a firm believer in talking to your doctors and counsellors... Because it, you feel so alone, with cancer.'

Helen: 'It's very important to know that someone that's in there is interested in me... And [my surgeon] – he's absolutely wonderful that man. He's brilliant. When he sees you, his face lights up. And he goes, "I can't get over you. You look so well. You look wonderful."' "

Jenny: 'There's just something about [the hospice] that makes you feel great... They've got a nice attitude... [They're] so caring... You don't want sympathy, you want a bit of understanding. Sympathy makes you more upset and cry. But a little bit of understanding goes a long way.'

Jim: 'I must say it's quite a relaxed clinic with Dr X. There seem to be two nurse practitioners... and they have established shall I say a sort of personal contact with you. And they're both experienced young ladies and they really do take care of you. It makes a world of difference, makes a world of difference.'

Ruth: 'In the [chest hospital] I didn't find that you got any different treatment because you had cancer... You were just another body there. There wasn't that warmth there. But in [the oncology hospital] oh, the care is wonderful. The attitude of people towards you. Not sympathy or namby-pamby treatment. But just so nice. You feel like a VIP actually... And you were just so special to them. You felt you were the only one there that had cancer.'

aspect of his sense of who he was. Peter described a conversation, which took place with his oncologist where he had described his delight at his improved mobility following the start of his Zomitor injections.

Peter: I mentioned to [my doctor] that I had walked down to [place]. 'Yes I know you

were a fit man,' he said, 'but unfortunately what you have likes bones.' Do you know Dr X? He was cold... He didn't seem concerned about what I want to do or what I had done. He just [gestures] out of the way, that's gone.

Peter was clearly distressed by his doctor's response; distress, which persisted until he died. There was no indication of an unrealistic perception that Peter thought he might fell-run again; only a desire to be recognized as a fell-runner and have others value his achievement. His physician's focus was only on the physical impact of the disease. It is this incongruence in perspective that was revealed as the cause for Peter's distress.

Another participant, Joyce, spoke of the delay in diagnosing her with spinal cord compression from metastatic disease. However, she was not concerned with the threat to her physical health from the delayed diagnosis. Instead, she described her dismay at her doctor's failure to acknowledge her as a competent and active woman, by acknowledging that her symptoms were significant because they were unusual *for her*.

Joyce: I saw three doctors four times. And by the last time I saw them, I could hardly walk... My own doctor let me down terribly I think. When he knows I was a fit woman... I walked in on [my husband's arm] and a stick. Surely to God he could have seen there was something radically wrong there. When I went in I didn't sit down, I fell down... But it rankles with me terribly. It hurts me terribly.

Other examples of threats were perhaps less stark, but nonetheless evident. Ruth visited her GP shortly after she had been told she had metastatic disease. She felt she was managing well, but was surprised when her GP offered her antidepressants. She describes a sense of anxiety from her perception of a mismatch in assessed need.

Ruth: Yes, [my GP] really was keen on the antidepressants. Maybe he'd had experience with people with cancer who had gone really down in the dumps and he was doing his best to sort of bring them back up to a bit of happiness...JR: Were you surprised when he asked you [whether you needed antidepressants]? Ruth: Yes, I was actually. Because I didn't think I looked depressed. I may have

looked worried though, possibly. Because often people say to me, 'It may never happen.' You know. But that's my normal look. And maybe that's how I looked to him. I don't know. But I was surprised at the depression and I came home a few times from there thinking, 'I'm not depressed.' And I was telling myself, you know I must look really miserable when I go. And I always made sure then that I smiled when I went in! [laughs] I always, as soon as I saw him I'd give him a big smile!

Although more surprised than distressed by her doctors' response, the disruptive effect is evident in Ruth's ongoing reflections on the interaction, suggesting a continuing need for reassurance that it was her doctor, and not herself, who had misinterpreted the situation.

Mary did not describe a problematic consultation with her doctor. Her experiences instead revealed a potential threat, which might arise from the mismatch between a biomedical and personal assessment of experience and need. Mary was the only participant who met ICD-10 criteria for depression (World Health Organization, 1992) on the day of her interview, as assessed using the revised Clinical Interview Schedule (Lewis *et al.*, 1992) immediately afterwards. Yet she described herself as a strong woman who had successfully dealt with a lifetime of difficult situations. Whilst she was managing to cope with her illness (lung cancer), she described it as a difficult and draining process. When asked how she dealt with the way she was feeling, she replied:

Mary: I accept [the way I feel] and I try to find an answer for myself. And deal with it... I ask myself questions and if the answer is not what I'm looking for then it just brings on a little bit of depression doesn't it?.. It's not depression. It's a quiet mode of deep thinking.

In contrast to the biomedical perspective, Mary viewed depression as part of 'coping,' and therefore an integral part of her core-self.

Discussion

Current research and clinical guidelines are concerned with the reported under detection and

treatment of depression in the terminally ill; resulting in a call for proactive screening and pharmacological intervention (Wilson *et al.*, 2000; Stiefel *et al.*, 2001; Potash and Breitbart, 2002). Guidance would highlight the need for Mary to be informed of her diagnosis and recommended treatment. Yet, we know that Ruth described being both surprised and slightly anxious when offered an unexpected diagnosis of depression. We can speculate as to what the impact might have been on Mary had someone told her she was suffering from a disease, depression. Such a diagnosis would have been incongruent with her more productive (Gut, 1989) account of her depression, which supported her sense of herself (her core-self) as a strong and competent woman. A pathological diagnosis could have threatened this sense of self, leading to noxious, rather than the intended therapeutic, effects. We know that Peter experienced significant distress when his doctor's disease-focused account conflicted with Peter's own sense of who he was and what was important to him. Our analysis raises concerns about the potential for a similarly negative impact on Mary.

The SIM offers a framework by which the observed effects of interactions with doctors may be explained in terms of their impact on the person's core-self (what matters most to them) and their efforts to continue to live their life, maintaining biographical flow. We have described examples of both positive and negative impacts arising from interactions with doctors. Therapeutic effects came from narrative support: offering explanations, opportunities to talk (Leventhal, Nerenz and Steele, 1984), and perhaps supporting the maintenance or restoration of narrative as described by Greenhalgh and Hurwitz (1998), Mattingley (1998), Launer (2002) and others. But participants also described the value of emotional support through empathy, reassurance and warmth. This emphasis on emotional experiences of illness, rather than just a narrative account of finding meaning, resonates with models of clinical practice which emphasize the importance of the relationship between patient and practitioner (Orlinsky, Grawe and Parks, 1994; Mercer and Reynolds, 2002; Burkitt Wright, Holcombe and Salmon, 2004). Both cognitive/narrative, and emotional aspects of care are valued by patients (Di Blasi *et al.*, 2001).

Noxious effects were observed, arising when there was incongruence between the patient's perception of the professional's account of illness and their own internal sense of themselves. May *et al.* (2004) have previously highlighted concerns about incongruence between doctors' and patients' accounts of sickness, arguing that future development of successful models of primary care communication and practice must tackle the differences in biomedical and lay approaches to understanding illness experience. Our findings suggest the need to look not only at differences in conceptual understanding of the illness itself, but to look more widely at how professional accounts support or undermine an individual's sense of themselves and the world, and hence their efforts to continue living their everyday lives, maintaining biographical flow.

Harrison, Moran and Wood (2002) have argued that current models of quality in clinical practice emphasize the use of objective, externally validated accounts of disease. This so-called scientific-bureaucratic model of medical care promotes the use of rigorously developed diagnostic tools, and guidelines or protocols of care in order to deliver the best quality of care to patients. Models of quality of care value scientific knowledge above other accounts given its origins in a scientific epistemology (Seale and Pattison, 1994). The model of doctor-patient interaction promoted by this approach mirrors that of the 'mining' metaphor seen in qualitative research methodology (Kvale, 1996). The doctor's task is regarded as being to interpret the patient's story to reveal the presence or absence of objective disease, and thus instigate protocols of care.

Yet illness is recognized to be more than the presence or absence of disease. Other models of care exist, including that of narrative medicine (Greenhalgh and Hurwitz, 1998; Mattingley, 1998; Launer, 2002) and the patient-centred, biopsychosocial model of clinical practice (Borrell-Carrio, Suchman and Epstein, 2004). Whilst valued within the profession, at least at a rhetorical level (Dowrick *et al.*, 1996; Checkland *et al.*, 2008), these alternative accounts are not reflected in current measures of quality of practice. Indeed, there is evidence that the emphasis on scientific-bureaucratic medicine is moving practice further towards a disease-centred, rather than a person-centred, focus of care (Checkland *et al.*, 2008).

Our study provides evidence raising concerns that failure to adequately acknowledge the individual within the interaction, that is the consultation, could result not just in 'consumer dissatisfaction,' but in a harmful effect resulting from the threat to an individual's core sense of what matters to them. It highlights the importance of viewing the consultation as more than a technical process of identifying a 'true' diagnosis, but a social interaction with potential consequences for the individual beyond the identification and selection of an evidence-based intervention.

Study limitations

Although our study met Maxwell's (2002) quality criteria for methodological rigour (Reeve, 2006), this was a small study using a deliberately select sample. Generalizability of our findings, therefore, stems from our contribution to development of theory (Doucet and Mauthner, 2002). Yet, it could be questioned whether we have offered anything new over and above, for example, the importance of personal meaning described in the narrative medicine literature (Greenhalgh and Hurwitz, 1998; Mattingley, 1998; Launer, 2002). We suggest that our findings also emphasize the emotional effects of interactions and the need to understand their impact on an embodied, emotional self (Williams and Bendelow, 1996). In addition, whilst the narrative literature focuses on the consultation itself, our work highlights the need to understand the consultation as one element in a broader social setting.

Given the interest in doctor-patient interactions, the impact of using a GP interviewer on what and how experience was reported must be considered. Yet people spontaneously revealed examples of both positive and negative interactions, with no evidence of inhibition in doing so. Some participants did not appear to consciously acknowledge JR as a GP. Indeed, although Mary initially described finding it easier to talk to JR because she was a doctor, she subsequently referred to JR as '*sweetheart*,' described speaking to her '*woman to woman*,' and described speaking to her '*not as a doctor now, but as a friend*.'

Perhaps the most significant limitation comes in knowing whether the findings can contribute to meaningful change in practice. We need further empirical testing of the ideas emerging from this

study to establish their validity, and especially utility, in the care of patients.

Future research

The emotional and narrative impacts of the consultation, including the impact of conceptual models of illness, may have important effects on outcomes. The SIM may offer a theoretical framework within which to explain, and further develop understanding of, the therapeutic and non-therapeutic nature of doctor–patient interactions. We propose that the consultation be viewed as a complex-intervention (Campbell *et al.*, 2007), and that future research focus on the nature and impact of this ‘therapeutic tool’ in supporting living with illness, including biographical flow and self-management (Foster *et al.*, 2007) of daily life.

Our findings highlight the importance of the practitioner–patient encounter as an important area for future research within palliative and supportive care. Research questions arising include whether congruence between doctor and patients’ conceptual models promotes therapeutic interactions; this could be tested by detailed qualitative studies of consultations utilizing the tape-assisted recall approach (Elliott and Shapiro, 1988). Educational approaches using reflective learning (Al Sheri, 1995) could be used to assess clinicians’ conceptual models for understanding patient illness experience and their impact on consultations, and hence the self-management of illness experience as part of on-going daily life.

Our findings suggest the need for a framework in which clinicians may legitimately utilize different illness models to deliver a personalized, patient-centred assessment of need and care. Whilst further exploratory work would strengthen the ideas presented in this paper, we propose this should focus on developing models of care which support both patient and practitioner in the process of co-constructing an individualized account of illness: one that supports, but certainly doesn’t undermine, individuals’ on-going efforts to live their lives.

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