Neurodegenerative diseases (NDDs) are incurable and debilitating, and result in progressive deterioration of cognitive (dementias) and physical (ataxias) functioning. People with these conditions have constantly changing needs due to steady deterioration, with episodes of rapid decline, which places a heavy burden both on patients and their carers. Greater emphasis is now placed on keeping patients in their own homes in order to meet their personal wishes and reduce hospital/institutional costs. Respite can offer several avenues of support including rehabilitation, maximisation of functionality and improved quality of life for the patient. It can also be crucial in enabling carers to continue in their caring roles.

Aim
The aim of our study was to determine what residential respite care can offer to patients with NDD and their carers. The research addressed the following questions:
- What is the patient’s experience of a respite admission?
- What are the issues and concerns for the carer in relation to respite?
- How can respite be used to provide a therapeutic outcome for patient and carer?

Methodology
A constructivist approach to grounded theory was adopted. This constructivist approach enabled the researcher to be situated within the research with the participants and form co-constructed meanings.

Setting, ethics and recruitment
The study was undertaken in the south-east of England. Participants were recruited from a specialist national hospital for NDDs, a community-based specialist neurological team and a hospice that has one dedicated respite bed. To be eligible for inclusion, patients had to:
- be an adult with an NDD and have a carer
- be able to communicate in English, either via speech, using simple letter/word boards, symbols or pictures, or using an electronic communication aid
- have received residential respite care within the past six months.

Ethical approval was obtained from the local Research Ethics Committee, the hospital’s research and development committee, and the ethics committee of the researcher’s university. Participants gave written consent and the researcher ensured that they had the mental capacity to take part.

Data collection and analysis
Data were collected using semi-structured interviews with patients and carers. In total, 17 interviews were conducted with seven
patients (who had a variety of NDDs, including motor neurone disease, Huntington’s disease, multiple sclerosis and multiple system atrophy) and ten carers. There were six matched pairs of patients and carers who had spousal relationships, and four interviews were conducted jointly with the patient and carer, because the patient’s ability to contribute was severely limited by their disease stage. All interviews took place in the patients’ homes and were audio-taped. The researcher wrote memos and kept a research diary.

Interviews were transcribed verbatim and listened to repeatedly. Data analysis was conducted using open coding following Charmaz’s approach to grounded theory: open, focused and theoretical coding. A constant comparison method was adopted, which involves a continuous movement back and forth between the emerging codes and the data; this allowed further verification that the developing categories were truly grounded in the data. Theory development involved analysing the collated data, emerging themes and memos, alongside relevant literature, in order to provide a working theory.

Initially, purposive selective sampling was adopted. A shift to theoretical sampling occurred as concepts and codes began to emerge, providing direction for the study. This made the sampling more responsive to the data and not predetermined. Recruitment ceased when saturation occurred and no more themes emerged from the data.

This paper focuses on two of the themes identified in the process:
- procuring the commodity of respite
- respite as restoration and biographical reconstruction for the carer.

**Seeking out suitable respite**

A male carer described how he went about finding further information about the suitability of respite care. He reported how he needed to be sure that his wife, who had Huntington’s disease, would be cared for in accordance with her complex needs, which included help with positioning, symptom control and management of her dementia.

Researcher: ‘So you recognised that you needed a break. Did you have a choice of places you could go?’ Carer 5: ‘Ummmm, I’m not really sure but I was quite … um … through doing a bit of research myself I became aware of [name of institution] and the fact that [this institution] specialised in her type of illness. Umm, so that was really where I wanted her to go to reassure me she would get the proper care and attention.’

When patients and carers eventually gained relevant knowledge about respite services, they then needed to explore the different options available for care placements, which were often limited. In addition, the referral and selection process, including criteria for acceptance, was difficult to understand, and there was limited flexibility around the respite stay in terms of dates and length of stay.

Carer 11 describes deterioration in her husband’s mobility following respite care in a nursing home: ‘Before he went in for the respite, he was able to walk using a frame and I would go just behind him ready to do any steadying that was necessary. But within a couple of days or so in respite, he had never stood or taken a step. The carers there just transferred him very, very quickly without giving him any time to straighten up … so he had become chair-shaped.’

This demonstrates that staff and resources in nursing homes might be inadequate to care for a person with the complex needs associated with neurological illness.

**Having a good experience of respite care which meets the needs of patient and carer**

Carer 4 had high expectations of respite care because her husband already accessed weekly day-care services at the local hospice: ‘Well before you came I actually went onto the internet and looked up respite care … ummmm … to see if what I felt was respite care was wrong because I [had] been made to feel that way. And interestingly enough one sentence flew off the page which [was] “respite also provides a positive experience for the person receiving care”, and to my mind that actually sums it all up.’
This carer identified the symbiotic and reciprocal nature of respite care whereby both people gain a positive benefit from it. A significant barrier to accessing good respite care identified by study participants was patients’ communication difficulties. Some felt that this was a major problem when using non-specialist care settings which offer respite: patients admitted for respite in such settings often felt ignored and misunderstood. Similarly, due to their communication difficulties, they felt excluded from activities and attempts at socialisation.

This contributed to one patient feeling frustrated that he was not being seen as a whole person because of his NDD. Patient 12: ‘Well, my mind is still very active and I like to be with other people, I don’t like being isolated … ummmmmm … and I like taking part in the activities that I can participate in, I can’t do anything where you are playing any games or anything like that as my manipulation is almost non-existent.’

One patient had had respite both in a hospice and a specialist care home, so he was able to compare the advantages and disadvantages of each setting. Patient 8: ‘The hospice is palliative care and most of the stuff is round the quality of dying. Specialist care home [name of the care home] is all about the quality of living – which I am still doing.’

This patient and his wife and carer were well aware that he had a life-limiting illness (multiple sclerosis), but wished for him to live well for as long as possible. They looked for respite care that would reinforce his strong will to make the most of what he was able to do, but equally welcomed the hospice’s input in the form of a review of his medical and nursing needs.

A positive aspect for most patients who received respite care in a hospice was access to members of the multidisciplinary team.

Carer 11: ‘Um, he definitely saw the physio and the OT [occupational therapist] on more than one occasion and they tried to use the … uh … they did some massage and stuff and they were looking to see if they could use another neck support … And they also tried the eye gaze technology …’

There appeared to be inequalities with regards to accessing appropriate care. Some had access to specialist neurological homes and/or a hospice, while others only managed to secure respite care in nursing homes which were not equipped to look after patients with complex needs. These nursing homes did not have any specialist equipment (families had to bring everything) and their staff had a limited understanding of patients’ needs.

Knowledge of funding
Carers had little knowledge of the funding available for respite care or processes involved in accessing it, and often came across it by accident. Families had to do their own research to ascertain the impact funding might have on the provision and accessibility of respite. When continuing care (that is, NHS funding provided for an ongoing package of care) was applied for and obtained, the process often became much easier and smoother.

Carer 10, who worked in the NHS, had heard about a ‘pot of money’ for respite/carer break by chance, when she visited the local carer support branch. ‘I think it was the guy I met there who said to me that the government will provide funding to allow me to have respite care. So my understanding of that is that there is a pot of money allowed that is available for carers so that their patient/loved one can go away somewhere, be it a care home or other type of care place, while we have a break, and I thought if that money is available I might as well make use of it and go and have a break.’

The Palliative Care Funding Review found that the ‘continuing care’ process was generally poorly understood and that there was a long assessment period.9 The current study found that there was inconsistent access to appropriate resources, accompanied by a potentially distressing means-tested approach.

Respite as restoration and biographical reconstruction for the carer
The caring role involves readjusting to a constantly changing life due to the deteriorating health of the patient. Patients and carers reminisce about life before the illness and the emerging revitalisation and restoration of the carer following good quality respite in preparation for their continued caring journey. The concept of ‘biographical disruption’ is relevant here, with the onset of the illness causing a deviation from the normal state of health, as well as challenging assumptions held about oneself and loved ones.
ones and one’s expectations about the future.10 The disruption that ensues from long-term illness creates a need to adapt to a different life, which is referred to as ‘biographical reconstruction’ – a coping mechanism to integrate the illness into the patient’s – and carer’s – life and identity.11 The process of biographical reconstruction was found in the data and was an outcome of a successful episode of respite care.

Facilitating respite care

Organising care was often burdensome and overwhelming. Organising an admission for respite care could add to the strains and pressures already present in the caring role and relationship.

Carer 8 recalls her husband’s views on respite. He used to be in control, but now there is nothing that he can manage to do physically; however, psychologically, he can encourage her to accept respite. ‘He actually says that … [Carer starts crying, finds it difficult to control herself, patient also starts crying] … that respite is something he can do for me because he’s the sort of person who would be doing everything, you know, the garden, mending the car, decorating, all the stuff that I have to do … um ... he sees it as contributing to me being OK.’

There was a magnitude of loss and a great deal of emotional expression in this interview. The patient was reciprocating the care he received from his wife by supporting her through his respite care, so she also benefited from having time off caring. This reciprocity in the caring relationship provided restoration for the carer, which enabled her to continue in the caring role.

Gratitude for respite and restoration

For the vast majority of participants there was an acknowledgement that the break provided by respite had been a positive experience.

Carer 6 was grateful for her husband’s extended respite stay in a hospice. She had experienced tearfulness and overwhelming tiredness before his admission. ‘They actually kept him in for a fortnight for me to stabilise him and stabilise me, really.’

Her words depict how an equilibrium, derived from the symbiotic relationship between carer and patient, is required in order for the carer to continue caring, thus demonstrating how respite can benefit both. Her husband, who had motor neurone disease, was going through a period of rapid decline (muscle weakness, swallowing and speech deterioration) that resulted in the need for additional help, for which the hospice provided advice. Respite care boosted her ability to continue caring, provided some stability and structure to help her and her husband, and allowed both to undertake biographical reconstruction.

Discussion and emerging theory

Some participants found that a good respite experience was a form of restoration, as it gave them a chance to receive individualised care from the multidisciplinary team, allowing them to target specific concerns and addressing them in a safe environment.1

Experimenting with alternative care patterns was found to be beneficial during residential respite: some patients were extremely limited in their ability to change their functional status, as they had already deteriorated to an irreversible state, but they were often motivated by having access to social activities such as quizzes, arts and crafts, topical discussions (for example, of daily news), and by meeting/talking to people who had led similar lives to them.

For carers, the respite experience could be valuable to take stock of their lives. They were able to redefine a future, which involved adapting to a new normality; this, in turn, helped them develop resilience and ultimately continue caring.

Overall, there have been insufficient studies into the benefits of regular respite care.6 The data collected in this study demonstrate that a well-planned, comprehensive and recurring (that is, offered on a regular basis) respite experience can address the specific needs of both patients and carers. Our findings led us to generate a model that illustrates the relationship between caring and respite, as well as the potential therapeutic outcomes of good respite (see Figure 1).

Study limitations

Our study only recruited participants who had experienced planned residential respite, therefore the grounded theory generated can only be applied to this area of care.

All participants spoke English and the majority were White British. They were mainly from a higher social class and none of them were from a minority ethnic group. This
may affect the efficacy of the model, as people from different cultures may experience different issues and have different perceptions of therapeutic outcomes. Many patients had communication problems as their conditions were very advanced: the carer’s interpretation of the patient’s experience may have introduced some subjectivity.

Conclusions
Residential respite can be a comprehensive and integrated intervention to support patients and carers, including psychological interventions and social activities, thus providing a well-rounded approach to care. However, in practice, there are limited funds for respite and commissioners are unlikely to see this as a priority. Professionals need to work with establishments that provide respite, and consider ways to improve and support innovation. Improving care practice would be advantageous, alongside up-skilling staff and linking with other services. Nursing home care is universally available in the UK, so preparing nursing home staff for delivering good-quality respite care – within the boundaries of their roles – could help address some of the inequalities in access.

Declaration of interests
The authors declare that there is no conflict of interest.

Acknowledgements
The authors are grateful to the study participants for their contribution.

References

Diane Laverty, Nurse Consultant, Palliative Care, St Joseph’s Hospice, London; Anne Arber, Senior Lecturer in Cancer and Palliative Care, University of Surrey; Sara Faithfull, Professor of Cancer Nursing Practice, University of Surrey, UK

Figure 1. The relationship between caring and respite for patients with neurodegenerative conditions and their carers; this model shows how a good respite experience creates sustainability of care.