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UNDER THE RADAR

Why young carers miss out on the support they need

By Elaine Cole [@prideinnursing](#)

One evening, nurses at Whittington Health NHS Trust in London noticed an 11-year-old girl sitting with a patient – her mother – on an adult ward late at night. ‘She had been there all day and nobody had noticed,’ says Colette Datt. ‘She had no idea how to get home.’

After hearing about the case from the safeguarding team, the trust’s nurse consultant for children and young people investigated what carer policies Whittington Health had, and discovered there wasn’t one for carers, whether child or adult.

With band 6 nurse Sandra Frimpong, medical student Naheeda Rahman and a group of young carers, Ms Datt began a project to empower young carers by teaching them their rights and co-creating an identity

card encouraging healthcare professionals to recognise the caring role.

A largely hidden population

Ms Datt, who was undertaking a Florence Nightingale Foundation scholarship, says: ‘Young carers are looking after a relative or friend who is ill, disabled or misuses drugs or alcohol.’

‘Despite their integral role in society, they remain a largely hidden population and initiatives specific to them in healthcare are absent. We wanted to hear from the young people themselves but young carers are traditionally difficult to engage – the whole

problem is that they are so under the radar.’

She contacted Tottenham Early Health and Prevention Centre, which had a drop-in centre, and Islington and Camden Family

‘We had an “outstanding” care rating but you wouldn’t think so if you had heard what these young people had experienced’

Colette Datt, nurse consultant for children and young people, Whittington Health NHS Trust



▲ A young carer takes part in a workshop exercise

➤ Action, which had a young carers' group. Because the latter was commissioned to provide services for young carers, it was able to bring 15 young carers to Whittington for an engagement session.

'We wanted to find out what they would find helpful but their stories were very difficult to hear,' recalls Ms Datt. 'I was shocked – we had an "outstanding" rating for caring but you wouldn't think so if you heard what these young people had experienced.'

'It was very upsetting,' adds Ms Frimpong. 'The vast majority had experience of not being listened to.'

'These accounts included healthcare professionals not including them in the cared-for person's care. They were not being taught when and what medication to give. They were seen as children

with no rights, rather than carers, and were not informed when appointments were cancelled even when they were missing school to attend.'

The team offered the young carers a session designed to help them assert their rights to the support to which they were entitled.

Quality improvement project

They registered their work as a quality improvement project to identify barriers for young carers in the trust and to create with them a policy to address their needs.

There was a rights workshop, which used the UN Convention on the Rights of the Child to frame discussions about the rights young carers felt most important.

'This time we went to them, rather than bringing them into the hospital,' recalls Ms Datt. 'It was much better in their own environment as they were more open and relaxed.'

Afterwards, the young people reported a 48% increase in knowledge, and a 56% increase in confidence to assert their rights.

Naheeda Rahman conducted semi-structured interviews with ten children's healthcare professionals, eight adult healthcare professionals and two young carers. The interviews revealed themes of lack of awareness, poor identification, young carers' voices, family dynamics and the impact of caring.

Identity cards

Lack of awareness or recognition of young carers were found to be the foundation of poor healthcare experience, says Ms Datt. 'The young carers wanted an identity

card to address this. They wanted an NHS logo on it – something official so they would be believed. And they wanted their rights on the back.'

The Healthy London Partnership, a local government/NHS collaboration, funded the prototype card with £1,120, and a design agency, Together Creative, helped the team and carers co-design the identity cards.

The six workshops held by the team were crucial, allowing them to hear the difficulties experienced by the young carers and develop the policy in a collaborative way.

'We enabled them to co-design everything on the card, which helped us to understand what was most important to the young carers,' says Ms Datt. 'The words "we matter too" is a direct quote from one of them.'

Feedback

The team collected feedback from 12 of the 21 young carers piloting the card every three months. This was used to create a carers' policy for Whittington Health as well as in the prototype of a second card.

Feedback from the young carers shows the difference the card has made to their experiences. Several have presented the card when picking up parents' prescriptions – previously they had not been allowed to do so. One young person used the card to get a free flu jab. Another reported a better level of respect: 'I showed the card to a consultant and he let me sit in my mum's appointment and explained things to me'.

'While these may seem like small steps, they alleviate certain



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In their own words: what carers and hospital staff say

'We'll never be acknowledged or appreciated because it's like the only person who really appreciates that is the person you're caring for'

– Young carer

'The card... helps because it makes young carers feel like they are actually worth something. That they're not just someone who's being ignored'

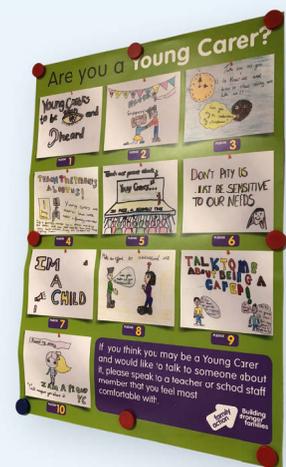
– Young carer

'Some parents probably don't perceive... their children as being carers. They just think they're being their children'

– Healthcare professional

'Sometimes when we first meet them we don't know they are young carers. It takes us weeks and months to establish a relationship'

– Healthcare professional





‘These seemingly small steps alleviate stresses and help alter young carers’ perception of the healthcare system’

Colette Datt, nurse consultant for children and young people, Whittington Health NHS Trust

stresses faced by young carers and help to alter their perception of the healthcare system to one that is more accessible, supportive and welcoming of them,’ says Ms Datt.

The team soon realised the project had room to improve.

‘We realised young carers didn’t know where and when to use the card so we created an A4 information sheet,’ says Ms Datt.

‘We also realised the main barrier to young carers using the card in healthcare was its design – they said the card was bulky and didn’t look professional enough.’

The second prototype is small, plastic and bears the carer’s name. Fifty young people will pilot it, thanks to an NHS England grant.

Winning awards

In 2018, the team won a prize for partnership working to improve patient experience at the Patient Experience Network National Awards. And this year, it was among finalists in the Commitment to Carers category of the RCNi Nurse Awards, sponsored by NHS England.

The partnerships required have proved a challenge as well as a strength. ‘Without them I’m not sure how else you would reach this group in the first place points out Ms Datt. ‘They are hidden because they are restricted by their caring

‘Supporting young carers is our duty’

Nurse Sandra Frimpong was keen to take part in the project because she already knew about some of the issues young carers faced.

‘All healthcare professionals need to be aware of young carers. I also wanted to write a policy as I had never done it before,’ she says.

Forgotten group

She investigated other trusts’ carer policies. ‘The three policies I found covered adult carers. While we initially wrote ours as a young carer policy, it made more sense to cover carers and young carers in one policy.’

The policy was ratified in October 2018 and staff will shortly be able to access it through the staff intranet.

‘We are now focusing on robust implementation across the trust,’ says Ms Frimpong. ‘I held a stall during carers’ week to raise awareness and introduce the policy to staff. They seemed extremely interested and keen for it to be used.’

‘A caring role can adversely affect young people’s physical and mental

health, educational outcomes and quality of life’.

Ms Frimpong plans to interview ten staff. ‘We will launch the policy based on qualitative feedback from staff that focuses on their ideas for implementation combined with my literature review on how to implement a policy for young carers.’

The policy has been the focus of Ms Frimpong’s master’s degree.

Being a carer comes at a cost

‘Research shows there are as many as 800,000 young carers in England and they save the NHS £132 billion yearly,’ she says. ‘While there are positive effects of caring, such as resilience, young carers often don’t have a choice. They need to be recognised and identified at an early stage because their caring role can adversely affect their health, educational outcomes and quality of life.’

‘In health we are ideally situated to advocate for and support young carers. Our policy and ID cards aim to enable them to be identified, recognised and supported in our trust. It is our duty.’



▲ From left, Whittington Health patient pathway coordinator Madeline Ioannou, nurse consultant Colette Datt, nurse Sandra Frimpong and medical student Naheeda Rahman

responsibilities in what they do.

‘But engaging through multiple workshops made it more difficult to schedule workshops and to agree priorities. Each organisation had its own commissioning commitments, which took priority over the project. We worked together to find dates that worked for all of us but it took longer than we anticipated.’

There are exciting developments ahead. A young carers policy will be ratified across Whittington

Health, including electing young people to be carer champions in the trust’s health teams.

An app and website making it easier for young carers to access information about their rights and the services available to them are planned for 2020. But most of all, the team wants to see other healthcare organisations change their approach to young carers.

Ms Datt adds: ‘This makes a difference and we have data to prove it.’