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Notes on the End of Life: The social interactions between patients, carers and professionals

Abstract

How people die and experience the road to death is important for all concerned - the patient who is dying, the family carers (carers hereafter) and loved ones they leave behind, and the health and social care practitioners. However, family carers often make great emotional and financial sacrifices and also assume heavy administrative roles to support the care of their loved one. The paper reports on the social interactions between patient, carers and professionals during End of Life (EOL) care. The findings are based on a PCT-funded consultation which examined the quality of EOL care services in one London borough. The project made use of ethnographic methods (open-ended qualitative interviews and observations) with 50 Borough residents of which 32 were patients and 18 were carers. The findings will consider in more detail the social relationships between patients, carers and professionals. It is suggested that while there are some encouraging signs of good practice among EOL agencies and professionals, greater care is needed on the part of frontline professionals in their day-to-day interaction with patients and carers to ensure a better quality of EOL care.

Key words

End of life care, patient, family carer, health professional, social interactions.

Introduction

The experience of dying and death has changed considerably over the last century (Age Concern, 2005). People now reach older ages and the growing population of older people in England are also increasingly diverse in their cultural, religious and individual beliefs (DoH, 2008). In addition, the majority of deaths for all age groups now happen in hospitals meaning that many people have little direct experience of the dying and death of relatives and friends (DoH, 2008; Han and Arnold, 2001; Help the Hospices, 2008; Higginson *et al*, 2003). In addition, the causes of death have changed stemming from the fact that older people can suffer from a number of conditions at the same time. This makes it difficult to determine the main causes of their death because:

- They are most commonly affected by multiple medical problems;
- The cumulative effect of these may be greater than any individual disease;

- They are at greater risk of adverse drug reactions and of iatrogenic illness;
- Minor problems may have a greater cumulative psychological impact;
- Problems of acute illness may be superimposed on physical or mental impairment, economic hardship and social isolation (WHO, 2004).

They may have chronic illnesses such as heart disease, cerebrovascular disease (including stroke), respiratory disease and cancer which makes it more complicated to support their needs and this has now become a difficult task for primary care providers (Auer, 2008). This is why family carers (Carers hereafter) play such an integral role in End of Life (EOL) care (Yoo *et al*, 2008). Indeed, recent research has indicated that during EOL care, carers' quality of life and satisfaction with patient care are integral to the ultimate success of the patient-carer/professional relationship (Fleming *et al*, 2006). Therefore, how people die and experience the road to death is important for all concerned - the patient who is dying, the family carers and loved ones they leave behind, and the health and social care practitioners (Henry and Fenner, 2007).

However, studies have found that carers often become over-burdened (Hudson *et al*, 2004; Pasacrete *et al*, 2000) which places them at risk of physical and mental health problems (Schultz *et al*, 1990; Steel and Fitch, 1996). This is because Carers must not only address the needs of their loved ones but also deal with their own physical, psychological, and financial needs, which are often substantial and unmet (DoH, 2008; Payne *et al*, 1999; Yoo *et al*, 2008). Therefore, the family's involvement in EOL care is important and has ramifications for the quality of care of the patient (Ha, 2004; Verhaeghe *et al*, 2005). This has recently been acknowledged in the EOL care strategy (DoH, 2008) which recommended a care pathway approach both for commissioning services and delivery of integrated care. The care pathway points to the support for Carers, both during a person's illness and after their death. This indicated that patients and Carers could expect:

- The opportunity to discuss personal needs and preferences with professionals;
- Coordinated care and support, ensuring that needs are met, irrespective of who is delivering the service;
- Rapid specialist advice and clinical assessment regardless of location;
- High quality care and support during the last days of life;

- To be treated with dignity and respect both before and after death;
- Receive appropriate advice and support for carers at every stage (DoH, 2008: 17-18).

Yet it has been suggested that despite these 'overdue' legislative changes (Bailey, 2008), people still suffer unnecessarily at the end of their lives. Carers and the bereaved still lack the support they need to manage the death of a loved one; and accessing services remains a lottery, dependant on both diagnosis and postcode (Help the Hospices, 2008). This paper therefore serves to contextualise some of the current experiences of EOL care service provision in one London borough ('Borough' hereafter). Based on ethnographic methods with patients and Carers, the paper will focus on the tense and emotional social relations between patient, carer and professional. This is particularly important given that researchers have tended to focus more on EOL patients, with only a few consulting family members and surveying their experiences (Verhaeghe *et al*, 2005).

Rationale and aims

The data for this paper originate from the findings of a NHS Primary Care Trust (PCT)-funded consultation in Borough. The patient and Carer consultation was commissioned to enable Borough's PCT to gain an understanding of the experiences and expectations of patients diagnosed with life-limiting diseases during the last year of life, and their Carers. Locally, the patient choice agenda was found to be a key motivating factor in service development to enable choice of type and place of care at the end of life. In addition, previous local research had indicated that much of the focus had been on the specialist care of cancer patients with less attention to patients with non-malignant diseases at the end of life, and those in generalist care. The outcomes of the consultation were used to help identify key priorities for the future development and commissioning of enhanced EOL services within Borough's PCT. The consultation took place from January to April 2009.

Methodology

The project made use of ethnographic methods (open-ended qualitative interviews and observations) with 50 Borough residents: 30 were patients and 20 were carers. The interviews examined the patient/Carer's knowledge of services, experiences of each service with which they had contact, the efficiency of those services and suggestions for improvements. Observations were also made of patient/Carer/professional interactions in some patients' home settings. These observations served to contextualize the 'EOL care experience' as, on most research

visits, participants often had professionals and home carers visit. Most interviews took place in patients and Carers' homes, however, some felt more comfortable speaking on the phone.

To qualify for inclusion in the study, participants needed to be Borough registered patients or Carers aged 16 years and over. Patients were being treated at various hospitals, hospices or were receiving treatment in their homes. Typically, they were accessing various forms of social support such as district nurses, palliative care, GPs, and help through various local charities. Open-ended interviews were also undertaken with 16 key professionals. These included palliative care nurses, charity managers, social workers, GPs, EOL consultants, carer support services, strategic commissioners, care home managers, and funeral directors. Interview questions revolved around the efficiency of current practice and gaps in service provision. Interviews lasted between 30 minutes to an hour and a half. Interviews were transcribed verbatim for inductive analysis, so data were categorised thematically, with the key areas of investigation providing the overall framework for coding (Ritchie and Spencer, 2004).

The sample of patients and carers

Of the 50 patients and Carers, 18 were men and 32 were women. Patients were aged between 40 and 90. Carers tended to be younger family members or partners. A high proportion of the sample were white British (n=35); five were black African; four were Asian; two were Irish; two were mixed race; one was white European; and one was white American. Thirteen of the 32 patients suffered from non-cancerous conditions such as Chronic Obstructive Pulmonary Disease (COPD), heart failure, Parkinson's, dementia, strokes, heart disease and HIV and 19 suffered from cancerous conditions (see Figure 1 for demographic data).

Figure 1 – Demographic data of interview sample

	Patient or carer	Gender	Age	Ethnic origin	Cancer/non-cancer	Profession/past profession
1	Patient	Female	57	Black African	Non-cancer	Unemployed
2	Patient	Female	73	White British	Cancer	Office cleric
3	Patient	Female	58	White British	Cancer	Nurse
4	Patient	Male	62	White British	Cancer	Unknown
5	Patient	Female	73	White British	Non-cancer	Unknown
6	Patient	Female	86	White British	Cancer	Nurse
7	Carer	Male	42	White British	N/A	Unknown
8	Carer	Female	76	White British	N/A	Nurse

9	Carer	Female	34	Mixed Race	N/A	Advocate worker
10	Carer	Female	51	White American	N/A	Publisher
11	Carer	Female	54	White British	N/A	Clerical staff
12	Patient	Female	88	White British	Non-cancer	RAF
13	Patient	Female	83	White British	Non-cancer	Housewife
14	Patient	Female	90	White British	Non-cancer	Housewife
15	Patient	Male	64	White British	Cancer	Unknown
16	Carer	Male	40	White British	N/A	Social services carer
17	Patient	Male	62	White British	Cancer	Psychologist
18	Carer	Female	38	White British	N/A	Carer support worker
19	Patient	Male	84	White British	Cancer	Unknown
20	Patient	Female	43	Mixed Race	Cancer	Nursery Nurse
21	Patient	Female	83	Asian	Non-cancer	Unemployed
22	Carer	Female	17	Asian	N/A	Student
23	Patient	Male	81	White British	Cancer	Unknown
24	Patient	Female	64	White British	Cancer	PA
25	Patient	Male	82	White British	Cancer	Electrician
26	Carer	Male	34	Asian	N/A	Unemployed
27	Carer	Female	33	Asian	N/A	Unemployed
28	Patient	Male	89	Black African	Non-cancer	Telephone engineer
29	Carer	Female	45	Black African	N/A	Housewife
30	Patient	Male	68	White British	Cancer	Electrician
31	Carer	Female	40	White British	N/A	Social services carer
32	Patient	Female	45	White British	Cancer	Unknown
33	Carer	Male	81	White British	N/A	Unknown
34	Patient	Male	61	White British	Non-cancer	Builder
35	Carer	Male	34	White British	N/A	Labourer
36	Patient	Male	82	White Irish	Cancer	Unknown
37	Carer	Male	45	White Irish	N/A	Labourer
38	Patient	Female	71	White British	Non-cancer	Receptionist
39	Patient	Female	82	White British	Cancer	Housewife
40	Carer	Female	65	White British	N/A	Writer
41	Carer	Female	79	White British	N/A	Hairdresser
42	Carer	Female	62	White European	N/A	Housewife
43	Patient	Female	66	White British	Both	Housewife
44	Carer	Female	84	White British	N/A	Illustrator
45	Carer	Female	45	White British	N/A	Therapist
46	Patient	Female	41	White British	Cancer	Unemployed
47	Patient	Male	40	Black African	Non-cancer	Factory worker
48	Patient	Female	39	Black African	Non-cancer	Student
49	Patient	Female	57	White British	Cancer	Unknown
50	Patient	Male	61	White British	Non-cancer	Editor

The sample was not representative as findings were to 'thematically' encompass experiences of EOL services in Borough.

Access

The PCT offered access to patients and Carers through existing patient/carer groups within Borough; palliative care nurses in local hospitals; Carer support services for patients; and local charities. Patients and Carers were firstly approached through service professionals and asked if they would consent to participate. If they agreed, their contact details were then passed to the researcher. The researcher made an

effort to call within a few days and agree a convenient time and place for the interview. Some patients, having consented to participate, did not feel well enough in the days following consent. A careful balance was therefore made so as to avoid pressuring them to participate. Courtesy phone calls were made several days later to learn of their progress.

Limitations of the consultation

There were a number of limitations to the EOL consultation. They included the following:

- Commissioning the consultation close to Christmas and New Year meant that many agencies did not have the opportunity to promote the consultation. In addition, some agencies advised against approaching patients during this time of year;
- Despite some persistence, some agencies were difficult to contact and a number failed to return calls or emails. A few agencies/departments indicated that the project raised potential practical problems vis-à-vis the timeframe of the consultation and so declined to take part;
- A few patients, having consented to participate, died just before the interview;
- In some interviews, some patients or carers were reluctant to answer some questions. Therefore the transcripts did not represent all the required data as patients and Carers emotions and feelings needed to be considered;
- Equally, some patients and carers, having been in contact with a number of different workers from a number of different agencies were confused about 'who' they were seeing and therefore could not able to accurately feedback about individual agencies or departments. Some attempts, however, were made in interviews to disaggregate these areas;
- Some patients and Carers had relatively little experience of some services while others had extensive experience of a wide range of services. Consequently, there were some areas of service provision on which patients and carers made little reflection.

Ethics

The consultation and its proposed methods were validated through Borough's Community Research Ethics Committee which considered the consultation to be audit/evaluation and not requiring formal ethical approval. Nonetheless the research was informed ethically by the British Sociological Association (BSA)

(<http://www.britsoc.co.uk/>) guidelines which state that researchers are obliged to protect their participants from physical and mental harm or discomfort during psychological research. A consent form was devised to the satisfaction of Borough's PCT which all participants signed. Information obtained from research participants was confidential and was not disclosed to a third party. Participants were informed of the study's aims and how they would contribute to the research. All respondents were guaranteed anonymity.

The author was experienced in undertaking interviews under difficult and emotional circumstances having carried out ethnographic research in prisons, crack houses, drug services, with gangs and mentally ill adults in the community. In this way, the author's extensive experience of interviewing and observing different social groups in different and difficult contexts was of use. A sensitive and careful balance was taken when presenting the research to participants and when interviewing participants. Both before and after the interview, the respective case worker or palliative care nurse were contacted. These professionals often followed up with patients and Carers to ensure participants had not been disturbed. Efforts were made to be as unobtrusive as possible for participants and in clinicians' daily duties and operations.

Validation of the findings

Throughout the project, regular contact was made with participants and empathy was displayed in an effort to reassure potential interviewees of the consultation's aims. Participants were given the opportunity to engage in further conversations/interviews to ensure the data gathered were accurate, help shape the findings of the consultation and to comment on the draft final report or executive summary (if they could not manage to read the lengthy report). Three carers and five patients, having come to 'learn' about the system in some detail, offered help with reviewing the consultation report. A draft final report was also circulated to three professionals for their views and comments.

Findings

Findings are presented here in three parts. The first contextual section looks at patients' and carers' views of EOL services. This shows both the strong areas and the shortfalls of current service provision and, specifically, how macro processes of service delivery affected patient and carers' emotions and feelings. The second section considers how emotions and social relations develop between patients and Carers and professionals. This is important because these are linked to how patients

and carers start to experience various services and how they react to various events throughout the process of qualifying for and organising care. The third and final section considers in more detail the resulting social relationships between patients, carers and professionals not only as a result of their experiences of those services but also as a consequence of the emotional suffering which they endure throughout the process. These feelings and interactions are particularly difficult to separate when dealing with professionals.

Context: Patients' and carers' views on Borough EOL care services

In general, high praise was given to most EOL care services in Borough. Palliative care teams were given positive feedback for the sensitive treatment by staff, good communication between GPs and hospitals, assisting patients in difficult circumstances and generally going 'the extra mile' to ensure comfort in difficult moments. Participants also appreciated GPs for their ability to respond to emergencies and prioritise EOL patients, as well as advocate for patients in the absence of effective communication from other agencies and departments. Similarly, most participants also liked the fact that hospices treated them 'humanely'. Carer support services and ambulance staff were praised for effective support, advice, advocacy and provision at pivotal times for carers. Citizen's Advice Bureau also played a key role in helping patients and Carers with form filling for financial support.

Despite some praise for community services, such as district nursing and carers through social services, there were, on frequent occasions, poor experiences of these provisions. The main problems were that they lacked strategic connection with the rest of EOL agencies; there was miscommunication between these agencies and a variable quality of carers and district nurses. Recent changes to privatise the structure of adult care services in Borough appeared to have had broad implications for how these services were configured and, as a result, what patients and carers experienced:

[Have there been] Improvements? Reverse the drift of NHS policy. I think much of the recent reforms have been counter productive in this direction because they try to open up to private companies so they loosened the connection between patient and practice but if patient registered with doctor it would be better. The result has broken the relationship between GP and patient. When ...bureaucratic systems are prioritised, the patient suffers – this is my experience of how the NHS works. [GP]

In Borough, it appeared that across the EOL sector, there had been an increasing reliance on agency workers, predominantly among carers and community nursing. While the palliative care teams appeared to neutralise some bad experiences of these care provisions, there was little they could do for some patients and Carers who had already developed significantly negative views and this was reflected in their interactions with professionals.

Developing tense emotions in the course of care

Diagnosis of a terminal condition and the subsequent period is a highly sensitive time which, for most patients and Carers, involved their families caring and dealing with the anticipated demise of their loved one. Large family and friend support networks helped where they could and often advocated on their behalf, but not all patients were blessed with this. In these instances, some patients tended not to be aware of service provision or were tired of reporting their social and practical circumstances because the persistence involved in 'speaking up', 'filling in forms', and 'making phone calls' made for heavy demands on these patients. This was why they tended to either 'get on as best they could' or gave up after a few phone calls or if no one 'followed up on them'.

This emotionally-challenging period not only involved accepting one's own death or the demise of a loved one, but coming to terms with the 'time that was left', and depending on circumstances, the roles in which the family may or may not play in providing care. For some carers, however, the 'time that was left' was often lost in form filling, 'fighting' to qualify for help, and ensuring that care standards were adequate. Many carers, however, found it difficult to balance a 'care' role with the administration which came with it – form filling and phone calls. Patients who were supported by Carers often had difficulty accepting the quality of care which was provided – especially if it was substandard. This appeared to motivate them to be more involved with the care of their loved one.

The consequences of assuming such intensive care roles jeopardised work, family relations and interest, and finances. It also heightened emotions on the part of the Carer/s. Carers' mental and physical health could also be seriously damaged in the process of maintaining the care for their loved ones which was exacerbated by 'fighting' for the additional care required for their loved ones. So an awkward set of feelings develop which appear to stem from dealing with the diagnosis of the patient's terminal illness and its impact on the Carer and other family members (if

there is such support), the sacrifices made by the Carer, pressure to qualify for care, and assuming the intensive care role. However, these feelings were exacerbated when patients and carers did not see consistency in the care or were critical of the quality of care which was provided. For these reasons, there were often difficult and tense relationships between Carers and patients, and professionals.

The complex social relations between carers and patients, and professionals

Carers had high expectations of how their loved ones should be cared for. Many, on learning about care processes, care standards, and the terminal condition of their loved one, made greater efforts to ensure care was as 'best as it could be'. Carers also carried the weight of the expectation of the way in which their loved one would want/would have wanted to be cared for. To alleviate these worries and to ensure the 'best care' possible, Carers concerned about the standard and quality of care, often resorted to educating themselves about legislation, rights of treatment, and specifics of the terminal condition. This made them quite educated and, as they saw it, 'almost qualified', to point out what their loved ones needed. However, as one ex-social service carer indicated, much of their experience and knowledge of care got dismissed by professionals:

[They are] so focused in care for that person [the Carer] and a lot of knowledge they have can get dismissed because they are seen as not medical or not qualified but sometimes if they do ask a lot or challenge, they will almost get labelled as the difficult family. [Shirley]

This dismissive treatment upset Carers and, at times, made it difficult for professionals to 'do their job', because on occasions Carers questioned the integrity and professionalism of various workers. This is a very grey area for EOL services and is made more complex by the high emotions running between family members and the pressured circumstances under which professionals operate. A few patients and Carers felt that being 'labelled' could not only affect the quality of care they received but could severely damage the relationship between family and professional. Indeed, a few Carers felt that they had to 'tread carefully' to avoid being put in this category. Monique, whose husband had passed away in November 2008, said that it was a difficult medium to negotiate – between highlighting that increased care was needed and complaining to the extent that nothing was gained:

You feel that you can't say too much in case you are perceived as someone who is creating too much fuss and they don't want to have anything to do with you. I know they tell you a lot of things but there needs to be openness.

When a few Carers received funding for home care, the interruption was constant and completely invaded their privacy. While on one hand, the burden of care had been eased, on the other, unpredictable appointment times, high frequency of calls, additional administrative duties and ensuring healthcare professionals acted in a 'satisfactory' way, sidelined the initial aim of additional care:

It is too much, you have no privacy, no control over what is happening and if you have control, you have to fight for what you want and this is the situation.
[Monique]

Reluctance to allow or the difficulty in adjusting to additional care could also result in family carers making large sacrifices to maintain support. Most gave up work, had a reduced social life, struggled to adjust to the lifestyle and greater emotional weight on Carers often wore them down:

I could cope up to a point with the care and the job but then it got too difficult and I decided to take the pay severance. They didn't really give me much choice but what can you do, it is just me, I am the only son, dad is dead so, I just stopped working. [Jack]

[She needs] 24 hour care, you can't leave her alone, she doesn't want to be alone – she was active and wants to do things. She kept this house clean [the house was pretty dirty when I visited] and now I can't do much else than care for her. [Mohammed]

In a few cases, however, the right balance had been found and carers reflected on the benefits of withdrawing from such an intensive care role:

It is reassuring that I can live my life knowing that my dad is being cared for. While I want to be around him as much as possible, it is not always healthy...that's not to say I don't want to be with him but the carer and the responsibility they have takes a lot of that away from me" [Henry2].

More often than not, however, having made such sacrifices, irregularities or poor quality care became amplified which instigated increased anxiety and tension on behalf of the Carer, and could contribute to the motivation to assume (or resume) a primary care role which was somewhere between that of an advocate and campaigner. Grace outlined that:

If I had the good carer in the beginning, then I wouldn't have had to worry about it but then this woman who she said [name] was suspended so suddenly the good carers was suspended then it was like new one, who are you, what's your name and they didn't know what to do – he [her brother] was screaming in the street which he never used to do!

Essentially, this appeared to reduce the trust in care provision and exacerbate emotions among the family. Palliative care nurses also agreed that such experiences could do irreparable damage to patient/professional relationships. One indicated that: *“There is no rehearsal. We have a one off shot to get it right and unfortunately services just don’t understand that and what happens is the patients, once you have not turned up for an appointment or turned up two hours late, you have lost trust in that patient and family. They then tend not to trust anyone else.”* Similarly, after Pauline moved from Thailand to London to care for her father, she employed a Thai carer to look after her father with motor neurone disease. After a short period, the carer returned to Thailand and Pauline and her brother were left to care for their father. For a month this continued:

We were exhausted and we could not sustain it, we had to call our care manager and they did a needs assessment and that’s when they started to provide carers.

Carers and nurses started to come in October 2006, however, they were unsatisfied with the quality of provision. On reflection, she realised what had held the family back:

What we should of have done was to get carers so we could go to work, but in fact we did not work until much later – a year later - because we had a wide range of carers, some good, some awful so we were reluctant to let them care for dad in case we got a bad one. We were over-protective.

These experiences were not aided by the way in which some patients were treated on a social level. Some of the day-to-day interaction by some health professionals in and around some patients tended to suggest that that the patients were ‘not all there’ – that is, they were incapable of interaction or communication. Although positive about the support she had got received from GPs, Monique was disappointed at the way in which one GP in particular had assumed that her husband ‘had given up’:

I was worried he was declining and on one occasion and the GP arrived and he had a chest infection and the GP said ‘he has given up’ but I wanted to know we had done everything and he hadn’t given up but to say that. I can’t assume he has given up on life because he has an infection. That was not the quite the right answer.

Tricia did not like the way district nurses talked to her: *“No, [indignantly] I don’t want them. Too rough. “come on, get up” Don’t talk to me like that. I think they have tiring days or bad days.”* Because different nurses visited her, she became concerned

about how they wrapped her legs in different ways. This made her worried they were doing it incorrectly:

You are waiting all the time [for them]. Every time the district nurse, they come and they are different, they don't know how long the patient is going to take. They do it different ways. I said "you're supposed to put the pad on first". "Don't tell me what I should be doing" they say.

Patients appreciated normal interaction. Tricia also objected to how the two physiotherapists from Respite Service talked to her: *"They talk to you like you're an imbecile. Two looking at you and they think you don't know much. I have all my faculties but just can't walk."* Even though Paul had mental health difficulties and a high dose of medication, assumptions were made about what he 'could or couldn't do'. In this conversation, he explains that different district nurses and carers assumed his mental difficulties superseded the ability to communicate effectively, when really there were just long pauses between words – his faculties, as Tricia had said, were perfectly in tact:

Paul: *The nurses that come, they vary. [Pause] I see them, not every day but different ones each day.*

Dan: *How do you feel about that?*

Paul: *It is unsettling sometimes because I don't always get the same carers day.*

Dan: *Would you prefer the same carers?*

Paul: *And the same nurses. [Pause] I sometimes have to keep explaining things to people and I can't always speak quickly so they assume I can't speak properly.*

Careless assumptions about patients were not just upsetting for patients but also for family carers, because they reinforced the patients' dependent state and damaged the opportunity for maximum self expression and dignity with which people should be treated. Until recently, Pauline's father used to watch music videos in his wheelchair. She reflected that *"some carers used to go with him and engage with him, treat him like he was normal but others just thought 'this person is not going to get it' because he was in a wheelchair and found it difficult to communicate."* She felt that some carers did not really *"get what they are doing or realise the impact they could have."* She continued:

Unfortunately, everybody assumes my dad is getting worse, everyone assumes it is the motor neurone and all those reasons are why no one goes further with things – like they are blinded from other issues.

She also objected to the tone of voice used by carers/nurses “*who don’t know my father*” and treat him as if he is “*stupid or not there.*”

Discussion

This paper has presented the findings from a consultation on EOL care services in one London borough. While not generalisable, findings are indicative of the pressured emotional social interactions between patient, carer and professional: how they develop, why they develop, how they are alleviated and how they are exacerbated. This is important to consider given the recent drive for greater consideration to the family carer in the equation of EOL care (DoH, 2008; Payne *et al*, 1999; Yoo *et al*, 2008). It is clear that, although there are encouraging signs of good practice in EOL care in Borough, this is jeopardised by a lack of strategic attention to key areas of EOL care delivery – i.e. frontline workers, working day in, day out with terminally ill patients and Carers. EOL care guidelines (DoH, 2008) may indicate what patients and carers can expect, but in the context of this consultation, this appeared to be a distant reality to patient and Carer experiences as some families continue to suffer unnecessarily in the delivery of EOL care services (Help the Hospices, 2008).

Diagnosis and the subsequent period was found to be a highly sensitive time which for most involved families caring and dealing with the slow or possibly quick demise of their loved one. Early ambiguities in diagnosis tended to lead to strained relations with professionals – relations which tarnished their experience with other EOL care services. Professionals cannot always be superheroes and science, despite its technological advances, cannot always offer clarity. In the eyes of patients and Carers, this process was confused by the inclusion of a number of different health professionals which was, in turn, exacerbated by the high emotions among families. These emotions did not disappear and often spilled over into other aspects of Carers’ lives.

Family and friend support networks helped, but not all were blessed with this available support network. Other patients and Carers were less articulate or had little patience to pursue advocacy and support. While these were often the most vulnerable patients, they were not necessarily the only ones who found it most difficult. Carers make heavy social and personal sacrifices and at the same time assumed intensive care roles which affected all areas of their lives (see Payne *et al*, 1999; Schultz *et al*, 1990; Steel and Fitch, 1996). This paper shows that, despite

some Carers receiving some support, Carers still become over-burdened (Hudson *et al*, 2004; Pasacrete *et al*, 2000). In addition, the frustration of administrative duties involved in dealing with care also lead to an amplification of negative feelings which were, more often than not, unleashed on professionals.

This thereby unwittingly heightened emotions on the part of the Carer which were also often disturbed further when they observed poor quality service provision or saw that the day-to-day social interactions on behalf of professionals was patronising and condescending. This did not add up to showing respect and dignity which would have ultimately gone some way to help Carers feel less awkward and avoid tense and frustrated feelings. While the family's involvement in EOL care is important as it has ramifications for the quality of care of the patient (Ha, 2004; Verhaeghe *et al*, 2005), this paper shows that these experiences unintentionally deviated Carers away from the intended focus on their loved one.

Managing social relations between patients and carers, and professionals while maintaining mutual respect and dignity is necessarily complex. Regular and consistent communication by one representative or department can be just as appropriate and may go some way to alleviating doubts and maintaining trust. If trust is lost, it is unlikely to be regained. To enhance the relationship and improve interactions between frontline professionals and patients and carers, workers need to be more perceptive about the different contexts and life circumstances of patients and their Carers. This will involve them in communicating more sensitively and empathically with patients and Carers. Each person's experience of care is unique and valid (Bailey, 2008) and all the more important because it is their last.

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