Perceived needs for support among care home staff providing end of life care for people with dementia: a qualitative study

Running Title: Impact of providing end of life care to people with dementia

Key words: care home, dementia, end of life, staff, stress

Key Points:

- Care home staff often experience a number of stresses associated with working with people with dementia at the end of life, leading to stress and anxiety

- Emotional aspects of caring for dying residents with dementia are further exacerbated by the close attachment they sometimes form with residents' families

- Care home staff sometimes desire dementia specific end of life training and emotional support to help manage stress

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ABSTRACT

Objective: The aim of the current exploratory study was to investigate the impact for care home staff of working with people with dementia at the end of life and to explore how they cope with this aspect of their work. With UK policy encouraging death in the place of residence, rather than hospital, more people with dementia are dying in care homes.

Method: A qualitative approach was employed; 20 care home staff working in five English care homes were interviewed. Thematic Analysis was used to analyse the data.

Results: Care home staff found the external demands on them and difficulties associated with interacting with people with dementia sometimes challenging, stressful and anxiety-provoking, particularly as residents approached end of life. Emotional aspects of caring for dying residents were sometimes heightened by close attachments with residents and their families. Staff were able to recognise these unmet needs and identified a need for further training and emotional support to manage these stressors.

Conclusions: This study revealed rich and complex understanding of the practice dimensions of caring for people with dementia at the end of life and the impact these have on staff. There is a need to develop effective psychosocial interventions that focus on emotional support for care home staff. There will be challenges in providing this in employment settings that are generally low paid, low status, have high turnover and are reliant on temporary or migrant staff, where training is not rewarded, mandatory or culturally valued.

Introduction

Care homes are increasingly caring for frail older people at the end of their lives, and older people with cognitive impairment or dementia are more likely to die in care homes than in other settings (Moriarty, Rutter, Ross & Holmes, 2012; National End-of-life Care Intelligence Network, 2013). In recent years in England, there are increasing ambitions to avoid premature and unnecessary moves to hospital in the last weeks of life (Murtagh et al. 2012). Current government policy encourages people to 'die in place' (Department of Health, 2013; Leadership Alliance for the Care of Dying People, 2014); consistent with wishes of many families (Bayer, 2006). Research has focused on ways in which care home staff make end-of-life care decisions (e.g. Goodman et al., 2010; Moriarty, Rutter, Ross & Holmes, 2012). However, there is a need to understand the impacts on care home staff of caring for dying residents who have dementia in order to better support these workers.

In England, care home staff are among the lowest paid employees (Resolution Foundation, 2015). Staff working in care homes are often under pressure in their work and experience both psychological and physical strain, including injuries and depression (Walsh, 2006; Zimmerman et al., 2005). There is high staff turnover in some care homes (Franklin, 2014) and staff working with people with dementia are less likely to be trained than other care workers (Hussein and Manthorpe 2011).

Furthermore, staff working with people with advanced dementia are at risk of high levels of stress (Carr 2014; Hudson & Moore, 2009; Zimmerman et al., 2005) and burnout (Pitfield et al., 2011). Firstly, they report being under significant pressure with the lack of time and high workload in care homes, which contribute to burnout (Hudson & Moore, 2009; Stacpoole et al., 2014) and may prompt staff turnover. Secondly, the physical nature of care work may

lead to injuries and contribute to absenteeism (Health and Safety Executive, 2014). Thirdly, residents' challenging or distressed behaviours are linked to burnout, due to care staff feelings of emotional exhaustion and depersonalisation (Scott et al., 2011). Finally, it has been argued that working with people with advanced dementia, amid a perception of lack of dementia specific training, results in stress among care staff (Zimmerman et al., 2005).

Providing end of life care potentially compounds the expectations placed on staff in care homes, but the psychological impacts of undertaking such care are unknown. Staff may feel ill-equipped and uncomfortable about broaching the topic of death with residents and their families (Livingston et al., 2011) but they may be expected to discuss advance care planning with residents with dementia or relatives (Handley et al., 2014; Robinson et al., 2012). End of life care encompasses not only the last few weeks/days before death, but when some people think death is approaching, or care for people with limited life expectancy (such as people with dementia) (Vandrevala, Samsi & Manthorpe, 2015). No research was identified that has specifically investigated the impact on care home staff providing end of life care to people with dementia and how they manage or cope with this, although some UK studies have suggested that repeatedly confronting death while caring for dying residents can create staff stress (Katz et al, 2001; Sidell et al, 2003) and concluded staff need emotional and practical support.

Providing end of life care in a care home entails physical and emotional labour. Emotional labour was defined by Hochschild (1983) as "suppressing feelings in order to sustain an outward appearance that produces in others a sense of being cared for in a convivial, safe place" (p.7). It involves consciously suppressing inner emotions to enable working effectively. The phenomenon of "emotional labour" is widely reported among intensive care

professionals (Sorensen & Iedema, 2009; Ryan, Seymour & Ryder, 2013), health care assistants caring for dying cancer patients (Herbert & Johnston, 2013; Lovatt et al, 2015); healthcare assistants in inpatient dementia services (Bailey et al., 2015); palliative care nurses (Skilbeck & Payne, 2003) and hospice staff (Sabo, 2008; Slocum-Gori, 2011). More recently, Colomer & de Vries (in press) and de Witt and Ploeg (in press) acknowledged that care home workers' emotional bonds with residents with dementia sometimes contributed to feeling physically, mentally and emotionally drained.

Methods

Aims

The broad aim of the study was to focus on the job-related stress experienced by care home staff working with residents with dementia. All staff spontaneously discussed the challenges of providing end of life care to residents with dementia. This paper presents accounts of working with people with dementia at the end of life and how care workers coped with the stress of such work.

Participants and Recruitment

Five care homes for people with dementia in Southern England were approached in order to recruit staff; all agreed to participate. All were registered for dementia care, ranging in size from 50 to about 120 residents. Nursing staff were excluded as they have considerable training compared to frontline care home workers. Table 1 shows participant characteristics, which are broadly reflective of the care home workforce in England (Hussein and Manthorpe 2011), except that three-quarters of our participants worked full-time.

(Insert Table 1 here)

Data collection

Interviews were conducted February- June 2015 using a semi-structured interview guide (see Box 1). Socio-economic details were collected and an interview guide with open-ended questions was used to elicit staff views and experiences of caring for residents with dementia who were dying.

(Insert Box 1 here)

Twenty face-to-face interviews were conducted at participants' workplaces during working hours in locations such as an office. Prior to the interview, participants were given a study information sheet, detailing what participation would involve, and asked to sign a consent form. Interviews lasted approximately 30-45 minutes. Prompts were used to gather as much relevant information as possible.

Ethical requirements

All participants were assured of confidentiality, but were told that confidentiality would have to be broken if risk of harm emerged. Ethical permission was received from (INSERT AFTER REVIEW) Ethics Committee. No personal details of residents were collected. Interviews were recorded with permission.

Data analysis

Interviews were transcribed verbatim and analysed using thematic analysis (Braun & Clarke, 2006). This systematic approach allows data interpretation, reporting patterns (themes) within data and summarising relevant findings. The analysis followed the 6 phases of thematic analysis: 1) familiarising with the text through repetitious transcript reading, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, 6) producing the report. Trustworthiness of the data was ensured using open-ended questions, multiple coding, and detailed descriptions of participants (Graneheim & Lundman 2004). The interviews and initial coding were conducted by CR, CA and CB. TV cross-coded a sample of transcripts, and a coding framework was drawn up. Further iterations of the coding framework were undertaken by KS and JM. Regular discussions were held to review, define themes and discuss emergent interpretations amongst all authors. Analysis was terminated when theoretical saturation was reached or no new themes could be identified. Pseudonyms are used to maintain confidentiality.

Findings

The process of thematic analysis resulted in three master themes, each with constituent sub-themes (see Table 2 below): (1) complexities of working with residents with dementia, (2) emotional labour of caring for dying residents, (3) managing stress and anxiety of caring at end of life. Findings are presented in terms of major themes, with prominent aspects of sub-themes highlighted. Table 3 presents illustrative quotations.

(Table 2 here)

(Table 3 here)

Complexities of working with residents with dementia

This theme depicts the stress that care home staff experience as a result of the complexities of caring for people with dementia. Working with people with dementia was considered demanding and stressful, but working with residents with dementia at the end of life was more complex and demanding than other residents at the end of life due to competing demands and difficulties interacting with residents with dementia. Staff consistently highlighted that they lacked the requisite skills to manage these growing demands, regardless of their years of experience.

Competing Demands

All participants reported competing and multiple job demands, time pressures and significant resident disability as contributing to feeling stressed and overwhelmed. Staff felt that the nature of dementia's symptoms made residents reliant on them and competing demands from residents, family members, and other colleagues contributed to work pressures. Each resident's needs seemed pressing and urgent and participants struggled with managing priorities. This was exacerbated at the end of life, where their role was to comfort and provide intimate care. Both workload and time pressures were perceived as obstacles to developing relationships with residents. Feelings of responsibility, and of inadequate skills, and inability to meet these demands made staff feel helpless when a situation seemed out of their control (See Table 3, 1a).

Difficulties associated with resident communication

Caring for residents with dementia, particularly at the end of life, was challenging as residents seemed to struggle to express their wants and needs. Many staff felt that communication difficulties led to resident distress and compromised quality of care. Behaviours such as apparent aggression or high level of distress, for example, shouting,

hitting out or throwing things, made them feel afraid and anxious (See Table 3, 1b). They acknowledged that building relationships and gaining resident trust were crucial to good care. However, staff did not seem to view aggression in dementia as a symptom of possible unmet needs (an attempt to communicate), but more a characteristic of the condition itself.

Emotional labour of caring for dying residents

Staff recognized that an integral part of their job involved responding to the emotional needs of residents with dementia, which some felt were more stressful to address than physical demands. Some revealed that growing closeness with residents increased their anxiety and made them feel doubly powerless in bearing witness to an approaching death. Frequent encounters with death, feeling unable to reduce suffering for the person with dementia and their families, and feelings of helplessness, exacerbated by established emotional relationships, further contributed to staff distress. Years of experience in such work did not necessarily alleviate the emotional labour experienced, as evidenced by quotations in Table 3 (2a, 2b, 2c).

Frequent encounters with death

Participants' accounts highlighted that working with dying residents was a significant source of emotional labour. Due to the amount of emotional and practical support they offered residents at the end of life, many felt they took on a significant fictive familial role in many residents' lives and therefore the resident's death affected them deeply. Some staff reflected that while supporting vulnerable dying residents, they ran the risk of identifying too closely

with such vulnerability and this could cause them to confront their own mortality and that of their own family (See Table 3, 2a).

Being unable to reduce resident suffering

Staff reported feeling helpless when residents moved to the end stages of life. Many staff were aware that the end was in sight but felt powerless from their inability to reduce pain and suffering. Residents' communication impairments exacerbated staff's problems of not understanding pain. Having to rely on external (off-site) clinical help led to feelings of loss of control among some staff. Many staff expressed profound sadness for residents who were approaching the end of life or had died. However, they were acutely aware of being required to act professionally, remain detached, and not express this sadness and discomfort at the approaching death. Many staff took comfort when residents had a "good death" (See Table 3, 2b).

Supporting families

Staff recognized that supporting families was not part of their job; however, they built strong relationships with some families, resulting in them providing emotional support to both residents and their families. Some families were described as putting unrealistic demands on staff or were in denial of their relative's condition. In contrast, some families helped alleviate stress when they thanked staff for their care. Some staff said they tried to act in the best interest of the person with dementia and worked with families to achieve this (See Table 3, 2c).

Managing the stress and anxiety of caring at the end of life

Most staff were able to identify ways of managing their work-related stress and anxiety.

Need for dementia specific end of life training

Several staff regretted limited training opportunities, and perceived a mismatch between expectations and responsibility. They hoped that training would prepare them to care for people with dementia at end of life. Staff took pride in their work but appeared to struggle with residents' increasing needs. They detected an underlying assumption that the job would become easier and stress levels would decrease as they became more experienced. More experienced members of staff who had received dementia training felt better equipped to deal with the multiple complexities of this work. A need for dementia-specific training to include interpersonal skills and improve communication skills was expressed, rather than clinical or practical skills training (See Table 3, 3a).

Coping with emotional labour

Staff wanted support in dealing with the uncertainty and helplessness they felt when encountering the emotional labour of caring for people with dementia at the end of their lives. Some had built strong relationships with residents and their families but felt uncertain about their roles in the resident's last few days and weeks. They were aware that others (generally outside professionals) addressed clinical aspects of care, but their sometimes substantial involvement in intimate tasks made them feel more distressed when residents died. They felt that they needed a 'space' and a channel to grieve, and described how support at work and self care (e.g. physical exercise, meditation) helped manage the anxieties associated with the emotional aspects of their role.

Peer Support at work: Support from colleagues and managers was crucial in coping with distress and anxieties when caring for dying residents. Many felt that a team spirit, especially if this was filtered down from managers, helped negate some everyday anxieties and prevented rumination on problems. Having an approachable manager and senior management team reduced workplace stress. Sharing experiences with colleagues and visiting healthcare professionals could promote understanding of how to best support people with dementia at the end of life.

Staff acknowledged the importance of having "emotional outlets" in the workplace and of a care home culture enabling discussion of death and dying. Unmet needs meant physical and psychological health could suffer. Some suggested that their workplace culture discouraged discussion about death and its emotional impacts. These staff often felt isolated and supressed emotional stress as they did not want to burden their colleagues (See Table 3, 3bi).

Discussion

This exploratory qualitative study focused on a small number of care home staff's experiences of providing care at the end of life to residents with dementia. The findings suggest that staff acknowledged the challenges and complexities of their increasing workloads and growing responsibilities. Specific to dementia, residents' communication impairments and occasional displays of aggression, distress, or other challenging behaviour heightened stress, anxiety, and feelings of burnout. It appeared that the emotional labour of caring for residents and their families at the end of life was exacerbated by limited training and unmet needs for emotional support. Work with relatives who are distressed, as reported by others (Chochinov, 2009; Johnson et al., 2012; Colomer and de Vries in press), suggests that this also contributes to the emotional labour of care work. The current study extends

these ideas by suggesting that the added emotional and practical tasks of caring for dying residents with dementia exacerbates the emotional labour of caring. The attachments staff form with residents are integral to care at the end of life, and, in the context of working with residents with dementia, this was felt to be particularly salient. This study suggests that staff may find it hard to remain detached but do so to protect themselves from grief, particularly if the care home culture does not enable expressions of grief or provide bereavement support. Other studies have suggested that staff conceal their emotions by keeping themselves too busy to allow time for self-reflection, while their attachments to residents are "unacknowledged and possibly unallowable" (Livingston et al., 2011, p.27). Continually confronting death in this way may affect staff wellbeing negatively, blunt emotions, and, potentially, affect the care provided, especially if managers and supervisors fail to acknowledge or discuss the impact of providing end of life care. This type of stress may present a risk to the emotional health but it is largely hidden in organisations, notwithstanding stress-related burnout, absenteeism and turnover. While only mentioned by a few participants, them feeling unsupported by the wider primary healthcare team suggests looking beyond the care home to the local health and care system in seeking improvements.

Healthcare professionals working within end of life care can also be at risk of compassion fatigue (CF) (Meadors & Lamson, 2008) and vicarious traumatisation (VT) (Sabo, 2008). Care home staff may similarly be at increased risk of VT and CF as they not only cope with their own grief, but that of other residents, families and their colleagues. Nursing home staff in one study reported their grief to be 'disenfranchised' as their relationship with the dying person was unacknowledged, and staff sought to remain professionally detached rather than recognising the impact of death on them (Wilson & Kirshbaum, 2011). Conversely, working with patients nearing the end of life is also associated with high levels of job satisfaction

(Sanso et al., 2015) and low levels of distress (Pitfield, Shajriyarmolki & Livingston, 2011). Other researchers claim that a certain level of stress in end of life care is required in order to function well (Sabo, 2008). Therefore, the question arises how to effectively manage stress and anxiety in the workplace to ensure that eustress (good stress) leads to higher levels of commitment and motivation and the negative impacts of stress (burnout, vicarious traumatisation and compassion fatigue) are kept at bay.

Limitations

The care homes approached were receptive to research and most participants worked full-time which may mean they had greater exposure to residents and less recreational time. The study took place in one area of England, which may influence the generalisability of the findings as may the self-selecting nature of the sample. It is possible that staff who were most troubled by end of life care may have declined to participate. The study took place before the introduction of the new Care Certificate for non-regulated staff that may improve care worker knowledge and role understanding (Skills for Care 2015). The impact of this mandatory training should be evaluated.

Practice and Policy Implications

Health and care funders and professionals consistently underestimate the challenges and difficulties faced by care home staff and the skills required to care and support people with dementia in the last years of life (Goodman, 2015). The inspector and regulator in England, the Care Quality Commission (2014), acknowledges that leaders should "offer support to staff who are trying to do the right thing in often difficult and stressful environments, and

enable them with the skills and the emotional support to do the job with compassion" (p.7).

Current training and practice to support care home staff may need to ensure that working with residents with dementia at the end of life does not have adverse impact on staff and thereby acknowledge the emotional aspects of care work. Psychosocial interventions (see Lawrence et al., 2012), person-centred care and Dementia Care Mapping may reduce burnout among care home staff (Jeon et al., 2012; Talbot & Brewer, 2015). This may entail a shift from task oriented training to individualised person-centred care or a relationship-centred approach, where the relationship between staff members, residents with dementia and their families is recognised and reciprocal emotional bonds are readily acknowledged (Talbot & Brewer, 2015). The reciprocal bonds between residents with dementia, their family and the care team, particularly at the end of life, have the potential to promote psychological wellbeing among all involved. Therefore, more emphasis could be placed on promoting personal, emotional and meaningful relationships between care home staff, residents and their families. Furthermore, care home staff may also need support to help them with their own anticipatory grief. Peer support in the form of supportive colleagues and managers who adopt a person-centred manner towards their staff (Burtney et al., 2014; Jeon et al., 2012; Manthorpe, 2014;) and who encourage open communication and discussion regarding death, bereavement and grief can facilitate staff wellbeing. These suppositions need to be tested to determine effectiveness and routes to implementation of change in care practice and organisation.

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Conflict of interest

None declared.

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Attitudes, Stress, and Satisfaction of Staff Who Care for Residents with Dementia. *The

Gerontologist* **45**: 96-105. DOI: 10.1093/geront/45.suppl_1.96.

Table 1: Participant characteristics (n-20)

Gender	Male	2 (10 %)
	Female	18 (90 %)
Age	Under 25 years	4 (20 %)
	26-35 years	5 (25 %)
	36-45 years	1 (5 %)
	46-50 years	3 (15 %)
	Over 50	7 (35 %)
Nationality	British	16 (80 %)
	Other European	3 (15 %)
	South Asian countries	1 (5 %)
Ethnicity	White	15 (75 %)
	Black	3 (15 %)
	Asian	2 (10 %)
Length of time as care worker	Under 1 year	3 (15%)
	1-3 years	4 (20%)
	4-5 years	5 (35%)
	6-10 years	5 (25%)
	Over 10 years	3 (15%)
Marital Status	Single	14 (70 %)
	Married	2 (10 %)
	Separated	3 (15 %)

	Widowed	1 (5 %)
Employment	Full time	15 (75 %)
	Part time	5 (25 %)

Box 1: Summary of topics in Interview Schedule

Please tell me about your job

Which aspects of your job do you like best?

Can you tell me more about your work that involved residents with dementia?

Which aspects of your job do you not like? What makes the job difficult? What makes the job stressful?

Please describe a difficult or stressful situation or occasion at work that may be recent or one that has been particularly memorable.

What impact do you think working in a care home has on your work?

Can you tell me how you cope with stress?

Table 2: Master Themes and Subthemes

Master Themes	Subthemes
Complexities of working with people with dementia	Competing Demands
	Difficulties associated with resident communication
Emotional labour of caring for dying residents	Frequent encounters with death
	Being unable to reduce resident suffering
	Support families
Managing the stress and anxiety of caring at the end of life	Need for dementia specific end of life training
	Coping with the emotional labour • Peer support at work • Self-care: Consciously "switching off" from work

Table 3: Quotes from participants

Master theme 1: Complexities of working with people with dementia	
1a Competing Demands	*"You're halfway through doing one thing, and someone is shouting "I need you, help me." And trying to explain to somebody "I'll be with you, as soon as I possibly can," "no, you won't, you will leave me here." So trying to convince them that you will be back to help them can be a challenge in itself."* (Debbie, 3 years' experience) *"Sometimes you feel like you don't really have enough time for them. The half an hour that I help one person in the morning might actually be the only half hour that they actually talk to someone that day one to one, but I am stressed because I have to run off and help someone else."* (Natasha, 8 months' experience)
1b Difficulties associated with resident communication	*"When some of the clients cannot communicate, we find it difficult, we don't really know what they want. They cannot communicate to you properly, so you really have to just think for them and try to understand what they want. It can be very frustrating, because you don't really know what they want and they are trying to tell you what they want and then you try to guess. And they keep saying that it's not what they want."* (Noella, 10 years' experience) *"He got very angry ...he threw everything out, breaking and throwing everything on the floor, bashed the television down. I was very fearful."* (Noella, 10 years' experience) *"Some of the people could be quite nasty, threatening you, running over your feet with the wheelchair."* (Pat, 18 years' experience) *"We had a particularly challenging elderly man with advanced dementia and staff struggled with his violence. I was lucky to build a relationship with him, he started seeing me as his old friend and I was able to control him in a non-restrictive way."* (John, 5 years' experience)
Master theme 2: Emotional labour of caring for dying residents	

2a Frequent encounters with death	*"The everyday tasks (are) not that stressful, it's the emotional aspects of caring and losing patients that keep me up at night, that I struggle with."* (Debbie, 3 years' experience) "Working in end-of-life, you just know that the next time you come in; you worry whether they're going to be there, and it makes me worry about when I'm that age, it's not nice." (Chloe, 6 years' experience) *"At the end it is sad… in the last stage we spend more time with them than their families, you get more attached to them. Most of them treat us like family. I spend more time with the residents than my own wife. It's like the death of a family member. I don't have any family here, apart from my wife. I wish I could look after my parents, but I'm here. For me they (residents) are like my parents. Emotionally it's very difficult".* (John, 5 years' experience) *"Some days, particularly when someone is dying, I can't take them out of my head, I find myself thinking of them when I'm home, I can't sleep, I get anxious."* (Sarah, 5 years' experience)
2b Being unable to reduce resident suffering	*"I feel very stressed when the client is sick and dying and unable to help themselves… especially when it is someone who cannot really explain what is wrong."* (Noella, 10 years' experience) *"My emotions come out if I am attached to someone and they die, where at the same time I have to draw the line between doing my job and being emotionally attached to the person… you need to pick yourself up and get on with caring for the others. There is no time for sadness, no time to grieve… we don't talk about it. Not in the care home, not with your colleagues.… I guess it's not the culture."* (Sarah, 5 years' experience)
2c Supporting families	*"Some families are in denial about the deaths, that their relative is going to die in a few weeks and this is really hard because they are still expecting you to do magical things. It's hard with people with dementia as they are unable to make the decision for themselves and you have to make the decision for them. Relatives knew their family members' needs years ago and don't take into account their current health and how the care home environment functions."* (John, 5 years' experience)

Master theme 3: Managing the stress and anxiety of caring at the end of life	
3a Need for dementia specific end of life training	*"I wasn't trained. I didn't know how to carry him and I was panicking because I didn't know whether I would injure him or myself, or if the client was going to flip and get angry with me."* (Noella, 10 years' experience) *"If you don't understand (that) you're dealing with a person with dementia and you don't understand the illness, then of course, it can very stressful but if you understanding what you are doing then your job would be all right."* (Sarah, 5 years' experience) *"You're feeling helpless and responsible really... the responsibility, the thought of what could have happened. Are you right for this job, sort of thing."* (Pat, 18 years' experience)
3b Coping with the emotional labour	<u>3bi Peer Support at work:</u> *"They're pretty good in terms of that, we do have that support and I know that our managers, the majority of our managers are reasonably good that you can go say 'argh' you know, if you just want a have a moan or a rant, and you know, get it off your chest. They also always come round to see us every day, make sure everything's in check and what not."* (Chloe, 6 years' experience) *"I think that I rely on the strong team at work. Sometimes at the end of the shift everyone says to each other, "how did we get through today?', 'We have a really strong team, and sometimes, when you get used to working with your team, you know what the other one is going to do before they do it. Just pick up where the other left off sort of thing."* (Demi, 4 years' experience) *"At times it could be slightly difficult, because you kind of want to talk about it, but then you don't want to upset, burden your colleagues. It's not fair on them."* (Natasha, 8 months' experience)